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Palliative Care

Evidence Update

November 2017 (Quarterly)

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November (13.00-14.00)

Fri 10th Critical Appraisal
Mon 13th Statistics
Tue 21st Literature searching
Wed 29th Critical Appraisal

December (12.00-13:00)

Thu 7th Statistics
Fri 15th Literature Searching

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Contents

Current Journals: Tables of Contents

Click on journal title (+ Ctrl) for hyperlink

Journal	Month	Volume	Issue
Journal of Palliative Medicine	November 2017	20	11
Journal of Pain and Symptom Management	November 2017	54	5
International Journal of Palliative Nursing	November 2017	23	10

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Latest Evidence

NICE National Institute for Health and Care Excellence

End of life care for infants, children and young people

Quality standard [QS160] Published date: September 2017

This quality standard covers end of life care for infants, children and young people (from birth to 18 years) who have a life-limiting condition. Life-limiting conditions are those that are expected to result in an early death for the person. It also covers support for family members and carers. It describes high-quality care in priority areas for improvement.

Next review: August 2018.

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 Last updated September 2017

Understanding patients' experiences of the wish to hasten death: an updated and expanded systematic review and meta-ethnography

Source: PubMed - 29 September 2017 - Publisher: Bmj Open

Cannabinoids in Pain Management and Palliative Medicine

Source: PubMed - 22 September 2017 - Publisher: Deutsches Arzteblatt International

Choice in end of life care: government progress

Source: Department of Health - Source: GOV UK - 21 September 2017

How the National End of Life Care Programme Board is delivering personalisation and choice in care for people at or near the end of life.

Safety and effectiveness of palliative drug treatment in the last days of life - a systematic literature review

Source: PubMed - 09 August 2017 - Publisher: Journal Of Pain And Symptom Management

Cochrane Library

Bajwah S, Yi D, Grande G, Todd C, Costantini M, Murtagh FE, Evans CJ, Higginson IJ. **The effectiveness**

and cost-effectiveness of inpatient specialist palliative care in acute hospitals for adults with advanced illness and their caregivers (Protocol). Cochrane Database of Systematic Reviews 2017, Issue 9. Art. No.: CD012780. DOI: 10.1002/14651858.CD012780.

Poort H, Peters M, Bleijenberg G, Gielissen MFM, Goedendorp MM, Jacobsen P, Verhagen S, Knoop H. **Psychosocial interventions for fatigue during cancer treatment with palliative intent**. Cochrane Database of Systematic Reviews 2017, Issue 7. Art. No.: CD012030. DOI: 10.1002/14651858.CD012030.pub2.

UpToDate®

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Overview of comprehensive patient assessment in palliative care
Author: Tomasz R Okon, MD
All topics are updated as new evidence becomes available and our peer review process is complete.
Literature review current through: Oct 2017. | **This topic last updated:** Jun 26, 2017.

What's new in palliative care
Author: Diane MF Savarese, MD
All topics are updated as new evidence becomes available and our peer review process is complete.
Literature review current through: Oct 2017. | **This topic last updated:** Nov 07, 2017.

The following represent additions to UpToDate from the past six months that were considered by the editors and authors to be of particular interest.

Approach to symptom assessment in palliative care
Author: Victor T Chang, MD
All topics are updated as new evidence becomes available and our peer review process is complete.
Literature review current through: Oct 2017. | **This topic last updated:** Oct 12, 2017.

Benefits, services, and models of subspecialty palliative care
Authors: Diane E Meier, MD, FACP; Elizabeth McCormick, MD
All topics are updated as new evidence becomes available and our peer review process is complete.
Literature review current through: Oct 2017. | **This topic last updated:** Sep 25, 2017.

Pediatric palliative care
Author: Julie Hauer, MD; Carrie Armsby, MD, MPH
All topics are updated as new evidence becomes available and our peer review process is complete.
Literature review current through: Oct 2017. | **This topic last updated:** Jul 26, 2017.
Palliative care: The last hours and days of life
Authors: F Amos Bailey, MD; Stephanie M Harman, MD
All topics are updated as new evidence becomes available and our peer review process is complete.
Literature review current through: Oct 2017. | **This topic last updated:** Oct 10, 2017.

The initial interview in palliative care consultation
Author: Timothy E Quill, MD
All topics are updated as new evidence becomes available and our peer review process is complete.
Literature review current through: Oct 2017. | **This topic last updated:** Sep 29, 2017.

Recent Database Articles

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. Family Satisfaction With End-of-Life Care in the Intensive Care Unit: A Systematic Review of the Literature.

Author(s): DeSanto-Madeya, Susan; Safizadeh, Parissa

Source: Dimensions of critical care nursing : DCCN; ; vol. 36 (no. 5); p. 278-283

Publication Type(s): Journal Article

Abstract:BACKGROUNDAssessment of family satisfaction after the death of a loved one in the intensive care unit (ICU) provides a way to determine whether quality end-of-life care was received by the patient and family. The purpose of this systematic review was to explore the factors associated with family satisfaction with end-of-life care in the ICU.METHODSA systematic literature review was conducted using electronic databases CINAHL, MEDLINE, EMBASE, and PsychINFO. Databases were searched using a combination of search terms: "family satisfaction," "end of life," "intensive care unit," and "family." Results were limited to English-language reports of empirical studies published from January 2000 to January 2016. Studies describing adult family members' satisfaction with end-of-life care of patients admitted or transferred to an ICU were included in the review.RESULTSThe search yielded 466 articles. Review of the titles and abstracts resulted in 122 articles that underwent full review; 30 articles met study inclusion and were included in the final analysis. Major themes identified from the literature reviewed included communication, decision making, nursing care, ICU environment, and spiritual care.CONCLUSIONSFamilies can provide valuable insight and information on the quality of care provided in the ICU at end of life. Their perceptions of communication, decision making, nursing care, the ICU environment, and spiritual support strongly influence their satisfaction or dissatisfaction with end-of-life care in the ICU. Personalized and frequent communication; assistance in the decision-making process; compassionate nursing care; a warm, family-friendly environment; and spiritual support can help alleviate the sequelae and enhance family satisfaction with end-of-life care in the ICU.

2. Population-based models of planning for palliative care in older people.

Author(s): Currow, David C; Phillips, Jane; Agar, Meera

Source: Current opinion in supportive and palliative care; Dec 2017; vol. 11 (no. 4); p. 310-314

Publication Type(s): Journal Article

Abstract:PURPOSE OF REVIEWHealth service planning requires demographic, clinical, and health systems data and is unique to each health system. Planning for palliative care in older people must include patients and their carers. This review explores literature from the last 24 months.RECENT FINDINGSThe proportion of people living in skilled nursing facilities is increasing and many residents require quality palliative care. Simultaneously, the complexity of care for older people is also increasing. Systematic approaches to improving palliative care in these facilities have shown benefits that are cost-effective.Although advance care planning is widely promoted, a randomized controlled trial failed to show the benefits seen in nonrandomized trials. This requires a reconceptualization of current programs that seek to increase uptake.Caregivers take on complex decision-making which can be stressful. By contrast, patients are often very confident that the people who are close to them will make good decisions on their behalf.Specific subgroups considered in this review include carers (and the challenges they face), the 'oldest old' and people with dementia.SUMMARYExcellent research is being done to improve the care of older people with palliative care needs. Ultimately, how can key findings be incorporated into clinical care?

3. Mindfulness for palliative care patients. Systematic review.

Author(s): Latorraca, Carolina de Oliveira Cruz; Martimbianco, Ana Luiza Cabrera; Pachito, Daniela Vianna; Pacheco, Rafael Leite; Riera, Rachel

Source: International journal of clinical practice; Nov 2017

Publication Type(s): Journal Article Review

Abstract:BACKGROUNDNineteen million adults worldwide are in need of palliative care. Of those who have access to it, 80% fail to receive an efficient management of symptoms.OBJECTIVESTo assess the effectiveness and safety of mindfulness meditation for palliative care patients.METHODSWe searched CENTRAL, MEDLINE, Embase, LILACS, PEDro, CINAHL, PsycINFO, Opengrey, ClinicalTrials.gov and WHO-ICTRP. No restriction of language, status or date of publication was applied. We considered randomised clinical trials (RCTs) comparing any mindfulness meditation scheme vs any comparator for palliative care. Cochrane Risk of Bias (Rob) Table was used for assessing methodological quality of RCTs. Screening, data extraction and methodological assessments were performed by two reviewers. Mean differences (MD) (confidence intervals of 95% (CI 95%)) were considered for estimating effect size. Quality of evidence was appraised by GRADE.RESULTSFour RCTs, 234 participants, were included. All studies presented high risk of bias in at least one RoB table criteria. We assessed 4 comparisons, but only 2 studies showed statistically significant difference for at least one outcome. 1. Mindfulness meditation (eight weeks, one session/week, daily individual practice) vs control: statistically significant difference in favour of control for quality of life - physical aspects. 2. Mindfulness meditation (single 5-minute session) vs control: benefit in favour of mindfulness for stress outcome in both time-points. None of the included studies analysed safety and harms outcomes.CONCLUSIONSAlthough two studies have showed statistically significant difference, only one showed effectiveness of mindfulness meditation in improving perceived stress. This study focused on one single session of mindfulness of 5 minutes for adult cancer patients in palliative care, but it was considered as possessing high risk of bias. Other schemes of mindfulness meditation did not show benefit in any outcome evaluated (low and very low quality evidence).

