1. Oncologist factors that influence referrals to subspecialty palliative care clinics.
Schenker Y; Crowley-Matoka M; Dohan D; Rabow MW; Smith CB; White DB; Chu E; Tiver GA; Einhorn S; Arnold RM. Journal of oncology practice/American Society of Clinical Oncology. 10(2):e37-44, 2014 Mar. [Journal Article. Multicenter Study. Research Support, N.I.H., Extramural. Research Support, Non-U.S. Gov't]
UI: 24301842
PURPOSE: Recent research and professional guidelines support expanded use of outpatient subspecialty palliative care in oncology, but provider referral practices vary widely. We sought to explore oncologist factors that influence referrals to outpatient palliative care.
METHODS: Multisite, qualitative interview study at three academic cancer centers in the United States with well-established palliative care clinics. Seventy-four medical oncologists participated in semistructured interviews between February and October 2012. The interview guide asked about experiences and decision making regarding outpatient palliative care use. A multidisciplinary team analyzed interview transcripts using constant comparative methods to inductively develop and refine themes related to palliative care referral decisions.
RESULTS: We identified three main oncologist barriers to subspecialty palliative care referrals at sites with comprehensive palliative care clinics: persistent conceptions of palliative care as an alternative philosophy of care incompatible with cancer therapy, a predominant belief that providing palliative care is an integral part of the oncologist's role, and a lack of knowledge about locally available services. Participants described their views of subspecialty palliative care as evolving in response to increasing availability of services and positive referral experiences, but emphasized that views of palliative care as valuable in addition to standard oncology care were not universally shared by oncologists.
CONCLUSIONS: Improving provision of palliative care in oncology will likely require efforts beyond increasing service availability. Raising awareness of ways in which subspecialty palliative...
care complements standard oncology care and developing ways for oncologists and palliative care physicians to collaborate and integrate their respective skills may help.

Status
MEDLINE
Authors Full Name
Crowley-Matoka, Megan; Dohan, Daniel; Rabow, Michael W; Smith, Cardinale B; White, Douglas B; Chu, Edward; Tiver, Greer A; Einhorn, Sara; Arnold, Robert M.
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Schenker, Yael. University of Pittsburgh Cancer Institute; University of Pittsburgh, Pittsburgh, PA; Feinberg School of Medicine, Northwestern University, Chicago, IL; Institute for Health Policy Studies; Helen Diller Family Comprehensive Cancer Center, University of California, San Francisco, CA; and Tisch Cancer Institute, Icahn School of Medicine at Mount Sinai, New York, NY.
Other ID
Source: NLM. PMC3948709 [Available on 03/01/15]
Date Created
20140317
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2014

2. Ethics and gender issues in palliative care in nursing homes: an Austrian participatory research project.
Reitinger E; Heimerl K.
[Journal Article. Multicenter Study. Research Support, Non-U.S. Gov't]
U1: 24862993
BACKGROUND: The development of palliative care in nursing homes in German-speaking countries has gained in importance within the past 15-20 years. Ethical and gender issues are core aspects of a palliative care culture and should therefore be better understood.
AIMS AND OBJECTIVES: The aim of this study was to highlight insights regarding ethical and gender issues, based on the experiences of professionals in nursing homes.
DESIGN: A 2-year participatory action research study was performed in collaboration with three nursing homes in Austria.
METHODS: The article focusses on 10 group discussions with interdisciplinary professional teams that were conducted to generate ethical narratives. Thematic and narrative analysis was undertaken both individually and within the interdisciplinary research team. Findings and interpretations were validated with practitioners and researchers.
FINDINGS: A total of 36 narratives were collected and summarised within eight themes concerning the theoretical journey of a nursing home resident with relatives from entry into the house until death. The most burdensome ethical dilemmas are not the ones around death and dying but rather those relating to small-scale everyday work/life issues. Sharing experiences and feelings in ethical discussions provides relief. Emotions are important facilitators of insight into
ethical dilemmas. Gender issues can be observed in care situations as well as in the organisational structure of nursing homes.

CONCLUSIONS: Opportunities to share experiences and perspectives around ethical questions in interdisciplinary group discussions help professionals to better understand difficult issues and find appropriate ways of managing them.

IMPLICATIONS FOR PRACTICE: There is a need for communication structures such as facilitated ethical discussions that enable nursing home staff to reflect their everyday decisions. Expression of emotions should be encouraged in ethical decision-making processes in nursing homes. Gender-sensitive reflection supports the development of palliative care as organisational culture.

Kaasalainen S; Brazil K; Kelley ML.
[Journal Article. Multicenter Study. Research Support, Non-U.S. Gov't]
UI: 23051621

BACKGROUND: Providing palliative care in long-term care (LTC) homes is an area of growing importance. As a result, attention is being given to exploring effective palliative care learning strategies for personal support workers (PSWs) who provide the most hands-on care to LTC residents.

AIM: The purpose of this intervention was to explore hospice visits as an experiential learning strategy to increase the capacity of PSWs in palliative care, specifically related to their new learning, and how they anticipated this experience changed their practices in LTC.

DESIGN: This study utilised a qualitative descriptive design.

METHODS: Eleven PSWs from four Ontario LTC homes were sent to their local hospice to shadow staff for one to two days. After the visit, PSWs completed a questionnaire with open-ended questions based on critical reflection. Data were analysed using thematic content analysis.

RESULTS: PSWs commented on the extent of resident-focused care at the hospice and how palliative care interventions were tailored to meet the needs of residents. PSWs were surprised with the lack of routine at the hospice but felt that hospice staff prioritised their time effectively in
order to meet family and client care needs. Some PSWs were pleased to see how well integrated the PSW role is on the community hospice team without any hierarchical relationships. Finally, PSWs felt that other LTC staff would benefit from palliative care education and becoming more comfortable with talking about death and dying with other staff, residents and family members.

CONCLUSION: This study highlighted the benefits of PSWs attending a hospice as an experiential learning strategy. Future work is needed to evaluate this strategy using more rigorous designs as a way to build capacity within PSWs to provide optimal palliative care for LTC residents and their family members.

IMPLICATIONS FOR PRACTICE: PSWs need to be recognised as important members within the interdisciplinary team. PSWs who shadow staff at hospices view this experience as a positive strategy to meet their learning needs related to palliative care.

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Status MEDLINE Authors Full Name Brazil, Kevin; Kelley, Mary L. Institution Kaasalainen, Sharon. Faculty of Health Sciences, McMaster University, Hamilton, ON, Canada. Date Created 20140527 Year of Publication 2014

4. Development of the measure of ovarian symptoms and treatment concerns: aiming for optimal measurement of patient-reported symptom benefit with chemotherapy for symptomatic ovarian cancer.

King MT; Stockler MR; Butow P; O'Connell R; Voysey M; Oza AM; Gillies K; Donovan HS; Mercieca-Bebber R; Martyn J; Sjoquist K; Friedlander ML.

[Journal Article. Research Support, Non-U.S. Gov't]
UI: 24844220

OBJECTIVE: The aim of this study was to determine the optimal patient-reported outcome measure (PROM) for assessing symptom benefit in trials of palliative chemotherapy for women with symptomatic ovarian cancer.

METHODS: Candidate PROMs were EORTC QLQ-C30 plus ovarian-specific QLQ-OV28, Functional Assessment of Cancer Therapy-Ovarian (FACT-O), FACT Ovarian Symptom Index (FOSI), and gynecologic cancer-specific Symptom Representation Questionnaire. Predefined optimality criteria were inclusion of all symptoms necessary for the specified purpose, recall period covering typical length of palliative chemotherapy, numerical item rating scales, and all necessary symptoms included in a single symptom index. Qualitative and quantitative methods were applied to data from stage 1 of the Gynecologic Cancer Intergroup Symptom Benefit Study.
to determine the set of necessary symptoms and to objectively assess candidate PROMs against the optimality criteria.

RESULTS: Ten necessary symptoms were identified: pain, fatigue, abdominal bloating/discomfort, sleep disturbance, bowel disturbance, nausea and vomiting, shortness of breath, poor appetite, urinary symptoms, and weight changes. Although QLQ-C30 and QLQ-OV28 together cover all these symptoms, they split them into numerous scales, dissipating potential symptom-benefit signal. Conversely, FACT-O does not cover all necessary symptoms and contains many other HRQoL-related items and treatment side effects, diluting potential symptom-benefit signal when summed into scales. Item response scales and composite scoring of all candidate PROMs were suboptimal to our specific purpose. We therefore developed a new PROM, the Measure of Ovarian Symptoms and Treatment (MOST) concerns, to provide optimal measurement for the specified purpose.

CONCLUSIONS: This article documents the development of the MOST, a new PROM designed to assess patient-reported benefits and burden as end points in clinical trials of palliative chemotherapy for women with symptomatic ovarian cancer. The validity, reliability, and statistical efficiency of the MOST, relative to the best candidate scales of existing PROMs, will be assessed in the stage 2 of Gynecologic Cancer Intergroup Symptom Benefit Study.

5.
Staff nurses' perceptions regarding palliative care for hospitalized older adults.
O'Shea MF.
[Journal Article]
UI: 25319523
PURPOSE: This exploratory study addressed the research question "What are the perceptions of staff nurses regarding palliative care for hospitalized older adults?"
DESIGN: A qualitative descriptive study design using focus groups was selected.
METHODS: Eighteen staff nurses participated in semistructured focus group interviews. The audio-recorded data were transcribed, sorted, and coded using NVivo 9 software and analyzed using Ritchie and Spencer's framework approach to qualitative data analysis.

FINDINGS: Five main thematic categories emerged that captured the essence of the nurses' perceptions: ambiguity regarding the concept of palliative care, communication challenges, a sense of informed advocacy, cognitive and emotional dissonance, and health care system constraints.

CONCLUSIONS: For many seriously ill hospitalized older patients, staff nurses can be pivotal as informed advocates for palliative care early in the course of an illness trajectory. But nurses (and other providers) often confuse palliative and hospice care; thus there is a need for increased understanding and knowledge in this area. Collaborative interdisciplinary education regarding the evolving concept of palliative care may be useful. Further research into the perceptions and experiences of staff nurses who care for hospitalized older adults is warranted.

Status
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O'Shea, Maureen F. Maureen F. O'Shea is an associate professor in the Department of Nursing at Curry College, Milton, MA. Contact author: moshea@curry.edu. The author and planners have disclosed no potential conflicts of interest, financial or otherwise.

Date Created
20141030
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2014

6. Home-based palliative care: a systematic literature review of the self-reported unmet needs of patients and carers. [Review]
Ventura AD; Burney S; Brooker J; Fletcher J; Ricciardelli L.
UI: 24292156
BACKGROUND: There have been many studies on the unmet needs of palliative care patients and carers from the perspective of bereaved caregivers. However, the unmet needs of palliative care patients and carers from the perspective of current patients and their carers have received little research attention.
AIM: As home-based services have become one of the main delivery models of palliative care, the aim of this review was to describe, evaluate and summarise the literature on the unmet needs of palliative home care patients and carers.
DESIGN: The systematic review of qualitative and quantitative studies was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.
DATA SOURCES: PubMed, CINAHL, Embase, MEDLINE, PsycINFO, AMED and CareSearch were searched to find empirical studies on the self-reported unmet needs of palliative home care patients and carers.

RESULTS: Nine qualitative studies, three quantitative studies and three mixed-design studies were identified. The most frequently reported unmet need was effective communication with health-care professionals, the lack of which negatively impacted on the care received by patients and carers. Physical care needs were met, which indicates that the examined palliative home care services were delivering satisfactory care in this domain, but lacking in other areas.

CONCLUSIONS: The focus therefore should be on improving other aspects of patient care, including communication by health professionals to prevent or reduce suffering in areas such as psychosocial domains. Valid and reliable quantitative measures of unmet needs in palliative care are needed to examine this area more rigorously.

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Comments
Date Created
20140423
Year of Publication
2014

7.
Ethical dilemmas around the dying patient with stroke: a qualitative interview study with team members on stroke units in Sweden.
Eriksson H; Andersson G; Olsson L; Milberg A; Friedrichsen M.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 24796473

In Sweden, individuals affected by severe stroke are treated in specialized stroke units. In these units, patients are attended by a multiprofessional team with a focus on care in the acute phase of stroke, rehabilitation phase, and palliative phase. Caring for patients with such a large variety in condition and symptoms might be an extra challenge for the team. Today, there is a lack of knowledge in team experiences of the dilemmas that appear and the consequences that emerge. Therefore, the purpose of this article was to study ethical dilemmas, different approaches, and what consequences they had among healthcare professionals working with the dying patients with stroke in acute stroke units. Forty-one healthcare professionals working in a stroke team were interviewed either in focus groups or individually. The data were transcribed verbatim and analyzed using content analysis. The ethical dilemmas that appeared were depending on "nondecisions" about palliative care or discontinuation of treatments. The lack of decision made
the team members act based on their own individual skills, because of the absence of common communication tools. When a decision was made, the healthcare professionals had "problems holding to the decision." The devised and applied plans could be revalued, which was described as a setback to nondecisions again. The underlying problem and theme was "communication barriers," a consequence related to the absence of common skills and consensus among the value system. This study highlights the importance of palliative care knowledge and skills, even for patients experiencing severe stroke. To make a decision and to hold on to that is a presupposition in creating a credible care plan. However, implementing a common set of values based on palliative care with symptom control and quality of life might minimize the risk of the communication barrier that may arise and increases the ability to create a healthcare that is meaningful and dignified.

8.
Communication about existential issues with patients close to death--nurses' reflections on content, process and meaning.
Strang S; Henoch I; Danielson E; Browall M; Melin-Johansson C.
Psycho-Oncology. 23(5):562-8, 2014 May.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 24323829
OBJECTIVE: Encountering dying patients with implicit existential questions requires the nurses to have positive and comfortable attitude to talking about existential issues. This paper describes the nurses' reflections on existential issues in their communication with patients close to death.
METHODS: Nurses (n=98) were recruited from a hospital, hospices and homecare teams. Each nurse participated in five group reflection sessions that were recorded, transcribed and analysed using qualitative content analysis.

RESULTS: Three domains and nine themes emerged. The content domain of the existential conversation covered living, dying and relationships. The process domain dealt with using conversation techniques to open up conversations, being present and confirming. The third domain was about the meaning of existential conversation for nurses. The group reflections revealed a distinct awareness of the value of sensitivity and supportive conversations.

CONCLUSION: This study supports the assertion that experience of talking about existential issues and supporting environment make nurses comfortable when counselling patients close to death. It was obvious from this study that having the courage to be present and confirming, having time and not trying to 'solve' every existential problem were the most important factors in conversations with the patients close to death.

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memories." "Illness" and "marriage and divorce" were related to "turning points in the life."
"Raising children and education" and "company or work" were identified as "roles in life."
"Achievements at work" were identified with "pride." "Message to my children" was identified with "what I want to say to my family." "To live sincerely" and "consideration for others" were identified as "advice for the next generation." Patients reviewed few for topics such as "pride," "what I want to say to my family," "advice for the next generation," and "summing up my life."
SIGNIFICANCE OF RESULTS: Factors such as human relationships, raising children, and education as a role and source of pride, and concerns about children's future, were associated with elevating spiritual well-being. Question to which that patients easily answered were selected.

OBJECTIVE: Advance care planning (ACP) has the potential to enhance end-of-life care, yet often fails to live up to that potential. This qualitative interpretive study was designed to explore the process and outcomes of ACP using the patient-centered Advance Care Planning Interview (PC-ACP) developed by the Respecting Choices program in Wisconsin.

METHOD: Patients diagnosed with advanced lung cancer and close family members were recruited. Nine family dyads participated in the PC-ACP interview, which was audio-recorded. Follow-up interviews took place 3 and 6 months after the PC-ACP interview and were also recorded. Thematic analysis was conducted on transcribed interviews using constant comparison.

RESULTS: Analysis showed that hope was a significant theme in the ACP process and this article reports on that theme. Hope for a cure was one of many hopes that supported quality of life for the participant dyads. Three themes were identified: hope is multifaceted, hope for a cure is well considered, and hope is resilient and persistent. The seeming paradox of hoping for a cure of an incurable cancer did not interfere with the process of ACP. The dyads engaged in explicit
discussions of end-of-life scenarios and preferences for care. ACP did not interfere with hope and hope for a cure did not interfere with ACP.

SIGNIFICANCE OF RESULTS: Concerns about false hope are called into question. The principle of honoring hope is not necessarily in conflict with the principle of truthful communication. This is clinically significant, as the findings suggest we need not disrupt hope that we think of as "unrealistic" as long as it supports the family to live well. Further, ACP can be successful even in the context of hoping for a cure.

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11. Quality palliative care for cancer and dementia in five European countries: some common challenges.
Davies N; Maio L; van Riet Paap J; Mariani E; Jaspers B; Sommerbakk R; Grammatico D; Manthorpe J; Ahmedzai S; Vernooij-Dassen M; Iliffe S; IMPACT research team.
Aging & Mental Health. 18(4):400-10, 2014 May.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 24131061
OBJECTIVES: There is a growing consensus worldwide that palliative care needs to be both more inclusive of conditions other than cancer and to improve. This paper explores some common challenges currently faced by professionals providing palliative care for patients with either cancer or dementia across five countries.

METHOD: One focus group (n=7) and 67 interviews were conducted in 2012 across five countries: England, Germany, Italy, the Netherlands and Norway, with professionals from dementia, cancer and palliative care settings.

RESULTS: The interviews revealed five common challenges faced across the five countries: communication difficulties (between services; and between professionals, and patients and their families); the variable extent of structural/functional integration of services; the difficulties in funding of palliative care services; problematic processes of care (boundaries, definitions, knowledge, skills and inclusiveness) and, finally, time constraints.

CONCLUSION: These are not problems distinct to palliative care, but they may have different origins and explanations compared to other areas of health care. This paper explored deeper themes hidden behind a discourse about barriers and facilitators to improving care.

Status
MEDLINE
Authors Full Name
Unmet needs of patients feeling severely affected by multiple sclerosis in Germany: a qualitative study.

Galushko M; Golla H; Strupp J; Karbach U; Kaiser C; Ernstmann N; Pfaff H; Ostgathe C; Voltz R.


BACKGROUND: The needs of patients feeling severely affected by multiple sclerosis (MS) have rarely been investigated. However this is essential information to know before care can be improved, including adding palliative care (PC) services where helpful. Since it remains unclear at what point specialized palliative care should begin for this patient group, this study focuses on needs in general.

OBJECTIVE: The objective was to explore the subjectively unmet needs of patients feeling severely affected by MS.

METHODS: The study used a qualitative cross-sectional approach for needs assessment. Fifteen patients self-reporting feeling severely affected by MS were recruited and interviewed using a combination of purposive and convenience sampling (five were accompanied by a caregiver relative). Interviews were recorded and transcribed verbatim, followed by qualitative content analysis.

RESULTS: Unmet needs were identified in the main categories "support of family and friends," "health care services," "managing everyday life," and "maintaining biographical continuity." Patients expressed the desire for more support from their families and to be viewed as distinct individuals. They see a substantial deficit in the physician-patient relationship and in the coordination of services. A decrease in expressed unmet needs was found for patients more severely affected and less socially integrated.

CONCLUSIONS: To address the unmet needs of severely affected MS patients, health care services need to be improved and linked with existing PC services. Special attention is required to form supporting professional-patient relationships. Multiprofessional services should be
accessible for patients, while integrating relatives. All services should have an individual approach to provide needs-tailored support.

Status
MEDLINE
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Source: NLM. PMC3952521 [Available on 03/01/15]
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20140312
Year of Publication
2014


CONTEXT: Patient safety is a concern in medicine, and the prevention of medical errors remains a challenge. The definition and understanding of an error is particularly difficult in palliative care, with scarce empirical evidence about the nature and causes of medical errors in that discipline.

OBJECTIVES: This study explored incidents palliative care professionals perceive as typical errors in their practice, and descriptions of such events.

METHODS: In the context of an exploratory, cross-sectional survey on errors in palliative care among professionals of palliative care institutions in Bavaria, Germany (n=168), participants described a typical case in which an error occurred. Data from free-text answers was qualitatively analyzed, and categories for areas and causes of errors were extracted.

RESULTS: The questionnaire was returned by 42% (n=70) of the sample. Two-thirds of respondents (n=46, 66%) gave a free-text answer describing a typical error in palliative care. Seven potential areas for errors were identified in the qualitative analysis: drug treatment, palliative sedation, communication, care organization, treatment plan, end-of-life care, and history taking. Six categories emerged as causes of errors: miscommunication, system failure, dysfunctional attitudes, lack of knowledge, wrong use of technology, and misjudgement.

CONCLUSION: Data showed that medical errors in palliative care, as seen by professionals in the field, primarily affect medication and communication, and miscommunication and system failures are perceived as the leading causes of errors. A better understanding of the characteristics of errors within palliative care and further qualitative research are warranted to prevent errors and enhance patient safety.
14.

How do palliative medicine specialists conceptualize depression? Findings from a qualitative in-depth interview study.

Ng F; Crawford GB; Chur-Hansen A.


[Journal Article]

UI: 24410323

BACKGROUND AND OBJECTIVE: Different professional conceptualizations of depression may complicate the clinical approach to depression in the palliative care setting. This study aimed to explore and characterize how palliative medicine specialists conceptualize depression. METHODS: Palliative medicine specialists (i.e., consultants/attending physicians in palliative medicine) practicing in Australia were recruited. Participants were purposively sampled. Individual semi-structured, in-depth interviews were conducted to explore their conceptualizations of depression. Nine participants were interviewed to reach data saturation. Interview transcripts were analyzed for themes.

RESULTS: Four main themes were identified in relation to the conceptualization of depression: (1) depression is a varied concept--it was variously considered as abnormal, a medical problem, an emotional experience, a social product, and an action-oriented construct; (2) depression has unclear boundaries, with differentiation between depression and sadness being especially challenging; (3) depression is different in the palliative care setting--it was seen as more understandable, and distinct from depression that predates life-limiting illnesses; and (4) depression is a challenging issue.

CONCLUSIONS: Depression is conceptualized by palliative medicine specialists in divergent, ontologically heterogeneous and ill-defined ways. A unitary concept of depression was not evident in this study. The concepts of depression need to be actively debated and refined in clinical practice, medical education, and research in order for more sophisticated and consistent models to be developed. The distinction of de novo depression from recurrent or persistent forms of depression also warrants further study.
15.
What are the supportive and palliative care needs of patients with cutaneous T-cell lymphoma and their caregivers? A systematic review of the evidence. [Review]
Beynon T; Radcliffe E; Child F; Orlowska D; Whittaker S; Lawson S; Selman L; Harding R. British Journal of Dermatology. 170(3):599-608, 2014 Mar.
[Journal Article. Research Support, Non-U.S. Gov't. Review]
UI: 24116897
BACKGROUND: Primary cutaneous T-cell lymphoma (CTCL) is progressive, can cause significant symptoms, and impacts on quality of life. Therefore supportive and palliative care might have a role in the care of patients and families.
OBJECTIVES: To identify and appraise the available peer-reviewed evidence on the supportive and palliative care needs of patients and their caregivers.
METHODS: A systematic review of the literature was conducted. Extracted data from eligible papers were collated in themes relating to supportive and palliative care needs and outcomes for patients, informal caregivers, health professionals and reported service models.
RESULTS: Eighteen retained papers reported a symptom or quality-of-life measure. Five reported only these measures, 13 reported outcomes in relation to an intervention. Systemic therapy targeted at disease remission was the most commonly reported intervention (12/13). No quality-of-life tool was consistently used. Pruritus was frequently reported as an outcome (n = 9) often using the visual analogue scale, VAS itch. Psychosocial, spiritual and caregiver needs were reported infrequently or not at all.
CONCLUSIONS: No measure is routinely used to measure supportive and palliative care outcomes in CTCL. Physical needs, particularly pruritus, were reported commonly; however, qualitative evidence of experience is limited. Caregivers' needs are rarely explored. To compare outcomes from clinical studies, a single multidimensional tool used in routine practice would be useful. Further work is needed to explore a model of service that meets the specific physical, psychosocial and spiritual needs of this group of patients and their carers. Copyright 2013 British Association of Dermatologists.
Status
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16.

[Struggling for normal in an instable situation - informal caregivers self-management in palliative home care. A meta-synthesis]. [German]

Kreyer C; Pleschberger S.
UI: 25253377

BACKGROUND: Family caregivers play a key role in palliative home care for persons with advanced cancer. Although research has shown numerous burdens and strains of family caregiving, there is a lack of family-oriented support strategies in palliative home care. Little is known about family caregivers' self-management in this context so far. Qualitative research provides insight into families' perspectives of the transition to and management of palliative care at home and can be used as a starting point.

AIM: The aim of the study was to increase knowledge of family caregivers' self-management in palliative home care by synthesizing evidence from qualitative research.

METHOD: Based on a systematic review of literature a meta-synthesis was conducted following the approach of Noblit and Hare (1988). A total of 13 qualitative studies from six countries, published from 2002 onward, formed the basis for an interpretative synthesis.

RESULTS: Caring for a person with advanced cancer at the end of life at home is characterized by an instable transition process in which families are 'struggling for normal'. Six different family self-management strategies to deal with this were identified: acknowledging the transition, restructuring everyday life, maintaining balance in family relationships, taking responsibility for care, using social support, and acquiring caring-skills.

CONCLUSION: Self-management strategies may provide a key for supporting family caregivers in palliative home care by focusing on resources and problem solving skills of families.

Status
MEDLINE
Institution
Other Abstract
Publisher: Abstract available from the publisher.; Language: German
Date Created
17. In the shadow of death: existential and spiritual concerns among persons receiving palliative care.
Asgeirsdottir GH; Sigurbjornsson E; Traustadottir R; Sigurdardottir V; Gunnarsdottir S; Kelly E.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 25241482
This study explores existential and spiritual concerns from the perspective of people receiving palliative care. It examines the meaning of these concerns, their influence on people's lives and investigates the connections between them. In-depth qualitative interviews were conducted with ten persons. Findings reveal existential and spiritual aspects as interconnected and an integral part of the participants' everyday existence. It concludes with a call for a better understanding of these phenomena in the palliative care context.

18. The role of practice nurses in providing palliative and end-of-life care to older patients with long-term conditions.
Raphael D; Waterworth S; Gott M.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 25151864
BACKGROUND: Many people with palliative care needs will receive care from a primary care provider. However, GPs often have limited time to deal with these patients' supportive care needs, which is where primary care nurses can make a significant contribution.
AIM: The aim of this qualitative descriptive study was to explore the role of practice nurses in the provision of palliative and end-of-life (EoL) care to older patients with long-term conditions.

METHODS: Twenty one practice nurses from a selection of rural and urban areas in New Zealand were interviewed about their EoL care experiences.

RESULTS: Three themes were identified relating to EoL care: variability of practice nurse involvement in EoL care, limited education and training in EoL care, and what practice nurses can (and do) contribute to EoL care.

CONCLUSION: Priority should be given to developing the palliative care skills and knowledge of primary care nurses and their ability to provide the necessary support to the growing number of patients who will require palliative care.

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Date Created
20140825
Year of Publication
2014

19.
Withdrawal of ventilatory support outside the intensive care unit: guidance for practice.
Laddie J; Craig F; Brierley J; Kelly P; Bluebond-Langner M.
Archives of Disease in Childhood. 99(9):812-6, 2014 Sep.
[Journal Article]
UI: 24951460

OBJECTIVE: To review the work of one tertiary paediatric palliative care service in facilitating planned withdrawal of ventilatory support outside the intensive care setting, with the purpose of developing local guidance for practice.

METHODS: Retrospective 10-year (2003-2012) case note review of intensive care patients whose parents elected to withdraw ventilation in another setting. Demographic and clinical data revealed common themes and specific incidents relevant to local guideline development.

RESULTS: 18 children (aged 2 weeks to 16 years) were considered. Three died prior to transfer. Transfer locations included home (5), hospice (8) and other (2). Primary pathologies included malignant, neurological, renal and respiratory diseases. Collaborative working was evidenced in the review including multidisciplinary team meetings with the palliative care team prior to discharge. Planning included development of symptom management plans and emergency care plans in the event of longer than anticipated survival. Transfer of children and management of extubations demonstrated the benefits of planning and recognition that unexpected events occur despite detailed planning. We identified the need for local written guidance supporting healthcare professionals planning and undertaking extubation outside the intensive care setting, addressing
the following phases: (i) introduction of withdrawal, (ii) preparation pretransfer, (iii) extubation, (iv) care postextubation and (v) care postdeath.

CONCLUSIONS: Planned withdrawal of ventilatory support outside the intensive care setting is challenging and resource intensive. The development of local collaborations and guidance can enable parents of children dependent on intensive care to consider a preferred place of death for their child, which may be outside the intensive care unit. Copyright Published by the BMJ Publishing Group Limited. For permission to use (where not already granted under a licence) please go to http://group.bmj.com/group/rights-licensing/permissions.


PURPOSE: End-of-life and palliative care (EOL/PC) education is a necessary component of undergraduate medical education. The extent of EOL/PC education in internal medicine (IM) clerkships is unknown. The purpose of this national study was to investigate the presence of formal EOL/PC curricula within IM clerkships; the value placed by IM clerkship directors on this
type of curricula; curricular design and implementation strategies; and related barriers and resources.

METHOD: The Clerkship Directors in Internal Medicine conducted its annual survey of its institutional members in April 2012. The authors analyzed responses to survey items pertaining to formal EOL/PC curriculum and content using descriptive statistics. The authors used qualitative techniques to analyze free-text responses.

RESULTS: The response rate was 77.0% (94/122). Of those responding, 75.8% (69/91) believed such training should occur in the IM clerkship, and 43.6% (41/94) reported formal curricula in EOL/PC. Multiple instructional modalities were used to deliver this content, with the majority of programs dedicating four or more hours to the curriculum. Curricula covered a wide range of topics, and student assessment tools were varied. Most felt that students valued this education. The qualitative analysis revealed differences in the values clerkship directors placed on teaching EOL/PC within the IM clerkship.

CONCLUSIONS: Although many IM clerkship directors have implemented formal curricula in EOL/PC, a substantial gap remains between those who have implemented and those who believe it belongs in the clerkship. Time, faculty, cost, and competing demands are the main barriers to implementation.


Jelinek GA; Boughey M; Marck CH; Phillip J; Weil J; Lane H; Weiland TJ. 
[Journal Article. Research Support, Non-U.S. Gov't] 
UI: 25058985
OBJECTIVE: It is difficult to provide optimal care to people with advanced cancer presenting to emergency departments (EDs). Recent data suggest that the ED environment, the skills and priorities of treating staff, and the lack of clear communication related to goals of care contribute to the difficulty. By exploring the views of emergency, palliative care (PC), and oncology clinicians on the care of these patients, this study aimed to describe potential solutions.

METHODS: This qualitative study involved focus groups with clinicians at two major hospitals and two community PC services in Melbourne, Australia, and semistructured telephone interviews with emergency clinicians from all other Australian states and territories. Discussions were recorded and transcribed verbatim. Thematic analysis identified ways to improve or enhance care.

RESULTS: Throughout discussions with 94 clinicians, a number of possible improvements to care were raised; these were broadly grouped into service areas: clinical care, pathways, information access, and education.

CONCLUSION: The provision of care to patients with advanced cancer in the ED occurs across sites, across disciplines, and across teams. To make improvements to care, we must address these complexities. The improvements suggested in this study place the patient (and the patient's family) at the centre of care.

Status
MEDLINE
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Jelinek, George A; Boughey, Mark; Marck, Claudia H; Phillip, Jennifer; Weil, Jennifer; Lane, Heather; Weiland, Tracey J.
Date Created
20140725
Year of Publication
2014

22.
UI: 25040866
BACKGROUND: As differing patient and carer information needs have been reported, and in light of changing health-system priorities and issues identified in a self-assessment study, a specialist palliative care service established an interdisciplinary psychosocial assessment clinic to separately assess patient and carer needs.
AIM: To determine the acceptability of the separate assessment to patients and carers.
METHOD: Patients with a high functional score and who were deemed well enough to manage an appointment were invited to attend the clinic. Consent to follow-up was obtained. Patient and carer satisfaction surveys were developed based on existing tools. Questionnaires were posted out with a pre-paid reply envelope to patients and carers. Data from completed surveys was
entered into a data management system and frequency analysis completed. A secondary analysis of the comments was undertaken.

FINDINGS: The clinic was attended by 41 patients and 37 carers between September 2011 and the end of February 2012. There was a 46% response rate, with 24 questionnaires returned from both the patient and their carer, 6 from patients only, and 6 from carers only (2 of whom were bereaved). The opportunity for privacy to discuss their own fears and concerns related to the illness was appreciated by 94% of the patients and 83% of the carers.

CONCLUSION: This initial pilot data shows patient and carer satisfaction with this clinic model. Further qualitative data would provide more information on the patient and carer experiences of the clinic.

23.
Final-year nursing undergraduates' understandings of palliative care: a qualitative study in Wales, UK.
Watts T.
[Jornal Article]
UI: 25040864

BACKGROUND: With worldwide population ageing and the increasing prevalence of chronic conditions, government policies promoting palliative care, and evidence of disparate or even blurred conceptions of palliative care, it is important for educators and practitioners who support undergraduate nurses to establish how these students conceptualise palliative care. Today's students are tomorrow's nurses, and their understanding will shape the ways in which palliative care is integrated into their professional practice.

AIM: The aim of this work was to explore nursing undergraduates' understandings of palliative care.

METHODS: As part of a larger qualitative study of palliative care for people with advanced dementia, 11 final-year adult-field nursing undergraduates' understandings of palliative care were explored through in-depth individual interviews. The data was subject to thematic content analysis.

FINDINGS: The analysis revealed that the participants were cognisant of the broad scope of palliative care. Moreover, they valued and appreciated compassionate comfort care and
emotional support. However, their understanding was rather superficial and focused on the imminently dying phase.

CONCLUSION: The findings are positive as they indicate that the participants appreciated and valued compassionate person- and family-centred care. However, they also illuminate where undergraduate nurse education could be further enhanced.

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20140721

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2014

24.
To what extent are the wishes of a signatory reflected in their advance directive: a qualitative analysis.
Nauck F; Becker M; King C; Radbruch L; Voltz R; Jaspers B.
BMC Medical Ethics. 15:52, 2014.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 24981101

BACKGROUND: Advance directives (ADs) are assumed to reflect the patients' preferences, even if these are not clearly expressed. Research into whether this assumption is correct has been lacking. This study explores to what extent ADs reflect the true wishes of the signatories.

METHODS: Semi-structured interviews (INT), pretest. Transcribed INT and the contents of ADs were inductively categorised (Mayring) and triangulated. Software: MAXQDA 2007.

PARTICIPANTS: Patients receiving palliative care (PPC), healthy (H) and chronically ill (CI) individuals with an AD completed >3 months prior to recruitment.

RESULTS: Between 08/2008 and 07/2009, 53 individuals (20 H, 17 CI, 16 PPC) were interviewed (mean age 63.2 years (55-70 years)), 34% male). Most important (in)consistencies between preferences as expressed in INT compared to ADs included preconditions for termination/rejection of life-sustaining measures, refusal of/demand for medical interventions and the nomination of proxies. Standardized AD forms were rarely tailored to the individual. We found a high tendency to use set phrases, such as want to die with dignity or do not want to suffer/vegetate. Likely events in the course of an existing progressive disease were not covered, even in ADs of PPC close to death.

CONCLUSIONS: Only some of the incongruities between verbally expressed preferences and the contents of the AD can be put down to use of standardized forms or lack of medical knowledge. Nevertheless, the non-involvement of a doctor in the process of making an AD must be seen as potentially problematic and seeking medical advice should be promoted by politics and physicians. Standardised forms should encourage amendments and present space for free text
Current debates on end-of-life sedation: an international expert elicitation study.
Papavasiliou EE; Payne S; Brearley S; EUROIMPACT.
Supportive Care in Cancer. 22(8):2141-9, 2014 Aug.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 24647491
PURPOSE: End-of-life sedation, though increasingly prevalent and widespread internationally, remains one of the most highly debated medical practices in the context of palliative medicine. This qualitative study aims to elicit and record the perspectives of leading international palliative care experts on current debates.
METHODS: Twenty-one professionals from diverse backgrounds, sharing field-specific knowledge/expertise defined by significant scholarly contribution on end-of-life sedation, were recruited. Open-ended, semi-structured interviews, following a topic-oriented structure reflecting on current debates, were conducted. Results were analysed using thematic content analysis.
RESULTS: Three main aspects of sedation were identified and discussed as potentially problematic: (a) continuous deep sedation as an extreme facet of end-of-life sedation, (b) psycho-existential suffering as an ambivalent indication for sedation and (c) withdrawal or withholding of artificial nutrition and hydration as potentially life-shortening. On these grounds, concerns were reported over end-of-life sedation being morally equivalent to euthanasia. Considerable emphasis was placed on intentions as the distinguishing factor between end-of-life acts, and protective safeguards were introduced to distance sedation from euthanasia.
CONCLUSIONS: This study shows that, despite the safeguards introduced, certain aspects of sedation, including the intentions associated with the practice, are still under question, parallels being drawn between end-of-life sedation and euthanasia. This reaffirms the existence of a grey area surrounding the two practices, already evidenced in countries where euthanasia is legalized. More clarity over the issues that generate this grey area, with their causes being uncovered and
eliminated, is imperative to resolve current debates and effectively inform research, policy and practice of end-of-life sedation.

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20140705

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Wheeler C; Anstey S; Lewis M; Jeynes K; Way H.
[Journal Article]
UI: 24902056
Successfully completing the 'Foundations in End of Life/Palliative Care' distance-learning module has had a measurable effect on the knowledge, competence and confidence of community nurses in the principles and practice of palliative and end-of-life care. An appropriate practice-based education module can empower community nursing practice and have a direct impact on improving the patient-carer experience at the end of life. This article provides evidence from the quantitative and qualitative data from pre- and post-module self-assessment questionnaires along with the successful completion of an electronic multiple-choice questionnaire and short-answer classroom test to demonstrate this.

Status
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Way, Helen. Clinical Nurse Specialist, Palliative Care, Velindre NHS Trust, Cardiff.
Does regional variation impact decision-making in the management and palliation of pancreatic head adenocarcinoma? Results from an international survey.

Hurdle V; Ouellet JF; Dixon E; Howard TJ; Lillemoe KD; Vollmer CM; Sutherland FR; Ball CG.


[Journal Article]

UI: 24869619

BACKGROUND: Management and palliation of pancreatic head adenocarcinoma is challenging. End-of-life decision-making is a variable process involving multiple factors.

METHODS: We conducted a qualitative, physician-based, 40-question international survey characterizing the impact of medical, religious, social, training and system factors on care.

RESULTS: A total of 258 international clinicians completed the survey. Respondents were typically fellowship-trained (78%), with a mean of 16 years' experience in a university-affiliated (93%) hepatopancreatobiliary group (96%) practice. Most (91%) believed resection is potentially curative. Most patients were discussed preoperatively by multidisciplinary teams (94%) and medical assessment clinics (68%), but rarely critical care (21%). Intraoperative surgical palliation included double bypass or no intervention for locally advanced nonresectable tumours (41% and 49% v. 14% and 85%, respectively, for patients with hepatic metastases). Postoperative admission to the intensive care unit was frequent (58%). Severe postoperative complications were often treated with aggressive cardiopulmonary resuscitation, intubation and critical care (96%), with no defined time points for futility (74%). Admitting surgeons guided most end-of-life decisions (97%). Formal medical futility laws were rarely available (26%). Insurance status did not alter treatment (97%) or palliation (95%) in non-universal care regions. Clinician experience, regional culture and training background impacted treatment (all p < 0.05).

CONCLUSION: Despite remarkable overall agreement, geographic and training differences are evident in the treatment and palliation of pancreatic head adenocarcinoma.
28.
Thematic synthesis of qualitative studies on patient and caregiver perspectives on end-of-life care in CKD.
Tong A; Cheung KL; Nair SS; Kurella Tamura M; Craig JC; Winkelmayer WC.
[Journal Article]
UI: 24411716
BACKGROUND: Although dialysis prolongs life for patients with end-stage kidney disease, 20% of deaths in this population are preceded by dialysis therapy withdrawal. Recently, there has been more focus on conservative (nondialytic) care as a legitimate option, particularly for elderly patients. This study aims to describe patients' and caregivers' perspectives on conservative treatment and end-of-life care in chronic kidney disease (CKD).
STUDY DESIGN: Systematic review and thematic synthesis of qualitative studies.
SETTING & POPULATION: Patients with CKD and caregivers.
SEARCH STRATEGY & SOURCES: MEDLINE, Embase, PsycINFO, CINAHL, and reference lists were searched to May 2013.
ANALYTICAL APPROACH: Thematic synthesis was used to analyze the findings.
RESULTS: 26 studies involving more than 711 patients (non-dialysis dependent [n=41], hemodialysis [n=544], peritoneal dialysis [n=9]; unspecified dialysis modality [n=31], conservative management [n=86]) and 178 caregivers were included. We identified 5 themes: invasive suffering (bodily deterioration, loss of freedom and independence, unyielding fatigue and pain, resignation, treatment burden and harm, financial strain), personal vulnerability (imminence of death, misunderstanding and judgment, autonomy and dignity, medical abandonment, trust and safety), relational responsibility (being a burden, demonstrating loyalty, protecting others from grief), negotiating existential tensions (accepting natural course of life, disrupted aging, worthlessness, living on borrowed time, respecting sanctity of life, life satisfaction, preserving self-identity), and preparedness (decisional clarity, informational power, spirituality and hope).
LIMITATIONS: Non-English articles were excluded; therefore, the transferability of findings to other populations is unclear.
CONCLUSIONS: Some patients with CKD experience physical and psychosocial frailty and feel ambivalent about prolonging life. Some caregivers believe in providing relief from suffering, but are uncertain about making decisions regarding dialysis therapy initiation and discontinuation. We suggest that CKD management should encompass palliative care strategies that promote emotional resilience, sense of well-being, and self-value. Also, respectful and attentive communication may empower patients to convey their values and preferences about their own care.
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Status
Community palliative care clinical nurse specialists: a descriptive study of nurse-patient interactions.
Howell D; Hardy B; Boyd C; Ward C; Roman E; Johnson M.
[Journal Article]
UI: 24852032
BACKGROUND: With an ageing population and changes to the UK process of commissioning health-care services, it is important that the role of the community palliative care clinical nurse specialist (CPC-CNS) is better understood.
AIM: This study aimed to describe CPC-CNS activities during interactions with patients.
METHODS: Four CPC-CNSs were observed and audio-recorded during interactions with 34 patients. The data was assessed qualitatively using thematic analysis.
RESULTS: An enormous breadth of activities were observed, within a framework of assessment, planning, intervention, and evaluation. Cross-cutting themes were real-time decision making, leadership, ability to respond to and coordinate complex and varied situations, and communication techniques. Data saturation was not achieved.
CONCLUSION: CPC-CNSs provide multifaceted care, requiring wide-ranging knowledge to enable them to act as liaison points in a complex health service, respond independently to the fluctuating needs of patients, and provide effective advance care planning, particularly to those with advanced disease, multi-morbidity, and frailty.
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Hardy, Beth. Senior Research Fellow, Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care, Faculty of Medicine and Health Sciences, University of Nottingham, England.
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Roman, Eve. Professor of Epidemiology, Epidemiology and Cancer Statistics Group, Department of Health Sciences, University of York, England.
Johnson, Miriam. Professor of Palliative Medicine, Hull York Medical School, University of Hull, England.

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20140523
Year of Publication
2014

30.
Nurses' perceptions of proactive palliative care: a Dutch focus group study.
MI Verschuur E; M Groot M; van der Sande R.
[Journal Article]
UI: 24852031

BACKGROUND: Early identification of pain and other problems is an important aspect of palliative care. Although nurses have an important role in palliative care, little is known about nurses' perceptions of proactive palliative care.
OBJECTIVES: This study aimed to explore nurses' perceptions and experiences of proactive identification of problems and requirements among patients with palliative care needs.
METHODS: This was a qualitative study in which 16 nurses working in palliative care took part in two focus groups.
RESULTS: All of the nurses underlined the importance of their early involvement in palliative care. Anticipation of possible future problems, advice and information about end-of-life care and palliative care facilities, and assessment of patients' wishes regarding care and preferred place of death were mentioned as important aspects of the early identification of problems and needs. Four themes were identified: the start of proactive palliative care; communication, support, and guidance; advocating for patients; and cooperation with health professionals.
CONCLUSIONS: Nurses' involvement in proactive palliative care is important in supporting patients' palliative care management. Ongoing education, focused on multidisciplinary communication and cooperation, professional development, and empowerment of nurses, remains of utmost importance.
Status
MEDLINE
Patients' experiences of ongoing palliative chemotherapy for metastatic colorectal cancer: a qualitative study.
Cameron J; Waterworth S.

BACKGROUND: Colorectal cancer is the second most common cause of cancer death in New Zealand. With new chemotherapy regimens, patients with metastatic colorectal cancer are now living longer with the condition and its treatment.

AIM: This study aimed to explore patients’ experiences of extended palliative chemotherapy for metastatic colorectal cancer.

METHODS: A convenience sample of 10 outpatients who had been receiving palliative chemotherapy for more than 12 months from a teaching hospital and regional cancer centre in New Zealand participated in face-to-face semi-structured interviews. The data was analysed using a general inductive approach.

FINDINGS: Three key themes were identified: the importance of relationships, presenting a positive face, and life is for living. The importance of interpersonal relationships with health professionals and a sense of comradery with other chemotherapy patients positively affected the patients’ experiences of treatment. Positivity was a key coping strategy that also has negative implications as patients may not reveal their concerns and needs.

CONCLUSION: The key to improving the care of people with advanced cancer is understanding their experiences of care. Communication between the patient, family, and health-care team ensures assumptions that misinterpret attributes of positivity are not made.
32. A qualitative study: potential benefits and challenges of traditional healers in providing aspects of palliative care in rural South Africa.
Campbell LM; Amin NN.
[JOURNAL ARTICLE]
UI: 24815856
INTRODUCTION: This article draws on selected palliative care providers' views and experiences to reflect on the potential benefits and possible challenges of involving traditional healers in palliative care in rural areas of South Africa. There is increasing consensus that palliative care should be offered by a range of professional and non-professional healthcare givers. Including non-professionals such as traditional healers in a palliative care team may strengthen care provisioning as they have intimate knowledge of patients' local culture and spiritual beliefs.
METHODS: Employing the qualitative method of photo-elicitation, one-on-one discussions about the photographs taken by participants were conducted. The participants - 4 palliative care nurses and 17 home-based care workers - were purposively selected to provide in-depth information about their experiences as palliative caregivers in rural homes.
RESULTS: Healthcare workers' experiences revealed that the patients they cared for valued traditional rituals connected to illness, dying, death and bereavement. Participants suggested that traditional healers should be included in palliative care training programs as they could offer appropriate psychological, cultural and spiritual care. A challenge identified by participants was the potential of traditional healers to foster a false sense of longevity in patients facing death.
DISCUSSION: The importance of recognising the value of traditional practices in palliative care should not be underrated in rural South Africa. Traditional healers could enhance palliative care services as they have deep, insider knowledge of patients' spiritual needs and awareness of cultural practices relating to illness, death, dying and bereavement. Incorporating traditional healers into healthcare services where there are differences in the worldviews of healthcare providers and patients, and a sensitivity to mediate cultural differences between caregivers and patients, could have the benefit of providing appropriate care in rural spaces.
CONCLUSIONS: Considering the influences of cultural and spiritual beliefs on the wellbeing of patients living in rural areas, the inclusion of traditional healers in a palliative care team is a sensible move. It is, nevertheless, important to note that unanticipated challenges may arise with respect to power differentials within the palliative care team and to beliefs that contradict medical prognosis.
Status
MEDLINE
Institution
33.
Improving dementia care in nursing homes: experiences with a palliative care symptom-assessment tool (MIDOS).
Krumm N; Larkin P; Connolly M; Rode P; Elsner F.
UI: 24763327
BACKGROUND: In the past decade, the palliative care approach has been used in the care of frail older people living with debilitating chronic conditions, including dementia.
AIM: To describe health professionals' experiences of assessing the symptoms of people with dementia using a cancer-patient-oriented symptom-assessment tool from a palliative care context.
METHOD: This was a qualitative study that used semi-structured interviews (n=13) with clinical staff in three nursing homes prior to and following the implementation of the Minimal Documentation system for Palliative care (MIDOS) tool for assessing symptoms over a period of 6 weeks.
RESULTS: Baseline interviews showed specific concerns about symptom assessment, such as uncertainty about underlying symptoms in residents who appeared to be in distress. After the implementation of the MIDOS tool, participants reported that daily use of the tool was perceived as helpful in evaluating symptoms other than pain and improved internal communication between staff regarding clinical decision making.
CONCLUSION: The MIDOS tool was perceived as a helpful and valuable complement to existing tools. Participants expressed some concerns regarding the subjective nature of perceiving symptoms and clinical decision making. The use of tools such as the MIDOS tool has the potential to enhance the quality of palliative care in dementia care.
Status
MEDLINE
Institution
Krumm, Norbert. Research Assistant, Department of Palliative Medicine, University Hospital RWTH Aachen University, Pauwelsstrasse 57, 52074 Aachen, Germany. Larkin, Philip. Professor of Clinical Nursing (Palliative Care), Head of Discipline Childrens Nursing, and Director of Clinical Academic Partnership, UCD School of Nursing, Midwifery and Health Systems and Our Ladys Hospice and Care Services, UCD College of Health Scie.
The lived experiences of the Sikh population of South East England when caring for a dying relative at home.

Cowan MM.
[Journal Article. Personal Narratives]
UI: 24763326

BACKGROUND: Few ethnic minorities access specialist palliative care (SPC) services when caring for a dying relative at home.

OBJECTIVE: This project aimed to explore and understand the experiences of the Sikh population of south east England when caring for a dying relative at home without support from SPC.

METHODS: Six semi-structured interviews were conducted with carers in Punjabi or English and the transcripts were analysed using interpretative phenomenology.

RESULTS: Five super-ordinate themes were identified: factors leading to the caring role, emotional effects of caring on the carer, impact of caring on the wider family, influence of healthcare services, and religious and cultural influence. The most common emergent theme was lack of support from health professionals, which emerged from a lack of awareness of services. A sense of duty and hard work was apparent throughout, and appeared to sustain the family. There seemed to be a sense of duty to care for the relative at home. Financial concerns were expressed frequently. The decision to adopt the caring role appeared to be made by the entire family. The Sikh faith seemed to give strength to carers. There appeared to be heightened awareness of what other community members think of carers’ actions.

CONCLUSIONS: There is a need for health professionals to reach out to this population to increase awareness of and trust in the services that are available to support care at the end of life. However, an unwillingness to accept assistance may persist in some cases.
35. Concepts of mental capacity for patients requesting assisted suicide: a qualitative analysis of expert evidence presented to the Commission on Assisted Dying.
Price A; McCormack R; Wiseman T; Hotopf M. BMC Medical Ethics. 15:32, 2014. [Journal Article. Research Support, Non-U.S. Gov't]
UI: 24755362

BACKGROUND: In May 2013 a new Assisted Dying Bill was tabled in the House of Lords and is currently scheduled for a second reading in May 2014. The Bill was informed by the report of the Commission on Assisted Dying which itself was informed by evidence presented by invited experts. This study aims to explore how the experts presenting evidence to the Commission on Assisted Dying conceptualised mental capacity for patients requesting assisted suicide and examine these concepts particularly in relation to the principles of the Mental Capacity Act 2005.

METHODS: This study was a secondary qualitative analysis of 36 transcripts of oral evidence and 12 pieces of written evidence submitted by invited experts to the Commission on Assisted Dying using a framework approach.

RESULTS: There was agreement on the importance of mental capacity as a central safeguard in proposed assisted dying legislation. Concepts of mental capacity, however, were inconsistent. There was a tendency towards a conceptual and clinical shift toward a presumption of incapacity. This appeared to be based on the belief that assisted suicide should only be open to those with a high degree of mental capacity to make the decision. The ‘boundaries’ around the definition of mental capacity appeared to be on a continuum between a circumscribed legal ‘cognitive’ definition of capacity (in which most applicants would be found to have capacity unless significantly cognitively impaired) and a more inclusive definition which would take into account wider concepts such as autonomy, rationality, voluntariness and decision specific factors such as motivation for decision making.

CONCLUSION: Ideas presented to the Commission on Assisted Dying about mental capacity as it relates to assisted suicide were inconsistent and in a number of cases at variance with the principles of the Mental Capacity Act 2005. Further work needs to be done to establish a consensus as to what constitutes capacity for this decision and whether current legal frameworks are able to support clinicians in determining capacity for this group.

Status
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36. Exploring occupation roles of hospice family caregivers from Maori, Chinese and Tongan ethnic backgrounds living in New Zealand.
   Angelo J; Wilson L.
   [Journal Article]
   UI: 24578104
   A major challenge to occupational therapists working in palliative care is determining the best ways to help family caregivers who are caring for family members. The purpose of this study was to explore palliative caregiver occupations among Maori, Chinese and Tongan ethnicities. Six informants participated, one woman and one man from each ethnic group. In each of their homes, informants were asked to discuss what it was like caring for their dying family member. The occupational themes resulting from these interviews were food preparation, spirituality and family gathering. Therapists need to be aware of the differences in how people care for family members within their ethnicity. Implications are that occupational therapists can help families identify activities important to them within the main occupational themes: different types of foods and their preparations, various ways to express spirituality and how families gather together members of their extended family. Further, clinicians need to take on the role of a "not-knowing" but curious health-care provider in order to meet the needs of caregivers. The limitation was the small number of participants who all lived in one geographic area. Future studies should include a wider group of ethnicities. Copyright 2014 John Wiley & Sons, Ltd.
   Status
   MEDLINE
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   Date Created
   20140416
   Year of Publication
   2014
Decisions that hasten death: double effect and the experiences of physicians in Australia. Trankle SA.
BMC Medical Ethics. 15:26, 2014. [Journal Article. Research Support, Non-U.S. Gov't]
UI: 24666431

BACKGROUND: In Australian end-of-life care, practicing euthanasia or physician-assisted suicide is illegal. Despite this, death hastening practices are common across medical settings. Practices can be clandestine or overt but in many instances physicians are forced to seek protection behind ambiguous medico-legal imperatives such as the Principle of Double Effect. Moreover, the way they conceptualise and experience such practices is inconsistent. To complement the available statistical data, the purpose of this study was to understand the reasoning behind how and why physicians in Australia will hasten death.

METHOD: A qualitative investigation was focused on palliative and critical/acute settings. A thematic analysis was conducted on semi-structured in-depth interviews with 13 specialist physicians. Attention was given to eliciting meanings and experiences in Australian end-of-life care.

RESULTS: Highlighting the importance of a multidimensional approach, physicians negotiated multiple influences when death was regarded as hastened. The way they understood and experienced end-of-life care practices were affected by politico-religious and cultural influences, medico-legal imperatives, and personal values and beliefs. Interpersonal and intrapsychic aspects further emphasised the emotional and psychological investment physicians have with patients and others. In most cases death occurred as a result of treating suffering, and sometimes to fulfil the wishes of patients and others who requested death. Experience was especially subject to the efficacy with which physicians negotiated complex but context-specific situations, and was reflective of how they considered a good death. Although many were compelled to draw on the Principle of Double Effect, every physician reported its inadequacy as a medico-legal guideline.

CONCLUSIONS: The Principle of Double Effect, as a simplistic and generalised guideline, was identified as a convenient mechanism to protect physicians who inadvertently or intentionally hastened death. But its narrow focus on the physician's intent illuminated how easily it may be manipulated, thus impairing transparency and a physician's capacity for honesty. It is suggested the concept of "force majeure" be examined for its applicability in Australian medical end-of-life law where, consistent with a multidimensional and complex world, a physician's motivations can also be understood in terms of the emotional and psychological pressures they face in situations that hasten death.

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38.
Connor S; Sisimayi C; Downing J; King E; Lim Ah Ken P; Yates R; Marston J.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 24675539

UNICEF and the International Children's Palliative Care Network undertook a joint analysis in three sub-Saharan countries—Zimbabwe, South Africa, and Kenya—to estimate the palliative care need among their children and to explore these countries' capacities to deliver children's palliative care (CPC). This report concerns the findings from South Africa. The study adopted a cross-sectional mixed-methods approach using both quantitative and qualitative data obtained from primary and secondary sources. CPC need was estimated using prevalence and mortality statistics. The response to the need and existing gaps were analysed using data obtained from a literature review, interviews with key persons, and survey data from service providers. The findings show very limited CPC service coverage for children in the public sector. In addition, services are mainly localised, with minimal reach. Less than 5% of the children needing care in South Africa are receiving it, with those receiving it being closer to the end of life. Barriers to the delivery of CPC include fear of opioid use, lack of education on CPC, lack of integration into the primary care system, lack of policies on CPC, and lack of community and health professional awareness of CPC needs and services. Estimating the need for CPC is a critical step in meeting the needs of children with life-threatening conditions and provides a sound platform to advocate for closure of the unacceptably wide gaps in coverage.

