

PALLIATIVE CARE BULLETIN

November 2023

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Carers

Comparison of palliative care education for family caregivers in high-and-low-income countries:

An integrative review

Authors: Kristanti, M. S.; Hidayati, N. W. and Maryadi

Journal: Belitung Nursing Journal. (2023)

Abstract:

BACKGROUND: In most resource-limited countries, palliative care is still under development. Despite the differences, the involvement of family caregivers is fundamental in both High-Income Countries (HICs) and Low-Income Countries (LICs). The lack of formal support in LICs implies that educational interventions to support family caregivers in this region could be more complex and urgently needed than in HICs. To comprehend the existing situation and identify the gaps in LICs, using HICs as a benchmark standard and conducting a review comparing educational interventions in both regions is essential.

OBJECTIVE: To identify and compare the existing implementation of education for family caregivers of patients with advanced cancer in LICs and HICs.

DESIGN: An integrative review guideline by Whittemore and Knafl was followed. Interventional studies related to education for family caregivers providing care for adult patients with cancer were included, and review articles were excluded.

DATA SOURCES: Data were obtained from PubMed, EBSCO, ProQuest, and ClinicalKey. The search was conducted on 18 November 2021 and updated on 9 August 2023.

REVIEW METHODS: Data reduction, data comparison, conclusion drawing, and data verification were conducted.

RESULTS: Out of the 11 studies included, nine were randomized controlled trials, and two were quasi-experimental studies. Among them, seven (63%) were conducted in HICs, and four (37%) were carried out in LICs. In both regions, the psychological aspect was the most commonly addressed subject in palliative care education for family caregivers. However, in LICs, no articles specifically addressed the social and spiritual aspects of family caregivers' education. Research conducted in LICs mostly involved nurses, while studies in HICs included a more diverse range of healthcare professionals. Typically, these programs required two to three sessions, with 30-60 minutes duration for 3-12 weeks.

CONCLUSION: The social and spiritual aspects can be integrated into family caregivers' training programs in LICs in the near future. Nurses, as an integral part of the multidisciplinary team, are capable of contributing to the development of educational programs for family caregivers, especially in resource-limited countries where patients rely heavily on their caregivers and relatives. Support from nurses is fundamental in such contexts.

Full text available online: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10600708/>

Evaluating the effects of dyadic intervention for informal caregivers of palliative patients with lung cancer: A systematic review and meta-analysis

Authors: Liu, X.; Jiang, L.; Peng, X., et al

Journal: International Journal of Nursing Practice. (2023)

Abstract:

AIM: To investigate the effects of dyadic intervention on anxiety, depression, care burden and quality of life in informal caregivers of palliative patients with lung cancer.

BACKGROUND: Informal caregivers of palliative lung cancer patients bear a large number of negative emotions during the process of caring for the patients. Dyadic intervention has the potential for improving them but the overall effect is unclear.

DESIGN: A systematic review and meta-analysis.

DATA SOURCES: All randomized controlled trials were retrieved from the following databases until 4 May 2023: Web of Science, Embase Ovid, PubMed, Cochrane Central Register of Randomized Controlled Trials, Weipu, Wanfang and Chinese National Knowledge Infrastructure databases.

REVIEW METHODS: This review was performed by Stata 12.0 and Review Manager 5.3.

RESULTS: Thirteen randomized controlled trials were in accordance with the inclusion and exclusion criteria (n = 1807). The results revealed that dyadic intervention significantly improved family caregivers' anxiety, depression and caregiver burden of palliative patients with lung cancer. There was no significant difference in quality of life between the dyadic intervention group and family caregivers who did not receive the dyadic intervention.

CONCLUSIONS: Dyadic intervention positively impacts the experience of family caregivers of palliative patients with lung cancer.

Full text available via the library: <https://libkey.io/10.1111/ijn.13217>

Communication

Do We Really Listen, Improving End-of-Life Conversations

Authors: Brooke Tucker, C.