4. The views of adults with neurodegenerative diseases on end-of-life care: a metasynthesis.

Author(s): Regan, Laurence; Preston, Nancy J; Eccles, Fiona J R; Simpson, Jane

Source: Aging & mental health; Nov 2017 ; p. 1-9

Publication Type(s): Journal Article

Abstract:OBJECTIVEImproving end-of-life care for people with neurodegenerative diseases is seen as a clinical priority. In order to do this, it is important to take into account the views expressed by people with these conditions on their experiences of this care. The purpose of this review was to provide a thematic synthesis of the views of adults with neurodegenerative diseases on end-of-life care.METHODSAfter a systematic search, 13 articles were included and thematic synthesis was used to collate and interpret findings.RESULTSFour analytical themes were identified; (1) Importance of autonomy and control; (2) Informed decision-making and the role of healthcare professionals; (3) Contextual factors in decision-making; (4) The pitfalls of care.CONCLUSIONParticipants' views were framed by the context of their lives and experience of their illness and these shaped their engagement with end-of-life care. Given the varying disease trajectories, care needs to be individualised and needs-based, implementing palliative care in a timely way to prevent crises and loss of autonomy.

5. Palliative Care in Critical Care Settings: A Systematic Review of Communication-Based Competencies Essential for Patient and Family Satisfaction.

Author(s): Schram, Andrew W; Hougham, Gavin W; Meltzer, David O; Ruhnke, Gregory W

Source: The American journal of hospice & palliative care; Nov 2017; vol. 34 (no. 9); p. 887-895

Publication Date: Nov 2017

Publication Type(s): Journal Article

Abstract:BACKGROUNDThere is an emerging literature on the physician competencies most meaningful to patients and their families. However, there has been no systematic review on physician competency domains outside direct clinical care most important for patient- and family-centered outcomes in critical care settings at the end of life (EOL). Physician competencies are an essential component of palliative care (PC) provided at the EOL, but the literature on those competencies relevant for patient and family satisfaction is limited. A systematic review of this important topic can inform future research and assist in curricular development.METHODSReview of qualitative and quantitative empirical studies of the impact of physician competencies on patient- and family-reported outcomes conducted in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses guidelines for systematic reviews. The data sources used were PubMed, MEDLINE, Web of Science, and Google Scholar.RESULTSFifteen studies (5 qualitative and 10 quantitative) meeting inclusion and exclusion criteria were identified. The competencies identified as critical for the delivery of high-quality PC in critical care settings are prognostication, conflict mediation, empathic communication, and family-centered aspects of care, the latter being the competency most frequently acknowledged in the literature identified.CONCLUSIONPrognostication, conflict mediation, empathic communication, and family-centered aspects of care are the most important identified competencies for patient- and family-centered PC in critical care settings. Incorporation of education on these competencies is likely to improve patient and family satisfaction with EOL care.

6. Gaps in Provision of Primary and Specialty Palliative Care in the Acute Care Setting by Race and Ethnicity.

Author(s): Chuang, Elizabeth; Hope, Aluko A.; Allyn, Katherine; Szalkiewicz, Elissa; Gary, Brittany; Gong, Michelle N.

Source: Journal of Pain & Symptom Management; Nov 2017; vol. 54 (no. 5); p. 645-645

Publication Type(s): Academic Journal

Abstract: Context: Previous research has identified a large unmet need in provision of specialist-level palliative care services in the hospital. How much of this gap is filled by primary palliative care provided by generalists or nonpalliative specialists has not been quantified. Estimates of racial and ethnic disparities have been inconsistent.Objectives: The objective of this study was to 1) estimate primary and specialty palliative care delivery and to measure unmet needs in the inpatient setting and 2) explore racial and ethnic disparities in palliative care delivery.Methods: This was a cross-sectional, retrospective study of 55,658 adult admissions to two acute care hospitals in the Bronx in 2013. Patients with palliative care needs were identified by criteria adapted from the literature. The primary outcomes were delivery of primary and specialist-level palliative care.Results: In all, 18.5% of admissions met criteria for needing palliative care. Of those, 18% received specialist-level palliative care, an estimated 30% received primary palliative care, and 37% had no evidence of palliative care or advance care planning. Black and Hispanic patients were not less likely to receive specialist-level palliative care (adjusted odds ratio [OR] black patients = 1.18, 95% CI 0.98, 1.42; adjusted OR Hispanic patients = 1.24, 95% CI 1.04, 1.48), but they were less likely to receive primary palliative care (adjusted OR black patients = 0.41, 95% CI 0.20, 0.84; adjusted OR Hispanic patients = 0.48, 95% CI 0.25, 0.94).Conclusion: Even when considering primary and specialty palliative care, hospitalized patients have a high prevalence of unmet palliative care need. Further research is needed understand racial and ethnic disparities in palliative care delivery.

7. What Impact Do Chaplains Have? A Pilot Study of Spiritual AIM for Advanced Cancer Patients in Outpatient Palliative Care.

Author(s): Kestenbaum, Allison; Shields, Michele; James, Jennifer; Hocker, Will; Morgan, Stefana; Karve, Shweta; Rabow, Michael W.; Dunn, Laura B.

Source: Journal of Pain & Symptom Management; Nov 2017; vol. 54 (no. 5); p. 707-714

Publication Type(s): Academic Journal

Abstract: Context: Spiritual care is integral to quality palliative care. Although chaplains are uniquely trained to provide spiritual care, studies evaluating chaplains' work in palliative care are scarce.Objectives: The goals of this pre-post study, conducted among patients with advanced cancer receiving outpatient palliative care, were to evaluate the feasibility and acceptability of chaplain-delivered spiritual care, utilizing the Spiritual Assessment and Intervention Model ("Spiritual AIM"), and to gather pilot data on Spiritual AIM's effects on spiritual well-being, religious and cancer-specific coping, and physical and psychological symptoms.Methods: Patients with advanced cancer (N = 31) who were receiving outpatient palliative care were assigned based on chaplains' and patients' outpatient schedules, to one of three professional chaplains for three individual Spiritual AIM sessions, conducted over the course of approximately six to eight weeks. Patients completed the following measures at baseline and post-intervention: Edmonton Symptom Assessment Scale, Steinhauser Spirituality, Brief RCOPE, Functional Assessment of Chronic Illness Therapy-Spiritual (FACIT-Sp-12), Mini-Mental Adjustment to Cancer (Mini-MAC), Patient Dignity Inventory, Center for Epidemiological

Studies-Depression (10 items), and Spielberger State Anxiety Inventory.Results: From baseline to post-Spiritual AIM, significant increases were found on the FACIT-Sp-12 Faith subscale, the Mini-MAC Fighting Spirit subscale, and Mini-MAC Adaptive Coping factor. Two trends were observed, i.e., an increase in Positive religious coping on the Brief RCOPE and an increase in Fatalism (a subscale of the Mini-MAC).Conclusion: Spiritual AIM, a brief chaplain-led intervention, holds potential to address spiritual needs and religious and general coping in patients with serious illnesses.

8. Preferred Place of Care and Death in Terminally Ill Patients with Lung and Heart Disease Compared to Cancer Patients.

Author(s): Skorstengaard, Marianne H.; Neergaard, Mette A.; Andreassen, Pernille; Brogaard, Trine; Bendstrup, Elisabeth; Løkke, Anders; Aagaard, Susanne; Wiggers, Henrik; Bech, Per; Jensen, Anders B.

Source: Journal of Palliative Medicine; Nov 2017; vol. 20 (no. 11); p. 1217-1224

Publication Type(s): Academic Journal

Abstract: Objectives: The dual aim of this study is, first, to describe preferred place of care (PPOC) and preferred place of death (PPOD) in terminally ill patients with lung and heart diseases compared with cancer patients and second, to describe differences in level of anxiety among patients with these diagnoses. Background: Previous research on end-of-life preferences focuses on cancer patients, most of whom identify home as their PPOC and PPOD. These preferences may, however, not mirror those of patients suffering from nonmalignant fatal diseases. Design: The study was designed as a cross-sectional study. Setting: Eligible patients from the recruiting departments filled in questionnaires regarding sociodemographics, PPOC and PPOD, and level of anxiety. Results: Of the 354 eligible patients, 167 patients agreed to participate in the study. Regardless of their diagnosis, most patients wished to be cared for and to die at home. Patients with cancer and heart diseases chose hospice as their second most common preference for both PPOC and PPOD, whereas patients with lung diseases chose nursing home and hospice equally frequent as their second most common preference. Regardless of their diagnosis, all patients had a higher level of anxiety than the average Danish population; patients with heart diseases had a much higher level of anxiety than patients with lung diseases and cancer. Conclusion: Patient preferences for PPOC and PPOD vary according to their diagnoses; tailoring palliative needs to patients' preferences is important regardless of their diagnosis.

9. A Review of Palliative and Hospice Care in the Context of Islam: Dying with Faith and Family.

Author(s): Mendieta, Maximiliano; Buckingham, Robert W.