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20140328
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2014
39.
German general practitioners' views on their involvement and role in cancer care: a qualitative study.
Dahlhaus A; Vanneman N; Guethlin C; Behrend J; Siebenhofer A.
Family Practice. 31(2):209-14, 2014 Apr.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 24465025
BACKGROUND: The multidisciplinary and sequential nature of cancer care makes continuity of care for patients difficult. Cancer patients have often known their general practitioners (GPs) for years and are often in constant contact with them. Objective(s). We examined German GPs' views on their involvement in the care of cancer patients.
METHODS: We conducted semi-structured interviews with 30 German GPs. Purposeful sampling was applied to secure maximum heterogeneity. Interviews were recorded, transcribed and then analyzed using qualitative content analysis according to Mayring.
RESULTS: GPs perceive a clear involvement in the latter phase of cancer care but a mainly sporadic role (as and when required) in earlier phases. They think that greater care contributions from GPs are generally beneficial to cancer patients, as their ability to take the patient's history, surroundings and co-morbidities into account enables them to provide more patient-centred care. GPs want to stay involved and to know how their cancer patients are progressing, and they complain about slow or non-existent information sharing between providers, as well as insufficient care coordination. They pro-actively try to overcome these obstacles through direct contact with patients and physicians, and by building networks of trusted care providers.
CONCLUSIONs: Given their long-lasting and close relationships with cancer patients, GPs are in a position to accompany them throughout the whole process of cancer care. However, such general involvement is as yet uncommon. Shared care models may have the potential to take into account the complementary character of primary and specialist care.
Status
MEDLINE
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Date Created
20140324
Year of Publication
2014
40.
Among neighbors: an ethnographic account of responsibilities in rural palliative care.
Pesut B; Robinson CA; Bottorff JL.
[Journal Article.  Research Support, Non-U.S. Gov't]
UI: 23510757
OBJECTIVE: Building high quality palliative care in rural areas must take into account the cultural dimensions of the rural context. The purpose of this qualitative study was to conduct an exploration of rural palliative care, with a particular focus on the responsibilities that support good palliative care from rural participants’ perspectives.
METHOD: This ethnographic study was conducted in four rural communities in Western Canada between June 2009 and September 2010. Data included 51 days of field work, 95 semistructured interviews, and 74 hours of direct participant observation. Thematic analysis was used to provide a descriptive account of rural palliative care responsibilities.
RESULTS: Findings focus on the complex web of responsibilities involving family, healthcare professionals, and administrators. Family practices of responsibility included provision of direct care, managing and coordinating care, and advocacy. Healthcare professional practices of responsibility consisted of interpreting their own competency in relation to palliative care, negotiating their role in relation to that interpretation, and individualizing care through a bureaucratic system. Administrators had three primary responsibilities in relation to palliative care delivery in their community: navigating the politics of palliative care, understanding the culture of the community, and communicating with the community.
SIGNIFICANCE OF RESULTS: Findings provide important insights into the complex ways rurality influences understandings of responsibility in palliative care. Families, healthcare providers, and administrators work together in fluid ways to support high quality palliative care in their communities. However, the very fluidity of these responsibilities can also work against high quality care, and are easily disrupted by healthcare changes. Proposed healthcare policy and practice changes, particularly those that originate from outside of the community, should undergo a careful analysis of their potential impact on the longstanding negotiated responsibilities.
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Bottorff, Joan L. Faculty of Health and Social Development, School of Nursing, University of British Columbia, Kelowna, British Columbia, Canada.
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2014
<td colspan=""
Understanding psycho-social processes underpinning engagement with services in motor neurone disease: a qualitative study.

Foley G; Timonen V; Hardiman O.

[Journal Article.  Research Support, Non-U.S. Gov't]
UI: 24637571

BACKGROUND: People with motor neurone disease access healthcare services from disease onset to end-of-life care, but there has been paucity of research on how people with motor neurone disease understand and use healthcare services.

AIM: To identify key psycho-social processes that underpin how people with motor neurone disease engage with healthcare services.

DESIGN: Grounded theory approach comprising in-depth qualitative interviews was used in this study. Data were collected and analysed using open, axial and selective coding procedures.

SETTING/PARTICIPANTS: A total of 34 people with motor neurone disease were recruited from the Irish motor neurone disease population-based register.

RESULTS: We identified that control, reassurance, resignation and trust are key variables that shape how people with motor neurone disease engage with healthcare services. Participants exerted control in care to cope with loss. Most participants were resigned to death and sought reassurances from healthcare professionals about end-of-life care. Participants questioned the benefit of life-sustaining interventions in motor neurone disease and few of them associated life-sustaining interventions with palliative care. Participants trusted healthcare professionals who reassured them about their care and who were attuned to how they were coming to terms with loss.

CONCLUSION: This study identified new and important aspects of control, trust and reassurance which shed light on how people with motor neurone disease engage with healthcare professionals and approach end-of-life care. People with motor neurone disease exert control in care and meaningful relationships with healthcare professionals are important to them. Some people with motor neurone disease prefer to die without life-sustaining interventions.

Status
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2014
<td colspan=""/>
Hospice support and the transition to adult services and adulthood for young people with life-limiting conditions and their families: a qualitative study.
Kirk S; Fraser C.
[Journal Article]
UI: 24142761
BACKGROUND: Transition to adult services and adulthood is now a prospect for young people with life-limiting conditions requiring palliative care. Little is known about their transition experiences or how children's hospices can support a young adult population during/following transition.
AIMS: (1) To examine how young people with life-limiting conditions and their parents experience transition. (2) To identify families' and hospice staff's perceptions of family support needs during transition. (3) To identify the implications for children's hospices.
DESIGN: Qualitative study using in-depth, semi-structured interviews. Analysis used a grounded theory approach.
SETTING/PARTICIPANTS: A total of 39 participants recruited from one children's hospice in the United Kingdom.
RESULTS: Transition planning was absent or poorly coordinated; for most families, there were no equivalent adult health/social services. Consequently, it was a time of uncertainty and anxiety for families. Moving to a young adult unit was a positive experience for young people as the building/support model recognised their adult status. However, they had unmet needs for emotional support and accessing information/services to realise their aspirations. Parents had unmet emotional needs and were unclear of support available once their children reached adulthood. Staff identified training needs in relation to working with adults, providing emotional support and acting as an advocate/key worker.
CONCLUSIONS: Providing an appropriate building is only one aspect of developing support for young adults. A different model of support is needed, one which promotes young people's independence and provides emotional support while continuing to support parents and siblings. Hospices could play a role in transition support and coordination.
Impact of supervised drug consumption services on access to and engagement with care at a palliative and supportive care facility for people living with HIV/AIDS: a qualitative study.

McNeil R; Dilley LB; Guirguis-Younger M; Hwang SW; Small W.


INTRODUCTION: Improvements in the availability and effectiveness of highly active antiretroviral therapy (HAART) have prolonged the lives of people living with HIV/AIDS. However, mortality rates have remained high among populations that encounter barriers to accessing and adhering to HAART, notably people who use drugs. This population consequently has a high burden of illness and complex palliative and supportive care needs, but is often unable to access these services due to anti-drug policies and discrimination. In Vancouver, Canada, the Dr. Peter Centre (DPC), which operates a 24-bed residential HIV/AIDS care facility, has sought to improve access to palliative and supportive care services by adopting a comprehensive harm reduction strategy, including supervised injection services. We undertook this study to explore how the integration of comprehensive harm reduction services into this setting shapes access to and engagement with care.

METHODS: Qualitative interviews were conducted with 13 DPC residents between November 2010 and August 2011. Interviews made use of a semistructured interview guide which facilitated discussion regarding how the DPC Residence's model of care (a) shaped healthcare access, (b) influenced healthcare interactions and (c) impacted drug use practices and overall health. Interview transcripts were analysed thematically.

RESULTS: Participant accounts highlight how the harm reduction policy altered the structural-environmental context of healthcare services and thus mediated access to palliative and supportive care services. Furthermore, this approach fostered an atmosphere in which drug use could be discussed without the risk of punitive action, and thus increased openness between residents and staff. Finally, participants reported that the environmental supports provided by the DPC Residence decreased drug-related risks and improved health outcomes, including HAART adherence and survival.

CONCLUSIONS: This study highlights how adopting comprehensive harm reduction services can serve to improve access and equity in palliative and supportive care for drug-using populations.

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Source: NLM. PMC3955762
Date Created
20140317
44. Why a carefully designed, nurse-led intervention failed to meet expectations: the case of the Care Programme for Palliative Radiotherapy.

Vahedi Nikbakht-Van de Sande CV; Braat C; Visser AP; Delnoij DM; van Staa AL. European Journal of Oncology Nursing. 18(2):151-8, 2014 Apr.

[Journal Article.  Research Support, Non-U.S. Gov't]

PURPOSE OF THE RESEARCH: Implement and evaluate the Care Programme for Palliative Radiotherapy (CPPR) in the Outpatient Clinic of the Department of Radiotherapy, Erasmus MC-Cancer Institute, Rotterdam, The Netherlands.

METHODS: Participatory Action Research (PAR). Qualitative descriptive design: participatory observations, semi-structured interviews with patients and professionals and focus groups with professionals; content analysis of documents.

SAMPLE: Patients with impending paraplegia due to metastatic spinal cord compression, nurse practitioners (NPs), nurse manager, staff and ward nurses, radiographers, radiotherapists and medical doctors.

KEY RESULTS: After a shift from inpatient to outpatient radiotherapy treatment, patients and healthcare professionals perceived shortcomings in the oncological chain care. The CPPR was developed in a participative way giving a key role to the NP. Evaluation after implementation of the programme showed that patients and professionals were predominantly positive about its effects. However, implementation was not sustained due to lack of institutional and managerial support.

CONCLUSIONS: The technological innovation far preceded the organisational changes needed to provide innovative, patient-centred care. Implementing this programme with a central role for the NP was seen as the solution to the problems identified. However, in spite of the systematic approach using PAR, the programme was not successful in bringing about sustained improvements. NPs fulfil a valuable role in the care and support of patients with palliative care needs but need institutional support. More attention should have paid to the organisational context. Involve all relevant actors; use a participatory approach to enhance commitment; ensure the support of management during the whole project. Copyright 2013 Elsevier Ltd. All rights reserved.

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Disclosing terminal diagnosis to children and their families: palliative professionals' communication barriers. [Review]
Coad J; Patel R; Murray S.
[Journal Article. Review]
UI: 24593008

Few studies have fully explored the problem of communication barriers in pediatric palliative care, particularly the detrimental effects of poor interaction between staff and families on children's health and well-being. A literature review was undertaken to expand the current body of knowledge about staff to patient communications. Articles meeting the inclusion criteria (N = 15) were systematically read and summarized using a data extraction sheet. A narrative synthesis identified 5 overarching themes as barriers to communication. Improvements in staff education and individualized palliative care plans for children and their families may help to overcome communication barriers.

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Date Created
20140305
Year of Publication
2014
Continuous sedation until death: the everyday moral reasoning of physicians, nurses and family caregivers in the UK, The Netherlands and Belgium.

Raus K; Brown J; Seale C; Rietjens JA; Janssens R; Bruinsma S; Mortier F; Payne S; Sterckx S.

BMC Medical Ethics. 15:14, 2014. [Journal Article. Research Support, Non-U.S. Gov't]

BACKGROUND: Continuous sedation is increasingly used as a way to relieve symptoms at the end of life. Current research indicates that some physicians, nurses, and relatives involved in this practice experience emotional and/or moral distress. This study aims to provide insight into what may influence how professional and/or family carers cope with such distress.

METHODS: This study is an international qualitative interview study involving interviews with physicians, nurses, and relatives of deceased patients in the UK, The Netherlands and Belgium (the UNBIASED study) about a case of continuous sedation at the end of life they were recently involved in. All interviews were transcribed verbatim and analysed by staying close to the data using open coding. Next, codes were combined into larger themes and categories of codes resulting in a four point scheme that captured all of the data. Finally, our findings were compared with others and explored in relation to theories in ethics and sociology.

RESULTS: The participants’ responses can be captured as different dimensions of ‘closeness’, i.e. the degree to which one feels connected or ‘close’ to a certain decision or event. We distinguished four types of ‘closeness’, namely emotional, physical, decisional, and causal. Using these four dimensions of ‘closeness’ it became possible to describe how physicians, nurses, and relatives experience their involvement in cases of continuous sedation until death. More specifically, it shined a light on the everyday moral reasoning employed by care providers and relatives in the context of continuous sedation, and how this affected the emotional impact of being involved in sedation, as well as the perception of their own moral responsibility.

CONCLUSION: Findings from this study demonstrate that various factors are reported to influence the degree of closeness to continuous sedation (and thus the extent to which carers feel morally responsible), and that some of these factors help care providers and relatives to distinguish continuous sedation from euthanasia.
47. The impact of advanced heart failure on social, psychological and existential aspects and personhood.
Leeming A; Murray SA; Kendall M.
[Journal Article]
UI: 24463728
BACKGROUND: Heart failure is a common cause of death and causes significant morbidity in its advanced stage. As the illness progresses, lack of physical health may overshadow psychological, social and existential distress.
AIMS: To explore the impact of advanced heart failure on other aspects of the patients' lives.
METHODS: We undertook a secondary analysis of interview data generated for a qualitative longitudinal study looking at the experiences of patients with advanced heart failure, and their family and professional carers. A sub set of patient, family and professional carer interview transcripts was selected for thematic analysis. The sample was chosen to reflect a range of age, gender and social situations.
RESULTS: Eighteen transcripts from five cases were examined. Three key themes were identified: 1) social isolation; 2) psychological issues and coping strategies; and 3) existential concerns.
CONCLUSIONS: Psychosocial and existential issues are important aspects of the lives of patients suffering from heart failure. Holistic management should encompass an awareness of exploration and support for these dimensions.
Status
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Date Created
20140304
Year of Publication
2014
48. End-of-life preferences and presence of advance directives among ethnic populations with severe chronic cardiovascular illnesses.
Piamjariyakul U; Myers S; Werkowitch M; Smith CE.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 24434048
BACKGROUND: Little end-of-life planning occurs among ethnic minorities with severe cardiovascular illnesses.

AIM: The purpose of this study was to explore end-of-life preferences and determine the presence of signed end-of-life advanced directives.

METHODS: Thirty ethnic minority patients volunteered for an open-ended question interview. Content analysis was used to summarize responses into themes using patients' terms.

FINDINGS: Five themes emerged: (a) importance of family involvement in care at end of life; (b) being pain free (or pain controlled) at the end of life; (c) having a comfortable environment for death was desired; (d) wanting no procedures for prolonging life; and (e) desiring a relationship with a professional for end-of-life decision making (reported as inconsistently available). New unique findings were related to concerns about multiple and repeatedly rotating professionals not allowing these ethnic patients end-of-life discussions and fear that signing forms would lead to deportation. Overall, 50% of the participants had signed standard advanced directives as requested upon entry to the home care agency.

CONCLUSIONS: Most of these very ill patients did readily discuss these sensitive issues with the research nurse. Cardiovascular training in end-of-life care should include sensitivity to ethnic and cultural preferences and competencies in interviewing on sensitive topics.

Status
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Date Created
20140304
Year of Publication
2014

49.
Perception and fulfillment of cancer patients' nursing professional social support needs: from the health care personnel point of view.
Hong J; Song Y; Liu J; Wang W; Wang W.
Supportive Care in Cancer. 22(4):1049-58, 2014 Apr.
[Journal Article. Research Support, Non-U.S. Gov't]
Ut: 24287509

PURPOSE: This study aimed to (1) explore the needs of cancer patients regarding common nursing professional social support from the perspective of physicians and nurses, (2) identify what type of needs clinical nurses actually fulfill and what remains to be improved, and (3) analyze the potential reasons for the gap between the identified needs and those that are fulfilled.

METHODS: A qualitative approach using focus group interviews was adopted to explore the perception and provision of cancer patients' needs regarding nursing professional social support. A purposive sample of 32 health care professionals was recruited from two teaching hospitals in
Anhui province, China. Five focus group interviews were conducted and all interviews were tape-recorded and transcribed verbatim. A content analysis was performed with the data.

RESULTS: The healthcare professionals perceived various nursing professional support needs of cancer patients; these include informational, emotional/psychological, and technical support needs; the mobilization of social resources; and palliative care during certain stages. The findings also indicated that there are still many unmet needs, especially needs related to the mobilization of social resources and palliative care. The reasons for the deficiencies in the fulfillment of these needs varied and included both subjective and objective aspects, such as the patients’ lack of awareness of how to search for professional support, a shortage of professional staff, and the lack of a culturally appropriate assessment tool.

CONCLUSIONS: Cancer patients’ supportive care needs were not always fully provided by nurses, even when these needs were identified by healthcare professionals. Nursing professional social support needs should be assessed quickly and effectively so that the appropriate interventions can be offered to cancer patients.


Current literature reports that nurses are the members of the health-care team who have the most contact with patients facing a life-threatening illness. The multidisciplinary palliative care approach means that hospice and palliative care nurses require a consistent theoretical foundation in order to be confident of and able to explain their role. The aim of this paper is to describe existing palliative care and hospice nursing models and theories and to identify their core concepts. Literature published between 2002 and 2012 on such models was reviewed and subjected to content analysis. Ten core concepts were identified that fell into three categories: patient, nurse, and therapeutic relationship. The themes and values identified in the end-of-life nursing models and theories are congruent with palliative care best practices based on a patient-centred and an interdisciplinary teamwork approach. In developing a therapeutic relationship with
patients, nurses have a 'privileged' experience that may lead to existential growth and job satisfaction.


AIM: The purpose of this study was to identify Iranian nurses' perceptions of palliative care for patients with cancer pain.

METHODS: The study took a qualitative approach. Semi-structured interviews were held with 15 nurses with Bachelor's degrees working in three teaching hospitals in Iran. Transcripts of the interviews underwent content analysis, and categories were extracted from the material.

FINDINGS: The findings came under two main categories: management of physical pain and psychological empowerment. Management of physical pain had two subcategories: the importance of communication, and pain palliation using drugs. Psychological empowerment also had two subcategories: supportive behaviour and distress reduction.

CONCLUSION: The sample felt that palliative care for patients with cancer pain must include psychological empowerment, support, and communication as well as physical pain relief.
52. Quality of end-of-life care for those who die at home: views and experiences of bereaved relatives and carers.
Lees C; Mayland C; West A; Germaine A.
[Journal Article]
UI: 24577211
Little is known about the quality of the end-of-life care patients receive at home. This paper reports findings from a study that explored bereaved relatives’ and carers’ experiences of end-of-life care at home using the Care of the Dying Evaluation (CODE) questionnaire. Narrative data from questionnaires completed by 72 carers of patients who had died at home in the North West of England underwent qualitative analysis. In general good quality care was provided, but there were times when adequate support was not evident in relation to pain control and what to expect when death was imminent. The study provides useful information for those who provide end-of-life care at home.
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Date Created
20140228
Year of Publication
2014

53. The “specter” of cancer: exploring secondary trauma for health professionals providing cancer support and counseling.
Breen LJ; O’Connor M; Hewitt LY; Lobb EA.
[Journal Article. Research Support, Non-U.S. Gov’t]
Health professionals are vulnerable to occupational stress and tend to report high levels of secondary trauma and burnout; this is especially so for those working in "high-death" contexts such as cancer support and palliative care. In this study, 38 health professionals (psychologists, social workers, pastoral carers/chaplains, nurses, group facilitators, and a medical practitioner) who provide grief support and counseling in cancer and palliative care each participated in a semistructured interview. Qualitatively, a grounded theory analysis revealed four themes: (a) the role of health professionals in supporting people who are experiencing grief and loss issues in the context of cancer, (b) ways of working with patients with cancer and their families, (c) the unique qualities of cancer-related loss and grief experiences, and (d) the emotional demands of the work and associated self-care. The provision of psychological services in the context of cancer is colored by the specter of cancer, an unseen yet real phenomenon that contributes to secondary trauma and burnout. The participants' reported secondary trauma has serious repercussions for their well-being and may compromise the care they provide. The findings have implications for the retention and well-being of personnel who provide psychosocial care in cancer and the quality and delivery of services for people with cancer and their families.

54.

Identification of potentially avoidable hospitalizations in patients with GI cancer.
Brooks GA; Abrams TA; Meyerhardt JA; Enzinger PC; Sommer K; Dalby CK; Uno H; Jacobson JO; Fuchs CS; Schrag D.
[Journal Article. Research Support, N.I.H., Extramural. Research Support, Non-U.S. Gov't]
UI: 24419123
PURPOSE: To identify and characterize potentially avoidable hospitalizations in patients with GI malignancies.
PATIENTS AND METHODS: We compiled a retrospective series of sequential hospital admissions in patients with GI cancer. Patients were admitted to an inpatient medical oncology or palliative care service between December 2011 and July 2012. Practicing oncology clinicians
used a consensus-driven medical record review process to categorize each hospitalization as "potentially avoidable" or "not avoidable." Patient demographic and clinical data were abstracted, and quantitative and qualitative analyses were performed to identify patient characteristics and outcomes associated with potentially avoidable hospitalizations.

RESULTS: We evaluated 201 hospitalizations in 154 unique patients. The median age was 62 years, and colorectal cancer was the most common diagnosis (32%). The majority of hospitalized patients had metastatic cancer (81%). In all, 53% of hospitalizations were attributable to cancer symptoms, and 28% were attributable to complications of cancer treatment. Medical oncologists identified 39 hospitalizations (19%) as potentially avoidable. Hospitalizations were more likely to be categorized as potentially avoidable for patients with the following characteristics: age > 70 years (odds ratio [OR], 2.63; 95% CI, 1.15 to 6.02), receipt of an oncologist's advice to consider hospice (OR, 6.09; 95% CI, 2.54 to 14.58), or receipt of three or more lines of chemotherapy (OR, 2.68; 95% CI, 1.01 to 7.08). Ninety-day mortality was higher after avoidable hospitalizations compared with hospitalizations that were not avoidable (OR, 6.4; 95% CI, 1.8 to 22.3).

CONCLUSION: Potentially avoidable hospitalizations are common in patients with advanced GI cancer. The majority of potentially avoidable hospitalizations occurred in patients with advanced treatment-refractory cancers near the end of life.

55.
Informational needs of patients with metastatic breast cancer: what questions do they ask, and are physicians answering them?.
Danesh M; Belkora J; Volz S; Rugo HS.
[Journal Article]
UI: 24142513
In the setting of breast oncology consultations, we sought to understand communication patterns between patients with advanced breast cancer and their oncologists during visits with Decision Support Services. This is a descriptive study analyzing themes and their frequencies of premeditated question lists of patients with metastatic breast cancer. We identified topics physicians most commonly discussed among themes previously found, documenting questions
patients with metastatic breast cancer prepare for physician consultations and oncologists' response. Inclusion criteria were as follows: diagnosis of metastatic breast cancer, completion of a question list before meeting with an oncologist, and receipt of a summary of the consultation. We identified 59 women with metastatic breast cancer who received both documents. We reviewed the question lists and consultation summaries of these patients. Of the 59 patients whose documents we reviewed, patients most often asked about prognosis (38), symptom management (31), clinical trials (43), and quality of life (38). Physicians answered questions about prognosis infrequently (37% of the time); other questions that were answered more than commonly are the following: symptom management (81%), clinical trials (79%), and quality of life (66%). Breast cancer patients have many questions regarding their disease, its treatment, and symptoms, which were facilitated in this setting by Decision Support Services. Question lists may be insufficient to bridge the divide between physicians and patient information needs in the setting of metastatic breast cancer, particularly regarding prognosis. Patients may need additional assistance defining question lists, and physicians may benefit from training in communication, particularly regarding discussions of prognosis and end of life.

56. Exploring public awareness and perceptions of palliative care: a qualitative study. McIlfatrick S; Noble H; McCorry NK; Roulston A; Hasson F; McLaughlin D; Johnston G; Rutherford L; Payne C; Kernohan G; Kelly S; Craig A. Palliative Medicine. 28(3):273-80, 2014 Mar. [Journal Article]
UI: 24026003
BACKGROUND: Research suggests that the public appear to be confused about the meaning of palliative care. Given the ageing population and associated increase in the number of patients requiring palliative care, it is vital to explore the public's understanding of this concept. Health-promoting palliative care seeks to translate hospice and palliative care ideals into broader public health practice.
AIM: To explore public perceptions of palliative care and identify strategies to raise awareness. DESIGN: An exploratory qualitative approach.
PARTICIPANTS: Semi-structured telephone interviews were undertaken (N = 50) with members of the public who volunteered to participate in the study. The interviews focused on knowledge and perceptions of palliative care, expectations of palliative care services and the identification of
strategies to raise public awareness of palliative care. The interviews were audio recorded and content analysed.

RESULTS: Most participants had a general knowledge of palliative care, largely influenced by their own personal experience. They identified that palliative care was about caring for people who were dying and maintaining comfort in the last days of life. Participant's expectations of services included the following: holistic support, symptom management, good communication and practical support to enable choice and carer support. Key aspects identified for promoting palliative care were the development of understanding and use of the term itself and targeted educational strategies.

CONCLUSION: Experience of palliative care generates understanding in the general public who also have ideas for increasing knowledge and awareness. The findings can inform policymakers about strategies to raise public awareness of palliative care.

Status
MEDLINE
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Noble, Helen; McCorry, Noleen K; Roulston, Audrey; Hasson, Felicity; McLaughlin, Dorry; Johnston, Gail; Rutherford, Lesley; Payne, Cathy; Kernohan, George; Kelly, Sheila; Craig, Avril.
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Date Created
20140210
Year of Publication
2014

57.
Observations of professional-patient relationships: a mixed-methods study exploring whether familiarity is a condition for nurses' provision of psychosocial support.
Hill HC; Paley J; Forbat L.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23935017
BACKGROUND: There is a popular belief that the professional-patient relationship is a prerequisite in the provision of psychosocial support. Studies suggest that professionals must know, or be familiar with, a patient in order to effectively provide psychosocial support.
AIM: To examine the association between familiarity and the provision of psychosocial care by professionals.
DESIGN: A mixed-methods study involving participant observation, interviews and organisational and documentary analysis was conducted over 8 months in an inpatient hospice setting.
PARTICIPANTS: In total, 38 nurses (registered and auxiliary) and 47 patients were included in a maximum variation sampling strategy. Data were analysed using both qualitative and quantitative techniques.
RESULTS: The data disconfirm the belief that familiarity is either a necessary or sufficient condition for the provision of psychosocial support. Nurses familiar with patients did not necessarily respond to patients' psychosocial needs, and nurses with no prior contact with the patient immediately dealt with psychosocial needs.

CONCLUSION: Psychosocial support can be provided on a patient's first contact with a clinician and does not rely on building a professional-patient relationship. This suggests that high-quality psychosocial care can be provided in the short time frame available to palliative care clinicians.
59. 
End-of-life decisions for extremely low-gestational-age infants: why simple rules for complicated decisions should be avoided. [Review] 
Dupont-Thibodeau A; Barrington KJ; Farlow B; Janvier A. 
[Journal Article. Review] 
UI: 24468567 
Interventions for extremely preterm infants bring up many ethical questions. Guidelines for intervention in the "perivable" period generally divide infants using predefined categories, such as "futile," "beneficial," and "gray zone" based on completed 7-day periods of gestation; however, such definitions often differ among countries. The ethical justification for using gestational age as the determination of the category boundaries is rarely discussed. Rational criteria used to make decisions regarding life-sustaining interventions must incorporate other important prognostic information. Precise guidelines based on imprecise data are not rational. Gestational age-based guidelines include an implicit judgment of what is deemed to be an unacceptably poor chance of "intact" survival but fail to explore the determination of acceptability. Furthermore, unclear definitions of severe disability, the difficulty, or impossibility, of accurately predicting outcome in the prenatal or immediate postnatal period make such simplistic formulae inappropriate. Similarly, if guidelines for intervention for the newborn are based on the "qualitative futility" of survival, it should be explicitly stated and justified according to established ethical guidelines. They should discuss whether newborn infants are morally different to older individuals or explain why thresholds recommended for intervention are different to recommendations for those in older persons. The aim should be to establish individualized goals of care with families while recognizing uncertainty, rather than acting on labels derived from gestational age categories alone. Copyright 2014 Elsevier Inc. All rights reserved. 
Status 
MEDLINE 
Institution
Clinical nurse specialists perspectives on advance care planning conversations: a qualitative study.

Boot M; Wilson C.


[Journal Article]

UI: 24464168

OBJECTIVE: The aim of the study was to identify the challenges experienced by clinical nurse specialists (CNSs) when facilitating advance care planning (ACP) conversations with terminally ill patients. This paper focuses on the factors that influence CNSs when they are deciding whether to open an ACP discussion.

METHODS: Semi-structured interviews were used to collect data from eight purposively selected palliative care CNSs working in two different community teams. The interviews were recorded, transcribed, and analysed to identify themes.

FINDINGS: ACP required the CNSs to ‘walk a tightrope’, balancing potential harm with purported benefit. The nurses identified that their decision to introduce an ACP discussion was influenced by three key factors: an assessment of the patient's readiness to discuss the topic, their physical condition, and the nurse's relationship with the patient and family.

CONCLUSION: ACP involves risk-taking on the part of those initiating it, owing to the potential for unforeseen or negative consequences. Further research is required to identify the factors that facilitate nurses involving patients in ACP.
[Palliative care for newborns: practices in a level-III unit during a 5-year period]. [French]
Mazille N; Litzler-Renault S; Weider I; Donato L; Astruc D; Kuhn P.
[English Abstract. Journal Article. Observational Study]
UI: 24398077
UNLABELLED: The "Patients' rights and end-of-life care" act known as "Leonetti's Law" promulgated in 2005 has promoted the use of palliative care to avoid unreasonable obstinacy when life-sustaining treatment appears disproportionate. Very little is known about this new practice for newborns in French neonatal units.
AIMS: To describe and evaluate the practice of palliative care in the newborn (mode of entry, characteristics, and modalities) and its evolution over time.
PATIENTS AND METHODS: Ambispective observational study conducted in a level III neonatal center. We included all newborns presenting conditions for which palliative care was introduced. Quantitative and qualitative analyses of routinely collected data, recorded from medical and nursing charts. We compared the recorded data between periods P1 (2006-2007) and P2 (2008-2010) using the Chi(2) test to assess changes over time.
RESULTS: A total of 93 newborns benefited from palliative care during the study period. The main medical conditions motivating palliative care initiation in the newborns were severe complications of prematurity (36/93, 39%), anoxic-ischemic encephalopathy (19/93, 20.5%), severe malformations (8/93, 8.5%), severe congenital heart disease (8/93, 8.5%), and other various etiologies (22/93, 23.5%). Both the number of newborns in palliative care/total number of births and the number of deaths after palliative care/total number of neonatal deaths remained stable. In case of prenatal diagnosis (n=31), there was an increase in the number of "palliative care from birth projects" (13/22 in P2 vs. 1/9 in P1, P=0.02). Collective meetings during the decision process were significantly more frequently reported in the infants' charts in P2 (48/59 in P2 vs. 18/34 in P1, P<0.01). Withdrawing and withholding life-sustaining treatment and limiting procedures of care and/or procedures of surveillance/monitoring were more frequent in P2 as compared to P1, respectively 12/34 vs. 37/59 (P=0.02) and 14/34 vs. 39/59 (P=0.03). A titration of level III analgesics treatment was high in both periods and remained stable. However, a trend toward an increase of systematic pain evaluation over time was observed (81.6% in P2 vs. 64.5% in P1; P=0.085).
CONCLUSION: A significant number of newborns affected by various pathologies undergo neonatal palliative care. Despite their recent introduction in neonatal medicine, palliative care practices have changed significantly. These practices are mostly in compliance with the "patients' rights and end-of-life care" act promulgated in France in 2005. Copyright 2013 Elsevier Masson SAS. All rights reserved.
INTRODUCTION: Prematurity is one of the etiologies for severe neurological complications. Decisions to withdraw therapeutics, including artificial nutrition and hydration (ANH), are sometimes discussed. But can one withdraw ANH if the patient is a child suffering from severe neurological conditions, based on his best interests? The aim of this study was to further the understanding of the complexity of the withdrawal of ANH and its implementation in the neonatal intensive care unit (NICU).

METHOD: This qualitative preliminary study based on a questionnaire was conducted on the staff in the NICU of the Pontoise medical center (France) in February 2012. The results were compared with the current knowledge on this issue and sociological data.

RESULTS: Ten of the hospital staff members responded to the questionnaire: 60% considered ANH as a treatment, but the status of ANH (i.e., treatment or care) remained undefined for several respondents. Comparison with the withdrawal of mechanical ventilation or adult practices seemed to be inadequate. The staff had little experience in the domain and therefore few certainties on practices. Half of the respondents indicated that terminal sedation needed to be used. For the other half, it depended on the patient's pain. Timing was also an important notion given that the newborn is a being developing and evolving each in its own way.
CONCLUSION: The withdrawal of ANH remains controversial in the NICU. Humanity, culture, and the relationship to others are ever present in the decision-making process, creating a moral opposition above and beyond ethical reflection. 

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The experiences of palliative care health service provision for people with non-malignant respiratory disease and their caregivers: an all-Ireland study.

Mc Veigh C; Reid J; Hudson P; Larkin P; Porter S; Marley AM. Journal of Advanced Nursing. 70(3):687-97, 2014 Mar.

[Journal Article. Research Support, Non-U.S. Gov't. Validation Studies]

UI: 23991762

AIM: To explore the perception of palliative care provision for people with non-malignant respiratory disease from the perspective of bereaved caregivers.

BACKGROUND: It is recognized that the majority of patients diagnosed with a malignant disease will have access to palliative care provision. However, it is less clear if the same standards of palliative care are available to those with non-malignant respiratory disease in Northern Ireland and the Republic of Ireland.

DESIGN: A qualitative study based on broad interpretivism.

METHODS: This research is a PhD study funded by the Department of Education and Learning in Northern Ireland (awarded February 2011). Data collection will consist of two stages; interviews with 20 bereaved caregivers of people who have died 3-18 months previously with a diagnosis of non-malignant respiratory disease and four focus groups with healthcare professionals involved in the care of this client group. This study will be carried out at four healthcare sites across the Island of Ireland. The data will be analysed using thematic content analysis. Research Ethics committee approval was obtained (March 2012).

DISCUSSION: This research will explore the experiences of patients with Chronic Obstructive Pulmonary Disease, Interstitial Lung Disease and Bronchiectasis and their caregivers from the
perspective of the bereaved caregiver. The outcomes of this study will provide a critical first step in the development of more responsive palliative care for this client group and have important implications for future practice and policy in the palliative care provided to this client group. Copyright 2013 John Wiley & Sons Ltd.

Status
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Date Created
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2014

64.
Feasibility and acceptability of a decision aid designed for people facing advanced or terminal illness: a pilot randomized trial.
Matlock DD; Keech TA; McKenzie MB; Bronsert MR; Nowels CT; Kutner JS. Health Expectations. 17(1):49-59, 2014 Feb.
[Journal Article. Randomized Controlled Trial. Research Support, Non-U.S. Gov't]
UI: 22032553
BACKGROUND: Patients nearing the end of their lives face an array of difficult decisions.
OBJECTIVE: This study was designed to assess the feasibility and acceptability of a decision aid (DA) designed for patients facing advanced or terminal illness.
DESIGN: We conducted a pilot randomized clinical trial of Health Dialog's Looking Ahead: choices for medical care when you're seriously ill DA (booklet and DVD) applied to patients on a hospital-based palliative care (PC) service.
PARTICIPANTS: All adult, English-speaking patients or their decision makers were potentially eligible. Patients were not approached if they were in isolation, did not speak English or if any provider felt that they were not appropriate because of issues such as family conflict or actively dying.
INTERVENTION: All participants received a standard PC consultation. Participants in the intervention arm also received a copy of the DA. Measurements Primary outcomes included decision conflict and knowledge. Participants in the intervention arm also completed an acceptability questionnaire and qualitative exit interviews.
RESULTS: Of the 239 patients or decision makers, 51(21%) enrolled in the trial. The DA had no significant effect on decision conflict or knowledge. Exit interviews indicated it was acceptable and empowering, although they wished they had access to the DA earlier.
CONCLUSIONS: While the DA was acceptable, feasibility was limited by late-life illness challenges. Future trials of this DA should be performed on patients earlier in their illness.
trajectory and should include additional outcome measures such as self-efficacy and confidence.

Continuous palliative sedation: not only a response to physical suffering.
Swart SJ; van der Heide A; van Zuylen L; Perez RS; Zuurmond WW; van der Maas PJ; van Delden JJ; Rietjens JA.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 24410419

BACKGROUND: Palliative sedation is a medical intervention aimed at relieving symptoms that can no longer be controlled by conventional treatment. Ample knowledge is available regarding the nature of such symptoms, but there is no in-depth information regarding how health care workers decide about palliative sedation.

OBJECTIVE: The study objective was to investigate considerations concerning the indications for continuous palliative sedation (CPS) and issues that influence these considerations.

DESIGN: The study consisted of qualitative interviews regarding patients who had recently received CPS.

SETTING/SUBJECTS: The study involved physicians and nurses working in general practice, nursing homes, and hospitals.

MEASUREMENT: Analyses by a multidisciplinary research team used the constant comparative method.

RESULTS: Together with physical symptoms, psychological and existential suffering may combine to produce a refractory state for which other treatment options than CPS were not available or considered inappropriate. A limited life expectancy was by many considered crucial (e.g., to avoid hastening death) and by some less important (e.g., because the patient's suffering was considered to be key). Issues influencing the decision to use CPS related to patient preferences (e.g., dignity, not wanting to experience further suffering) or family issues (impact of suffering on family, family requesting CPS).

CONCLUSIONS: The indication for CPS typically originates from physical symptoms and nonphysical problems producing a refractory state in which a patient suffers unbearably. In such
states, preferences of patients and families and the life expectancy criterion are weighed against the severity of refractory symptoms. Therefore the use of CPS is not only a response to the physical suffering of patients in the dying phase.


BACKGROUND: Consumerism in health care defines patients as self-determined, rational customers. Yet, it is questionable whether vulnerable patients, such as the terminally ill, also fulfill these criteria. Vulnerable contexts and the patient's perspective on being a customer remain relatively unexplored. The present study addresses this research gap by analyzing terminally ill patients' views on being customers.

AIM: To explore the ways in which patients in palliative care refer to themselves as patients/customers, and how the patients' concepts of self-determination are related to their attitudes toward the patient/customer role.

DESIGN: Qualitative interviews were conducted. Data were analyzed in three steps: narrative analysis, thematic content analysis, and typology construction.

SETTING/PARTICIPANTS: Researchers recruited 25 patients via the Department of Palliative Care, University Medical Center Freiburg, Germany.

RESULTS: In many ways, palliative patients contradict the image of a self-determined customer. The palliative patient role is characterized by the concept of relational self-determination rather than an unrestricted self-determination. Self-attribution as a customer still occurs when positively associated with a person-centered, individualized treatment. Thus, the customer and patient role overlap within the palliative care setting because of the focus on the individual.

CONCLUSIONS: The idealized customer role cannot be arbitrarily applied to all medical fields. Palliative patients are dependent on the physician, regardless of whether the customer or patient role is preferred. Hence, self-determination must be understood in relational terms, and
physicians must recognize their crucial role in promoting patients' self-determination in the context of shared decision-making.

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67.
Siblings caring for and about pediatric palliative care patients.
Gaab EM; Owens GR; MacLeod RD.
[Journal Article]
UI: 24313781
BACKGROUND: The experiences of young people who have siblings with life-limiting illnesses are not well understood.
AIM: The study proposed to identify the concerns of siblings of pediatric palliative care (PPC) patients.
DESIGN AND MEASUREMENT: Semistructured interviews were administered to participants and analyzed using qualitative inductive thematic analysis.
SETTING AND PARTICIPANTS: Study subjects were 18 siblings of PPC patients aged 9 to 22 living in the Auckland area.
RESULTS: The siblings of PPC patients held concerns about their siblings' impending death and desires to be involved in their lives and care.
CONCLUSIONS: Siblings may benefit from opportunities to be involved in conversations about mortality and the care of their ill sibling. They are able to express their concerns and help provide care to PPC patients.
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Chronicles of informal caregiving in cancer: using 'The Cancer Family Caregiving Experience' model as an explanatory framework.

Stamataki Z; Ellis JE; Costello J; Fielding J; Burns M; Molassiotis A.
[Journal Article]
UI: 24091719

BACKGROUND: Cancer caregiving has emerged as a dominant focus of research in recent years. A striking feature of this vast amount of literature is that it is static, examining certain points of the cancer trajectory, mostly the diagnosis and palliative care. Only The Cancer Caregiving Experience Model conceptualised the caregiving experience and explored the conceptual implications of cancer family caregiving research.

AIM: The data from this paper aim to empirically support the Cancer Caregiving Experience model, by exploring the cancer caregiving experience longitudinally.

METHODS: Semi-structured interviews with 53 caregivers were carried out at patient's diagnosis (T1), 3 months (T2), 6 months (T3) and 12 months (T4) post diagnosis.

RESULTS: Analysis of 139 interviews generated four themes that reflected a complex and dynamic process. The themes that mapped those of the model were "Primary stressors", "Secondary stressors", "Appraisal", "Cognitive-Behavioural responses" and "Health and Well Being".

CONCLUSIONS: The study adds empirical support to The Cancer Caregiving Experience Model and confirms that different primary and secondary stressors influence how the caregivers perceive the caregiving demands, the coping mechanisms they employ and their health and well being during the cancer trajectory. Access to support services should be offered to all the caregivers from as early as the diagnosis period and take into account their specific needs.

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69.
"I'm just waiting...": an exploration of the experience of living and dying with primary malignant glioma.

Philip J; Collins A; Brand CA; Moore G; Lethborg C; Sundararajan V; Murphy MA; Gold M. Supportive Care in Cancer. 22(2):389-97, 2014 Feb.

[Journal Article. Research Support, Non-U.S. Gov't]

PURPOSE: Referral to supportive and palliative care services for people with high-grade primary malignant glioma (PMG) often occurs late in the illness course, despite significant care needs and overall poor prognosis. This study aimed to understand patient experience at the end of life and document supportive and palliative care needs.

METHODS: A qualitative study was conducted involving ten PMG patients who were at different stages in the illness course including the end of life and had varying levels of physical and cognitive function. Consecutive, eligible patients attending neurosurgery, oncology, and palliative care services of two metropolitan hospitals were recruited. In-depth interviews explored supportive and palliative care needs across the disease trajectory. Interviews were analysed independently by three investigators consistent with a grounded theory approach, and emerging ideas were compared and refined to define key patient experiences.

RESULTS: Despite the medical treatment and supportive care available, there remains a gap in services addressing complex existential and psychosocial needs that were markedly valued by patients. Patient experience was characterised by a pervasive loss of all that encompassed their former sense of self and a focus on immediate needs.

CONCLUSIONS: Patients in this study had substantial needs, which were often not shared and not addressed by the current medical system of care. An improved multidisciplinary care model is indicated, which proactively (1) engages care coordination and advocacy; (2) minimises patients' sense of waiting and uncertainty through mapping out a plan, including involvement of palliative care in a timely fashion; and (3) actively invites discussion around goals and preferences for care to promote patients' sense of self.

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"Not the 'grim reaper service'": an assessment of provider knowledge, attitudes, and perceptions regarding palliative care referral barriers in heart failure.
BACKGROUND: Although similar to cancer patients regarding symptom burden and prognosis, patients with heart failure (HF) tend to receive palliative care far less frequently. We sought to explore factors perceived by cardiology, primary care, and palliative care providers to impede palliative care referral for HF patients.

METHODS AND RESULTS: We conducted semistructured interviews regarding (1) perceived needs of patients with advanced HF; (2) knowledge, attitudes, and experiences with specialist palliative care; (3) perceived indications for and optimal timing of palliative care referral in HF; and (4) perceived barriers to palliative care referral. Two investigators analyzed data using template analysis, a qualitative technique. We interviewed 18 physician, nurse practitioner, and physician assistant providers from 3 specialties: cardiology, primary care, and palliative care. Providers had limited knowledge regarding what palliative care is, and how it can complement traditional HF therapy to decrease HF-related suffering. Interviews identified several potential barriers: the unpredictable course of HF; lack of clear referral triggers across the HF trajectory; and ambiguity regarding what differentiates standard HF therapy from palliative care. Nevertheless, providers expressed interest for integrating palliative care into traditional HF care, but were unsure of how to initiate collaboration.

CONCLUSIONS: Palliative care referral for HF patients may be suboptimal due to limited provider knowledge and misperceptions of palliative care as a service reserved for those near death. These factors represent potentially modifiable targets for provider education, which may help to improve palliative care referral for HF patients with unresolved disease-related burden.
This was a phenomenological investigation into musical meetings, structured according to the existential analytics of Martin Heidegger, that aimed at scrutinizing the perception of patients with cancer living in a support home. Seven users of the support home of the Rede Feminina de Combate ao Cancer in Maringa, Parana, took part in the study, during which eight musical meetings took place during the months of January and February 2011. For the purposes of data collection individual interviews were used, starting with the following question: What do these musical meetings represent to you at this time of your life? During the process of understanding the investigated phenomenon, two ontological themes emerged: a feeling of being taken care of in the musical meetings; and transcending their existential facticity. It was observed that a meeting mediated by music represents a resource in oncologic palliative care nursing; and that it brings inspiration to the patients' daily life, instilling a feeling of being cared for and giving a new meaning to their being-in-the-world.

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72.
Symptoms, unbearability and the nature of suffering in terminal cancer patients dying at home: a prospective primary care study.
Ruijs CD; Kerkhof AJ; van der Wal G; Onwuteaka-Philipsen BD.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 24373224
BACKGROUND: Primary care physicians provide palliative home care. In cancer patients dying at home in the Netherlands (45% of all cancer patients) euthanasia in about one out of every seven patients indicates unbearable suffering. Symptom prevalence, relationship between
intensity of symptoms and unbearable suffering, evolvement of symptoms and unbearable over
time and quality of unbearable suffering were studied in end-of-life cancer patients in primary
care.
METHODS: 44 general practitioners during three years recruited cancer patients estimated to die
within six months. Every two months patients quantified intensity as well as unbearable of 69
symptoms with the State-of-Suffering-V (SOS-V). Also overall unbearable suffering was
quantified. The five-point rating scale ranged from 1 (not at all) to 5 (hardly can be worse). For
symptoms assessed to be unbearable the nature of the suffering was additionally investigated
with open-ended questions. The final interviews were analyzed; for longitudinal evolvement also
the pre-final interviews were analyzed. Symptom intensity scores 4 and 5 were defined to indicate
high intensity. Symptom unbearability scores 4 and 5 were defined to indicate unbearable
suffering. Two raters categorized the qualitative descriptions of unbearable suffering.
RESULTS: Out of 148 requested patients 51% participated; 64 patients were followed up until
death. The SOS-V was administered at least once in 60 patients (on average 30 days before
death) and at least twice in 33 patients. Weakness was the most frequent unbearable symptom
(57%). Pain was unbearable in 25%. Pain, loss of control over one's life and fear of future
suffering frequently were unbearable (89-92%) when symptom intensity was high. Loss of control
over one's life, vomiting and not being able to do important things frequently were unbearable
(52-80%) when symptom intensity was low. Unbearable weakness significantly increased
between pre-final and final interview. Physical suffering, loss of meaning, loss of autonomy,
experiencing to be a burden, fear of future suffering and worrying more frequently occurred in
patients suffering unbearably overall.
CONCLUSIONS: Weakness was the most prevalent unbearable symptom in an end-of-life
primary care cancer population. Physical suffering, loss of meaning and loss of autonomy more
frequently occurred in patients who suffered unbearably overall.

73.
The voices of young New Zealanders involved in pediatric palliative care.
Gaab EM; Owens RG; MacLeod RD.
The perspectives of young New Zealanders receiving pediatric palliative care (PPC) are not well understood. A qualitative study of the perceptions of 16 PPC patients and their siblings, aged 9 to 18, was conducted through audio and written diary accounts. Inductive thematic analysis revealed several concerns of participants, including special treatment that patients had received, spending time with their families, their feelings of being judged or discriminated against, their sense of being understood themselves and of understanding others, and mortality. A nonjudgemental, open approach is recommended when consulting with patients and their siblings in order to determine their needs.

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Date Created
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2013

74.
Nurses' experiences caring for patients and families dealing with malignant bowel obstruction.
Daine P; Stilos K; Moura S; Fitch M; McAndrew A; Gill A; Wright F.

Malignant bowel obstruction (MBO) is a well-recognised complication of advanced abdominal and pelvic cancers. Often surgical intervention is not feasible, resulting in complex symptoms and an unpredictable course. Although symptom management is a crucial part of nursing care, psychosocial and emotional issues frequently emerge for patients and families. This qualitative study explored the perspectives of nurses from a palliative care unit, in-patient acute care oncology units, ambulatory cancer setting, and the community on their experiences of caring for patients with MBO and their families. Six individual interviews and two focus groups were conducted. Eight overarching messages were identified related to nurses' experiences. Highlights include aspects of patients' and families' emotional distress, and the nurse-patient relationship in relieving suffering. Nurses have an important and privileged role that involves identifying MBO signs and symptoms, having knowledge of treatment and symptom management options, and helping patients transition from a curative to a palliative philosophy of care.

Status
Care of the complex chronically ill child by generalist pediatricians: lessons learned from pediatric palliative care.
Walter JK; DeCamp LR; Warrier KS; Murphy TP; Keefer PM.
Hospital Pediatrics. 3(2):129-38, 2013 Apr.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 24340413

BACKGROUND AND OBJECTIVE: Parents of children with complex chronic conditions report fragmented care, unmet medical needs, and financial strain from health care costs. The aim of this study was to identify both prevalent themes discussed during pediatric palliative care consultation of patients with complex chronic conditions cared for by pediatric generalists and variation in consultation content by age and timing of consultation in disease course.

METHODS: Forty randomly selected initial inpatient or outpatient consultation notes authored by the pediatric palliative care team at an academic, tertiary care children's hospital. Inclusion required that patients were primarily cared for by general pediatricians, pediatric hospitalists, or pediatric intensivists, instead of subspecialists. Qualitative analysis by 5 team members utilizing consensus-based findings was used to develop themes. Descriptive statistics were used to describe variations in themes across age and disease course.

RESULTS: Common themes included thorough review of patient baseline functioning, current symptoms, assessment of family's understanding of the prognosis of the patient, coordination of communication with other medical teams and outpatient health care services, consideration of caregiver resources and burdens, and offering a framework for decision-making. Variation in consult themes by age/disease course included more discussion of communication problems and symptom management when patients were at their baseline, but otherwise little variation was found.

CONCLUSIONS: Common themes covered in initial consultations correspond with documented unmet needs for chronically ill children. There was no significant variation in consultation themes.
by age/disease course, suggesting that generalists could broadly apply palliative care techniques to improve family-centered care.

A health economics response to the review of the Liverpool Care Pathway.
Kinghorn P; Coast J.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 24199790
BACKGROUND: In 2011 the Palliative Care Funding Review highlighted concerns about the funding, provision, and quality of care at the end of life. Two years on, an independent review of the Liverpool Care Pathway--prompted by a storm of negative media coverage--has raised concerns around a lack of funding, availability of support for the dying and their relatives, and patient centered care. There are recommendations to increase funding through a national tariff for palliative care services, address inconsistencies, and replace the Liverpool Care Pathway with individual end-of-life care plans.
OBJECTIVE: This paper explores the economic implications of the review's recommendations and links these to inadequacies with the current economic framework currently recommended for use in the United Kingdom by the National Institute for Health and Care Excellence, before highlighting aspects of ongoing research aimed at addressing these inadequacies.
METHODS: As well as the published report More Care, Less Pathway, we draw upon preliminary qualitative evidence from 19 semistructured interviews conducted with academics specializing in economics and/or end-of-life care.
CONCLUSIONS: While there is a need for increased funding in the short term (highlighted in recent reviews), increasing funding to services that have little evidence base appears to be an irresponsible long-term strategy. Hence there should also be increased investment in research and increased emphasis in particular on developing economic tools to evaluate services.
Mixed methods research in the development and evaluation of complex interventions in palliative and end-of-life care: report on the MORECare consensus exercise.

Farquhar M; Preston N; Evans CJ; Grande G; Short V; Benalia H; Higginson IJ; Todd C; MOREcare.


BACKGROUND: Complex interventions are common in palliative and end-of-life care. Mixed methods approaches sit well within the multiphase model of complex intervention development and evaluation. Generic mixed methods guidance is useful but additional challenges in the research design and operationalization within palliative and end-of-life care may have an impact on the use of mixed methods.

OBJECTIVE: The objective of the study was to develop guidance on the best methods for combining quantitative and qualitative methods for health and social care intervention development and evaluation in palliative and end-of-life care.

METHODS: A one-day workshop was held where experts participated in facilitated groups using Transparent Expert Consultation to generate items for potential recommendations. Agreement and consensus were then sought on nine draft recommendations (DRs) in a follow-up exercise.

RESULTS: There was at least moderate agreement with most of the DRs, although consensus was low. Strongest agreement was with DR1 (usefulness of mixed methods to palliative and end-of-life care) and DR5 (importance of attention to respondent burden), and least agreement was with DR2 (use of theoretical perspectives) and DR6 (therapeutic effects of research interviews). Narrative comments enabled recommendation refinement. Two fully endorsed, five partially endorsed, and two refined DRs emerged. The relationship of these nine to six key challenges of palliative and end-of-life care research was analyzed.

CONCLUSIONS: There is a need for further discussion of these recommendations and their contribution to methodology. The recommendations should be considered when designing and operationalizing mixed methods studies of complex interventions in palliative care, and because they may have wider relevance, should be considered for other applications.

Status
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78.
An ecological perspective on medical care: environmental, occupational, and public health impacts of medical supply and pharmaceutical chains.

Vatovec C; Senier L; Bell M.
[Journal Article]
UI: 23842665

Healthcare organizations are increasingly examining the impacts of their facilities and operations on the natural environment, their workers, and the broader community, but the ecological impacts of specific healthcare services provided within these institutions have not been assessed. This paper provides a qualitative assessment of healthcare practices that takes into account the life-cycle impacts of a variety of materials used in typical medical care. We conducted an ethnographic study of three medical inpatient units: a conventional cancer ward, palliative care unit, and a hospice center. Participant observations (73 participants) of healthcare and support staff including physicians, nurses, housekeepers, and administrators were made to inventory materials and document practices used in patient care. Semi-structured interviews provided insight into common practices. We identified three major domains that highlight the cumulative environmental, occupational health, and public health impacts of medical supplies and pharmaceuticals used at our research sites: (1) medical supply procurement; (2) generation, handling, and disposal of medical waste; and (3) pharmaceutical handling and disposal. Impacts discovered through ethnographic inquiry included occupational exposures to chemotherapy and infectious waste, and public health exposures to pharmaceutical waste. This study provides new insight into the environmental, occupational, and public health impacts resulting from medical practices. In many cases, the lack of clear guidance and regulations regarding environmental impacts contributed to elevated harms to the natural environment, workers, and the broader community.

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79.
Cancer-related pain in older adults receiving palliative care: patient and family caregiver perspectives on the experience of pain.
McPherson CJ; Hadjistavropoulos T; Lobchuk MM; Kilgour KN.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23957019
BACKGROUND: Despite an emphasis on pain management in palliative care, pain continues to be a common problem for individuals with advanced cancer. Many of those affected are older due to the disproportionate incidence of cancer in this age group. There remains little understanding of how older patients and their family caregivers perceive patients’ cancer-related pain, despite its significance for pain management in the home setting.
OBJECTIVES: To explore and describe the cancer pain perceptions and experiences of older adults with advanced cancer and their family caregivers.
METHODS: A qualitative descriptive approach was used to describe and interpret data collected from semistructured interviews with 18 patients (>65 years of age) with advanced cancer receiving palliative care at home and their family caregivers.
RESULTS: The main category 'Experiencing cancer pain' incorporated three themes. The theme 'Feeling cancer pain' included the sensory aspects of the pain, its origin and meanings attributed to the pain. A second theme, 'Reacting to cancer pain', included patients' and family caregivers' behavioural, cognitive (ie, attitudes, beliefs and control) and emotional responses to the pain. A third theme, 'Living with cancer pain' incorporated individual and social-relational changes that resulted from living with cancer pain.
CONCLUSIONS: The findings provide an awareness of cancer pain experienced by older patients and their family caregivers within the wider context of ongoing relationships, increased patient morbidity and other losses common in the aged.

Status
MEDLINE
Authors Full Name
McPherson, Christine J; Hadjistavropoulos, Thomas; Lobchuk, Michelle M; Kilgour, Kelly N.
Other ID
Source: NLM. PMC3917792
Date Created
20131205
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2013

<td colspan=""/>

The growing HIV burden on families and health systems is exerting a shift toward community caregivers, and is increasing the demand for functional community systems. In Uganda, where the number of people with HIV is increasing against a background of weak health systems, the role of community systems is poorly understood. We investigated the role of community systems in palliative care and the system elements required for an effective community response in Uganda. Qualitative interviews and focus group discussions were conducted among providers and recipients of palliative care, their family members, and governmental and community stakeholders in Mbale and Jinja, Uganda. Results showed that community systems play an important role in many aspects of palliative care—including personal, livelihood, nutritional and bereavement support—and often strengthen care linkages and referrals. For community systems to fulfill these roles effectively, multiple system elements—including leadership, training, partnerships, and enabling policies—are essential. Strengthening community systems could be an effective strategy to alleviate HIV burden on families and health systems. A systems approach could be a potent mechanism for determining which community structures to strengthen in order to maximize the impact of palliative care programs, and for guiding investments in HIV and health.

