Lunchtime Drop-in Sessions
All sessions last one hour

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NHS Health Education England
Current Journals: Tables of Contents

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Latest Evidence

End of life care for adults
Quality standard [QS13] Published date: November 2011 Last updated: March 2017

End of life care for infants, children and young people: Draft Quality Standard for consultation

End of life care for people with life-limiting conditions
Everything NICE has said about the care of people with a progressive life-limiting condition who are at the end of their life in an interactive flowchart.
NICE Pathway Published March 2017

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Overview of managing common non-pain symptoms in palliative care
Authors: Eduardo Bruera, MD; Rony Dev, DO; Section Editor: Thomas J Smith, MD, FACP, FASCO, FAAHPM; Deputy Editor: Diane MF Savarese, MD

All topics are updated as new evidence becomes available and our peer review process is complete. Literature review current through: Jun 2017. | This topic last updated: Apr 03, 2017.

What’s new in palliative care
Author: Diane MF Savarese, MD
Benefits, services, and models of subspecialty palliative care

Authors: Diane E Meier, MD, FACP; Elizabeth McCormick, MD; Section Editor: Robert M Arnold, MD
Deputy Editor: Diane MF Savarese, MD

Overview of spirituality in palliative care

Authors: Christina M Puchalski, MD, MS, FACP, FAAPM; Betty Ferrell, PhD, MA, FAAN, FPCN; Shirley Otis-Green, MSW, MA, LCSW, ACSW, OSW-C; George Handzo, BCC, CSSBB
Section Editor: Susan D Block, MD; Deputy Editor: Diane MF Savarese, MD

NHS Choices: Behind the Headlines
Below is a selection of articles recently added to the healthcare databases.

If you would like any of the articles in full text, or if you would like a more focused search on your own topic, please contact us: library@bristol.nhs.uk

### Palliative/End of Life Support and Care Services

1. **Use of Improving Palliative Care in the ICU (Intensive Care Unit) Guidelines for a Palliative Care Initiative in an ICU.**
   - **Author(s):** Mun, Eluned; Nakatsuka, Craig; Umbarger, Lillian; Ruta, Ruth; Mccarty, Tracy; Machado, Cynthia; Ceria-Ulep, Clementina
   - **Source:** The Permanente journal; 2017; vol. 21
   - **Publication Type(s):** Journal Article Review
   - **PubMedID:** 28241905
   - Available in full text at Permanente Journal, The - from National Library of Medicine
   - **Abstract:** OBJECTIVE For improved utilization of the existing palliative care team in the intensive care unit (ICU), a process was needed to identify patients who might need a palliative care consultation in a timelier manner. METHODS A systematic method to create a new program that would be compatible with our specific ICU environment and patient population was developed. A literature review revealed a fairly extensive array of reports and numerous clinical practice guidelines, which were assessed for information and strategies that would be appropriate for our unit. RESULTS The recommendations provided by the Center to Advance Palliative Care from its Improving Palliative Care in the ICU project were used to successfully implement a new palliative care initiative in our ICU. CONCLUSION The guidelines provided by the Improving Palliative Care in the ICU project were an important tool to direct the development of a new palliative care ICU initiative.

2. **Effect of specialist palliative care services on quality of life in adults with advanced incurable illness in hospital, hospice, or community settings: systematic review and meta-analysis.**
   - **Author(s):** Gaertner, Jan; Siemens, Waldemar; Meerpohl, Joerg J; Antes, Gerd; Meffert, Cornelia; Xander, Carola; Stock, Stephanie; Mueller, Dirk; Schwarzer, Guido; Becker, Gerhild
   - **Source:** BMJ (Clinical research ed.); Jul 2017; vol. 357 ; p. j2925
   - **Publication Type(s):** Journal Article
   - **PubMedID:** 28676557
   - Available in full text at The BMJ - from Highwire Press
   - **Abstract:** Objective To assess the effect of specialist palliative care on quality of life and additional outcomes relevant to patients in those with advanced illness. Design Systematic review with meta-analysis. Data sources Medline, Embase, Cochrane Central Register of Controlled Trials, PsycINFO, and trial registers searched up to July 2016. Eligibility criteria for selecting studies Randomised controlled trials with adult inpatients or outpatients treated in hospital, hospice, or community settings with any advanced illness. Minimum requirements for specialist palliative care included the multiprofessional team approach. Two reviewers independently screened and extracted data, assessed the risk of bias (Cochrane risk of bias tool), and evaluated the quality of evidence (GRADE tool). Data synthesis Primary outcome was quality of life with Hedges’ g as standardised mean difference (SMD) and random effects model in meta-analysis. In addition, the pooled SMDs of the analyses of quality of life were re-expressed on the global health/QoL scale (item 29 and 30, respectively) of the European Organization for Research and Treatment of Cancer QLQ-C30 (0-100, high values=good quality of life, minimal clinically important difference 8.1). Results Of 3967 publications, 12 were included (10 randomised controlled trials with 2454 patients randomised, of whom 72% (n=1766) had cancer). In no trial was integration of specialist palliative care triggered according to patients’ needs as identified by screening. Overall, there was a small effect in favour of specialist palliative care (SMD 0.16, 95% confidence interval 0.01 to 0.31; QLQ-C30 global health/QoL 4.1, 0.3 to 8.2; n=1218, six trials). Sensitivity analysis showed an SMD of 0.57 (-
Due to several methodological limitations, the evidence offered in these studies ranged from low to high. The results for pain and other secondary outcomes were inconclusive. Some methodological problems (such as lack of blinding) reduced the strength of the evidence. Conclusions: Specialist palliative care was associated with a small effect on QoL and might have most pronounced effects for patients with cancer who received such care early. It could be most effective if it is provided early and if it identifies those patients with unmet needs. Systematic review registration PROSPERO CRD42015020674.

3. Dying in the hospital setting: A meta-synthesis identifying the elements of end-of-life care that patients and their families describe as being important.

Author(s): Virdun, Claudia; Luckett, Tim; Lorenz, Karl; Davidson, Patricia M; Phillips, Jane

Source: Palliative medicine; Jul 2017; vol. 31 (no. 7); p. 587-601

Publication Type(s): Journal Article

PubMedID: 27932631

Abstract: BACKGROUND Despite most expected deaths occurring in hospital, optimal end-of-life care is not available for all in this setting. AIM To gain a richer and deeper understanding of elements of end-of-life care that consumers consider most important within the hospital setting. DESIGN A meta-synthesis. DATA SOURCES A systematic search of Academic Search Complete, AMED, CINAHL, MEDLINE, EMBASE, PsycINFO, PubMed, Google, Google Scholar and CareSearch for qualitative studies published between 1990 and April 2015 reporting statements by consumers regarding important elements of end-of-life hospital care. Study quality was appraised by two independent researchers using an established checklist. A three-stage synthesis approach focusing on consumer quotes, rather than primary author themes, was adopted for this review. RESULTS Of 1922 articles, 16 met the inclusion criteria providing patient and family data for analysis. Synthesis yielded 7 patient and 10 family themes including 6 common themes: (1) expert care, (2) effective communication and shared decision-making, (3) respectful and compassionate care, (4) adequate environment for care, (5) family involvement and (6) financial affairs. Maintenance of sense of self was the additional patient theme, while the four additional family themes were as follows: (1) maintenance of patient safety, (2) preparation for death, (3) care extending to the family after patient death and (4) enabling patient choice at the end of life. CONCLUSION Consumer narratives help to provide a clearer direction as to what is important for hospital end-of-life care. Systems are needed to enable optimal end-of-life care, in accordance with consumer priorities, and embedded into routine hospital care.


Author(s): Holmenlund, Kristina; Sjögren, Per; Nordly, Mie

Source: Palliative & supportive care; Jun 2017; p. 1-17

Publication Type(s): Journal Article

PubMedID: 28606211

Abstract: OBJECTIVE Due to the multiple physical, psychological, existential, and social symptoms involved, patients with advanced cancer often have a reduced quality of life (QoL), which requires specialized palliative care (SPC) interventions. The primary objective of the present systematic review was to review the existing literature about SPC and its effect on QoL, on physical and psychological symptoms, and on survival in adult patients with advanced cancer. METHOD We utilized a search strategy based on the PICO (problem/population, intervention, comparison, and outcome) framework and employed terminology related to cancer, QoL, symptoms, mood, and palliative care. The search was performed in Embase, PubMed, and the Cochrane Central Register of Controlled Trials. Selected studies were analyzed and categorized according to methods, results, quality of evidence, and strength of recommendation. RESULTS Six randomized controlled trials (RCTs) were selected for analysis (out of a total of 1,115 studies). Two other studies were found by hand search, one of which was only published in conference abstract form. The RCTs differed in terms of aims, interventions, control groups, and outcomes; however, the primary aim of all of them was to investigate the effect of SPC on patient QoL. Five studies found improved QoL in the intervention group. Physical symptom intensity decreased in two studies, and three studies found improved mood in the intervention group. However, physical and psychological symptoms were secondary outcomes in these studies. Survival was improved in two studies. All the studies offered generalizability, but the level of evidence validity varied among them. SIGNIFICANCE OF RESULTS Due to several methodological limitations, the evidence offered in these studies ranged from low to high. The evidence in this field of study in general is still nascent, but there is growing support for the utilization of SPC to
improve the quality of life of adult patients with advanced cancer. The evidence that SPC reduces physical and psychological symptoms is moderate, while the evidence that it prolongs survival is low.

5. Early palliative care for adults with advanced cancer.

Author(s): Haun, Markus W; Estel, Stephanie; Rücker, Gerta; Friederich, Hans-Christoph; Villalobos, Matthias; Thomas, Michael; Hartmann, Mechthild

Source: The Cochrane database of systematic reviews; Jun 2017; vol. 6 ; p. CD011129

Publication Type(s): Research Support, Non-u.s. Gov't Journal Article Review

Available in full text at Cochrane Library, The - from John Wiley and Sons

Abstract: BACKGROUND Incurable cancer, which often constitutes an enormous challenge for patients, their families, and medical professionals, profoundly affects the patient's physical and psychosocial well-being. In standard cancer care, palliative measures generally are initiated when it is evident that disease-modifying treatments have been unsuccessful, no treatments can be offered, or death is anticipated. In contrast, early palliative care is initiated much earlier in the disease trajectory and closer to the diagnosis of incurable cancer.

OBJECTIVES To compare effects of early palliative care interventions versus treatment as usual/standard cancer care on health-related quality of life, depression, symptom intensity, and survival among adults with a diagnosis of advanced cancer.

SEARCH METHODS We searched the Cochrane Central Register of Controlled Trials (CENTRAL), MEDLINE, Embase, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO, OpenGrey (a database for grey literature), and three clinical trial registers to October 2016. We checked reference lists, searched citations, and contacted study authors to identify additional studies.

SELECTION CRITERIA Randomised controlled trials (RCTs) and cluster-randomised controlled trials (cRCTs) on professional palliative care services that provided co-ordinated comprehensive care for adults at early advanced stages of cancer.

DATA COLLECTION AND ANALYSIS We used standard methodological procedures as expected by Cochrane. We assessed risk of bias, extracted data, and collected information on adverse events. For quantitative synthesis, we combined respective results on our primary outcomes of health-related quality of life, survival (death hazard ratio), depression, and symptom intensity across studies in meta-analyses using an inverse variance random-effects model. We expressed pooled effects as standardised mean differences (SMDs, or Hedges' adjusted g). We assessed certainty of evidence at the outcome level using GRADE (Grading of Recommendations Assessment, Development, and Evaluation) and created a 'Summary of findings' table.