Source: Journal of Palliative Medicine; Nov 2017; vol. 20 (no. 11); p. 1284-1290

Publication Type(s): Academic Journal

Abstract: Background: By starting to understand Muslim culture, we can seek common ground with Islamic culture within the American experience and bridge opportunities for better palliative and hospice care here and in Middle Eastern countries. The United States, Canada, and Europe are education hubs for Middle Eastern students, creating an opportunity for the palliative and hospice care philosophy to gain access by proxy to populations of terminally ill patients who can benefit from end-of-life care. Objective: The aim was to assess the state of research and knowledge about palliative and hospice care within the context of Muslim culture and religion. Results: Within the guide of the key search terms, we learned that at a glance, over 100 articles meet the search criteria, but after a closer inspection, only a portion actually contributed knowledge to the literature. This confirmed the need for research in this vein. More importantly, we posit that once the layers of culture, religion, norms, and nationality are removed, human beings share a kinship based on family, spirituality, death and dying, and fear of pain. This is evident when we compare the Middle Eastern end-of-life experience with the western end-of-life care. Conclusions: A true opportunity to make a lasting impact at the patient level exists for palliative and hospice care researchers if we seek to understand, gain knowledge, and respect Muslim culture and Islamic issues at the end of life.

10. Palliative care in the USA and England: a critical analysis of meaning and implementation towards a public health approach.

Author(s): Seymour, Jane; Cassel, Brian

Source: Mortality; Nov 2017; vol. 22 (no. 4); p. 275-290

Publication Type(s): Academic Journal

Abstract: Delivering optimal and equitable palliative care is an international challenge. There are few cross-national comparisons examining challenges in expanding palliative care along public health lines. This paper presents a critical review of palliative care in the USA and England, which share similar challenges but have different contexts of healthcare. Beyond some obvious differences in the organisation of palliative care, a set of underlying common issues can be identified. A key tension in both is balancing attention ‘downstream’ in the dying phase, as well as ‘upstream’ earlier in the course of serious illness. In both, the dominant models of palliative care provision have resulted in excellent care towards the end of life for some patients, but there remain major deficiencies in care for the majority. England has a National Strategy for End-of-life care; the US has no equivalent, although a number of influential agencies have published statements. Achieving a public health approach in palliative care requires international consensus on the meaning and target population of palliative care, replacement of prognosis based understandings of entitlement to palliative care with a needs-based approach and development of an evidence base for cost-effective partnerships between providers across the specialist–generalist divide.

11. 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; Oct 2017; vol. 31 (no. 9); p. 781-797

Publication Type(s): Journal Article

Abstract:BACKGROUNDA 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.AIMTo 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.DESIGNA 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 SOURCESMEDLINE, 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.RESULTSMuch 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.CONCLUSIONIrrespective 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.

12. Clinician-Targeted Mobile Apps in Palliative Care: A Systematic Review.

Author(s): Meghani, Salimah H; MacKenzie, Meredith A; Morgan, Brianna; Kang, Youjeong; Wasim, Anum; Sayani, Saleem

Source: Journal of palliative medicine; Oct 2017; vol. 20 (no. 10); p. 1139-1147

Publication Type(s): Journal Article

Abstract:BACKGROUNDThe availability of smartphone applications has increased rapidly including applications related to palliative care. The scope of these available apps has not been synthesized.OBJECTIVEThe purpose of this study was to identify and review available palliative care-related smartphone applications for clinicians.DESIGNSmartphone application platform stores, for example, App Store iOS, Google Play Store, Windows App-Microsoft Store, and Blackberry World App store were searched (December 2016) using relevant key words.RESULTSForty-six palliative care applications targeting clinicians were identified, including clinical guidelines (n = 17), advance care planning (n = 9), training materials in palliative care (n = 7), and pharmaceutical tools (n = 7), and platforms for distributing current palliative care news, articles, and opinions (n = 6). The majority of the applications were free and available in English. The most common platforms were Android and iOS.CONCLUSIONSThe number of palliative care apps targeting clinicians has increased dramatically for the past five years. However, many apps did not report adequate information to judge the evidence upon which the apps were based.

13. 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; Oct 2017; vol. 102 (no. 10); p. 923-929

Publication Type(s): Journal Article Review

Available at Archives of Disease in Childhood - from BMJ Journals - NHS

Available at Archives of Disease in Childhood - from BMJ Journals

Abstract:BACKGROUNDThe 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.AIMTo 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.METHODSystematic 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.RESULTSEight 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.CONCLUSIONSCurrent 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.

14. Palliative Care: Improving nursing knowledge, attitudes, and behaviors.

Author(s): Harden, Karen; Price, Deborah; Duffy, Elizabeth; Galunas, Laura; Rodgers, Cheryl

Source: Clinical Journal of Oncology Nursing; Oct 2017; vol. 21 (no. 5)

Publication Type(s): Academic Journal

Abstract:BACKGROUND: Oncology nurses affect patient care at every point along the cancer journey. This creates the perfect opportunity to educate patients and caregivers about palliative care early and often throughout treatment. However, healthcare providers frequently do not have the knowledge and confidence to engage in meaningful conversations about palliative care. OBJECTIVES: The specific aims were to improve oncology nurses' palliative care knowledge, attitudes, and behaviors by providing a palliative care nursing education program. An additional aim was to increase the number of conversations with patients and families about palliative care. METHODS: This project had a pre-/post-test design to assess knowledge, attitudes, and behaviors at baseline and one month after implementation of an established education curriculum. The teaching strategy included one four-hour class for oncology RNs with topics about the definition of palliative care, pain and symptom management, and how to have palliative care conversations. FINDINGS: Results showed a statistically significant difference after the educational intervention for knowledge, attitudes, and behaviors. The number of conversations with patients and caregivers about palliative and end-of-life care increased significantly.

15. Discontinuation of Preventive Medicines in Older People with Limited Life Expectancy: A Systematic Review.

Author(s): Narayan, Sujita; Nishtala, Prasad

Source: Drugs & Aging; Oct 2017; vol. 34 (no. 10); p. 767-776

Publication Type(s): Academic Journal

Abstract: Background: In the presence of multimorbidity and limited life expectancy (LLE), the need for continued use of preventive medicines becomes uncertain as they may neither improve health nor confer continued health benefits. Objective: Our objective was to systematically review the literature to examine the discontinuation of preventive medicines in older people with LLE. Methods: A systematic literature search was conducted using the Ovid MEDLINE, Embase, Cumulative Index to Nursing and Allied Health Literature, and the Cochrane Central Register databases. Studies investigating discontinuation of preventive medicines in older individuals (mean age ≥65 years) with LLE (≤12 months) published between 1 January 1997 and 28 February 2017 were included. The Cochrane risk-of-bias assessment criteria and the Newcastle-Ottawa Scale were used to assess the quality of the studies. Results: Ten studies-a randomized controlled trial (RCT), two case-control studies, and seven cohort studies-involving 26,854 participants with a mean age ranging from 66.0 to 85.0 years were included in this review. The studies were primarily conducted in palliative care (n = 3), residential facility (n = 2), and community (n = 1) settings, and the remainder were pharmacoepidemiological studies (n = 4). The most common life-limiting illnesses were cancer (n = 5), followed by other unspecified illnesses (n = 4) and advanced dementia (n = 1). The most common preventive medicine discontinued was statins, followed by warfarin and aspirin. LLE potentially prompted discontinuation; however, some individuals continued to receive preventive medicines until they died. Conclusions: The review found that withdrawal of preventive medicines at the end of life is challenging. Decisions about the discontinuation of preventive medicines for individuals approaching the end of life are increasingly complicated by the lack of clear deprescribing guidelines for these medicines.

16. Improving delirium recognition and assessment for people receiving inpatient palliative care: a mixed methods meta-synthesis.

Author(s): Hosie, Annmarie; Agar, Meera; Lobb, Elizabeth; Davidson, Patricia M.; Phillips, Jane

Source: International Journal of Nursing Studies; Oct 2017; vol. 75 ; p. 123-129

Publication Type(s): Academic Journal

Abstract: Background Delirium is a serious acute neurocognitive condition frequently occurring for hospitalized patients, including those receiving care in specialist palliative care units. There are many delirium evidence-practice gaps in palliative care, including that the condition is under-recognized and challenging to assess. Objectives To report the meta-synthesis of a research project investigating delirium epidemiology, systems and nursing practice in palliative care units. Methods The Delirium in Palliative Care (DePAC) project was a two-phase sequential transformative mixed methods design with knowledge translation as the theoretical framework. The project answered five different research questions about delirium epidemiology, systems of care and nursing practice in palliative care units. Data integration and metasynthesis occurred at project conclusion. Results There was a moderate to high rate of delirium occurrence in palliative care unit populations; and palliative care nurses had unmet delirium knowledge needs and worked within systems and team processes that were inadequate for delirium recognition and assessment. The meta-inference of the DePAC project was that a widely-held but paradoxical view that palliative care and dying patients are different from the wider hospital population has separated them from the overall generation of delirium evidence, and contributed to the extent of practice deficiencies in palliative care units. Conclusion Improving palliative care nurses' capabilities to recognize and assess delirium will require action at the patient and family, nurse, team and system levels. A broader, hospital-wide perspective would accelerate implementation of evidence-based delirium care for people receiving palliative care, both in specialist units, and the wider hospital setting.