The importance of place and time in translating knowledge about Canada's Compassionate Care Benefit to informal caregivers. Dykeman S; Williams A.
Canada’s Compassionate Care Benefit (CCB), an employment insurance program designed to allow Canadian workers time off to care for a dying relative or friend, has had low uptake since its inception. Due to their role in working with family caregivers, social workers are one group of primary health care professionals who have been identified as benefiting from a knowledge translation campaign. Knowledge tools about the CCB have been developed through social worker input in a prior study. This article presents the findings of a qualitative exploratory intervention. Social workers (n = 8) utilized the tools for 6 months and discussed their experiences with them. Data analysis revealed references to time and space constraints in using the tools, and demonstrated the impact of time geography on knowledge translation about the CCB. The results suggest that knowledge translation about the CCB could be targeted toward caregivers earlier on in the disease progression before the terminal diagnosis, and knowledge tools must be disseminated to more locations. These results may be valuable to policymakers and palliative care providers, as well as theorists interested in ongoing applications of time geography in knowledge translation and the consumption/production of care.

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Date Created
20131203
Year of Publication
2013

82.
Living in liminality--being simultaneously visible and invisible: caregivers’ narratives of palliative care.
Dahlborg Lyckhage E; Lindahl B.
[Journal Article]
UI: 24295097
Palliative care is an integral part of care and takes place in many settings--including the home, special accommodations, and hospitals. However, research shows that palliative care often ends with a death in the hospital due to the heavy burden on the primary caregiver. This study explores the meaning of being the primary caregiver of a close one who is terminally ill and is based on qualitative interviews with six primary caregivers of a terminally ill individual at home. The findings
are discussed in the light of the theoretical concepts of liminality, lived body, and power. A potential impending risk exists of being abandoned when one is the primary caregiver to a close one who is terminally ill. This situation calls for professional caregivers to take responsibility and to respond to these, often unspoken, needs. This is particularly important concerning bodily care and the medical treatment regimen. In addition, when friends and relatives are absent, there is an ethical demand on professional caregivers to compensate for this lack and to compensate for this need. Palliative home care demands care that is person-centered--including the individual's history, family and loved ones, and individual strengths and weaknesses.

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Date Created
20131203
Year of Publication
2013

83.
Death is not always a failure: outcomes from implementing an online virtual patient clinical case in palliative care for family medicine clerkship.
Tan A; Ross SP; Duerksen K.
Medical Education Online. 18:22711, 2013.
[Evaluation Studies. Journal Article]
Ut: 24267774
BACKGROUND: The dying patient is a reality of medicine. Medical students, however, feel unprepared to effectively manage the complex end-of-life (EOL) management issues of the dying patient and want increased experiential learning in Palliative Care.
AIMS: To address the need for more formal curriculum in EOL care, we developed and implemented an online virtual patient (VP) clinical case in Palliative Care into the 2010-2011 Year Three Family Medicine Clerkship rotation curriculum.
METHODS: A mixed-method design was used to measure the change in knowledge and perceived preparedness level in EOL care before and after completing the online VP case. A survey collected qualitative descriptions of the students' educational experience of using this case.
RESULTS: Ninety five percent (130/137) of the students voluntarily consented to have their results analyzed. The group knowledge score (n=127) increased significantly from a pre-course average of 7.69/16+/−2.27, to a post-course average of 10.02/16+/−2.39 (p<0.001). The students' self-assessed comfort level increased significantly with all aspects of EOL management from pre-course to post-course (p<0.001). Nearly, 91.1% of the students rated the VP realism as 'Good to Excellent', 86% rated the case as educationally beneficial. Nearly 59.3% of students felt
emotionally engaged with the VP. Qualitative feedback found that the case content was very useful and realistic, but that the interface was sometimes awkward to navigate.

CONCLUSIONS: The online VP case in Palliative Care is a useful teaching tool that may help to address the need for increased formal Palliative Care experience in medical school training programs.

84.
PURPOSE: The aim of this study was to explore and understand the lived experience of older people living alone and suffering from incurable cancer in rural Norway.
METHODS AND SAMPLE: Narrative interviews were conducted with five older people with incurable cancer (three women and two men, aged 71-79), receiving outpatient and life-prolonging chemotherapy and living alone in their homes in rural areas. A phenomenological hermeneutical approach was used to interpret the meaning of the lived experience.
KEY RESULTS: Four main themes were found: enduring by keeping hope alive, becoming aware that you are on your own, living up to expectations of being a good patient and being at risk of losing one's identity and value. Enduring this situation means struggling with terminal illness and facing death in a brave manner, and replacing former ways of living. The process of providing treatment may threaten dignity and cause additional distress.
CONCLUSIONS: These results show a complex and comprehensive situation where physical symptoms and emotions are interwoven. Further the results describe how the ways of suffering caused by the manner in which care is delivered, suffering related to the cancer disease and existential suffering, may increase each other's impact. The social and rural context calls for special attention as the patients may lack recourses to gain sufficient care. Their comfort depends to a large extent on the health professionals' sensitivity. Copyright 2013 Elsevier Ltd. All rights reserved.
85.
The experience of Chinese American parents of children with life-limiting illness: a comprehensive review. [Review]
Wang J; Kearney JA.
[Journal Article. Review]
UI: 24273812
Life-limiting childhood illness is a traumatic experience presenting parents with psychological, physical, and social challenges. While cultural influences affect all parents coping with the life-limiting illness and end-of-life period of their child, little is known about the experiences of Chinese American parents. The purpose of this comprehensive literature review was to describe Chinese American parents’ experiences during their children's end-of-life period from a culturally informed perspective. Important themes in the literature are revealed including culture-based phenomena regarding philosophy of life and illness that can affect treatment choices, cultural mores that influence parental behaviour in Western health-care systems, specific communication patterns within families and between families and providers, certain coping risks, and gender-based roles and caregiving activities that have implications for provider communication patterns. The findings are consonant with the larger literature regarding the impact of traditional culture and values on Chinese family and health behaviours. Health professionals must be sensitive to Chinese American parents’ communication styles, unspoken concerns, and unresolved cultural conflicts in American health-care settings. Educational interventions may be very helpful in this regard.
Status
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Date Created
Discussing preferred place of death with patients: staff experiences in a UK specialist palliative care setting.
Fields A; Finucane AM; Oxenham D.
[Journal Article]
UI: 24263900
BACKGROUND: National end-of-life care policies propose that health professionals regularly discuss matters such as preferred place of death (PPD) with patients.
AIM: To explore clinician experiences of discussing PPD with palliative care patients.
METHOD: Six clinicians from a Scottish hospice each participated in a semi-structured interview. Interview data was analysed using interpretative phenomenological analysis.
RESULTS: Four themes were integral to the participants' accounts: the importance of discussing preferences at the end of life (staff recognise the value of discussing patients' final wishes), identifying how and when to discuss PPD (discussions are tailored to the individual), reflecting on the emotional aspects of discussing PPD (discussing PPD is challenging but rewarding), and a journey from expectations to experience (discussing PPD becomes easier with time).
CONCLUSION: Although potentially difficult, the participants believed that advance care planning is important and beneficial. With time, they had developed communication strategies enabling them to discuss PPD in an effective, patient-centred way.

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Date Created
20131122

Year of Publication
2013
Lived experiences of adult community nurses delivering palliative care to children and young people in rural areas.
Reid FC.
[Journal Article]
UI: 24263898

The anticipated death of a child or young person is a relatively rare occurrence in the Western world. Many families receive support from children's health-care services until the late stages of palliation, with adult community nurses being involved in just an occasional end-of-life care episode in the home during their entire career. This creates challenges in nurses' experiential reflection, development of knowledge and skills, and building of nurse-family relationships.

Individual semi-structured interviews were conducted with 10 adult community nurses from a rural part of Scotland to explore their experiences of providing palliative care to children. The material was analysed using a qualitative phenomenological thematic approach. Four key themes emerged: emotional preparedness, navigating the professional 'road', becoming part of the family, and it's everybody's business. Significant issues were highlighted in relation to nurses' coping, with implications for practice. Recommendations are made for further research into rural contextual dilemmas.

Status
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Date Created
20131122
Year of Publication
2013

How do nurses in specialist palliative care assess and manage breakthrough cancer pain? A multicentre study.
Soden K; Ali S; Alloway L; Barclay D; Barker S; Bird L; Hall L; Perkins P.
[Journal Article. Multicenter Study. Research Support, Non-U.S. Gov't]
UI: 24263896

OBJECTIVE: To gain a better understanding of how registered nurses working in specialist palliative care assess and manage breakthrough cancer pain.

METHODS: A mixed-methodology study was undertaken in two stages-this paper reports findings from stage two. Anonymous postal questionnaires, designed based on themes identified in interviews undertaken during stage one, were sent to trained nurses working in ten specialist palliative care services in England.

RESULTS: A total of 104 questionnaires were returned. Respondents were experienced nurses mainly working in inpatient settings. Some 82% of the nurses wanted more training on the
assessment of breakthrough cancer pain. Although there were inconsistencies around the use of terminology, pain management appeared to be good.

CONCLUSION: The use of terminology in the field of breakthrough cancer pain remains variable. However, this does not appear to have a negative impact on patient management, which was broadly in line with recently published consensus recommendations. There is a desire for more education within this area of practice.

Status
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Date Created
20131122
Year of Publication
2013

89.
Palliative care communication: linking patients' prognoses, values, and goals of care.
Norton SA; Metzger M; DeLuca J; Alexander SC; Quill TE; Gramling R.
[Journal Article. Research Support, N.I.H., Extramural. Research Support, Non-U.S. Gov't]
UI: 24114740
Prognostic communication is a primary component of goals of care conversations in palliative care (PC) practice. Little is known about these conversations in the natural setting. This study's aim was to describe the processes of prognostic communication in PC goals of care consultations. Using line-by-line qualitative analysis, we examined prognostic conversation in 66 audio-taped PC consultations. We identified five processes by which clinicians link prognoses, values, and goals of care: (1) signposting the crossroads; (2) closing off a goal; (3) clarifying current path; (4) linking paths and patients' values; and (5) choosing among paths. The findings add to our understanding of PC consultation by describing how prognoses link with patients' values and choices in goals of care conversations.Copyright 2013 Wiley Periodicals, Inc.
Status
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Date Created
20131118
Awareness contexts revisited: indeterminacy in initiating discussions at the end-of-life.

Richards N; Ingleton C; Gardiner C; Gott M.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23600793

AIMS: To explore if and how information about a transition to a palliative care approach was communicated to patients recently discharged from hospital and who fulfilled standardized criteria for palliative care need.

BACKGROUND: Palliative care philosophy and, more recently, UK palliative care policy, endorse a context of 'open' awareness, where all parties openly acknowledge that the patient's death is approaching. The perceived benefits of making the patient aware of their prognosis encompass a variety of planning activities, which mean that death, when it occurs, is arguably more in keeping with the wishes of the patient.

DESIGN: A qualitative inductive interview study conducted in 2010-2011.

METHODS: Fifteen semi-structured interviews were conducted with 15 patients and 3 family carers. All patients were identified as having palliative care needs according to standardized criteria, 3-6 months after discharge from hospital. A thematic analysis was undertaken.

FINDINGS: Contrary to the professed ideal of 'open' awareness, some participants were only partially aware and others wholly unaware that they were likely to be approaching the end-of-life. Those identified as unaware were over 85. Participants displayed a reluctance to acquire knowledge which would require them to face the imminence of death.

CONCLUSION: Philosophy and policy aside, people do not always conform to the autonomy paradigm of a self-directed life followed by a self-directed death. Copyright 2013 John Wiley & Sons Ltd.
Development and evaluation of the feasibility and effects on staff, patients, and families of a new tool, the Psychosocial Assessment and Communication Evaluation (PACE), to improve communication and palliative care in intensive care and during clinical uncertainty.

Higginson IJ; Koffman J; Hopkins P; Prentice W; Burman R; Leonard S; Rumble C; Noble J; Dampier O; Bernal W; Hall S; Morgan M; Shipman C.


[Journal Article. Research Support, Non-U.S. Gov't]
UI: 24083470

BACKGROUND: There are widespread concerns about communication and support for patients and families, especially when they face clinical uncertainty, a situation most marked in intensive care units (ICUs). Therefore, we aimed to develop and evaluate an interventional tool to improve communication and palliative care, using the ICU as an example of where this is difficult.

METHODS: Our design was a phase I-II study following the Medical Research Council Guidance for the Development and Evaluation of Complex Interventions and the (Methods of Researching End-of-life Care (MORECare) statement. In two ICUs, with over 1900 admissions annually, phase I modeled a new intervention comprising implementation training and an assessment tool. We conducted a literature review, qualitative interviews, and focus groups with 40 staff and 13 family members. This resulted in the new tool, the Psychosocial Assessment and Communication Evaluation (PACE). Phase II evaluated the feasibility and effects of PACE, using observation, record audit, and surveys of staff and family members. Qualitative data were analyzed using the framework approach. The statistical tests used on quantitative data were t-tests (for normally distributed characteristics), the chi2 or Fisher's exact test (for non-normally distributed characteristics) and the Mann-Whitney U-test (for experience assessments) to compare the characteristics and experience for cases with and without PACE recorded.

RESULTS: PACE provides individualized assessments of all patients entering the ICU. It is completed within 24 to 48 hours of admission, and covers five aspects (key relationships, social details and needs, patient preferences, communication and information status, and other concerns), followed by recording of an ongoing communication evaluation. Implementation is supported by a training program with specialist palliative care. A post-implementation survey of 95 ICU staff found that 89% rated PACE assessment as very or generally useful. Of 213 family members, 165 (78%) responded to their survey, and two-thirds had PACE completed. Those for whom PACE was completed reported significantly higher satisfaction with symptom control, and the honesty and consistency of information from staff (Mann-Whitney U-test ranged from 616 to 1247, P-values ranged from 0.041 to 0.010) compared with those who did not.

CONCLUSIONS: PACE is a feasible interventional tool that has the potential to improve communication, information consistency, and family perceptions of symptom control.
The facilitating role of chemotherapy in the palliative phase of cancer: qualitative interviews with advanced cancer patients.

Buiting HM; Terpstra W; Dalhuisen F; Gunnink-Boonstra N; Sonke GS; den Hartogh G.


[Journal Article. Research Support, Non-U.S. Gov't]

UI: 24223130

OBJECTIVE: To explore the extent to which patients have a directing role in decisions about chemotherapy in the palliative phase of cancer and (want to) anticipate on the last stage of life.

DESIGN: Qualitative interview study.

METHODS: In depth-interviews with 15 patients with advanced colorectal or breast cancer at the medical oncology department in a Dutch teaching hospital; interviews were analysed following the principles of thematic content-analysis.

RESULTS: All patients reported to know that the chemotherapy they received was with palliative intent. Most of them did not express the wish for information about (other) treatment options and put great trust in their physicians’ treatment advice. The more patients were aware of the severity of their disease, the more they seemed to 'live their life' in the present and enjoy things besides having cancer. Such living in the present seemed to be facilitated by the use of chemotherapy. Patients often considered the 'chemotherapy-free period' more stressful than periods when receiving chemotherapy despite their generally improved physical condition. Chemotherapy (regardless of side-effects) seemed to shift patients’ attention away from the approaching last stage of life. Interestingly, although patients often discussed advance care planning, they were reluctant to bring on end-of-life issues that bothered them at that specific moment. Expressing real interest in people 'as a person' was considered an important element of appropriate care.

CONCLUSIONS: Fearing their approaching death, patients deliberately focus on living in the present. Active (chemotherapy) treatment facilitates this focus, regardless of the perceived side-effects. However, if anxiety for what lies ahead is the underlying reason for treatment, efforts should be made in assisting patients to find other ways to cope with this fear. Simultaneously, such an approach may reduce the use of burdensome and sometimes costly treatment in the last stage of life.

Terpstra, Wim; Dalhuisen, Floriske; Gunnink-Boonstra, Nicolette; Sonke, Gabe S; den Hartogh, Govert.

Institution
Determinants of the effect of existential behavioral therapy for bereaved partners: a qualitative study.
Kogler M; Brandl J; Brandstatter M; Borasio GD; Fegg MJ.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 24215249

BACKGROUND: Informal caregivers of palliative patients took part in existential behavioral therapy (EBT), a group intervention comprising mindfulness exercises to reduce psychological distress and improve quality of life.

OBJECTIVES: This study examined what the participants perceived as helpful to cope with their loss during the first year of bereavement, particularly with regard to the EBT intervention.

DESIGN: Sixteen problem-centered, semi-structured interviews were evaluated with content analysis.

RESULTS: Two main categories were found: social support and self-regulation. Social support includes sense of belonging as well as emotional, cognitive, and practical help experienced from others. Mindfulness and acceptance, a clear focus on the positive, and orientation toward the future were helpful strategies of self-regulation; these were also part of the EBT intervention.

Mindfulness was understood as permitting emotions and acceptance of one's inner processes, even if they were not pleasant, and was found to be helpful to stop ruminative thinking.

CONCLUSIONS: The categories considered as being helpful parallel core elements of EBT and recent grief theories. The intervention was found to be supportive and met the needs of the participants. The interviewees appreciated the continuity of EBT support from palliative care into bereavement.
The standard of care and conflicts at the end of life in critical care: lessons from medical-legal
crossroads and the role of a quasi-judicial tribunal in decision-making.
Hawryluck L; Sibbald R; Chidwick P.
[Journal Article]
UI: 23891135
PURPOSE: The goals of this qualitative study were to review the last 7 years of end of life legal
decisions within the critical care field to explore how medical benefit is defined and by whom and
the role of the standard of care (SoC) in conflict resolution.
METHODS: A public online, non-profit database of the Federation of Law Societies of Canada
was searched for relevant Consent and Capacity Board decisions from 2003 to 2012. In total,
1486 cases were collected, and purposive sampling identified a total of 29 decisions regarding
use of life-sustaining treatments at end of life. Using modified grounded theory, decisions were
read and analyzed from a central SoC concept to understand definitions of benefit, rationales for
case adjudication, and repercussions of legal recourse in conflict resolution.
RESULTS: Medical benefit was clearly defined, and its role in determining SoC, transparent.
Perceptions of variability in SoC were enhanced by physicians in intractable conflicts seeking
legal validation by framing SoC issues as "best interest" determinations. The results reveal some
key problems in recourse to the Consent and Capacity Board for clinicians, patients and
substitute decision makers in such conflict situations.
CONCLUSIONS: This study can help improve decision-making by debunking myth of variability in
determinations of medical benefit and the standards of care at end of life and reveal the pitfalls of
legal recourse in resolving intractable conflicts.Copyright 2013.
95. Involvement of general practitioners in palliative cancer care: a qualitative study.
Dahlhaus A; Vanneman N; Siebenhofer A; Brosche M; Guethlin C.
Supportive Care in Cancer. 21(12):3293-300, 2013 Dec.
[Journal Article]
UI: 23887739
PURPOSE: General practitioners play an important role in palliative care for cancer patients. The intensity of care and its medical complexity make palliative care a demanding task for general practitioners. This study explored general practitioners' perceptions of their involvement in palliative cancer care and the constraints they confront.
METHODS: We conducted semi-structured interviews with 13 German general practitioners. Recruitment occurred by means of purposeful sampling to secure maximum heterogeneity. The interviews were electronically recorded, transcribed, and then analyzed using qualitative content analysis according to Mayring.
RESULTS: A number of themes were identified. General practitioners describe being intensely involved in the final phase of their patients' lives. When providing home-based end-of-life care to cancer patients, general practitioners become aware of the limitations in their medical skills and knowledge and their ability to provide round-the-clock care. They find it helpful and satisfying to collaborate with trusted care providers and seek to cooperate with specialized palliative care services for outpatients.
CONCLUSIONS: The substantial involvement of general practitioners in end-of-life care for cancer patients pushes them to their limits because of the major time commitment required, and the need for special skills for which they have received no training. It will be a challenge to provide general practitioners with the structural and personal support they need to provide home-based palliative care for their cancer patients at end of life.
Status
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Date Created
20131108
Year of Publication
2013
<td colspan=""ере>96. Grief and the experiences of nurses providing palliative care to children and young people at home.
Reid F.
Nursing Children and Young People. 25(9):31-6, 2013 Nov.
[Journal Article]
UI: 24200187
AIMS: To elicit the views of children's nurses with regard to the personal, contextual and interprofessional challenges faced when delivering palliative and end of life care to children and young people in the community.
METHODS: Semi-structured interviews were conducted with seven nurses who provided palliative care to one or more child or young person in the home. Data generated were analysed thematically to define topics.
FINDINGS: Four themes emerged: service delivery, nurse-family relationships, nurses' grief, funeral rites and bereavement support.
CONCLUSIONS: Nurses experienced considerable internal and external pressures. Some are inevitable but others, such as organisation of care provision to families and nurses' personal coping, could be improved by adequately resourced workforces, integrated service structures and guidance on reflective practice. Further research is needed.
Status
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Reid,Fiona. Raigmore Hospital, Inverness.
Date Created
20131108
Year of Publication
2013

97.
Finding your way through EOL challenges in the ICU using Adaptive Leadership behaviours: A qualitative descriptive case study.
Adams JA; Bailey DE Jr; Anderson RA; Thygeson M.
[Case Reports. Journal Article. Research Support, N.I.H., Extramural]
UI: 23879936
OBJECTIVE: Using the Adaptive Leadership framework, we describe behaviours that providers used while interacting with family members facing the challenges of recognising that their loved one was dying in the ICU.
RESEARCH METHODOLOGY: In this prospective pilot case study, we selected one ICU patient with end-stage illness who lacked decision-making capacity. Participants included four family members, one nurse and two physicians. The principle investigator observed and recorded three family conferences and conducted one in-depth interview with the family. Three members of the research team independently coded the transcripts using a priori codes to describe the Adaptive Leadership behaviours that providers used to facilitate the family's adaptive work, met to compare and discuss the codes and resolved all discrepancies.
FINDINGS: We identified behaviours used by nurses and physicians that facilitated the family's ability to adapt to the impending death of a loved one. Examples of these behaviours include defining the adaptive challenges for families and foreshadowing a poor prognosis.

CONCLUSIONS: Nurse and physician Adaptive Leadership behaviours can facilitate the transition from curative to palliative care by helping family members do the adaptive work of letting go. Further research is warranted to create knowledge for providers to help family members adapt. Copyright 2013 Elsevier Ltd. All rights reserved.
Healthcare professionals’ response to cachexia in advanced cancer: a qualitative study.
Millar C; Reid J; Porter S.
[Journal Article]
UI: 24161643

PURPOSE/OBJECTIVES: To explore healthcare professionals’ experience, understanding, and perception of the needs of patients with cachexia in advanced cancer.

RESEARCH APPROACH: A qualitative approach based on symbolic interactionism.

SETTING: A regional cancer center in a large teaching hospital in the United Kingdom.

PARTICIPANTS: 34 healthcare professionals who had experience providing care to patients with cachexia in advanced cancer.

METHODOLOGIC APPROACH: Data collection consisted of two phases: focus group and semistructured interviews. Interviews were digitally recorded and transcribed verbatim for analysis. This article reports on findings from the second phase of data collection.

FINDINGS: Analysis revealed that professional approaches to cachexia were influenced by three overarching and interthinking themes: knowledge, culture, and resources. Healthcare professionals commonly recognized the impact of the syndrome; however, for nonpalliative healthcare professionals, a culture of avoidance and an overreliance on the biomedical model of care had considerable influence on the management of cachexia in patients with advanced cancer.

CONCLUSIONS: Cachexia management in patients with advanced cancer can be difficult and is directed by a variable combination of the influence of knowledge, culture of the clinical area, and available resources. Distinct differences exist in the management of cachexia among palliative and nonpalliative care professionals.

INTERPRETATION: This study presented a multiprofessional perspective on the management of cachexia in patients with advanced cancer and revealed that cachexia is a complex and challenging syndrome that needs to be addressed from a holistic model of care.

KNOWLEDGE TRANSLATION: Cachexia management in patients with advanced cancer is complex and challenging and is directed by a combination of variables. An overreliance on the biomedical model of health and illness occurs in the management of cachexia in patients with advanced cancer. Cachexia needs to be addressed from a holistic model of care to reflect the multidimensional needs of patients and their families.
100.
Role of the nurse practitioner in providing palliative care in long-term care homes.
Kaasalainen S; Ploeg J; McAiney C; Schindel Martin L; Donald F; Martin-Misener R; Brazil K; Taniguchi A; Wickson-Griffiths A; Carter N; Sangster-Gormley E.
[Case Reports. Journal Article]
UI: 24162278
AIM: The purpose of this study, which was part of a large national case study of nurse practitioner (NP) integration in long-term care (LTC), was to explore the NP role in providing palliative care in LTC.
METHODS: Using a qualitative descriptive design, data was collected from five LTC homes across Canada using 35 focus groups and 25 individual interviews. In total, 143 individuals working in LTC participated, including 9 physicians, 20 licensed nurses, 15 personal support workers, 19 managers, 10 registered nurse team managers or leaders, 31 allied health care providers, 4 NPs, 14 residents, and 21 family members. The data was coded and analysed using thematic analysis.
FINDINGS: NPs provide palliative care for residents and their family members, collaborate with other health-care providers by providing consultation and education to optimise palliative care practices, work within the organisation to build capacity and help others learn about the NP role in palliative care to better integrate it within the team, and improve system outcomes such as accessibility of care and number of hospital visits.
CONCLUSIONS: NPs contribute to palliative care in LTC settings through multifaceted collaborative processes that ultimately promote the experience of a positive death for residents, their family members, and formal caregivers.

Status
MEDLINE
Authors Full Name
Ploeg, Jenny; McAiney, Carrie; Schindel Martin, Lori; Donald, Faith; Martin-Misener, Ruth; Brazil, Kevin; Taniguchi, Alan; Wickson-Griffiths, Abigail; Carter, Nancy; Sangster-Gormley, Esther.
Institution

van der Kallen HT; Raijmakers NJ; Rietjens JA; van der Male AA; Bueving HJ; van Delden JJ; van der Heide A.


[Journal Article. Research Support, Non-U.S. Gov't]

UI: 24152482

BACKGROUND: Palliative sedation is defined as deliberately lowering a patient's consciousness, to relieve intolerable suffering from refractory symptoms at the end of life. Palliative sedation is considered a last resort intervention in end-of-life care that should not be confused with euthanasia.

AIM: To inform healthcare professionals about attitudes of the general public regarding palliative sedation.

design and setting: A cross-sectional survey among members of the Dutch general public followed by qualitative interviews.

METHOD: One thousand nine hundred and sixty members of the general public completed the questionnaire, which included a vignette describing palliative sedation (response rate 78%); 16 participants were interviewed.

RESULTS: In total, 22% of the responders indicated knowing the term 'palliative sedation'. Qualitative data showed a variety of interpretations of the term. Eighty-one per cent of the responders agreed with the provision of sedatives as described in a vignette of a patient with untreatable pain and a life expectancy of <1 week who received sedatives to alleviate his suffering. This percentage was somewhat lower for a patient with a life expectancy of <1 month (74%, P = 0.007) and comparable in the case where the physician gave sedatives with the aim of ending the patient's life (79%, P = 0.54).

CONCLUSION: Most of the general public accept the use of palliative sedation at the end of life, regardless of a potential life-shortening effect. However, confusion exists about what palliative sedation represents. This should be taken into account by healthcare professionals when communicating with patients and their relatives on end-of-life care options.

Status

MEDLINE

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Aim: To explore family members' supportive interactions in palliative care and the emotional experiences that they associate with these interactions.

Methods: Qualitative individual interviews were performed with bereaved family members recruited from an urban palliative care service in Sweden. The interviews were analysed using inductive qualitative content analysis.

Results: Five categories of supportive interactions with staff members were linked with emotional consequences: informational support, supportive encounters, professional focus of staff, a supportive environment, and bereavement support. Having a dialogue with family members nurtured certainty and security, supportive encounters gave a warm and comforting feeling, and bereavement support contributed to feelings of strength. Environmental factors contributed to dignity.

Conclusion: Supportive interactions with staff and within a home-like environment help to build resilience if tailored to the family member's own needs.
Palliative care needs of terminally ill people living alone: a service provider perspective.
Aoun SM;  Wall D;  Kristjanson LJ;  Shahid S.
[Journal Article.  Multicenter Study.  Research Support, Non-U.S. Gov't]
UI: 24151696

BACKGROUND: Community-based palliative care services face challenges in meeting the needs of terminally ill clients who live alone without a primary caregiver. Yet, there is a dearth of literature on the perceptions of health service providers (HSPs) regarding the care needs and possible management options to assist this growing group to remain at home.

OBJECTIVE: This paper investigated the support needs of people living alone with a terminal illness from a service provider perspective.

DESIGN: In depth semi-structured interviews were conducted with nine HSPs from community based services in three Australian states.

RESULTS: Four main themes emerged: care challenges, differences in care provision, appropriate approaches to care and essentials for an effective service such as 24 h care, cost-free provision of personal alarm systems, supported and coordinated housekeeping services, funded respite care and financial care packages. HSPs expressed a respect for the autonomy and independence of the clients, yet felt pressured to ensure that safe and attentive care was possible. HSPs recognised the central importance of maintaining the independence and autonomy of palliative care clients living alone.

CONCLUSIONS: This study is the first in-depth account of what HSPs perceive they need to effectively look after home alone dying clients. The study provided directions to inform service planning for this growing and challenging population group regarding adequate and timely services that will lead to more complying with the clients' wishes, more care being delivered at home, a reduction in hospitalisations, a better quality of life and a capacity to die at home.
BACKGROUND: The purpose of this study was to describe the impact of clinical ethics consultations among patients with head and neck cancer in order to better anticipate and manage clinical challenges.

METHODS: A database was queried to identify patients with head and neck cancer for whom ethics consultation was performed at a comprehensive cancer center (n = 14). Information from the database was verified via data abstraction and analyzed qualitatively and quantitatively.

RESULTS: Common requests for ethics consultation involved code status (6 of 14) and withdrawal/withholding life-sustaining treatments (6 of 14). Common contextual features were interpersonal conflicts (6 of 14) and communication barriers (5 of 14). Airway management concerns were frequent (5 of 14). Whereas 21% of patients had do not resuscitate (DNR) orders before ethics consultation, 79% were DNR subsequently.

CONCLUSION: Ethics consultations among patients with head and neck cancer reflect distinctive complexities inherent to their disease, but are entirely consistent with global clinical ethical themes. Consideration of communication barriers, social isolation/stigma, symptom control, and airway management are critical.

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105.
When expressions make impressions-nurses' narratives about meeting severely ill patients in home nursing care: a phenomenological-hermeneutic approach to understanding.
Devik SA; Enmarker I; Hellzen O.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 24138930
Registered nurses (RNs) working in homecare encounter severely ill and palliative patients whose expressions may cause ethical challenges and influence their daily work. The aim of this qualitative study was to illuminate and interpret the meaning of nurses' lived experiences when meeting these patients. Narrative interviews were conducted with 10 RNs working in home nursing care. These interviews were audiotaped and transcribed verbatim to a text and interpreted by a phenomenological-hermeneutic method inspired by Ricoeur. The meaning of the RNs' lived experience of patients' expressions was formulated into four themes. The first theme,
Being open for the presence of the Other, includes two subthemes: "Sensing vulnerability" and "Empathizing with." The second theme, Being satisfied, entails the subthemes, "Feeling exceptional" and "Being trusted." The third theme, Being frustrated, contains the subthemes, "Being disappointed" and "Being angry." The fourth and final theme, Being ambivalent, includes one subtheme: "Being generous or reserved." Patients' expressions that make impressions on nurses create emotional waves. Expressions leave impressions that call upon the nurse, and confront her with taking the risk of letting intuition and pre-reflexive feelings gain entry to her care. Allowing for the Other's presence is seen as a precondition, which means facing humanity and sensing a vulnerability in herself as well as in the Other. Understanding and balancing this emotional dimension in care seems to cause confusion and distress within the nurses. Realizing how their feelings may lead to either generosity or aloofness towards the patient is upsetting. Our interpretation suggests that these impressions echo confusion according to the role of being a professional nurse. There is a need to pay more attention to how the emotional dimension in care is understood and impacts the way nurses perform their professional role.

106.
Geriatric palliative care: do medical students' narrative reflections after a hospice clinical experience link to geriatric competencies?
Corcoran AM; True G; Charles N; Margo KL.
UI: 23972213
Since the Association of American Medical Colleges geriatric competencies were released, educators are striving to incorporate them into medical student curricula. The purpose of this study is to examine medical students' reflections after an interdisciplinary, hospice staff-precepted clinical experience, and whether these reflections relate to the geriatric competencies which focus on palliative care. From July 2010 to June 2011, 155 2nd- and 3rd-year medical students participated in a required, half-day hospice experience, with 120 (77%) submitting narrative reflections for analysis. The narratives were analyzed using the constant comparative method associated with grounded theory, followed by consensus-building in an iterative process, to
identify themes. Six themes were identified from the analysis of student narratives: demonstrating a new or expanded knowledge of hospice care (79%, 95/120), developing new insights about self and others (74%, 89/120), changing attitudes toward hospice care (63%, 76/120), linking patient needs with appropriate team members (43%, 52/120), understanding patient goals of care (43%, 51/120), and discussing palliative care as a treatment option (27%, 32/120). The authors conclude that a brief, interdisciplinary, hospice staff-precepted clinical experience is an effective model to inspire medical students to reflect on geriatric palliative care. Students clearly reflected on the geriatric palliative care competencies of symptom assessment and management, and gained insight into the role of the hospice team members and how hospice care can be a positive treatment option. Future educators should think about building on this type of high impact learning experience, and developing items to measure application of knowledge gained.

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107.
Medical oncologists’ perception of palliative care programs and the impact of name change to supportive care on communication with patients during the referral process. A qualitative study. Rhondali W; Burt S; Wittenberg-Lyles E; Bruera E; Dalal S. Palliative & Supportive Care. 11(5):397-404, 2013 Oct. [Journal Article]
UI: 23302500
OBJECTIVE: In a simultaneous care model, patients have concurrent access to both cancer-directed therapies and palliative care. As oncologists play a critical role in determining the need/timing of referral to palliative care programs, their understanding of the service and ability to communicate this with patients is of paramount importance. Our study aimed to examine oncologists’ perceptions of the supportive care program at M.D. Anderson Cancer Center, and to determine whether renaming "palliative care" to "supportive care" influenced communication regarding referrals.
METHOD: This qualitative study used semi-directed interviews, and we analyzed data using grounded theory and qualitative methods.
RESULTS: We interviewed 17 oncologists. Supportive care was perceived as an important time-saving application, and symptom control, transitioning to end-of-life care, family counseling, and improving patients’ ability to tolerate cancer therapies were cited as important functions. Although most claimed that early referrals to the service are preferable, oncologists identified several
challenges, related to the timing and communication with patients regarding the referral, as well as with the supportive care team after the referral was made. Whereas oncologists stated that the name change had no impact on their referral patterns, the majority supported it, as they perceived their patients preferred it.

SIGNIFICANCE OF RESULTS: Although the majority of oncologists favorably viewed supportive care, communication barriers were identified, which need further confirmation. Simultaneous care models that effectively incorporate palliative care with cancer treatments need further development.


BACKGROUND: The provision of emotional and psychological support for all family members who need it is an essential element of holistic palliative care. Within East Anglia's Children's Hospice, teams of professionally trained and experienced workers offer psychosocial support to all family members at all times during the child's and family's journey. However, the effectiveness and appropriateness of current psychosocial provision is unclear, as is the requirement for any additional psychological services.

OBJECTIVE: The purpose of this study was to elicit perceptions about current psychological support within the hospice from a group of stakeholders (parents, hospice staff, and external professionals).

METHOD: Forty-five parents participated in family focus groups, telephone interviews, individual interviews in their home, or a web-based survey. Ninety-five hospice staff (including nurses, carers, play specialists, therapists, and family support practitioners) and 28 external staff (including physicians, nurses, and commissioning managers) were seen using a mixture of focus group and individual meetings. Focus groups and meetings were held at the hospice building or at an external venue. Interviews were recorded and transcribed verbatim and analyzed using thematic coding.
RESULTS: Two main themes addressing perceptions of current psychological provision emerged: "understanding psychological support" and "unmet psychological need." Subthemes linked to support included choice, staff roles and labels, communication, and flexibility, whereas the themes within unmet need had a stronger focus on people and problems.

SIGNIFICANCE OF RESULTS: Understanding different user perspectives is an important first step in enhancing current psychological provision; operationalizing the findings will be challenging.

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20131014
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109.
Oncologists' perspectives on concurrent palliative care in a National Cancer Institute-designated comprehensive cancer center.
Bakitas M; Lyons KD; Hegel MT; Ahles T.
[Journal Article. Research Support, N.I.H., Extramural. Research Support, Non-U.S. Gov't]
UI: 23040412

OBJECTIVE: The purpose of this study was to understand oncology clinicians' perspectives about the care of advanced cancer patients following the completion of the ENABLE II (Educate, Nurture, Advise, Before Life Ends) randomized clinical trial (RCT) of a concurrent oncology palliative care model.

METHOD: This was a qualitative interview study of 35 oncology clinicians about their approach to patients with advanced cancer and the effect of the ENABLE II RCT.

RESULTS: Oncologists believed that integrating palliative care at the time of an advanced cancer diagnosis enhanced patient care and complemented their practice. Self-assessment of their practice with advanced cancer patients comprised four themes: (1) treating the whole patient, (2) focusing on quality versus quantity of life, (3) "some patients just want to fight," and (4) helping with transitions; timing is everything. Five themes comprised oncologists' views on the complementary role of palliative care: (1) "refer early and often," (2) referral challenges: "Palliative" equals "hospice"; "Heme patients are different," (3) palliative care as consultants or co-managers, (4) palliative care "shares the load," and (5) ENABLE II facilitated palliative care integration.

SIGNIFICANCE OF RESULTS: Oncologists described the RCT as holistic and complementary, and as a significant factor in adopting concurrent care as a standard of care.

Status
Cartwright JC; Hickman SE; Nelson CA; Knafl KA.
[Journal Article. Research Support, N.I.H., Extramural]
UI: 23813748
This study was designed to identify successful strategies used by investigators for working with their Institutional Review Boards (IRBs) in conducting human subjects research. Telephone interviews were conducted with 46 investigators representing nursing, medicine, and social work. Interview transcripts were analyzed using qualitative descriptive methods. Investigators emphasized the importance of intentionally cultivating positive relationships with IRB staff and members, and managing bureaucracy. A few used evasive measures to avoid conflict with IRBs. Few successful strategies were identified for working with multiple IRBs. Although most investigators developed successful methods for working with IRBs, further research is needed on how differences in IRB culture affect human subjects protection, and on best approaches for obtaining IRB approval of multi-site studies. Copyright 2013 Wiley Periodicals, Inc.
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Source: NLM. NIHMS556456  Source: NLM. PMC3967853
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<td colspan=""/>

112. Integrating palliative care in lung cancer: an early feasibility study. Johnston B; Buchanan D; Papadopoulos C; Sandeman G; Lord H. International Journal of Palliative Nursing. 19(9):433-7, 2013 Sep. [Journal Article. Research Support, Non-U.S. Gov't] UI: 24071834 AIM: The aim of this preliminary study was to evaluate the feasibility of conducting an effectiveness trial of early access to palliative care services for people with lung cancer through use of an integrated outpatient model. METHODS: Newly diagnosed patients with lung cancer receiving palliative-intent treatment or best supportive care treatment were recruited over a 5-month period from one out-patient clinic in Scotland. Patients were offered a clinical review appointment with a palliative medicine consultant at two time points: baseline and 12 weeks later. Prior to each appointment patients completed three outcome measures addressing symptom severity, wellbeing, and health-care needs. One-to-one interviews were also conducted to explore patients' experiences of being involved in the study. RESULTS: Three patients participated in the study. The main reasons for low recruitment were patients' deteriorating condition and unwillingness to undertake extra hospital visits. However,
qualitative data indicated that the participants found this extra layer of supportive care useful in identifying and managing their needs, as well as enabling future planning.

CONCLUSION: Further testing is needed to ascertain the feasibility of conducting a trial of integrating early access to palliative care services into routine practice for people with lung cancer.

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20130927
Year of Publication
2013

113.
The palliative care needs for fibrotic interstitial lung disease: a qualitative study of patients, informal caregivers and health professionals.
Bajwah S; Higginson IJ; Ross JR; Wells AU; Birring SS; Riley J; Koffman J.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23885010

BACKGROUND: While there have been some studies looking at the impact on quality of life of patients with idiopathic pulmonary fibrosis, to date no qualitative research looking at the specialist palliative care needs of these patients has been conducted.

AIM: This study aims to explore the specialist palliative care needs of people living with end-stage progressive idiopathic fibrotic interstitial lung disease.

DESIGN AND SETTINGS/PARTICIPANTS:
In total, 18 qualitative semi-structured in-depth interviews were conducted with patients, their informal caregivers and health professionals across two specialist interstitial lung disease centres in London and in the community.

RESULTS: Many participants reported uncontrolled symptoms of shortness of breath, cough and insomnia, which profoundly impacted every part of patients' and informal caregivers' lives. Psychologically, patients were frustrated and angry at the way in which their illness severely limited their ability to engage in activities of daily living and compromised their independence. Furthermore, both patients and informal caregivers also reported that the disease seriously affected family relationships where strain was pronounced. There was varied knowledge and confidence among health professionals in managing symptoms, and psychosocial needs were often underestimated.

CONCLUSION: This study is the first of its kind to examine in depth the impact of symptoms and psychosocial needs revealing the profound effect on every aspect of progressive idiopathic fibrotic interstitial lung disease patients' and informal caregivers' lives. Education and guidance of
appropriate palliative care interventions to improve symptom control are needed. A case conference intervention with individualised care plans may help in addressing the substantial symptom control and psychosocial needs of these patients and informal caregivers.

114.
Palliative care for Parkinson's disease: a summary of the evidence and future directions.
Richfield EW; Jones EJ; Alty JE.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23838377
BACKGROUND: Parkinson's disease is a common, life-limiting, neurodegenerative condition. Despite calls for improved access to palliative care for people with Parkinson's disease, services have been slow in developing. Obstacles include poor understanding and recognition of palliative care needs, the role for specialist palliative care services and an agreed structure for sustainable palliative care provision.
AIM: To summarise the evidence base for palliative care in Parkinson's disease, linking current understanding with implications for clinical practice and identifying areas for future research. WHAT IS KNOWN: Convention recognises a final 'palliative phase' in Parkinson's disease, while qualitative studies suggest the presence of palliative care need in Parkinson's disease from diagnosis. Clinical tools to quantify palliative symptom burden exist and have helped to identify targets for intervention. Dementia is highly prevalent and influences many aspects of palliative care in Parkinson's disease, with particular implications for end-of-life care and advance care planning.
IMPLICATIONS FOR CLINICAL PRACTICE: The 'palliative phase' represents a poor entry point for consideration of palliative care need in Parkinson's disease. An alternative, integrated model of care, promoting collaboration between specialist palliative and neurological services, is discussed, along with some specific palliative interventions. WHAT IS UNKNOWN: Limited evidence exists regarding timing of palliative interventions, triggers for specialist referral and management of terminal care.
IMPLICATIONS FOR FUTURE RESEARCH: Research examining access to palliative care and management of terminal symptoms will assist development of sustainable, integrated palliative care services for Parkinson's disease.

115.
Understanding the experience of patients with chronic obstructive pulmonary disease who access specialist palliative care: a qualitative study.
Hayle C; Coventry PA; Gomm S; Caress AL.
[Journal Article]
UI: 23681494

BACKGROUND: Palliative care for people with life-limiting non-malignant disease is increasingly prioritised. People with end-stage chronic obstructive pulmonary disease are among a key group of non-cancer patients likely to benefit from specialist palliative care, but it remains uncertain whether the needs of this group are met by existing services.
AIM: To evaluate the experiences of patients with chronic obstructive pulmonary disease who accessed specialist palliative care.
DESIGN: Data from semi-structured interviews were analysed using a hermeneutic phenomenological approach.
SETTING/PARTICIPANTS: Eight patients accessing specialist palliative care within one city in North West England.
RESULTS: Perceived benefits of specialist palliative care included reduced frequency of hospital admission, improved physical and psychological symptoms, reduced social isolation and a broadened physical environment. Participants were mainly aware of their poor prognosis, but discussion of referral to palliative care sometimes caused distress owing to the historical associations between dying and hospice care. Following engagement with services, participants' perceptions changed: palliative care was associated with social inclusion and opportunities to engage in reciprocal and altruistic social action. Negative associations were replaced by uncertainty and anxiety about the prospect of discharge.
CONCLUSIONS: Much within existing services works well for people with chronic obstructive pulmonary disease, but opportunities to enhance palliative care for this underserved group remain. Future research might focus on prospectively evaluating the impact of key components of
palliative care on core patient-centred outcomes. Additionally, work must be done to raise awareness of the benefits of specialist palliative care for non-cancer patients, as negative associations can form a barrier to access.

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Year of Publication
2013

116.
Provision of palliative and end-of-life care in stroke units: a qualitative study.
Gardiner C; Harrison M; Ryan T; Jones A.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23579262
BACKGROUND: Stroke is a leading cause of death; between 20% and 30% of people die within 30 days of a stroke. High-quality palliative and end-of-life care are advocated for patients not expected to recover from stroke.
AIM: To explore the perspectives of health professionals regarding the provision of palliative and end-of-life care in UK stroke units.
DESIGN AND SETTING: Qualitative focus groups and individual interviews were held with 66 health professionals working in UK specialist stroke units. Data were analysed thematically.
RESULTS: Three themes emerged from the data. Palliative care was recognised as an important component of stroke care; however, there was uncertainty when initiating transitions to palliative care in stroke, and issues were identified with the integration of acute stroke care and palliative care.
CONCLUSIONS: The findings provide encouraging evidence that palliative and end-of-life care have been adopted as key components of specialist stroke care in UK stroke units. However, many patients stand to benefit from earlier identification of palliative care need and a consideration of quality-of-life approaches during active care. Encouraging collaboration and partnership when working with specialist palliative care services would optimise palliative care service delivery and may provide patients and their families with greater opportunities for documenting and achieving preferences for care and achieving a better quality of death.

Status
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Over the past decade, research has documented the positive consequences individuals attribute to the experience of traumatic, life-threatening events, including enhanced life appreciation, improved social relationships, and a deepened sense of self and meaning. Despite evidence that individuals with cancer frequently perceive growth as a result of their experience, personal growth in the context of advanced cancer has received markedly less attention. In light of the unique challenges accompanying the experience of advanced cancer, the phenomenon of perceiving positive consequences and making meaning of the cancer experience (i.e., personal growth) may be distinct in patients with life-limiting disease as compared with more commonly studied early-stage cancer survivor samples. The purpose of this article was to review studies examining personal growth in adults diagnosed with advanced cancer to encourage medical professionals to consider and respond to their concerns around meaning within palliative care. We conducted a systematic review of the PubMed and PsycINFO electronic databases for studies examining personal growth in patients with advanced cancer published between January 1960 and January 2013. Of the 197 studies reviewed, 12 quantitative studies and 10 qualitative studies met criteria for inclusion. The review revealed that many patients with advanced cancer both cite finding meaning at the end of life as important and perceive positive consequences as a result of their experience. In comparison to early-stage cancer or benign disease, advanced cancer may serve to prompt higher levels of personal growth. However, these findings are mixed and may indicate a complex, nonlinear relationship between cancer prognosis and personal growth. The most promising candidates for promoting personal growth during advanced disease include younger adult age, spirituality, and psychosocial resources (optimism, marriage, and social support from close others and health care providers). Importantly, a co-occurrence of personal growth with both distress and well-being in advanced cancer suggests that personal growth in this unique context is characterized by perceived positive consequences in the face of considerable demands, which may be reflected by greater negative and positive markers of adjustment. Understanding and awareness of personal growth in individuals with advanced cancer may facilitate health care providers' ability to consider and respond to concerns around meaning and personal growth within palliative care, given the growing literature on psychosocial interventions.
for patients with advanced cancer. Integration of the existing research base with intervention development is an opportunity for future research.

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20130920

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2013

118.
Differences between heart failure clinics and primary health care.
Andersson L; Eriksson H; Nordgren L.
[Journal Article]
UI: 24046927

There is a paucity of knowledge concerning how people with heart failure experience differences between specialised heart failure clinics and primary healthcare in Sweden. This study aimed to describe differences regarding information and follow-up in heart failure clinics and primary healthcare. The study was conducted in Sweden in 2011. Four people (three men, one woman; aged 60 to 84) with heart failure (NYHA II) were interviewed. The interviews were analysed with qualitative content analysis. The findings revealed after referral from the heart failure clinic to primary healthcare, follow-ups were omitted. Still, the patients needed care, support and information. The findings are illuminated in four themes. The patients' varying and individual needs can be difficult to recognise and manage unless they are followed-up from either HFC or PHC on a regular basis.

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BACKGROUND: Teamwork is a standard of care in palliative care and that is emphasized by leading organizations. When interdisciplinary teams communicate their varied assessments, outcomes may be more than additive due to the synthesis of information. Interprofessionality does not guarantee multidimensionality in health care interventions, however, and that interprofessional teams promote collaboration may be questioned.

AIM: The aim was to explore team interaction among team members in specialized palliative care teams.

DESIGN: Semistructured interviews were conducted with health professionals working in specialized palliative home care teams. The interviews were analyzed by content analysis.

SETTING/PARTICIPANTS: Participants were recruited from specialized palliative care units in Sweden. The 15 interviewees included 4 men and 11 women. Physicians, nurses, paramedical staff, and social workers were included.

RESULTS: Organizational issues like resources and leadership have a great impact on delivery of care. Competence was mirrored in education, collaboration, approach, and support within the team; while communication was described as key to being a team, resolving conflict, and executing palliative care.

CONCLUSION: Communication and communication patterns within the team create the feeling of being a team. Team climate and team performance are significantly impacted by knowledge and trust of competence in colleagues, with other professions, and by the available leadership. Proportions of different health professionals in the team have an impact on the focus and delivery of care. Interprofessional education giving clarity on one's own professional role and knowledge of other professions would most likely benefit patients and family caregivers.
Pediatric oncology providers’ perceptions of barriers and facilitators to early integration of pediatric palliative care.

Dalberg T; Jacob-Files E; Carney PA; Meyrowitz J; Fromme EK; Thomas G.


BACKGROUND: Pediatric patients experience significant symptoms during cancer treatment. Symptom management is frequently inadequate. We studied perceptions of pediatric oncology care providers regarding early integration of palliative care (PC) for pediatric patients to identify barriers and facilitators that might assist in understanding how care could be improved.

PROCEDURES: Pediatric oncology providers were recruited to participate in four focus groups. A proposal for early integration of a pediatric palliative care team (PPCT) was presented and followed by a facilitated discussion. Data were analytically categorized into themes by three independent coders using constant comparative analysis and crystallization techniques. A consensus approach was used to identify final themes.

RESULTS: Barriers to the proposed care model of early integration of a PPCT included provider role, conflicting philosophy, patient readiness, and emotional influence and were more prevalent in the physician participants compared to nurse practitioner, nursing, and social work participants. Facilitators included patient eligibility, improved patient care, education, and evidence-based medicine. Though all participants were invested in providing optimal patient care, physician participants believed the current standard of care model is meeting the needs of patients and family, while the nurse practitioner, nursing, and social work participants working on the same healthcare team believed the proposed care model would improve the overall care of children diagnosed with cancer.

CONCLUSIONS: Differing perceptions among healthcare providers regarding the care of children with cancer suggest that team functioning could be improved. Avenues for pilot testing early integration of PC could provide useful information for a next study.
Residents learning from a narrative experience with dying patients: a qualitative study.
Tait GR; Hodges BD.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23053870
For patients at the end of life, it is crucial to address the psychological, existential, and spiritual distress of patients. Medical education research suggests trainees feel unprepared to provide the whole person, humanistic care held as the ideal. This study used an empirically based narrative intervention, the dignity interview, as an educational intervention with first year residents. The interview helps patients tell and make meaning of their life story. The intervention was aimed at addressing trainee perceived gaps in the non-physical aspects of end-of-life care. It was also intended to stimulate broader reflection on lessons learned in medical education about the value of narrative as part of humanistic care. Twelve first year residents administered a 1 h interview to dying patients. The resident returned to read the transcribed story back to the patient. Semi-structured interviews of the residents were transcribed and analyzed using the constant comparative method to identify emergent themes. This experience was seen as distinct from the "traditional" medical interview. Residents reflected on lessons learned from patients and on their own professional and personal lives. Residents felt conversations with dying patients, and more broadly the art of soliciting a patient's story are poorly taught and modeled. More concerning, the hidden curriculum seems to be sending messages that learning a patient's story is not the domain of a physician and that it is not valued like the curing and technical imperatives. These findings have implications for medical education's ongoing attempts to better produce humanistic physicians.
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122.
Patient and family perceptions of hospice services: 'I knew they weren't like hospitals'.
Bray Y; Goodyear-Smith F.
INTRODUCTION: The vision for palliative care service provision in New Zealand is for all people who are dying and their families to have timely access to culturally appropriate, quality palliative care services. An Auckland hospice's records show that the ethnically diverse population statistics were not reflected in the referrals for hospice services. The aim of this research was to gain a patient-and-their-family perspective on the hospice, including exploration of components of service care that could be improved for various cultural groups.

METHODS: Patients currently under the care of the hospice and family members were recruited from hospice records. Semi-structured interviews were conducted to explore the emerging issues. The study collected data from a purposive sample of 18 palliative care patients or carer family members, ranging in age from 39 to 81 years, who reflected the ethnic diversity of the population of the region. Interviewing was carried out by an experienced research assistant and continued until data saturation was reached.

FINDINGS: Four key themes emerged—hospice personnel's approach to patients, quality of service, cultural barriers, and strategies for future improvement. It was determined that the latter two were the most significant to address in this article.

CONCLUSION: The study revealed the need for information-giving and education, including public profiling of the hospice to strengthen community involvement. Strategies to reduce ethnic disparities include strengthening the awareness of, and access to, services by connecting with cultural groups through churches, community and specific cultural media.

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2013

123.
The Carer Support Needs Assessment Tool (CSNAT) for use in palliative and end-of-life care at home: a validation study.

CONTEXT: Family carers need to be supported in their central role of caring for patients at the end of life, but brief practical tools to assess their support needs have been missing. To address
this gap, we developed a brief evidence-based Carer Support Needs Assessment Tool (CSNAT) suitable for everyday practice.

OBJECTIVES: To assess face, content, and criterion validity of the CSNAT and measure sensitivity to change over time.

METHODS: Participants were 225 adult carers of patients from six U.K. Hospice Home Care services. Carers were surveyed at baseline and at four-week follow-up using self-completed questionnaires, including CSNAT, standard measures (distress, strain, positive appraisals, preparedness, and global health), help provided with activities of daily living, and patients’ symptom levels. Qualitative feedback on CSNAT was sought through 10 pilot carer interviews and professional and carer advisory group input.

RESULTS: The CSNAT has good face, content, and criterion validity. CSNAT domains comprehensively covered carer support needs. CSNAT scores showed clear and consistent positive correlations with strain and distress and negative correlations with preparedness for caregiving and global health. There also were clear correlations with help with activities of daily living and some relationships with positive appraisals and symptom burden. The CSNAT's sensitivity to change in relevant domains was similar to other measures.

CONCLUSION: The CSNAT is a valid tool for the direct measurement of carers' support needs. It combines comprehensiveness of content with feasibility of administration and has utility both as a research tool and a tool for everyday palliative care practice. Copyright 2013 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

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20130902
Year of Publication
2013
<td colspan=""">124.
[Experience in palliative care for children with leukemia: the professionals' viewpoint].
[Portuguese][Erratum appears in Cien Saude Colet. 2013 Nov;18(11):3447]
Nascimento DM; Rodrigues TG; Soares MR; Rosa ML; Viegas SM; Salgado Pde O.
Ciencia & Saude Coletiva. 18(9):2721-8, 2013 Sep.
[English Abstract. Journal Article]
UI: 23989579
Palliative care is developed through multi-professional assistance with actions to provide support and comfort for the children and their families. The support involves the alleviation of suffering by controlling the pain and its symptoms, as well as ensuring psychosocial and spiritual support. This is a qualitative case study which sought to understand the multidisciplinary view of the team
vis-a-vis a child with leukemia in palliative care, in a hospital in Belo Horizonte. The subjects of research were 17 health professionals of the direct assistance team to the child receiving such care and the data were analyzed using the content analysis technique. The professional experience in palliative care is intrinsic to the success and continuity of the patient's care. It was found that the professionals have little experience in this area and have difficulty dealing with their emotions, and sometimes become unable to act when faced with the anguish of those involved and with death. However, despite the fact that the area of activity causes suffering and anguish to the professional, the multi-professional team still identifies with and likes the area, which is important for the children and their families to feel safe, respected and well cared for by the professionals.