Journal: Critical Care Nursing Clinics of North America. (2023)

Abstract:

Having end-of-life (EOL) conversations is often difficult for even seasoned clinicians. There are many well-developed conversation guidelines used in the specialty of palliative medicine. There is no one ultimate guide that makes having an emotion-filled conversation easy. However, using the tenets of medical ethics, cloaked with experience, compassion, empathy, and respect makes EOL conversations less traumatic for the patient-family system and for the provider. Palliative specialists have the training and experience in effectively having EOL conversations, especially

when death is unavoidable. Utilizing shared decision making, palliative specialists ensure there is mutual respect and communication between providers and the family system.

Full text available via NHS OpenAthens: <https://libkey.io/10.1016/j.cnc.2023.06.002>

Understanding how shared decision-making approaches and patient aids influence patients with advanced cancer when deciding on palliative treatments and care: A realist review

Authors: Edwards, M.; Holland-Hart, D.; Mann, M., et al

Journal: Health Expectations : An International Journal of Public Participation in Health Care and Health Policy. (2023)

Abstract:

BACKGROUND: Patients with advanced incurable cancer face difficult decisions about palliative treatment options towards their end of life. However, they are often not provided with the appropriate information and support that is needed to make informed decisions. This review aimed to identify contexts and mechanisms associated with communication tools, patient decision-aids and shared decision-making (SDM) approaches that influence patient outcomes.

METHODS: We used a realist review method to search for published studies of patients (adults > 18) with advanced cancer who were expected to make a decision about palliative treatment and/or supportive care in consultation with healthcare practitioners. We appraised and synthesised literature describing the contexts of (when and how) decision aids and SDM approaches are used, and how these contexts interact with mechanisms (resources and reasoning) which impact patient outcomes. Stakeholders including academics, palliative healthcare professionals (HCPs) and people with lived experience of supporting people with advanced incurable cancer contributed to identifying explanatory accounts. These accounts were documented, analysed and consolidated to contribute to the development of a programme theory.

RESULTS: From the 33 included papers, we consolidated findings into 20 explanatory accounts to develop a programme theory that explains key contexts and mechanisms that influence patient and SDM. Contexts include underlying patients' and HCPs' attitudes and approaches. These need to be understood in relation to key mechanisms, including presenting information in multiple formats and providing adequate time and opportunities to prepare for and revisit decisions. Contexts influenced mechanisms which then influence the levels of patient decisional satisfaction, conflict and regret.

CONCLUSIONS: Our programme theory highlights mechanisms that are important in supporting shared treatment decisions for advanced noncurative cancer. The findings are informative for developing and evaluating interventions to improve understanding and involvement in SDM for patients with advanced incurable cancer.

PATIENT AND PUBLIC CONTRIBUTION: We included patient and public involvement (PPI) representatives in four stakeholder meetings. PPI helped to define the scope of the review, identify their unique experiences and perspectives, synthesise their perspectives with our review findings, make decisions about which theories we included in our programme theory and develop recommendations for policy and practice and future research.

Full text available online: <https://onlinelibrary.wiley.com/doi/10.1111/hex.13822>

Dyadic advance care planning: systematic review of patient-caregiver interventions and effects

Authors: Liu, X.; Wang, T.; Cheung, D. S. T., et al

Journal: BMJ Supportive & Palliative Care. (2023)

Abstract:

INTRODUCTION: Family caregiver's involvement in advance care planning (ACP) is essential to provide high-quality end-of-life (EOL) care and to ease the surrogate decision-making burden. However, no systematic review has focused on existing ACP interventions involving patients and their families.

AIM: To systematically summarise current ACP interventions involving patients and their families.

METHODS: Five English and two Chinese databases were searched from inception to September 2022. The eligible studies were experimental studies describing original data. The Joanna Briggs Institute critical appraisal tools assessed the methodological quality. Narrative synthesis was conducted for data analysis.