17. Forgiveness facilitation in palliative care: a scoping review protocol.

Author(s): Silva, Rita Santos; Caldeira, Sílvia; Coelho, Adriana Neves; Apóstolo, João Luís Alves

Source: JBI Database of Systematic Reviews & Implementation Reports; Oct 2017; vol. 15 (no. 10); p. 2469-2479

Publication Type(s): Academic Journal

Abstract: Review question/objective: The objective of this scoping review is to map the nature and extent of forgiveness facilitation interventions that have been implemented and evaluated in palliative care contexts. More specifically, the review questions are: 1. Which activities have been implemented and evaluated to provide the forgiveness facilitation intervention in palliative care? 2. What are the characteristics of this intervention (single or/and related activities, name, resources, frequency, duration, cultural or spiritual background)? 3. Which members of the healthcare team provide forgiveness facilitation? 4. Which outcomes (topics) have been assessed after the intervention?

18. Burnout in Palliative Care Settings Compared With Other Settings: A Systematic Review.

Author(s): Parola, Vitor; Coelho, Adriana; Cardoso, Daniela; Sandgren, Anna; Apóstolo, João

Source: Journal of Hospice & Palliative Nursing; Oct 2017; vol. 19 (no. 5); p. 442-451

Publication Type(s): Academic Journal

Available at Journal of hospice and palliative nursing : JHPN : the official journal of the Hospice and Palliative Nurses Association - from EBSCO (CINAHL with Full Text)

Abstract:A systematic review, using the guideline of the Joanna Briggs Institute, was conducted to explore the effect of working in palliative care settings, compared with other settings, on burnout among health care professionals. Multiple databases were searched VCINAHL, PubMed, Scopus, and SciELOV as well as gray literature for studies published since 1975 that compared health professionals caring for patients older than 18 years in specialized palliative care settings (palliative care units, home care, or hospices) with health professionals working in other settings. Of the 539 studies retrieved, 7 cross-sectional studies were included in this review. Of these, six were conducted with nurses, and six used the Maslach Burnout Inventory. Working in palliative care (palliative care unit or hospices) was associated with lower levels of emotional exhaustion and depersonalization, as well as higher levels of personal accomplishment, compared with working in other settings. Evidence indicates that burnout levels seem to be lower among professionals working in palliative care compared with professionals working in other settings. Further research is needed to explore the strategies used by nurses working in palliative care that help them deal with burnout and to apply these same strategies to professionals working in other settings.

19. Relationship Between Spirituality, Meaning in Life, Psychological Distress, Wish for Hastened Death, and Their Influence on Quality of Life in Palliative Care Patients.

Author(s): Bernard, Mathieu; Strasser, Florian; Gamondi, Claudia; Braunschweig, Giliane; Forster, Michaela; Kaspers-Elekes, Karin; Walther Veri, Silvia; Borasio, Gian Domenico; Veri, Silvia Walther; SMILE consortium team

Source: Journal of Pain & Symptom Management; Oct 2017; vol. 54 (no. 4); p. 514-522

Publication Type(s): Academic Journal

Abstract: Context: Spiritual, existential, and psychological issues represent central components of quality of life (QOL) in palliative care. A better understanding of the dynamic nature underlying these components is essential for the development of interventions tailored to the palliative context.Objectives: The aims were to explore 1) the relationship between spirituality, meaning in life, wishes for hastened death and psychological distress in palliative patients and 2) the extent to which these nonphysical determinants influence QOL.Methods: A cross-sectional study involving face-to-face interviews with Swiss palliative patients was performed, including the Schedule for Meaning in Life Evaluation (SMILE), the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale (FACIT-Sp), the Idler Index of Religiosity (IIR), the Hospital Anxiety and Depression Scale (HADS), and the Schedule of Attitudes toward Hastened Death (SAHD). QOL was measured with a single-item visual analogue scale (0-10).Results: Two hundred and six patients completed the protocol (51.5% female; mean age = 67.5 years). The results indicated a significant negative relationship between FACIT-Sp/SMILE and HADS total scores (P = 0.000). The best model for QOL explained 32.8% of the variance (P = 0.000) and included the FACIT-Sp, SMILE, and SAHD total scores, the IIR "private religiosity" score, as well as the HADS "depression" score.Conclusion: Both spiritual well-being and meaning in life appear to be potential protective factors against psychological distress at the end of life. Since nonphysical determinants play a major role in shaping QOL at the end of life, there is a need for the development of meaning-oriented and spiritual care interventions tailored to the fragility of palliative patients.

20. The impact of specialized palliative care on cancer patients' health-related quality of life: a systematic review and meta-analysis.

Author(s): Kassianos, Angelos P; Ioannou, Myria; Koutsantoni, Marianna; Charalambous, Haris

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

Publication Type(s): Journal Article Review

Abstract:PURPOSESpecialized palliative care (SPC) is currently underutilized or provided late in cancer care. The aim of this systematic review and meta-analysis is to critically evaluate the impact of SPC on patients' health-related quality of life (HRQoL).METHODSFive databases were searched through June 2016. Randomized controlled trials (RCTs) and prospective studies using a pre- and post- assessment of HRQoL were included. The PRISMA reporting statement was followed. Criteria from available checklists were used to evaluate the studies' quality. A meta-analysis followed using random-effect models separately for RCTs and non-RCTs.RESULTSEleven studies including five RCTs and 2939 cancer patients published between 2001 and 2014 were identified. There was improved HRQoL in patients with cancer following SPC especially in symptoms like pain, nausea, and fatigue as well as improvement of physical and psychological functioning. Less or no improvements were observed in social and spiritual domains. In general, studies of inpatients showed a larger benefit from SPC than studies of outpatients whereas patients' age and treatment duration did not moderate the impact of SPC. Methodological shortcomings of included studies include high attrition rates, low precision, and power and poor reporting of control procedures.CONCLUSIONSThe methodological problems and publication bias call for higher-quality studies to be designed, funded, and published. However, there is a clear message that SPC is multi-disciplinary and aims at palliation of symptoms and burden in line with current recommendations.

21. Environmental design for end-of-life care: An integrative review on improving quality of life and managing symptoms for patients in institutional settings.

Author(s): Sagha Zadeh, Rana; Eshelman, Paul; Setla, Judith; Kennedy, Laura; Hon, Emily; Basara, Aleksa

Source: Journal of pain and symptom management; Sep 2017

Publication Type(s): Journal Article Review

Abstract:CONTEXTThe environment in which end-of-life care is delivered can support or detract from the physical, psychological, social, and spiritual needs of patients, their families, and their caretakers.OBJECTIVESThis review aims to organize and analyze the existing evidence related to environmental design factors that improve the quality of life and total well-being of people involved in end-of-life care and to clarify directions for future research.METHODThis integrated literature review synthesized and summarized research evidence from the fields of medicine, environmental psychology, nursing, palliative care, architecture, interior design, and evidence-based design.RESULTSThis synthesis analyzed 225 documents, including 9 systematic literature reviews, 40 integrative reviews, 3 randomized controlled trials, 118 empirical research studies, and 55 anecdotal evidence. Of the documents, 192 were peer-reviewed, while 33 were not. The key environmental factors shown to affect end-of-life care were those that improved 1) social interaction, 2) positive distractions, 3) privacy, 4) personalization and creation of a home-like environment, and 5) the ambient environment. Possible design interventions relating to these topics are discussed. Examples include improvement of visibility and line of sight, view of nature, hidden medical equipment, and optimization of light and temperature.CONCLUSIONSStudies indicate several critical components of the physical environment that can reduce total suffering and improve quality of life for end-of-life patients, their families, and their caregivers. These factors should be considered when making design decisions for care facilities to improve physical, psychological, social, and spiritual needs at end of life.

22. Palliative Care in Undergraduate Medical Education-How Far Have We Come?

Author(s): Fitzpatrick, Danielle; Heah, Rebecca; Patten, Simon; Ward, Helena

Source: The American journal of hospice & palliative care; Sep 2017; vol. 34 (no. 8); p. 762-773

Publication Type(s): Journal Article

Abstract:PURPOSEThere is an increasing demand for quality palliative care teaching within undergraduate medical education. Studies suggest that many junior doctors feel underprepared to perform end-of-life care. Previous systematic reviews on palliative care teaching within medical schools have identified significant variability and lack of consistency in teaching. This review aims to update the literature on the current status of palliative care teaching to undergraduates within medical schools.METHODA systematic review was undertaken on articles published from December 2001 to November 2015 on palliative care teaching for undergraduate medical students. In all, 650 abstract citations were obtained, of which 126 were relevant to the research questions. Thematic analysis was performed on remaining articles according to whether they discussed content and/or methodology of palliative care education, and data collated.RESULTSThere is greater consistency in the content being delivered as part of end-of-life care education within medical schools. The most frequently taught topics include attitudes to death and dying, communication skills, and pain management. Pediatric care and religious/cultural issues are less frequently addressed. Teaching institutions are also utilising a broader range of teaching modalities.CONCLUSIONThere is significant progress in palliative care education within medical schools. Ongoing challenges relate to correlating our current practice in medical education to professional recommendations and the expressed needs of junior doctors to practice competent end-of-life care.

23. Physiotherapy programme reduces fatigue in patients with advanced cancer receiving palliative care: randomized controlled trial.

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; Sep 2017; vol. 25 (no. 9); p. 2899-2908

Publication Type(s): Journal Article

Abstract:PURPOSECancer-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.METHODSThe 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.RESULTSThe 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.CONCLUSIONThe 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.

24. What happens during early outpatient palliative care consultations for persons with newly diagnosed advanced cancer? A qualitative analysis of provider documentation.