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Year of Publication
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125.
[Perceptions of the multi-professional team on the implementation of palliative care in intensive care units]. [Portuguese]
da Silva CF; Souza DM; Pedreira LC; dos Santos MR; Faustino TN.
[English Abstract. Journal Article]
UI: 23989566
The scope of this paper was to analyze the perceptions of the multi-professional team on the implementation of palliative care in an adult intensive care unit. An exploratory-descriptive study using a qualitative approach was conducted with 14 health professionals from a public teaching hospital. The information was collected between February and April 2012, by means of semi-structured interviews and non-participatory observation interpreted using content analysis. Three thematic categories were identified: Care for terminal patients in an ICU fostering physical comfort; Lack of preparation of the team in dealing with terminal patients; and Challenges of palliative care practices in the intensive care environment. The interviewed parties reported having some knowledge of the proposal for palliative care though divergences were observed in the therapeutic conduct of the team in the care provided, demonstrating a lack of interaction and communication among the professionals. The drafting of a national policy to promote care for terminally ill patients is necessary, as well as ongoing training of professionals and the creation of
care protocols for promoting the comfort of the patients and their families during the end of life phase.

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Year of Publication
2013

126.
[The perception by nurses of the significance of palliative care in patients with terminal cancer].
[Portuguese]
Fernandes MA; Evangelista CB; Platel IC; Agra G; Lopes Mde S; Rodrigues Fde A.
[English Abstract. Journal Article]
UI: 23989565

This study sought to assess the perception of nurses with respect to cancer patients under palliative care. It is an exploratory study with a qualitative approach conducted with nurses from a hospital attending cancer patients under palliative care located in the city of Joao Pessoa, State of Paraiba. The study included nine nurses who worked in the hospital. The empirical material was collected using the technique of semi-structured interviews and analyzed using the content analysis technique. The interpretative analysis of the interviews led to the definition of three categories: Improving the quality of life through the alleviation of pain and suffering; Palliative Care: a multi-professional study of terminal patients and their families in the grieving process; Communication: a source of dignity in the terminal care process. The conclusion reached is that the study revealed that the nurses involved acknowledge the importance of the multidisciplinary team. It enables the nurses to reflect on the use of communication as an essential element of care for patient and family under palliative care. It is hoped that the data obtained may foster further research on the topic.

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This study sought to investigate the principles of bioethics considered by nurses involved in research while caring for patients with HIV/AIDS under palliative care. An exploratory study, with a qualitative approach, was conducted with twelve nurses in a public hospital in the municipality of Joao Pessoa in the State of Paraiba. A form was used for data collection and the empirical material was analyzed qualitatively using the content analysis technique. The following categories emerged from the qualitative analysis: Respect for the autonomy of HIV/AIDS patients under palliative care; and Enhancement of the principles of charity, non-malevolence and justice in providing palliative care to HIV/AIDS patients. The results revealed that the participants acknowledge the importance of bioethical principles while caring for patients with HIV/AIDS under palliative care. The work provides a reflection on and elicits the pursuance of further studies which can contribute to improve the quality of life of these patients with care based on ethical principles.
This is a study conducted in the palliative care unit of the INCA National Cancer Institute, in an attempt to understand the nature of the work and its effects on the health of the professionals. A qualitative approach is adopted, based on participant observation and semi-structured interviews with professionals from the hospital. Most of the professionals are female and were unaware of the concept of palliative care when they started their careers in the Unit. Teamwork is highly valued by the professionals who involve the families in the care actions and motivate the participation of patients and relatives in decision-making. However, these workers experience high emotional stress due to their involvement in the suffering of patients and families. They are also exposed to considerable physical stress caused by the intense demand of the daily routine and the dependence of the majority of patients. The study revealed that there are many professionals on leave of absence due to musculoskeletal problems and psychiatric disorders. There is a pressing need for health support programs for these professionals and awareness of daily care measures for their own health. However, their suggestions for improvement of working and health conditions are merely passed on to be implemented by the institutions themselves.

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This paper analyzes the palliative care of terminal patients, examining the tensions between the humanization of care and the progressive medicalization at the end-of-life situation. The research
upon which the article is based adopts a qualitative methodological approach derived from interviews with professionals and patients and ethnographic observations in a palliative care unit in the City of Buenos Aires, Argentina. The article describes the configuration of personalized and comprehensive health care based on the core values of more humanized end-of-life care promoted by palliative care supporters. Similarly, the paper analyzes how these practices are assisted by progress in the medicalization process in which the dimension of care is considered less an unprofessional area of medical practice than an area of care in which specific technical skills and know-how are employed. The article explores how instead of being divergent, the logic of care and medicalization work in a complementary fashion.

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130.
[A qualitative study of cancer patients receiving palliative support in hospital care]. [Spanish]
Getino Canseco M.
Ciencia & Saude Coletiva. 18(9):2531-9, 2013 Sep.
[English Abstract. Journal Article]
UI: 23989559
This article focuses on patients with cancer during the terminal phase. It deals with the care that individuals need after trying to seek health solutions in different hospitals when the disease is deemed incurable and they then require palliative care (PC) to obtain welfare and assist them to die. In the Spanish health system these patients are cared for in palliative care units or services. The main objective of palliative care is to give comfort. Comforting is destined to alleviate and support patients and families during the process of health / disease / care / patient death. During this period, it is important to care for the ailing body. Similarly, when a disease is incurable, the pain and suffering runs its inexorable course and leaves perceptible traces. These signs can be an indication that death is nigh. Although scientific advances have produced positive results in the control of pain, in some cases there are critical moments when situations of misery and despair arise for the terminal patients.
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Palliative care involves an approach in the field of care for terminal patients and their families that seeks to assure them better quality of life by establishing good communication. The scope of this study was to verify how nurses use communication in the field of palliative care when assisting patients in the terminal phase. This is exploratory research of a qualitative nature in which 28 nurses working in wards of a hospital in the city of Joao Pessoa in the State of Paraiba participated in the period from August to October 2012. A form was used for data collection that was then analyzed using the content analysis technique. Three categories emerged from the analysis of the material: “palliative care and communication - interpersonal relationship between the nurse and the terminal patient”; “communication in palliative care as a strategy for strengthening the bond between the nurse and the terminal patient”; and “the importance of communication between the nurse and the family of the terminal patient under palliative care.” The conclusion reached was that communication is seen to be an effective element of care for the patient in the terminal phase and it is extremely important for the promotion of palliative care.
Nurses' perspectives on the discharge of cancer patients with palliative care needs from a gastroenterology ward.
Thon Aamodt IM; Lie I; Helleso R.
[Journal Article]
UI: 23970296
BACKGROUND: People with cancer usually like to spend as much time as possible at home rather than in the hospital. Nurses have a pivotal role when patients are discharged to a unit in hospital or from hospital to the community health-care system.
AIM: To explore how frontline surgical nurses assess patients with gastrointestinal cancer receiving palliative care and the implications of their assessment and competency for the patients' discharge destinations.
METHODS: A descriptive exploratory approach was used involving focus group interviews with a purposive sample of ten nurses from an inpatient gastroenterology surgical ward at a university hospital in Norway. Transcriptions of the interviews were analysed using Kvale and Brinkman's thematic approach.
RESULTS: Two overall themes emerged that had implications for the nurses' recommendations for optimal patient follow-up care after discharge: 'the complexity of and fluctuations in the patients' health status' and 'considering the competency of the nurses at the discharge destinations'.
CONCLUSIONS: This study illustrates surgical nurses' perspectives on the discharge destinations of cancer patients receiving palliative care. The findings have implications for initiatives aimed at providing more home-based palliative care.

Essential knowledge for family caregivers: a qualitative study.
Angelo JK; Egan R; Reid K.
[Journal Article]
UI: 23970294
BACKGROUND: Family caregivers are the backbone of the social care delivery system. With cancer and other life-limiting diseases on the rise, the need for well-informed informal/family caregivers has never been greater.

AIM: To uncover the information that palliative care teams routinely provide to family caregivers.

DESIGN: The methodology used was the nominal group technique, a type of focus group.

PARTICIPANTS: A total of 17 community palliative care health professionals participated in one of three focus groups.

RESULTS: Three themes emerged as dominant priorities for the education of family caregivers:
caring for oneself physically, emotionally, and spiritually; learning practical skills; and knowing what to expect and plan for as the family member's health declines.

CONCLUSIONS: The participants encourage caregivers to meet their own needs as well as care for family members. They help to empower family caregivers by encouraging them to take time for themselves, providing practical information for individual situations, and educating them on the signs and symptoms of approaching death. Successful terminal home care is possible through family caregiver support and empowerment.

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20130823

Year of Publication
2013

134.
Living and dying with heart failure in long-term care: experiences of residents and their family members.
Kaasalainen S; Strachan PH; Heckman GA; D'Elia T; McKelvie RS; McAiney C; Stolee P; van der Horst ML; Kelley ML; Demers C.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23970293

The purpose of this study was to explore the experiences of long-term care (LTC) residents living and dying with heart failure (HF) and their family members. An exploratory descriptive design was used to collect data from seven LTC residents and seven family members. The data was analysed using thematic content analysis. The main themes that emerged from the data were: limited understanding of the HF diagnosis, living with restrictions and other comorbidities, making decisions about transitioning to end-of-life care, and learning and negotiating the lines of communication. Residents and family members communicated with many health-care providers about managing the HF symptoms but most often worked through the nurse when problems
arose or decisions about care needed to be made. The findings from this study contribute to our understanding of residents’ and family members’ experiences in managing residents’ HF in LTC.

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**Date Created**
20130823

**Year of Publication**
2013

135.
A question prompt list for patients with advanced cancer in the final year of life: development and cross-cultural evaluation.
Walczak A; Mazer B; Butow PN; Tattersall MH; Clayton JM; Davidson PM; Young J; Ladwig S; Epstein RM.
[Journal Article. Research Support, Non-U.S. Gov’t]
UI: 23630055

**BACKGROUND:** Clinicians and patients find prognosis and end-of-life care discussions challenging. Misunderstanding one’s prognosis can contribute to poor decision-making and end-of-life quality of life. A question prompt list (booklet of questions patients can ask clinicians) targeting these issues may help overcome communication barriers. None exists for end-of-life discussions outside the palliative care setting.

**AIM:** To develop/pilot a question prompt list facilitating discussion/planning of end-of-life care for oncology patients with advanced cancer from Australia and the United States and to explore acceptability, perceived benefits/challenges of using the question prompt list, suggestions for improvements and the necessity of country-specific adaptations.

**DESIGN:** An expert panel developed a question prompt list targeting prognosis and end-of-life issues. Australian/US semi-structured interviews and one focus group elicited feedback about the question prompt list. Transcribed data were analysed using qualitative methods.

**SETTING/PARTICIPANTS:** Thirty-four patients with advanced cancer (15 Australian/19 US) and 13 health professionals treating such patients (7 Australian/6 US) from two Australian and one US cancer centre participated.

**RESULTS:** Most endorsed the entire question prompt list, though a minority queried the utility/appropriateness of some questions. Analysis identified four global themes: (1) reinforcement of known benefits of question prompt lists, (2) appraisal of content and suggestions for further developments, (3) perceived benefits and challenges in using the question prompt list
and (4) contrasts in Australian/US feedback. These contrasts necessitated distinct Australian/US final versions of the question prompt list.

CONCLUSIONS: Participants endorsed the question prompt list as acceptable and useful. Feedback resulted in two distinct versions of the question prompt list, accommodating differences between Australian and US approaches to end-of-life discussions, highlighting the appropriateness of tailoring communication aides to individual populations.

136.
The nature of, and reasons for, 'inappropriate' hospitalisations among patients with palliative care needs: a qualitative exploration of the views of generalist palliative care providers.
Gott M; Frey R; Robinson J; Boyd M; O'Callaghan A; Richards N; Snow B.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23295813

BACKGROUND: Recent studies have concluded that there is significant potential to reduce the extent of 'inappropriate' hospitalisations among patients with palliative care needs. However, the nature of, and reasons for, inappropriate hospitalisations within a palliative care context is under-explored.

AIM: To explore the opinions of 'generalist' palliative care providers regarding the nature of, and reasons for, inappropriate admissions among hospital inpatients with palliative care needs.

DESIGN: Qualitative study with data collected via individual interviews and focus groups.

SETTING/PARTICIPANTS: Participants (n = 41) comprised 'generalist' palliative care providers working in acute hospital and community settings.

SETTING: One District Health Board in an urban area of New Zealand.

RESULTS: The majority of participants discussed 'appropriateness' in relation to their own understanding of a good death, which typically involved care being delivered in a 'homely' environment, from known people. Differing attitudes among cultural groups were also evident. The following reasons for inappropriate admissions were identified: family carers being unable to cope, the 'rescue culture' of modern medicine, the financing and availability of community services and practice within aged residential care.
CONCLUSIONS: On the basis of our findings, we recommend a shift to the term 'potentially avoidable' admission rather than 'inappropriate admission'. We also identify an urgent need for debate regarding the role of the acute hospital within a palliative care context. Interventions to reduce hospital admissions within this population must target societal understandings of death and dying within the context of medicalisation, as well as take into account cultural and ethnic diversity in attitudes, if they are to be successful.

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137.
End-of-life decisions for people with intellectual disabilities, an interview study with patient representatives.
Wagemans AM; Van Schrojenstein Lantman-de Valk HM; Proot IM; Metsemakers J; Tuffrey-Wijne I; Curfs LM.
[Journal Article. Research Support, Non-U.S. Gov't]
Ui: 23295812
BACKGROUND: Not much is known about the process of end-of-life decision-making for people with intellectual disabilities.
AIM: To clarify the process of end-of-life decision-making for people with intellectual disabilities from the perspective of patient representatives.
DESIGN: A qualitative study based on semi-structured interviews, recorded digitally and transcribed verbatim. Data were analysed using Grounded Theory procedures.
PARTICIPANTS: We interviewed 16 patient representatives after the deaths of 10 people with intellectual disabilities in the Netherlands.
RESULTS: The core category 'Deciding for someone else' describes the context in which patient representatives took end-of-life decisions. The patient representatives felt highly responsible for the outcomes. They had not involved the patients in the end-of-life decision-making process, nor any professionals other than the doctor. The categories of 'Motives' and 'Support' were connected to the core category of 'Deciding for someone else'. 'Motives' refers to the patient representatives' ideas about quality of life, prevention from suffering, patients who cannot understand the burden of interventions and emotional reasons reported by patient representatives. 'Support' refers to the
support that patient representatives wanted the doctors to give to them in the decision-making process.

CONCLUSIONS: From the perspective of the patient representatives, the process of end-of-life decision-making can be improved by ensuring clear roles and an explicit description of the tasks and responsibilities of all participants. Regular discussion between everyone involved including people with intellectual disabilities themselves can improve knowledge about each other's motives for end-of-decisions and can clarify expectations towards each other.

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138.
Influences on the decision to prescribe or administer anticholinergic drugs to treat death rattle: a focus group study.
Hirsch CA; Marriott JF; Faull CM.
[Journal Article]
Ut: 23175510
BACKGROUND: The evidence supporting pharmacological treatment of death rattle is poor; yet, anticholinergic drugs feature in end-of-life care pathways and guidelines worldwide as a treatment option.
AIM: This qualitative arm of a wider study aimed to explore important issues which health-care professionals associated with decision-making to prescribe or administer anticholinergics at the end of life.
DESIGN: After purposive sampling, five focus groups were conducted. Discussions were audiotaped and transcribed verbatim.
SETTING: Thirty medical and nursing personnel working in inpatient and community settings from two specialist palliative care units in the United Kingdom took part in the study.
RESULTS: Thematic analysis of transcripts from audiotapes revealed perceived pressures to prescribe and/or administer anticholinergics from colleagues and carers, and drugs were often prescribed or administered in order to be seen to 'do something', although the benefit in terms of therapeutic response was considered minimal. Familiarity with drug regimens and dosing was often based on personal experience. The monitoring of side effects of anticholinergics at the end of life was recognised as problematic and had little influence on prescribing and administration.
There was also an indication that patients and carers in the community were more likely to receive timely verbal preparation and explanation around death rattle than those cared for in an inpatient setting.

CONCLUSION: The study raises questions about the routine inclusion of anticholinergic treatment in UK end of life care pathways for the treatment of death rattle.

139.
"You've only got one chance to get it right": children's cancer nurses' experiences of providing palliative care in the acute hospital setting.
Pearson HN.
[Journal Article]
UI: 23758218
The aim of this study was to understand children's cancer nurses experiences of providing palliative care in the acute hospital setting. Palliative care for children with cancer is rarely hospital- centred and predominately care is provided in the community or hospice setting. Vast research has looked at the experiences of children's nurses providing palliative care within the child's home environment or the hospice. This research has suggested that nurses need adequate support to avoid stress and burnout. Parental views focus on the nurses attributes as opposed to the clinical skills which are required. This research study wanted to ascertain whether specific educational preparation or support is needed to prepare children's cancer nurses in providing palliative care in the acute hospital setting. The research study used a qualitative approach with semi-structured in-depth interviews across three primary treatment centers within the United Kingdom that provide cancer care to children. Data were collected and analyzed using a phenomenological approach. Data were collected between October 2011 and February 2012. Interviews took place in the participants preferred location and lasted between 45 and 60 min. Data were analyzed using the Strauss and Corbin method. Five themes emerged which were "lack of a plan", "managing the symptoms", "family", and "experience". Categories within these themes were devised from participant narratives. The findings of this research study suggest nurses need specific palliative care education not only at pre-registration level but also continuing professional development.

Status
140. 'Where do I go from here'? A cultural perspective on challenges to the use of hospice services. Frey R; Gott M; Raphael D; Black S; Teleo-Hope L; Lee H; Wang Z. Health & Social Care in the Community. 21(5):519-29, 2013 Sep. [Journal Article. Research Support, Non-U.S. Gov't]

Do hospice services as shaped by a western perspective adequately fulfil the needs of persons from non-Western cultures? Based on a Western view of palliative care, the vision outlined in the New Zealand Palliative Care Strategy (2001) is to deliver palliative care services, including hospice services, to all patients and their families requiring them in the context of an increasingly pluralistic and multicultural society. It is predicted that over the next two decades the proportion of people identifying as Maori, Pacific and Asian will dramatically increase within New Zealand. Ministry of Health information provided through a GAP analysis identified hospices as facing access-to-care pressures for Maori, Pacific and Asian patients. It is therefore critical to identify the challenges to hospice service access for Maori, Asian and Pacific patients. This project involved qualitative interviews with 37 cancer patients (Maori, Pacific and Asian self-identified ethnicities), whanau/family and bereaved whanau/family, as well as 15 health professionals (e.g. referring GPs, oncologists, allied health professionals) within one District Health Board. Patients and their families included both those who utilised hospice services, as well as those non-users of hospice services identified by a health professional as having palliative care needs. Challenges to hospice service utilisation reported in the findings include a lack of awareness in the communities of available services, as well as continuing misconceptions concerning the nature of hospice services. Language barriers were particularly reported for Asian patients and their families. Issues concerning the ethnic representativeness of the hospice services staff were raised. The findings highlight the importance of patient and family knowledge of hospice care for utilisation of services. This information can be used for future planning to enable hospices to both provide high quality evidence based palliative care services for patients and families and provide consultative services to primary healthcare providers in the community. Copyright 2013 John Wiley & Sons Ltd.
141.
The importance of communication in pediatric oncology palliative care: focus on Humanistic Nursing Theory.
Franca JR; da Costa SF; Lopes ME; da Nobrega MM; de Franca IS.
[Journal Article]
UI: 23918025
OBJECTIVE: to investigate and analyze communication in palliative care contexts from the perspective of nurses, based on Humanistic Nursing Theory.
METHOD: this is a field study with a qualitative approach, in which ten nurses working in the pediatric oncology unit of a Brazilian public hospital participated. Semi-structured interviews were used to collect data. The testimonies were qualitatively analyzed using Humanistic Nursing Theory and based on the five phases of Nursing Phenomenology.
RESULTS: two thematic categories emerged from the analysis of the study's empirical material: "strategy to humanize nursing care, with an emphasis on relieving the child's suffering" and "strategy to strengthen ties of trust established between nurse and child."
CONCLUSION: communication is an efficacious element in the care provided to the child with cancer and is extremely important to promoting palliative care when it is based on Humanistic Nursing Theory.
Status
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20130806
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2013
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OBJECTIVE: to understand the meaning baccalaureate nurses and nursing technicians attribute to night work in the context of clinical palliative oncology nursing care services, as well as how nursing works to attend to clients and caregivers’ needs in this period.

METHOD: in this exploratory and qualitative study, grounded theory was used. Seven nurses and four nursing technicians were interviewed, who composed two sample groups. Nine categories were produced and, in their comparative content analysis, a knowledge emphasis was evidenced with implications for nighttime nursing work. In this study, these aspects were discussed in two of the categories, which are: to describe care practice in order to understand nursing care management and to point out the difficulties in care practice and nursing care management.

RESULTS: The results evidence the complexity in the nighttime care context, considering the clients’ clinical conditions and clients and caregivers’ psychological demands, mainly because of the threat of death.

CONCLUSION: The team attempts to respond to these needs through communication, but reveals a lack of assistential services and an overload. Interdisciplinarity is a palliative care premise, favoring holistic care delivery, and cannot be neglected at, which requires attention and investment to develop better practices.

143.
The experiences of suffering of palliative care informal caregivers in Malaysia: a thematic analysis.
Beng TS; Guan NC; Seang LK; Pathmawathi S; Ming MF; Jane LE; Chin LE; Loong LC. American Journal of Hospice & Palliative Medicine. 30(5):473-89, 2013 Aug.

UI: 23341445
A qualitative study was conducted with semi-structured interviews to explore the experiences of suffering in 15 palliative care informal caregivers in University Malaya Medical Centre. The data were thematically analyzed. Seven basic themes were generated (1) empathic suffering, (2) anticipatory grief, (3) obsessive-compulsive suffering, (4) helpless-powerless suffering, (5) obligatory suffering, (6) impedimental suffering, and (7) repercussion suffering. A model of compassion suffering was conceptualized from the analysis. This model may serve as a guide in the assessment and management of suffering in palliative care informal caregivers.

Status
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Date Created
20130806

Year of Publication
2013

144.
Outcome measures of spiritual care in palliative home care: a qualitative study.
Vermandere M; De Lepeleire J; Van Mechelen W; Warmenhoven F; Thoonsen B; Aertgeerts B.
[Journal Article. Research Support, Non-U.S. Gov't]
Ui: 22833554

The purpose of this study was to identify key outcome measures of spiritual care in palliative home care. A qualitative study was conducted with experts from 3 stakeholder groups (physicians, professional spiritual caregivers, and researchers) representing 2 countries (Belgium and The Netherlands). Three key outcome measures were identified: the extent to which the patient feels that he or she is being heard and taken seriously, the extent to which the patient experiences that there is a place for that which is insoluble, and the extent to which the patient experiences that there is a place for that which cannot be said. Further research is needed to implement and evaluate these new outcome measures.

Status
MEDLINE

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145.
[Palliative sedation in a university hospital: experience after introducing a specific protocol].
[Spanish]
Boceta Osuna J; Nabala Vicuna M; Martinez Penalver F; Blanco Picabia A; Aguayo Canela M;
[English Abstract. Journal Article]
UI: 23369525

PATIENTS AND METHODS: A descriptive prospective study of palliative sedation (PS) records
during a one year period after starting the PS protocol.
INCLUSION CRITERIA: Patients included in the PS protocol and those who had completed the
"data registry form".
DATA SOURCES: Registry forms included in the PS protocol as Annex 5 (included as Annex 1 in
this study).
VARIABLES: Personal data, data regarding basal disease, prognosis, level of information.
Refractory symptoms: type, time of evolution and treatments employed. Involvement of the
patient and/or representatives in decision making. Type of sedation, continuity, depth, employed,
duration and results, and readjustment of other therapeutic measures.
STATISTICAL ANALYSIS: The SPSS 14.0 was used. For qualitative variables we studied
absolute frequencies and proportions. For quantitative variables with normal distribution, we used
means and standard deviations, and for non-normal distribution, medians and ranges.
RESULTS: In the study period 90 cases of PS were counted. This represented 27.6% of the
patients treated in the hospital palliative care support team (PCST), and 7.03% of the total
deceased patients in our hospital. Mean age of patients undergoing PS was 59.22 years old,
range between 40.86 and 77.58 years, and 68.1% were men. All patients were in an advanced or
terminal stage of their condition, and 49.5% in an agonal phase. In 90.4% of the cases, the main
pathology was oncological. Regarding PS indication, this was jointly made between the PCST
physician and the patient's usual doctor in 60 cases (66.6%). Symptoms leading to sedation were
mainly dyspnea, delirium and pain. The Ethics committee was consulted in five cases. Mean time
under sedation was 134.02 hours (5.5 days). In 90% of the cases, duration ranged from 50 to
218.04 hours (2-9 days). Depth of PS after induction was registered in 88.8% of the cases.
Informed consent (IC) was explicit in 11.2% of the cases, and given prior to the appearance of
refractory symptoms and/or agonal phase. In 88.8% of sedation cases, the IC was given by a
representative. Midazolam was the most used drug of choice in 87.8% of the cases, and
levomepromazine in 10.2%. Up to 15% of sedations required drug changes or combinations.
CONCLUSION: 1) The application of a PS Protocol and the availability of a hospital PCST and an
Ethical Care Committee favored a safe (correct) use of PS in a hospital lacking a palliative care
unit (PCU), and a homogeneous data registry for their analysis, with quality criteria similar to
those offered by a PCU. 2) We have detected areas of improvement that will be applied in the second version of our protocol.

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146.

Do patients die well in your emergency department?.

Bradley V; Burney C; Hughes G.


[Journal Article]

UI: 23911024

OBJECTIVES: Although the role of the ED in the management of patients needing palliative care is recognised internationally, there are little Australasian data on this issue. This study aimed to determine the current knowledge and attitude to the provision of palliative care in Australasian EDs.

METHODS: All ED directors in Australasia were invited to complete an online survey about the provision of palliative care in their department. Quantitative data were described using counts and proportions, and qualitative data were summarised thematically.

RESULTS: Of 165 eligible ED directors, 35 completed the survey (22%; 95% CI, 15-28%). Only 17/35 (49%; 95% CI, 32-65%) believed that ED provided good palliative care, and 28/35 (80%; 95% CI, 67-93%) were unaware of international gold standard palliative care protocols. Most had access to hospital-based palliative care specialists 27/35 (77%; 95% CI, 63-91%); however, only 5/27 (19%; 95% CI, 4-33%) used them. Few EDs undertake formal training in palliative care 10/35 (29%; 95% CI, 16-45%). Respondents showed concern about the quality of palliative care they provide and advocated for more palliative care training.

CONCLUSION: Although limited by the low response rate, this survey indicates that there is a need and a desire for greater integration of the values and standards of high-quality palliative care in Australasian EDs.
147.
Psychosocial service use: a qualitative exploration from the perspective of rural Australian cancer patients.
Gunn K; Turnbull D; McWha JL; Davies M; Olver I.
Supportive Care in Cancer. 21(9):2547-55, 2013 Sep.
[Journal Article]
UI: 23636646
PURPOSE: This study aims to identify key issues associated with the provision of psychosocial care from the perspective of rural Australian cancer patients and determine culturally appropriate methods that may reduce barriers to service use.
METHOD: Seventeen purposively sampled adult South Australians who lived outside metropolitan Adelaide, had a diagnosis of cancer and various demographic and medical histories participated in semi-structured, face-to-face interviews. Participants also completed a demographic questionnaire. Qualitative data were analysed using thematic analysis.
RESULTS: Five key themes were identified: (1) psychosocial support is highly valued by those who have accessed it, (2) having access to both lay and professional psychosocial support is vitally important, (3) accessing psychosocial services is made difficult by several barriers (lack of information about services, initial beliefs they are unnecessary, feeling overwhelmed and concerns about stigma and dual relationships), (4) medical staff located in metropolitan treatment centres are not sufficiently aware of the unique needs of rural patients and (5) patients require better access to psychosocial services post-treatment. Methods through which rural patients believe access to psychosocial services could be improved include: (1) providing more rural-specific information on psychosocial care, (2) improving communication between health care providers and referral to psychosocial services and (3) making psychosocial services a standard part of care.
CONCLUSIONS: Rural cancer patients want their unique needs to be recognised and to be treated differently to their urban counterparts. There is a need for more targeted and rurally relevant information for rural cancer patients, both to inform them of, and change their attitudes towards, psychosocial services. Other practical recommendations are also discussed.
Status
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148.
Palliative medicine practitioners’ views on the concept of depression in the palliative care setting. Ng F; Crawford GB; Chur-Hansen A.
[Journal Article]
UI: 23721427
BACKGROUND: Despite its clinical importance in palliative care, depression remains an ambiguous concept.
OBJECTIVE: The purpose of this study was to explore how medical practitioners working in palliative care conceptualize depression in that setting.
DESIGN: Medical practitioners who attended a palliative medicine conference (N=185) were invited to respond to a questionnaire, which explored their views on the concept of depression in the palliative care context. Descriptive statistics were used to summarize responses, and comparison between groups was conducted using nonparametric statistics. Themes in free-text comments were identified.
RESULTS: Seventy-nine responses were obtained (response rate 43%). Depression was not a unified concept, but was generally considered to be an illness with psychological, spiritual, and existential causes. Respondents were more uncertain about depression being an illness in the palliative care setting compared with other settings, and were ambivalent about its causality. Treatment preferences leaned towards psychological interventions. Depression being different in the palliative care setting was a theme. It was considered to be more prevalent, different in quality, harder to define, and associated with greater barriers to diagnosis and treatment. Conceptual differences were associated with the respondents’ area of work, work position, duration of practice, and previous mental health training.
CONCLUSIONS: Depression in the palliative care setting is a variable concept for palliative medicine practitioners. The conceptual diversity and complexities of depression in this setting must be acknowledged and further explored in order to develop nuanced approaches in clinical practice and in research.
Experiences of carers supporting dying renal patients managed without dialysis.
Noble H; Kelly D; Hudson P.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23167619
AIM: To explore the impact of being a family carer to patients with stage 5 chronic kidney disease managed without dialysis.
BACKGROUND: Increasing numbers of patients with renal disease worldwide are making the decision not to embark on dialysis. This group has significant physical and psychological symptom burdens similar to or greater than those in advanced cancer patients. Little is known about the impact on family carers.
DESIGN: Exploratory, qualitative design.
METHODS: The study was undertaken with 19 carers caring for patients managed in a Renal Supportive Care Service in the UK between 2006-2008. Sixty-one semi-structured interviews and detailed field notes inform the analysis.
FINDINGS: 'Caring from diagnosis to death' was the overarching theme illustrated by three sub-themes: (i) Caregiver's plight - making sense of the disease and potential deterioration; (ii) Having to care indefinitely; and (iii) Avoiding talk of death. 'Caring from diagnosis to death' coincides with an original concept analysis of renal supportive care, which is considered an adjunct to the management of patients with renal disease at all stages of their illness.
CONCLUSION: There is a clear need for further research internationally and theory-based nursing interventions to support carers of patients managed without dialysis. The development of a holistic, integrated care pathway based on carer perspectives, which includes identification of information needs related to original diagnosis, associated comorbidities, treatment options, prognosis, and assistance in developing strategies to manage communication with patients as the end of life approaches, is required.

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Teleconsultation in geriatrics: impact on professional practice.

Esterle L; Mathieu-Fritz A.


[Journal Article. Research Support, Non-U.S. Gov't]

UI: 23746716

UNLABELLED: Teleconsultations in medicine are encouraged by authorities and decision-makers to improve access to specialty services for isolated patients. For elderly patients in geriatric hospitals, they thus avoid trips to consult with specialists. However, teleconsultation can modify clinical practice and it may be abandoned for reasons not related to technical issues. Qualitative research on the impact of teleconsultation on medical practice and organisation are thus crucial for an understanding of the changes it can generate.

METHODS: We used qualitative methods to analyse the impact on professional work practices and care organisation of an initially experimental and then permanent teleconsultation system using a video conference system set up between a geriatric hospital and a tertiary care hospital. Sixty-six teleconsultations (56 during the experimental phase and 10 when the system was in routine use) were observed and ten semi-structured interviews were carried out with the actors in the teleconsultations.

RESULTS: Our study shows that the uses of teleconsultation affected work practices of both the consulted specialist and the geriatrician who participated in the consultation alongside the patient. The interactions of specialists with the patient were more difficult than in a face-to-face setting and delegation of the clinical examination of the patient depended on a specific form of cooperation and on trust in the person doing the examination. New kinds of relationships between health professionals contributed to sharing and transmission of knowledge between practitioners. While teleconsultations established alliances between geriatricians and specialists, they none-the-less called for a certain humility on the part of geriatricians. In order for these relationships to become routine and to facilitate interaction among participants, the project manager carried out important work during the experimental phase of the teleconsultations by organising these interactions. Finally, the teleconsultations went through several local reorganisations, especially within the geriatric hospital. These included changes in the geriatrician's schedule and the added presence of an assistant knowledgeable in telemedicine.

CONCLUSIONS: Specialists found the system used for teleconsultation between a geriatric hospital and a tertiary care hospital to be suitable for their consultations. The main advantage brought about by the teleconsultation system studied resulted from its collaborative nature, which created relationships between health professionals. This resulted in improved care for elderly patients. However, using the system required effort on the part of both the specialists and the geriatricians. Adapting to the system was facilitated by coordination work carried out by the project manager during the experimental phase that created a favourable context for cooperation between actors, allowing diagnoses to be made at a distance. Finally, teleconsultations do not appear suitable for all specialties, by reason of the limits imposed on the delegation of tasks, or to all situations. They require setting up new forms of organisation that must be encouraged by decision-makers.

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Does a half-day course about palliative care matter? A quantitative and qualitative evaluation among health care practitioners.
Friedrichsen M; Heedman PA; Astradsson E; Jakobsson M; Milberg A.
[Journal Article]
UI: 23600332

BACKGROUND: To date there has been a paucity of research examining whether a course in palliative care influences the clinical work. Therefore a half-day course was started for different professionals.

OBJECTIVES: The aims of this study were to quantitatively and qualitatively explore professionals’ experience of the usefulness and importance of such a course.

DESIGN: An evaluation study was used with two measurement points in the quantitative part; qualitative focus group interviews were conducted three times.

SETTING AND SUBJECTS: Data was collected in Sweden through structured and open-ended questions (n=355) and in focus group discussions (n=40).

RESULTS: The majority of participants were allied professionals (86%). Course evaluation immediately after the intervention showed high scores. At three months, 78% of the 86 participants who had cared for a dying patient since the course claimed that the course had been useful in their work. In addition, there were improvements regarding symptom management (37%), support to family members (36%), more frequent break point conversations (31%), and improved cooperation in the teams (26%). The qualitative analysis showed that the course made participants start to compare their own working experiences with the new knowledge. When returning to work, the participants feel strengthened by the newly acquired knowledge, but the will to improve the care also led to frustration, as some of the participants described that they wanted to change routines in the care of the dying, but felt hindered.

CONCLUSION: The course was appreciated and useful in the professionals’ work, but it also created problems.
Pediatric palliative care in Canada and the United States: a qualitative metasummary of the needs of patients and families.
Stevenson M; Achille M; Lugasi T.
[Journal Article. Meta-Analysis]
UI: 23556988

OBJECTIVE: Qualitative research is becoming more common in pediatric palliative care and end-of-life care. The present article systematically reviews and summarizes qualitative and survey-based research on pediatric palliative and end-of-life care pertaining to the needs of patients and their families.

METHOD: Twenty-one qualitative and survey-based studies published between 2000 and 2010 that met the selection criteria were retrieved from MEDLINE, PsycINFO, and CINAHL. All studies reported on the needs of patients and families receiving pediatric palliative and end-of-life care--from either the patient's, parent's, sibling's, or health care provider's perspective. Findings from these studies were aggregated using a metasummary technique.

RESULTS: Findings were extracted and grouped into the following 10 thematic domains pertaining to patient and family needs: interactions with staff, health care delivery and accessibility, information needs, bereavement needs, psychosocial needs, spiritual needs, pain and symptom management, cultural needs, sibling's needs, and decision making.

CONCLUSIONS: The results of this metasummary highlight the needs of patients and families to be taken into consideration in the creation of high-quality pediatric palliative and end-of-life care services and guidelines.
Examining palliative care team involvement in automatic consultations for children on extracorporeal life support in the pediatric intensive care unit.

Doorenbos AZ; Starks H; Bourget E; McMullan DM; Lewis-Newby M; Rue TC; Lindhorst T; Aisenberg E; Oman N; Curtis JR; Hays R; Seattle Ethics in ECLS (SEE) Consortium; Clark JD; Baden HP; Brogan TV; Di Gennaro JL; Mazor R; Roberts JS; Turnbull J; Wilfond BS. Journal of Palliative Medicine. 16(5):492-5, 2013 May.

BACKGROUND: Extracorporeal life support (ECLS) is an advanced form of life-sustaining therapy that creates stressful dilemmas for families. In May 2009, Seattle Children's Hospital (SCH) implemented a policy to involve the Pediatric Advanced Care Team (PACT) in all ECLS cases through automatic referral.

OBJECTIVE: Our aim was to describe PACT involvement in the context of automatic consultations for ECLS patients and their family members.

METHODS: We retrospectively examined chart notes for 59 consecutive cases and used content analysis to identify themes and patterns.

RESULTS: The degree of PACT involvement was related to three domains: prognostic uncertainty, medical complexity, and need for coordination of care with other services. Low PACT involvement was associated with cases with little prognostic uncertainty, little medical complexity, and minimal need for coordination of care. Medium PACT involvement was associated with two categories of cases: 1) those with a degree of medical complexity but little prognostic uncertainty; and 2) those that had a degree of prognostic uncertainty but little medical complexity. High PACT involvement had the greatest medical complexity and prognostic uncertainty, and also had those cases with a high need for coordination of care.

CONCLUSIONS: We describe a framework for understanding the potential involvement of palliative care among patients receiving ECLS that explains how PACT organizes its efforts toward patients and families with the highest degree of need. Future studies should examine whether this approach is associated with improved patient and family outcomes.
End-of-life care discussions with nonmalignant respiratory disease patients: a systematic review.

[Review]
Stephen N; Skirton H; Woodward V; Prigmore S; Endacott R.
[Journal Article. Review]
UI: 23461301

BACKGROUND: Patients with nonmalignant respiratory diseases have limited access to palliative care services and health professionals do not adequately address discussions about end-of-life care preferences.

OBJECTIVE: The aim of this systematic literature review was to highlight key components and challenges for patients and health professionals discussing end-of-life care in nonmalignant respiratory disease.

DESIGN: A mixed methods systematic review was conducted. Included studies were assessed for quality and data were synthesized thematically, while original data were presented in tabular form.

DATA SOURCES: PubMed, CINAHL, BNI, ASSIA, PsycINFO, Science Direct, and Web of Science were searched (1999-2010) for studies on end-of-life discussions. Additional studies were identified by hand searching key journals and reference lists of included articles.

RESULTS: Fourteen studies were identified. Three themes involving components and challenges in end-of-life discussions were identified: the discussion, the health professional/patient relationship, and patient perceptions.

CONCLUSIONS: End-of-life discussions should be initiated by health professionals, who must be aware of patient expectations regarding palliative care and end-of-life care planning. Efforts must be made to develop relationships with patients with terminal illness and allow sufficient time to discuss the end of life during clinical encounters. Future research should address palliative care uptake in nonmalignant disease and implications for health education should be addressed.

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'Peace' and 'life worthwhile' as measures of spiritual well-being in African palliative care: a mixed-methods study.
Selman L; Speck P; Gysels M; Agupio G; Dinat N; Downing J; Gwyther L; Mashao T; Mmoledi K; Moll T; Sebuyira LM; Ikin B; Higginson IJ; Harding R.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23758738

BACKGROUND: Patients with incurable, progressive disease receiving palliative care in sub-Saharan Africa experience high levels of spiritual distress with a detrimental impact on their quality of life. Locally validated measurement tools are needed to identify patients' spiritual needs and evaluate and improve spiritual care, but up to now such tools have been lacking in Africa. The African Palliative Care Association (APCA) African Palliative Outcome Scale (POS) contains two items relating to peace and life worthwhile. We aimed to determine the content and construct validity of these items as measures of spiritual wellbeing in African palliative care populations.

METHODS: The study was conducted at five palliative care services, four in South Africa and one in Uganda. The mixed-methods study design involved: (1) cognitive interviews with 72 patients, analysed thematically to explore the items' content validity, and (2) quantitative data collection (n=285 patients) using the POS and the Spirit 8 to assess construct validity.

RESULTS: (1) Peace was interpreted according to the themes 'perception of self and world', 'relationship to others', 'spiritual beliefs' and 'health and healthcare'. Life worthwhile was interpreted in relation to 'perception of self and world', 'relationship to others' and 'identity'. (2) Conceptual convergence and divergence were also evident in the quantitative data: there was moderate correlation between peace and Spirit 8 spiritual well-being (r=0.46), but little correlation between life worthwhile and Spirit 8 spiritual well-being (r=0.18) (both p<0.001). Correlations with Spirit 8 items were weak to moderate.

CONCLUSIONS: Findings demonstrate the utility of POS items peace and life worthwhile as distinct but related measures of spiritual well-being in African palliative care. Peace and life worthwhile are brief and simple enough to be integrated into routine practice and can be used to measure this important but neglected outcome in this population.

Status
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Source: NLM. PMC3687576
GOAL OF THE STUDY: In the study "possibilities and limits of ambulatory palliative care" there was a survey with family doctors about their own subjective views of ambulatory palliative care. The different parameters of home care, the role of caring relatives as well as burdening and supporting factors for family doctors occupied the focus in these interviews.

METHODS: With the help of the results from 9 qualitative interviews, a questionnaire was compiled and sent by post to all family doctors within 50 km (N=427). For analysis questionnaires were available from N=89 family doctors. Statements about various areas of outpatient palliative work were collected with Likert scales and open questions.

RESULTS: The personal overloads of the care-giving relatives, the inadequate payment and their own time pressures for the family doctors were the main obstacles in home care of palliative patients. On the other hand the family doctors considered as supporting factors for an ambulatory care: a good pain and symptom management, a high satisfaction of the patients and a good teamwork between the caring service and other people taking part in the care.

CONCLUSION: In order to minimise the time overload of family doctors and to focus the psychosocial distress of the caring relatives the expansion of non-medical offers should be supported, e.g., ambulatory hospice services and consultative forms of care by psychologists and religious personnel.

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Aged parents' experiences during a critical illness trajectory and after the death of an adult child: a review of the literature. [Review]
Van Humbeeck L; Piers RD; Van Camp S; Dillen L; Verhaeghe ST; Van Den Noortgate NJ. Palliative Medicine. 27(7):583-95, 2013 Jul.
[Journal Article. Research Support, Non-U.S. Gov't. Review]
UI: 23579261

BACKGROUND: Given the growing life expectancy, the likelihood increases that health-care providers are confronted with older people having an adult child with a life-limiting disease.
AIM: This literature review aimed to (1) explore the experiences of aged parents with regard to their position and role as a parent of an adult child with a life-limiting illness, (2) detect gaps in the existing literature and (3) make recommendations for future research.
DESIGN: A literature search of English articles, including both quantitative and qualitative designs.
DATA SOURCES: Four electronic databases and the reference lists of included studies.
RESULTS: In total, 19 studies (7 quantitative and 12 qualitative) were included. Few studies describe the experiences of older people whose adult child has cancer or has died of cancer. Existing studies are merely descriptive and give no concrete recommendations for health-care providers in daily practice. The studies suggest that aged parents carry deep burdens from the prospect of losing their adult child. Aged parents want to stay involved but need to reconfigure their parent role. As soon as the cancer diagnosis is disclosed, parents are confronted with a re-awakening of parental nurturing, which clashes with the autonomy of the adult child. Even after the adult child is deceased, older parents retain the image of themselves as parents.
CONCLUSIONS: There is a need for more in-depth research to understand the lived experience of these parents and what health-care providers can do to assist them.

Status
MEDLINE
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Signs of post-traumatic stress disorder in caregivers following an expected death: a qualitative study.
Sanderson C; Lobb EA; Mowll J; Butow PN; McGowan N; Price MA. Palliative Medicine. 27(7):625-31, 2013 Jul.

BACKGROUND: Complications of grief are an important area of investigation with potential to improve the well-being of palliative care caregivers. There has been little study of the prevalence or significance of post-traumatic stress disorder for those bereaved after an expected death.

AIM: To identify evidence suggestive of post-traumatic stress disorder symptoms in a population of bereaved caregivers of patients who have died of ovarian cancer.

DESIGN: Caregivers' recollections of their end-of-life experiences were coded and analysed, using qualitative data obtained from interviews 6 months after the patient's death.

SETTING/PARTICIPANTS: Australian Ovarian Cancer Study-Quality of Life Study is a population-based epidemiological study using mixed methods to explore caregivers' experiences following the expected death of a woman with ovarian cancer. Thirty-two caregivers from the Australian Ovarian Cancer Study-Quality of Life Study participated in semi-structured telephone interviews 6 months post-bereavement.

RESULTS: When describing the patient's death at their 6-month interview, all interviewees used language consistent with some degree of shock and traumatisation. For the majority, there was also evidence suggesting resilience and resolution. However, a number of interviewees describe intrusive memories associated with physical sights and sounds that they witnessed at the deathbed.

CONCLUSIONS: This exploratory study demonstrates the phenomenon of the 'shocked caregiver'. If trauma symptoms are present in bereaved carers in palliative care, it has implications for palliative care provision. Given that trauma symptoms may be distinct from prolonged grief disorder, this may also have implications for provision of bereavement counselling. Further research into this phenomenon is required.

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BACKGROUND: Patients approaching death often have a decreasing oral intake, which can be distressing for relatives. Little is known about the relatives' experiences with and perceptions of oral intake at the end of life.

AIM: This study aims to contribute to a more thorough understanding of relatives' concerns regarding decreased oral intake of the patient at the end of life.

DESIGN: Qualitative interview study: semi-structured interviews were transcribed verbatim and analysed using qualitative content analysis.

SETTING/PARTICIPANTS: Twenty-three bereaved relatives of patients who had been referred to a New Zealand palliative care service were interviewed.

RESULTS: All relatives experienced significant changes in patients' oral intake at the end of life. Oral intake towards the end of life was considered important and is perceived as meaningful by relatives in different ways, such as nutritional value, enjoyment, social time, daily routine and a way of caring. Relatives responded differently to decreasing oral intake; some accepted it as inherent to the dying process, others continued efforts to support the patient's oral intake. Some relatives perceived decreasing oral intake as the patient's choice, and some viewed maintaining oral intake as part of the battle against the disease. Relatives recalled limited communication with health-care professionals concerning oral intake at the end of life.

CONCLUSIONS: This study revealed the complexity of meaning relatives' experiences with dying patients' decreasing oral intake. Their perceptions and concerns were related to their awareness of the imminent death. These findings can guide staff involved in care delivery to better support relatives.

160.
Tools to measure quality of life and carer burden in informal carers of heart failure patients: a narrative review. [Review]
Whittingham K; Barnes S; Gardiner C.
[Journal Article. Review]
BACKGROUND: Heart failure is a complex cardiac syndrome prevalent in an older population. Caring for heart failure patients through the disease trajectory presents physical and emotional challenges for informal carers. Carers have to deal with clinically unstable patients, the responsibility of managing and titrating medication according to symptoms and frequent admissions to acute care. These challenges compound the demands on caregivers' physical and psychosocial well-being. Alongside the negative impact of being a carer, positive aspects have also been demonstrated; carers describe feelings of shared responsibility of caring with professional carers and the reward of supporting a loved one, which creates a new role in their relationship.

AIM: This review explores the dimensions that impact caregiver burden and quality of life in carers of patients with heart failure and highlights both the negative and positive aspects of being an informal carer for heart failure patients.

DESIGN: This review followed the processes recommended for a narrative review. Studies identified were selected systematically following the PRISMA guidelines.

DATA SOURCES: Searches were conducted using the Medical Subject Headings (MeSH) and keywords of the following search engines: MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Embase, Applied Social Sciences Index and Abstracts (ASSIA), PsycINFO and Cochrane for literature published until January 2012.

RESULTS: Quality assessment of the studies was conducted using quality indicators, and the studies included in this review were categorised as fair or good according to the criteria. Of the 1008 studies initially identified, 16 studies met the inclusion criteria. A thematic synthesis was undertaken, and the following themes were identified: Perceived carer control; Mental and emotional well-being; Types and impact of caregiving tasks; Impact of patients' physical condition; Impact of age/gender/demographic factors; Positive aspects of caregiving.

CONCLUSIONS: This review highlights evidence that informal carers supporting patients with heart failure face many challenges impacting their physical and mental well-being. The studies described provide an insight into the individual dimensions that make a carer particularly vulnerable, namely, younger carers, female carers and carers with existing physical and emotional health issues. Additionally, there are external influences that increase risk of burden, including New York Heart Association Score status of the patient, if the patient has had recurrent emergency admissions or has recently been discharged home and the level of social support available to the carer. A further finding from conducting this review is that there are still limited measures of the positive aspects of caregiving.

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PURPOSE: To explore how nurses experienced catastrophic upper gastrointestinal bleeding in hepatocellular carcinoma (HCC) patients.

METHODS: A qualitative descriptive method was used. Data were collected by semi-structured interviews. Twenty-one registered nurses who had taken care of HCC patients with catastrophic upper gastrointestinal bleeding were purposely recruited from the Department of Hepatobiliary Cancer, Tianjin Medical University Cancer Institute and Hospital located in mainland China.

RESULTS: Four themes explicated from the study were: feelings expressed during the process of rescuing the lives of patients, feelings expressed from succeeding or failing to save the lives of patients, feelings expressed from family members’ response to nurses’ actions, the impact of the experience on the personal life, work and philosophy of life of the nurse subjects.

CONCLUSIONS: The findings of this study indicate that it is necessary for nursing leaders to take effective measures to improve nurses’ nursing skills, to provide more education in care of the dying, to offer nurses services that address their psychosocial health and to provide them with emotional support. Copyright 2012 Elsevier Ltd. All rights reserved.

162.
BACKGROUND AND PURPOSE: Supportive care for people living with a diagnosis of lung cancer is paramount. The purpose of this systematic review was to determine the supportive care needs of people with lung cancer, and explore trends and gaps in the assessment of these needs emerging from this literature.

METHODS: Through use of a wide range "free text" terms, a systematic search of five electronic databases (Medline, CINAHL, EMBASE, PsychINFO and BNI) was carried out for the period between January 2000 and September 2012. Two validated scoring systems were used to appraise eligible studies for methodological quality and level of evidence.

RESULTS: Based on pre-specified selection criteria, 59 articles (25 of quantitative methodology; 34 of qualitative methodology) reporting on 53 studies were retrieved and considered for further analysis. Overall, studies were of acceptable methodological quality. A wide spectrum of health care needs was evident among people with lung cancer. These needs were classified into nine domains: physical; daily living; psychological/emotional; spiritual/existential; informational; practical; patient-clinician communication; social and family-related; and cognitive. Daily living, practical, and cognitive needs were given less attention in this literature.

CONCLUSIONS: People with lung cancer have a complex array of supportive care needs that impact on various life aspects. Yet, our knowledge still remains fragmentary. Embarking on new longitudinal exploratory studies and well-designed clinical trials is therefore strongly encouraged. The use of patient reported outcome measures as a clinical intervention tool may be viewed as a means of identifying and managing unmet needs in this patient population.

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Status
MEDLINE
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Date Created
20130618
Year of Publication
2013

163.
Living and dying with dignity in Chinese society: perspectives of older palliative care patients in Hong Kong.
Ho AH; Chan CL; Leung PP; Chochinov HM; Neimeyer RA; Pang SM; Tse DM.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23443510
BACKGROUND: the empirical Dignity Model has profoundly influenced the provision of palliative care for older terminally ill patients in the West, as it provides practical guidance and intervention strategies for promoting dignity and reducing distress at the end-of-life.

OBJECTIVE: to examine the concept of ‘living and dying with dignity’ in the Chinese context, and explore the generalisability of the Dignity Model to older terminal patients in Hong Kong.

METHODS: using qualitative interviews, the concept of dignity was explored among 16 older Chinese palliative care patients with terminal cancer. Framework analysis with both deductive and inductive methods was employed.

RESULTS: the three major categories of themes of the Dignity Model were broadly supported. However, the subtheme of death anxiety was not supported, while two subthemes of generativity/legacy and resilience/fighting spirit manifested differently in the Chinese context. Furthermore, four new emergent themes have been identified. They include enduring pain, moral transcendence, spiritual surrender and transgenerational unity.

CONCLUSION: these findings highlight both a cultural and a familial dimension in the construct of dignity, underline the paramount importance of cultural awareness and competence for working with ethnically diverse groups, and call for a culturally sensitive and family oriented approach to palliative care interventions with older Chinese terminal patients.

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2013

164.

Subjective experiences of coping among caregivers in palliative care.
Uren SA; Graham TM.
[Journal Article]
UI: 23758426

Several research studies have sought to quantify the effects of formal caregiving on the caregivers; however, limited research has described the experiences of caregiving using a qualitative research design. In this study, we used an interpretative, phenomenological method to explore how coping operates as a central resource for trained caregivers and professional nurses in a palliative care setting. Eleven participants from a community-based, palliative care organisation in South Africa provided narrative accounts of coping within the caregiving process. Our findings identified seven themes related to the different dimensions of coping and the
implications of these responses on individual caregivers. In this article, we discuss the cumulative effect of caregiver exposure to stressors, consider future directions to enhance caregiving, and conclude that effective caregiver coping plays a substantial role in caregiver and patient wellbeing and should therefore be a central component of enhancing palliative care interventions.

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Year of Publication
2013

165.
Effects of a programme of interventions on regional comprehensive palliative care for patients with cancer: a mixed-methods study.
Morita T; Miyashita M; Yamagishi A; Akiyama M; Akizuki N; Hirai K; Imura C; Kato M; Kizawa Y; Shirahige Y; Yamaguchi T; Eguchi K.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23664708
BACKGROUND: Improvement of palliative care is an important public health issue, but knowledge about how to deliver palliative care throughout a region remains inadequate. We used surveys and in-depth interviews to assess changes in the quality of palliative care after regional interventions and to gain insights for improvement of palliative care at a regional level.
METHODS: In this mixed-methods study, a comprehensive programme of interventions for regional palliative care for patients with cancer was implemented from April 1, 2008, to March 31, 2011 in Tsuruoka, Kashiwa, Hamamatsu, and Nagasaki in Japan. Interventions included education, specialist support, and networking. We surveyed patients, bereaved family members, physicians, and nurses before and after the interventions were introduced. We also did qualitative interviews with health-care professionals after the interventions were introduced. Primary endpoints were numbers of home deaths, coverage of specialist services, and patient-reported and family-reported qualities of care. This trial is registered with UMIN Clinical Trial Registry, Japan (UMIN000001274).
FINDINGS: 859 patients, 1110 bereaved family members, 911 physicians, and 2378 nurses provided analysable preintervention surveys; 857 patients, 1137 bereaved family members, 706 physicians, and 2236 nurses provided analysable postintervention surveys. Proportions of home deaths increased significantly, from 348 of 5147 (6.76%) before the intervention programme to 581 of 5546 (10.48%) after the intervention programme (p<0.0001). Furthermore, 194 of 221 (87.78%) family members of patients who died at home answered that these patients had wanted
to die at home. The ratio of patients who received palliative care services to all patients who died of cancer increased significantly (from 0.31 to 0.50; p<0.0001). The patient-reported (effect size 0.14; adjusted p=0.0027) and family-reported (0.23; p<0.0001) qualities of care were significantly better after interventions than before interventions. Physician-reported and nurse-reported difficulties decreased significantly after the introduction of the interventions. Qualitative interviews showed improved communication and cooperation between health-care professionals because of greater opportunities for interactions at various levels.

INTERPRETATION: A regional programme of interventions could improve the quality of palliative care. Improvement of communication between health-care professionals is key to improvement of services.

FUNDING: Third Term Comprehensive Control Research for Cancer Health and Labor Sciences Research Grants of the Ministry of Health, Labour and Welfare of Japan. Copyright 2013 Elsevier Ltd. All rights reserved.

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166.
Bereaved caregivers as educators in pediatric palliative care: their experiences and impact.
Adams G; Green A; Towe S; Huett A.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23725232
BACKGROUND: With the continuing growth of pediatric palliative care, there is an increasing need to develop effective training for health care professionals. Bereaved parents have participated in the training of health care professionals utilizing curriculum from the Initiative for Pediatric Palliative Care (IPPC), but the experience of bereaved parents as educators has not been studied.
OBJECTIVES: This qualitative research examined the experience of bereaved parents involved in pediatric palliative care education of health care professionals and the challenges and possible benefits for the health care professionals.