RESULTS: In total, twenty-eight articles were included. Fifteen studies were randomised controlled trials, and the rest 13 studies were quasi-experimental studies. The data synthesis identified: (1) Key intervention components: strategies to promote ACP, ACP discussion and follow-up, as well as the role of family caregivers; (2) Effects on intended outcomes: interventions have shown benefit on completion of ACP actions, while inconsistent findings were found on the process outcomes and quality of EOL care. In addition, a logic model for patient-caregiver dyadic ACP was created, and the underlying mechanisms of action included well-preparation, open discussion and adequate support for plan/action.

CONCLUSIONS: This review provides comprehensive evidence about patient-caregiver dyadic ACP, a promising intervention to better prepare for EOL communication and decision-making. A logic model has been mapped to give a preliminary indication for future implementation. More empirical studies are needed to improve this model and culturally adapt it in a real-world setting.

Full text available via NHS OpenAthens: <https://libkey.io/10.1136/spcare-2023-004430>

Perceptions, Attitudes, and Knowledge toward Advance Directives: A Scoping Review

Authors: Macedo, J. C.; Rego, F. and Nunes, R.

Journal: Healthcare (Basel, Switzerland). (2023)

Abstract:

BACKGROUND: Advance directives are an expression of a person's autonomy regarding end-of-life care. Several studies have shown that the level of completion in countries where advance directives are legalised is low. To better understand this phenomenon, it is important to know the perceptions, attitudes, and knowledge that the population has about this instrument. The aim of this article was to explore a population's perceptions and/or attitudes and/or knowledge toward advance directives.

METHODS: A search was conducted in March 2023 in the ISI Web of Knowledge, Scopus, and PubMed databases using the following keywords: "advance care directives", "advance care planning", "perceptions", "attitudes", and "knowledge". Two hundred and twenty-four articles were identified, and thirteen were included for analysis.

RESULTS: The selected articles point to a low level of knowledge toward advance directives: they recognise a strong positive attitude of the population toward the implementation of advance directives but a low level of achievement.

CONCLUSIONS: Studies on perceptions/attitudes/knowledge toward advance directives are important to understand the real needs of the population regarding this issue and to implement more adequate and effective promotion and dissemination measures.

Full text available online: <https://libkey.io/10.3390/healthcare11202755>

Discussions About Goals of Care and Advance Care Planning Among Adolescents and Young Adults With Cancer Approaching the End of Life

Authors: Mack, J. W.; Cernik, C.; Uno, H., et al

Journal: Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology. (2023)

Abstract:

PURPOSE: Adolescents and young adults (AYAs) with cancer receive high rates of medically intensive measures at the end of life. This study aimed to characterize the prevalence and timing of conversations about goals of care and advance care planning among AYAs at the end of life as one potential influence on care received.

METHODS: This was a review of electronic health data and medical records for 1,929 AYAs age 12-39 years who died after receiving care at one of three sites between 2003 and 2019, including documented conversations about goals of care and advance care planning, and care received.

RESULTS: A majority of AYAs were female (54%) and White (61%); 12% were Asian, 8% Black, and 27% Hispanic. Most patients had documented discussions about prognosis (86%), goals of

care (83%), palliative care (79%), hospice (79%), and preferred location of death (64%). When last documented goals of care were evaluated, 69% of patients wanted care focused on palliation; however, 29% of those with palliative goals spent time in the intensive care unit (ICU) in the last month of life, and 32% had multiple emergency room (ER) visits. When goals-of-care discussions happened earlier, >30 days before death, AYAs were less likely to receive chemotherapy in the last 14 days of life ($P = .001$), ICU care ($P < .001$), ER visits ($P < .001$), and hospitalizations in the last month ($P < .001$).