MAIN RESULTS We included seven randomised and cluster-randomised controlled trials that together recruited 1614 participants. Four studies evaluated interventions delivered by specialised palliative care teams, and the remaining studies assessed models of co-ordinated care. Overall, risk of bias at the study level was mostly low, apart from possible selection bias in three studies and attrition bias in one study, along with insufficient information on blinding of participants and outcome assessment in six studies. Compared with usual/standard cancer care alone, early palliative care significantly improved health-related quality of life at a small effect size (SMD 0.27, 95% confidence interval (CI) 0.15 to 0.38; participants analysed at post treatment = 1028; evidence of low certainty). As re-expressed in natural units (absolute change in Functional Assessment of Cancer Therapy-General (FACT-G) score), health-related quality of life scores increased on average by 4.59 (95% CI 2.55 to 6.64) points more among participants given early palliative care than among control participants. Data on survival, available from four studies enrolling a total of 800 participants, did not indicate differences in efficacy (death hazard ratio 0.85, 95% CI 0.56 to 1.28; evidence of very low certainty). Levels of depressive symptoms among those receiving early palliative care did not differ significantly from levels among those receiving usual/standard cancer care (five studies; SMD -0.11, 95% CI -0.26 to 0.03; participants analysed at post treatment = 762; evidence of very low certainty). Results from seven studies that analysed 1054 participants post treatment suggest a small effect for significantly lower symptom intensity in early palliative care compared with the control condition (SMD -0.23, 95% CI -0.35 to -0.10; evidence of low certainty). The type of model used to provide early palliative care did not affect study results. One RCT reported potential adverse events of early palliative care, such as a higher percentage of participants with severe scores for pain and poor appetite; the remaining six studies did not report adverse events in study publications. For these six studies, principal investigators stated upon request that they had not observed any adverse events.

AUTHORS' CONCLUSIONS This systematic review of a small number of trials indicates that early palliative care interventions may have more beneficial effects on quality of life and symptom intensity among patients with advanced cancer than among those given usual/standard cancer care alone. Although we found only small effect sizes, these may be clinically relevant at an advanced disease stage with limited prognosis, at which time further decline in quality of life is very common. At this point, effects on morta
now under way will present a clearer picture of the effect and specific indication of early palliative care. Upcoming results from several ongoing studies (N = 20) and studies awaiting assessment (N = 10) may increase the certainty of study results and may lead to improved decision making. In perspective, early palliative care is a newly emerging field, and well-conducted studies are needed to explicitly describe the components of early palliative care and control treatments, after blinding of participants and outcome assessors, and to report on possible adverse events.

6. Underreported use of palliative care and patient reported outcome measures to address reduced Quality of Life in calciphylaxis patients: A systematic review.

Author(s): Riemer, C A; El-Azhary, R A; Wu, K L; Strand, J J; Lehman, J S

Source: The British journal of dermatology; Jun 2017

Publication Type(s): Journal Article Review

PubMedID: 28580642

Abstract: Calciphylaxis is associated with significant morbidity and mortality. Palliative care (PC) is a subspecialty that treats the pain and stress of serious illness. We performed a systematic review to assess whether quality of life (QoL) indices and the role of palliative care have been studied in calciphylaxis patients. We hypothesize PC services are underutilized to address reduced QoL in calciphylaxis. Several databases were searched from inception to October 2016 according to modified PRISMA criteria. We searched for papers about calciphylaxis that mentioned the symptoms and supportive needs of patients, QoL or outcome measures to report symptom severity, and the involvement of PC. Twelve papers met inclusion criteria. Reported patient symptoms included pain, skin lesion resolution, and pruritus, with the first being the most frequently reported. Four papers measured pain using a previously verified patient reported outcome measure, including the Visual Analogue Scale (VAS pain). One paper used a verified QoL measure, the Dermatology Quality of Life Index (DQLI). No tool was used consistently. Eight papers reported the use of hospice or PC in the treatment of calciphylaxis. No outcome measure was used to prompt PC involvement. Overall, QoL indices, patient reported outcome measures, and PC are underreported in the treatment of calciphylaxis. Because dermatologists are frequently involved in calciphylaxis patient care, and symptoms can present significant challenges to clinical practice, we aim to raise clinician awareness of PC as a resource to assist in symptom management and adaptive coping strategies for patients from the onset of disease. This article is protected by copyright. All rights reserved.

7. Family Caregivers' Pain Management in End-of-Life Care: A Systematic Review.

Author(s): Chi, Nai-Ching; Demiris, George

Source: The American journal of hospice & palliative care; Jun 2017; vol. 34 (no. 5); p. 470-485

Publication Type(s): Journal Article

PubMedID: 26975303

Abstract: CONTEXT Pain management was the most identified burden faced by family caregivers in end-of-life caregiving. OBJECTIVES To synthesize current scientific evidence on family caregivers' experience of pain management in end-of-life care. METHODS A systematic review was conducted using CINAHL, Embase, PubMed, and Cochrane Library electronic databases. Data were extracted from each included paper and organized into tables to synthesize the findings. RESULTS Fourteen research papers focusing on family caregivers' experience of pain management and strategies in end-of-life care were included. Nine were observational studies, 3 were case studies, and 2 were experimental studies. These studies mainly focused on exploring family caregivers' engagement in pain management and communication with the hospice care team about pain control; family caregivers' knowledge, skills, and self-efficacy in pain management; and family caregivers' concerns and experience of pain management. CONCLUSION This review identified themes similar to previous reviews on family caregivers of patients with cancer or in palliative care: inadequate knowledge and assessment skills in pain management, misunderstanding of pain medications, and poor communication with the care team. Future research should design educational programs and material for family caregivers to improve their pain management knowledge and skills, communication, and engagement in care. The scientific knowledge on this topic is scarce, and level of evidence is low; it is therefore imperative to have more exploratory studies to expand the quality and quantity of evidence and increase our understanding of family caregivers' needs and barriers to pain management based on larger and more diverse patient and caregiver samples.
8. Supporting carers to manage pain medication in cancer patients at the end of life: A feasibility trial.

**Author(s):** Latter, Sue; Hopkinson, Jane B; Lawson, Elizabeth; Hughes, Jane A; Hughes, Jacki; Duke, Sue; Anstey, Sally; Bennett, Michael I; May, Carl; Smith, Peter; Richardson, Alison

**Source:** Palliative medicine; Jun 2017 ; p. 269216317711322

**Publication Type(s):** Journal Article

**PubMedID:** 28679073

**Abstract:** BACKGROUND Carers of people with advanced cancer play a significant role in managing pain medication, yet they report insufficient information and support to do so confidently and competently. There is limited research evidence on the best ways for clinicians to help carers with medication management. AIMS To develop a pain medicines management intervention (Cancer Carers Medicines Management) for cancer patients’ carers near the end of life and evaluate feasibility and acceptability to nurses and carers. To test the feasibility of trial research procedures and to inform decisions concerning a full-scale randomised controlled trial. DESIGN Phase I-II clinical trial. A systematic, evidence-informed participatory method was used to develop CCMM: a nurse-delivered structured conversational process. A two-arm, cluster randomised controlled feasibility trial of Cancer Carers Medicines Management was conducted, with an embedded qualitative study to evaluate participants’ experiences of Cancer Carers Medicines Management and trial procedures. SETTING Community settings in two study sites. PARTICIPANTS Phase I comprises 57 carers, patients and healthcare professionals and Phase II comprises 12 nurses and 15 carers. RESULTS A novel intervention was developed. Nurses were recruited and randomised. Carer recruitment to the trial was problematic with fewer than predicted eligible participants, and nurses judged a high proportion unsuitable to recruit into the study. Attrition rates following recruitment were typical for the study population. Cancer Carers Medicines Management was acceptable to carers and nurses who took part, and some benefits were identified. CONCLUSION Cancer Carers Medicines Management is a robustly developed medicines management intervention which merits further research to test its effectiveness to improve carers’ management of pain medicines with patients at the end of life. The study highlighted aspects of trial design that need to be considered in future research.


**Author(s):** Salamanca-Balen, Natalia; Seymour, Jane; Caswell, Glenys; Whynes, David; Tod, Angela

**Source:** Palliative medicine; Jun 2017 ; p. 269216317711570

**Publication Type(s):** Journal Article

**PubMedID:** 28655289

**Abstract:** BACKGROUND Patients with palliative care needs do not access specialist palliative care services according to their needs. Clinical Nurse Specialists working across a variety of fields are playing an increasingly important role in the care of such patients, but there is limited knowledge of the extent to which their interventions are cost-effective. OBJECTIVES To present results from a systematic review of the international evidence on the costs, resource use and cost-effectiveness of Clinical Nurse Specialist-led interventions for patients with palliative care needs, defined as seriously ill patients and those with advanced disease or frailty who are unlikely to be cured, recover or stabilize. DESIGN Systematic review following PRISMA methodology. DATA SOURCES Medline, Embase, CINAHL and Cochrane Library up to 2015. Studies focusing on the outcomes of Clinical Nurse Specialist interventions for patients with palliative care needs, and including at least one economic outcome, were considered. The quality of studies was assessed using tools from the Joanna Briggs Institute. RESULTS A total of 79 papers were included: 37 randomized controlled trials, 22 quasi-experimental studies, 7 service evaluations and other studies, and 13 economic analyses. The studies included a wide variety of interventions including clinical, support and education, as well as care coordination activities. The quality of the studies varied greatly. CONCLUSION Clinical Nurse Specialist interventions may be effective in reducing specific resource use such as hospitalizations/re-hospitalizations/admissions, length of stay and health care costs. There is mixed evidence regarding their cost-effectiveness. Future studies should ensure that Clinical Nurse Specialists’ roles and activities are clearly described and evaluated.

10. Pilot randomised controlled trial of focused narrative intervention for moderate to severe depression in palliative care patients: DISCERN trial.

**Author(s):** Lloyd-Williams, Mari; Shiels, Christopher; Ellis, Jacqueline; Abba, Katharine; Gaynor, Edward; Wilson, Kenneth; Dowrick, Christopher

**Source:** Palliative medicine; Jun 2017 ; p. 269216317711322
11. 'Dignity therapy', a promising intervention in palliative care: A comprehensive systematic literature review.

**Author(s):** Martínez, Marina; Arantzamendi, María; Belar, Alazne; Carrasco, José Miguel; Carvajal, Ana; Rullán, María; Centeno, Carlos

**Source:** Palliative medicine; Jun 2017; vol. 31 (no. 6); p. 492-509

**Publication Type(s):** Journal Article

**PubMedID:** 27566756

**Abstract:** BACKGROUND Dignity therapy is psychotherapy to relieve psychological and existential distress in patients at the end of life. Little is known about its effect. AIM To analyse the outcomes of dignity therapy in patients with advanced life-threatening diseases. DESIGN Systematic review was conducted. Three authors extracted data from the articles and evaluated quality using Critical Appraisal Skills Programme. Data were synthesized, considering study objectives. DATA SOURCES PubMed, CINAHL, Cochrane Library and PsycINFO. The years searched were 2002 (year of dignity therapy development) to January 2016. 'Dignity therapy' was used as search term. Studies with patients with advanced life-threatening diseases were included. RESULTS Of 121 studies, 28 were included. Quality of studies is high. Results were grouped into effectiveness, satisfaction, suitability and feasibility, and adaptability to different diseases and cultures. Two of five randomized control trials applied dignity therapy to patients with high levels of baseline psychological distress. One showed statistically significant decrease on patients' anxiety and depression scores over time. The other showed statistical decrease on anxiety scores pre-post dignity therapy, not on depression. Nonrandomized studies suggested statistically significant improvements in existential and psychosocial measurements. Patients, relatives and professionals perceived it improved end-of-life experience. CONCLUSION Evidence suggests that dignity therapy is beneficial. One randomized controlled trial with patients with high levels of psychological distress shows DT efficacy in anxiety and depression scores. Other design studies report beneficial outcomes in terms of end-of-life experience. Further research should understand how dignity therapy functions to establish a means for measuring its impact and assessing whether high level of distress patients can benefit most from this therapy.