METHODS: Nine bereaved parents and eleven health care professionals were interviewed about their experiences in a pediatric palliative care education program utilizing the IPPC curriculum. The interviews were recorded, transcribed, coded and analyzed for themes and subthemes.

RESULTS: Major themes found were a sense of purpose for the parents and benefits and challenges for both parents and professionals. The experience for parents contributed to their meaning-making for both their children's lives and deaths. Parents and professionals identified mutual learning and increased mutual understanding. Some professionals noted that the presence of parents may have limited the openness of discussion of the professionals and parents acknowledged challenges of emotional management in their participation in the educational program. Both parents and professionals recognized and described challenges involved in working sensitively with patients and families without being overwhelmed by the intensity of situations where children die.

CONCLUSION: More benefits than burdens were experienced by both parents and health care professionals from the participation of bereaved parents in the palliative care trainings.

167.
Latent classes of prognosis conversations in palliative care: a mixed-methods study.
Gramling R; Norton S; Ladwig S; Winters P; Metzger M; Quill T; Alexander S.
UI: 23659459

BACKGROUND: Prognosis conversations are complex phenomena of substantial importance to palliative care (PC), yet these remain poorly understood. This study empirically identifies and describes major types of prognosis conversations that occur in the natural setting of PC consultation.
METHODS: We audio-recorded and coded 71 inpatient "goals of care" PC consultations at a large academic medical center in the northeastern United States. We used quantitative Latent Class Analyses for identifying discrete prognosis conversation types and qualitative Dimensional Analyses for more fully describing the process and content of the latent classes.

RESULTS AND CONCLUSIONS: We observed three discrete types of prognosis conversations, each placing different communication demands upon all participants for achieving goal-concordant care: Navigating Options & Goals (56% of consultations), Facilitating New Goals (23%) and Preparing for End-of-Life (21%). This study provides the first step for developing educational and clinical prognosis communication interventions that are tailored to common decision-making contexts facing seriously ill patients, their families, and PC clinicians.

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Cancer patients' experiences with and perceived outcomes of yoga: results from focus groups.
van Uden-Kraan CF; Chinapaw MJ; Drossaert CH; Verdonck-de Leeuw IM; Buffart LM.
Supportive Care in Cancer. 21(7):1861-70, 2013 Jul.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23400315

PURPOSE: Yoga is a "mind-body" exercise, a combination of physical poses with breathing and meditation, and may have beneficial effects on physical and psychosocial symptoms. We aimed to explore cancer patients' motives for practicing yoga, experiences of practicing yoga, and perceived physical and psychosocial outcomes.

METHODS: Participants (n = 45) following yoga classes for cancer patients were asked to participate in focus group interviews, of whom 29 participated. The focus groups (n = 5) were audio taped with prior consent and transcribed verbatim. Data were analyzed by two coders and independently coded into key issues and themes.

RESULTS: Mean age of the participants was 53.8 (SD 10.8) years, of whom 25 were women, and 18 were diagnosed with breast cancer. Motives for participation in yoga were relaxation, the will to be physically active, the wish to pay more attention to one's body, coping with psychosocial symptoms, contributing to their cancer rehabilitation process, and combing physical and mental
processes. Main physical and psychosocial experiences of yoga mentioned by patients were regaining body awareness, raising attention to the inner self, learning how to relax, enjoyment, and finding recognition and understanding. Increased physical fitness and function, mental strength and resilience, increased coping, being more relaxed, and happiness were frequently mentioned experiences of patients.

CONCLUSIONS: Patients with different types of cancer perceived several benefits on physical and psychosocial outcomes by practicing yoga. Therefore, yoga can be a valuable form of supportive care for cancer patients.

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20130531

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169.
Pancreatic cancer and supportive care—pancreatic exocrine insufficiency negatively impacts on quality of life.
Gooden HM; White KJ.
Supportive Care in Cancer. 21(7):1835-41, 2013 Jul.
[Journal Article. Research Support, Non-U.S. Gov't]

PURPOSE: Pancreatic cancer is a fatal cancer with a median survival from diagnosis of around 5 months Speer et al. (Med J Aust 196(8):511-515, 2012). Given the short survival time for people with pancreatic cancer, effective supportive care is imperative to enable best quality of life. This article presents an unexpected finding from research into the psychosocial supportive care needs of people affected by pancreatic cancer that management of pancreatic exocrine insufficiency is an area of unmet need that severely impacts on quality of life and increases carer burden in people affected by pancreatic cancer.

METHODS: A qualitative inquiry framework was used to explore participants’ perspectives and experience. Two groups of participants (N = 35) were recruited across Australia from people accessing the Cancer Helpline or direct referral from clinicians/nurses: patients diagnosed with pancreatic cancer (N = 12) and carers/family (N = 23) including a subgroup of bereaved participants (N = 14). Sampling continued until saturation. A thematic content analysis was conducted.

RESULTS: The findings revealed that the major quality of life theme was difficulty in managing gut symptoms and complex dietary issues. Issues were related to lack of information about malabsorption and managing symptoms of pancreatic exocrine insufficiency. This was
compounded by a lack of routine dietary consultation: perceived reluctance of clinicians to prescribe enzyme supplements and poor understanding of dose to diet guidelines.

CONCLUSION: Participants expressed distress relating to the effects of pancreatic exocrine insufficiency. Pancreatic enzyme supplement therapy with clear dosage guidelines and associated dietary advice could resolve symptoms of malabsorption and markedly improve quality of life. For people affected by pancreatic cancer, this is an essential supportive care.

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170.
Families' experiences with patients who died after assisted suicide: a retrospective interview study in southern Switzerland.
Gamondi C; Pott M; Payne S.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23446094
BACKGROUND: In Switzerland, if certain conditions are met, assisted suicide is not prosecuted. International debate suggests that requests for hasten death are often altered by the provision of palliative care. Aims of the study were to explore patients' reasons for choice of assisted suicide and family perceptions of the interactions with health care professionals.

PATIENTS AND METHODS: This is a qualitative study upon 11 relatives of 8 patients cared for by a palliative care team, deceased of assisted suicide.

RESULTS: Pain and symptom burden were not regarded by patients as key reasons to seek assisted suicide: existential distress and fear of loss of control were the determinants. Most patients had made pre-illness decisions to use assisted suicide. A general need for perceived control and fear of dependency were reported as a common characteristic of these patients. Patients held misunderstandings about the nature and purpose of palliative care, and the interviewed indicated that patients did not regard provision of palliative care services as influential in preventing their decision.

CONCLUSIONS: Assisted suicide was preferred despite provision of palliative care. Better understanding of the importance placed on perceived control and anticipated dependency is needed. Further research is needed to develop appropriate support for patients contemplating assisted suicide.

Status
Hospital administrators' views on barriers and opportunities to delivering palliative care in the emergency department.
Grudzen CR; Richardson LD; Major-Monfried H; Kandarian B; Ortiz JM; Morrison RS.
[Journal Article. Research Support, N.I.H., Extramural. Research Support, Non-U.S. Gov't]
UI: 22771203
STUDY OBJECTIVE: We identify hospital-level factors from the administrative perspective that affect the availability and delivery of palliative care services in the emergency department (ED).
METHODS: Semistructured interviews were conducted with 14 key informants, including hospital executives, ED directors, and palliative care directors at a tertiary care center, a public hospital, and a community hospital. The discussions were digitally recorded and transcribed to conduct a thematic analysis using grounded theory. A coding scheme was iteratively developed to subsequently identify themes and subthemes that emerged from the interviews.
RESULTS: Barriers to integrating palliative care and emergency medicine from the administrative perspective include the ED culture of aggressive care, limited knowledge, palliative care staffing, and medicolegal concerns. Incentives to the delivery of palliative care in the ED from these key informants' perspective include improved patient and family satisfaction, opportunities to provide meaningful care to patients, decreased costs of care for admitted patients, and avoidance of unnecessary admissions to more intensive hospital settings, such as the ICU, for patients who have little likelihood of benefit.
CONCLUSION: Though hospital administration at 3 urban hospitals on the East coast has great interest in integrating palliative care and emergency medicine to improve quality of care, patient and family satisfaction, and decrease length of stay for admitted patients, palliative care staffing, medicolegal concerns, and logistic issues need to be addressed. Copyright 2012 American College of Emergency Physicians. Published by Mosby, Inc. All rights reserved.
172.
[Treatment for cancer pain at the end of life: a case study in a palliative care service in the Autonomous City of Buenos Aires]. [Spanish]
Alonso JP.
[English Abstract. Journal Article]
UI: 23680748
Cancer pain relief has been defined as a worldwide public health challenge in the last decades and has recently been included in public debates as a human rights issue. However, barriers to the provision of adequate pain management continue to exist. This article analyzes the cancer pain treatment provided in a palliative care setting in the Autonomous City of Buenos Aires, focusing on how professionals and patients implement and negotiate the terms and adherence to the pain treatment. Based on a qualitative approach that triangulates data from semi-structured interviews and from ethnographic observations, the article addresses the way pain is measured and assessed and the strategies of health professionals in establishing pain treatment protocols. The article also describes the rhetoric regarding the right to pain relief developed by health professionals through their practice and discusses the limitations of that rhetoric.
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173.
From qualitative work to intervention development in pediatric oncology palliative care research.
Akard TF; Gilmer MJ; Friedman DL; Given B; Hendricks-Ferguson VL; Hinds PS.
Qualitative methods can be particularly useful approaches to use with individuals who are experiencing a rare disease and thus who comprise a small sample (such as children with cancer) and are at points in care that few experience (such as end of life). This data-based methods article describes how findings from a qualitative study were used to guide and shape a pediatric oncology palliative care intervention. Qualitative data can lay a strong foundation for subsequent pilot intervention work by facilitating the development of an underlying study conceptualization, providing recruitment feasibility estimates, helping establish clinically meaningful inclusion criteria, establishing staff acceptability of a research intervention, and providing support for face validity of newly developed interventions. These benefits of preliminary qualitative research are described in the context of this study on legacy-making, which involves reports of children (7-12 years of age) living with advanced cancer and of their parent caregivers.

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174.
[Good palliative care in the intensive care unit]. [French]
Guay D; Michaud C; Mathieu L.
Recherche en Soins Infirmiers. (112)61-75, 2013 Mar.
[English Abstract. Journal Article]
UI: 23671987
UNLABELLED: The aging population, the complexity and irreversibility of certain conditions lead to the deaths of 20% of patients admitted to intensive care units (ICU). However, in Quebec, as elsewhere in America, few of them currently receive palliative care.

METHOD: inspired by a conceptual model considering nursing as a moral practice, this phenomenological study was conducted in four phases: focus groups (n = 6) observation sessions (n = 6) followed by individual interviews and group validation activities (n = 5). In its first part, this study shows that through several caring behaviours, "good palliative care" in the ICU is manifested by the consideration of six dimensions of the person, physical, relational,
psychological, moral, social and spiritual. This article presents the second part of this study and reveals three main themes summarizing the conditions facilitating "good the palliative care" according to ICU nurses: Sharing a common vision enhanced by a collective and specific palliative care knowledge, an informed and concerted decision-making process in a favourable organisational and physical environment.

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175.
Parental perceptions of forgoing artificial nutrition and hydration during end-of-life care.
Rapoport A; Shaheed J; Newman C; Rugg M; Steele R.
[Comparative Study. Journal Article. Research Support, Non-U.S. Gov't]
UI: 23569099
BACKGROUND AND OBJECTIVE: Forgoing artificial nutrition and hydration (FANH) in children at the end of life (EOL) is a medically, legally, and ethically acceptable practice under specific circumstances. However, most of the evidence on FANH involves dying adults. There is a paucity of pediatric evidence to guide health care providers' and parents' decision-making around this practice. Objectives were (1) to explore the experiences of bereaved parents when a decision had been made to FANH during EOL care for their child and (2) to describe the perceived quality of death in these children, as reported by their parents.
METHODS: This was a qualitative study using in-depth interviews with parents whose children died after a decision to FANH. Parental perceptions about the experience and their child's quality of death were explored. Interviews were audiotaped and transcribed, then data were analyzed by using interpretive description methodology.
RESULTS: All parents were satisfied with their decision to FANH and believed that their child's death was generally peaceful and comfortable. The child's perceived poor quality of life was central to the decision to FANH, with feeding intolerance often contributing to this perception. Despite overall satisfaction, all parents had doubts and questions about the decision and benefited from ongoing assurances from the clinical team.
CONCLUSIONS: FANH in children at the EOL is an acceptable form of palliation for some parents and may contribute to a death that is perceived to be peaceful and comfortable. In situations in which FANH may be a reasonable possibility, physicians should be prepared to introduce the option.
A qualitative study: professionals' experiences of advance care planning in dementia and palliative care, 'a good idea in theory but ...'.

Robinson L; Dickinson C; Bamford C; Clark A; Hughes J; Exley C.
Palliative Medicine. 27(5):401-8, 2013 May.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23175508

BACKGROUND: Advance care planning comprises discussions about an individual's wishes for future care while they have capacity.

AIM: To explore professionals' experiences on the implementation of advance care planning in two areas of clinical care, dementia and palliative care.

DESIGN: Qualitative study, focus groups and individual interviews.


SAMPLE: Ninety-five participants from one Primary Care Trust, two acute National Health Service Hospital Trusts, one Ambulance Trust, one Local Authority and voluntary organisations and the legal sector.

RESULTS: Fourteen focus groups and 18 interviews were held with 95 participants. While professionals agreed that advance care planning was a good idea in theory, implementation in practice presented them with significant challenges. The majority expressed uncertainty over the general value of advance care planning, whether current service provision could meet patient wishes, their individual roles and responsibilities and which aspects of advance care planning were legally binding; the array of different advance care planning forms and documentation available added to the confusion. In dementia care, the timing of when to initiate advance care planning discussions was an added challenge.

CONCLUSIONS: This study has identified the professional, organisational and legal factors that influence advance care planning implementation; professional training should target these specific areas. There is an urgent need for standardisation of advance care planning documentation. Greater clarity is also required on the roles and responsibilities of different professional groups. More complex aspects of advance care planning may be better carried out
by those with specialist skills and experience than by generalists caring for a wide range of patient groups with different disease trajectories.

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177.
The legacy of "Joanna": the role of ethical debate in nurse preparation.
Willsher KA.
[Comparative Study. Journal Article]
UI: 23428364
INTRODUCTION: The author was involved in nursing "Joanna", a neonate who was born in 1980 with a serious form of spina bifida. A scenario describing the Joanna case was introduced to two groups of students in order to enhance critical thinking skills and encourage ethical debate in the classroom. Critical thinking skills, which are essential in professional practice, include the honest appraisal of intellectual positions adopted by one’s self and others, and caring about the dignity and worth of each person (Ennis 1996, cited in Robinson, 2011).
METHODOLOGY: The scenario was presented as a case study to two classes, one of which comprised undergraduate nursing students, the other, mature-aged retirees. The International Council of Nurses Code of Ethics (2006) was used to critically analyze the concepts of quality of life and empowerment. The qualitative raw data was collected from both groups and compared.
DISCUSSION: Nurses are in a key position to identify potential ethical conflicts but need adequate supports in place in order to become empowered and advocate for patients. The differing attitudes towards Joanna and the care she received reflected the different quantities and types of life experiences available in the two class groups.
CONCLUSION: Nurse education programs now accept greater numbers of students from diverse backgrounds; therefore, educators need to plan for these differences in life experience when inducting students into professional practice. The outcome of introducing the scenario into the classroom demonstrates the imperative of seeking a wide variety of perspectives to develop ethical debate and preparation for professional practice. Copyright 2013 Elsevier Ltd. All rights reserved.
Status
Illness-related emotional experiences of patients living with incurable lung cancer: a qualitative metasynthesis.
UI: 23051865
BACKGROUND: Living with incurable lung cancer often drastically changes the patients' lives physically, socially, psychologically, and spiritually. The emotional experiences of patients with incurable lung cancer have been studied with a qualitative approach, but the findings are yet to be synthesized.
OBJECTIVE: The objective of this study was to synthesize interpreted knowledge on the illness-related emotional experiences of patients with incurable lung cancer.
METHODS: A qualitative metasynthesis was carried out to integrate the findings from 10 qualitative studies conducted between 1995 and 2011. The studies were critically appraised according to the method defined by Sandelowski and Barroso, and the findings were extracted, edited, and abstracted. The concept "loss" was imported as a method to synthesize the findings.
CONCLUSION: This study supports that patients with incurable lung cancer undergo illness-related emotions that can be identified as losses. Further studies are required to determine the best way for nurses to implement emotional care.
IMPLICATIONS FOR PRACTICE: Nurses play an important role in the acknowledgement of unrecognized and clear losses while caring for patients with incurable lung cancer.
More than physical function? Exploring physiotherapists’ experiences in delivering rehabilitation to patients requiring palliative care in the community setting.
Carson K; Mcllfatrick S.
[Journal Article]
UI: 23614169

BACKGROUND: Physiotherapists, as essential members of the multidisciplinary palliative care team, are key to the successful rehabilitation of palliative patients. There is, however, a scarcity of literature on the experiences of primary care physiotherapists delivering this service.
AIM: This study explored the experiences of physiotherapists delivering rehabilitation in palliative care and identified perceived barriers and enablers.
METHOD: A qualitative approach was adopted involving semistructured interviews with a purposive sample of primary care physiotherapists (n = 11).
FINDINGS: Participants viewed rehabilitation as helping to maximize independence and improve quality of life for palliative patients. Their role was primarily focused on physical functioning but within an overall philosophy of providing comfort and supportive care. Several barriers and enablers to delivering rehabilitation were identified; these were related to communication, resources, teamwork, and training.
CONCLUSION: Physiotherapists believed that rehabilitation adds value to palliative care, but existing barriers limit the service. Improved collaboration and timely access to resources could assist in the provision of rehabilitation to palliative patients.

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Multicultural long-term care nurses’ perceptions of factors influencing patient dignity at the end of life.
Periyakoil VS; Stevens M; Kraemer H.
UI: 23496266
The goal of this mixed-methods study was to characterize the perceptions of multicultural long-term care nurses about patient dignity at the end-of-life (EOL). The study was conducted in a large, urban, long-term care (LTC) facility. Participants were 45 long-term care nurses and 26 terminally ill nursing home residents. Nurses completed an openended interview about their perceptions of the concept of dying with dignity, and the data were analyzed using grounded theory methods. Main themes identified as promoting resident dignity at the EOL included treating them with respect, helping them prepare for the EOL, promoting shared decision-making, and providing high-quality care. The nurses’ cultural and religious backgrounds influenced their perceptions of what constitutes dignity-conserving care. Foreign-born nurses stressed the need for EOL rituals, but this was strikingly absent in the statements of U.S.-born nurses. Foreign-born Catholic nurses stated that the dying experience should not be altered using analgesics to relieve suffering or by attempts to hasten death by forgoing curative therapy or by other means. Nurses and terminally ill individuals completed the Dignity Card-sort Tool (DCT). A comparison of the DCT responses of the LTC nurses cohort with those of the terminally ill participants revealed that the nurses felt patient dignity was eroded when patient wishes were not followed and when they were treated without respect. In contrast, dying LTC residents felt that poor medical care and loss of ability to choose care options were the most important factors leading to erosion of dignity.

Provider approaches to palliative dyspnea assessment: implications for informatics-based clinical tools.
Ahluwalia SC; Leos RL; Goebel JR; Asch SM; Lorenz KA.
AIM: To understand provider practices around dyspnea assessment to inform the development of an electronic medical record (EMR)-based dyspnea assessment module in an inpatient palliative care consultation template.

DESIGN: Qualitative analysis of palliative care provider interviews.

RESULTS: Three themes emerged: (1) integration of patient self-report of breathlessness with a clinical observation of dyspnea; (2) identification of patients for dyspnea assessment based on perceived patient need; and (3) variability in preferences for and use of existing severity scales for dyspnea.

CONCLUSIONS: The assessment approaches described by providers underscore the challenge of developing an informatics tool that supports the natural clinical experience and facilitates standardized care. The complexity of the dyspnea assessment process and variation in provider practices necessitate a level of flexibility and choice to be built into a computer-based tool.

182.
Increasing access--a qualitative study of homelessness and palliative care in a major urban center.
Krakowsky Y; Gofine M; Brown P; Danziger J; Knowles H.

Rates of morbidity and mortality are significantly higher in homeless populations. Homeless people experience many barriers to receive adequate palliative care. This qualitative study examines how a major urban city's palliative care resources can be improved to increase access and better serve the homeless. Audiotaped interviews were preformed with 7 homeless care providers in Toronto, Canada, and their transcripts were analyzed using thematic analysis. The findings of the study suggest that in order to increase access and to serve the city's terminally ill homeless better, the following 4 areas must be addressed: (1) increasing positive interaction between the health care system and the homeless, (2) training staff to deal with the unique issues
confronting the homeless, (3) providing patient-centered care, and (4) diversifying the methods of delivery.

Status
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20130418
Year of Publication
2013

183.
Patients' views on failure to gain expected clinical beneficial outcomes from participation in palliative medicine clinical trials.
Siu SW; Leung PP; Liu RK; Leung TW.
[Journal Article]
UI: 22645394
UNLABELLED: REASON FOR THE STUDY: This study aims to understand patients' views on failing to gain expected beneficial outcomes from palliative medicine clinical trials. This is a qualitative study involving semistructured interviews.
MAIN FINDINGS: Seven patients were interviewed. Despite loss of initial hope in benefiting themselves in terms of better disease or symptom control, patients interviewed still found joining clinical trials meaningful experience in terms of benefiting future patients and being valuable life experience. Experience in interacting with research staff partly formulated final impressions on clinical trial participation experience.
PRINCIPAL CONCLUSIONS: Joining well-designed clinical trials unlikely causes harm to patients. Caring attitudes of researchers and maintaining good researcher-patient relationships can help patients in meaning-finding process, especially if they have failed to gain anticipated clinical benefits.
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20130418
Year of Publication
Psychological impact of working with patients with cystic fibrosis at end-of-life, pre-transplant stage.

Clisby N; Shaw S; Cormack M.
Palliative & Supportive Care. 11(2):111-21, 2013 Apr.
[Journal Article]
UI: 23234801

OBJECTIVE: Multidisciplinary staff who work with end-of-life, pre-transplant patients with cystic fibrosis (CF) have to juggle two seemingly opposing care approaches; active care to maintain their patients’ health and condition in anticipation of a transplant, and sensitive palliative care that takes their end-of-life wishes into consideration should they not receive a transplant. Little is known about the psychological impact on staff working within this care dichotomy. The aim of this study is to explore staff’s experiences and understand more about the psychological impact of this work on them professionally and personally, and how this affects their ability to provide appropriate care for their patients.

METHOD: A qualitative explorative research design was used. Ten semistructured interviews with multidisciplinary staff working in cystic fibrosis centers and units across the United Kingdom were analyzed using interpretative phenomenological analysis (IPA).

RESULTS: Two superordinate themes emerged from the analysis: factors contributing to the "juggle" of active and palliative care, and extent of emotional impact on staff.

SIGNIFICANCE OF RESULTS: The study indicates that there is an emotional impact on staff working with patients with CF at end-of-life, pre-transplant stages. Specifically, it reveals the extent of the unpredictability that staff work with, and the range of emotions that staff experience, including uncertainty about professional identity and anxiety about working practices. The depth and intimacy of professional-patient relationships is highlighted, particularly for staff in close contact with and similar in age to their patients. Additionally, the strength of staff's commitment and desire to care for patients within broader humanistic terms that mesh with their own personal values is brought to light. Despite the difficulties with their work, the majority of staff adopted numerous coping strategies to manage their emotions, many of which emphasized the link between their professional and personal values in undertaking their roles.
"There's no cure for this condition": how physicians discuss advance care planning in heart failure.
Ahluwalia SC; Levin JR; Lorenz KA; Gordon HS.
[Journal Article. Research Support, U.S. Gov't, Non-P.H.S.]
UI: 23369373

OBJECTIVE: To evaluate the extent to which physicians engage in recommended elements of advance care planning (ACP) communication during outpatient clinic visits with heart failure (HF) patients.

METHODS: We conducted a qualitative content analysis of 71 audio-recorded and transcribed outpatient visits with 52 patients >65 years recently hospitalized for HF and their physicians (n=44).

RESULTS: We identified 25 instances of ACP-related communication over 15 of the 71 visits: in 17 instances, physicians explained the nature of HF but only once was the life-limiting potential of HF mentioned. Physicians discussed goals of care in 6 instances but elicited their patients' preferences in only 2 of those instances. Finally, physicians encouraged documentation of preferences in 2 instances.

CONCLUSIONS: Despite recommendations for early ACP with HF patients, physicians rarely engaged in fundamental elements of ACP discussions during outpatient visits. We suggest a stepwise approach to supporting the process of ACP communication in practice.

PRACTICE IMPLICATIONS: Given the importance of ACP in helping patients plan for their future care, outpatient clinicians should be helped to incorporate these discussions in the routine care of their HF patients. Using a simple heuristic might help physicians engage in fundamental elements of ACP during busy outpatient visits.

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Date Created
20130408

Year of Publication
2013
186.
Palliative and supportive care needs of patients with high-grade glioma and their carers: a systematic review of qualitative literature. [Review]
Moore G; Collins A; Brand C; Gold M; Lethborg C; Murphy M; Sundararajan V; Philip J. Patient Education & Counseling. 91(2):141-53, 2013 May. [Journal Article. Research Support, Non-U.S. Gov't. Review]
UI: 23218925

OBJECTIVE: Patients diagnosed with primary malignant glioma (PMG) face substantial challenges with poor prognosis, high symptom burden and care needs. This study aims to collate current literature detailing the supportive and palliative care needs of patients with PMG and their carers, and to subject it to a novel approach of formal evaluation.

METHODS: Medline, EMBASE, CiNAHL, PsychInfo were searched with core concepts: (1) glioma, (2) high-grade disease, and (3) palliative and supportive care needs. A narrative synthesis approach was undertaken including a quality appraisal of the 21 included studies.

RESULTS: Key themes related to the need for consistent well-delivered information around disease sequelae, treatment, and resources available; health service needs including a key professional identified to coordinate care; the need for psychological and social supports, and clear avenues of communication with treating professionals.

CONCLUSION: The literature remains limited in the number and quality of evidence with two level I, eight level II, and eleven level III studies. The findings call for improved information, communication and support practices to address the complexity and breadth of needs.

PRACTICE IMPLICATIONS: Specialised and individually tailored information, attention to clear, consistent communication and support practices should be incorporated into a future needs-based model of care. Copyright 2012 Elsevier Ireland Ltd. All rights reserved.

Status
MEDLINE
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20130408
Year of Publication
2013

187.
How do GPs identify a need for palliative care in their patients? An interview study.
Claessen SJ; Francke AL; Engels Y; Deliens L. BMC Family Practice. 14:42, 2013. [Journal Article. Research Support, Non-U.S. Gov't]
UI: 23530627
BACKGROUND: Little is known about how GPs determine whether and when patients need palliative care. Little research has been done regarding the assumption underpinning Lynn and Adamson’s model that palliative care may start early in the course of the disease. This study was conducted to explore how GPs identify a need for palliative care in patients.

METHODS: A qualitative interview study was performed among 20 GPs in the Netherlands.

RESULTS: GPs reported that a combination of several signals, often subtle and not explicit, made them identify a need for palliative care: signals from patients (increasing care dependency and not recuperating after intercurrent diseases) and signals from relatives or reports from medical specialists. GPs reported differences in how they identified a need for palliative care in cancer patients versus those with other diseases. In cancer patients, the need for palliative care was often relatively clear because of a relatively strict demarcation between the curative and palliative phase. However, in patients with e.g. COPD or in the very old, GPs’ awareness of palliative care needs often arises gradually, relatively late in the disease trajectory. GPs consider the diagnosis of a life-threatening illness as a key point in the disease trajectory. However, this does not automatically mean that a patient needs palliative care at that point.

CONCLUSIONS: GPs recognize a need for palliative care on the basis of various signals. They do not support the idea underlying Lynn and Adamson’s model that palliative care always starts early in the course of the disease.

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Date Created
20130405
Year of Publication
2013

188.
"To cherish each day as it comes": a qualitative study of spirituality among persons receiving palliative care.
Asgeirsdottir GH; Sigurbjornsson E; Traustadottir R; Sigurdardottir V; Gunnarsdottir S; Kelly E. Supportive Care in Cancer. 21(5):1445-51, 2013 May.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23288396
PURPOSE: Spirituality is one of the main aspects of palliative care. The concept is multidimensional and encompasses the existential realm as well as value-based and religious considerations. The aim of this study was to explore spirituality from the perspective of persons
receiving palliative care and examine their experience of spirituality and its influence on their lives and well-being.

METHODS: Qualitative interviews were conducted with ten persons receiving palliative care from Palliative Care Services in Iceland. The interviews were tape-recorded, transcribed and analysed. The study is in the field of practical theology and used the theoretical approach of hermeneutical phenomenology.

RESULTS: Thematic analysis found that the spiritual dimension was of significance for the participants who understood it as a vital element connected to seeking meaning, purpose and transcendence in life. Religious and non-religious aspects of spirituality were expressed including strong spiritual components of family relationships, the meaning of God/a higher being and spiritual practices which served as a key factor in giving strength, activating inner resources and motivating hope. Nine of the participants expressed their spirituality as faith.

CONCLUSIONS: Spirituality was experienced broadly as an important dimension of how participants lived with terminal illness. Religious and non-religious characteristics were recognised which reveals the complex nature of the phenomenon. Faith was a significant part of the participants' spirituality indicating the importance of attending to this aspect of palliative care. The study suggests the potential contributions of theological approaches which are relevant for palliative care research and practice.

Status
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Date Created
20130401
Year of Publication
2013

189.
Barriers to the diagnosis and treatment of venous thromboembolism in advanced cancer patients: a qualitative study.
Sheard L; Prout H; Dowding D; Noble S; Watt I; Maraveyas A; Johnson M.
[Journal Article]
UI: 23093572
BACKGROUND: Venous thromboembolism is common in patients with cancer and the risk increases with advanced disease. Evidence-based treatment is administration of low-molecular-weight heparin daily by subcutaneous injection. Clinical uncertainty exists as to whether treating venous thromboembolism in advanced disease is in the patient's best interests.
AIM: To explore the barriers faced by doctors when diagnosing and treating patients with cancer-associated thrombosis.

DESIGN: Qualitative, in-depth interview study using framework analysis.

PARTICIPANTS: Forty-five UK doctors across urban and rural settings, from three specialties, oncology, palliative medicine and general practice, with a mixture of senior and junior staff.

RESULTS: Organisational constraints served to act as barriers to the diagnosis and treatment of this patient group. Issues were identified around access to diagnostic testing. A cancer-associated thrombosis patient having to wait for a scan as an inpatient was sometimes deemed unnecessary. Patient ambulance transport (especially transportation of hospice patients) was often viewed as inflexible and bureaucratic. Low-molecular-weight heparin prescribing had sometimes led to tension between the acute, community and hospice sectors about whose prescribing responsibility this was, with different areas having divergent 'rules' and practices. Finally, the doctors interviewed discussed the role of nurses.

CONCLUSIONS: Multiple logistical barriers are hindering best patient care for people with cancer-associated thrombosis. There is scope for some of these barriers to be reduced to improve service delivery and ultimately patient care. The research team proposes practical recommendations, which could yield direct benefit for patients and the health services.

190. Early support visits by district nurses to cancer patients at home: a multi-perspective qualitative study.
Griffiths J; Ewing G; Rogers M.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 22801979

BACKGROUND: Many palliative cancer patients spend much of their last year at home. In the UK, district nurses make frequent support visits to patients and carers at this time, yet surprisingly little is known about their supportive role in palliative care. Current studies are limited to district nurses' reports of practice, which offer limited insight into their content. Patients' and carers' views on district nurse support visits are largely unknown.
AIM: To present findings of a multi-perspective study that explored how district nurse early support visits are both described and carried out.

DESIGN: Focus groups with district nurses to explore views on the purpose of early support visits. Observation of support visits to identify how they are conducted. Patient and carer interviews to elucidate and verify district nurse data.

SETTING AND PARTICIPANTS: Participants included 58 district nurses, 10 palliative care patients and nine carers from four Primary Care Trusts in contrasting urban and rural locations.

RESULTS: District nurses had difficulty articulating early support visits. Observations however revealed a complex role comprising extensive physical and practical assessments, practical interventions, information giving, liaison, facilitation and referral. Patients and carers confirmed that they felt valued, reassured and supported by district nurses.

CONCLUSIONS: A multi-perspective approach provided new insights into district nurse support visits. Monitoring work described appears to have additional psycho-social benefits for patients and carers. The supportive role of district nurses needs to be clearly articulated and recognised so that colleagues, patients and carers access this valuable resource for palliative care patients.

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Date Created
20130329
Year of Publication
2013

Patient perspectives on participation in the ENABLE II randomized controlled trial of a concurrent oncology palliative care intervention: benefits and burdens.
Maloney C; Lyons KD; Li Z; Hegel M; Ahles TA; Bakitas M.
[Journal Article. Research Support, N.I.H., Extramural. Research Support, Non-U.S. Gov't]
UI: 22573470

BACKGROUND: ENABLE (Educate, Nurture, Advise Before Life Ends) II was one of the first randomized controlled trials (RCTs) examining the effects of a concurrent oncology palliative care intervention on quality of life, mood, and symptom control for advanced cancer patients and their caregivers. However, little is known about how participants experience early palliative care and the benefits and burdens of participating in a palliative care clinical trial.

AIM: To gain a deeper understanding of participants’ perspectives of the intervention and palliative care trial participation.

DESIGN: A qualitative descriptive study using thematic analysis to determine benefits and burdens of a new palliative care intervention and trial participation.
SETTING/PARTICIPANTS: Of the 72 participants who were alive when the study commenced, 53 agreed to complete an in-depth, semi-structured interview regarding the ENABLE II intervention and clinical trial participation.

RESULTS: Participants' perceptions of intervention benefits were represented by four themes: enhanced problem-solving skills, better coping, feeling empowered, and feeling supported or reassured. Three themes related to trial participation: helping future patients and contributing to science, gaining insight through completion of questionnaires, and trial/intervention aspects to improve.

CONCLUSIONS: The benefits of the intervention and the positive aspects of trial participation outweighed trial "burdens". This study raises additional important questions relevant to future trial design and intervention development: when should a palliative care intervention be initiated and what aspects of self-care and healthy living should be offered in addition to palliative content for advanced cancer patients when they are feeling well?

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Other ID Source: NLM. NIHMS458601 Source: NLM. PMC3657725
Date Created 20130329
Year of Publication 2013

192.
Transmural palliative care by means of teleconsultation: a window of opportunities and new restrictions.
van Gurp J; van Selm M; van Leeuwen E; Hasselaar J.
BMC Medical Ethics. 14:12, 2013.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23497307
BACKGROUND: Audio-visual teleconsultation is expected to help home-based palliative patients, hospital-based palliative care professionals, and family physicians to jointly design better, proactive care. Consensual knowledge of the possibilities and limitations of teleconsultation in transmural palliative care is, however, largely lacking. This paper aims at describing elements of both the physical workplace and the cultural-social context of the palliative care practice, which are imperative for the use of teleconsultation technologies.

METHODS: A semi-structured expert meeting and qualitative, open interviews were deployed to explore professionals’ assumptions and wishes, which are considered to contain latent presumptions about the practice's physical workplace and latent elements of the cultural-social
context, regarding (1) the mediating potential of audio-visual teleconsultation, (2) how the audio-
visual teleconsultations will affect medical practice, and (3) the design and usage of the
teleconsultation technology. We used a qualitative analysis to investigate how palliative care
professionals interpret the teleconsultation package in preparation. The analysis entailed open
and axial coding techniques developed in a grounded theory approach.
RESULTS: Respondents assume: 1. teleconsultation will hinder physical proximity, thereby
compromising anamnesis and diagnosis of new or acutely ill patients as well as "real contact"
with the person behind the patient; 2. teleconsultation will help patients becoming more of a
pivotal figure in their own care trajectory; 3. they can use teleconsultation to keep a finger on the
pulse; 4. teleconsultations have a healing effect of their own due to offered time and digital
attention; 5. teleconsultation to open up an additional "gray" network outside the hierarchical
structures of the established chain of transmural palliative care. This network could cause
bypassing of caregivers and uncertainty about responsibilities; 6. teleconsultations lead to an
extended flow of information which helps palliative care professionals to check the stories of
patients and medical specialists.
CONCLUSIONS: Professionals assume teleconsultation co-defines a new patient-professional
relationship by extending hospital-based caregivers’ perceptions of as well as attention for their
patients. At the cost, however, of clinical and personal connectedness. Secondly, a hermeneutics
is needed to carefully interpret teleconsultation images. Thirdly, teleconsultations transform
caregiving cultures as formerly separated care domains collide, demanding a redefinition of roles
and responsibilities.

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Date Created
20130327
Year of Publication
2013

193.
Palliative care consultations for heart failure patients: how many, when, and why?.
Bakitas M; Macmartin M; Trzepkowski K; Robert A; Jackson L; Brown JR; Dionne-Odom JN;
Kono A.
[Journal Article. Research Support, N.I.H., Extramural. Research Support, Non-U.S. Gov’t]
UI: 23482081
OBJECTIVE: In preparation for development of a palliative care intervention for patients with heart failure (HF) and their caregivers, we aimed to characterize the HF population receiving palliative care consultations (PCCs).

METHODS AND RESULTS: Reviewing charts from January 2006 to April 2011, we analyzed HF patient data including demographic and clinical characteristics, Seattle Heart Failure scores, and PCCs. Using Atlas qualitative software, we conducted a content analysis of PCC notes to characterize palliative care assessment and treatment recommendations. There were 132 HF patients with PCCs, of which 37% were New York Heart Association functional class III and 50% functional class IV. Retrospectively computed Seattle Heart Failure scores predicted 1-year mortality of 29% [interquartile range (IQR) 19-45] and median life expectancy of 2.8 years [IQR 1.6-4.2] years. Of the 132 HF patients, 115 (87%) had died by the time of the audit. In that cohort the actual median time from PCC to death was 21 [IQR 3-125] days. Reasons documented for PCCs included goals of care (80%), decision making (24%), hospice referral/discussion (24%), and symptom management (8%).

CONCLUSIONS: Despite recommendations, PCCs are not being initiated until the last month of life. Earlier referral for PCC may allow for integration of a broader array of palliative care services. Copyright 2013 Elsevier Inc. All rights reserved.

INTRODUCTION: This paper investigates the qualitative and quantitative situation of palliative care medicine in Germany. The challenge of palliative care is the improvement of the quality of life of patients who are expected to die within months. In head and neck surgery most of these patients are suffering from cancer. Palliative care may incorporate symptom control and may support self-determination, including psychological, social and spiritual aspects. Treatment is not intended to cure the patients. Palliative care focuses on care of the patient and family rather than on the underlying disease.
MATERIALS AND METHODS: A databank search was performed using key words such as palliative medicine, palliative care, hospice, AAPV, SAPV and PCT.

RESULTS: The search demonstrates the restoration of quality of life as a guiding principle of palliative care in Germany. This may be achieved by symptom control and support of self-determination as well as psychosocial or spiritual support. Furthermore, relatives including children receive emotional support. A further principle is the proactive coordination of palliative procedures.

CONCLUSION: Improved legal conditions for realistic specialized ambulatory palliative care (spezialisierte ambulante Palliativversorgung, SAPV) as well as strengthening of general palliative care (allgemeine ambulante Palliativversorgung, AAPV) should be encouraged so that a sustainable palliative care net with cooperation of SAPV and AASP can be developed throughout Germany.

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Date Created
20130307
Year of Publication
2013

195.
UI: 23341407
PURPOSE: To assess, using qualitative methods, the knowledge African Canadians living in Nova Scotia have regarding their options for palliative and end-of-life (EOL) care.
DESIGN: This project engaged caregivers in a Black community in Nova Scotia, Canada, in an exploration of palliative and EOL care. A group of six caregivers who cared for someone who had died were recruited through purposive sampling. The caregivers met three times to (1) discuss their experiences, (2) receive a presentation from the palliative care service, and (3) discuss whether those services would be beneficial. This was followed by a community meeting to discuss the findings.
FINDINGS: Knowledge of options for palliative care services is limited. Family centered care may be a reason why "system" is generally not aware of the EOL experiences of African Nova Scotians.
DISCUSSION: Information about palliative care services is not filtering down to the community in a way that is meaningful to families. Families tend to self-select services that assist them in providing care in the home setting. There is a need to engage Black communities and palliative care services in developing culturally appropriate services.
[Identification of people with chronic advanced diseases and need of palliative care in sociosanitary services: elaboration of the NECPAL CCOMS-ICO tool]. [Spanish]
Gomez-Batiste X; Martinez-Munoz M; Blay C; Amblas J; Vila L; Costa X. Medicina Clinica. 140(6):241-5, 2013 Mar 16.

BACKGROUND AND OBJECTIVE: Around 75% of the population in our country will die as a consequence of chronic advanced diseases. Advanced chronic care is one of the major challenges for public health systems. This study describes the development of a tool to identify patients with advanced chronic diseases and life limited prognosis that might require some type of palliative intervention in our health and social environment.

MATERIAL AND METHODS: Spanish translation of PIG/GSF, cultural and clinical adaptation, identification of indicators of severity and progression -general and specific-; study of content validity and pre-test.

RESULTS: The NECPAL CCOMS-ICO() tool proposes a quantitative-qualitative, multifactorial, indicative and not dichotomous evaluation combining subjective perception assessment (surprise question) with demand and perceived needs; parameters of severity and progression, geriatric syndromes, emotional aspects, comorbidity and use of resources; and indicators for selected pathologies.

CONCLUSIONS: The NECPAL CCOMS-ICO() tool, feasible and easy to use, would identify patients with advanced chronic palliative needs of any cause, early and in all resources. Copyright 2012 Elsevier Espana, S.L. All rights reserved.
Patient and family members’ perceptions of palliative care in heart failure.
Metzger M; Norton SA; Quinn JR; Gramling R.
[J. Article. Research Support, N.I.H., Extramural. Research Support, Non-U.S. Gov’t]
UI: 23257236
PURPOSE: To describe patients with HF and their family members’ (FMs) experiences with, and perceptions of, inpatient PC consultations.
METHODS: 40 semi-structured interviews were completed with 24 patients with late-stage HF and/or 16 designated FMs. Content analysis was used to derive themes from the data.
RESULTS: Four main themes resulted.
PARTICIPANTS: 1) were generally ill-prepared for the PC consult; 2) pursued a plan that reflected their own understanding of patient prognosis, rather than that of the clinician; 3) described a primarily supportive role for PC; 4) often rejected or deferred PC services if they viewed hospice and PC as synonymous.
CONCLUSION: Lack of awareness of PC and the conflation of PC and hospice were barriers to PC, and many participants felt that PC services are needed to fill the gaps in their care. A collaborative model of care may best meet the complex needs of this group.Copyright 2013 Elsevier Inc. All rights reserved.
Troubles and hardships faced by psychologists in cancer care.
Iwamitsu Y; Oba A; Hirai K; Asai M; Murakami N; Matsubara M; Kizawa Y.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23300170

OBJECTIVE: The aim of this study was to identify problems experienced by psychologists involved in cancer and palliative care and consider an education system for psychologists.

METHODS: We conducted a questionnaire survey of psychologists involved in cancer care and palliative care. At the 403 facilities, 419 psychologists who received the questionnaire were asked to fill it out anonymously. A total of 294 people (61 male, 233 female, average age +/- SD = 36.3 +/- 9.4) responded about troubles and hardships actually faced by psychologists working in cancer care. We performed qualitative content analysis of free responses.

RESULTS: We obtained the following five categories: 'Hospital system', 'Psychologist role and specialization (ambiguity of the role expected of psychologists and problems arising because psychologists are not nationally licensed)', 'Collaboration with other medical professionals (problems with the method of requesting psychologist cooperation and problems of consultation and liaison work within the hospital)', 'Specialized support provided by psychologists (difficulty of interaction with patients and their families, inadequate provision of psychological support in cancer care, problems related to death care and lack of psychiatric knowledge)', 'Stress faced by psychologists (psychologist's isolation and anxiety, psychologist's internal conflicts, psychologist burnout and helplessness and psychologist self-improvement)'.

CONCLUSIONS: Psychologists must acquire at least a minimal level of medical knowledge and understanding of cancer treatment. Furthermore, they require training through specific case studies in order to facilitate collaboration with other medical professionals and concrete training in aspects of psychological support that are specifically tailored to cancer treatment through case studies.

199.
Palliative care: an approach for all internists: comment on "Early palliative care in advanced lung cancer: a qualitative study".
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[Comment. Journal Article]
UI: 23358724
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20130226
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2013
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200.
Early palliative care in advanced lung cancer: a qualitative study.
Yoong J; Park ER; Greer JA; Jackson VA; Gallagher ER; Pirl WF; Back AL; Temel JS.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23358690
BACKGROUND Early ambulatory palliative care (PC) is an emerging practice, and its key elements have not been defined. We conducted a qualitative analysis of data from a randomized controlled trial that demonstrated improved quality of life, mood, and survival in patients with newly diagnosed metastatic non-small cell lung cancer who received early PC integrated with standard oncologic care vs standard oncologic care alone. Our objectives were to (1) identify key elements of early PC clinic visits, (2) explore the timing of key elements, and (3) compare the content of PC and oncologic visit notes at the critical time points of clinical deterioration and radiographic disease progression. METHODS We randomly selected 20 patients who received early PC and survived within 4 periods: less than 3 months (n = 5), 3 to 6 months (n = 5), 6 to 12 months (n = 5), and 12 to 24 months (n = 5). We performed content analysis on PC and oncologic visit notes from the electronic health records of these patients. RESULTS Addressing symptoms and coping were the most prevalent components of the PC clinic visits. Initial visits focused on building relationships and rapport with patients and their families and on illness understanding, including prognostic awareness. Discussions about resuscitation preferences and hospice predominantly occurred during later visits. Comparing PC and oncologic care visits around critical
time points, both included discussions about symptoms and illness status; however, PC visits emphasized psychosocial elements, such as coping, whereas oncologic care visits focused on cancer treatment and management of medical complications. CONCLUSIONS Early PC clinic visits emphasize managing symptoms, strengthening coping, and cultivating illness understanding and prognostic awareness in a responsive and time-sensitive model. During critical clinical time points, PC and oncologic care visits have distinct features that suggest a key role for PC involvement and enable oncologists to focus on cancer treatment and managing medical complications.

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Date Created
20130226
Year of Publication
2013

End-of-life care in hematology: update from Australia.
McGrath P.
[Journal Article]
UI: 23438647
The purpose of this article is to provide recent findings on the perceptions and experiences about end-of-life care for individuals with a hematological malignancy. A qualitative design based on a series of open-ended interviews and one focus group was utilized to explore and document the experience of survivorship from the perspective of adult patients diagnosed with a hematological malignancy. Fifty participants (n = 26 male; n = 24 female) were interviewed representing the major hematological diagnostic groups: Multiple Myeloma, Lymphoma, and Leukemia. The interviews and focus group were recorded, transcribed verbatim, coded, and thematically analyzed. The findings presented are from the participants’ experiences with end-of-life care. The findings indicated that those fortunate enough to know about the benefits of palliative care are more likely to access palliative care during end-of-life care. However, for many hematology patients there are still problems with timely referrals to the palliative system. Within the context of an Australian research program, the findings provide a useful "snapshot" of current issues for Australian hematology patients and their families.

Status
The clinical and social dimensions of prescribing palliative home oxygen for refractory dyspnea.

Breaden K; Phillips J; Agar M; Grbich C; Abernethy AP; Currow DC.


[Journal Article]

UI: 23289922

BACKGROUND: Chronic breathlessness is a significant problem in palliative care and oxygen is often prescribed in an attempt to ameliorate it. Often, this prescription falls outside the current funding guidelines for long-term home oxygen use. The aim of this qualitative study was to understand the factors that most influence Australian specialist palliative care nurses' initiation of home oxygen for their patients.

METHODS: A series of focus groups were held across three states in Australia in 2011 involving specialist palliative care nurses. The invitation to the nurses was sent by e-mail through their national association. Recorded and transcribed data were coded for themes and subthemes. A summary, which included quotes, was provided to participants to confirm.

RESULTS: Fifty-one experienced palliative care nurses participated in seven focus groups held in three capital cities. Two major themes were identified: 1) logistic/health service issues (not reported in this paper as specific to the Australian context) involving the local context of prescribing and, 2) clinical care issues that involved assessing the patient's need for home oxygen and ongoing monitoring concerns. Palliative care nurses involved in initiating or prescribing oxygen often reported using oxygen as a second-line treatment after other interventions had been trialed and these had not provided sufficient symptomatic benefit. Safety issues were a universal concern and a person living alone did not emerge as a specific issue among the nurses interviewed.

CONCLUSION: The role of oxygen is currently seen as a second-line therapy in refractory dyspnea by specialist palliative care nurses.
This paper aims to explicate the essence of spiritual engagement from the perspective of palliative care clients and their caregivers. Van Manen's hermeneutic phenomenological approach guided this study. In-depth interviews of 14 rural Australian participants with experience of a life-limiting condition provided rich discourse of the lived experience of spiritual engagement. This research highlights spiritual engagement represented in a relational model developed from a creative synthesis of the emerging themes. Spiritual engagement is associated with 'personal transformation', 'human values of love, compassion and altruism', 'maintaining relationships', 'participating in religious practices' and 'culture'. The findings of this research are supported by Mayes' observations on spirituality, that is, the 'pursuit of a trans-personal and trans-temporal reality that serves as the ontological ground for an ethic of compassion and service'. Copyright 2013 Wiley Publishing Asia Pty Ltd.
Status MEDLINE
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Date Created 20130225
Year of Publication 2013

BACKGROUND: Patients with advanced life-limiting diseases have high information needs concerning prognosis yet discussions between patients and healthcare professionals are either avoided or inaccurate due to over-optimism. Available prognostic models are problematic. Literature indicates that hospital specialist palliative care professionals are frequently asked to prognosticate, although their experience of prognostication is unknown. Identifying this experience will support the development of prognosis training for hospital specialist palliative care professionals.

AIM: To explore hospital specialist palliative care professionals' experience of prognostication.

RESEARCH QUESTIONS: 'How do specialist palliative care team members prognosticate?'; 'How do they view prognostication?'

DESIGN: Qualitative research - focus group interviews.

SETTING/PARTICIPANTS: Three UK hospital specialist palliative care teams. Participants included medical doctors and palliative care nurses. Inclusion/exclusion criteria: member of hospital specialist palliative care team with knowledge and experience of prognostication.

Numbers of participants: four hospital specialist palliative medicine consultants, three senior doctors in training, nine clinical nurse specialists.

RESULTS: Two major themes: Difficulties of prognostication; Benefits of prognostication. Eleven sub-themes: Difficulties (Non-malignant disease; Communicating uncertainty; Seeking definitive prognosis; Participants' feelings; Confidence in prognostication; Estimating prognosis; Dealing with reaction of prognosis; Prognostic error); Benefits (Patient informed decision-making prioritizing needs and care; Family-prioritizing commitments; Services accessing funding and services planning patient care).

CONCLUSIONS: Findings highlight lack of evidence to support practice, and identify the complexity and emotional labour involved in prognostication by hospital specialist palliative care team members, and are used to discuss recommendations for further research and practice.

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2013

205.
Patient-perceived usefulness and practical obstacles of patient-held records for cancer patients in Japan: OPTIM study.
Komura K; Yamagishi A; Akizuki N; Kawagoe S; Kato M; Morita T; Eguchi K.
BACKGROUND: Although the use of a patient-held record (PHR) for cancer patients has been introduced in many settings, little is known about the role of the PHR in palliative care settings and use in Asian cultures.

AIM: This study investigated the patient-perceived usefulness and practical obstacles of using the PHR specifically designed for palliative care patients.

DESIGN: This study adopted a qualitative design based on semi-structured interviews and content analysis.

SETTING/PARTICIPANTS: Fifty cancer patients were recruited from two regions in Japan. They used the PHR for more than three months, and then were asked to participate in a face-to-face interview.

RESULTS: The content analysis revealed the following patient-perceived usefulness of the PHR: (1) increase in patient-staff communication; (2) increase in patient-family communication; (3) increase in patient-patient communication; (4) increase in understanding of medical conditions and treatments; and (5) facilitating end-of-life care discussion. The practical obstacles to using the PHR were also indicated: (1) the lack of adequate instruction about the role of the PHR; (2) undervaluing the role of the PHR and sharing information by medical professionals; (3) patients’ unwillingness to participate in decision making; (4) concerns about privacy; (5) burdensome nature of self-reporting; and (6) patients’ preference for their own ways of recording.

CONCLUSIONS: The PHR can be helpful in facilitating communication, understanding medical conditions and treatments, and facilitating end-of-life care discussion; however, for wide-spread implementation, resolving the obstacles related to both patients and health-care professionals is required.
BACKGROUND: As end-of-life (EoL) care expands across Europe and the world, service developments are increasingly studied. The sociocultural context in which such changes take place, however, is often neglected in research.

AIM: To explore sociocultural factors in EoL care in Belgium as represented by the literature.

DESIGN: A scoping of the empirical research literature following a systematic search procedure with a focus on thematic analysis based on the literature findings.

DATA SOURCES: Searches were carried out in eight electronic databases, five journals, reference lists, and grey literature (through September 2010). Articles informing about sociocultural issues in EoL care were included.

RESULTS: One hundred and fifteen original studies met the inclusion criteria, the majority (107) published between 2000 and 2010. Four major themes were: Setting; Caregivers; Communication; and Medical EoL Decisions (the largest category). Minority Ethnic Groups was an emerging theme. Gaps included: research in Wallonia and Brussels; the role and experiences of informal caregivers; issues of access to palliative care; and experiences of minority ethnic groups. There was a paucity of in-depth qualitative studies.

CONCLUSIONS: Various sociocultural factors influence the provision of EoL care in Belgium. This country provides a unique opportunity to witness how euthanasia is put into practice when legalized, in a context where palliative care is also highly developed and where many health care institutions have Catholic affiliation, providing an important example to others. Attention to how the sociocultural context affects EoL care adds to the current evidence base of service provision, which is essential in the further development of EoL care.

[Cohen, Joachim; Evans, Natalie; Menaca, Arantza; Harding, Richard; Higginson, Irene; Pool, Robert; Gysels, Marjolein; PRISMA]

[Expressing the holistic character of nursing care]. [French]
Warnet S.
[English Abstract. Journal Article]
UI: 23379097
After a nursing career focused on clinical practice, Martine Nectoux is now head of mission at the National Observatory on End of Life Care (ONFV). As such, she emphasises the nursing skills of nurses, considered as a real resource for contributing to discussions around these themes. A meeting with an inspired nurse.

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20130205
Year of Publication
2013

208.
Malignant wound management in advanced illness: new insights. [Review]
Grocott P; Gethin G; Probst S.
[Journal Article. Research Support, Non-U.S. Gov't. Review]
UI: 23254858

PURPOSE OF REVIEW: This article describes why this review is timely and relevant. To report on the recent research, which advances our understanding and practice of palliative wound care (wound-related pain and symptom management or wound palliation).

RECENT FINDINGS: This article describes the main themes in the literature covered by the article. The main themes include the problem of malodour and the palliative management of cutaneous and subcutaneous malignancy of skin and nonskin origins. The findings from an international survey of measures to combat wound malodour are reported, which indicate that malodour is one of the most distressing and difficult to manage symptoms associated with malignant wounds. A relatively novel palliative treatment for cutaneous malignancy, electrochemotherapy, is outlined, together with the growing evidence supporting its use.

SUMMARY: This article describes the implications of the findings for clinical practice or research. The findings of the wound malodour survey indicate that approaches to managing malodour are wide ranging, but ineffective. Collaborate research and development is needed with industry into interventions to combat malodour, which are based on the causal agents. The growing evidence of the effectiveness of electrochemotherapy, as an uncomplicated palliative treatment and method of managing symptoms, offers palliative care clinicians a means of managing the otherwise relentless progression of cutaneous malignancy.

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Identifying treatment burden as an important concept for end of life care in those with advanced heart failure. [Review]
Jani B; Blane D; Browne S; Montori V; May C; Shippee N; Mair FS.
[Journal Article. Research Support, Non-U.S. Gov't. Review]
UI: 23196381

PURPOSE OF REVIEW: The concept of treatment burden is receiving increasing attention and this review seeks to show that treatment burden is an important issue for end-of-life care in those with advanced heart failure.

RECENT FINDINGS: Review of the qualitative literature on patient experience of end-stage heart failure since the year 2000, including 2012, suggests that treatment burden, the work that patients have to do to manage their condition, is a readily identifiable concept in advanced heart failure. Treatment burden relates to four main areas of work, namely: coherence (sense making work) which refers to the work of developing an understanding of the illness (including its implications), treatment and management; appraisal, which refers to the work of judging, monitoring and adjusting treatments; relationship work which describes the effort put into engaging with others for support; and enacting work, that is the effort put into operationalizing treatments, which includes activities such as taking medications, attending appointments, enduring side effects of treatments and dealing with communication difficulties.