CONCLUSION: High rates of medically intensive measures among AYAs near the end of life do not appear to be the result of a lack of discussions about goals of care and advance care planning. Although some interventions may be used to support palliative goals, earlier discussions have potential to reduce late-life intensive measures.

Full text available via the library: <https://libkey.io/10.1200/JCO.23.00641>

Forms or Free-Text? Measuring Advance Care Planning Activity Using Electronic Health Records

Authors: Zupanc, S. N.; Lakin, J. R.; Vollandes, A. E., et al

Journal: Journal of Pain and Symptom Management. (2023)

Abstract:

Advance care planning (ACP) discussions seek to guide future serious illness care. These discussions may be recorded in the electronic health record by documentation in clinical notes, structured forms and directives, and physician orders. Yet, most studies of ACP prevalence have only examined structured electronic health record elements and ignored data existing in notes. We sought to investigate the relative comprehensiveness and accuracy of ACP documentation from structured and unstructured electronic health record data sources. We evaluated structured and unstructured ACP documentation present in the electronic health records of 435 patients with cancer drawn from three separate healthcare systems. We extracted structured ACP documentation by manually annotating written documents and forms scanned into the electronic health record. We coded unstructured ACP documentation using a rule-based natural language processing software that identified ACP keywords within clinical notes and was subsequently reviewed for accuracy. The unstructured approach identified more instances of ACP documentation (238, 54.7% of patients) than the structured ACP approach (187, 42.9% of patients). Additionally, 16.6% of all patients with structured ACP documentation only had documents that were judged as misclassified, incomplete, blank, unavailable, or a duplicate of a previously entered erroneous document. ACP documents scanned into electronic health records represent a limited view of ACP activity. Research and measures of clinical practice with ACP should incorporate information from unstructured data.

Full text available via the library: <https://libkey.io/10.1016/j.jpainsymman.2023.07.016>

Conditions

End-of-Life and Palliative Care Issues for Patients Living with Pulmonary Arterial Hypertension: Barriers and Opportunities

Authors: Ali, H. and Sahay, S.

Journal: Seminars in Respiratory and Critical Care Medicine. (2023)

Abstract:

Pulmonary arterial hypertension (PAH) is a progressive, incurable disease that results in significant symptom burden, health care utilization, and eventually premature death. Despite the advancements made in treatment and management strategies, survival has remained poor. End-of-life care is a challenging issue in management of PAH, especially when patients are in younger age group. End-of-life care revolves around symptom palliation and reducing psychosocial disease burden for a dying patient and entails advanced care planning that are often challenging. Thus, support from palliative care specialist becomes extremely important in these patients. Early introduction to palliative care in patients with high symptom burden and psychosocial suffering is suggested. Despite of the benefits of an early intervention, palliative care remains underutilized in patients with PAH, and this significantly raises issues around end-of-life care in PAH. In this review, we will discuss the opportunities offered and the existing barriers in addressing high symptom burden and end-of-life care issues. We will focus on the current evidence, identify areas for future research, and provide a call-to-action for better guidance to PAH specialists in making timely, appropriate interventions that can help mitigate end-of-life care issues.

Full text available via the library: <https://libkey.io/10.1055/s-0043-1770124>

Referral Criteria to Specialist Palliative Care for People with Advanced Chronic Kidney Disease: A Systematic Review

Authors: Collins, A.; Hui, D.; Davison, S. N., et al

Journal: Journal of Pain and Symptom Management. (2023)

Abstract:

CONTEXT: People with advanced chronic kidney disease (CKD) have significant morbidity, yet for many, access to palliative care occurs late, if at all.

OBJECTIVES: This study sought to examine criteria for referral to specialist palliative care for adults with advanced CKD with a view to improving use of these essential services.

METHODS: Systematic review of studies detailing referral criteria to palliative care in advanced CKD conducted and reported according to the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) guideline and registered (PROSPERO: CRD42021230751).