12. Palliative care for terminally ill patients in the intensive care unit: Systematic review and metaanalysis.

**Author(s):** Martins, Belmira D C P C C; Oliveira, Reinaldo A; Cataneo, Antonio J M

**Source:** Palliative & supportive care; Jun 2017; vol. 15 (no. 3); p. 376-383

**Publication Type(s):** Journal Article

**PubMedID:** 27460968

**Abstract:** OBJECTIVE The purpose of our systematic review was to determine whether the introduction of palliative care (PC) teams reduces length of stay and/or mortality for terminally ill patients (TIPs) in an intensive care unit (ICU). METHOD We hoped to examine studies that compared TIPs in an ICU who received...
recruited from a specialist palliative care program in southern Adelaide, were expected to live symptom, quality of life (QoL), performance status, and survival.

used to investigate independent associations multiple outcome measures. At each time point, MEDD and DEDD were calculated. Multilevel modeling was cognitive, and symptom outcomes in patients receiving palliative care.

drug-related harms have important clinical implications, may impact on patients' compliance and contribute to symptoms. OBJECTIVE To explore the longitudinal relationship between oral, morphine equivalent daily dose (MEDD) and oral diazepam equivalent daily dose (DEDD) with functional, cognitive, and symptom outcomes in patients receiving palliative care. DESIGN Secondary longitudinal study. SETTING/SUBJECTS Participants were recruited from a specialist palliative care program in southern Adelaide, were expected to live 

Abstract: BACKGROUND: Meditations for symptom management in palliative care have associated, but poorly understood, harms. Drug-related harms may impact on patients' compliance and contribute to symptoms. OBJECTIVE To explore the longitudinal relationship between oral, morphine equivalent daily dose (MEDD) and oral diazepam equivalent daily dose (DEDD) with functional, cognitive, and symptom outcomes in patients receiving palliative care. DESIGN: Multilevel modeling was used to investigate independent associations between MEDD and DEDD, and cognitive and gastrointestinal symptoms, quality of life (QoL), performance status, and survival.

METHODS: Participants were recruited from a specialist palliative care program in southern Adelaide, were expected to live symptom, quality of life (QoL), performance status, and survival.

OBJECTIVE To explore the longitudinal relationship between oral, morphine equivalent daily dose (MEDD) and oral diazepam equivalent daily dose (DEDD) with functional, cognitive, and symptom outcomes in patients receiving palliative care.

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METHODS: Participants were recruited from a specialist palliative care program in southern Adelaide, were expected to live symptom, quality of life (QoL), performance status, and survival.
pain in the previous 3 months, and a baseline Folstein Mini-Mental Status Examination score ≥25.

RESULTSCognitive and gastrointestinal symptoms, performance status, and QoL worsened over time. In the adjusted multilevel analysis, statistically significant relationships remained between MEDD/DEDD and worsening performance status (p < 0.001), DEDD and gastrointestinal effects (p < 0.001), MEDD and QoL (p < 0.022).

CONCLUSIONS Commonly used palliative medications were associated with deteriorating performance status. The lack of association between MEDD with gastrointestinal or cognitive symptoms underlines that these associations are not inevitable with close attention. This analysis highlights the importance of including other medications as confounders when exploring medication-related harms. An understanding of the risk-benefit balance of medications is needed to maximize net benefits for patients.

15. Effectiveness of supporting intensive care units on implementing the guideline 'End-of-life care in the intensive care unit, nursing care': a cluster randomized controlled trial.

Author(s): Noome, Marijke; Dijkstra, Boukje M; van Leeuwen, Evert; Vloet, Lilian C M

Source: Journal of advanced nursing; Jun 2017; vol. 73 (no. 6); p. 1339-1354

Publication Type(s): Journal Article

PubMedID: 27878847

Abstract: AIM The aim of this study was to examine the effectiveness of supporting intensive care units on implementing the guidelines. BACKGROUND Quality of care can be achieved through evidence-based practice. Guidelines can facilitate evidence-based practice, such as the guidelines 'End-of-life care in the intensive care unit, nursing care'. Before intensive care nurses are able to use these guidelines, they needs to be implemented in clinical practice. Implementation is a complex process and may need support. DESIGN Cluster randomized controlled trial. METHODS Intensive care nurses of eight intensive care units in the intervention group followed a supportive programme that educated them on implementation, strategies, goals, project management and leadership. The intervention group focused on a stepwise approach to implement the guidelines. The control group (n = 5) implemented the guidelines independently or used the standard implementation plan supplementary to the guideline. The effectiveness of the programme was measured using questionnaires for nurses, interviews with nurses and a questionnaire for family of deceased patients, in the period from December 2014-December 2015. RESULTSOverall, an increase in adherence to the guidelines was found in both groups. Overall, use of the guidelines in the intervention group was higher, but on some aspects the control group showed a higher score. Care for the patient and the overall nursing care scored significantly higher according to family in the intervention group. CONCLUSION The increase in adherence to the guidelines and the significantly higher satisfaction of family in the intervention group indicate that the supportive programme had a more positive effect.

16. Experiences and Preferences for End-of-Life Care for Young Adults with Cancer and Their Informal Carers: A Narrative Synthesis.

Author(s): Ngwenya, Nothando; Kenten, Charlotte; Jones, Louise; Gibson, Faith; Pearce, Susie; Flately, Mary; Hough, Rachael; Stirling, L Caroline; Taylor, Rachel M; Wong, Geoff; Whelan, Jeremy

Source: Journal of adolescent and young adult oncology; Jun 2017; vol. 6 (no. 2); p. 200-212

Publication Type(s): Journal Article

PubMedID: 28075655

Abstract: To review the qualitative literature on experiences of and preferences for end-of-life care of people with cancer aged 16-40 years (young adults) and their informal carers. A systematic review using narrative synthesis of qualitative studies using the 2006 UK Economic and Social Research Council research methods program guidance. Seven electronic bibliographic databases, two clinical trials databases, and three relevant theses databases were searched from January 2004 to October 2015. Eighteen articles were included from twelve countries. The selected studies included at least 5% of their patient sample within the age range 16-40 years. The studies were heterogeneous in their aims, focus, and sample, but described different aspects of end-of-life care for people with cancer. Positive experiences included facilitating adaptive coping and receiving palliative home care, while negative experiences were loss of “self” and nonfacilitative services and environment. Preferences included a family-centered approach to care, honest conversations about end of life, and facilitating normality. There is little evidence focused on the end-of-life needs of young adults. Analysis of reports including some young adults does not explore experience or preferences by age; therefore, it is difficult to identify age-specific issues clearly. From this review, we suggest that supportive interventions and education are needed to facilitate open and honest communication at an appropriate level with young people. Future research should focus on age-specific evidence about the end-of-life experiences and preferences for young
17. Experiences of non-specialist nurses caring for patients and their significant others undergoing transitions during palliative end-of-life cancer care: a systematic review.

**Author(s):** Thorn, Hróun; Uhrenfeldt, Lisbeth

**Source:** JBI database of systematic reviews and implementation reports; Jun 2017; vol. 15 (no. 6); p. 1711-1746

**Publication Type(s):** Journal Article

**PubMedID:** 28628524

**Abstract:** BACKGROUND Non-specialist nurses, who are providing palliative end-of-life cancer care to patients and significant others undergoing psychosocial and existential transitions, may experience dissatisfaction, frustration and sorrow. On the other hand, they may also experience happiness, increased knowledge and personal growth. OBJECTIVE/QUESTION What are non-specialist nurses’ experiences when providing palliative end-of-life cancer care that involves the psychosocial and existential transitions of their patients and significant others? INCLUSION CRITERIA TYPES OF PARTICIPANTS The current review considered studies that included a description of the experiences of non-specialist trained registered nurses (RNs) working in non-specialist wards. PHENOMENA OF INTEREST The current review considered studies that investigated experiences of RNs when providing palliative end-of-life cancer care that involves the psychosocial and existential transitions of their patients and significant others. CONTEXT The contact and care for patients and their significant others during palliative end-of-life cancer care. TYPES OF STUDIES The current review considered studies that focused on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research. SEARCH STRATEGY The search aimed at finding both published and unpublished studies in English, Danish, Norwegian, Swedish and German, and was unrestricted by time. Eleven electronic databases and seven websites were searched. METHODOLOGICAL QUALITY Methodological validity of the qualitative papers was assessed independently by two reviewers using the standardized critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI).DATA EXTRACTION Data were extracted from papers included in the review using the standardized data extraction tool from the JBI-QARI.DATA SYNTHESIS Qualitative research findings were synthesized using the JBI-QARI.RESULTS A total of 81 findings were extracted from the three studies and allocated to five categories and merged into a meta-synthesis with the overarching synthesized finding related to the challenges that non-specialist nurses faced when providing palliative end-of-life cancer care. The summary of findings is illustrated below. CONCLUSION The studies in this review provided useful and credible statements from non-specialist nurses working in non-specialist wards about their challenges when providing palliative end-of-life cancer care to patients and their significant others undergoing psychosocial and existential transitions.

18. Specialist palliative care improves the quality of life in advanced neurodegenerative disorders: NE-PAL, a pilot randomised controlled study.

**Author(s):** Veronese, Simone; Gallo, G; Valle, A; Cugno, C; Chiò, A; Calvo, A; Cavalla, P; Zibetti, M; Rivoiro, C; Oliver, D J

**Source:** BMJ supportive & palliative care; Jun 2017; vol. 7 (no. 2); p. 164-172

**Publication Type(s):** Journal Article

**PubMedID:** 26182947

**Abstract:** BACKGROUND This study analysed the impact on palliative care outcomes of a new specialist palliative care service for patients severely affected by amyotrophic lateral sclerosis (ALS/MND), multiple sclerosis, Parkinson’s disease and related disorders (multiple system atrophy progressive supranuclear palsy, MSA-PSP). METHODS The design followed the Medical Research Council Framework for the evaluation of complex interventions. A phase II randomised controlled trial (RCT) was undertaken comparing an immediate referral to the service (FT, fast track) to a 16-week wait (standard track (ST), standard best practice) using a parallel arm design. The main outcome measures were Quality of Life (measured with Schedule for the Evaluation of Individual Quality of Life Direct Weight, SEIQoL-DW) and burden of the carers (Caregivers Burden Inventory, CBI), with secondary outcomes of symptoms, psychosocial and spiritual issues. RESULTS 50 patients severely affected by neurodegenerative conditions and their informal family carers were randomised: 25 FT, 25 ST. At baseline (T0), there were no differences between groups. 4 patients died during the follow-up (2 FT, 2 ST) and 2 FT patients dropped out before the end of the study. After 16 weeks (T1), FT participants scored significant improvement in the SEIQoL-DW index, pain dyspnoea sleep disturbance and bowel symptoms. CONCLUSIONS This exploratory RCT provides evidence that no harm was experienced by SPCS.
for patients severely affected by neurodegenerative disorders. There was an improvement in quality of life and physical symptoms for neurological patients in palliative care. Caregiver burden was not affected by the service.