SUMMARY: Treatment burden has the potential to be an important barometer of quality of care from the patient perspective in advanced heart failure.
Quality of life from the perspective of the palliative care patient in a resource-poor community in South Africa.

Jansen van Rensburg JJ; Maree JE; van Belkum C.
[Journal Article. Research Support, Non-U.S. Gov't]

OBJECTIVE: Quality of life is an ill-defined term, as it means different things to different people. Quality of life has been well researched, especially with respect to people with cancer, but not necessarily from the perspective of the patient, and also, not in Third World, resource-poor countries. The objective of this study was to explore quality of life from the perspective of palliative care patients managed at a palliative care clinic serving a resource-poor community in Tshwane, South Africa.

METHOD: An exploratory, qualitative phenomenological study was conducted. The target population for this study was all patients managed at a palliative care clinic serving a resource-poor community in Tshwane. Self-report data were gathered by means of in-depth interviews. The data were analyzed using a template analysis style as well as content analysis using open coding. Data analysis was done concurrently with data gathering. Data saturation was reached after 10 interviews (n = 10).

RESULTS: Three themes arose from the data: factors that had a positive influence on quality of life, factors that had a negative influence on quality of life, and experience of quality of life. Work played the most important role in quality of life whereas only one participant linked symptom control with quality of life. Experiencing symptoms, rejection, and stigmatization had a negative influence on quality of life. Friends and religion played a significant role and added to quality of life.

SIGNIFICANCE OF RESULTS: Life was a daily struggle for survival. Poverty was so overwhelming that quality of life was primarily measured in terms of the ability to buy food and other basic commodities.

Cultural and religious considerations in pediatric palliative care. [Review]
OBJECTIVE: A growing multicultural society presents healthcare providers with a difficult task of providing appropriate care for individuals who have different life experiences, beliefs, value systems, religions, languages, and notions of healthcare. This is especially vital when end-of-life care is needed during childhood. There is a dearth of literature addressing cultural considerations in the pediatric palliative care field. As members of a specific culture often do not ascribe to the same religious traditions, the purpose of this article was to explore and review how culture and religion informs and shapes pediatric palliative care.

METHOD: Comprehensive literature searches were completed through an online search of nine databases for articles published between 1980 and 2011: PsychINFO, MEDLINE, Journal of Citation Reports-Science Edition, Embase, Scopus, CINAHL, Social Sciences Citation Index (SSCI), EBSCO, and Ovid. Key terms included: culture, transcultural, spiritual, international, ethnic, customs or religion AND end-of-life, palliative care, death, dying, cancer, or hospice, and children, pediatrics, or pediatric oncology. Reference lists in the retrieved articles were examined for additional studies that fit the inclusion criteria, and relevant articles were included for review. In addition, web-based searches of specific journals were conducted. These included, but were not limited to: Qualitative Health Research, Psycho-Oncology, Journal of Psychosocial Oncology, Journal of Pediatric Psychology, Journal of Pediatric Health Care, Journal of Pediatric Oncology Nursing, Omega, Social Work in Health Care, and Journal of Palliative Medicine.

RESULTS: Thirty-seven articles met eligibility criteria. From these, seven distinct themes emerged that have implications for pediatric palliative care. These include the role of culture in decision-making, faith and the involvement of clergy, communication (spoken and unspoken language), communicating to children about death (truth telling), the meaning of pain and suffering, the meaning of death and dying, and location of end-of-life care.

SIGNIFICANCE OF RESULTS: The review of the literature provides insight into the influence of religion and how culture informs lifestyle and shapes the experiences of illness, pain, and end-of-life care. Recommendations for providing culturally sensitive end-of-life care are offered through the framework outlined in the Initiative for Pediatric Palliative Care Quality Improvement Project of 2002. Cultural traditions are dynamic, never static, and cannot be generalized to all families. Guidelines to aid in approaches to palliative care are provided, and providers are encouraged to define these important differences for each family under their care.

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Date Created
20130130
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2013
Oral health perceptions of paediatric palliative care nursing staff.

Couch E; Mead JM; Walsh MM.


[Journal Article]

UI: 23354428

Systematic oral care reduces oral complications among children in paediatric palliative care (PPC), yet little is known about the oral health perceptions of PPC nursing staff. This qualitative cross-sectional study used semi-structured interviews based on phenomenography to explore PPC nursing staff’s perceptions of oral health and the relationship of oral care to comfort and quality of life. A purposive sample of nine nursing staff employed at a California PPC facility participated. Five themes emerged from the analysis of the interviews: signs of oral health, reasons for oral care, adaptation of oral care on a case-by-case basis, barriers to providing oral care, and facilitators of improving oral care. The perceived importance of oral health was the underlining similarity between the themes. A need for further research in the area of oral PPC is indicated. Collaboration with dental professionals may be needed to create oral PPC guidelines that fit the complex needs of children with life-limiting illnesses.

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Date Created
20130128

Year of Publication
2013

AIM: To work with service users and providers to optimise the design and implementation of handover forms to support the transfer of information between daytime and out-of-hours primary care services for patients with palliative care needs.
BACKGROUND: There is a need for improved informational continuity between daytime and out-of-hours primary care services for patients with palliative care needs. Research suggests that while handover forms are vital to ensure continuity of care, they remain underused for such patients. Audit work in an out-of-hours primary care service in South West England identified that their current system of handover forms was underused.

METHODS: An action research study consisting of two phases was undertaken. In phase one, the views of general practitioners and nurses working in the out-of-hours and daytime primary care services (29 health professionals) in Devon (population c.1.4 million) and patients with palliative care needs and their carers (8 participants) were investigated using qualitative interviews and focus group methods. Participants' views on the content and use of handover forms, and of the systems supporting their generation were sought. In phase two, additional feedback from the health professional stakeholder groups was collected and collaborative work undertaken with the out-of-hours service to implement recommendations emerging from the qualitative research. Findings Respondents identified variable use of handover forms and inconsistent practice in terms of: who was responsible for generating and updating forms; when and where they were discussed in primary care; the criteria used to define which patient needed a form; and the information forms should contain. There was uncertainty about how handover forms were used by the out-of-hours service and concerns about incomplete access to forms for certain groups of staff. An action plan to improve the existing system was developed. This included distribution of educational materials (desktop guide, newsletter) to key stakeholders, and the modification of information systems to facilitate the updating of messages and the accessibility of electronic records for previously under-served staff.

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Date Created
20130121
Year of Publication
2013

214.
Translation and cross-cultural adaptation of a family booklet on comfort care in dementia: sensitive topics revised before implementation.
van der Steen JT; Hertogh CM; de Graas T; Nakanishi M; Toscani F; Arcand M.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23144015
INTRODUCTION: Families of patients with dementia may need support in difficult end-of-life decision making. Such guidance may be culturally sensitive.
METHODS: To support families in Canada, a booklet was developed to aid decision making on palliative care issues. For reasons of cost effectiveness and promising effects, we prepared for its implementation in Italy, the Netherlands and Japan. Local teams translated and adapted the booklet to local ethical, legal and medical standards where needed, retaining guidance on palliative care. Using qualitative content analyses, we grouped and compared adaptations to understand culturally sensitive aspects.

RESULTS: Three themes emerged: (1) relationships among patient, physician and other professionals—the authority of the physician was more explicit in adapted versions; (2) patient rights and family position—adding detail about local regulations; and (3) typology of treatments and decisions. Considerations underlying palliative care decisions were detailed (Dutch and Italian versions), and the Japanese version frequently referred to professional and legal standards, and life-prolongation was a competing goal. Text on artificial feeding or fluids and euthanasia was revised extensively.

CONCLUSIONS: Providing artificial feeding and fluids and discussing euthanasia may be particularly sensitive topics, and guidance on these subjects needs careful consideration of ethical aspects and possible adaptations to local standards and practice. The findings may promote cross-national debate on sensitive, core issues regarding end-of-life care in dementia.

status

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Date Created
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Year of Publication
2013

215.
The needs of professionals in the palliative care of children and adolescents.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23207735

UNLABELLED: The main objectives of this qualitative study were to describe the perceptions and needs of pediatric health care professionals (HCPs) taking care of children with palliative care needs and to develop a concept for the first Center of Competence for Pediatric Palliative Care (PPC) in Switzerland. Within two parts of the study, 76 HCPs were interviewed. The main interview topics were: (1) definition of and attitude toward PPC; (2) current provision of PPC; (3) the support needs of HCPs in the provision of PPC; and (4) the role of specialized PPC teams.
HCPs expressed openness to PPC and reported distinctive needs for support in the care of these patients. The main tasks of specialized PPC teams in Switzerland would encompass the coaching of attending teams, coordination of care, symptom control, and direct support of affected families during and beyond the illness of their child.

CONCLUSION: This study indicates the need for specialized PPC in Switzerland both inside and outside of centers providing top quality medical care (Spitzenmedizin). Specialized PPC teams could have a significant impact on the care of children and families with PPC needs. Whether hospices are an option in Switzerland remains unanswered; however, a place to meet other families with similar destinies was emphasized.

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20130114
Year of Publication
2013

216.
Barriers to the detection and management of depression by palliative care professional carers among their patients: perspectives from professional carers and patients' family members. Mellor D; McCabe MP; Davison TE; Goldhammer DL; Halford DJ. American Journal of Hospice & Palliative Medicine. 30(1):12-20, 2013 Feb. [Journal Article. Research Support, Non-U.S. Gov't]
UI: 22389189

INTRODUCTION: Clinical depression is highly prevalent yet underdetected and poorly managed within palliative care settings.

OBJECTIVES: This qualitative study explored the identification, monitoring, and management of symptoms of depression in patients receiving palliative care from 2 juxtaposed perspectives that are of care providers and care recipients' family members. Examining the barriers that restrict professional carers detecting and managing depression in their patients was a central focus of the study.

METHODS: Focus groups were held with 18 professional carers, including 8 holding managerial positions, across 2 palliative care services, 1 regional and 1 metropolitan, which provided both inpatient and community-based care. Individual interviews were conducted with 10 family members of patients who had received or were receiving palliative care through these services.
RESULTS: Thematic analysis of these data identified that both professional carers and family members perceived that depression is a wide-spread concern for patients receiving palliative care; however, numerous barriers were identified that affect professional carers' ability to identify depression. These included knowledge and training deficits, low self-efficacy, prioritization of physical concerns and time constraints, patient/family characteristics, and system/process issues. These themes (and related subthemes) are discussed in this article.

CONCLUSIONS: Specialized training in depression is recommended for professional carers in order to improve their depression-related knowledge, detection skills, and self-efficacy. The ultimate goal of such training is to increase the rate of recognition of depression that in turn will lead to appropriate treatment for depressed patients.

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Date Created
20121228
Year of Publication
2013

217.
A new model for breaking bad news to people with intellectual disabilities.
Tuffrey-Wijne I.
Palliative Medicine. 27(1):5-12, 2013 Jan.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 22249925
OBJECTIVES: To develop a model for breaking bad news that meets the needs of people with intellectual disabilities (IDs).
DESIGN: A two-phase qualitative study featuring: (I) focus group meetings, on-line focus groups and one-to-one interviews; (II) structured feedback from participants and other stakeholders.
SETTING: Participants were drawn from National Health Service hospitals, Primary Care Trusts, independent organisations and on-line forums across England.
PARTICIPANTS: 109 participants were purposively selected: 21 people with mild/moderate IDs, 28 family carers, 26 ID professionals and 34 general health professionals.
OUTCOME MEASURE: Feedback on a preliminary model for breaking bad news to people with IDs was collected from 60 participants and other stakeholders to assess relevance and acceptability, before the model was finalised.
RESULTS: Breaking bad news is best seen as a process, not an event or a linear series of events. Bad news situations usually constitute a wide range of discrete items or chunks of information. 'Building a foundation of knowledge' is central to the model. Information needs to be broken down into singular chunks of knowledge that can be added over time to people's existing
framework of knowledge. Three other aspects should be considered at all times: capacity, people and support.

CONCLUSIONS: Patients who have IDs do not easily process verbal information in a clinical setting. The new model for breaking bad news to people with IDs needs to be tested in practice using robust outcome measures. The model's relevance to wider patient groups should also be evaluated.

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218.
Best interests at end of life: an updated review of decisions made by the Consent and Capacity Board of Ontario. [Review]
Chidwick P; Sibbald R; Hawryluck L.
[Consensus Development Conference. Journal Article. Review]
UI: 23228726
PURPOSE: To increase our understanding of the notion of "best interests" in end of life disagreements through an updated review of decisions made by the Consent and Capacity Board of Ontario. There was a significant increase (235%) in decisions from this tribunal between 2009 and 2011. "Best interests" test is used when no prior expressed wishes are known to the surrogate decision-makers.
METHODS: Purposively sampled written decisions of the Consent and Capacity Board of Ontario between 2003 and 2011 that focused on the "best interests" of patients at the end of life. Interpretive content analysis was performed independently by 3 reviewers, and themes were identified by consensus.
RESULTS: We found substitute decision makers (SDMs) rely on an appeal to their own values or religion in their interpretation of best interests; physicians rely on clinical conditions; board emphasizes alignment with Health Care Consent Act. In the more recent cases, we found that SDMs report that patients value suffering; that SDMs have unrealistic hope for recovery and can communicate and get direction from the incapable patient; that SDMs need education on their role and responsibility as SDM; and that SDMs need time to provide consent, and that most proposed treatment plans that were sources of conflict included "palliative care."
INTERPRETATION: Several lessons are drawn for the benefit of health care teams engaged in disagreements at end of life with SDMs over the best interests of patients.

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Status
219.
Narratives of 'terminal sedation', and the importance of the intention-foresight distinction in palliative care practice.
Douglas CD;  Kerridge IH;  Ankeny RA.
[Journal Article]
UI: 21726263
The moral importance of the 'intention-foresight' distinction has long been a matter of philosophical controversy, particularly in the context of end-of-life care. Previous empirical research in Australia has suggested that general physicians and surgeons may use analgesic or sedative infusions with ambiguous intentions, their actions sometimes approximating 'slow euthanasia'. In this paper, we report findings from a qualitative study of 18 Australian palliative care medical specialists, using in-depth interviews to address the use of sedation at the end of life. The majority of subjects were agnostic or atheistic. In contrast to their colleagues in acute medical practice, these Australian palliative care specialists were almost unanimously committed to distinguishing their actions from euthanasia. This commitment appeared to arise principally from the need to maintain a clear professional role, and not obviously from an ideological opposition to euthanasia. While some respondents acknowledged that there are difficult cases that require considered reflection upon one's intention, and where there may be some 'mental gymnastics,' the nearly unanimous view was that it is important, even in these difficult cases, to cultivate an intention that focuses exclusively on the relief of symptoms. We present four narratives of 'terminal' sedation--cases where sedation was administered in significant doses just before death, and may well have hastened death. Considerable ambiguities of intention were evident in some instances, but the discussion around these clearly exceptional cases illustrates the importance of intention to palliative care specialists in maintaining their professional roles. Copyright 2011 Blackwell Publishing Ltd.
220.
The psychological experience of hospice workers during encounters with death.
DeArmond IM.
[Journal Article]
UI: 23785981
While the nature of their experience is unknown, hospice workers may unconsciously strive for
encounters with death as a way of healing themselves and preparing for death. The purpose of
this case study was to explore the psychological experience of hospice workers, whose repeated
encounters with death may affect their own psyche. The study integrated psychobiographical and
hermeneutic methods. Personal growth was conceptually defined as a process of turning inward
and integration of personal experiences into a larger reality. The elements supporting personal
growth were present in 53 to 88% of the 17 hospice workers of the sample. The emerging themes
were interconnectedness, suffering and sacrifice, and birth and rebirth. Caring to the dying
becomes practice for one's own death and a form of renewal in the life of the hospice workers.
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2012
<td colspan=""">
AIMS: The study reported here formed part of a larger study that explored the experiences of health-care workers providing palliative care in patients' homes in rural South Africa. This paper hones in on the experiences of male caregivers. Zulu culture has been strongly patriarchal and the gender of a caregiver may affect both patients' and caregivers' experiences.

METHODS: The study was exploratory, qualitative, and combined a visual methodology with unstructured interviews. The setting was a hospice and three home-based care organisations in rural KwaZulu-Natal, South Africa. Participants were a male Zulu nurse and two male informal home-based caregivers who have been trained in components of palliative care.

RESULTS: These male caregivers appeared to care deeply and altruistically for their patients and appeared to provide gender-appropriate care for male patients. Female patients were wary of being cared for by a man, for example having concerns that male caregivers may perpetrate physical abuse, including rape. Thus, challenges of being a male caregiver included the potential to not be appreciated by and/or to be subject to physical and verbal abuse from the community they serve.

CONCLUSIONS: This study contests South African literature that presents male caregivers in a negative way. It emphasises a need to value and support male caregivers. The challenges faced by male caregivers are largely unexplored and further research is required as men could potentially play a valuable part in providing palliative care in rural homes.

222. Treatment outcomes in palliative care: the TOPCare study. A mixed methods phase III randomised controlled trial to assess the effectiveness of a nurse-led palliative care intervention for HIV positive patients on antiretroviral therapy.
Lowther K; Simms V; Selman L; Sherr L; Gwyther L; Kariuki H; Ahmed A; Ali Z; Jenkins R; Higginson IJ; Harding R.
[Clinical Trial, Phase III. Journal Article. Randomized Controlled Trial. Research Support, Non-U.S. Gov't]
UI: 23130740

BACKGROUND: Patients with HIV/AIDS on Antiretroviral Therapy (ART) suffer from physical, psychological and spiritual problems. Despite international policy explicitly stating that a multidimensional approach such as palliative care should be delivered throughout the disease...
trajectory and alongside treatment, the effectiveness of this approach has not been tested in ART-experienced populations.

METHODS/DESIGN: This mixed methods study uses a Randomised Controlled Trial (RCT) to test the null hypothesis that receipt of palliative care in addition to standard HIV care does not affect pain compared to standard care alone. An additional qualitative component will explore the mechanism of action and participant experience. The sample size is designed to detect a statistically significant decrease in reported pain, determined by a two tailed test and a p value of <0.05. Recruited patients will be adults on ART for more than one month, who report significant pain or symptoms which have lasted for more than two weeks (as measured by the African Palliative Care Association (APCA) African Palliative Outcome Scale (POS)). The intervention under trial is palliative care delivered by an existing HIV facility nurse trained to a set standard. Following an initial pilot the study will be delivered in two African countries, using two parallel independent Phase III clinical RCTs. Qualitative data will be collected from semi structured interviews and documentation from clinical encounters, to explore the experience of receiving palliative care in this context.

DISCUSSION: The data provided by this study will provide evidence to inform the improvement of outcomes for people living with HIV and on ART in Africa. ClinicalTrials.gov Identifier: NCT01608802.

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20130108

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2012

GPs’ views concerning spirituality and the use of the FICA tool in palliative care in Flanders: a qualitative study.

Vermandere M; Choi YN; De Brabandere H; Decouttere R; De Meyere E; Gheysens E; Nickmans B; Schouteten M; Seghers L; Truijens J; Vandenberghhe S; Van de Wiele S; Van Oevelen LA; Aertgeerts B.


UI: 23265232
BACKGROUND: According to recent recommendations, healthcare professionals in palliative care should be able to perform a spiritual history-taking. Previous findings suggest that the FICA tool is feasible for the clinical assessment of spirituality. However, little is known about the views of GPs on the use of this tool.

AIM: To provide a solid overview of the views of Flemish GPs concerning spirituality and the use of the FICA tool for spiritual history-taking in palliative care.

DESIGN AND SETTING: Qualitative interview study in Flanders, Belgium.

METHOD: Twenty-three GPs participated in a semi-structured interview. The interviews were analysed by thematic analysis, which includes line-by-line coding and the generation of descriptive and analytical themes.

RESULTS: The interviewees stated that they would keep in mind the questions of the FICA tool while having a spiritual conversation, but not use them as a checklist. The content of the tool was generally appreciated as relevant, however, many GPs found the tool too structured and prescribed, and that it limited their spontaneity. They suggested rephrasing the questions into spoken language. The perceived barriers during spiritual conversations included feelings of discomfort and fear, and the lack of time and specific training. Factors that facilitated spiritual conversations included the patients' acceptance of their diagnosis, a trusting relationship, and respect for the patients' beliefs.

CONCLUSION: A palliative care process with attention focused on the patient's spirituality was generally perceived as a tough but rewarding experience. The study concludes that the FICA tool could be a feasible instrument for the clinical assessment of spirituality, provided that certain substantive and linguistic adjustments are made. Additional research is needed to find the most suitable model for spiritual history-taking, in response to the specific needs of GPs.

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Choi, Yoo-Na; De Brabandere, Heleen; Decouttere, Ruth; De Meyere, Evelien; Gheysens, Elien; Nickmans, Brecht; Schouteten, Melanie; Seghers, Lynn; Truijens, Joachim; Vandenberghe, Stien; Van de Wiele, Sofie; Van Oevelen, Laure-Anne; Aertgeerts, Bert.

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Year of Publication
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Palliative and therapeutic harmonization: a model for appropriate decision-making in frail older adults.
Moorhouse P; Mallery LH.
Frail older adults face increasingly complex decisions regarding medical care. The Palliative and Therapeutic Harmonization (PATH) model provides a structured approach that places frailty at the forefront of medical and surgical decision-making in older adults. Preliminary data from the first 150 individuals completing the PATH program shows that the population served is frail (mean Clinical Frailty Score = 6.3), has multiple comorbidities (mean 8), and takes many medications (mean = 9). Ninety-two percent of participants were able to complete decision-making for an average of three current or projected health issues, most often (76.7%) with the help of a substitute decision-maker (SDM). Decisions to proceed with scheduled medical or surgical interventions correlated with baseline frailty level and dementia stage, with participants with a greater degree of frailty (odds ratio (OR) = 3.41, 95% confidence interval (CI) = 1.39-8.38) or more-advanced stage of dementia (OR = 1.66, 95% CI = 1.06-2.65) being more likely to choose less-aggressive treatment options. Although the PATH model is in the development stage, further evaluation is ongoing, including a qualitative analysis of the SDM experience of PATH and an assessment of the effectiveness of PATH in long-term care. The results of these studies will inform the design of a larger randomized controlled trial. 2012, Copyright the Authors Journal compilation  2012, The American Geriatrics Society.

Procedure versus process: ethical paradigms and the conduct of qualitative research.
Pollock K.
[Journal Article]
UI: 23016663
BACKGROUND: Research is fundamental to improving the quality of health care. The need for regulation of research is clear. However, the bureaucratic complexity of research governance has raised concerns that the regulatory mechanisms intended to protect participants now threaten to undermine or stifle the research enterprise, especially as this relates to sensitive topics and hard to reach groups.
DISCUSSION: Much criticism of research governance has focused on long delays in obtaining ethical approvals, restrictions imposed on study conduct, and the inappropriateness of evaluating qualitative studies within the methodological and risk assessment frameworks applied to biomedical and clinical research. Less attention has been given to the different epistemologies underlying biomedical and qualitative investigation. The bioethical framework underpinning current regulatory structures is fundamentally at odds with the practice of emergent, negotiated micro-ethics required in qualitative research. The complex and shifting nature of real world settings delivers unanticipated ethical issues and (occasionally) genuine dilemmas which go beyond easy or formulaic 'procedural' resolution. This is not to say that qualitative studies are 'unethical' but that their ethical nature can only be safeguarded through the practice of 'micro-ethics' based on the judgement and integrity of researchers in the field.

SUMMARY: This paper considers the implications of contrasting ethical paradigms for the conduct of qualitative research and the value of 'empirical ethics' as a means of liberating qualitative (and other) research from an outmoded and unduly restrictive research governance framework based on abstract principialism, divorced from real world contexts and values.

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Considerations in developing and delivering a nonpharmacological intervention for symptom management in lung cancer: the views of patients and informal caregivers.
Ellis J; Wagland R; Tishelman C; Williams ML; Bailey CD; Haines J; Caress A; Lorigan P; Smith JA; Booton R; Blackhall F; Molassiotis A.
[Clinical Trial. Journal Article. Research Support, Non-U.S. Gov't]
UI: 22672922
CONTEX: Few studies consider patient's and caregiver's preferences when developing nonpharmacological interventions. This is important to develop acceptable and accessible nonpharmacological interventions for patients with cancer.
OBJECTIVES: The objective of this study was to identify the views of patients with lung cancer and their informal caregivers on the desirable components of a novel nonpharmacological intervention for the management of the symptom cluster of cough, breathlessness, and fatigue, and their needs and preferences regarding uptake and delivery of the intervention.
METHODS: This study was qualitative in orientation, using semistructured interviews and framework analysis to elicit the views of 37 patients with lung cancer and 23 caregivers regarding the issues that were perceived to be important regarding the development and delivery of a nonpharmacological intervention.

RESULTS: A number of key issues were identified that carried important implications for patient participation and adherence to the intervention, including the perceived relevance of potential techniques; appreciable benefits in the short term; convenience; variation in patient preferences; timing of the intervention; venue; caregiver involvement; the provider of the intervention, and contact with other patients.

CONCLUSION: The data from this study have provided insight into the key issues that are likely to influence the development, uptake, and delivery of a nonpharmacological intervention to help manage the respiratory symptom cluster of cough, breathlessness, and fatigue. It is crucial that these findings are considered when developing and modeling a nonpharmacological symptom management intervention. Copyright 2012 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Performance and palliative care: a drama module for medical students.
Jeffrey EJ; Goddard J; Jeffrey D.
[Journal Article]
UI: 22977064
This paper describes an innovative 2 weeks module for medical students facilitated by drama educators and a palliative medicine doctor. The module incorporates drama, end-of-life care, teamwork and reflective practice. The module contents, practical aspects of drama teaching and learning outcomes are discussed. Various themes emerged from a study of Harold Pinter's play, The Caretaker, which were relevant to clinical practice: silence, power, communication, uncertainty and unanswered questions. Drama teaching may be one way of enhancing students' confidence, increasing self-awareness, developing ethical thinking and fostering teamwork.
Informing social work practice through research with parent caregivers of a child with a life-limiting illness.
Cadell S; Kennedy K; Hemsworth D.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23194170
Pediatric palliative care is an evolving field of practice in social work. As such, research plays a critical role in informing best social work practices in this area. For parents, caring for a child with a life-limiting illness (LLI) is a stressful experience that compounds the usual challenges of parenting. The negative aspects of caring for a child with an LLI are well documented. In the face of such adversity, parent caregivers can also experience positive changes caring for children with even the most serious conditions. This article presents results from a research study of posttraumatic growth in parents who are caring for a child with a LLI. Using mixed methods, two overarching themes were prominent in both the quantitative and qualitative data. The first describes stress related to financial burden associated with caregiving. The second theme concerns the posttraumatic growth experienced by the parent caregivers. The quantitative and qualitative data have been woven together to underscore issues and parental perspectives related to these two themes. This provides a unique and important platform for parent caregivers' experiences that can inform the work of social workers and other pediatric palliative care professionals.
Bereaved parents' perspectives on pediatric palliative care.
Robert R; Zhukovsky DS; Mauricio R; Gilmore K; Morrison S; Palos GR.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23194168
This study's goal was to describe and begin to understand the experience of bereaved parents whose deceased child had received pediatric oncology services at a tertiary comprehensive cancer center. Focus groups were conducted with parents whose children were age 10 years and older at the time of death. Potential participants were contacted by mail and telephone. Sessions were audiotaped and transcribed verbatim. The ATLAS.ti qualitative software program was used to identify and analyze dominant themes. Fourteen parents identified four major themes: standards of care, emotional care, communication, and social support. Bereaved parents discussed the challenges associated with institutional procedures and interpersonal aspects of care in anticipation of and following their child's death. The results of these personal narratives may be used to guide care plans and deliver pediatric palliative and end-of-life interventions.

230.
Team collaboration in pediatric palliative care. [Review]
Remke SS; Schermer MM.
[Journal Article. Review]
UI: 23194166
This article explores themes related to team development in pediatric palliative care. A review of the literature, observations from the field, and an analysis of dynamics from the point of view of
the social work knowledge base are included. Recommendations for team development and sustainability are shared.

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Year of Publication
2012

231.
Using observation as a data collection method to help understand patient and professional roles and actions in palliative care settings. [Review]
Walshe C; Ewing G; Griffiths J.
[Journal Article. Research Support, Non-U.S. Gov't. Review]
UI: 22179595
BACKGROUND: Observational research methods are important for understanding people's actions, roles and behaviour. However, these techniques are underused generally in healthcare research, including research in the palliative care field.
AIM: The aim in this paper is to place qualitative observational data collection methods in their methodological context and provide an overview of issues to consider when using observation as a method of data collection. This paper discusses practical considerations when conducting palliative care research using observation.
FINDINGS: Observational data collection methods span research paradigms, and qualitative approaches contribute by their focus on 'natural' settings which allow the explanation of social processes and phenomena. In particular, they can facilitate understanding of what people do and how these can alter in response to situations and over time, especially where people find their own practice difficult to articulate. Observational studies can be challenging to carry out: we focus on the potentially problematic areas of sampling, consent and ethics, data collection and recording, data management and analysis.
CONCLUSION: Qualitative observational data collection methods can contribute to theoretical and conceptual development and the explanation of social processes in palliative care. In particular this contribution to understanding care structures and processes should improve understanding of patients' experiences of their care journey and thus impact on care outcomes.

Status
MEDLINE
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Ewing, Gail; Griffiths, Jane.
Qualitative evaluation of a problem-solving intervention for informal hospice caregivers.
Washington KT; Demiris G; Parker Oliver D; Wittenberg-Lyles E; Crumb E.
UI: 22075164

BACKGROUND: Informal hospice caregivers may experience compromised well-being as a result of significant stress. Although quite limited, problem-solving interventions with this population have garnered empirical support for improved caregiver well-being.

AIM: Researchers sought to answer the following question: which specific intervention processes impacted informal hospice caregivers who participated in a problem-solving intervention?

DESIGN: Researchers conducted a thematic analysis of open-ended exit interviews with informal hospice caregivers who had participated in a structured problem-solving intervention.

SETTING/PARTICIPANTS: Participants were friends and family members who provided unpaid care for a home hospice patient receiving services from one of two hospice agencies located in the Pacific Northwest region of the United States.

RESULTS: During their participation in the problem-solving intervention, caregivers actively reflected on caregiving, structured problem-solving efforts, partnered with interventionists, resolved problems, and gained confidence and control.

CONCLUSIONS: The study findings provide much needed depth to the field’s understanding of problem-solving interventions for informal hospice caregivers and can be used to enhance existing support services.
What is the role of specialist palliative care in an acute hospital setting? A qualitative study exploring views of patients and carers.

Yang GM; Ewing G; Booth S.


[Journal Article. Research Support, Non-U.S. Gov't]

UI: 22005106

BACKGROUND: Since the medical specialty of palliative medicine was recognized in 1988, the role of hospital specialist palliative care services has been developing, extending to patients who have a life-limiting illness but are not in the terminal phase.

AIM: This qualitative study aims to explore patient and carer perspectives of the role of palliative care in the acute hospital setting, with patients not imminently dying.

DESIGN: Semi-structured interviews with 12 patients and 10 carers. Data were analysed using framework analysis.

SETTING/PARTICIPANTS: Patients recruited were adults who had palliative care input for symptom control or psychological support and were discharged either to general ward care or to home. The family member/friend designated as their carer was also approached to take part.

RESULTS: All patients in this study were treated in an acute hospital, described as a bewildering and pressured environment of care. Initial perceptions of palliative care were varied, some interpreting referral as an indication that they were approaching the end of life. However, after palliative care input, patients and carers developed an understanding of their role which they saw as three-fold: physical symptom control, psychological support and a reliable liaison. The theme of cross-cutting interviews was that the palliative care team made time for patients, giving them a sense of value and worth. Feeling their care was a priority and being listened to made palliative care input effective.

CONCLUSIONS: These findings will aid continuing development and evaluation of palliative care teams, in the domains of effectiveness as well as patient experience.
Establishing hospice care for prison populations: An integrative review assessing the UK and USA perspective. [Review]
Stone K; Papadopoulos I; Kelly D.
[Journal Article. Review]
UI: 21993807

BACKGROUND: models of care based on the hospice model have delivered effective support to dying people since their inception. Over the last 20 years this form of care has also been introduced into the prison system (mainly in the United States) to afford terminally ill inmates the right to die with dignity.

AIM: the aim of this review is to examine the evidence from the United States and the United Kingdom on the promotion of palliative care in the prison sector, summarizing examples of good practice and identifying barriers for the provision of end-of-life care within the prison environment both in the USA and UK.

DESIGN: an integrative review design was adopted using the Green et al. model incorporating theoretical and scientific lines of enquiry.

DATA SOURCES: literature was sourced from six electronic databases between the years 2000 and 2011; the search rendered both qualitative and quantitative papers, discussion papers, ‘grey literature’ and other review articles.

RESULTS: the results highlight a number of issues surrounding the implementation of palliative care services within the prison setting and emphasize the disparity between the USA model of care (which emphasizes the in-prison hospice) and the UK model of care (which emphasizes palliative care in-reach) for dying prisoners.

CONCLUSION: the provision of palliative care for the increasing prison population remains under-researched globally, with a notable lack of evidence from the United Kingdom.

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Year of Publication
2012

Reliability and validity of the Thai translation (Thai PPS Adult Suandok) of the Palliative Performance Scale (PPSv2).
Chewaskulyong B; Sapinun L; Downing GM; Intaratat P; Lesperance M; Leautarakul S; Somwangprasert A; Leerapun T.
PURPOSE: the Thai PPS Adult Suandok tool was translated from the Palliative Performance Scale (PPSv2) and had been used in Chiang Mai, Thailand for several years.
AIM: to test the reliability and validity of the Thai translation of PPSv2.
DESIGN: a set of 22 palliative cases were used to determine a PPS score on Time-1, and repeated two weeks later as Time-2. A survey questionnaire was also completed for qualitative analysis.
PARTICIPANTS: a total of 70 nurses and physicians from Maharaj Nakorn Hospital in Chiang Mai participated.
RESULTS: The Time-1 intraclass correlation coefficient (ICC) for absolute agreement is 0.911 (95% CI 0.86-0.96) and for consistency is 0.92 (95% CI 0.87-0.96). The Time-2 ICC for agreement is 0.905 (95% CI 0.85-0.95) and for consistency is 0.912 (95% CI 0.86-0.96). These findings indicate good agreement among participants and also were somewhat higher in the Time-2 re-test phase. Cohen's kappa score is 0.55, demonstrating a moderate agreement.
Thematic analysis from the surveys showed that 91% felt PPS to be a valuable clinical tool overall, with it being 'very useful' or 'useful' in several areas, including care planning (78% and 20%), disease monitoring (69% and 27%) and prognostication (61% and 31%), respectively. Some respondents noted difficulty in determining appropriate scores in paraplegic patients or those with feeding tubes, while others found the instructions long or difficult.
CONCLUSION: the Thai PPS Adult Suandok translated tool has good inter- and intra-rater reliability and can be used regularly for clinical care.
Continuous sedation until death (CSD), the act of reducing or removing the consciousness of an incurably ill patient until death, often provokes medical-ethical discussions in the opinion sections of medical and nursing journals. Some argue that CSD is morally equivalent to physician-assisted death (PAD), that it is a form of "slow euthanasia." A qualitative thematic content analysis of opinion pieces was conducted to describe and classify arguments that support or reject a moral difference between CSD and PAD. Arguments pro and contra a moral difference refer basically to the same ambiguous themes, namely intention, proportionality, withholding artificial nutrition and hydration, and removing consciousness. This demonstrates that the debate is first and foremost a semantic rather than a factual dispute, focusing on the normative framework of CSD. Given the prevalent ambiguity, the debate on CSD appears to be a classical symbolic struggle for moral authority.

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20121126
Year of Publication
2012

237.
Follow-up evaluation of a course to develop effective communication and relationship skills for palliative care.
Andrew J; Taylor C.
[Evaluation Studies. Journal Article]
UI: 23180499
This paper reports on a longitudinal follow-up evaluation of an interprofessional experiential course to support the development of effective communication and interpersonal relationship skills in palliative care: 'It's good to listen: advanced communication skills in end of life care'. The course was developed from evidence-based guidance produced by the West of Scotland Cancer Network and NHS Education for Scotland in 2009. The aim of the study was to explore the factors that support or hinder the sustainable integration of skills and learning from the course into clinical practice. Three focus groups were held across the NHS Board area. Following analysis of the transcripts the emergent themes were grouped under four headings; impact on practice, facilitating factors, hindering factors, and organisational issues. The findings suggest that organisations should consider the value they place on supporting interpersonal skills in end-of-life care and how they can enhance sustainability and behavioural change.
Status

AIMS: This paper provides an overview of 80 papers on research into spiritual care in nursing between 2006 and 2010, to enable nurses and nurse managers to make use of evidence available to them to improve quality of care and implement best practice.

BACKGROUND: Research into spiritual care has grown rapidly since a review of the field in 2006.

EVALUATION: The CINAHL database was used to search for 'spirituality' OR 'spiritual care' AND 'nursing, looking for original research papers involving health-care practitioners.

KEY ISSUES: Research is discussed in the following themes: nursing education; care of health-care practitioners, including nurses; descriptive and correlational research; assessment tools used in research; palliative care and oncology; culture and spiritual care research. Future research should take into account the risks of research that does not involve patients and the need for research that is translatable into contexts other than the setting under study.

IMPLICATIONS FOR NURSING MANAGEMENT: Spiritual care research has implications for staff training and education, staff motivation and health, organisational culture, best practice, quality of care and, most importantly, for the health of patients. Nurse managers, and indeed all involved in management of nursing, should use this growing body of evidence to inform their spiritual care training, planning and delivery. Copyright 2012 Blackwell Publishing Ltd.
239.  
Case conferences in palliative care - a substudy of a cluster randomised controlled trial. 
Shelby-James TM; Butow P; Davison G; Currow DC. 
[Journal Article. Randomized Controlled Trial. Research Support, Non-U.S. Gov't] 
UI: 23145404 
BACKGROUND: In palliative care, case conferences have demonstrated improved maintenance 
of function and a significant reduction in hospitalisations. This study aimed to define the content 
and themes of palliative care case conferences. 
METHODS: This was a substudy of a cluster randomised controlled trial. Case conferences 
meeting the requirements for Medicare Benefits Schedule reimbursement were organised by the 
research officer in conjunction with the general practitioner and the participating palliative care 
service. All were audiotaped, coded and analysed for content and themes, using qualitative 
methods and interaction analysis. 
RESULTS: Seventeen case conferences were transcribed and coded. Physical issues were the 
dominant topic. Management of psychosocial concerns were rarely discussed. Lack of 
information was a common theme and time was spent during each conference ensuring all 
people were familiar with the issues and patient history. Healthcare professionals tended to 
respond to the content of patient concerns, but not the emotion. 
DISCUSSION: The discussions were complex and health professional participants rarely 
summarised information or checked that patients and carers had understood the information 
provided.
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<td colspan=""">
Trappings of technology: casting palliative care nursing as legal relations.
Larsen AC.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 23134278
Community palliative care nurses in Perth have joined the throng of healthcare workers relying on personal digital assistants (PDAs) to store, access and send client information in 'real time'. This paper is guided by Heidegger's approach to technologies and Habermas' insights into the role of law in administering social welfare programs to reveal how new ethical and legal understandings regarding patient information add to nursing's professional responsibilities. This qualitative research interprets data from interviews with twenty community palliative care nurses about clients' legal rights to informational privacy and confidentiality. It explores nurses' views of their nursing responsibilities regarding clients' legal rights, liability issues, bureaucratic monitoring and enforcement procedures. It concludes that nurses and clients are construed as legal subjects entrenched in legal relations that have magnified since these nurses began using PDAs in 2005/2006. Copyright 2011 Blackwell Publishing Ltd.

Purpose of Review: Mixed methods research designs have been recognized as important in addressing complexity and are recommended particularly in the development and evaluation of complex interventions. This article reports a review of studies in palliative care published between 2010 and March 2012 that combine qualitative and quantitative approaches.

Recent findings: A synthesis of approaches to mixed methods research taken in 28 examples of published research studies of relevance to palliative and supportive care is provided, using a typology based on a classic categorization put forward in 1992.

Summary: Mixed-method studies are becoming more frequently employed in palliative care research and resonate with the complexity of the palliative care endeavour. Undertaking mixed methods research requires a sophisticated understanding of the research process and recognition of some of the underlying complexities encountered when working with different
The search for a higher power among terminally ill people with no previous religion or belief.
Collin M.
[Journal Article]
UI: 23123983
In a palliative care setting, there is evidence from the practice of spiritual care delivery to suggest that some terminally ill patients may seek, with varying degrees of openness and articulation, to connect with a higher power, or God, despite having expressed no previous interest in religion or belief. Developing a better understanding of the thoughts and feelings of such patients requires insight into the initial triggers of their search. In this small qualitative study involving six patients, fear, hope, and a natural connection are posited as possible prompts. The results highlight the complexity of ambivalent feelings toward a transcendent being that can be the focus of anger and blame while simultaneously offering a source of comfort and hope for an afterlife. Moreover, the study revealed something of the extent to which health professionals may feel limited in facilitating necessary discussion by a need to protect patients and themselves from entering an unfamiliar and complex area.

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2012
<td colspan=""">
Specialists' experiences and perspectives on the timing of referral to palliative care: a qualitative study.

Broom A; Kirby E; Good P; Wootton J; Adams J.

BACKGROUND: Specialist referral practices regarding palliative care are variable and their decision-making practices regarding timing and communication remains an under-researched issue. More effective referral practices have been shown to enhance patient and carer experiences at the end of life, reduce the burden on pre-palliative care services, and even extend life expectancy in some cases.

OBJECTIVE: The aim of this study was to examine the logics underpinning the timing of referral to palliative care according to a range of medical specialists in a regional center on the east coast of Australia, in order to facilitate improvements in referral practices.

METHODS: We conducted semi-structured, qualitative interviews with 20 medical specialists and carried out a thematic analysis of the interview data, utilising the framework analysis approach and NVivo 9 software. Key themes were tested for rigour through inter-rater reliability.

RESULTS: The major themes identified within this analysis of the interviews were: a) strategies for preparing for palliative care and the importance of planning timely referrals; b) perception of inter-professional variation and reasons for delayed or difficult referrals; and c) the importance of inter-specialty communication and cross-disciplinary dialogue.

CONCLUSIONS: Significant barriers exist to the timely referral to palliative care, and, in order to improve patient and care quality of life and lessen clinical difficulties, further work is needed to develop streamlined practices that are sensitive to specialty needs and patient desires.

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Year of Publication
2012

Development and evaluation of a palliative medicine curriculum for third-year medical students.

von Gunten CF; Mullan P; Nelesen RA; Soskins M; Savoia M; Buckholz G; Weissman DE.

UI: 22845026
OBJECTIVE: To assess the impact, retention, and magnitude of effect of a required didactic and experiential palliative care curriculum on third-year medical students' knowledge, confidence, and concerns about end-of-life care, over time and in comparison to benchmark data from a national study of internal medicine residents and faculty.

DESIGN: Prospective study of third-year medical students prior to and immediately after course completion, with a follow-up assessment in the fourth year, and in comparison to benchmark data from a large national study.

SETTING: Internal Medicine Clerkship in a public accredited medical school.


MAIN OUTCOME MEASURES: Pre- and postinstruction performance on: knowledge, confidence (self-assessed competence), and concerns (attitudes) about end-of-life care measures, validated in a national study of internal medicine residents and faculty. Medical student's reflective written comments were qualitatively assessed.

INTERVENTION: Required 32-hour didactic and experiential curriculum, including home hospice visits and inpatient hospice care, with content drawn from the AMA-sponsored Education for Physicians on End-of-life Care (EPEC) Project.

RESULTS: Analysis of 487 paired t-tests shows significant improvements, with 23% improvement in knowledge (F(1,486)=881, p<0.001), 56% improvement in self-reported competence (F(1,486)=2,804, p<0.001), and 29% decrease in self-reported concern (F(1,486)=208, p<0.001). Retesting medical students in the fourth year showed a further 5% increase in confidence (p<0.0002), 13% increase in allaying concerns (p<0.0001), but a 6% drop in knowledge. The curriculum's effect size on M3 students' knowledge (0.56) exceeded that of a national cross-sectional study comparing residents at progressive training levels (0.18) Themes identified in students' reflective comments included perceived relevance, humanism, and effectiveness of methods used to teach and assess palliative care education.

CONCLUSIONS: We conclude that required structured didactic and experiential palliative care during the clinical clerkship year of medical student education shows significant and largely sustained effects indicating students are better prepared than a national sample of residents and attending physicians.
Nursing: not the problem, but leading solutions.  
Smadu M; Shamian J.  
[Journal Article]  
UI: 23107904  
One of the major themes uncovered by Graham and Sibbald in their analysis of the 50-year-old issues of Hospital Administration in Canada (HAC) is the evolution of nursing. However, the HAC approach 50 years ago was that nursing was a problem to be solved, not a resource for health, the health system and the public, and that image would stay with nursing in Canada for many years to come. The recent commissioning by the Canadian Nurses Association of a National Expert Commission to examine sustainability of health and the healthcare system, and the resultant report, The Health of Our Nation, the Future of Our Health System: A Nursing Call to Action, released in June 2012, reflect a significantly different expectation about nurses and the nursing profession - they are not problems to be addressed, but are leading the solutions to better health, better care and better value. And patients are not passive recipients of care decided on by professionals alone, but central team members - "CEOs of their own healthcare" - in an interprofessional patient-/family-focused team that collectively supports people in their health journey. A number of examples of potential articles about and from nursing, based on the findings of the National Expert Commission, are included to illustrate how nursing should be reflected in an issue of HAC in 2012.

Palliative care in emergency departments: an impossible challenge?.  
Couilliot MF; Leboul D; Douguet F.  
[Journal Article. Research Support, Non-U.S. Gov't]  
UI: 22157178  
The aim of this study was to investigate the care practices surrounding end-of-life patients and the scope for providing palliative care in two emergency department short-stay units. Two
qualitative methods of investigation were used: direct ethnographic-type observation and semi-directed group interviews. The results highlight the fact that end-of-life situations inflect the practices of care and give rise to adjustments in the organization of work. These practices operate in two registers: that of supporting the family and that of attention to the patient's comfort. We propose a typology of end-of-life patients. In conclusion, the practices, termed 'palliative care' by the caregivers, are addressed to terminally ill patients expected to die shortly. This issue should be debated within emergency departments.

Status
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20121030

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2012

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248.
Interdisciplinary education in palliative care: impact on attitudes of students in medicine, nursing, pharmacy, social work, and chaplaincy.
Schrader SL; Brechtelsbauer D; Heins J; Holland P; Schroeder PA.
[Comparative Study. Journal Article]
UI: 23097999
INTRODUCTION: Interdisciplinary education among health professions has been recommended, and related evaluation can be found in the literature. However questions remain on how effective interdisciplinary education is and what impact it has. The objective of this study was to determine changes in student attitudes and perceptions upon completion of a 5-week interdisciplinary palliative care seminar.
METHODS: Pre-test and post-test instruments were administered at three five-week Interdisciplinary Palliative Care Seminars in Sioux Falls, SD during 2009-2010. The central hypotheses were that, at the conclusion of the seminar, students will have greater familiarity with their role in a team and more understanding of the roles of other disciplines in palliative care, and will identify positive contributions to professional practice and patient care using the team approach. Both quantitative and qualitative data were analyzed.
RESULTS: Participating students in medicine, nursing, pharmacy, social work, and chaplaincy (N = 88) completed surveys. Quantitative data suggest that interdisciplinary education enhances students’ understanding of their discipline and the work of other disciplines. Data show students perceive the team approach as enhancing patient outcomes, goal setting, and communication among colleagues. Qualitative data reinforced the importance of interdisciplinary education while revealing strains among disciplines in hierarchy and valuing.
CONCLUSIONS: Playing one’s part in the team strengthens students' confidence and comfort in interdisciplinary settings. Yet, the hazard of experiencing the limitations of teamwork in action must be acknowledged for some.
Hypnosis is recognised in medicine as an effective complementary therapy. However, few qualitative data are available concerning the benefits it may bring. This qualitative exploratory study aimed to examine the contribution of hypnosis to the care of advanced cancer patients. Results demonstrate that hypnosis is an effective and efficient means of developing the resources of people suffering from serious illness. After an average of four hypnotherapy sessions, patients said they were able to locate previously unexploited resources within themselves and were able to become autonomous in the use of self-hypnosis. The major benefit reported concerned a reduction in anxiety. For patients experiencing anxiety about death, hypnosis allowed them, within a therapeutic environment perceived as safe, to explore different facets of their fears and to develop adaptive strategies. Aside from slight fatigue experienced during the sessions, no adverse side-effects were reported. In conclusion, this study exploring the effects of hypnosis allowed us to identify important benefits for patients suffering from advanced cancer. Consequently, replication on a larger scale is recommended in order to ascertain the extent to which it is possible to generalise from these results and in order better to define the characteristics of patients most likely to benefit from this therapy.
Talking in triads: communication with Turkish and Moroccan immigrants in the palliative phase of cancer.

De Graaff FM; Francke AL; Van den Muijsenbergh ME; van der Geest S.

AIMS AND OBJECTIVES: To gain insight into the factors that influence communication between health professionals and Turkish and Moroccan immigrants in the palliative phase of cancer.

BACKGROUND: In palliative care, communication is crucial. The question, however, is whether Dutch healthcare providers, on the one hand, and Turkish and Moroccan patients and their family members, on the other, agree on what is constituted by good communication.

DESIGN: A descriptive qualitative method is used.

METHODS: Data of semi-structured interviews with 83 persons (six patients, 30 relatives and 47 professional care providers) were analysed to determine perceptual communication differences about care and treatment during the palliative phase of 33 cases.

RESULTS: As many patients with a Turkish or Moroccan background speak little Dutch, conversations often take place in triads, which makes it difficult for the actors to understand and resolve communication problems arising from diverging perceptions of 'good communication'.

CONCLUSION: Miscommunication around palliative care cannot solely be explained by the different cultural backgrounds of patients and their care providers. The multilingual communication triangle of patient - family - care provider often also complicates the bridging of differences in care perceptions.

RELEVANCE TO CLINICAL PRACTICE: Professional care providers should develop adequate strategies to handle triads, explore their own conventions and those of patients and relatives.

End of life care for people with a learning disability.

Morton-Nance S; Schafer T.

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2012

AIM: To explore the experiences of learning disability and district nurses caring for people with a learning disability at the end of their lives.

METHOD: A small-scale semi-structured qualitative study involving interviews was carried out to explore the experiences of healthcare professionals from two specialist healthcare settings.

FINDINGS: Healthcare professionals felt that formal guidelines and support were needed in this complex area. The study also revealed that successful provision of palliative care for people with a learning disability requires a person-centred approach.

CONCLUSION: Modifications to existing palliative care services, involving joint working, improved co-ordination and reasonable adjustments, is recommended. This aims to address any inequalities in care provision for people with a learning disability who are at the end of their lives.

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The phantom of death improving quality of life: you live until you die.
Vargens OM; Bertero C.
[Journal Article]
UI: 22241458

The purpose of this study was, using secondary analysis on data collected from previous empirical studies, to focus on improving the quality of life due to the new possibilities for living after a cancer diagnosis. No matter how long or short the life will be, quality of life in palliative care is about "living in the best way" until death. The data analysis identified 4 main themes; death as a main concern, reevaluating life, living a normal life with support, and living until death. The key message is that the patients are living until they die. Palliative care should facilitate and support the patients in their new life situation in order to sustain their quality of life. They are still alive--living until death.

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A poststructural glimpse at the World Health Organization's palliative care discourse in rural South Africa.
Campbell LM; Amin N.
[Journal Article]
UI: 23061979

INTRODUCTION: The World Health Organization (WHO) defines palliative care in terms of three constructs of care, namely, physical, psychosocial and spiritual, for a person who has a life-limiting illness. Life-limiting illness from WHO's perspective signifies and qualifies a patient for palliative care. Poststructuralism offers insights into how language constructs reality and sets up the limitations and possibilities of palliative care when it is practiced in a rural and remote area of the developing world, such as in South Africa.

METHODS: The study employed the qualitative method of photo-elicitation, which was used as a launching point for one-on-one discussion around photographs taken by participants. The participants, four palliative care nurses and two home-based care workers who work in rural homes in KwaZulu-Natal, South Africa, were purposively selected to provide rich information based on their personal experiences.

RESULTS: Defining palliative care in terms of a life-limiting illness may present challenges in rural areas where there is limited access to the diagnosis and prognosis of an illness. Limiting care to those with a life-limiting illness may not be culturally appropriate. Physical care did not prove to be a common care requirement and cultural care, which is not included in the WHO palliative care discourse, was common and necessary.

CONCLUSION: The WHO palliative care discourse can be thought of as not presenting a neutral way of looking at care and an irresolvable dichotomy may be set up in traditional rural, isolated areas. The question emerging is whether palliative care can be offered if it is not known whether an illness is life-limiting or not? Further poststructural work, in conjunction with exploration of palliative care practice, is required in this context.
Applying the Pictor technique to research interviews with people affected by advanced disease.
Hardy B; King N; Firth J.
[Journal Article]
UI: 23061268
AIM: To outline some of the challenges facing people affected by advanced disease who want to participate in research interviews, and to present Pictor, a method that can help manage some of these challenges.
BACKGROUND: Patients and lay-carers may have many issues that affect their ability to participate in qualitative research interviews. These issues can include the physical effects of disease, its treatments and emotional distress.
DATA SOURCE: An ongoing study exploring experiences of advanced disease when multiple agencies are involved.
REVIEW METHODS: The Pictor technique involves the creation of a chart that supports the exploration of the participant's experience of roles and relationships. The technique has previously been used with health professionals and this paper reports on its use with lay-participants.
DISCUSSION: The technique accommodates some disease-related difficulties which helped people with advanced disease to reflect on their experiences of primary care service provision. Participants then communicated these experiences with the researcher.
CONCLUSION: Pictor is a tool that can help manage some of the difficulties experienced by people with advanced disease who are participating in research interviews. This has benefits for researchers and participants.

Do models of care designed for terminally ill 'home alone' people improve their end-of-life experience? A patient perspective.
Palliative care patients who live alone report greater psychological distress, and are less likely to die at home than those living with a family carer. However, there is a lack of research on the value of models of care that specifically address this disadvantage. This article describes the experiences of terminally ill 'home alone' people using one of two models of care aimed at maintaining participants’ need for independent living, focusing on the effect of these two models of care on their physical, social and emotional needs. Twenty six palliative care patients of Silver Chain Hospice Care, in Western Australia, were randomly assigned to either having a personal alarm or additional care-aide hours in their home. An in-depth qualitative study was conducted in two phases in 2010 using face-to-face interviews. The care-aide model of care resulted in benefits such as easing the burden of everyday living; supporting well-being; enhancing quality of life and preserving a sense of dignity; and reducing loneliness and isolation. The personal alarm model of care imparted a sense of security; provided peace of mind; and helped to deal with feelings of isolation. Participants in both groups felt that they could remain at home longer. By providing a safer, more secure environment through the use of a personal alarm or additional care-aide hours, patients were able to continue their activities of daily living, could build a sense of 'normality' into their lives, and they could live independently through support and dignity.

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The ethical decisions UK doctors make regarding advanced cancer patients at the end of life—the perceived (in) appropriateness of anticoagulation for venous thromboembolism: a qualitative study.

Sheard L; Prout H; Dowding D; Noble S; Watt I; Maraveyas A; Johnson M.


BACKGROUND: Cancer patients are at risk of developing blood clots in their veins - venous thromboembolism (VTE) - which often takes the form of a pulmonary embolism or deep vein
thrombosis. The risk increases with advanced disease. Evidence based treatment is low molecular weight heparin (LMWH) by daily subcutaneous injection. The aim of this research is to explore the barriers for doctors in the UK when diagnosing and treating advanced cancer patients with VTE.

METHOD: Qualitative, in-depth interview study with 45 doctors (30 across Yorkshire, England and 15 across South Wales). Doctors were from three specialties: oncology, palliative medicine and general practice, with a mixture of senior and junior staff. Framework analysis was used.

RESULTS: Doctors opinions as to whether LMWH treatment was ethically appropriate for patients who were symptomatic from VTE but at end of life existed on a shifting continuum, largely influenced by patient prognosis. A lack of immediate benefit coupled with the discomfort of a daily injection had influenced some doctors not to prescribe LMWH. The point at which LMWH injections should be stopped in patients at the end of life was ambiguous. Some perceived 'overcaution' in their own and other clinicians' treatment of patients. Viewpoints were divergent on whether dying of a PE was considered a "good way to go". The interventionalism and ethos of palliative medicine was discussed.

CONCLUSIONS: Decisions are difficult for doctors to make regarding LMWH treatment for advanced cancer patients with VTE. Treatment for this patient group is bounded to the doctors own moral and ethical frameworks.
may benefit from palliative forms of care, but evidence indicates that many fail to access such provision at the end of life. The role of the health care team is pivotal if people with dementia are to benefit from the transition to palliative care.