DATA SOURCES: Electronic databases (Ovid, MEDLINE, Ovid Embase, and PubMed) were used to identify potential studies, which were subjected to double review, data extraction, thematic coding, and descriptive analyses.

RESULTS: Searches yielded 650 unique titles ultimately resulting in 56 studies addressing referral criteria to specialist palliative care in advanced CKD. Of 10 categories of referral criteria, most commonly discussed were: Critical times of treatment decision making (n = 23, 41%); physical or emotional symptoms (n = 22, 39%); limited prognosis (n = 18, 32%); patient age and comorbidities (n = 18, 32%); category of CKD/ biochemical criteria (n = 13, 23%); functional decline (n = 13, 23%); psychosocial needs (n = 9, 16%); future care planning (n = 9, 16%); anticipated decline in illness course (n = 8, 14%); and hospital use (n = 8, 14%).

CONCLUSION: Clinicians consider referral to specialist palliative care for a wide range of reasons, with many related to care needs. As palliative care continues to integrate with nephrology, our findings represent a key step towards developing consensus criteria to standardize referral for patients with chronic kidney diseases.

Full text available online: [https://www.jpsmjournal.com/article/S0885-3924\(23\)00613-9/fulltext](https://www.jpsmjournal.com/article/S0885-3924(23)00613-9/fulltext)

Meta-Analysis of Effects of Early Palliative Care on Health-Related Outcomes Among Advanced Cancer Patients

Authors: Cui, J.; Fang, P.; Bai, J., et al

Journal: Nursing Research. (2023)

Abstract:

BACKGROUND: Early palliative care (PC) has received more attention for improving health-related outcomes for advanced cancer patients in recent years, but the results of previous studies are inconsistent.

OBJECTIVES: This study aimed to use meta-analysis and trial sequence analysis to evaluate the effect of early PC on health-related outcomes of advanced cancer patients.

METHODS: All English publications were searched in PubMed, Web of Science, Embase, and the Cochrane Library from inception to March 2023, with a restriction that the study type was a randomized controlled trial.

RESULTS: The results showed that early PC positively affected quality of life, satisfaction with care, and symptom burden reduction. However, early PC had no significant effect on anxiety or survival. Trial sequence analysis results showed that the effect of early PC on the quality of life was stable.

DISCUSSION: This systematic review suggested that early PC could positively affect health-related outcomes for advanced cancer patients. Early PC can be used widely in clinical settings to improve health-related outcomes of advanced cancer. However, because of the trial sequence analysis results, further well-designed, clinical, randomized controlled trials with larger sample

sizes are necessary to draw definitive conclusions.

Full text available via the library: <https://libkey.io/10.1097/NNR.0000000000000687>

Palliative Care for Patients With Heart Failure With Preserved Ejection Fraction

Authors: Godfrey, S.; Peng, Y.; Lorusso, N., et al

Journal: Circulation.Heart Failure. (2023)

Abstract:

Heart failure with preserved ejection fraction (HFpEF) has become the leading form of heart failure worldwide, particularly among elderly patient populations. HFpEF is associated with significant morbidity and mortality that may benefit from incorporation of palliative care (PC). Patients with HFpEF have similarly high mortality rates to patients with heart failure with reduced ejection fraction. PC trials for heart failure have shown improvement in quality of life, quality of death, and health care utilization, although most trials defined heart failure clinically without differentiating between HFpEF and heart failure with reduced ejection fraction. As such, the timing and role of PC for HFpEF care remains uncertain, and PC referral rates for HFpEF are very low despite potential improvements in important patient-centered outcomes. Specific barriers to referral include limited data, prognostic uncertainty, provider misconceptions about PC, inadequate specialty PC workforce, complexities of treating multimorbidity, and limited home care options for patients with heart failure. While there are many barriers to integration of PC into HFpEF care, there are multiple potential benefits to patients with HFpEF throughout their disease course. As this population continues to grow, targeted efforts to study and implement PC interventions are needed to improve patient quality of life and death.