| Author(s): Waller, Amy; Dodd, Natalie; Tattersall, Martin H N; Nair, Balakrishnan; Sanson-Fisher, Rob |
| Source: BMC palliative care; May 2017; vol. 16 (no. 1); p. 34 |
| Publication Type(s): Journal Article |
| PubMedID: 28526095 |
| Available in full text at BMC Palliative Care - from ProQuest |
| Available in full text at BMC Palliative Care - from BioMed Central |
| Available in full text at BMC Palliative Care - from National Library of Medicine |
| Abstract: BACKGROUND As in other areas of health delivery, there is a need to ensure that end-of-life care is guided by patient centred research. A systematic review was undertaken to examine the quantity and quality of data-based research aimed at improving the (a) processes and (b) outcomes associated with delivering end-of-life care in hospital settings. METHODS Medline, EMBASE and Cochrane databases were searched between 1995 and 2015 for data-based papers. Eligible papers were classified as descriptive, measurement or intervention studies. Intervention studies were categorised according to whether the primary aim was to improve: (a) end of life processes (i.e. end-of-life documentation and discussions, referrals); or (b) end-of-life outcomes (i.e. perceived quality of life, health status, health care use, costs). Intervention studies were assessed against the Effective Practice and Organisation of Care methodological criteria for research design, and their effectiveness examined. RESULTS A total of 416 papers met eligibility criteria. The number increased by 13% each year (p < 0.001). Most studies were descriptive (n = 351, 85%), with fewer measurement (n = 17) and intervention studies (n = 48; 10%). Only 18 intervention studies (4%) met EPOC design criteria. Most reported benefits for end-of-life processes including end-of-life discussions and documentation (9/11). Impact on end-of-life outcomes was mixed, with some benefit for psychosocial distress, satisfaction and concordance in care (3/7). CONCLUSION More methodologically robust studies are needed to evaluate the impact of interventions on end-of-life processes, including whether changes in processes translate to improved end-of-life outcomes. Interventions which target both the patient and substitute decision maker in an effort to achieve these changes. |

| 20. Identifying models of delivery, care domains and quality indicators relevant to palliative day services: a scoping review protocol. |
| Author(s): O’Connor, Seán R; Dempster, Martin; McCorry, Noleen K |
| Source: Systematic reviews; May 2017; vol. 6 (no. 1); p. 100 |
| Publication Type(s): Journal Article |
| PubMedID: 28511720 |
| Available in full text at Systematic Reviews - from ProQuest |
| Available in full text at Systematic Reviews - from BioMed Central |
| Abstract: BACKGROUND With an ageing population and increasing numbers of people with life-limiting illness, there is a growing demand for palliative day services. There is a need to measure and demonstrate the quality of these services, but there is currently little agreement on which aspects of care should be used to do this. The aim of the scoping review will be to map the extent, range and nature of the evidence around models of delivery, care domains and existing quality indicators used to evaluate palliative day services. METHODS Electronic databases (MEDLINE, EMBASE, CINAHL, PsycINFO, Cochrane Central Register of Controlled Trials) will be searched for evidence using consensus development methods; randomised or quasi-randomised controlled trials; mixed methods; and prospective, longitudinal or retrospective case-control studies to develop or test quality indicators for evaluating palliative care within non-residential settings, including day hospices and community or primary care settings. At least two researchers will independently conduct all searches, study selection and data abstraction procedures. Meta-analyses and statistical methods of synthesis are not planned as part of the review. Results will be reported using numerical counts, including number of indicators in each care domain and by using qualitative approach to describe important indicator characteristics. A conceptual model will also be developed to summarise the impact of different aspects of quality in a palliative day service context. Methodological quality relating to indicator development will be assessed using the Appraisal of Indicators through Research and Evaluation (AIRE) tool. Overall strength of evidence will be assessed using the Grading.
of Recommendations, Assessment, Development, and Evaluation (GRADE) system. Final decisions on quality assessment will be made via consensus between review authors. DISCUSSION Identifying, developing and implementing evidence-based quality indicators is critical to the evaluation and continued improvement of palliative care. Review findings will be used to support clinicians and policymakers make decisions on which quality indicators are most appropriate for evaluating day services at the patient and service level, and to identify areas for further research.


Author(s): Pyszora, Anna; Budzyński, Jacek; Wójcik, Agnieszka; Prokop, Anna; Krajnik, Małgorzata

Source: Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer; May 2017

Publication Type(s): Journal Article

PubMedID: 28508278

Abstract: PURPOSE Cancer-related fatigue (CRF) is a common and relevant symptom in patients with advanced cancer that significantly decreases their quality of life. The aim of this study was to evaluate the effect of a physiotherapy programme on CRF and other symptoms in patients diagnosed with advanced cancer.

METHODS The study was designed as a randomized controlled trial. Sixty patients diagnosed with advanced cancer receiving palliative care were randomized into two groups: the treatment group (n = 30) and the control group (n = 30). The therapy took place three times a week for 2 weeks. The 30-min physiotherapy session included active exercises, myofascial release and proprioceptive neuromuscular facilitation (PNF) techniques. The control group did not exercise. The outcomes included Brief Fatigue Inventory (BFI), Edmonton Symptom Assessment Scale (ESAS) and satisfaction scores.

RESULTS The exercise programme caused a significant reduction in fatigue scores (BFI) in terms of severity of fatigue and its impact on daily functioning. In the control group, no significant changes in the BFI were observed. Moreover, the physiotherapy programme improved patients' general well-being and reduced the intensity of coexisting symptoms such as pain, drowsiness, lack of appetite and depression. The analysis of satisfaction scores showed that it was also positively evaluated by patients. CONCLUSION The physiotherapy programme, which included active exercises, myofascial release and PNF techniques, had beneficial effects on CRF and other symptoms in patients with advanced cancer who received palliative care. The results of the study suggest that physiotherapy is a safe and effective method of CRF management.

22. Productivity in Pediatric Palliative Care: Measuring and Monitoring an Elusive Metric.

Author(s): Kaye, Erica C; Abramson, Zachary R; Snaman, Jennifer M; Friebert, Sarah E; Baker, Justin N

Source: Journal of pain and symptom management; May 2017; vol. 53 (no. 5); p. 952-961

Publication Type(s): Journal Article

PubMedID: 28062335

Abstract: CONTEXT Workforce productivity is poorly defined in health care. Particularly in the field of pediatric palliative care (PPC), the absence of consensus metrics impedes aggregation and analysis of data to track workforce efficiency and effectiveness. Lack of uniformly measured data also compromises the development of innovative strategies to improve productivity and hinders investigation of the link between productivity and quality of care, which are interrelated but not interchangeable. OBJECTIVES To review the literature regarding the definition and measurement of productivity in PPC; to identify barriers to productivity within traditional PPC models; and to recommend novel metrics to study productivity as a component of quality care in PPC.

METHODS PubMed® and Cochrane Database of Systematic Reviews searches for scholarly literature were performed using key words (pediatric palliative care, palliative care, team, workforce, workflow, productivity, algorithm, quality care, quality improvement, quality metric, inpatient, hospital, consultation, model) for articles published between 2000 and 2016. Organizational searches of Center to Advance Palliative Care, National Hospice and Palliative Care Organization, National Association for Home Care & Hospice, American Academy of Hospice and Palliative Medicine, Hospice and Palliative Nurses Association, National Quality Forum, and National Consensus Project for Quality Palliative Care were also performed. Additional semistructured interviews were conducted with directors from seven prominent PPC programs across the U.S. to review standard operating procedures for PPC team workflow and productivity. RESULTS Little consensus exists in the PPC field regarding optimal ways to define, measure, and analyze provider and program productivity. Barriers to accurate monitoring of productivity include difficulties with identification, measurement, and interpretation of metrics applicable to an interdisciplinary care paradigm. In the context of
inefficiencies inherent to traditional consultation models, novel productivity metrics are proposed.

CONCLUSIONS Further research is needed to determine optimal metrics for monitoring productivity within PPC teams. Innovative approaches should be studied with the goal of improving efficiency of care without compromising value.

23. Specialist paediatric palliative care services: what are the benefits?

**Author(s):** Mitchell, Sarah; Morris, Andrew; Bennett, Karina; Sajid, Laiba; Dale, Jeremy

**Source:** Archives of disease in childhood; Apr 2017

**Publication Type(s):** Journal Article

**PubMedID:** 28377450

Available in full text at [Archives of disease in childhood](https://www.highwire.org/articles/adr/vol97/iss3/28377450.xml) - from Highwire Press

**Abstract:** BACKGROUND The number of children and young people (CYP) living with life-limiting and life-threatening conditions is rising. Paediatric palliative care is a relatively new aspect of healthcare, the delivery of which is variable, with a wide range of healthcare and voluntary sector providers involved. Policy recommendations are for Specialist Paediatric Palliative Care (SPPC) services to be supported by a physician with specialist training. AIM To examine the research evidence regarding the distinct benefits of SPPC services, with 'Specialist Paediatric Palliative Care' defined as palliative care services supported by a specialist physician.

**METHOD** Systematic review of studies of SPPC services published in English from 1980 to 2016. Keyword searches were carried out in medical databases (Cochrane, PubMed, EMBASE, CINAHL and AMED) and a narrative synthesis. RESULTS Eight studies were identified, most of which were retrospective surveys undertaken within single institutions; three were surveys of bereaved parents and three were medical notes reviews. Together they represented a heterogeneous body of low-level evidence. Cross-cutting themes suggest that SPPC services improve the quality of life and symptom control and can impact positively on place of care and family support. CONCLUSIONS Current evidence indicates that SPPC services contribute beneficially to the care and experience of CYP and their families, but is limited in terms of quantity, methodological rigour and generalisability. Further research is necessary given the significant workforce and resource implications associated with policy recommendations about the future provision of SPPC and to address the need for evidence to inform the design and delivery of SPPC services.


**Author(s):** Wong, Frances Kam Yuet; So, Ching; Ng, Alina Yee Man; Lam, Po-Tin; Ng, Jeffrey Sheung Ching; Ng, Nancy Hiu Yim; Chau, June; Sham, Michael Mau Kwong

**Source:** Palliative medicine; Apr 2017; p. 269216317706450

**Publication Type(s):** Journal Article

**PubMedID:** 28434275

**Abstract:** BACKGROUND Studies have shown positive clinical outcomes of specialist palliative care for end-stage heart failure patients, but cost-effectiveness evaluation is lacking. AIM To examine the cost-effectiveness of a transitional home-based palliative care program for patients with end-stage heart failure patients as compared to the customary palliative care service. DESIGN A cost-effectiveness analysis was conducted alongside a randomized controlled trial (Trial number: NCT02086305). The costs included pre-program training, intervention, and hospital use. Quality of life was measured using SF-6D SETTING/PARTICIPANTS The study took place in three hospitals in Hong Kong. The inclusion criteria were meeting clinical indicators for end-stage heart failure patients including clinician-judged last year of life, discharged to home within the service area, and palliative care referral accepted. A total of 84 subjects (study = 43, control = 41) were recruited. RESULTS When the study group was compared to the control group, the net incremental quality-adjusted life years gain was 0.0012 (28 days)/0.0077 (84 days) and the net incremental costs per case was -HK$7935 (28 days)/-HK$26,084 (84 days). The probability of being cost-effective was 85% (28 days)/100% (84 days) based on the cost-effectiveness thresholds recommended both by National Institute for Health and Clinical Excellence (£20,000/quality-adjusted life years) and World Health Organization (Hong Kong gross domestic product/capita in 2015, HK$328117). CONCLUSION Results suggest that a transitional home-based palliative care program is more cost-effective than customary palliative care service. Limitations of the study include small sample size, study confined to one city, clinic consultation costs, and societal costs including patient costs and unpaid caregiving costs were not included.
25. What do we know about different models of providing palliative care? Findings from a systematic review of reviews.