Author(s): Bagcivan, Gulcan; Dionne-Odom, J Nicholas; Frost, Jennifer; Plunkett, Margaret; Stephens, Lisa A; Bishop, Peggy; Taylor, Richard A; Li, Zhongze; Tucker, Rodney; Bakitas, Marie

Source: Palliative medicine; Sep 2017 ; p. 269216317733381

Publication Type(s): Journal Article

Abstract:BACKGROUNDEarly outpatient palliative care consultations are recommended by clinical oncology guidelines globally. Despite these recommendations, it is unclear which components should be included in these encounters.AIMDescribe the evaluation and treatment recommendations made in early outpatient palliative care consultations.DESIGNOutpatient palliative care consultation chart notes were qualitatively coded and frequencies tabulated.SETTING/PARTICIPANTSOutpatient palliative care consultations were automatically triggered as part of an early versus delayed randomized controlled trial (November 2010 to April 2013) for patients newly diagnosed with advanced cancer living in the rural Northeastern US.RESULTSIn all, 142 patients (early = 70; delayed = 72) had outpatient palliative care consultations. The top areas addressed in these consultations were general evaluations-marital/partner status (81.7%), spirituality/emotional well-being (80.3%), and caregiver/family support (79.6%); symptoms-mood (81.7%), pain (73.9%), and cognitive/mental status (68.3%); general treatment recommendations-counseling (39.4%), maintaining current medications (34.5%), and initiating new medication (23.9%); and symptom-specific treatment recommendations-pain (22.5%), constipation (12.7%), depression (12.0%), advanced directive completion (43.0%), identifying a surrogate (21.8%), and discussing illness trajectory (21.1%). Compared to the early group, providers were more likely to evaluate general pain ($p = 0.035$) and hospice awareness ($p = 0.005$) and discuss/recommend hospice ($p = 0.002$) in delayed group participants.CONCLUSIONOutpatient palliative care consultations for newly diagnosed advanced cancer patients can address patients' needs and provide recommendations on issues that might not otherwise be addressed early in the disease course. Future prospective studies should ascertain the value of early outpatient palliative care consultations that are automatically triggered based on diagnosis or documented symptom indicators versus reliance on oncologist referral.

25. Training hospital staff on spiritual care in palliative care influences patient-reported outcomes: Results of a quasi-experimental study.

Author(s): van de Geer, Joep; Groot, Marieke; Andela, Richtsje; Leget, Carlo; Prins, Jelle; Vissers, Kris; Zock, Hetty

Source: Palliative medicine; Sep 2017; vol. 31 (no. 8); p. 743-753

Publication Type(s): Journal Article

Abstract:BACKGROUNDSpiritual care is reported to be important to palliative patients. There is an increasing need for education in spiritual care.AIMTo measure the effects of a specific spiritual care training on patients' reports of their perceived care and treatment.DESIGNA pragmatic controlled trial conducted between February 2014 and March 2015.SETTING/PARTICIPANTSThe intervention was a specific spiritual care training implemented by healthcare chaplains to eight multidisciplinary teams in six hospitals on regular wards in which patients resided in both curative and palliative trajectories. In total, 85 patients were included based on the Dutch translation of the Supportive and Palliative Care Indicators Tool. Data were collected in the intervention and control wards pre- and post-training using questionnaires on physical symptoms, spiritual distress, involvement and attitudes (Spiritual Attitude and Involvement List) and on the perceived focus of healthcare professionals on patients' spiritual needs.RESULTSAll 85 patients had high scores on spiritual themes and involvement. Patients reported that attention to their spiritual needs was very important. We found a significant (p = 0.008) effect on healthcare professionals' attention to patients' spiritual and existential needs and a significant (p = 0.020) effect in favour of patients' sleep. No effect on the spiritual distress of patients or their proxies was found.CONCLUSIONThe effects of spiritual care training can be measured using patient-reported outcomes and seemed to indicate a positive effect on the quality of care. Future research should focus on optimizing the spiritual care training to identify the most effective elements and developing strategies to ensure long-term positive effects. This study was registered at the Dutch Trial Register: NTR4559.

26. A Systematic Review of End-of-Life Care Communication Skills Training for Generalist Palliative Care Providers: Research Quality and Reporting Guidance.

Author(s): Brighton, Lisa Jane; Koffman, Jonathan; Hawkins, Amy; McDonald, Christine; O'Brien, Suzanne; Robinson, Vicky; Khan, Shaheen A; George, Rob; Higginson, Irene J; Selman, Lucy Ellen

Source: Journal of pain and symptom management; Sep 2017; vol. 54 (no. 3); p. 417-425

Publication Type(s): Journal Article Review

Abstract:CONTEXTEnd-of-life care (EoLC) communication skills training for generalist palliative care providers is recommended in policy guidance globally. Although many training programs now exist, there has been no comprehensive evidence synthesis to inform future training delivery and evaluation.OBJECTIVESTo identify and appraise how EoLC communication skills training interventions for generalist palliative care providers are developed, delivered, evaluated, and reported.METHODSSystematic review. Ten electronic databases (inception to December 2015) and five relevant journals (January 2004 to December 2015) were searched. Studies testing the effectiveness of EoLC communication skills training for generalists were included. Two independent authors assessed study quality. Descriptive statistics and narrative synthesis are used to summarize the findings.RESULTSFrom 11,441 unique records, 170 reports were identified (157 published, 13 unpublished), representing 160 evaluation studies of 153 training interventions. Of published papers, eight were of low quality, 108 medium, and 41 high. Few interventions were developed with service user involvement (n = 7), and most were taught using a mixture of didactics (n = 123), reflection and discussion (n = 105), and role play (n = 86). Evaluation designs were weak: <30% were controlled, <15% randomized participants. Over half (n = 85) relied on staff self-reported outcomes to assess effectiveness, and 49% did not cite psychometrically validated measures. Key information (e.g., training duration, participant flow) was poorly reported.CONCLUSIONSDespite a proliferation of EoLC communication skills training interventions in the literature, evidence is limited by poor reporting and weak methodology. Based on our findings, we present a CONSORT statement supplement to improve future reporting and encourage more rigorous testing.

27. The Effect of Communication Skills Training for Generalist Palliative Care Providers on Patient-Reported Outcomes and Clinician Behaviors: A Systematic Review and Meta-analysis.

Author(s): Selman, Lucy Ellen; Brighton, Lisa J; Hawkins, Amy; McDonald, Christine; O'Brien, Suzanne; Robinson, Vicky; Khan, Shaheen A; George, Rob; Ramsenthaler, Christine; Higginson, Irene J; Koffman, Jonathan

Source: Journal of pain and symptom management; Sep 2017; vol. 54 (no. 3); p. 404

Publication Type(s): Journal Article Review

Abstract:CONTEXTAs most end-of-life care is provided by health care providers who are generalists rather than specialists in palliative care, effective communication skills training for generalists is essential.OBJECTIVESTo determine the effect of communication training interventions for generalist palliative care providers on patient-reported outcomes and trainee behaviors.METHODSSystematic review from searches of 10 databases to December 2015 (MEDLINE, EMBASE, PsycINFO, ERIC, CINAHL, CENTRAL, Web of Science, ICTRP, CORDIS, and OpenGrey) plus hand searching. Randomized controlled trials of training interventions intended to enhance generalists' communication skills in end-of-life care were included. Two authors independently assessed eligibility after screening, extracted data, and graded quality. Data were pooled for meta-analysis using a random-effects model. PRISMA guidelines were followed.RESULTSNineteen of 11,441 articles were eligible, representing 14 trials. Eleven were included in meta-analyses (patients n = 3144, trainees n = 791). Meta-analysis showed no effect on patient outcomes (standardized mean difference [SMD] = 0.10, 95% CI -0.05 to 0.24) and high levels of heterogeneity (chi-square = 21.32, degrees of freedom [df] = 7, P = 0.003; I2 = 67%). The effect on trainee behaviors in simulated interactions (SMD = 0.50, 95% CI 0.19-0.81) was greater than in real patient interactions (SMD = 0.21, 95% CI -0.01 to 0.43) with moderate heterogeneity (chi-square = 8.90, df = 5, P = 0.11; I2 = 44%; chi-square = 5.96, df = 3, P = 0.11; I2 = 50%, respectively). Two interventions with medium effects on showing empathy in real patient interactions included personalized feedback on recorded interactions.CONCLUSIONSThe effect of communication skills training for generalists on patient-reported outcomes remains unclear. Training can improve clinicians' ability to show empathy and discuss emotions, at least in simulated consultations. Personalized feedback on recorded patient interactions may be beneficial.REGISTRATION NUMBERCRD42014014777.

28. Paediatric palliative care and intellectual disability—a unique context

Author(s): Duc, Jacqueline K; Herbert, Anthony Robert; Heussler, Helen S

Source: Journal of Applied Research in Intellectual Disabilities; Aug 2017 ; p. No

Publication Type(s): Journal Peer Reviewed Journal

Abstract: Background Paediatric palliative care is a nuanced area of practice with additional complexities in the context of intellectual disability. There is currently minimal research to guide clinicians working in this challenging area of care. Method This study describes the complex care of children with life-limiting conditions and intellectual disability by means of a literature synthesis and commentary with "best-practice" guide. Results As few articles concerning children with intellectual disability and palliative care needs were identified by formal systematic review, our expert consensus group has drawn from the paediatric palliative, oncology and adult intellectual disability literature to highlight common clinical challenges encountered in the day-to-day care of children with intellectual disability and life-limiting conditions. Conclusion A longitudinal child- and family-centred approach is key to ensuring best-practice care for families of children with life-limiting conditions and intellectual disability. As highlighted by the great absence of literature addressing this important patient population, further research in this area is urgently required. (PsycINFO Database Record (c) 2017 APA, all rights reserved) (Source: journal abstract)

29. Patient- and Caregiver-Reported Assessment Tools for Palliative Care: Summary of the 2017 Agency for Healthcare Research and Quality Technical Brief.