Full text available via the library: <https://libkey.io/10.1161/CIRCHEARTFAILURE.123.010802>

Palliative Care in Adolescents and Young Adults With Cancer

Authors: Johnston, E. E. and Rosenberg, A. R.

Journal: Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology. (2023)

Abstract:

Palliative care (PC) aims to improve quality of life (QOL) for patients with serious illness and their families by recognizing and alleviating the physical, emotional, social, existential, and spiritual suffering of patients and their communities. Because adolescents and young adults (AYAs, age 15-39 years) with cancer commonly report distress across all these domains and because that distress translates to their QOL during and after their cancers, PC is particularly relevant for this population. Here, we review the evidence for PC among AYAs with cancer, including its rationale, gaps, opportunities, and implications for care delivery. For example, nearly 90% of AYAs with cancer report distressing symptoms during their treatment, those who survive report ongoing

unmet psychosocial and physical health needs, and those who die from their cancers are highly likely to receive medically intense care that is discordant with their goals and values. AYA communication and decision making can be challenging because of ethical and developmental considerations regarding the patient's autonomy and competing priorities of patients and caregivers. PC interventions (including primary PC delivered by oncologists, routine PC subspecialty care, symptom tracking, advance care planning, and psychosocial programs promoting AYA resilience) are all associated with improved patient-centered outcomes. However, PC is inconsistently integrated into AYA oncology care, and access to PC programs is not equitable; marginalized groups continue to experience poorer outcomes. Ongoing and future research and clinical initiatives must continue to bridge these gaps. Improving the QOL of AYAs with cancer is a shared goal of the larger clinical oncology community, and including PC in AYA cancer care delivery can help attain that goal.

Full text available online: <https://journals.sagepub.com/doi/10.1177/107327481502200413>

What is an "early palliative care" intervention? A scoping review of controlled studies in oncology

Authors: Nadolny, S.; Schildmann, E.; Gaßmann, E. S. and Schildmann, J.

Journal: Cancer Medicine. (2023)

Abstract:

INTRODUCTION: Early palliative care (EPC) has been advocated to improve cancer patients' health. However, EPC differs with regard to its elements and target groups. It is not known which parts of EPC contribute to effectiveness for which patient group. This scoping review provides a structured analysis of EPC interventions and outcome measures.

DESIGN: We searched EMBASE, MEDLINE, CINAHL, and CENTRAL up to February 2022. We included randomized controlled trials (RCT), nonrandomized trials, cohort studies (CS), and controlled before-after studies of EPC in adult patients in English, Dutch, and German language. Interventions had to be self-labeled as EPC. Screening and data extraction were performed by two raters. A structured analysis incorporating the TIDieR checklist was performed to describe the elements of the interventions.

RESULTS: We screened 2651 articles, resulting in 40 articles being included: 34 studies were RCT and six studies were CS with a mean sample size of 208 patients. Patients with pancreatic (n = 10) and lung cancer (n = 9) were most often included. Studies reported different reference points for the onset of EPC such as time after diagnosis of incurable cancer (n = 18) or prognosis (n = 9). Thirteen studies provided information about elements of EPC and eight studies about the control intervention. Most frequent elements of EPC were symptom management (n = 28), case management (n = 16), and advance care planning (ACP; n = 15). Most frequently reported outcome measures were health-related quality of life (n = 26), symptom intensity (n = 6), resource use, and the patient's mood (n = 4 each).

CONCLUSION: The elicited heterogeneity of EPC in combination with deficits of reporting are considerable barriers that should be addressed to further develop effective EPC interventions for different groups of cancer patients.