AIM: This paper reports on qualitative research conducted in the UK that sought to explore the experiences of health care practitioners working in palliative care and sought to establish the issues relating to end-of-life care for people with dementia.

DESIGN: Eight focus groups and four individual interviews were held. Data were analysed using a thematic approach.

SETTING/PARTICIPANTS: The study included palliative care practitioners (n = 58) including medical, nursing and allied health professionals. Participants were recruited from acute hospitals, general practice, hospices and specialist palliative care units in the UK.

RESULTS: Four themes were identified: Making the transition; Competence challenged; 'The long view' and Working together. Whilst there exists good practice in this area, the barriers to timely and appropriate transitions to palliative care for people with dementia and their families continue to exist. The paper concludes with recommendations for policy and practice development.

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2012

258.
Making decisions about delirium: a qualitative comparison of decision making between nurses working in palliative care, aged care, aged care psychiatry, and oncology.
Agar M; Draper B; Phillips PA; Phillips J; Collier A; Harlum J; Currow D.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 21908522
BACKGROUND: Delirium has a significant impact on nursing practice from diagnosis and management, with under-detection and variable management of delirium being international problems. This study aimed to explore nurses' assessment and management of delirium when caring for people with cancer, the elderly or older people requiring psychiatric care in the inpatient setting.

METHODS: Participants in this qualitative study were nurses working in Australian public hospital inpatient dedicated units in palliative care, aged care (geriatrics), aged care (geriatric) psychiatry and oncology. Semi-structured interviews were used to explore nurses' views about specific
areas of delirium assessment and management. Purposive sampling was used and interviews conducted until thematic saturation reached. A thematic content analysis was performed from a grounded theory perspective.

RESULTS: A total of 40 participants were included in the study. The analysis revealed four broad analytical themes: (1) superficial recognition and understanding of the operational definition of delirium or recognition of delirium as a syndrome; (2) nursing assessment: investigative versus a problem solving approach; (3) management: maintaining dignity and minimizing chaos; and (4) distress and the effect on others.

DISCUSSION: Nurses have limited knowledge of the features of delirium regardless of their specialty discipline. Delirium was uniformly identified as a highly distressing experience for patients, families and staff alike. The majority of nurses had a superficial understanding of delirium management, and adopted a task-orientated approach aimed at addressing the more noticeable problems. These findings have implications for both education and knowledge translation. Innovative approaches are needed to align health professional behaviours with best evidence delirium care.

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We conducted a prospective study in the ICU of life-sustaining treatment and comfort care decisions over time in patients with end-stage liver disease (ESLD) from the perspectives of patients, family members, and healthcare professionals. Six patients with ESLD, 19 family members, and 122 professionals participated. The overarching theme describing the decision-making process was "on the train." Four sub-themes positioned patients and family members as passengers with limited control, unable to fully understand the decision-making process. Findings suggest that including patients and family members in non-immediate life-saving decisions and
verifying early on their understanding may help to improve the decision-making process.

Understanding and improving communication and decision-making in palliative care for Turkish and Moroccan immigrants: a multiperspective study.

de Graaff FM; Francke AL; van den Muijsenbergh ME; van der Geest S.

OBJECTIVE: The aim of this study is to explore how communication and decision-making in palliative care among Turkish and Moroccan patients is influenced by different styles of care management between Turkish and Moroccan families and Dutch professional care providers. Problems as well as solutions for these problems are highlighted.

DESIGN: A qualitative design was used, totally interviewing 83 people (6 patients, 30 relatives and 47 care providers) covering 33 cases of incurable cancer patients receiving palliative care. Data were analysed thematically and contextually.

RESULTS: The analysis reveals that problems in decision-making are partly related to differences in ethnic-cultural views on 'good care' at the end of life: Dutch palliative care providers prefer to focus on quality of life rather than on prolonging life, while Turkish and Moroccan families tend to insist on cure. Another barrier is caused by conflicting views on the role of the 'care management group': Dutch care providers see the patient as their primary discussion partner, while in Turkish and Moroccan families, relatives play a major part in the communication and decision-making. Moreover, the family's insistence on cure often leads to the inclusion of additional care providers in communication, thus complicating joint decision-making.

CONCLUSION: Care providers need to understand that for Turkish and Moroccan patients, decision-making is seldom a matter of one-to-one communication. Next to acknowledging these patients' different cultural backgrounds, they must also recognise that the families of these patients often function as care management groups, with an 'equal' say in communication and
decision-making. In addition, professionals should optimise communication within their own professional care management group.

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Year of Publication
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261.
Religious beliefs and practices in end-stage renal disease: implications for clinicians.
Elliott BA; Gessert CE; Larson P; Russ TE.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 22762965

CONTEXT: Several components of palliative care are particularly applicable in end-stage renal disease (ESRD), including the spiritual domain.
OBJECTIVES: To investigate how ESRD patients and their families make decisions and cope with their circumstances and dialysis treatment.
METHODS: A prospective qualitative study interviewed 31 elderly dialysis patients and their family members; interviews lasted 30-90 minutes. Interviews were transcribed and coded independently by three investigators. The codes were collected into content-specific "nodes" and themes. Investigators identified and reconciled their interpretations by returning to the transcripts to assure that conclusions reflected participants' sentiments.
RESULTS: Five themes pertaining to religious beliefs and practices emerged. Two themes were related to decision making: their faith-based beliefs and the meaning that emerges from these beliefs; two described how their coping is impacted: the participants' religious practices and their perceived support from the church community; and one described the participants' spiritual distress.
CONCLUSION: These findings offer insights into chaplains' roles in the ESRD setting and the issues that they and other palliative care team members can anticipate and address in patient support and decision making. The results also support recent work to develop methodologies for research on religious and spiritual issues in medical settings.

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Status
MEDLINE
Authors Full Name
Gessert, Charles E; Larson, Pamela; Russ, Thomas E.

CONTEXT: Guidelines about palliative sedation typically include recommendations to protect the well-being of relatives.

OBJECTIVES: The aim of this study was to systematically review evidence on the experiences of relatives with the practice of palliative sedation.

METHODS: PubMed, Embase, Web of Science, PsycINFO, and CINAHL were searched for empirical studies on relatives’ experiences with palliative sedation. We investigated relatives’ involvement in the decision-making and sedation processes, whether they received adequate information and support, and relatives’ emotions.

RESULTS: Of the 564 studies identified, 39 were included. The studies (30 quantitative, six qualitative, and three mixed methods) were conducted in 16 countries; three studies were based on relatives’ reports, 26 on physicians’ and nurses’ proxy reports, seven on medical records, and three combined different sources. The 39 studies yielded a combined total of 8791 respondents or studied cases. Caregivers involved relatives in the decision making in 69%–100% of all cases (19 quantitative studies), and in 60%–100% of all cases, relatives were reported to have received adequate information (five quantitative studies). Only two quantitative studies reported on relatives’ involvement in the provision of sedation. Despite the fact that the majority of relatives were reported to be comfortable with the use of palliative sedation (seven quantitative studies, four qualitative studies), several studies found that relatives were distressed by the use of sedation (five quantitative studies, five qualitative studies). No studies reported specifically about the support provided to the relatives.

CONCLUSION: Relatives’ experiences with palliative sedation are mainly studied from the perspective of proxies, mostly professional caregivers. The majority of relatives seems to be comfortable with the use of palliative sedation; however, they may experience substantial distress by the use of sedation. Copyright 2012 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.
The advanced cancer patient experience of undertaking meaning and purpose (MaP) therapy.
Lethborg C; Schofield P; Kissane D.
Palliative & Supportive Care. 10(3):177-88, 2012 Sep.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 22436684

OBJECTIVE: The objective of this study was to describe the experience of undertaking meaning and purpose (MaP) therapy for patients with advanced cancer, with an aim of refining therapeutic processes involved prior to pilot testing. Specifically, we were interested in examining the themes arising from participation in the intervention in relation to our therapeutic goals, and how acceptable both the number of sessions and processes used were.

METHOD: A convenience sample of people living with advanced cancer was recruited to participate in this process, resulting in 24 therapy sessions for analysis.

RESULTS: A thematic analysis of each session illustrated that the process of MaP therapy is one that encourages reflection, offers insights, and can be confrontational, but can also allow participants to "shift" their perspective and focus onto meaningful goals. Results illustrate how the therapist creates a therapeutic frame that holds up a poignant portrayal of the meaning of life lived, and mirrors this to the patient, such that they grasp its rich texture. Participants' descriptions showed how they were buoyed forward as a result, with renewed vigor and enthusiasm, despite their illness and any physical restrictions that it imposed.

SIGNIFICANCE OF RESULTS: A planned pilot test of this intervention will enable us to determine potential effect sizes of this therapy in reducing distress and increasing meaning prior to a full randomized controlled trial. Understanding the processes involved and the experiences of participation in meaning-based therapies is crucial to the future strength of this area of psychotherapy.

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The needs of parents with children suffering from lethal epidermolysis bullosa.
Yuen WY; Duipmans JC; Jonkman MF.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 22512671

BACKGROUND: Some subtypes of the heterogeneous genetic blistering disease epidermolysis bullosa (EB) lead to lethality in childhood. The severity and extent of blistering leaves these patients living in excruciating pain and distress their entire lives. Parents of these patients experience some specific problems, such as the unfamiliarity of EB amongst healthcare professionals and the suffering and loss of their child.

OBJECTIVE: To identify the needs of parents who have lost their child to lethal EB.

METHODS: A qualitative study was performed, comprising semistructured, in-depth interviews with 16 parents. The transcripts were analysed and common themes were identified.

RESULTS: Parents indicated that they have the need (i) for a fast and correct referral to a specialized EB clinic, (ii) to be informed as honestly as possible about the diagnosis and lethal prognosis, (iii) to have a structured network of caregivers in the palliative care, (iv) to be involved in the care and the medical decisions involving their child, (v) to be informed about the end of life and to discuss euthanasia, (vi) for guidance and to have remembrances of their child, and (vii) for genetic counselling.

CONCLUSIONS: Our job as healthcare professionals is to provide the best care not only for children suffering from lethal EB, but also for their parents. In this study, parents have provided us with some guidelines to care for them. However, it is important to keep in mind that every parent is different, and that the guidance should be tailored to their individual needs.

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Motor Neurone Disease family carers’ experiences of caring, palliative care and bereavement: an exploratory qualitative study.
Aoun SM; Connors SL; Priddis L; Breen LJ; Colyer S. Palliative Medicine. 26(6):842-50, 2012 Sep. [Journal Article]
UI: 21775409
BACKGROUND: Motor Neurone Disease (MND) is a neurodegenerative disease with a sudden onset, a rapid progression, a profile of complex disabilities and fatal consequences. Caring for a person with MND is an unremitting commitment, yet little research has examined the experiences and needs of carers for palliative care and bereavement care.
AIM: This study explored the experiences of MND family carers, both during their time as carers and following bereavement. Particular attention was paid to the carers' prolonged grief status and to the implications for service delivery, including palliative care.
DESIGN: A qualitative approach consisted of interviews with 16 bereaved family carers. The Prolonged Grief tool (PG-13) measured the carers' prolonged grief.
SETTING/PARTICIPANTS: sixteen family carers participated in the study, between one and four years after the death of their spouse from MND in Western Australia.
RESULTS: The thematic analysis of the interview transcripts revealed five themes - the work of family carers, the change in relationship from spouse to family carer, family caring as a series of losses, coping mechanisms of family carers and supportive and palliative care experiences of family carers. The six participants who met the criteria for prolonged grief disorder accessed palliative care at a later stage in the disease trajectory.
CONCLUSIONS: The study provided a basis for more research into the role palliative care services has in supporting MND carers before and after the death of their spouse and in particular the provision of more tailored respite and bereavement support.
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20120824
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2012
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Medical futility at the end of life: the perspectives of intensive care and palliative care clinicians.
Jox RJ; Schaider A; Marckmann G; Borasio GD. Journal of Medical Ethics. 38(9):540-5, 2012 Sep.
OBJECTIVES: Medical futility at the end of life is a growing challenge to medicine. The goals of the authors were to elucidate how clinicians define futility, when they perceive life-sustaining treatment (LST) to be futile, how they communicate this situation and why LST is sometimes continued despite being recognised as futile.

METHODS: The authors reviewed ethics case consultation protocols and conducted semi-structured interviews with 18 physicians and 11 nurses from adult intensive and palliative care units at a tertiary hospital in Germany. The transcripts were subjected to qualitative content analysis.

RESULTS: Futility was identified in the majority of case consultations. Interviewees associated futility with the failure to achieve goals of care that offer a benefit to the patient's quality of life and are proportionate to the risks, harms and costs. Prototypic examples mentioned are situations of irreversible dependence on LST, advanced metastatic malignancies and extensive brain injury. Participants agreed that futility should be assessed by physicians after consultation with the care team. Intensivists favoured an indirect and stepwise disclosure of the prognosis. Palliative care clinicians focused on a candid and empathetic information strategy. The reasons for continuing futile LST are primarily emotional, such as guilt, grief, fear of legal consequences and concerns about the family's reaction. Other obstacles are organisational routines, insufficient legal and palliative knowledge and treatment requests by patients or families.

CONCLUSION: Managing futility could be improved by communication training, knowledge transfer, organisational improvements and emotional and ethical support systems. The authors propose an algorithm for end-of-life decision making focusing on goals of treatment.

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Year of Publication
2012

267.
The impact of Asian American value systems on palliative care: illustrative cases from the family-focused grief therapy trial.
Mondia S; Hichenberg S; Kerr E; Eisenberg M; Kissane DW.
[Journal Article. Research Support, N.I.H., Extramural]
UI: 22096204
BACKGROUND: Clinicians meet people from different ethnic backgrounds, yet need to respond in culturally sensitive ways. This article focuses on Asian American families.

METHODS: Within a randomized controlled trial of family therapy commenced during palliative care and continued into bereavement, 3 families of Asian American background were examined qualitatively from a cultural perspective by listening to recordings of 26 therapy sessions and reviewing detailed supervision notes compiled by each therapist.

RESULTS: A synopsis of each family's therapy narrative is presented. Prominent themes include family closeness, respect for hierarchy within the family, gender-determined roles, intergenerational tensions, preoccupation with shame and limited emotional expressiveness.

CONCLUSIONS: Family therapists working with culturally diverse families need to pay thoughtful attention to ethnic issues as they strive to support them during palliative care and bereavement.

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Date Created
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Year of Publication
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268.
Caring for caregivers: a right way to do it?. [Review]
Simonic A;  Furlan M;  Ravnjak T;  Dirkse D.
[Journal Article.  Review]
UI: 22801466
PURPOSE OF REVIEW: The support of family caregivers in palliative care is critical and well recognized; yet the fact that caregivers still face significant unmet needs highlights a considerable gap in addressing this issue. Current themes on the caregiving experience in palliative care are presented.

RECENT FINDINGS: The recent literature suggests a shift towards a broader understanding of the caregiving experience in palliative care in terms of better integration of caregivers of patients with noncancer illnesses into palliative care, improved continuity of care among different settings and better integration of guidelines and evidence into practice. Several risk groups and factors of caregiving in palliative care have been identified. The literature review emphasizes a public health approach as an important step in addressing the caregivers' burden. While 'the right way' of supporting caregivers is still to be established, consideration of caregivers' roles as co-providers and co-recipients of care offers numerous implications for research and clinical practice.

SUMMARY: This review demonstrates the need for the development of specific strategies aimed at supporting informal caregivers in caring for their loved ones in different settings and periods of
advanced life-threatening illnesses. Open issues in searching for 'the right way' to care for caregivers in palliative care are presented.

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I don't want to talk about it.' Raising public awareness of end-of-life care planning in your locality.
Hickey D; Quinn S.
[Journal Article]
UI: 22885861

The UK Department of Health's (2008) End of Life Care Strategy highlighted the need for greater public awareness around planning and the choices available as people approach the end of their life. Despite efforts to 'normalise' death and dying and recognise that they are an inevitable part of life, a taboo persists and open communication about these issues is often limited or restricted to periods of crisis. Translating national policy into meaningful local dialogue requires creative interventions that are adaptable to each community. This article explores these key themes and reports on the responses of the first 304 people to complete an end-of-life survey as part of local engagement with the general public in South West Essex regarding issues around death and dying.

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20120813

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2012

269.
A pilot study to evaluate an outpatient service for people with advanced lung cancer. 
Roulston A; Bickerstaff D; Haynes T; Rutherford L; Jones L. 
[Journal Article. Research Support, Non-U.S. Gov't]

UI: 22885859

Many patients with lung cancer are symptomatic from diagnosis, and quality of life (QoL) may be maximised through the use of specialist palliative care in parallel with other treatments. This study explored anxiety, depression, and QoL in five patients, predominantly male (n=4) and with mean age 74 years, using a 'Breathing Space' clinic over a 4-week period. Breathing Space is a nurse-led multidisciplinary outpatient clinic using integrative care with lung cancer patients. The patients received weekly interventions to improve their wellbeing. Qualitative data were collected to explore their expectations and experiences of the clinic, and quantitative data were captured using the Eastern Cooperative Oncology Group Performance Status Rating (ECOG-PSR), the Hospital Anxiety and Depression Scale (HADS), the EQ-VAS, and the EQ-5D. These data were analysed using thematic content analysis and SPSS respectively. It was found that preconceived ideas about clinic attendance were replaced with positive impressions. Anxiety and EQ-VAS scores improved for all patients, and depression scores improved for four of the five patients, although no tests of significance were made. The qualitative data indicated that there were psychosocial benefits to attending the clinic.

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Dignity conserving care at end-of-life: a narrative review. [Review]
Ostlund U; Brown H; Johnston B. 
[Journal Article. Research Support, Non-U.S. Gov't. Review]

UI: 21917517
PURPOSE OF THE RESEARCH: This narrative literature review uses systematic principles to define evidence regarding dignity conserving care at end-of-life from published research on dignity or distress in end-of-life care.

METHODS: The Chochinov model of dignity was used as a pre-defined framework. Articles were reviewed using thematic analysis to produce a synthesis of findings. A total of 39 articles (26 qualitative and 13 quantitative) fulfilled the inclusion criteria and were found to give suggestions on care actions.

KEY RESULTS: Several care actions were identified related to all themes contained within the Dignity Model, except aftermath concerns. Examples include: controlling symptoms; listening to the patient and taking them seriously; providing advice concerning how to cope on a daily basis; treating patients as equals and with respect, and; encouraging the family members' presence.

CONCLUSIONS: Evidence for supporting palliative care services has previously been found to be weak in determining solutions to meet individual's important needs. Drawing together primary research, as in this study, is therefore of importance. The suggested care actions will be used to develop a dignity care pathway for end-of-life care, which is currently being evaluated by the authors. The intention is to provide more valid evidence for the effectiveness of the care actions suggested. Copyright 2011 Elsevier Ltd. All rights reserved.

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272.
Attitudes of health care professionals to opioid prescribing in end-of-life care: a qualitative focus group study.
Gardiner C; Gott M; Ingleton C; Hughes P; Winslow M; Bennett MI.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 22672918

CONTEXT: Opioid therapy is central to the management of pain in the field of generalist palliative and end-of-life care, and international guidelines highlight the need for opioids to be used as part of a comprehensive strategy to treat pain. However, evidence suggests that the use of opioids in palliative care is suboptimal, and many patients do not receive adequate pain control at the end of life.

OBJECTIVES: This study aimed to explore the attitudes of health care professionals to opioid prescribing in generalist end-of-life care.
METHODS: Thirty-one health and allied health professionals participated in four focus groups. Two focus groups took place in general practitioner practices and two in hospices.

RESULTS: Findings revealed that significant barriers exist to the appropriate use of opioids in end-of-life care. Particular barriers exist for professionals working in primary care and include concerns about giving high doses and having insufficient training in opioid use. Working partnerships between specialist and generalist palliative care providers are important for increasing generalist confidence in prescribing. Patients and their families often have concerns about initiating opioids, and specialist nursing staff are crucial to managing and alleviating these concerns.

CONCLUSION: Significant barriers exist to the appropriate use of opioids in end-of-life care. If international priorities on improving pain management at the end of life are to be achieved, educational opportunities for generalists need to be enhanced, and effective interprofessional working models need to be developed so that pain management for patients at the end of life is optimized. Copyright 2012 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

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Year of Publication
2012

273.
Hospital admissions from nursing homes: a qualitative study of GP decision making.
McDermott C; Coppin R; Little P; Leydon G.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 22867677
BACKGROUND: Decisions regarding the hospitalisation of nursing home residents may present a difficult dilemma for GPs. There are pressures to admit very frail patients with exacerbations of illness even though such frailty may limit the possible health gains. As 'gatekeepers' to NHS, GPs are expected to make best use of resources and may be criticised for 'inappropriate' admissions. Little is understood about the influences on GPs as they make such decisions.
AIM: To explore GPs views on factors influencing decisions on admitting frail nursing home residents to hospital.
DESIGN AND SETTING: A purposive sample of 21 GPs from two counties in the South of England.
METHOD: Data from semi-structured, one-to-one interviews with GPs were analysed using thematic analysis following principles of the constant comparative method.

RESULTS: This study suggests that while clinical assessment, perceived benefits and risks of admission, and patients' and relatives' preferences are key factors in determining admissions, other important factors influencing decision making include medico-legal concerns, communications, capability of nursing homes and GP workload. These factors were also perceived by GPs as influencing the feasibility of keeping patients in the nursing home when this was clinically appropriate. Key areas suggested by GPs to improve practice were improving communication (particularly informational continuity), training and support for nursing staff, and peer support for GPs. Local initiatives to address these issues were very variable.

CONCLUSION: Developing a systematic palliative care approach to address poor documentation and communication, the capability of nursing homes, and medico-legal concerns has the potential to improve decision-making regarding hospital admissions.

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274.
What are the perceived needs and challenges of informal caregivers in home cancer palliative care? Qualitative data to construct a feasible psycho-educational intervention.

Harding R; Epiphaniou E; Hamilton D; Bridger S; Robinson V; George R; Beynon T; Higginson IJ.
Supportive Care in Cancer. 20(9):1975-82, 2012 Sep.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 22072049
PURPOSE: Tailored and specific interventions for informal caregivers in palliative care are rare. We aimed to generate evidence to inform a subsequent appropriate intervention based on caregivers' experiences.

METHOD: Single, semi-structured qualitative interviews were undertaken with 20 informal cancer caregivers of home cancer palliative care.

RESULTS: Carers reported the need to be prepared for their caring role, to be visible to professionals, to receive clear and specific information about the patient's condition, and to be emotionally supported. They described challenges as uncertainty, distress at witnessing disease
progression and the daily struggle with financial issues, personal time, own health and sleep problems.

CONCLUSIONS: Considering the time pressures and restricted caregiver time, the intervention should be brief and should aim to enhance their visibility as service recipients, patient-specific information giving, preparation for their role, and emotional support.

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20120806
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275.
Palliative and end-of-life care in Newfoundland's deaf community.
Maddalena V; O'Shea F; Murphy M.
Journal of Palliative Care. 28(2):105-12, 2012.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 22860383
The deaf community is a distinct cultural and linguistic community (the uppercase D is a cultural identification). Compared to the general population, the deaf community, as a social group, experiences poorer health status. Deaf people seek care less frequently than the general population and have fewer interactions with the health system. Their encounters with the health system are often characterized by communication difficulties, fear, mistrust, and frustration. Qualitative research was used to explore the experiences of family caregivers who provided end-of-life care for a deaf person. Key findings indicate that the deaf community has limited understanding of their options for palliative and end-of-life care. Communication and health literacy are key barriers to accessing appropriate end-of-life care. Pain and symptom management, consideration of physical environments, and limited access to bereavement care are common issues faced by deaf people when caring for loved ones at the end of life.
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276.
What is symptom burden: a qualitative exploration of patient definitions.
Gill A; Chakraborty A; Selby D.
[Journal Article]
UI: 22860380
Current definitions of "symptom burden" are largely derived from clinicians, and there are many
variations in the way the term is used, defined, and operationalized. The aim of this study was to
explore patient perceptions of symptom burden in the context of advanced and incurable disease.
A group of 58 cancer patients followed by a palliative care team answered a single open-ended
question: "Please define 'symptom burden'". Three authors independently coded and analyzed
patient responses using a grounded theory approach. They identified six themes, the most
frequently coded of which were: "can't do usual activities", "psychological suffering" and "specific
severe symptoms". Our findings indicate that the concept of symptom burden is complex and
extends beyond numerical symptom-scoring systems. In addition to inquiring about specific
symptoms, it may be important to directly ask patients about their overall burden or experience of
symptoms.
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This paper reports the principle findings of a national, cross-sectional, interview-based study of the experiences of people who cared for a dying family member in the Republic of Moldova. Study data, collected from 102 interviews, covered four broad areas: the experiences of the dying person; family members’ own experiences of caring; the practice (or non-practice) of any traditional customs for dying or death; and family carers’ views of their own needs in these circumstances. Most carers reported high levels of psychological distress. Dying persons were reported to experience significant and unrelieved suffering. The practice of traditional customs was uneven, and there were significant levels of non-practice. Most respondents expressed a need for greater professional support, respite, specialized equipment and medicines, and home help from health care professionals. The implications of these findings are discussed in terms of potential local developments and international aid.

278.
Compassion and vigilance: investigators' strategies to manage ethical concerns in palliative and end-of-life research.
Hickman SE; Cartwright JC; Nelson CA; Knafl K.
[Journal Article. Research Support, N.I.H., Extramural]
UI: 22731516
BACKGROUND: Ethical concerns were identified as a potential barrier to advancing palliative and end-of-life science at the 2004 National Institutes of Health State of the Science Meeting. However, data are lacking about the nature of ethical concerns and strategies for balancing the need to advance science with human subjects protections.
METHODS: A qualitative case-study design was used to follow 43 end-of-life studies from proposal development through the review process and implementation. Investigators participated in semi-structured telephone interviews and provided document data regarding their experiences with grant and IRB reviews. Using constant comparative analysis within and across cases, the investigators identified commonly encountered and unique concerns and strategies for managing these concerns.
FINDINGS: Investigator strategies fell into two broad categories: 1) Recruitment and consent strategies related to subject identification and enrollment; and 2) Protocol-related strategies related to the process of data collection. These strategies shared the overarching meta-themes of
compassion, as evidenced by a heightened sensitivity to the needs of the population, coupled with vigilance, as evidenced by close attention to the possible effects of study participation on the participants' well-being, clinical care, and the needs of research staff.

CONCLUSIONS: Ethical concerns have led to the development of compassionate and vigilant strategies designed to balance the potential for risk of harm with the need to advance the science of palliative and end-of-life care. These strategies can be used by investigators to address ethical concerns and minimize barriers to the development of palliative and end-of-life care science.

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Nurse-perceived barriers to effective communication regarding prognosis and optimal end-of-life care for surgical ICU patients: a qualitative exploration.
Aslakson RA; Wyskiel R; Thornton I; Copley C; Shaffer D; Zyra M; Nelson J; Pronovost PJ. Journal of Palliative Medicine. 15(8):910-5, 2012 Aug.
[Journal Article. Research Support, N.I.H., Extramural]
UI: 22676315
BACKGROUND: Integration of palliative care for intensive care unit (ICU) patients is important but often challenging, especially in surgical ICUs (SICUs), in part because many surgeons equate palliative care with terminal care and failure of restorative care. SICU nurses, who are key frontline clinicians, can provide insights into barriers for delivery of optimal palliative care in their setting.
METHODS: We developed a focus group guide to identify barriers to two key components of palliative care-optimal communication regarding prognosis and optimal end-of-life care-and used the tool to conduct focus groups of nurses providing bedside care in three SICUs at a tertiary care, academic, inner city hospital. Using content analysis technique, responses were organized into thematic domains that were validated by independent observers and a subset of participating nurses.
RESULTS: Four focus groups included a total of 32 SICU nurses. They identified 34 barriers to optimal communication regarding prognosis, which were summarized into four domains: logistics, clinician discomfort with discussing prognosis, inadequate skill and training, and fear of conflict. For optimal end-of-life care, the groups identified 24 barriers in four domains: logistics, inability to
acknowledge an end-of-life situation, inadequate skill and training, and cultural differences relating to end-of-life care.

CONCLUSIONS: Nurses providing bedside care in SICUs identify barriers in several domains that may impede optimal discussions of prognoses and end-of-life care for patients with surgical critical illness. Consideration of these perceived barriers and the underlying SICU culture is relevant for designing interventions to improve palliative care in this setting.

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280.
Negotiating uncertain terrain: a qualitative analysis of clinicians' experiences of refractory suffering.
Breaden K; Hegarty M; Swetenham K; Grbich C.
[Journal Article]
UI: 22621305
In palliative care, the witnessing of unrelieved (refractory) suffering takes its toll on all concerned; however, the effect on experienced palliative clinicians of witnessing such suffering has largely been unexplored. The aim of this study was to examine health care professionals’ (nurses, doctors, and allied health workers) experiences of working with a patient's refractory suffering, together with their clinical management strategies. A qualitative research design involving semistructured interviews and an online questionnaire was used to collect the data. Seventeen experienced palliative care clinicians participated; 13 with face-to-face interviews and a further 4 by an online questionnaire. The overarching theme of negotiating uncertain terrain was common across all clinician narratives. In order for them to work successfully with a patient's refractory suffering, the clinicians had to negotiate areas of practice characterized by uncertainty, with no clear directions and with few expert guides. In reviewing their experiences, they identified within an overarching theme of negotiating uncertain terrain four subthemes: Changing Approach from "Fixing" to "Being With," Maintaining Perspective, Negotiating and Maintaining Boundaries, and Living the Paradoxes. This study highlights that dealing with patients' refractory suffering involves
Clinicians moving into uncertain and unexplored territory. For them to work effectively in this terrain, the clinicians need wisdom, courage, and a commitment to journeying alongside the suffering person.

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Year of Publication
2012

Advance care planning in COPD: care versus "code status". [Review]
Simpson C.
[Journal Article. Research Support, Non-U.S. Gov't. Review]
UI: 22729389

Chronic obstructive pulmonary disease (COPD) in advanced stages runs an unpredictable downward course with increasingly frequent, ultimately fatal exacerbations. Worldwide financial and human costs are huge. Responsibility for initiating advance care planning in COPD has usually fallen to the physicians. The tendency has been to avoid this aspect of care, which can result in inadequate, rushed, reactive, crisis decision-making in the form of a "code status" discussion. In this article, I review the relevant literature and report findings from a qualitative study designed within my doctoral program to explore the question, "What is required for meaningful and effective advance care planning in the context of advanced COPD?" I describe the "collaborative care" approach to advance care planning I used with eight patients and carers living with advanced COPD. Along with a skilled clinician facilitator, user-friendly education elements, and attention to readiness, unique aspects of the approach included a focus on caring, engaging hope, facilitator reflective praxis, and contextual sensitivity. This approach has significant potential for enhancing decision making and goal setting, efficiency of resource utilization, and satisfaction with outcomes. Done well, it may reclaim the care element in advance care planning as it addresses barriers cited by physicians and patients/families.

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20120731
Use of home telehealth in palliative cancer care: a case study.
Stern A; Valaitis R; Weir R; Jadad AR.
[Journal Article]
UI: 22790013
We conducted a mixed-methods case study to explore the perceptions of family caregivers and palliative cancer patients of home telehealth, and their experience with it. The intervention in the randomized controlled trial from which study participants were selected consisted of specialist nurses available 24 hours per day who communicated with patients and families using videophones, with optional remote monitoring. Qualitative data were collected from interviews with five patient/caregiver dyads and seven bereaved family caregivers, direct observation and nursing documentation. Quantitative data were collected from computerized nursing documentation and analyzed for patterns of use. During the study there were 255 contacts, including videophone, telephone or face-to-face visits, between tele-nurses and families. Overall the patients, family caregivers and tele-nurses felt that home telehealth enabled family caregiving, citing increased access to care, and patient and family caregiver reassurance. Pain management was the most common reason for initiating contact with the nurse, followed by emotional support. Concerns included lack of integration of services, inappropriate timing of the intervention and technical problems. The case study confirmed the importance of timely and accessible care for a group of clinically vulnerable, dying cancer patients and their family caregivers.
PalliPA: How can general practices support caregivers of patients at their end of life in a home-care setting? A study protocol.
Hermann K; Boelter R; Engeser P; Szecsenyi J; Campbell SM; Peters-Klimm F.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 22583663

BACKGROUND: The care of patients with a life-threatening, progressive and far advanced illness in a home-care setting requires appropriate individual care and requires the active support of family caregivers. General practice teams are usually the primary caregivers and first contact and are best placed to offer support to family caregivers and to recognise and respond to the burden of care giving on family members. The aim of this project is to develop a best practice model for engaging with and supporting family caregivers.

FINDINGS: The project is framed as an exploratory trial for a subsequent implementation study, covering phases 0, I and II of the MRC (Medical Research Council) framework for development, design and evaluation of complex interventions. The project is a multi-method procedure and has two phases. In the first phase, which has already been completed, we used a reflective practice procedure where general practice teams were asked about how they currently deal with family caregivers. In the second phase, a participatory action research approach aims to improve identification and response to when support is necessary for family caregivers. Ten participating general practice teams each enrol 40 eligible patients and their family caregiver, to identify structures and tools feasible for use in their practice. Standardised self-reported questionnaires (Burden Scale for Family Caregivers and Quality of Life Questionnaire Core 15 Palliative) are being applied at study inclusion (prior to or during the implementation period) and after 6 and 12 months to explore implementation effects. Qualitative assessment of general practice teams’ experiences will be triangulated with the quantitative evaluation of the implementation.

DISCUSSION: This two-step approach, which is appropriate to primary palliative care in the German health care context, will enable general practice teams to develop feasible, acceptable and successful strategies for the implementation of best practice to successfully support family caregivers of patients at the end of life.
Experience of services as a key outcome in amyotrophic lateral sclerosis (ALS) care: the case for a better understanding of patient experiences.

Foley G; Timonen V; Hardiman O.


People with amyotrophic lateral sclerosis (ALS) frequently express dissatisfaction with services. Patient satisfaction with services in ALS care is not always measured and service user perspectives are not usually included when evaluating the outcomes of care. There is a lack of consensus on what constitutes satisfaction for patients in ALS care. To date, health care professionals’ conceptualization of outcomes in ALS care has excluded measures of patient satisfaction with services. Exploring the context of the ALS service user experience of care will identify a conceptual framework that will include the domains of satisfaction with care for patients with ALS. An instrument that draws on the ALS patient perspective of services, developed on the basis of qualitative investigation, should be used to measure satisfaction with services.

Millennial health care: change you can believe in.

Pingleton SK.


A millennium is 1,000 years. In little over a decade after the beginning of the new millennium in 2000, remarkable changes have occurred in health-care education and health-care delivery. A new millennial generation of students, trainees, junior faculty, and young practicing physicians has come of age. The numbers of women in medicine have vastly increased. Technology has impacted education with an array of educational content-delivery techniques vastly different from the usual broadcast method of teaching. New curricula have expanded to encompass teamwork with interprofessional education of the entire team. Outcomes of educational efforts now include
not only knowledge transfer but also performance improvement. Delivery of health care is also dramatically different. The sentinel driver of the quality and patient safety moment, To Err Is Human, was published only 12 years ago, yet fundamental changes in expectations and measurement for health-care quality and safety have occurred to alter the health-care landscape. Financing health care has become a prime issue in the current state of the US economy. New themes in health-care delivery include teamwork and highly functioning teams to improve patient safety, the dramatic increase in palliative care and end-of-life care, and the expanded role of nursing in health-care delivery. Each issue emanating since the beginning of the millennium does not have a right vs wrong implication. This discussion is an apolitical "environmental scan" with the purpose of illuminating these dramatic changes and then outlining the implications for health-care education and health-care delivery in the coming years.

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20120716
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2012

286.
Using opioids to treat dyspnea in advanced COPD: attitudes and experiences of family physicians and respiratory therapists.
Young J; Donahue M; Farquhar M; Simpson C; Rocker G. Canadian Family Physician. 58(7):e401-7, 2012 Jul.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 22798476
OBJECTIVE: To explore the experiences of family physicians and respiratory therapists in treating advanced chronic obstructive pulmonary disease (COPD) and their attitudes to the use of opioids for dyspnea in this context.
DESIGN: Qualitative methodology using one-on-one semistructured interviews.
SETTING: Southern New Brunswick (St Stephen to Sussex).
PARTICIPANTS: Ten family physicians and 8 respiratory therapists who worked in primary care settings.
METHODS: Participant interviews were audiorecorded, transcribed verbatim, coded conceptually, and thematically analyzed using interpretive description.
MAIN FINDINGS: Participants reported that patients with advanced COPD often suffered from inadequate control of their dyspnea in advanced stages and that they saw the potential value of opioids in this context; however, family physicians described discomfort prescribing opioids. Barriers included insufficient knowledge, lack of education and guidelines, and fear of censure. Those with palliative care experience tended to be more comfortable with opioid prescribing.
CONCLUSION: Findings suggest an important need to address barriers related to more effective treatment of refractory dyspnea in advanced COPD. Further, findings indicate these efforts should focus on effective palliation and innovative educational initiatives, as well as the development, promotion, and uptake of evidence-based practice guidelines related to prescribing opioids for these patients.

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AIMS AND OBJECTIVES: The study aim was to develop a service evaluation tool for an advance care planning model developed for community palliative care services.
BACKGROUND: Internationally, advance care planning programmes usually measure success by completion rate of advance directives or plans. This outcome measure provides little information to assist nurse managers to embed advance care planning into usual care and measure their performance and quality over time. An evaluation tool was developed to address this need in Australian community palliative care services.
DESIGN: Multisite action research approach.
METHODS: Three community palliative care services located in Victoria, Australia, participated. Qualitative and quantitative data collection strategies were used to develop the Advance Care Planning-Service Evaluation Tool.
RESULTS: The Advance Care Planning-Service Evaluation Tool identified advance care planning progress over time across three stages of Establishment, Consolidation and Sustainability within previously established Model domains of governance, documentation, practice, education, quality improvement and community engagement. The tool was used by nurses either as a peer-assessment or self-assessment tool that assisted services to track their implementation progress as well as plan further change strategies.
CONCLUSION: The Advance Care Planning-Service Evaluation Tool was useful to nurse managers in community palliative care. It provided a clear outline of service progress, level of achievement and provided clear direction for planning future changes.

RELEVANCE TO CLINICAL PRACTICE: The Advance Care Planning-Service Evaluation Tool enables nurses in community palliative care to monitor, evaluate and plan quality improvement of their advance care planning model to improve end-of-life care. As the tool describes generic healthcare processes, there is potential transferability of the tool to other types of services.

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Year of Publication
2012


Jennings AL; Davies AN; Higgins JP; Anzuera-Cabrera J; Broadley KE.
Cochrane Database of Systematic Reviews. 7:CD002066, 2012.
[Journal Article. Review]
UI: 22786477

BACKGROUND: Breathlessness is a common symptom in people with advanced disease. The most effective treatments are aimed at treating the underlying cause of the breathlessness but this may not be possible and symptomatic treatment is often necessary. Strategies for the symptomatic treatment of breathlessness have never been systematically evaluated. Opioids are commonly used to treat breathlessness: the mechanisms underlying their effectiveness are not completely clear and there have been few good-sized trials in this area.

OBJECTIVES: To determine the effectiveness of opioid drugs given by any route in relieving the symptom of breathlessness in patients who are being treated palliatively.

SEARCH METHODS: An electronic search was carried out of Medline, Embase, CINAHL, The Cochrane Library, Dissertation Abstracts, Cancercd and SIGLE. Review articles and reference lists of retrieved articles were hand searched. Date of most recent search: May 1999.

SELECTION CRITERIA: Randomised double-blind, controlled trials comparing the use of any opioid drug against placebo for the relief of breathlessness were included. Patients with any illness suffering from breathlessness were included and the intervention was any opioid, given by any route, in any dose.
DATA COLLECTION AND ANALYSIS: Studies identified by the search were imported into a reference manager database. The full texts of the relevant studies were retrieved and data were independently extracted by two review authors. Studies were quality scored according to the Oxford Quality scale. The primary outcome measure used was breathlessness and the secondary outcome measure was exercise tolerance. Studies were divided into non-nebulised and nebulised and were analysed both separately and together. A qualitative analysis was carried out of adverse effects of opioids. Where appropriate, meta-analysis was carried out.

MAIN RESULTS: Eighteen studies were identified of which nine involved the non-nebulised route of administration and nine the nebulised route. A small but statistically significant positive effect of opioids was seen on breathlessness in the analysis of studies using non-nebulised opioids. There was no statistically significant positive effect seen for exercise tolerance in either group of studies or for breathlessness in the studies using nebulised opioids.

AUTHORS' CONCLUSIONS: There is evidence to support the use of oral or parenteral opioids to palliate breathlessness although numbers of patients involved in the studies were small. No evidence was found to support the use of nebulised opioids. Further research with larger numbers of patients, using standardised protocols and with quality of life measures is needed.

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289.
[Communication strategies used by health care professionals in providing palliative care to patients]. [Portuguese]
Trovo de Araujo MM; da Silva MJ.
UI: 22773483
The objective of this study is to verify the relevance and utilization of communication strategies in palliative care. This is a multicenter qualitative study using a questionnaire, performed from August of 2008 to July of 2009 with 303 health care professionals who worked with patients receiving palliative care. Data were subjected to descriptive statistical analysis. Most participants (57.7%) were unable to state at least one verbal communication strategy, and only 15.2% were able to describe five signs or non-verbal communication strategies. The verbal strategies most commonly mentioned were those related to answering questions about the disease/treatment. Among the non-verbal strategies used, the most common were affective touch, looking, smiling,
physical proximity, and careful listening. Though professionals have assigned a high degree of importance to communication in palliative care, they showed poor knowledge regarding communication strategies. Final considerations include the necessity of training professionals to communicate effectively in palliative care.

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290.
Are opioid risk evaluation and mitigation strategies (REMS) interrupting your sleep?.
Craig DS.
[Comment. Journal Article]
UI: 22764851

The article entitled "Risk Evaluation and Mitigation Strategies (REMS) for Extended-Release and Long-Acting Opioid Analgesics: Considerations for Pain and Palliative Care Practice" that appears in this issue of the journal addresses the important new Food and Drug Administration (FDA) REMS program. This commentary expands on themes introduced by Dr. Gudin, projects future directions for REMS, and discusses possible benefits, limitations, and risks associated with the extended-release long-acting opioid REMS.

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2012

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Managing Cancer and Living Meaningfully (CALM): a qualitative study of a brief individual psychotherapy for individuals with advanced cancer.
Nissim R; Freeman E; Lo C; Zimmermann C; Gagliese L; Rydall A; Hales S; Rodin G. Palliative Medicine. 26(5):713-21, 2012 Jul.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 22042225

BACKGROUND: Although psychosocial care has been regarded as central to palliative and supportive care, there have been few empirically tested approaches to individual intervention. AIM: The subjective experience of advanced cancer patients receiving a new manualized brief individual psychotherapy, referred to as Managing Cancer and Living Meaningfully (CALM), was examined prior to the initiation of a randomized controlled trial testing the effectiveness of this intervention.

DESIGN: Semi-structured interviews were conducted with patients who had a diagnosis of advanced cancer, and who underwent the intervention.

SETTING/PARTICIPANTS: Patients were recruited from a large urban regional cancer center in Toronto, Canada. The 10 interviewees included seven women and three men. All had completed between three to six CALM sessions prior to the interview.

RESULTS: The CALM intervention was associated with profound and unique patient-identified benefits and no patient-identified risks or concerns. Five interrelated benefits of the intervention were identified: (1) a safe place to process the experience of advanced cancer; (2) permission to talk about death and dying; (3) assistance in managing the illness and navigating the healthcare system; (4) resolution of relational strain; and (5) an opportunity to 'be seen as a whole person' within the healthcare system. These benefits were regarded by participants as unique in their cancer journey.

CONCLUSIONS: Findings from a qualitative study suggest that the CALM intervention provides substantial benefits for patients with advanced cancer prior to the end of life. Findings informed the development of a randomized controlled trial to evaluate the effectiveness of this intervention.

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292.
The personal value of being a palliative care Community Volunteer Worker in Uganda: a qualitative study.
Jack BA; Kirton JA; Birakurataki J; Merriman A.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 21920988
BACKGROUND: Volunteers in palliative care play a key role, particularly in the hospice setting. The expansion of palliative care into developing countries has been accompanied by the emergence of volunteer workers, who are providing a main source of support and care for patients, many of whom never see a health professional.
AIM: The aim of this study was to evaluate the motivation for becoming a volunteer and the personal impact of being a palliative care Community Volunteer Worker in Uganda.
DESIGN: A qualitative methodology using semi-structured individual and group digitally recorded interviews was adopted for the study. Data were analysed for emerging themes using thematic analysis.
SETTING/PARTICIPANTS: Forty-three interviews were undertaken, 32 with Community Volunteer Workers and 11 with the Hospice clinical teams, using semi-structured digitally recorded individual, group and focus group interviews at the Hospice Africa sites in Uganda.
RESULTS: The results identified the cultural wish to help people as a key motivator in becoming a volunteer. Additionally, the volunteers reported having a sense of pride in their volunteering role, and this role had a positive impact on their perceived status in their local community.
CONCLUSION: This model of volunteering is clearly having an impact on the volunteers, both personally and also in terms of how they are treated in their communities. Further research to explore the long-term personal benefits of being a palliative care volunteer is recommended.

293.
What are cancer patients' experiences and preferences for the provision of written information in the palliative care setting? A focus group study.
Tomlinson K; Barker S; Soden K.
[Journal Article. Research Support, Non-U.S. Gov't]
BACKGROUND: Whilst there is a wide range of literature pertaining to the need for excellent verbal communication within the palliative care setting, there is a paucity of research designed to identify the written informational needs of such patients.

AIM: To identify the experiences and wishes of patients known to a specialist palliative care service in England with regards to written information. We considered both generalizable written information (such as leaflets, books and internet resources) as well as individualized information (for example, copies of letters given to patients).

DESIGN: Five focus group discussions were recorded and transcribed for analysis.

SETTING/PARTICIPANTS: The focus groups took place at one specialist palliative care unit in England. Twenty-two patients with cancer over the age of 18 years were recruited.

RESULTS: Inductive, realist thematic analysis of the data set was performed. Themes have been broadly categorized into three main areas: (i) patients' views on the role of written information, (ii) their experiences of written information in different formats, and (iii) their thoughts on what written information they would most value.

CONCLUSIONS: Written information needs for this patient group vary greatly, sometimes in ways which can be predicted. Using a patient-centred approach to elicit information around an individual's coping strategies, desire for knowledge and empowerment may be helpful. The data supports a proactive approach to making available (to those who want them) clear, concise and attractive leaflets.

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294.
Shared care: the barriers encountered by community-based palliative care teams in Ontario, Canada.
DeMiglio L;  Williams A.
[Journal Article.  Research Support, Non-U.S. Gov't]
UI: 22469189
To meet the complex needs of patients requiring palliative care and to deliver holistic end-of-life care to patients and their families, an interprofessional team approach is recommended. Expert palliative care teams work to improve the quality of life of patients and families through pain and symptom management, and psychosocial spiritual and bereavement support. By establishing
shared care models in the community setting, teams support primary healthcare providers such as family physicians and community nurses who often have little exposure to palliative care in their training. As a result, palliative care teams strive to improve not only the end-of-life experience of patients and families, but also the palliative care capacity of primary healthcare providers. The aim of this qualitative study was to explore the views and experiences of community-based palliative care team members and key-informants about the barriers involved using a shared care model to provide care in the community. A thematic analysis approach was used to analyse interviews with five community-based palliative care teams and six key-informants, which took place between December 2010 and March 2011. Using the 3-I framework, this study explores the impacts of Institution-related barriers (i.e. the healthcare system), Interest-related barriers (i.e. motivations of stakeholders) and Idea-related barriers (i.e. values of stakeholders and information/research), on community-based palliative care teams in Ontario, Canada. On the basis of the perspective of team members and key-informants, it is suggested that palliative care teams experience sociopolitical barriers in an effort to establish shared care in the community setting. It is important to examine the barriers encountered by palliative care teams to address how to better develop and sustain them in the community. Copyright 2012 Blackwell Publishing Ltd.

295.
Stressors experienced by nurses providing end-of-life palliative care in the intensive care unit.
Gelinas C; Fillion L; Robitaille MA; Truchon M.
Ut: 22679843
The purpose of this study was to describe stressors experienced by nurses in providing end-of-life palliative care (EoL/PC) in intensive care units (ICUs). A descriptive qualitative design was used. A total of 42 nurses from 5 ICUs in the province of Quebec, Canada, participated in 10 focus groups. Stressors were found to be clustered in 3 categories: organizational, professional, and emotional. The major organizational stressors were lack of a palliative care approach, interprofessional difficulty, lack of continuity in life-support and treatment plans, and conflicting demands. Professional stressors included lack of EoL/PC competencies and difficulty communicating with families and collaborating with the medical team. Emotional stressors were
described as value conflicts, lack of emotional support, and dealing with patient and family suffering. The authors conclude that providing EoL/PC is stressful for ICU nurses and that education and support programs should be developed to ensure quality EoL/PC in the critical care environment.

Objectives: Little is known about caregiver experiences during the end-of-life period. Our objective was to characterize caregiver perceptions of their experiences in cancer survivorship with special reference to the end-of-life stage considering depression in bereavement.

Methods: Qualitative research using in-depth interviews of 34 caregivers from two palliative care units in Japan. Data were analyzed inductively using framework analysis. Depression and personality traits were measured using the Center for Epidemiological Studies Depression (CES-D) and Sense of Coherence (SOC) scales, respectively.

Results: Caregiver perceptions were characterized along two axes. One axis involved four caregiver-cancer patient relationships: strengthening, reconstruction, intimacy-maintained, and estrangement-maintained. The core concept was transformation of relationships: caregivers reappraised aspects of caregiver-patient interactions through caregiving. The other axis involved subjective caregiving experiences divided into five concepts: spontaneity of care, discussing death, sympathy for patient emotions, impressions on first witnessing death, and introspective reflections in bereavement. Strengthening and reconstruction relationships appeared similar among the four relationship types, but only the former tended to overcompensate by sacrificing private time. Although median CES-D scores in each relationship type were under the cutoff for possible depression, four of eight caregivers suspected to have depressive tendencies belonged to the strengthening type. The mean SOC score for all caregivers was intermediate relative to scores previously reported in Japanese studies.

Conclusions: While caregivers’ subjective experiences can be classified, their relationship to depression in bereavement needs future research. The present findings indicate that caregivers
should also be considered in clinicians’ views of cancer survivorship. Copyright 2011 John Wiley & Sons, Ltd.

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CONTEXT: Cultural dimensions related to illness are triggered at significant times in an illness trajectory, such as at illness onset or when death approaches. These factors influence views on how illness is understood and managed, which is likely more difficult for minority populations. Although Latinos experience barriers to high-quality health care, late-stage cancer diagnoses, and poor health outcomes, little is known about their experiences with advanced, life-threatening cancers.

OBJECTIVES: We examined Latinas’ experiences with advanced, metastatic cancers to identify sociocultural beliefs that influenced their care.

METHODS: We interviewed 24 Latinas taking part in a randomized controlled trial focused on improving quality-of-life outcomes for co-occurring cancer and depression and explored their beliefs about the cause, course, and cure of cancer. This study used a phenomenological analytical approach to explore women’s lived experiences of having advanced cancer.

RESULTS: Themes revealed issues about experiencing advanced cancer that included the following: initial reactions to cancer, disbelief about the lack of pain, economic impact, beliefs about the cause, coping with cancer, beliefs about the cure, and confusion about cancer severity. Sociocultural factors influence misunderstanding and confusion about cancer care but also can be a source of strength.

CONCLUSION: Providers need to become culturally sensitive to the needs of underserved Latinas. Denial or ignorance of these issues can create other problems, such as gaps in patient-centered decision making from diagnosis through the end of life. Copyright Published by Elsevier Inc.
Enhancing patient-reported outcome measurement in research and practice of palliative and end-of-life care.

Simon ST; Higginson IJ; Harding R; Daveson BA; Gysels M; Deliens L; Echteld MA; Radbruch L; Toscani F; Krzyzanowski DM; Costantini M; Downing J; Ferreira PL; Benalia A; Bausewein C; PRISMA.

Supportive Care in Cancer. 20(7):1573-8, 2012 Jul.

[Journal Article. Research Support, Non-U.S. Gov't]

UI: 22391595

PURPOSE: Patient-reported outcome measurement (PROM) plays an increasing role in palliative and end-of-life (EOL) care but their use in EOL care and research remains varied and inconsistent. We aimed to facilitate pan-European collaboration to improve PROMs in palliative and EOL care and research.

METHODS: The study includes a workshop with experts experienced in using PROMs in clinical care and research from Europe, North America, and Africa. Information from presentations, and plenary and group discussions was analysed using content analysis for extracting the main themes.

RESULTS: Thirty-two professionals from 15 countries and eight different professional backgrounds participated in the workshop. The discussion identified: 1) the need for standardisation with improvement of existing PROMs, e.g., with a modular system and an optional item pool; 2) the aspects of further development with a multi-professional approach taking into account cultural sensitivity especially for translated versions; and 3) the need for guidance, training, and resources. An international network for sharing concepts, experiences, and solutions could enhance these steps of further development.

CONCLUSION: PROMs must be based on rigorous scientific methods and respond to patient complexity. Coordinated pan-European collaboration including researchers and clinicians is required to develop and attain quality care and systematic research in outcome measurement in palliative and EOL care.
How do nurses assess quality of life of cancer patients in oncology wards and palliative settings?

Bahrami M; Arbon P.


[Journal Article]

PURPOSE: How Quality of Life (QoL) assessment is conducted across different oncology wards and palliative settings is a challenging issue and needs to be searched further. There is a lack of interpretive research study in Australian populations in which QoL assessment for cancer patients in oncology and palliative areas has deeply been explored. Therefore, an interpretive research study was conducted to explore in-depth nurses' QoL assessment conducted in oncology wards and palliative settings.

METHOD: The study was completed in 2007 in two major public hospitals in Adelaide, South Australia. Ten nurses were selected from different inpatient and outpatient oncology services and a palliative setting to take part in semi-structured interviews. The study was a 'grounded theory approach' in which some aspects of the grounded theory were used to gain a fundamental understanding and broad description of the experience of QoL assessment as conducted by nurses.

RESULTS: After the data collection and analysis six main themes were identified. Four of the themes are presented as: a) Cues-based QoL assessment, and b) Purpose-based QoL assessment, c) Facilitators of QoL assessment, and d) Barriers of QoL assessment.

CONCLUSIONS: Findings of the research study generally supported the notion that nurses mainly pick up on patients' cues as a way for QoL assessment when they communicate with patients in the clinical area rather than using QoL tools. Also, nurses are, at times, uncertain if they are doing a QoL assessment and if their assessment of patients' QoL is correct or not. Therefore, this supports a need for nurses to develop a more holistic relationship and stronger rapport with patients which underpins the assessment of cancer patients' QoL through various cues.

Copyright 2011 Elsevier Ltd. All rights reserved.
Health system characteristics of quality care delivery: a comparative case study examination of palliative care for cancer patients in four regions in Ontario, Canada.
Sussman J; Barbera L; Bainbridge D; Howell D; Yang J; Husain A; Librach SL; Viola R; Walker H.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 21831915

BACKGROUND: A number of palliative care delivery models have been proposed to address the structural and process gaps in this care. However, the specific elements required to form competent systems are often vaguely described.

AIM: The purpose of this study was to explore whether a set of modifiable health system factors could be identified that are associated with population palliative care outcomes, including less acute care use and more home deaths.

DESIGN: A comparative case study evaluation was conducted of 'palliative care' in four health regions in Ontario, Canada. Regions were selected as exemplars of high and low acute care utilization patterns, representing both urban and rural settings. A theory-based approach to data collection was taken using the System Competency Model, comprised of structural features known to be essential indicators of palliative care system performance. Key informants in each region completed study instruments. Data were summarized using qualitative techniques and an exploratory factor pattern analysis was completed.

RESULTS: 43 participants (10+ from each region) were recruited, representing clinical and administrative perspectives. Pattern analysis revealed six factors that discriminated between regions: overall palliative care planning and needs assessment; a common chart; standardized patient assessments; 24/7 palliative care team access; advanced practice nursing presence; and designated roles for the provision of palliative care services.

CONCLUSIONS: The four palliative care regional 'systems' examined using our model were found to be in different stages of development. This research further informs health system planners on important features to incorporate into evolving palliative care systems.

Status
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Barbera, Lisa; Bainbridge, Daryl; Howell, Doris; Yang, Jinghao; Husain, Amna; Librach, S Lawrence; Viola, Raymond; Walker, Hugh.
301. Providing in-home palliative care within a generalist caseload: a chance for nurses to reflect on life and death.
UI: 22584314
At a time when the need for in-home palliative care is on the rise, the aim of this interpretive phenomenological study was to understand the experiences of homecare nurses providing palliative care within a generalist caseload. Eight such nurses from one district of Quebec were interviewed. Data analysis was carried out according to the phenomenological method developed by Giorgi. Three themes emerged from the analysis: supporting the patient and his/her family, being concerned about providing quality care, and being confronted with death fosters personal development. The findings that gave rise to the first two themes echo similar findings from the literature, but those from which the third theme emerged are more novel. Important considerations for personal and professional development are extrapolated from these findings.