Author(s): Aslakson, Rebecca A; Dy, Sydney M; Wilson, Renee F; Waldfogel, Julie; Zhang, Allen; Isenberg, Sarina R; Blair, Alex; Sixon, Joshua; Lorenz, Karl A; Robinson, Karen A

Source: Journal of pain and symptom management; Aug 2017

Publication Type(s): Journal Article

Abstract:CONTEXTAssessment tools are data collection instruments that are completed by or with patients or caregivers and which collect data at the individual patient or caregiver level.OBJECTIVESThe objectives of this study are to 1) summarize palliative care assessment tools completed by or with patients or caregivers and 2) identify needs for future tool development and evaluation.METHODSWe completed 1) a systematic review of systematic reviews; 2) a supplemental search of previous reviews and Web sites, and/or 3) a targeted search for primary articles when no tools existed in a domain. Paired investigators screened search results, assessed risk of bias, and abstracted data. We organized tools by domains from the National Consensus Project Clinical Practice Guidelines for Palliative Care and selected the most relevant, recent, and highest quality systematic review for each domain.RESULTSWe included 10 systematic reviews and identified 152 tools (97 from systematic reviews and 55 from supplemental sources). Key gaps included no systematic review for pain and few tools assessing structural, cultural, spiritual, or ethical/legal domains, or patient-reported experience with end-of-life care. Psychometric information was available for many tools, but few studies evaluated responsiveness (sensitivity to change) and no studies compared tools.CONCLUSIONFew to no tools address the spiritual, ethical, or cultural domains or patient-reported experience with end-of-life care. While some data exist on psychometric properties of tools, the responsiveness of different tools to change and/or comparisons between tools have not been evaluated. Future research should focus on developing or testing tools that address domains for which few tools exist, evaluating responsiveness, and comparing tools.

30. Examining the effects of a home-based palliative heart failure program on quality of life, symptom burden, satisfaction with care and caregiver burden among patients with end-stage heart failure.

Author(s): Ng, Alina Yee Man; Wong, Frances Kam Yuet

Source: Journal of pain and symptom management; Aug 2017

Publication Type(s): Journal Article

Abstract:CONTEXTProvision of home-based palliative care for seriously ill patients is important, yet few home-based palliative care services specifically or exclusively focus on end-stage heart failure (ESHF) patients.OBJECTIVESThis study aimed to examine the effect of a home-based palliative heart failure (HPHF) program on quality of life (QOL), symptoms burden, functional status, patient satisfaction and caregiver burden among patients with ESHF.METHODSA two-group randomized controlled trial in three hospitals. We recruited a total of 84 hospitalized ESHF patients who were referred to palliative care. They were randomized to the intervention or control group. The intervention group received a 12-week structured program with regular home visits/telephone calls provided by the nurse case managers. Data were collected at baseline (T1) and at 4 (T2) and 12 weeks (T3) post-discharge.RESULTSA statistically significant between-group effect was found, with the HPHF group had significantly higher McGill QOL total score than the control group (p=0.016) and there was significant group x time interaction effect (p=0.032). There was no significant between-group effects detected for the measures of symptom distress or functional status at 12 weeks. The intervention group had higher satisfaction (p=0.001) and lower caregiver burden (p=0.024) than the control group at 12 weeks.CONCLUSIONThe HPHF program is effective in enhancing the QOL of ESHF patients, satisfaction with care and caregiver burden. The program has potential to reduce distress for some of the symptoms.

31. Advance Care Planning in Palliative Care for People With Intellectual Disabilities: A Systematic Review.

Author(s): Voss, Hille; Vogel, Anique; Wagemans, Annemieke M A; Francke, Anneke L; Metsemakers, Job F M; Courtens, Annemie M; de Veer, Anke J E

Source: Journal of pain and symptom management; Aug 2017

Publication Type(s): Journal Article Review

Abstract:CONTEXTAdvance care planning (ACP) is defined as a person-centered, ongoing process of communication that facilitates patients' understanding, reflection, and discussion of goals, values, and preferences for future care. There is evidence for the general palliative care population that ACP increases compliance with patients' end-of-life preferences and improves quality of care near the end of life.OBJECTIVESTo gain insight into what is known about the use and effects of ACP in palliative care for people with intellectual disabilities (IDs).METHODSFour databases were searched systematically: PubMed, PsycINFO, Embase, and CINAHL. A stepwise procedure was used to identify relevant studies based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Statement. The review included empirical quantitative, qualitative, and mixed methods studies concerning people with ID who receive palliative care or who died non-acutely, and describing ACP. Methodological quality was graded using a critical appraisal tool.RESULTSA total of 14 studies were included. Most studies examined the perspective of professionals and/or relatives. None of the studies focused on the perspective of patients with ID. The studies concerned different elements of ACP, mainly decision-making and organizational policies. No effect studies were found. Obstructing factors were difficulties in recognizing palliative needs and uncertainties among relatives and professionals about their roles and tasks in ACP. Conducive factors were good working relationships between professionals and relatives.CONCLUSIONThere are some indications that ACP could be useful for people with ID, but more knowledge is needed about whether and how ACP should be used.

32. The effectiveness of advance care planning in improving end of life outcomes for people with dementia and their carers: A systematic review and critical discussion.

Author(s): Dixon, Josie; Karagiannidou, Maria; Knapp, Martin

Source: Journal of pain and symptom management; Aug 2017

Publication Type(s): Journal Article Review

Abstract:CONTEXTEnd of life care for people with dementia can be poor, involving emergency hospital admissions, burdensome treatments of uncertain value and under-treatment of pain and other symptoms. Advance care planning (ACP) is identified, in England and elsewhere, as a means of improving end of life outcomes for people with dementia and their carers.OBJECTIVETo systematically and critically review empirical evidence concerning the effectiveness of ACP in improving end of life outcomes for people with dementia and their carers.METHODSSystematic searches of academic databases (CINAHL Plus with full text, PsycINFO, SocINDEX with full text and PubMed) were conducted to identify research studies, January 2000 - January 2017, involving statistical methods, in which ACP is an intervention or independent variable, and in which end of life outcomes for people with dementia and/or their carers are reported.RESULTSA total of 18 relevant studies were identified. Most found ACP to be associated with some improved end of life outcomes. Studies were predominantly, but not exclusively, from the US and care home-based. Type of ACP and outcome measures varied. Quality was assessed using NICE quality appraisal checklists. Over half of the studies were of moderate to high quality. Three were randomised controlled trials, two of which were low quality.CONCLUSIONThere is a need for more high-quality outcome studies, particularly using randomised designs to control for confounding. These need to be underpinned by sufficient development work and process evaluation, to clarify the appropriateness of outcome measures, explore implementation issues and to identify 'active elements'.

33. A Pilot Trial of Early Specialty Palliative Care for Patients with Advanced Pancreatic Cancer: Challenges Encountered and Lessons Learned.

Author(s): Schenker, Yael; Bahary, Nathan; Claxton, Rene; Childers, Julie; Chu, Edward; Kavalieratos, Dio; King, Linda; Lembersky, Barry; Tiver, Greer; Arnold, Robert M

Source: Journal of palliative medicine; Aug 2017

Publication Type(s): Journal Article

Abstract:BACKGROUNDPatients with advanced pancreatic cancer suffer from high morbidity and mortality. Specialty palliative care may improve quality of life.OBJECTIVEAssess the feasibility, acceptability, and perceived effectiveness of early specialty physician-led palliative care for patients with advanced pancreatic cancer and their caregivers.DESIGNA mixed-methods pilot randomized controlled trial in which patient-caregiver pairs were randomized (2:1) to receive specialty palliative care, in addition to standard oncology care versus standard oncology care alone.SETTING/SUBJECTSAt a National Cancer Institute-designated comprehensive cancer center in Western Pennsylvania, 30 patients with advanced pancreatic adenocarcinoma and their caregivers (N = 30), oncologists (N = 4), and palliative care physicians (N = 3) participated.MEASUREMENTSFeasibility (enrollment, three-month outcome-assessment, and intervention completion rates), acceptability, and perceived effectiveness (process interviews with patients, caregivers, and physicians).RESULTSConsent:approach rate was 49%, randomized:consent rate 55%, and three-month outcome assessment rate 75%. Two patients and three caregivers withdrew early. The three-month mortality rate was 13%. Patients attended a mean of 1.3 (standard deviation 1.1) palliative care visits during the three-month period. Positive experiences with palliative care included receiving emotional support and symptom management. Negative experiences included inconvenience, long travel times, spending too much time at the cancer center, and no perceived palliative care needs. Physicians suggested embedding palliative care within oncology clinics, tailoring services to patient needs, and facilitating face-to-face communication between oncologists and palliative physicians.CONCLUSIONSA randomized trial of early palliative care for advanced pancreatic cancer did not achieve feasibility goals. Integrating palliative care within oncology clinics may increase acceptability and perceived effectiveness.