Full text available online: <https://onlinelibrary.wiley.com/doi/10.1002/cam4.6490>

Palliative clinical trials in advanced chronic liver disease: Challenges and opportunities

Authors: Verma, S.; Hingwala, J.; Low, J. T. S., et al

Journal: Journal of Hepatology. (2023)

Abstract:

Patients with advanced chronic liver disease have a complex symptom burden and many are not candidates for curative therapy. Despite this, provision of palliative interventions remains woefully inadequate, with an insufficient evidence base being a contributory factor. Designing and conducting palliative interventional trials in advanced chronic liver disease remains challenging for a multitude of reasons. In this manuscript we review past and ongoing palliative interventional trials. We identify barriers and facilitators and offer guidance on addressing these challenges. We hope that this will reduce the inequity in palliative care provision in advanced chronic liver disease.

Full text available online: [https://www.journal-of-hepatology.eu/article/S0168-8278\(23\)04941-3/fulltext](https://www.journal-of-hepatology.eu/article/S0168-8278(23)04941-3/fulltext)

COVID-19

Trends in Palliative Care Research During the COVID-19 Pandemic

Authors: Wang, C.; Chen, Y.; Tsao, S. and Lee, C.

Journal: The American Journal of Hospice & Palliative Care. (2023)

Abstract:

To demonstrate the trends and variety of research on palliative care during the COVID-19 pandemic. A systematic search of the Web of Science database. Since the outbreak of the COVID-19 pandemic, the adjustment of palliative care systems is warranted to maintain a high quality of care. The COVID-19 -related palliative care studies account for approximately 4% of all publications on palliative care. However, there is a dearth of research investigating the nature of these studies. A total of 293 studies were included. Of the included studies, those related to system improvement were the most common (181/293, 61.8%), followed by those related to patient care (79/293, 27.0%), bereavement support for patients or family members (19/293, 6.5%), and the mental health of frontline practitioners (14/293, 4.8%). From these studies, 82, 137, and 74 studies were published in 2020, 2021, and 2022 (until August 1), respectively. The research trends of palliative care demonstrate the flexibility and rapid response of the global

palliative care system to the COVID-19 pandemic and show how the palliative care system is evolving. While most studies are interested in system improvement, patient care, and bereavement support, the mental health of frontline practitioners has received less attention. Our findings provide palliative care practitioners with current valuable information and highlight possible future trends.

Full text available online: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9748525/>

Equality and diversity

Hospice and Palliative Care-Men and Gender-Specific Roles

Authors: MacWilliams, B. and McArthur, E.

Journal: The Nursing Clinics of North America. (2023)

Abstract:

All people face end of life as the final health outcome. When a person's health focus shifts from quantity to quality of life, palliative care comes into view. Clinicians serving patients across the health care spectrum must be aware of the nature and efficacy of palliative and hospice care, indications for referral to services, and current best practices. Creating an end-of-life trajectory requires an individualized and global personal plan, which palliative and hospice care can provide. Gender-specific care that includes gender minorities provides special and unique challenges to those seeking palliative and hospice care.

Full text available via NHS OpenAthens: <https://libkey.io/10.1016/j.cnur.2023.06.004>

Families

Family members' participation in palliative inpatient care: An integrative review

Authors: Saarinen, J.; Mishina, K.; Soikkeli-Jalonen, A. and Haavisto, E.

Journal: Scandinavian Journal of Caring Sciences. (2023)

Abstract:

AIM: To analyse how family members participate in hospital inpatient palliative care, and how their participation could be supported.

METHODS: This review followed a methodology outlined in the literature for integrative reviews. A literature search supplemented by a manual search was conducted on four electronic databases during 2020 to 2021: PubMed, CINAHL, PsycINFO, and Cochrane Library. A critical appraisal of the included studies was performed, and data were analysed using inductive content analysis.

RESULTS: The literature search resulted in 4990 articles, of which 14 articles were included in this review. Four main categories were identified concerning the participation of family members

in hospital inpatient palliative care: participation in the physical care, provision of emotional support, promoting good patient care, and support provided by healthcare professionals for family members' participation. Family members' participation can be supported in different ways, including active communication and adequate information.