Author(s): Brereton, Louise; Clark, Joseph; Ingleton, Christine; Gardiner, Clare; Preston, Louise; Ryan, Tony; Goyder, Elizabeth

Source: Palliative medicine; Apr 2017; p. 269216317701890

Publication Type(s): Journal Article

PubMedID: 28376681

Abstract: BACKGROUND A wide range of organisational models of palliative care exist. However, decision makers need more information about which models are likely to be most effective in different settings and for different patient groups. AIM To identify the existing range of models of palliative care that have been evaluated, what is already known and what further information is essential if the most effective and cost-effective models are to be identified and replicated more widely. DESIGN A review of systematic and narrative reviews according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines. Study quality was assessed using the AMSTAR (A MeaSurement Tool to Assess Reviews) tool. DATA SOURCES MEDLINE, EMBASE, PsycINFO, CINAHL, Cochrane Library, Web of Science and ASSIA were searched for reviews about models of service provision from 2000 to 2014 and supplemented with Google searches of the grey literature. RESULTS Much of the evidence relates to home-based palliative care, although some models are delivered across care settings. Reviews report several potential advantages and few disadvantages of models of palliative care delivery. However, under-reporting of the components of intervention and comparator models are major barriers to the evaluation and implementation of models of palliative care. CONCLUSION Irrespective of setting or patient characteristics, models of palliative care appear to show benefits and some models of palliative care may reduce total healthcare costs. However, much more detailed and systematic reporting of components and agreement about outcome measures is essential in order to understand the key components and successfully replicate effective organisational models.

26. What cost components are relevant for economic evaluations of palliative care, and what approaches are used to measure these costs? A systematic review.

Author(s): Gardiner, Clare; Ingleton, Christine; Ryan, Tony; Ward, Sue; Gott, Merryn

Source: Palliative medicine; Apr 2017; vol. 31 (no. 4); p. 323-337

Publication Type(s): Journal Article

PubMedID: 27670418

Abstract: BACKGROUND It is important to understand the costs of palliative and end-of-life care in order to inform decisions regarding cost allocation. However, economic research in palliative care is very limited and little is known about the range and extent of the costs that are involved in palliative care provision. AIM To undertake a systematic review of the health and social care literature to determine the range of financial costs related to a palliative care approach and explore approaches used to measure these costs. DESIGN A systematic review of empirical literature with thematic synthesis. Study quality was evaluated using the Weight of Evidence Framework. DATA SOURCES The databases CINAHL, Cochrane, PsycINFO and Medline were searched from 1995 to November 2015 for empirical studies which presented data on the financial costs associated with palliative care. RESULTS A total of 38 papers met our inclusion criteria. Components of palliative care costs were incurred within four broad domains: hospital care, community or home-based care, hospice care and informal care. A wide variety of costing approaches were used to derive costs. CONCLUSION The evidence base regarding the economics of palliative care is sparse, particularly relating to the full economic costs of palliative care. Our review provides a framework for considering these costs from a variety of economic viewpoints; however, further research is required to develop and refine methodologies.

27. Developing a Research Agenda for Integrating Palliative Care into Critical Care and Pulmonary Practice To Improve Patient and Family Outcomes.

Author(s): Aslakson, Rebecca A; Reinke, Lynn F; Cox, Christopher; Kross, Erin K; Benzo, Roberto P; Curtis, J Randall

Source: Journal of palliative medicine; Apr 2017; vol. 20 (no. 4); p. 329-343

Publication Type(s): Journal Article

PubMedID: 28379812
Abstract: BACKGROUND Palliative care is a medical specialty and philosophy of care that focuses on reducing suffering among patients with serious illness and their family members, regardless of disease diagnosis or prognosis. As critical illness or moderate to severe pulmonary disease confers significant disease-related symptom burdens, palliative care and palliative care specialists can aid in reducing symptom burden and improving quality of life among these patients and their family members. OBJECTIVE The objective of this article is to review the existing gaps in evidence for palliative care in pulmonary disease and critical illness and to use an interdisciplinary working group convened by the National Institutes of Health and the National Palliative Care Research Center to develop a research agenda to address these gaps. METHODS We completed a narrative review of the literature concerning the integration of palliative care into pulmonary and/or critical care. The review was based on recent systematic reviews on these topics as well as a summary of relevant articles identified through hand search. We used this review to identify gaps in current knowledge and develop a research agenda for the future. RESULTS We identified key areas of need and knowledge gaps that should be addressed to improve palliative care for patients with pulmonary and critical illness. These areas include developing and validating patient- and family-centered outcomes, identifying the key components of palliative care that are effective and cost-effective, developing and evaluating different models of palliative care delivery, and determining the effectiveness and cost-effectiveness of palliative care interventions. CONCLUSIONS The goal of this research agenda is to encourage researchers, clinicians, healthcare systems, and research funders to identify research that can address these gaps and improve the lives of patients with pulmonary and critical illness and their family members.

28. Assessing Palliative Care Content in Dementia Care Guidelines: A Systematic Review.

Author(s): Durepos, Pamela; Wickson-Griffiths, Abigail; Hazzan, Afeez Abiola; Kaasalainen, Sharon; Vastis, Vasilia; Battistella, Lisa; Papaioannou, Alexandra

Source: Journal of Pain and Symptom Management; Apr 2017; vol. 53 (no. 4); p. 804-813

Publication Type(s): Journal Article Review

PubMedID: 28063859

Abstract: CONTEXT Families of persons with dementia continue to report unmet needs during end of life (EOL). Strategies to improve care and quality of life for persons with dementia include development of clinical practice guidelines (CPGs) and an integrative palliative approach. OBJECTIVES We aimed to assess palliative care content in dementia CPGs to identify the presence or limitations of recommendations and discussion pertaining to common issues or domains affected by illness as described by the Canadian Hospice Palliative Care Association "Square of Care." DESIGN A systematic review of databases and gray literature was conducted for recent CPGs. Guidelines meeting inclusion criteria were evaluated using the Appraisal of Guidelines for Research and Evaluation II instrument. Quality CPGs were analyzed through organizational template analysis using illness domains described by the "Canadian Hospice Palliative Care Association Model." The study protocol is registered at PROSPERO (CRD 42015025369). RESULTS Eleven CPGs were selected and analyzed from 3779 citations. Nine guidelines demonstrated the maximum level of content regarding physical, psychological, and social care. Conversely, spiritual care was either absent (three) or minimal (three) in CPGs. Six CPGs did not address loss or grief, and seven CPGs did not address or had minimal content regarding EOL care. CONCLUSIONS The lack of content surrounding grief represents a gap for this population at high risk for complicated grief and chronic sorrow. Results of this review require attention by CPG developers and researchers to develop evidence-based recommendations surrounding spiritual care, EOL, and grief.

29. Palliative and end-of-life care conversations in COPD: a systematic literature review.

Author(s): Tavares, Nuno; Jarrett, Nikki; Hunt, Katherine; Wilkinson, Tom

Source: ERJ open research; Apr 2017; vol. 3 (no. 2)

Publication Type(s): Journal Article Review

PubMedID: 28462236

Abstract: Chronic obstructive pulmonary disease (COPD) is a chronic life-limiting disorder characterised by persistent airflow obstruction and progressive breathlessness. Discussions/conversations between patients and clinicians ensure palliative care plans are grounded in patients' preferences. This systematic review aimed to explore what is known about palliative care conversations between clinicians and COPD patients. A comprehensive search of all major healthcare-related databases and websites was performed following Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. Studies were quality assessed, employing widely used quality-assessment tools, with only papers scoring moderate-to-high quality
included. All relevant data were extracted. A narrative synthesis was used to analyse, process and present the final data. The findings indicated that the frequency and quality of palliative care conversations is generally poor. Patients and physicians identified many barriers and important topics were not discussed. Patients and clinicians reported tension between remaining hopeful and the reality of the patients' condition. When discussions did happen, they often occurred at an advanced stage of illness and in respiratory wards and intensive care units. In conclusion, current care practices do not facilitate satisfactory conversations about palliative care between COPD patients and clinicians. This impacts upon the fulfilment of patients' preferences at the end of life.


Author(s): von Heymann-Horan, Annika B; Puggaard, Louise B; Nissen, Kathrine G; Benthen, Kirstine Skov; Bidstrup, Pernille; Coyne, James; Johansen, Christoffer; Kjellberg, Jakob; Nordly, Mie; Sjøgren, Per; Timm, Helle; von der Maase, Hans; Guldin, Mai-Britt

Source: Palliative & supportive care; Mar 2017 ; p. 1-9

Publication Type(s): Journal Article

PubMedID: 28357972

Abstract: OBJECTIVE Patients with incurable cancer and their informal caregivers have numerous psychological and psychosocial needs. Many of these patients wish to receive their care and die at home. Few home-based specialized palliative care (SPC) interventions systematically integrate psychological support. We present a psychological intervention for patient-caregiver dyads developed for an ongoing randomized controlled trial (RCT) of home-based SPC, known as Domus, as well as the results of an assessment of its acceptability and feasibility. METHOD The Domus model of SPC for patients with incurable cancer and their caregivers offered systematic psychological assessment and dyadic intervention as part of interdisciplinary care. Through accelerated transition to SPC, the aim of the model was to enhance patients' chances of receiving care and dying at home. Integration of psychological support sought to facilitate this goal by alleviating distress in patients and caregivers. Psychologists provided needs-based sessions based on existential-phenomenological therapy. Feasibility and acceptability were investigated by examining enrollment, nonparticipation, and completion of psychological sessions. RESULTS Enrollment in the RCT and uptake of the psychological intervention indicated that it was feasible and acceptable to patients and caregivers. The strengths of the intervention included its focus on dyads, psychological distress, and existential concerns, as well as interdisciplinary collaboration and psychological interventions offered according to need. Its main limitation was a lack of an intervention for other family members. SIGNIFICANCE OF RESULTS Our results show that psychological intervention can be systematically integrated into SPC and that it appears feasible to provide dyadic needs-based sessions with an existential therapeutic approach. The Domus RCT will provide evidence of the efficacy of a novel model of multidisciplinary SPC.


Author(s): Nilsson, Jonas; Blomberg, Carl; Holgersson, Georg; Carlsson, Tobias; Bergqvist, Michael; Bergström, Stefan

Source: Asia-Pacific journal of clinical oncology; Mar 2017

Publication Type(s): Journal Article Review

PubMedID: 28294576

Abstract: The importance to die at preferred death place is substantial among terminally ill cancer patients. Previously, several studies have investigated this issue, but no systematic review has been made for many years. This systematic review was made in order to investigate preferred death place among cancer patients. A systematic search was made in PubMed library and a total of 399 articles were found, of which 23 were eligible and included in the review. Preference of home death averaged by 59.9% (39.7-100%) across all studies. Information about actual death place was only reported in 12 studies with an average of 40.4% (14-65.2%); thus, the incongruence between preferred and actual death place seems to be substantial. This highlights the importance of health care providers to discuss the issue with the patients and their families. However, study designs must improve and publications of socioeconomic data should be unified to ease interpretation in future studies.
32. What is the evidence for conducting palliative care family meetings? A systematic review.