34. Acupuncture for Symptom Relief in Palliative Care-Study Protocol and Semistandardized Treatment Schemes.

Author(s): Kramer, Sybille; Irnich, Dominik; Lorenzl, Stefan

Source: Journal of acupuncture and meridian studies; Aug 2017; vol. 10 (no. 4); p. 294-302

Publication Type(s): Randomized Controlled Trial Journal Article

Abstract: The use of complementary and alternative medicine methods such as acupuncture in palliative care has increased over the past years. Well-planned trials are warranted to show its effectiveness in relieving distressing symptoms. The development of treatment schemes to be used in the trial for both acupuncture and medical symptom control is challenging, as both acupuncture and palliative care are highly individualized. Thus, standardized care plans of a randomized controlled trial will have difficulties in producing treatment results that compare to the clinical practice. As an alternative, treatment protocols for both acupuncture and medical symptom control of dyspnea, pruritus, hypersalivation, depression, anxiety, and xerostomia were designed with the input of experts. They are designed to provide sufficient symptom control and comparability for a three-arm, randomized controlled trial. Medical symptom control will be provided to all groups. The two control groups will be medical treatment and sham-laser acupuncture.

35. The nurse's role in palliative care: A qualitative meta-synthesis

Author(s): Sekse, Ragnhild Johanne Tveit; Hunskår, Irene; Ellingsen, Sidsel

Source: Journal of Clinical Nursing; Jul 2017 ; p. No

Publication Type(s): Journal Peer Reviewed Journal

Abstract: Aims and objectives To explore how nurses, across various health systems, describe their role in providing palliative care for patients with life-threatening illnesses. Background Despite the fact that nurses make up the largest group of healthcare professionals, little is known about their role in palliative care, across health services. Design A qualitative systematic review of studies. Methods A search was made for relevant articles, published between January 2000–June 2016. Twenty-eight articles were selected and analysed using thematic synthesis. Results The themes that emerged from the analysis were as follows: Being available, which gave nurses a pivotal role in palliative care and paved the way for Being a coordinator of care for patients and relatives, as well as for other health personnel. Doing what's needed was to handle an enormous breadth of activities, always in a holistic framework of understanding. Being attentively present and dedicated as well as using flexible and nontraditional methods was essential in the role. Standing in demanding situations dealt with lack of time and resources, limited legitimacy, handling ethical dilemmas and being in need of support and knowledge. Conclusion Being available as well as a coordinator characterises the nurse's role across healthcare systems. The nurse acts as a link between different levels of health care, between different professions and between patient and family, which contribute to ensuring the quality of care to the individual patient. The review illuminates that the basic tenets of care in nursing are also fundamental to the nurse's role in palliative care. To be able to give individually tailored palliative care to patients with life-threatening illnesses and their relatives, the nurses need all their knowledge of basic nursing. Situations challenge nurses in practical, relational and moral dimensions of care and make demands on their role in a comprehensive way. Relevance to clinical practice Nurses need knowledge and training, guidance and support to fulfil their role. (PsycINFO Database Record (c) 2017 APA, all rights reserved) (Source: journal abstract)

36. Research protocol on early palliative care in patients with acute leukaemia after one relapse.

Author(s): Barbaret, Cécile; Berthiller, Julien; Schott Pethelaz, Anne-Marie; Michallet, Mauricette; Salles, Gilles; Sanchez, Stéphane; Filbet, Marilène

Source: BMJ supportive & palliative care; Jul 2017

Publication Type(s): Journal Article

Abstract:OBJECTIVESAccording to the American Society of Clinical Oncology palliative care referrals are made within the last 3 weeks of patients' lives and most frequently when oncological treatments have ceased especially for patients with haematological malignancies. Recent publications indicate that patients with acute leukaemia are prone to symptoms, an indication for which a close collaboration between the patient's haematologist and a palliative care team might result in improved symptom management. The object of this pilot study is to evaluate the feasibility of a clinical research trial to assess the effect of early palliative care in patients with acute leukaemia after one relapse.METHODSThis project is a multicentre, non-blinded, randomised, controlled trial. Patients in group 1 will receive standard haematological care associated with palliative care (intervention group). Patients in group 2 will receive standard haematological care with palliative care only if requested by the haematologist (control group). In order to measure an accurate sample size, patients who participate will complete a standardised questionnaire to assess their quality of life, as well as their psychological and physical symptoms, before being randomised to one of two groups in a 1:1 ratio without stratified randomisation.RESULTSThe aim of this study is to analyse causes of dropout, non-adherence and missing data in order to refine the protocol for the subsequent clinical research trial.CONCLUSIONThe ultimate objective of this project is to develop collaboration between haematologists and palliative care teams in order to improve patients' quality of life.

37. A Proposed Framework of Supportive and Palliative Care for people with High Grade Glioma.

Author(s): Philip, Jennifer; Collins, Anna; Brand, Caroline; Sundararajan, Vijaya; Lethborg, Carrie; Gold, Michelle; Lau, Rosalind; Moore, Gaye; Murphy, Michael

Source: Neuro-oncology; Jul 2017

Publication Date: Jul 2017

Publication Type(s): Journal Article

Abstract: BackgroundPatients with high-grade malignant glioma (HGG) have significant supportive and palliative care needs yet few tailored guidelines exist to inform practice. This study sought to develop a HGG framework of supportive and palliative care informed by patient, family and health care professional (HCP) reported needs.MethodsThis study integrates a mixed-methods research program involving: (1) Qualitative study: exploring experiences through systematic literature review and qualitative study (10 patients, 23 carers and 36 HCPs); (2) Epidemiological cohort study (N=1,821) describing care of cases of HGG in Victoria, Australia using linked hospital datasets. Recommendations based on these studies were developed by a multidisciplinary advisory committee for a framework of supportive and palliative care based on the findings of (1) and (2).ResultsKey principles guiding framework development were that care: (1) aligns with patient/family caregiver needs according to illness transition points; (2) involves continuous monitoring of patient/family caregiver needs; (3) be proactive in response to anticipated concerns; (4) includes routine bereavement support; and (5) involves appropriate partnership with patients/families. Framework components and resulting activities designed to address unmet needs were enacted at illness transition points and included: Co-ordination, repeated assessment, staged information provision according to the illness transition, proactive responses and referral systems, and specific regular enquiry of patient's and family caregivers' concerns.ConclusionThis evidence based, collaborative framework of supportive and palliative care provides an approach for patients with HGG that is responsive, relevant and sustainable. This conceptual framework requires evaluation in robust clinical trials.

38. Bereavement support standards and bereavement care pathway for quality palliative care.

Author(s): Hudson, Peter; Hall, Chris; Boughey, Alison; Roulston, Audrey

Source: Palliative & supportive care; Jul 2017 ; p. 1-13

Publication Type(s): Journal Article

Abstract:OBJECTIVEProvision of bereavement support is an essential component of palliative care service delivery. While bereavement support is integral to palliative care, it is typically insufficiently resourced, under-researched, and not systematically applied. Our aim was to develop bereavement standards to assist palliative care services to provide targeted support to family caregivers.METHODWe employed a multiple-methods design for our study, which included: (1) a literature review, (2) a survey of palliative care service providers in Australia, (3) interviews with national (Australian) and international experts, (4) key stakeholder workshops, and (5) a modified Delphi-type survey.RESULTSA total of 10 standards were developed along with a pragmatic care pathway to assist palliative care services with implementation of the standards.SIGNIFICANCE OF RESULTSThe bereavement standards and care pathway constitute a key initiative in the evolution of bereavement support provided by palliative care services. Future endeavors should refine and examine the impact of these standards. Additional research is required to enhance systematic approaches to quality bereavement care.

39. Prevalence of burnout in health professionals working in palliative care: a systematic review.

Author(s): Parola, Vitor; Coelho, Adriana; Cardoso, Daniela; Sandgren, Anna; Apóstolo, João

Source: JBI database of systematic reviews and implementation reports; Jul 2017; vol. 15 (no. 7); p. 1905-1933