The subject of death denial in the West has been examined extensively in the sociological literature. However, there has not been a similar examination of its "opposite", the acceptance of death. In this study, I use the qualitative method of discourse analysis to examine the use of the term "acceptance" of dying in the palliative care literature from 1970 to 2001. A Medline search was performed by combining the text words "accept or acceptance" with the subject headings "terminal care or palliative care or hospice care", and restricting the search to English language articles in clinical journals discussing acceptance of death in adults. The 40 articles were coded and analysed using a critical discourse analysis method. This paper focuses on the theme of acceptance as integral to palliative care, which had subthemes of acceptance as a goal of care, personal acceptance of healthcare workers, and acceptance as a facilitator of care. For patients and families, death acceptance is a goal that they can be helped to attain; for palliative care staff, acceptance of dying is a personal quality that is a precondition for effective practice. Acceptance not only facilitates the dying process for the patient and family, but also renders care easier. The analysis investigates the intertextuality of these themes with each other and with previous texts. From a Foucauldian perspective, I suggest that the discourse on acceptance of dying represents a productive power, which disciplines patients through apparent psychological and spiritual gratification, and encourages participation in a certain way to die. Copyright 2012 Elsevier Ltd. All rights reserved.

Intensive communication skills teaching for specialist training in palliative medicine: development and evaluation of an experiential workshop.
Clayton JM; Adler JL; O'Callaghan A; Martin P; Hynson J; Butow PN; Laidsaar-Powell RC; Arnold RM; Tulsky JA; Back AL.
[Evaluation Studies. Journal Article]
UI: 22433021
BACKGROUND: The Australasian Chapter of the Palliative Medicine (AChPM) Curriculum Development Group identified communication as a core skill that trainees in palliative medicine need to acquire, and proposed the development of a communication skills workshop that should
become a compulsory part of training to achieve accreditation as a palliative medicine specialist in Australia and New Zealand. This paper describes the development and subsequent evaluation of this module.

METHODS: A three-day communication workshop was developed in collaboration with expert communication skills facilitators from the United States and Australia. The teaching consists of: (1) brief plenary presentations providing an evidence-based framework for communication and a demonstration of suggested strategies; (2) small group experiential learning providing opportunities to practice communication skills with clinically relevant simulated patients, self-appraisal, constructive feedback, and reflective exercises; and (3) accompanying course-specific written material. Participants completed de-identified questionnaires before, after, and three months following completion of the workshop.

RESULTS: Forty-one participants completed the training in two workshops held in 2008 and 2009. Participants said in their questionnaire responses that the training was useful, would be helpful for their communication with patients, and that they would recommend the training to others. Qualitative feedback was highly positive. Self-assessed confidence in communication skills significantly increased following the workshop (p<.001) and was sustained at three months (p<.001).

CONCLUSION: The training is highly valued by participants and increases confidence in communication skills. Facilitator training and capacity planning will be critical for the ongoing success of the communication workshop.
known about how health professionals facilitate education with patients with other advanced progressive diseases.

OBJECTIVES: The aim of this review was to synthesize qualitative research examining health professionals' knowledge of, attitudes toward, and ability to deliver educational interventions for symptom and disease management to patients with advanced progressive diseases other than cancer.

METHODS: The synthesis was conducted using meta-ethnography. Systematic searching of five electronic databases (CINAHL, Medline, PsycInfo, Web of Science Social Science Citation Index, and EMBASE) was performed. Included studies were data extracted and assessed for quality.

RESULTS: Systematic searching of four electronic databases identified 911 records; 17 studies met review inclusion criteria and underwent data extraction and quality appraisal. Three key factors were identified that influenced the delivery of education by health professionals to patients with advanced disease: capacity (to educate and aid decision making), context (of educational delivery), and timing (of education).

CONCLUSION: Health professionals identify and acknowledge a range of factors that influence their ability to deliver education to patients with advanced disease. The types of circumstantial factors identified in this review can influence the successful delivery of educational interventions and need to be considered when such interventions are being developed. Copyright 2012 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.
METHODS: A cross-sectional survey of 301 consecutive eligible patients recruited from a palliative care service in south London, U.K. Measures used included the Brief Illness Perception Questionnaire (Brief IPQ), the Mental Adjustment to Cancer (MAC) Scale, and the Primary Care Evaluation of Mental Disorders Patient Health Questionnaire-9.

RESULTS: Scores were not normally distributed for most questions on the Brief IPQ. The correlations found between items on the Brief IPQ were understandable in the context of advanced disease. MAC helplessness-hopelessness and fighting spirit were highly correlated with items on the Brief IPQ in opposite directions. The Brief IPQ domains of consequences, identity, concern, personal control, and emotion were associated with depression, a relationship that was not explained by adaptive coping. Seven causal attribution themes were identified: don't know, personal responsibility, exposure, pathological process, intrinsic personal factors, chance, fate or luck, and other. Both lung cancer diagnosis and gender were found to be independently associated with personal responsibility attribution. None of the attribution themes were associated with the presence of depression.

CONCLUSION: Assessment of illness perceptions in palliative care is likely to yield important information about risk of depression and will help clinicians to personalize management of advanced disease. Copyright 2012 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

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2012

Evaluating a complex intervention: a process evaluation of a psycho-education program for lung cancer patients receiving palliative radiotherapy.
Chan CW; Richardson A; Richardson J.
[JOURNAL ARTICLE. RESEARCH SUPPORT, NON-U.S. GOV'T]
UI: 22554216
This study was to examine the integrity of intervention delivery and identify precursory factors contributing to successful delivery and the effectiveness of a psycho-educational intervention comprising progressive muscle relaxation and health education in patients receiving palliative lung cancer radiotherapy. This mixed methods study employed both quantitative and qualitative methods to investigate intervention integrity and to identify key precursory factors among 70
Hong Kong Chinese lung cancer patients. Results show that the intervention conducted by two support nurses, in line with that planned at the outset of the study, achieved a high degree of consistency. Full adherence to the 20-minute muscle relaxation component was an important factor contributing to better symptom management. Other contributing factors included use of supplementary audio and reading materials and frequent self-practice of muscle relaxation. Reinforcement strategies, together with the use of supplementary learning materials and a flexible approach to progressive muscle relaxation, are recommended for future research.

Reinforcement strategies, together with the use of supplementary learning materials and a flexible approach to progressive muscle relaxation, are recommended for future research.

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Year of Publication
2012

A survey of chaplains' roles in pediatric palliative care: integral members of the team.
Lyndes KA; Fitchett G; Berlinger N; Cadge W; Misasi J; Flanagan E.

To date, the field of health care chaplaincy has had little information about how pediatric palliative care (PPC) programs meet the spiritual needs of patients and families. We conducted a qualitative study consisting of surveys of 28 well-established PPC programs in the United States followed by interviews with medical directors and professional chaplains in 8 randomly selected programs among those surveyed. In this report, we describe the PPC chaplain activities, evidence regarding chaplain integration with the PPC team, and physician and chaplain perspectives on the chaplains' contributions. Chaplains described their work in terms of processes such as presence, while physicians emphasized outcomes of chaplains' care such as improved communication. Learning to translate what they do into the language of outcomes will help chaplains improve health care colleagues' understanding of chaplains' contributions to care for PPC patients and their families. In addition, future research should describe the spiritual needs and resources of PPC patients and families and examine the contribution chaplains make to improved outcomes for families and children facing life-limiting illnesses.

Status
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Fitchett, George; Berlinger, Nancy; Cadge, Wendy; Misasi, Jennifer; Flanagan, Erin.

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Are UK primary care teams formally identifying patients for palliative care before they die?.
Harrison N; Cavers D; Campbell C; Murray SA.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 22546594

BACKGROUND: The palliative care approach has the potential to improve care for patients with progressive life-threatening illnesses from the time of diagnosis. Policy and clinical directives in the UK advocate early identification.

AIM: To determine the extent to which practices identify patients for palliative care, including factors influencing early identification and possible effects on place of death.

DESIGN AND SETTING: Qualitative and quantitative data were collected from six general practices from three Scottish NHS boards and analysed.

METHOD: Records of patients who had died in the previous 6 months were analysed and interviews with practice staff (n = 21) and with patients currently on the practice palliative care register and bereaved relatives (n = 14) were conducted. In addition, a practice meeting was observed.

RESULTS: In total, 29% of patients who died were recorded as being on the practice palliative care register before death. Two-thirds of patients with cancer were recorded on the register, but for those with non-malignant conditions only around 20% had any palliative care documented.

This was a result of GPs not finding the current guidelines useful and being reluctant to discuss palliative care overtly with patients early in their illness. Palliative care services and documentation were geared towards patients with cancer. More district nurses than GPs saw the benefits of inclusion on the palliative care register. Only 25% of patients on the register died in hospital.

CONCLUSION: Most patients with advanced progressive illnesses, especially those with non-malignant disease, are not being formally identified for a palliative care approach before they die. Those identified are more likely to benefit from coordinated care and may be more likely to die at home.

Status
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Research into the value of music therapy in pediatric palliative care (PPC) has identified quality of life as one area of improvement for families caring for a child in the terminal stages of a life-threatening illness. This small-scale investigation collected data in a multisite, international study including Minnesota, USA, and Melbourne, Australia. An exploratory mixed method design used the qualitative data collected through interviews with parents to interpret results from the PedsQL Family Impact Module of overall parental quality of life. Parents described music therapy as resulting in physical improvements of their child by providing comfort and stimulation. They also valued the positive experiences shared by the family in music therapy sessions that were strength oriented and family centered. This highlighted the physical and communication scales within the PedsQL Family Impact Module, where minimal improvements were achieved in contrast to some strong results suggesting diminished quality of life in cognitive and daily activity domains. Despite the significant challenges faced by parents during this difficult time, parents described many positive experiences in music therapy, and the overall score for half of the parents in the study did not diminish. The value of music therapy as a service that addresses the family-centered agenda of PPC is endorsed by this study.
The healing and spiritual properties of music therapy at a cancer care center.
McClean S; Bunt L; Daykin N.  
[Journal Article]  
UI: 22384974  
BACKGROUND: This article explores the theme of spirituality, health, and well-being, in relation to an emerging body of research on the impact of music therapy in cancer care. The focus of this article is a music therapy service established as part of a residential 5-day retreat program at a cancer care center.  
AIMS: The aim of the study was to explore the experiences of patients with cancer with one-off group music therapy at a cancer care center. Central emphasis is given to exploring a range of themes relating to the healing and spiritual properties of music therapy group work.  
METHODS: This is a qualitative study, following a modified grounded-theory approach. Twenty-three (23) in-depth tape-recorded telephone interviews were conducted with people who had taken part in the music therapy sessions.  
RESULTS: The results focus on those findings relevant to notions of spirituality and healing, drawing on four overarching spirituality themes of transcendence, connectedness, search for meaning, and faith and hope.  
CONCLUSIONS: The authors consider the applicability of broader schemas that attempt to define and explore the role and significance of spirituality.  
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Date Created  
20120420  
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Palliative care case conferencing involving general practice: an argument for a facilitated standard process.  
Davison G; Shelby-James TM.  
[Journal Article]  
UI: 22513031
OBJECTIVE: To discuss the results of a qualitative analysis of the group dynamics of General Practitioner (GP)-led case conferences for palliative care patients, where the GP becomes the care coordinator. Two outcomes are sought: (1) raise the understanding of this type of case conferencing for palliative care patients; and (2) recommend improvements to this process that will positively affect its efficacy.

METHODS: Original data is the qualitative component of quantitative and qualitative study of 17 GP-led case conferences for palliative care patients. Data were analysed using Carney’s Ladder of Analytical Abstraction.

RESULTS: Analysis produced four persistent themes: ambiguity of purpose; ambiguity of role; lack of information; and involvement of multiple interconnected and dynamic groups. These themes are a natural result of the case conferencing process that occurred during the study.

CONCLUSION: Case conferences were inherently uncertain and complex. Complexity results from the range of people and groups interacting with the patient before the case conference who do not attend the conference. Uncertainty results from a lack of direction, leadership and agreed outcomes against which the conference can be structured and measured. A standard process facilitated by someone other than the GP and containing necessary information would offer a better chance of optimising this process.

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Date Created
20120419
Year of Publication
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312.
Considerations of physicians about the depth of palliative sedation at the end of life.
Swart SJ; van der Heide A; van Zuylen L; Perez RS; Zuurmond WW; van der Maas PJ; van Delden JJ; Rietjens JA.
CMAJ Canadian Medical Association Journal. 184(7):E360-6, 2012 Apr 17.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 22331961

BACKGROUND: Although guidelines advise titration of palliative sedation at the end of life, in practice the depth of sedation can range from mild to deep. We investigated physicians’ considerations about the depth of continuous sedation.

METHODS: We performed a qualitative study in which 54 physicians underwent semistructured interviewing about the last patient for whom they had been responsible for providing continuous palliative sedation. We also asked about their practices and general attitudes toward sedation.
RESULTS: We found two approaches toward the depth of continuous sedation: starting with mild sedation and only increasing the depth if necessary, and deep sedation right from the start. Physicians described similar determinants for both approaches, including titration of sedatives to the relief of refractory symptoms, patient preferences, wishes of relatives, expert advice and esthetic consequences of the sedation. However, physicians who preferred starting with mild sedation emphasized being guided by the patient's condition and response, and physicians who preferred starting with deep sedation emphasized ensuring that relief of suffering would be maintained. Physicians who preferred each approach also expressed different perspectives about whether patient communication was important and whether waking up after sedation is started was problematic.

INTERPRETATION: Physicians who choose either mild or deep sedation appear to be guided by the same objective of delivering sedation in proportion to the relief of refractory symptoms, as well as other needs of patients and their families. This suggests that proportionality should be seen as a multidimensional notion that can result in different approaches toward the depth of sedation.

313. Nurses’ attitudes and experiences surrounding palliative sedation: components for developing policy for nursing professionals.
Patel B; Gorawara-Bhat R; Levine S; Shega JW.
[Journal Article. Research Support, N.I.H., Extramural. Research Support, Non-U.S. Gov't]
UI: 22500480
BACKGROUND: Nurses play an integral role in providing care for patients with end of life (EOL) symptoms refractory to conventional treatments and that may necessitate palliative sedation (PS). A paucity of research on nurses' attitudes, knowledge, and experience with PS exists, despite nurses being instrumental in evaluating its appropriateness and carrying out the care plan.
OBJECTIVE: The objective of the study was to elicit nurses’ perspectives and conceptualizations of knowledge and skills needed to administer PS in order to inform development of a hospital policy that addresses identified concerns.

METHODS: Four focus groups were conducted with nurses likely to have had exposure to PS (oncology, intensive care, and hospice) at an academic medical center. Focus groups were audiotaped, transcribed verbatim, and coded for salient themes. Grounded theory principles were used for the analysis.

RESULTS: Among the four focus groups (n=31), 87% were female, 58% between the ages of 36 and 55, and more than 40% reported 10-plus years of providing patient care. Five domains emerged as important in developing a PS policy: 1) ability to define PS; 2) criterion for using PS; 3) skill set for administering PS; 4) policy and procedural guidelines; and 5) education on PS and EOL care.

CONCLUSIONS: Nurses identified knowledge, skills, and guidelines as key considerations for implementing PS. Comprehensive policies along with adequate training are needed to expand the availability of PS in acute care hospitals and hospice programs.

314.
Thai Buddhist families’ perspective of a peaceful death in ICUs.
Kongsuwan W; Chaipetch O; Matchim Y.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 22497919
AIM: To describe the concept of a peaceful death in intensive care units (ICUs) from the perspective of Thai Buddhist family members.

METHODS: This descriptive qualitative study was based on data generated from individual in-depth interviews of nine Thai Buddhist family members from the southern region of Thailand whose loved ones died in adult ICUs. Colaizzi's phenomenological approach was used to analyse the data. Rigour for the study was established by Lincoln and Guba's guidelines for qualitative research studies.
FINDINGS: Five core qualities emerged that made-up the concept of a peaceful death as described by Thai Buddhist family members who cared for their loved ones while they were dying in ICUs. These core qualities were 'knowing death was impending, preparing for a peaceful state of mind, not suffering, being with family members and not alone, and family members were not mourning'.

CONCLUSION: Thai Buddhist family members described what they meant by a peaceful death. 'This was: preparing for a peaceful state of mind in knowing that one's impending death is not a situation of suffering or being alone, but rather a time of being with family members who are not yet mourning one's death.' The findings support that family members should participate in promoting a peaceful death for their loved ones dying in ICUs.

IMPLICATIONS FOR PRACTICE: The five core qualities of a peaceful death reported in this study could be used as a framework for nurses to create nursing practice interventions for quality end-of-life care for Thai Buddhists.

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Year of Publication
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The model of Palliative Care in the perinatal setting: a review of the literature. [Review]
Balaguer A; Martin-Ancel A; Ortigoza-Escobar D; Escribano J; Argemi J.
[Journal Article. Research Support, Non-U.S. Gov't. Review]
UI: 22409881
BACKGROUND: The notion of Palliative Care (PC) in neonatal and perinatal medicine has largely developed in recent decades. Our aim was to systematically review the literature on this topic, summarise the evolution of care and, based on the available data, suggest a current standard for this type of care.

METHODS: Data sources included Medline, the Cochrane Library, CINAHL, and the bibliographies of the papers retrieved. Articles focusing on neonatal/perinatal hospices or PC were included. A qualitative analysis of the content was performed, and data on the lead author, country, year, type of article or design, and direct and indirect subjects were obtained.

RESULTS: Among the 1558 articles retrieved, we did not find a single quantitative empirical study. To study the evolution of the model of care, we ultimately included 101 studies, most of which were from the USA. Fifty of these were comments/reflections, and only 30 were classifiable
as clinical studies (half of these were case reports). The analysis revealed a gradual conceptual evolution of the model, which includes the notions of family-centered care, comprehensive care (including bereavement) and early and integrative care (also including the antenatal period). A subset of 27 articles that made special mention of antenatal aspects showed a similar distribution. In this subset, the results of the four descriptive clinical studies showed that, in the context of specific programmes, a significant number of couples (between 37 and 87%) opted for PC and to continue with the pregnancy when the foetus has been diagnosed with a lethal illness.

CONCLUSIONS: Despite the interest that PC has aroused in perinatal medicine, there are no evidence-based empirical studies to indicate the best model of care for this clinical setting. The very notion of PC has evolved to encompass perinatal PC, which includes, among other things, the idea of comprehensive care, and early and integrative care initiated antenatally.

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316.
Health care providers’ perspectives about working with parents of children with cancer: a qualitative study.
Klassen A; Gulati S; Dix D.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 22415857

Research to understand the sources of stress and job satisfaction in pediatric oncology staff is limited. The aim of the authors' qualitative study was to describe the key work-related demands and rewards in relation to working closely with parents from the perspective of health care providers (HCPs). Semistructured interviews were conducted with 13 doctors, 9 nurses, 5 social workers, and 6 child life specialists. Line-by-line, focused, and theoretical coding was used to establish categories and themes. Constant comparisons were used to examine the relationships within and across codes and categories. Interviewing continued until no new themes emerged. HCPs found it rewarding when they established close or long-term relationships with parents and to help families through the entire cancer journey, including palliative care. HCPs found it challenging to work with complex families; with parents who are demanding, rude, or angry; with parents who have differing views about the treatments and palliative care; and with having to
The Catalonia World Health Organization demonstration project for palliative care implementation: quantitative and qualitative results at 20 years. Gomez-Batiste X; Caja C; Espinosa J; Bullich I; Martinez-Munoz M; Porta-Sales J; Trejo J; Espejalba J; Stjernsward J. Journal of Pain & Symptom Management. 43(4):783-94, 2012 Apr. [Journal Article] UI: 22265127

Catalonia (Spain) has a total population of 7.3 million citizens for whom the National Health Service (NHS) provides health care that is free at the point of access. The prevalence of terminally ill patients is between 30,100 and 39,600. Twenty years ago, the World Health Organization (WHO), in collaboration with the Catalan Department of Health and the Catalan Institute of Oncology, began a demonstration project (WHO Demonstration Project) in palliative care (PC) with the aim of implementing specialist PC services, generating experience in this field, identifying areas for improvement, and introducing educative procedures (clinical and nonclinical). Over the past 20 years, 237 PC clinical services (72 home care support teams, 49 hospital support teams, 60 units with 742 dedicated beds, 50 outpatient clinics, and six psychosocial support teams) have been implemented. In the five years since the previous evaluation, 57 new clinical services (15 new hospital support teams, 36 outpatient clinics, and six psychosocial support teams among others) and four nonclinical services (education, research, WHO Collaborating Center, and planning) have been implemented. During the year 2010, a total of 46,200 processes were undertaken for the care of 23,100 patients, of whom 12,100 (52%) had cancer and 11,000 (48%) had other chronic advanced diseases. The overall yearly costs are around 52,568,000, with an overall savings of 69,300,000 (2275 per patient, net savings to the NHS of 16,732,000). In the last five years, three qualitative evaluations and a benchmarking process have been performed to identify weak points and inequities in care provision among districts. Systematic assessments indicate high cost-effectiveness of care as well as high levels of satisfaction by patients and their relatives, thus reinforcing the principle that access to PC under the auspices of the NHS at the end of life is a basic human right. Copyright 2012 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.
Suffering and euthanasia: a qualitative study of dying cancer patients' perspectives.
Karllsson M; Milberg A; Strang P.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 21573739
PURPOSE: Although intolerable suffering is a core concept used to justify euthanasia, little is known about dying cancer patients' own interpretations and conclusions of suffering in relation to euthanasia.
METHODS: Sixty-six patients with cancer in a palliative phase were selected through maximum-variation sampling, and in-depth interviews were conducted on suffering and euthanasia. The interviews were analyzed using qualitative content analysis with no predetermined categories.
RESULTS: The analysis demonstrated patients' different perspectives on suffering in connection to their attitude to euthanasia. Those advocating euthanasia, though not for themselves at the time of the study, did so due to (1) perceptions of suffering as meaningless, (2) anticipatory fears of losses and multi-dimensional suffering, or (3) doubts over the possibility of receiving help to alleviate suffering. Those opposing euthanasia did so due to (1) perceptions of life, despite suffering, as being meaningful, (2) trust in bodily or psychological adaptation to reduce suffering, a phenomenon personally experienced by informants, and (3) by placing trust in the provision of help and support by healthcare services to reduce future suffering.
CONCLUSIONS: Dying cancer patients draw varying conclusions from suffering: suffering can, but does not necessarily, lead to advocations of euthanasia. Patients experiencing meaning and trust, and who find strategies to handle suffering, oppose euthanasia. In contrast, patients with anticipatory fears of multi-dimensional meaningless suffering and with lack of belief in the continuing availability of help, advocate euthanasia. This indicates a need for healthcare staff to address issues of trust, meaning, and anticipatory fears.
319.
Systematic review of supportive care needs in patients with primary malignant brain tumors.
[Review]
Ford E; Catt S; Chalmers A; Fallowfield L.
[Journal Article. Research Support, Non-U.S. Gov't. Review]
UI: 22307475
In adults, primary malignant brain tumors (PMBT) are rare, but they have a devastating impact and the chances for survival are limited. UK clinical guidance on supportive care for patients with brain and central nervous system tumors was published in 2006 and relied on very limited evidence. The current article reviews literature from 2005 through 2011 on the psychosocial and supportive needs of patients with PMBT and their families or caregivers. Searches were conducted in PubMed, Web of Science, Psychinfo, Cochrane, Scopus, ASSIA, and Sciencedirect. The search initially yielded 6220 articles, of which 60 were found to be eligible (1%). Eleven qualitative and 49 quantitative studies are reviewed here and mapped onto the structure of the existing UK clinical guidance. Studies suggest rates of depression and anxiety up to 48% in patients and up to 40% in caregivers, with many unmet needs and dissatisfaction with health care provider communication and information. Cognitive deficits increase as the disease progresses, hampering communication and decision-making. A range of neurological and physical symptoms at the end of life need recognition. Some successful supportive and neuropsychological interventions are reported. Although the volume of available studies has increased since UK guidance, many remain observational in nature, with few trials of interventions. However, this review provides an up to date resource for clinicians involved with patients with PMBT, describing current knowledge on patients' psychosocial needs, the type of care which has been found to be beneficial, and highlighting areas where more research needs to be done.
Status
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Source: NLM. PMC3309849
'That's part of everybody's job': the perspectives of health care staff in England and New Zealand on the meaning and remit of palliative care.

Gott M; Seymour J; Ingleton C; Gardiner C; Bellamy G.


[Journal Article. Research Support, Non-U.S. Gov't]

BACKGROUND: the right for patients of all diagnoses to be in receipt of palliative care from an early point in the diagnosis of a life-limiting condition is now enshrined in policy in a number of countries and increased emphasis is placed upon the role of generalist palliative care. However, little is known as to how this policy is enacted on the ground.

AIM: to explore understandings of, and perceived roles in relation to, palliative care provision amongst generalist and specialist health care providers in England and New Zealand.

DESIGN: qualitative data were collected via individual interviews and focus groups.

SETTING/PARTICIPANTS: participants comprised generalist and specialist palliative care providers working in a variety of settings in England (n = 58) and New Zealand (n = 80).

RESULTS: the following issues with significant implications for this new phase of development for palliative care were identified: (1) difficulties with terminology and perceived roles/responsibilities; (2) problems of integrating palliative care into a generalist workload; (3) challenges in generalist/specialist partnership working; and (4) the potential negative consequences of specialization.

CONCLUSIONS: these data indicate that, within England and New Zealand, the policy rhetoric of universal palliative care provision is not being straightforwardly translated into service delivery and individual clinical practice. Further research is required to explore and evaluate different models of organization and service provision that empower 'generalists' to provide palliative care, without resulting in deskilling. Finally, definitional clarity at an academic/policy level is also needed.
Palliative care research in Latin America and the Caribbean: from the beginning to the Declaration of Venice and beyond.
Pastrana T;  De Lima L;  Eisenchlas J;  Wenk R.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 22401357

BACKGROUND: Research in palliative care has increased significantly in the last decade, while the vast majority of the global disease burden occurs in developing countries.
AIMS: To explore the palliative care research activity in Latin America and the Caribbean (LAC) and its visibility in the international palliative care literature, with a special focus on research studies.

METHODS: A bibliometric analysis was conducted in MEDLINE(), Embase(), PsycINFO(), and CINAHL(). Inclusion criteria were: (1) articles published in peer-reviewed scientific journals; (2) main subject was palliative care; (3) research study; (4) the first author or coauthors was based in LAC; and/or (5) the data collected derived from LAC.

RESULTS: One hundred six articles from 10 countries were identified in the literature research. The first publication dates from 1989 and was a qualitative study in Brazil. This study shows a modest contribution of publications from LAC. However, the volume of publications within the region is distributed unequally, reflecting the heterogeneity of the region: Brazil published more than half of the articles, while 35 countries have no publications. Most of the studies were quantitative research, predominantly cross-sectional studies. Qualitative studies often used interviews. Health care service was the most researched issue. Seventy percent of studies were carried out in institutions.

CONCLUSIONS: Palliative care research should have a place in LAC. The development of a regional research agenda tailored to the needs and features of the region considering the health care structure and local resources available is indispensable.
Effective delivery of pharmaceutical palliative care: challenges in the community pharmacy setting.

Akram G; Bennie M; McKellar S; Michels S; Hudson S; Trundle J.


[Evaluation Studies. Journal Article]

UI: 22339286

BACKGROUND: Medication, particularly analgesia, is an important component of palliative care. However, timely access to medication, particularly opioids, can become problematic for patients receiving palliative care in the community setting. In Scotland in 2009, NHS Greater Glasgow & Clyde Health Board (NHS GG&C), in partnership with Macmillan Cancer Support, established a programme to improve the local provision of pharmaceutical palliative care services with the appointment of Macmillan Pharmacist Facilitators. Researchers at the University of Strathclyde were commissioned to support the development and evaluation of this new service. We report the findings of this initial investigation into the provision of current palliative care services and outline an evidence-based action plan to support service improvement.

METHODS AND RESULTS: Qualitative data were gathered using focus group interviews. Three key themes were identified: medication supply, communication, and education and training.

CONCLUSIONS: The study findings have been used to develop an evidence-based action plan for the Macmillan Pharmacist Facilitators. This program of work is due for completion by December 2012.

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2012

Palliative care outcomes in surgical oncology patients with advanced malignancies: a mixed methods approach.

Wallen GR; Baker K; Stolar M; Miller-Davis C; Ames N; Yates J; Bolle J; Pereira D; St Germain D; Handel D; Berger A.

Quality of Life Research. 21(3):405-15, 2012 Apr.

[Comparative Study. Journal Article. Randomized Controlled Trial]

UI: 22101861
PURPOSE: To prospectively compare outcomes and processes of hospital-based early palliative care with standard care in surgical oncology patients (N = 152).

METHODS: A randomized, mixed methods, longitudinal study evaluated the effectiveness of a hospital-based Pain and Palliative Care Service (PPCS). Interviews were conducted presurgically and at follow-up visits up to 1 year. Primary outcome measures included the Gracely Pain Intensity and Unpleasantness Scales and the Symptom Distress Scale. Qualitative interviews assessed social support, satisfaction with care, and communication with providers. Survival analysis methods explored factors related to treatment crossover and study discontinuation. Models for repeated measures within subjects over time explored treatment and covariate effects on patient-reported pain and symptom distress.

RESULTS: None of the estimated differences achieved statistical significance; however, for those who remained on study for 12 months, the PPCS group performed better than their standard of care counterparts. Patients identified consistent communication, emotional support, and pain and symptom management as positive contributions delivered by the PPCS.

CONCLUSIONS: It is unclear whether lower pain perceptions despite greater symptom distress were clinically meaningful; however, when coupled with the patients' perceptions of their increased resources and alternatives for pain control, one begins to see the value of an integrated PPCS.

Status MEDLINE
Authors Full Name Baker, Karen; Stolar, Marilyn; Miller-Davis, Claiborne; Ames, Nancy; Yates, Jan; Bolle, Jacques; Pereira, Donna; St Germain, Diane; Handel, Daniel; Berger, Ann.
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Date Created 20120307
Year of Publication 2012

324.
Optimizing pain relief in a specialized outpatient palliative radiotherapy clinic: contributions of a clinical pharmacist.
Gagnon L; Fairchild A; Pituskin E; Dutka J; Chambers C.
[Journal Article]
Ui: 21490115
PURPOSE: Bone metastases are the most common cause of cancer pain, with palliative radiotherapy (RT) the mainstay of treatment. However, relief from RT may be delayed, incomplete, or short-lived and therefore optimized pharmacologic therapy is essential. Our
objective was to describe the contribution of the clinical pharmacist (CP) to an outpatient palliative RT clinic.

METHODS: The Edmonton Symptom Assessment System, an 11-point scale for measuring nine symptoms, and other validated screening tools were administered, and a medication history performed by the CP. Baseline CP assessment also included opioid toxicity, need for supportive medications, and drug interactions. Anonymized clinical information was collected prospectively and descriptive statistics were compiled including themes of counselling performed by the CP.

RESULTS: The CP reviewed 114 patients over 140 clinic visits (01/2007-12/2008). Median age was 68.3 years, 68.4% were male and 36.8% had prostate cancer. All symptoms improved or stabilized in > 80% by 4 weeks. Median pain score was 6/10 (SD 2.6) at baseline, and 2.1/10 (SD 2.4) by week 4. Average morphine equivalent daily dose was 76.8 mg at baseline and 44.5 mg at week 4. CP assessment included screening for opioid toxicity (87.9%), recommending a change in analgesic (28.9%), and liaison with the community pharmacy (17.1%). Medication counselling took place in 84.3% of visits, on bowel routine (85.6% of the time), opioids (82.2%), and hydration (40.7%).

CONCLUSIONS: The CP plays a key role in holistic patient assessment and optimization of pharmacologic therapy, contributing to improved symptom control of patients receiving palliative RT.

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Date Created
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Year of Publication
2012

325.
Hopp FP; Thornton N; Martin L; Zalenski R.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 22352363
This study addresses the need for more information about how urban African-American elders experience advanced heart failure. Participants included 35 African Americans aged 60 and over with advanced heart failure, identified through records from a community hospital in Detroit, Michigan. Four focus groups (n=13) and 22 individual interviews were conducted. We used thematic analysis to examine qualitative focus groups and interviews. Themes identified included life disruption, which encompassed the sub-themes of living scared, making sense of heart
failure, and limiting activities. Resuming life was a contrasting theme involving culturally relevant coping strategies, and included the sub-themes of resiliency, spirituality, and self-care that helped patients regain and maintain a sense of self amid serious illness. Participants faced numerous challenges and invoked a variety of strategies to cope with their illness, and their stories of struggles, hardship, and resilience can serve as a model for others struggling with advanced illness.

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20120222
Year of Publication
2012

326.
Recognition by family members that relatives with neurodegenerative disease are likely to die within a year: a meta-ethnography. [Review]
Hubbard G; McLachlan K; Forbat L; Munday D.
[Journal Article. Research Support, Non-U.S. Gov't. Review]
UI: 21586618
OBJECTIVE: To synthesize evidence of family members recognizing that their relative is likely to die within the year, and identifying the need for palliative care.
DESIGN: A meta-ethnography of studies of family members in multiple sclerosis (MS), Parkinson's disease (PD) and motor neuron disease (MND).
REVIEW METHODS: Systematic search in electronic databases; thematic synthesis guided by the principles of meta-ethnography, which is a method for thematic synthesis of qualitative studies.
RESULTS: Nine articles were included. The results of the synthesis identified two key themes. First, family members are intimately aware of changes in their relative's health and well-being. Sub-themes include family member awareness of different and progressive stages of the disease, noticing deterioration, noticing decline in functional abilities and recognizing that their relative will die. The second key theme is dilemmas of being involved in prognostication. Sub-themes include family member ambivalence toward hearing about prognostication, health professionals not being knowledgeable of the disease and family reluctance to receive palliative care.
CONCLUSIONS: Family members monitor and recognize changes in their relative with PD, MND and MS and in themselves. Thus, drawing on the expertise of family members may be a useful tool for prognostication.
Status
Unmet needs of severely affected multiple sclerosis patients: the health professionals' view.
Golla H; Galushko M; Pfaff H; Voltz R.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 21543525
BACKGROUND: Research has only started recently to specifically concentrate on the group of patients severely affected by multiple sclerosis (MS).
AIM: The aim of this study was to assess the perception on patients' unmet needs by healthcare professionals.
METHODS: Focus groups and expert interviews were recorded, transcribed verbatim and analysed by qualitative content analysis.
RESULTS: Unmet needs were identified in four main categories ('support from family/friends'; 'healthcare services'; 'managing everyday life'; 'maintaining biographical continuity'). Whereas physicians assessed most unmet needs in the category 'healthcare services', nurses and social workers focussed on unmet needs in the categories 'support from family/friends' and 'maintaining biographical continuity'. Although the study focused on unmet needs of patients, professionals also voiced their unmet needs when caring for these patients. The group of professionals identified more subcategories than patients and included unmet needs of relatives.
CONCLUSION: Adding professionals' perspective to that of patients is essential to gain a holistic view on patients' unmet needs and to further optimize their care. The perspective of palliative care might contribute to meet unmet needs of severely affected MS patients.
Social services homecare for people with motor neurone disease/amyotrophic lateral sclerosis: why are such services used or refused?.
O'Brien MR; Whitehead B; Murphy PN; Mitchell JD; Jack BA.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 21383059

Many patients with the terminal condition motor neurone disease/amyotrophic lateral sclerosis (MND/ALS) do not access social service homecare, which may have implications for the location of end-of-life care. We aimed to identify factors related to uptake of such care in MND/ALS. A case note review of patients at a UK MND/ALS clinic (N = 97) provided data concerning disease onset and severity, demographic variables and care received. Narrative interviews with people with MND/ALS (N=24) and family carers (N=18) explored their perspectives on social services homecare. Quantitative analyses highlighted the role of increasing disease severity and age for social services homecare uptake. However, qualitative findings revealed a number of barriers delaying the uptake of such care. 'Internal' issues focused on retaining control and normality within the home. 'External' issues arose from limited understanding of the disease amongst service providers and lack of awareness of service entitlement amongst patients and carers. Multiple factors are implicated in the uptake of social services homecare. Uncertainties surrounding service entitlement must be addressed, including the simplification of bureaucratic procedures and clarification of the roles of health and social care professionals. Service providers need a greater awareness of the nature of the disease and their role in its management.

An evaluation of the use of Telehealth within palliative care settings across Scotland.
There is a lack of evidence-based research in the use of Telehealth within palliative care in the UK, particularly in Scotland. The aim of this project was to evaluate the current use of Telehealth applications within palliative care across Scotland, and how these and future applications are perceived by patients, carers and professionals. This paper reports on the qualitative findings from focus groups with patients and carers in three geographical areas in Scotland, and individual interviews with key stakeholders from across Scotland, who currently work within areas of high and low Telehealth activity. The key findings indicated that Telehealth initiatives are welcomed by patients and carers but that these should be an adjunct to clinical care rather than an alternative. The stakeholder interviews revealed several notable differences between those working within areas of high and low Telehealth activity. Principally, areas of high Telehealth activity appear to be driven by national and local policy and seem to benefit from a greater level of investment in Telehealth equipment and facilities than in the more central, and hence accessible, parts of Scotland.

Complexity in non-pharmacological caregiving activities at the end of life: an international qualitative study.

BACKGROUND: In late-stage palliative cancer care, relief of distress and optimized well-being become primary treatment goals. Great strides have been made in improving and researching pharmacological treatments for symptom relief; however, little systematic knowledge exists about the range of non-pharmacological caregiving activities (NPCAs) staff use in the last days of a patient's life.
METHODS AND FINDINGS: Within a European Commission Seventh Framework Programme project to optimize research and clinical care in the last days of life for patients with cancer, OPCARE9, we used a free-listing technique to identify the variety of NPCAs performed in the last days of life. Palliative care staff at 16 units in nine countries listed in detail NPCAs they performed over several weeks. In total, 914 statements were analyzed in relation to (a) the character of the statement and (b) the recipient of the NPCA. A substantial portion of NPCAs addressed bodily care and contact with patients and family members, with refraining from bodily care also described as a purposeful caregiving activity. Several forms for communication were described; information and advice was at one end of a continuum, and communicating through nonverbal presence and bodily contact at the other. Rituals surrounding death and dying included not only spiritual/religious issues, but also more subtle existential, legal, and professional rituals. An unexpected and hitherto under-researched area of focus was on creating an aesthetic, safe, and pleasing environment, both at home and in institutional care settings.

CONCLUSIONS: Based on these data, we argue that palliative care in the last days of life is multifaceted, with physical, psychological, social, spiritual, and existential care interwoven in caregiving activities. Providing for fundamental human needs close to death appears complex and sophisticated; it is necessary to better distinguish nuances in such caregiving to acknowledge, respect, and further develop end-of-life care.

Status
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20120220
Year of Publication
2012

331.
Family management style framework and its use with families who have a child undergoing palliative care at home.
Bousson RS; Misko MD; Mendes-Castillo AM; Rossato LM.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 22223493
Palliative care settings in many countries acknowledge families as their prime focus of care, but in Brazil, to date, researchers have devoted scant attention to that practice setting. In this article, we report the findings of a study that explored how families define and manage their lives when they have a child or adolescent undergoing palliative care at home. Data included individual semistructured interviews with 14 family members of 11 different families. Interviews were transcribed and the coding procedure featured qualitative content analysis methods. The deductive coding was based on the major components of the Family Management Style Framework and the eight dimensions comprising these components. The analysis provides insight into families’ daily practices and problems inherent in managing their everyday lives that are encountered when they have a child in palliative care. The article features discussion of implications for the palliative care related development of family nursing practice.

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332.
Complexities of care for patients and families living with advanced cardiovascular diseases: overview.
Albert NM; Paul S; Murray M.
[Journal Article]
UI: 22210145

The complexities of care in patients with advanced heart failure, ischemic coronary artery disease, and dysrhythmias span a wide spectrum of physiologic, psychologic, emotional, functional, social, and financial factors. In addition, families may be troubled by care needs associated with the cardiovascular disease itself or its complexities. The purpose of this overview was to gain a better understanding of the complexities associated with advanced heart failure, ischemic heart disease, and dysrhythmias and to highlight a few themes that have received recent attention from healthcare providers. The focus of the overview will include overcoming clinical and financial burdens and improving patient and family quality of life.

Status
MEDLINE

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Paul, Sara; Murray, Margaret.

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"In pain waiting to die": everyday understandings of suffering. [Review]
Schwartz KD; Lutfiyya ZM.
[Case Reports. Journal Article. Research Support, Non-U.S. Gov't. Review]
UI: 22329934

OBJECTIVE: The notion of "suffering" is understood in very different ways in a variety of contexts. In palliative care, the relief and prevention of suffering is considered to be a fundamental goal (Pastrana et al., 2008). However, the avoidance of suffering has also been used as an argument by those campaigning for the legalization of euthanasia and assisted suicide (Finlay, 2009). In reflecting upon suffering in these two contexts, we were intrigued by Finlay's (2009) contention that to laypeople, the phrase "unbearable suffering' conjures up images of patients on their deathbeds wracked with uncontrolled pain" (p. 1841).

METHOD: This article explores how suffering is used and understood in an "everyday" discourse, by analyzing comments posted to a website debating assisted suicide in the context of the Canadian case of Sue Rodriguez.

RESULTS: Using a broad social approach to discourse analysis (Tonkiss, 2004), three themes emerged in our analysis: (1) when people suffer, (2) how people are understood to suffer, and (3) how suffering should be dealt with. We also examined what was not said in this discussion: there was little consideration of the more holistic goals of palliative care and how suffering might be understood and managed in ways other than within the frame of assisted suicide.

SIGNIFICANCE OF RESULTS: Paying attention to the everyday discourse of suffering is important because, as members of society, we all play a role in negotiating the meaning of suffering. Such meaning has a significant impact upon patients and palliative care professionals alike.

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Dignity therapy: a feasibility study of elders in long-term care. [Review]
Chochinov HM; Cann B; Cullihall K; Kristjanson L; Harlos M; McClement SE; Hack TF; Hassard T.
[Journal Article. Review]
UI: 22329932
OBJECTIVE: The purpose of this study was to assess the feasibility of dignity therapy for the frail elderly.
METHOD: Participants were recruited from personal care units contained within a large rehabilitation and long-term care facility in Winnipeg, Manitoba. Two groups of participants were identified; residents who were cognitively able to directly take part in dignity therapy, and residents who, because of cognitive impairment, required that family member(s) take part in dignity therapy on their behalf. Qualitative and quantitative methods were applied in determining responses to dignity therapy from direct participants, proxy participants, and healthcare providers (HCPs).
RESULTS: Twelve cognitively intact residents completed dignity therapy; 11 cognitively impaired residents were represented in the study by way of family member proxies. The majority of cognitively intact residents found dignity therapy to be helpful; the majority of proxy participants indicated that dignity therapy would be helpful to them and their families. In both groups, HCPs reported the benefits of dignity therapy in terms of changing the way they perceived the resident, teaching them things about the resident they did not previously know; the vast majority indicated that they would recommend it for other residents and their families.
SIGNIFICANCE OF RESULTS: This study introduces evidence that dignity therapy has a role to play among the frail elderly. It also suggests that whether residents take part directly or by way of family proxies, the acquired benefits—and the effects on healthcare staff—make this area one meriting further study.

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We explored family involvement in decisions about life support interventions in the intensive care unit study using a critical incident technique to focus on specific case exemplars contributed by participants. A total of 6 family members and 9 health care professionals were interviewed. Participants described 2 options (life support or comfort care) and values associated with options: maintaining quality of life, surviving critical illness, minimizing pain and suffering, not being attached to machines, needing adjustment time, and judicious health care resource use. Barriers to involvement included not being offered alternative options; no specific trigger to initiate decision making; dominant influence of professionals' values; and families lacking understandable information. Family members are unlikely to engage in decision making unless professionals identify the decision and address other barriers to family involvement.


PURPOSE: Individuals diagnosed with cancer close to death have low access to enrollment in palliative care programs. The purpose of this literature review was to assess the usefulness of pre-diagnostic comorbidity and healthcare utilization as indicators of late-stage colorectal cancer (CRC) diagnosis, to help with early identification of individuals who may benefit from palliative care.
METHODS: A literature search was conducted in relevant databases using title/abstract terms which included "cancer," "stage," "diagnosis," "determinants," "predictors," and "associated." Included studies examined whether comorbidity and/or healthcare utilization had an impact on the stage at which CRC was diagnosed. A standardized data abstraction form was used to assess the eligibility of each study. Thirteen articles were included in the literature review. These studies were assessed and synthesized using qualitative methodology.

RESULTS: We found much heterogeneity among study variables. The findings of this literature review point to the presence of comorbidity and non-emergent healthcare utilization as having no association with late-stage diagnosis. Conversely, emergency room presentation (ERP) was associated with late-stage diagnosis.

CONCLUSIONS: The results of this literature review did not find strong evidence to suggest that comorbidity and healthcare utilization are potential indicators of late-stage diagnosis. However, ERP may be useful as a flag for consideration of prompt referral to palliative care. Additional research is required to identify potential indicators of late-stage diagnosis that may be available in administrative databases, particularly in the area of healthcare utilization.

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Date Created
20120119
Year of Publication
2012

337.
Systematic review of the primary research on minority ethnic groups and end-of-life care from the United Kingdom. [Review]
Evans N; Menaca A; Andrew EV; Koffman J; Harding R; Higginson IJ; Pool R; Gysels M; PRISMA.
[Journal Article. Research Support, Non-U.S. Gov't. Review]
UI: 22001070
CONTEXT: Patients from minority ethnic groups experience lower rates of referrals to end-of-life (EoL) care services, higher levels of dissatisfaction with services, and perceive some services as culturally inappropriate.
OBJECTIVES: To systematically review original studies of minority ethnic groups and EoL care in the U.K. and appraise their quality.
METHODS: Searches were carried out in 13 electronic databases, eight journals, reference lists, and the gray literature. Studies of minority ethnic groups and End-of-Life (EoL) care in the U.K. were included. Studies were graded for quality and key themes were identified.

RESULTS: Forty-five studies met inclusion criteria. Study quality was good on average. Identified key themes included age structure; inequality by disease group; referrals; caregivers; place of care and death; awareness of services and communication; and cultural competency. Strategies described for the reduction of inequities were partial and reactive. The format of 10 studies prevented quality grading; these were, however, reviewed as they provided unique insights. Variations in terminology and sampling frames complicated comparison across studies.

CONCLUSION: The results highlight the multiple and related factors that contribute to low service use and substandard quality of services experienced by minority ethnic groups, and the need for authors to clarify what they mean by "culturally competent" EoL care. The synthesis of diverse and disparate studies underpins a number of key recommendations for health care professionals and policymakers. Tackling these epidemiological, demographic, institutional, social, and cultural factors will require a systematic and organization-wide approach rather than the current piecemeal and reactive interventions.

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Does palliative care have a future in the emergency department? Discussions with attending emergency physicians.

Grudzen CR; Richardson LD; Hopper SS; Ortiz JM; Whang C; Morrison RS.


[Journal Article. Research Support, N.I.H., Extramural]

UI: 21802899

CONTEXT: Palliative care focuses on the relief of pain and suffering and achieving the best possible quality of life for patients. Although traditionally delivered in the inpatient setting, emergency departments (EDs) are a new focus for palliative care consultation teams.

OBJECTIVES: To explore attitudes and beliefs among emergency care providers regarding the provision of palliative care services in the ED.
METHODS: Three semistructured focus groups were conducted with attending emergency physicians from an academic medical center, a public hospital center, and a community hospital. The discussions were digitally recorded and transcribed to conduct a thematic analysis using grounded theory. A coding scheme was iteratively developed to subsequently identify themes and subthemes that emerged from the interviews.

RESULTS: Twenty emergency physicians participated (mean age 41 years, range 31-61 years, median practice time nine years, 40% female). Providers acknowledged many benefits of palliative care presence in the ED, including provision of a specialized skill set, time to discuss goals of care, and an opportunity to intervene for seriously ill or injured patients. Providers believed that concerns about medicolegal issues impaired their ability to forgo treatments where risks outweigh benefits. Additionally, the culture of emergency medicine-to provide stabilization of acute medical emergencies-was sometimes at odds with the culture of palliative care, which balances quality of life with the burdens of invasive treatments. Some providers also felt it was the primary physician's responsibility, and not their own, to address goals of care. Finally, some providers expressed concern that palliative care consultation was only available on weekdays during daytime hours. Automatic consultation based on predetermined criteria was suggested as a way to avoid conflicts with patients and family.

CONCLUSION: Emergency providers identified many benefits to palliative care consultation. Solving logistical problems and developing clear indications for consultation might help increase the use of such services.

Karlsson M; Milberg A; Strang P.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 21543526
INTRODUCTION: Deliberations on euthanasia are mostly theoretical, and often lack first-hand perspectives of the affected persons.
METHOD: Sixty-six patients suffering from cancer in a palliative phase were interviewed about their perspectives of euthanasia in relation to autonomy. The interviews were transcribed verbatim and analysed using qualitative content analysis with no predetermined categories.

RESULTS: The informants expressed different positions on euthanasia, ranging from support to opposition, but the majority were undecided due to the complexity of the problem. The informants' perspectives on euthanasia in relation to autonomy focused on decision making, being affected by (1) power and (2) trust. Legalization of euthanasia was perceived as either (a) increasing patient autonomy by patient empowerment, or (b) decreasing patient autonomy by increasing the medical power of the health care staff, which could be frightening. The informants experienced dependence on others, and expressed various levels of trust in others’ intentions, ranging from full trust to complete mistrust.

CONCLUSIONS: Dying cancer patients perceive that they cannot feel completely independent, which affects true autonomous decision making. Further, when considering legalization of euthanasia, the perspectives of patients fearing the effects of legalization should also be taken into account, not only those of patients opting for it.

340.
A mixed-methods evaluation of complementary therapy services in palliative care: yoga and dance therapy.
Selman LE; Williams J; Simms V.
[Evaluation Studies. Journal Article]
UI: 21880079
To inform service provision and future research, we evaluated two complementary therapy services: yoga classes and dance therapy [The Lebed Method (TLM)]. Both were run as 6-week group courses. Patients completed the Measure Yourself Concerns and Wellbeing questionnaire pre- and post-course. Mean change over time was calculated for patient-nominated concern and well-being scores. Qualitative data regarding factors affecting health other than the therapy and benefits of the service were analysed using content analysis. Eighteen patients participated (mean age 63.8 years; 16 female; 14 cancer diagnoses); 10 were doing yoga, five TLM, and three both yoga and TLM; 14 completed more than one assessed course. Patients' most prevalent concerns were: mobility/fitness (n= 20), breathing problems (n= 20), arm, shoulder and
neck problems (n= 18), difficulty relaxing (n= 8), back/postural problems (n= 8), fear/anxiety (n= 5). Factors affecting patients’ health other than the therapy were prevalent and predominantly negative (e.g. treatment side effects). Patients reported psycho-spiritual, physical and social benefits. Concern scores improved significantly (P < 0.001) for both therapies; improved well-being was clinically significant for yoga. Evaluations of group complementary therapy services are feasible, can be conducted effectively and have implications for future research. Yoga and TLM may be of benefit in this population.Copyright 2011 Blackwell Publishing Ltd.

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20111219
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341.
Information technology and hospice palliative care: social, cultural, ethical and technical implications in a rural setting.
Kuziemsky C; Jewers H; Appleby B; Foshay N; Maccaull W; Miller K; Macdonald M. Informatics for health & social care. 37(1):37-50, 2012 Jan.
[Journal Article]
UI: 22017505
OBJECTIVE: There is a need to better understand the specific settings in which health information technology (HIT) is used and implemented. Factors that will determine the successful implementation of HIT are context-specific and often reside not at the technical level but rather at the process and people level. This paper provides the results of a needs assessment for HIT to support hospice palliative care (HPC) delivery in rural settings.
METHODS: Roundtable discussions using the nominal group technique were done to identify priority issues regarding HIT usage to support rural HPC delivery. Qualitative content analysis was then used to identify sociotechnical themes from the roundtable data.
RESULTS: Twenty priority issues were identified at the roundtable session. Content analysis grouped the priority issues into one central theme and five supporting themes to form a sociotechnical framework for patient-centered care in rural settings.
CONCLUSION: There are several sociotechnical themes and associated issues that need to be considered prior to implementing HIT in rural HPC settings. Proactive evaluation of these issues can enhance HIT implementation and also help to make ethical aspects of HIT design more explicit.
Status
MEDLINE
A health economics response to the review of the Liverpool Care Pathway.

Kinghorn P; Coast J.


[Journal Article. Research Support, Non-U.S. Gov't]

UI: 24199790

BACKGROUND: In 2011 the Palliative Care Funding Review highlighted concerns about the funding, provision, and quality of care at the end of life. Two years on, an independent review of the Liverpool Care Pathway--prompted by a storm of negative media coverage--has raised concerns around a lack of funding, availability of support for the dying and their relatives, and patient centered care. There are recommendations to increase funding through a national tariff for palliative care services, address inconsistencies, and replace the Liverpool Care Pathway with individual end-of-life care plans.

OBJECTIVE: This paper explores the economic implications of the review's recommendations and links these to inadequacies with the current economic framework currently recommended for use in the United Kingdom by the National Institute for Health and Care Excellence, before highlighting aspects of ongoing research aimed at addressing these inadequacies.

METHODS: As well as the published report More Care, Less Pathway, we draw upon preliminary qualitative evidence from 19 semistructured interviews conducted with academics specializing in economics and/or end-of-life care.

CONCLUSIONS: While there is a need for increased funding in the short term (highlighted in recent reviews), increasing funding to services that have little evidence base appears to be an irresponsible long-term strategy. Hence there should also be increased investment in research and increased emphasis in particular on developing economic tools to evaluate services.

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Source: NLM. PMC3868289
Mixed methods research in the development and evaluation of complex interventions in palliative and end-of-life care: report on the MORECare consensus exercise.
Farquhar M; Preston N; Evans CJ; Grande G; Short V; Benalia H; Higginson IJ; Todd C; MOREcare.
[Journal Article. Research Support, Non-U.S. Gov't]
UI: 24195755

BACKGROUND: Complex interventions are common in palliative and end-of-life care. Mixed methods approaches sit well within the multiphase model of complex intervention development and evaluation. Generic mixed methods guidance is useful but additional challenges in the research design and operationalization within palliative and end-of-life care may have an impact on the use of mixed methods.

OBJECTIVE: The objective of the study was to develop guidance on the best methods for combining quantitative and qualitative methods for health and social care intervention development and evaluation in palliative and end-of-life care.

METHODS: A one-day workshop was held where experts participated in facilitated groups using Transparent Expert Consultation to generate items for potential recommendations. Agreement and consensus were then sought on nine draft recommendations (DRs) in a follow-up exercise.

RESULTS: There was at least moderate agreement with most of the DRs, although consensus was low. Strongest agreement was with DR1 (usefulness of mixed methods to palliative and end-of-life care) and DR5 (importance of attention to respondent burden), and least agreement was with DR2 (use of theoretical perspectives) and DR6 (therapeutic effects of research interviews). Narrative comments enabled recommendation refinement. Two fully endorsed, five partially endorsed, and two refined DRs emerged. The relationship of these nine to six key challenges of palliative and end-of-life care research was analyzed.

CONCLUSIONS: There is a need for further discussion of these recommendations and their contribution to methodology. The recommendations should be considered when designing and operationalizing mixed methods studies of complex interventions in palliative care, and because they may have wider relevance, should be considered for other applications.

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344.
Finding your way through EOL challenges in the ICU using Adaptive Leadership behaviours: A qualitative descriptive case study.
Adams JA; Bailey DE Jr; Anderson RA; Thygeson M.
[Case Reports. Journal Article. Research Support, N.I.H., Extramural]
UI: 23879936
OBJECTIVE: Using the Adaptive Leadership framework, we describe behaviours that providers used while interacting with family members facing the challenges of recognising that their loved one was dying in the ICU.
RESEARCH METHODOLOGY: In this prospective pilot case study, we selected one ICU patient with end-stage illness who lacked decision-making capacity. Participants included four family members, one nurse and two physicians. The principle investigator observed and recorded three family conferences and conducted one in-depth interview with the family. Three members of the research team independently coded the transcripts using a priori codes to describe the Adaptive Leadership behaviours that providers used to facilitate the family's adaptive work, met to compare and discuss the codes and resolved all discrepancies.
FINDINGS: We identified behaviours used by nurses and physicians that facilitated the family's ability to adapt to the impending death of a loved one. Examples of these behaviours include defining the adaptive challenges for families and foreshadowing a poor prognosis.
CONCLUSIONS: Nurse and physician Adaptive Leadership behaviours can facilitate the transition from curative to palliative care by helping family members do the adaptive work of letting go. Further research is warranted to create knowledge for providers to help family members adapt.Copyright 2013 Elsevier Ltd. All rights reserved.
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