Author(s): Cahill, Philippa J; Lobb, Elizabeth A; Sanderson, Christine; Phillips, Jane L
Source: Palliative medicine; Mar 2017; vol. 31 (no. 3); p. 197-211
Publication Type(s): Journal Article
PubMedID: 27492159

Abstract: BACKGROUND Structured family meeting procedures and guidelines suggest that these forums enhance family-patient-team communication in the palliative care inpatient setting. However, the vulnerability of palliative patients and the resources required to implement family meetings in accordance with recommended guidelines make better understanding about the effectiveness of this type of intervention an important priority. Aim and design: This systematic review examines the evidence supporting family meetings as a strategy to address the needs of palliative patients and their families. The review conforms to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Statement. DATA SOURCES Six medical and psychosocial databases and "CareSearch," a palliative care-specific database, were used to identify studies reporting empirical data, published in English in peer-reviewed journals from 1980 to March 2015. Book chapters, expert opinion, and gray literature were excluded. The Cochrane Collaboration Tool assessed risk of bias. RESULTS Of the 5051 articles identified, 13 met the inclusion criteria: 10 quantitative and 3 qualitative studies. There was low-level evidence to support family meetings. Only two quantitative pre- and post-studies used a validated palliative care family outcome measure with both studies reporting significant results post-family meetings. Four other quantitative studies reported significant results using non-validated measures. CONCLUSION Despite the existence of consensus-based family meeting guidelines, there is a paucity of evidence to support family meetings in the inpatient palliative care setting. Further research using more robust designs, validated outcome measures, and an economic analysis are required to build the family meeting evidence before they are routinely adopted into clinical practice.

33. A cluster randomized trial of a primary palliative care intervention (CONNECT) for patients with advanced cancer: Protocol and key design considerations.

Author(s): Becker, Claire L; Arnold, Robert M; Park, Seo Young; Rosenzweig, Margaret; Smith, Thomas J; White, Douglas B; Smith, Kenneth J; Schenker, Yael
Source: Contemporary clinical trials; Mar 2017; vol. 54 ; p. 98-104
Publication Type(s): Journal Article
PubMedID: 28104470

Abstract: BACKGROUND The addition of specialty palliative care to standard oncology care improves outcomes for patients with advanced cancer and their caregivers, but many lack access to specialty care services. Primary palliative care-meaning basic palliative care services provided by clinicians who are not palliative care specialists—is an alternative approach that has not been rigorously evaluated. METHODS A cluster randomized, controlled trial of the CONNECT (Care management by Oncology Nurses to address supportive care needs) intervention, an oncology nurse-led care management approach to providing primary palliative care for patients with advanced cancer and their family caregivers, is currently underway at 16 oncology practices in Western Pennsylvania. Existing oncology nurses are trained to provide symptom management and emotional support, engage patients and families in advance care planning, and coordinate appropriate care using evidence-based care management strategies. The trial will assess the impact of CONNECT versus standard oncology care on patient quality of life (primary outcome), symptom burden, and mood; caregiver burden and mood; and healthcare resource use. DISCUSSION This trial addresses the need for more accessible models of palliative care by evaluating an intervention led by oncology nurses that can be widely disseminated in community oncology settings. The design confronts potential biases in palliative care research by randomizing at the practice level to avoid contamination, enrolling patients prior to informing them of group allocation, and conducting blinded outcome assessments. By collecting patient, caregiver, and healthcare utilization outcomes, the trial will enable understanding of the full range of a primary palliative care intervention’s impact.

34. Psychosocial needs and interventions for heart failure patients and families receiving palliative care support: a systematic review.

Author(s): Cagle, John G; Bunting, Morgan; Kelemen, Anne; Lee, Joonyup; Terry, Dorothy; Harris, Ryan
Source: Heart failure reviews; Feb 2017
Publication Type(s): Journal Article Review
PubMedID: 28217818
Abstract: Although diseases of the heart are the leading cause of death in the USA, palliative care research has largely focused on populations of cancer patients. However, a diagnosis of heart failure differs substantially than that of cancer. They differ in terms of signs and symptoms, disease trajectories, treatment options, stigma, and prognosis. Additionally, the populations affected by these differing illnesses are also unique in a number of fundamental ways. Based on these differences, it is reasonable to hypothesize that palliative care patients with heart failure, and their families, have a distinct set of psychosocial needs. The purpose of this review is to describe the psychosocial needs of palliative care heart failure patients, and their families, as well as the interventions that address those needs. Six electronic databases were searched in June 2016 resulting in 962 identified abstracts. After removal of 388 duplicates, 574 abstracts were screened based on the following criteria: (1) available in English, (2) peer-reviewed, (3) empirical data reported, (4) patient receiving palliative care or hospice care, and (5) measured psychosocial needs of heart failure patients and/or their family caregivers. After screening 574 abstracts and conducting a full-text review of 150 articles, a total of 17 studies were identified in our review. Only three intervention studies were identified, two of which evaluated the impact of palliative care over usual care. The remaining study was a clinical trial of a psycho-educational support intervention, which failed to demonstrate beneficial outcomes. Heart failure patients and their family caregivers receiving palliative or hospice care have unique psychosocial needs that are largely unexamined by previous research. The need for further research is discussed.

35. Effects of hospital palliative care on health, length of stay, and in-hospital mortality across intensive and non-intensive-care units: A systematic review and metaanalysis.

Author(s): Liu, Xibe; Dawod, Yaser; Wonnaparhown, Alex; Shafi, Amaan; Doo, Loomee; Yoo, Ji Won; Ko, Eunjeong; Choi, Youn Seon

Source: Palliative & supportive care; Feb 2017; p. 1-12

Publication Type(s): Journal Article

PubMedID: 28196551

Abstract: OBJECTIVE Hospital palliative care has been shown to improve quality of life and optimize hospital utilization for seriously ill patients who need intensive care. The present review examined whether hospital palliative care in intensive care (ICU) and non-ICU settings will influence hospital length of stay and in-hospital mortality. METHODA systematic search of CINAHL/EBSCO, the Cochrane Library, Google Scholar, MEDLINE/Ovid, PubMed, and the Web of Science through 12 October 2016 identified 16 studies that examined the effects of hospital palliative care and reported on hospital length of stay and in-hospital death. Random-effects pooled odds ratios and mean differences with corresponding 95% confidence intervals were estimated. Heterogeneity was measured by the I2 test. The Grading of Recommendations Assessment, Development, and Evaluation (GRADE) system was utilized to assess the overall quality of the evidence. RESULTS Of the reviewed 932 articles found in our search, we reviewed the full text of 76 eligible articles and excluded 60 of those, which resulted in a final total of 16 studies for analysis. Five studies were duplicated with regard to outcomes. A total of 18,330 and 9,452 patients were analyzed for hospital length of stay and in-hospital mortality from 11 and 10 studies, respectively. Hospital palliative care increased mean hospital length of stay by 0.19 days (pooled mean difference = 0.19; 95% confidence interval [CI 95%] = -2.22-2.61 days; p = 0.87; I2 = 95.88%) and reduced in-hospital mortality by 34% (pooled odds ratio = 0.66; CI 95% = 0.52-0.84; p < 0.01; I2 = 48.82%). The overall quality of evidence for both hospital length of stay and in-hospital mortality was rated as very low and low, respectively. SIGNIFICANCE OF RESULTS Hospital palliative care was associated with a 34% reduction of in-hospital mortality but had no correlation with hospital length of stay.

36. Systematic review of the effectiveness, barriers and facilitators to general practitioner engagement with specialist secondary services in integrated palliative care.

Author(s): Carmont, Sue-Ann; Mitchell, Geoffrey; Senior, Hugh; Foster, Michele

Source: BMJ supportive & palliative care; Feb 2017

Publication Type(s): Journal Article Review

PubMedID: 28196828

Abstract: The general practitioner (GP) has a critical role in an integrated model of palliative care as they often know the patient and carer well, are experts in generalist care and have knowledge of health and social services in the community. Specialist palliative services have insufficient capacity to meet demand and those with non-cancer terminal conditions and those from rural and remote areas are underserved. Research has focused on improving access to palliative care by engaging the GP with specialist secondary services in integrated palliative
care. **OBJECTIVES** (1) Evaluate the effectiveness of interventions designed to engage GPs and specialist secondary services in integrated palliative care; and (2) identify the personal, system and structural barriers and facilitators to integrated palliative care. **METHOD** MEDLINE, EMBASE and CINAHL were searched. Any study of a service that engaged the GP with specialist secondary services in the provision of palliative care was included. GP engagement was defined as any organised cooperation between the GP and specialist secondary services in the care of the patient including shared consultations, case conferences that involved at least both the GP and the specialist clinician and/or other secondary services, and/or any formal shared care arrangements between the GP and specialist services. The specialist secondary service is either a specialist palliative service or a service providing specialist care to a palliative population. A narrative framework was used to describe the findings. **RESULTS** 17 studies were included. There is some evidence that integrated palliative care can reduce hospitalisations and maintain functional status. There are substantial barriers to providing integrated care. Principles and facilitators of the provision of integrated palliative care are discussed. **CONCLUSIONS** This is an emerging field and further research is required assessing the effectiveness of different models of integrated palliative care.

37. **Advance care planning, palliative care, and end-of-life care interventions for homeless people: A systematic review.**

**Author(s):** Sumalinog, Rafael; Harrington, Katy; Dosani, Naheed; Hwang, Stephen W

**Source:** Palliative medicine; Feb 2017; vol. 31 (no. 2); p. 109-119

**Publication Type(s):** Journal Article

**PubMedID:** 27260169

**Abstract:** **BACKGROUND** Homeless individuals have a high prevalence of multiple chronic comorbidities and early mortality compared to the general population. They also experience significant barriers to access and stigmatization in the healthcare system. Providing advance care planning, palliative care, and end-of-life care for this underserved population is an important health issue. **AIM** To summarize and evaluate the evidence surrounding advance care planning, palliative care, and end-of-life care interventions for homeless persons. **DESIGN** A systematic review based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement. **DATA SOURCES** Articles from MEDLINE, EMBASE, CINAHL, PsycINFO, Social Work Abstracts, Cochrane Library, Web of Science, and PubMed databases were searched through 13 June 2015. Peer-reviewed studies that implemented advance care planning, palliative care, and end-of-life care interventions for homeless populations were included. Data from studies were independently extracted by two investigators using pre-specified criteria, and quality was assessed using modified Cochrane and Critical Appraisal Skills Programme tools. **RESULTS** Six articles met inclusion criteria. Two studies were randomized controlled trials involving advance directive completion. Two cohort studies investigated the costs of a shelter-based palliative care intervention and predictors for completing advance directives. These studies were rated low to fair quality. Two qualitative studies explored the interface between harm-reduction services and end-of-life care and the conditions for providing palliative care for homeless persons in a support home. **CONCLUSION** The effectiveness of advance care planning, palliative care, and end-of-life care interventions for homeless individuals is uncertain. High-quality studies of interventions that reflect the unique and complex circumstances of homeless populations and investigate patient-related outcomes, caregiver burden, and cost-effectiveness are needed.