Publication Type(s): Journal Article

Abstract:BACKGROUNDMore than ever, the current increasing need for palliative care leads to health professionals providing this type of care which further leads to multiple challenges, and stressful and demanding situations. The multiple challenges of working in palliative care put health professionals working in this context at the risk of burnout.OBJECTIVESTo examine the evidence on the prevalence of burnout among health professionals working in palliative care.INCLUSION CRITERIA TYPES OF PARTICIPANTSThe current review included studies that encompass qualified health professionals working in palliative care, caring for patients 18 years of age or older.CONDITIONThe current review considered studies reporting on the point prevalence of burnout, measured by a burnout scale, such as, but not limited to, the Maslach Burnout Inventory, Burnout Measure and Copenhagen Burnout Inventory.CONTEXTThe current review considered studies conducted in the context of specialist palliative care, more specifically, palliative care units, specialized palliative home care or hospices.TYPES OF STUDIESThe current review considered observational study designs, including prospective and retrospective cohort, case-control and cross-sectional studies.SEARCH STRATEGYAn initial search of MEDLINE (via PubMed) and CINAHL was undertaken, followed by a second search for published and unpublished studies since 1975 in major healthcare-related electronic databases. Studies written in English, Spanish and Portuguese were included.METHODOLOGICAL QUALITYTwo independent reviewers assessed the methodological quality of studies using the standardized critical appraisal instrument from the Joanna Briggs Institute. No studies were excluded from the review based on the methodological appraisal.DATA EXTRACTIONData were extracted using a data extraction table, taking into account the review questions.DATA SYNTHESISSignificant differences were found between condition measures, thus we were unable to perform a meta-analysis.RESULTSEight cross-sectional studies met the inclusion criteria, with a total of 1406 health professionals. The sample was limited to nurses, physicians and social workers. None of the included articles presented data about other health professionals. Seven of the included studies assessed the prevalence of burnout using the same instrument - the Maslach Burnout Inventory. Data revealed a prevalence of burnout of 17.3% among health professionals. Personal Accomplishment was the sub-scale from the Maslach Burnout Inventory that had the highest prevalence (19.5%). Nurses had higher levels of Emotional Exhaustion (19.5%) and Depersonalization (8.2%), and physicians had lower levels of Personal Accomplishment (41.2%). The prevalence of burnout was, however, higher in social workers (27%). The palliative care context with the highest prevalence of burnout was home care (19.6%).CONCLUSIONThe current systematic review contributes to a body of empirical knowledge that can facilitate the professional development of palliative care teams by highlighting the prevalence of burnout in health professionals, which staff category is the most affected (social workers), and which palliative care context has the highest prevalence (home care).

40. Use of non-pharmacological interventions for comforting patients in palliative care: a scoping review.

Author(s): Coelho, Adriana; Parola, Vítor; Cardoso, Daniela; Bravo, Miguel Escobar; Apóstolo, João

Source: JBI database of systematic reviews and implementation reports; Jul 2017; vol. 15 (no. 7); p. 1867-1904

Publication Type(s): Journal Article

Abstract:BACKGROUNDPalliative care aims to provide the maximum possible comfort to people with advanced and incurable diseases. The use of non-pharmacological interventions to promote comfort in palliative care settings has been increasing.However, information on implemented and evaluated interventions, their characteristics, contexts of application, and population is scattered in the literature, hampering the formulation of accurate questions on the effectiveness of those interventions and, consequently, the development of a systematic review.OBJECTIVEThe objective of this scoping review is to examine and map the non-pharmacological interventions implemented and evaluated to provide comfort in palliative care.INCLUSION CRITERIA TYPES OF PARTICIPANTSThis scoping review considered all studies that focused on patients with advanced and incurable diseases, aged 18 years or older, assisted by palliative care teams.CONCEPTThis scoping review considered all studies that addressed non-pharmacological interventions implemented and evaluated to provide comfort for patients with advanced and incurable diseases.It considered non-pharmacological interventions implemented to provide not only comfort but also well-being, and relief of pain, suffering, anxiety, depression, stress and fatigue which are comfort-related concepts.CONTEXTThis scoping review considered all non-pharmacological interventions implemented and evaluated in the context of palliative care. This included home care, hospices or palliative care units (PCUs).TYPES OF SOURCESThis scoping review considered quantitative and qualitative studies, and systematic reviews.SEARCH STRATEGYA three-step search strategy was undertaken: 1) an initial limited search of CINAHL and MEDLINE; 2) an extensive search using all identified keywords and index terms across all included databases; and 3) a hand search of the reference lists of included articles.This review was limited to studies published in English, Spanish and Portuguese in any year.EXTRACTION OF RESULTSA data extraction instrument was developed. Two reviewers extracted data independently. Any disagreements that arose between the reviewers were resolved through discussion, or with a third reviewer. When necessary, primary authors were contacted for further information/clarification of data.PRESENTATION OF RESULTSEighteen studies were included covering 10 non-pharmacological interventions implemented and evaluated to provide comfort. The interventions included one to 14 sessions. The interventions lasted between five and 60 minutes. Most of the interventions were implemented in PCUs and hospice settings. Ten of the 18 interventions were implemented and evaluated exclusively in cancer patients.CONCLUSIONSTen non-pharmacological interventions were identified, of which the most common were music therapy and massage therapy. Their characteristics differed significantly across interventions and even in the same intervention. They were mostly implemented in palliative care units and hospices, and in patients with a cancer diagnosis. These data raise questions for future primary studies and systematic reviews.IMPLICATIONS FOR RESEARCHFuture research should focus on the implementation of interventions not only with cancer patients but also with non-cancer patients and patients receiving palliative care at home. Systematic reviews on the effect of massage therapy and music therapy should be conducted.

41. Family caregivers’ pain management in end-of-life care: A systematic review

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

Source: American Journal of Hospice & Palliative Medicine; Jun 2017; vol. 34 (no. 5); p. 470-485

Publication Type(s): Journal Peer Reviewed Journal Journal Article

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. (PsycINFO Database Record (c) 2017 APA, all rights reserved) (Source: journal abstract)

42. Clinical Usefulness of Tools to Support Decision-making for Palliative Treatment of Metastatic Colorectal Cancer: A Systematic Review.

Author(s): Engelhardt, Ellen G; Révész, Dóra; Tamminga, Hans J; Punt, Cornelis J A; Koopman, Mirjam; Onwuteaka-Philipsen, Bregje D; Steyerberg, Ewout W; Jansma, Ilse P; De Vet, Henrica C W; Coupé, Veerle M H

Source: Clinical colorectal cancer; Jun 2017

Publication Type(s): Journal Article

Abstract:BACKGROUNDDecision-making regarding palliative treatment for patients with metastatic colorectal cancer (mCRC) is complex and comprises numerous decisions. Decision-making should be guided by the premise of maintaining and/or improving patients' quality of life, by patient preference, and by the trade-off between treatment benefits and harm. Decision support systems (DSSs) for clinicians (eg, nomograms) can assist in this process. The present systematic review aimed to provide a comprehensive overview of the available DSSs for incurable mCRC and to assess their clinical usefulness.MATERIALS AND METHODSA systematic literature search was performed in PubMed, Embase, and the Cochrane Library. We extracted information on the DSS characteristics and their discriminatory ability, calibration, and user-friendliness.RESULTSFrom 5205 studies, we identified 14 DSSs for decisions regarding palliative resection of the primary tumor (n = 3), radiotherapy for metastases (n = 2), treatment type (invasive vs. symptomatic only; n = 7), and selection of chemotherapy (n = 2). The predictors varied greatly among the DSSs, and only 1 DSS incorporated a genetic marker (ie, UGT1A1). None of the DSSs included > 1 treatment option, nor did any DSS present estimates of treatment benefits and harms. Five tools had not been externally validated, two had only been validated in < 35 patients, and the rest had only been validated in populations similar to the population used for their development. Discriminatory accuracy was generally moderate to poor. Calibration measures were only reported for 2 tools.CONCLUSIONA limited number of DSSs are available to support palliative treatment decisions for patients with mCRC, and the evidence regarding their discriminatory ability and calibration is too limited to recommend their use. New DSSs comparing multiple treatment options and presenting both treatment benefits and harms are needed.

43. 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

Abstract:BACKGROUNDIncurable 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.OBJECTIVESTo 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 METHODSWe 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 CRITERIARandomised controlled trials (RCTs) and cluster-randomised controlled trials (cRCTs) on professional palliative care services that provided or co-ordinated comprehensive care for adults at early advanced stages of cancer.DATA COLLECTION AND ANALYSISWe 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 RESULTSWe 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 6.46) 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' CONCLUSIONSThis 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 mortality and depression are uncertain. We have to interpret current results with caution owing to very low to low certainty of current evidence and between-study differences regarding participant populations, interventions, and methods. Additional research 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.

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

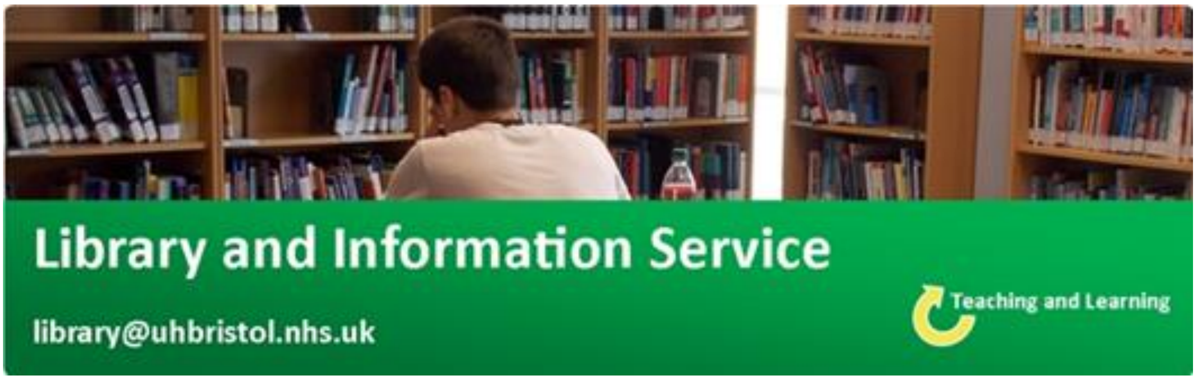
Author(s): Riemer, C A; El-Azhary, R A; Wu, K L; Strand, J J; Lehman, J S

Source: The British journal of dermatology; Jun 2017

Publication Type(s): Journal Article Review

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.



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