38. **Inpatient transfer to a care home for end-of-life care: What are the views and experiences of patients and their relatives? A systematic review and narrative synthesis of the UK literature.**

**Author(s):** Thomas, Tabitha; Kuhn, Isla; Barclay, Stephen

**Source:** Palliative medicine; Feb 2017; vol. 31 (no. 2); p. 102-108

**Publication Type(s):** Journal Article

**PubMedID:** 27468912

**Abstract:** **BACKGROUND** Transfers from hospital or 'hospice palliative care units' to care homes for end-of-life care are an increasingly common part of clinical practice but are a source of anxiety and distress for patients, relatives and healthcare professionals. **AIM** To understand the experiences of patients discharged to care homes for end-of-life care. **DESIGN** Systematic review and narrative synthesis of the UK literature concerning inpatient transfer from a hospital or hospice palliative care unit to a care home for end-of-life care. **RESULTS** The published literature is very limited: only three papers and one conference abstract were identified, all of low quality using Gough's weight of evidence assessment. No papers examined transfer from hospital: all were of transfers from hospices and were retrospective case note reviews. Many patients were reported to have been
negative or ambivalent about moving and experienced feelings of anxiety or abandonment when transferred. Relatives were often either vehemently opposed or ambivalent. Although some came to accept transfer, others reported the transfer to have seriously affected their loved one's quality of life and that the process of finding a care home had been traumatic. No studies investigated patients' views prospectively, the views of staff or the processes of decision-making. CONCLUSION The UK literature is very limited, despite such transfers being an increasingly common part of clinical practice and a source of concern to patients, relatives and staff alike. Further research is urgently needed in this area, especially studies of patients themselves, in order to understand their experiences and views.

**Database:** Medline

**39. Patient reported outcome measures of quality of end-of-life care: A systematic review.**

**Author(s):** Kearns, Tara; Cornally, Nicola; Molloy, William

**Source:** Maturitas; Feb 2017; vol. 96 ; p. 16-25

**Publication Type(s):** Journal Article Review

**PubMedID:** 28041590

**Abstract:** End-of-life (EoL) care is increasingly used as a generic term in preference to palliative care or terminal care, particularly with reference to individuals with chronic disease, who are resident in community and long-term care (LTC) settings. This review evaluates studies based on patient reported outcome measures (PROMS) of quality of EoL care across all health-care settings. From 1041 citations, 12 studies were extracted by searches conducted in EBSCO, Scopus, Web of Science, PubMed, Cochrane, Open Grey and Google Scholar databases. At present, the evidence base for EoL care is founded on cancer care. This review highlights the paucity of studies that evaluate quality of EoL care for patients with chronic disease outside the established cancer-acute care paradigm, particularly in LTC. This review highlights the absence of any PROMs for the estimated 60% of patients in LTC with cognitive impairment. Patient-reported outcomes (PROs) are critical to understanding how EoL care services and practices affect patients' health and EoL experience. PROMs describe the quality of care from the patient's perspective and add balance to existing clinical or proxy-derived knowledge on the quality of care and services provided.

**40. Dignity Therapy and Life Review for Palliative Care Patients: A Randomized Controlled Trial.**

**Author(s):** Vuksanovic, Dean; Green, Heather J; Dyck, Murray; Morrissey, Shirley A

**Source:** Journal of pain and symptom management; Feb 2017; vol. 53 (no. 2); p. 162

**Publication Type(s):** Journal Article

**PubMedID:** 27810568

**Abstract:** CONTEXT Dignity therapy (DT) is a psychotherapeutic intervention with increasing evidence of acceptability and utility in palliative care settings. OBJECTIVES The aim of this study was to evaluate the legacy creation component of DT by comparing this intervention with life review (LR) and waitlist control (WC) groups. METHODS Seventy adults with advanced terminal disease were randomly allocated to DT, LR, or WC followed by DT, of which 56 completed the study protocol. LR followed an identical protocol to DT except that no legacy document was created in LR. Primary outcome measures were the Brief Generativity and Ego-Integrity Questionnaire, Patient Dignity Inventory, Functional Assessment of Cancer Therapy-General, version 4, and treatment evaluation questionnaires. RESULTS Unlike LR and WC groups, DT recipients demonstrated significantly increased generativity and ego-integrity scores at study completion. There were no significant changes for dignity-related distress or physical, social, emotional, and functional well-being among the three groups. There were also no significant changes in primary outcomes after the provision of DT after the waiting period in the WC group. High acceptability and satisfaction with interventions were noted for recipients of both DT and LR and family/carers of DT participants. CONCLUSION This study provides initial evidence that the specific process of legacy creation is able to positively affect sense of generativity, meaning, and acceptance near end of life. High acceptability and satisfaction rates for both DT and LR and positive impacts on families/carers of DT participants provide additional support for clinical utility of these interventions. Further evaluation of specific mechanisms of change post-intervention is required given DT’s uncertain efficacy on other primary outcomes.

**41. A systematic review on the role of vitamins, minerals, proteins, and other supplements for the treatment of cachexia in cancer: a European Palliative Care Research Centre cachexia project.**

**Author(s):** Mochamat; Cuhls, Henning; Marinova, Milka; Kaasa, Stein; Stieber, Christiane; Conrad, Rupert;
Radbruch, Lukas; Mücke, Martin

**Abstract**: We provide a systematic review to support the European Palliative Care Research Collaboration development of clinical guidelines for cancer patients suffering from cachexia. CENTRAL, MEDLINE, PsycINFO, ClinicalTrials.gov, and a selection of cancer journals have been searched up until 15 April 2016. The systematic literature research yielded 4214 publications with 21 of these included in the final evaluation. Regarding minerals, our search identified only one study examining the use of magnesium with no effect on weight loss. As far as vitamins are concerned, vitamin E in combination with omega-3 fatty acids displayed an effect on survival in a single study, vitamin D showed improvement of muscle weakness in prostate cancer patients, and vitamin C supplementation led to an improvement of various quality of life aspects in a sample with a variety of cancer diagnoses. For proteins, a combination therapy of β-hydroxy-β-methylbutyrate (HMB), arginine, and glutamine showed an increase in lean body mass after 4 weeks in a study of advanced solid tumour patients, whereas the same combination did not show a benefit on lean body mass in a large sample of advanced lung and other cancer patients after 8 weeks. L-carnitine led to an increase of body mass index and an increase in overall survival in advanced pancreatic cancer patients. Adverse effects of food supplementation were rare and showed mild intensity. There is not enough solid evidence for the use of minerals, vitamins, proteins, or other supplements in cancer. No serious adverse effects have been reported with dietary supplementation.

42. Encouraging early discussion of life expectancy and end-of-life care: A randomised controlled trial of a nurse-led communication support program for patients and caregivers.

**Author(s)**: Walczak, Adam; Butow, Phyllis N; Tattersall, Martin H N; Davidson, Patricia M; Young, Jane; Epstein, Ronald M; Costa, Daniel S J; Clayton, Josephine M

**Source**: International journal of nursing studies; Feb 2017; vol. 67 ; p. 31-40

**Abstract**: BACKGROUND Patients are often not given the information needed to understand their prognosis and make informed treatment choices, with many consequently experiencing less than optimal care and quality-of-life at end-of-life. OBJECTIVES To evaluate the efficacy of a nurse-facilitated communication support program for patients with advanced, incurable cancer to assist them in discussing prognosis and end-of-life care. DESIGN A parallel-group randomised controlled trial design was used. SETTINGS This trial was conducted at six cancer treatment centres affiliated with major hospitals in Sydney, Australia. PARTICIPANTS 110 patients with advanced, incurable cancer participated. METHODS The communication support program included guided exploration of a question prompt list, communication challenges, patient values and concerns and the value of discussing end-of-life care early, with oncologists cued to endorse question-asking and question prompt list use. Patients were randomised after baseline measure completion, a regular oncology consultation was audio-recorded and a follow-up questionnaire was completed one month later. Communication, health-related quality-of-life and satisfaction measures and a manualised consultation-coding scheme were used. Descriptive, Mixed Modelling and Generalised Linear Mixed Modelling analyses were conducted using SPSS version 22. RESULTS Communication support program recipients gave significantly more cues for discussion of prognosis, end-of-life care, future care options and general issues not targeted by the intervention during recorded consultations, but did not ask more questions about these issues or overall. Oncologists’ question prompt list and question asking endorsement was inconsistent. Communication support program recipients’ self-efficacy in knowing what questions to ask their doctor significantly improved at follow-up while control arm patients’ self-efficacy declined. The communication support program did not impact patients’ health-related quality-of-life or the likelihood that their health information or shared decision-making preferences would be met. Satisfaction with the communication support program was high. CONCLUSIONS Given the importance of clarifying prognostic expectations and end-of-life care wishes in the advanced cancer context, the communication support program appears to be an effective and well-received solution to encourage early information seeking related to these issues though, its long-term impact remains unclear. The manualised nature of the intervention, designed with existing clinical staff in mind, may make it suited for implementation in a clinical setting, though additional work is needed to identify why question asking was unaffected and establish its impact later in the illness trajectory.
43. When One Knows a Fetus Is Expected to Die: Palliative Care in the Context of Prenatal Diagnosis of Fetal Malformations.

Author(s): Catania, Taisa Rocha; Bernardes, Lisandra Stein; Benute, Glaucia Rosana Guerra; Gibeli, Maria Augusta Bento Cicaroni; do Nascimento, Nathalia Berlottassi; Barbosa, Tercilia Virginia Aparecida; Krebs, Vera Lucia Jornada; Francisco, Rossana P V

Source: Journal of palliative medicine; Jan 2017

Publication Type(s): Journal Article

PubMedID: 28140755

Abstract: BACKGROUND Fetal malformations occur in 2% of gestations and are the fifth most common cause of neonatal death in the world. In many cases, fetal malformations result in neonatal death or long stay in intensive care facilities. Families that continue the pregnancy in such a situation need to make choices and cope with an overwhelming number of potential issues. Palliative care starting at the prenatal period is a growing field that allows the entire family to prepare for this difficult situation. OBJECTIVE To perform a systematic review of published data on palliative care in the prenatal period. DESIGN PubMed and the Cochrane Library were searched using the keywords ("perinatal" OR "prenatal" OR "fetal") AND "palliative care" and also ("perinatal" OR "prenatal" OR "fetal") AND "hospice." SETTING/SUBJECTS Studies focusing on the long-term impact of prenatal palliative care published up to December 2015 were used. MEASUREMENTS Quantitative and qualitative studies. RESULTS In total, 541 studies were retrieved; 29 articles met the inclusion criteria. Studies were organized into different categories according to the design or main focus. The majority of studies retrieved were reflexives or presented a narrative proposal on palliative care started in the prenatal period (45%). Clinical studies comprised 17% of all articles found. No studies were found on the long-term impact of prenatal palliative care. CONCLUSIONS Prenatal palliative care is a growing field and an important supportive care measure that can help grieving parents and families who do not want to or cannot interrupt their pregnancy. More studies should be carried out, specifically concerning long-term impact of prenatal palliative care. Guidelines and training of health professionals must be developed so that more families can benefit from this type of care.

44. Clinical trials in palliative care: a systematic review of their methodological characteristics and of the quality of their reporting.

Author(s): Bouça-Machado, Raquel; Rosário, Madalena; Alarcão, Joana; Correia-Guedes, Leonor; Abreu, Daisy; Ferreira, Joaquim J

Source: BMC palliative care; Jan 2017; vol. 16 (no. 1); p. 10

Publication Type(s): Journal Article Review

PubMedID: 28122560

Abstract: BACKGROUND Over the past decades there has been a significant increase in the number of published clinical trials in palliative care. However, empirical evidence suggests that there are methodological problems in the design and conduct of studies, which raises questions about the validity and generalisability of the results and of the strength of the available evidence. We sought to evaluate the methodological characteristics and assess the quality of reporting of clinical trials in palliative care. METHODS We performed a systematic review of published clinical trials assessing therapeutic interventions in palliative care. Trials were identified using MEDLINE (from its inception to February 2015). We assessed methodological characteristics and describe the quality of reporting using the Cochrane Risk of Bias tool. RESULTS We retrieved 107 studies. The most common medical field studied was oncology, and 43.9% of trials evaluated pharmacological interventions. Symptom control and physical dimensions (e.g. intervention on pain, breathlessness, nausea) were the palliative care-specific issues most studied. We found under-reporting of key information in particular on random sequence generation, allocation concealment, and blinding. CONCLUSIONS While the number of clinical trials in palliative care has increased over time, methodological quality remains suboptimal. This compromises the quality of studies. Therefore, a greater effort is needed to enable the appropriate performance of future studies and increase the robustness of evidence-based medicine in this important field.
45. Treatment targeted at underlying disease versus palliative care in terminally ill patients: a systematic review.

Author(s): Reljic, Tea; Kumar, Ambuj; Klocksieben, Farina A; Djulbegovic, Benjamin

Source: BMJ open; Jan 2017; vol. 7 (no. 1); p. e014661

Publication Type(s): Journal Article

PubMedID: 28062473

Available in full text at BMJ Open - from ProQuest

Abstract: OBJECTIVE To assess the efficacy of active treatment targeted at underlying disease (TTD)/potentially curative treatments versus palliative care (PC) in improving overall survival (OS) in terminally ill patients. DESIGN We performed a systematic review and meta-analysis of randomised controlled trials (RCT). Methodological quality of included RCTs was assessed using the Cochrane risk of bias tool. DATA SOURCES Medline and Cochrane databases were searched, with no language restriction, from inception to 19 October 2016. ELIGIBILITY CRITERIA FOR SELECTING STUDIES Any RCT assessing the efficacy of any active TTD versus PC in adult patients with terminal illness with a prognosis of <6-month survival were eligible for inclusion. RESULTS Initial search identified 8252 citations of which 10 RCTs (15 comparisons, 1549 patients) met inclusion criteria. All RCTs included patients with cancer. OS was reported in 7 RCTs (8 comparisons, 1158 patients). The pooled results showed no statistically significant difference in OS between TTD and PC (HR (95% CI) 0.85 (0.71 to 1.02)). The heterogeneity between pooled studies was high (I²=62.1%). Overall rates of adverse events were higher in the TTD arm. CONCLUSIONS Our systematic review of available RCTs in patients with terminal illness due to cancer shows that TTD compared with PC did not demonstrably impact OS and is associated with increased toxicity. The results provide assurance to physicians, patients and family that the patients' survival will not be compromised by referral to hospice with focus on PC.

46. Experiences of patients and caregivers with early palliative care: A qualitative study.

Author(s): Hannon, Breffni; Swami, Nadia; Rodin, Gary; Pope, Ashley; Zimmermann, Camilla

Source: Palliative medicine; Jan 2017; vol. 31 (no. 1); p. 72-81

Publication Type(s): Journal Article

PubMedID: 27495814

Abstract: BACKGROUND Early palliative care improves quality of life and satisfaction with care and is increasingly endorsed for patients with advanced cancer. However, little is known about the experience of receiving early palliative care from a patient and caregiver perspective. AIM The aim of this qualitative study was to determine, from a participant perspective, the experience of receiving early palliative care and elements of that care. DESIGN Qualitative grounded theory study using individual interviews. SETTING/PARTICIPANTS The study took place at a comprehensive cancer centre. Patients (n = 26) and caregivers (n = 14) from the intervention arm of a cluster-randomised controlled trial of early palliative care versus standard oncology care participated in qualitative interviews. Participants were asked to comment on their quality of life, the quality of care provided over the intervention period and their experiences with the palliative care team. RESULTS Participants described feeling supported and guided in their illness experience and in their navigation of the healthcare system. Specific elements of early palliative care included prompt, personalised symptom management; holistic support for patients and caregivers; guidance in decision-making; and preparation for the future. Patients with symptoms particularly valued prompt attention to their physical concerns, while those without symptoms valued other elements of care. Although three patients were ambivalent about their current need for palliative care, no distress was reported as a consequence of the intervention. CONCLUSION The elements of care described by participants may be used to develop, support and refine models of early palliative care for patients with cancer.

47. Evidence on the analgesic role of bisphosphonates and denosumab in the treatment of pain due to bone metastases: A systematic review within the European Association for Palliative Care guidelines project.

Author(s): Porta-Sales, Josep; Garzón-Rodríguez, Cristina; Llorens-Torromé, Silvia; Brunelli, Cinzia; Pigni, Alessandra; Caraceni, Augusto

Source: Palliative medicine; Jan 2017; vol. 31 (no. 1); p. 5-25

Publication Type(s): Journal Article
Abstract: BACKGROUND Bisphosphonates and denosumab are well-established therapies to reduce the frequency and severity of skeletal-related events in patients with bone metastasis. However, the analgesic effect of these medications on bone pain is uncertain. AIM To identify, critically appraise and synthesize existing evidence to answer the following questions: 'In adult patients with metastatic bone pain, what is the evidence that bisphosphonates and denosumab are effective and safe in controlling pain?' and 'What is the most appropriate schedule of bisphosphonate/denosumab administration to control bone pain?'. This review also updates the 2002 Cochrane review 'Bisphosphonates for the relief of pain secondary to bone metastases'. DESIGN Standard systematic review and narrative synthesis. DATA SOURCES MEDLINE, EMBASE and Cochrane CENTRAL databases were searched for relevant articles published through 31 January 2014. A manual search was also performed. Study inclusion criteria were: a) conducted in adult patients; b) randomized controlled trial or meta-analysis; c) reported efficacy of bisphosphonates or denosumab on pain and/or described side effects versus placebo or other bisphosphonate; and d) English language. RESULTS The database search yielded 1585 studies, of which 43 (enrolling 8595 and 7590 patients, respectively, in bisphosphonate and denosumab trials) met the inclusion criteria. Twenty-two (79%) of the 28 placebo-controlled trials found no analgesic benefit for bisphosphonates. None of the denosumab studies assessed direct pain relief. CONCLUSION Evidence to support an analgesic role for bisphosphonates and denosumab is weak. Bisphosphonates and denosumab appear to be beneficial in preventing pain by delaying the onset of bone pain rather than by producing an analgesic effect per se.

48. Palliative Care Interventions for Patients with Heart Failure: A Systematic Review and Meta-Analysis.

Author(s): Diop, Michelle S; Rudolph, James L; Zimmerman, Kristin M; Richter, Mary A; Skarf, L Michal

Source: Journal of palliative medicine; Jan 2017; vol. 20 (no. 1); p. 84-92

PubMedID: 27912043

Abstract: OBJECTIVE To systematically characterize interventions and effectiveness of palliative care for advanced heart failure (HF) patients. BACKGROUND Patients with advanced heart failure experience a high burden of distressing symptoms and diminished quality of life. Palliative care expertise with symptom management and healthcare decision-making benefits HF patients. METHODS A systematic PubMed search was conducted from inception to June 2016 for studies of palliative care interventions for HF patients. Studies of humans with a HF diagnosis who underwent a palliative care intervention were included. Data were extracted on study design, participant characteristics, intervention components, and in three groups of outcomes: patient-centered outcomes, quality-of-death outcomes, and resource utilization. Study characteristics were examined to determine if meta-analysis was possible. RESULTS The fifteen identified studies varied in design (prospective, n = 10; retrospective, n = 5). Studies enrolled older patients, but greater variability was found for race, sex, and marital status. A majority of studies measuring patient-centered outcomes demonstrated improvements including quality of life and satisfaction. Quality-of-death outcomes were mixed with a majority of studies reporting clarification of care preferences, but less improvement in death at home and hospice enrollment. A meta-analysis in three studies found that home-based palliative care consults in HF patients lower the risk of rehospitalization by 42% (RR = 0.58; 95% Confidence Interval 0.44, 0.77). DISCUSSION Available evidence suggests that home and team-based palliative interventions for HF patients improve patient-centered outcomes, documentation of preferences, and utilization. Increased high quality studies will aid the determination of the most effective palliative care approaches for the HF population.

49. Integration of Palliative Care into Standard Oncology Care: American Society of Clinical Oncology Clinical Practice Guideline Update.

Author(s): Ferrell, Betty R; Temel, Jennifer S; Temin, Sarah; Alesi, Erin R; Balboni, Tracy A; Basch, Ethan M; Firn, Janice I; Paice, Judith A; Peppercorn, Jeffrey M; Phillips, Tanyanika; Stovall, Ellen L; Zimmermann, Camilla; Smith, Thomas J

Source: Journal of clinical oncology : official journal of the American Society of Clinical Oncology; Jan 2017; vol. 35 (no. 1); p. 96-112

Publication Type(s): Journal Article

PubMedID: 28034065

Abstract: Purpose To provide evidence-based recommendations to oncology clinicians, patients, family and friend caregivers, and palliative care specialists to update the 2012 American Society of Clinical Oncology (ASCO) provisional clinical opinion (PCO) on the integration of palliative care into standard oncology care for all patients diagnosed with cancer. Methods ASCO convened an Expert Panel of members of the ASCO Ad Hoc Palliative Care Expert Panel to develop an update. The 2012 PCO was based on a review of a randomized controlled trial (RCT) by the National Cancer Institute Physicians Data Query and additional trials. The panel conducted an updated systematic review seeking randomized clinical trials, systematic reviews, and meta-analyses, as well as secondary analyses of RCTs in the 2012 PCO, published from March 2010 to January 2016. Results The guideline update reflects changes in evidence since the previous guideline. Nine RCTs, one quasiexperimental trial, and five secondary analyses from RCTs in the 2012 PCO on providing palliative care services to patients with cancer and/or their caregivers, including family caregivers, were found to inform the update. Recommendations Inpatients and outpatients with advanced cancer should receive dedicated palliative care services, early in the disease course, concurrent with active treatment. Referral of patients to interdisciplinary palliative care teams is optimal, and services may complement existing programs. Providers may refer family and friend caregivers of patients with early or advanced cancer to palliative care services.

50. Implementing Evidence-Based Palliative Care Programs and Policy for Cancer Patients: Epidemiologic and Policy Implications of the 2016 American Society of Clinical Oncology Clinical Practice Guideline Update.

Author(s): Isenberg, Sarina R; Aslakson, Rebecca A; Smith, Thomas J

Source: Epidemiologic reviews; Jan 2017; vol. 39 (no. 1); p. 123-131

Publication Type(s): Journal Article

PubMedID: 28472313

Abstract: The American Society of Clinical Oncology (ASCO) recently convened an Ad Hoc Palliative Care Expert Panel to update a 2012 provisional clinical opinion by conducting a systematic review of clinical trials in palliative care in oncology. The key takeaways from the updated ASCO clinical practice guidelines (CPGs) are that more people should be referred to interdisciplinary palliative care teams and that more palliative care specialists and palliative care-trained oncologists are needed to meet this demand. The following summary statement is based on multiple randomized clinical trials: "Inpatients and outpatients with advanced cancer should receive dedicated palliative care services, early in the disease course, concurrent with active treatment. Referral of patients to interdisciplinary palliative care teams is optimal, and services may complement existing programs" (J Clin Oncol. 2017;35(1):96). This paper addresses potential epidemiologic and policy interpretations and implications of the ASCO CPGs. Our review of the CPGs demonstrates that to have clinicians implement these guidelines, there is a need for support from stakeholders across the health-care continuum, health system and institutional change, and changes in health-care financing. Because of rising costs and the need to improve value, the need for coordinated care, and change in end-of-life care patterns, many of these changes are already underway.
Exercise: Study Design Timeframes

Match the study design with the timeframe it covers.

1. Randomised Controlled Trial
2. Cross-Sectional Study
3. Case-control Study
4. Cohort Study
5. Case Report

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