CONCLUSION: Family members' participation in hospital inpatient palliative care has been an important part of palliative care in hospital settings. Family members should be offered the opportunity to participate in patient care, and their presence in the hospital should be accommodated. Research on the topic is still scarce, and future research is needed from different perspectives, including intervention research.

Full text available online: <https://onlinelibrary.wiley.com/doi/full/10.1111/scs.13062>

Medicines and treatments

Review of Dopamine Antagonists for Nausea and Vomiting in Palliative Care Patients

Authors: Jenkins, G.

Journal: Journal of Pain & Palliative Care Pharmacotherapy. (2023)

Abstract:

Symptoms of nausea and vomiting are common in palliative care and hospice patients. One of the many classes of medications used for the treatment of nausea and vomiting is dopamine receptor antagonists which are particularly helpful for treating nausea mediated by the chemoreceptor trigger zone (CTZ) and impaired gastrointestinal function. While dopamine antagonists can be very effective treatments for nausea they should be used with caution as they carry the risk of QTc prolongation, have a FDA black box warning for tardive dyskinesia (TD), and increased risk of precipitating psychosis and death in patients with dementia. This review will cover haloperidol, olanzapine, prochlorperazine, and metoclopramide for treatment of nausea and vomiting including evidence of efficacy, pharmacokinetics, and pharmacodynamics to improve safe and effective utilization in clinical practice. This includes medication receptor site affinities at histaminic, muscarinic, serotonergic, and alpha-adrenergic receptors which can help providers anticipate potential adverse effects and risk of extrapyramidal symptoms (EPS), TD, and QTc prolongation. This review also includes considerations for dose adjustments based on renal function, hepatic function, and age. Understanding the pharmacology of dopamine antagonists can help providers choose the best treatment for control of nausea and vomiting and subsequently improve patients' quality of life.

Full text available via the library: <https://libkey.io/10.1080/15360288.2023.2268065>

Effectiveness of Subcutaneous Administration of Antibiotics to Control Infections in Elder Palliative Patients: A Systematic Review

Authors: Sánchez-Cárdenas, M. A.; Vargas-Escobar, L. M.; Correa-Morales, J. E., et al

Journal: The American Journal of Hospice & Palliative Care. (2023)

Abstract:

Background: Infections are common in patients with advanced illnesses for whom the intravenous or oral route is not possible. The subcutaneous administration of antibiotics is a promising alternative, but there is not enough theoretical support for its use. This study aims to explore the effectiveness and safety of subcutaneous antibiotic therapy in the context of palliative care in elderly patients. Methods: A systematic review was conducted using PubMed and Embase, without time or language limits. Seven articles were selected on the effectiveness of subcutaneous antibiotic therapy in adult patients with chronic progressive diseases. The quality of the articles was assessed with the Newcastle Ottawa Scale and relevant data was extracted using a selection capture file. Results: Seven quasi-experimental studies evaluated 865 elderly patients with advanced diseases, comorbidities, and infections (ie, urinary tract, respiratory system, and bone joint) who received subcutaneous antibiotic therapy (ie, Ceftriaxone, Ertapenem, and Teicoplanin). The pooled success rate of subcutaneous antibiotics for the 7 studies was 71%, the therapy failure rate was 22%, its withdrawal mean was 8%, and the mean mortality rate was 7%. The studies were of low quality and were heterogeneous in the types of infections, types of antibiotics, time of follow-up, and outcomes assessed. Conclusions: Pilot studies have found a limited number of antibiotics that can be safely used to treat specific infections. Nevertheless, the data isn't robust enough to recommend their use.

Full text available via the library: <https://libkey.io/10.1177/10499091231156866>

Palliative Emergency General Surgery

Authors: Schaefer, G.; Regier, D. and Stout, C.

Journal: The Surgical Clinics of North America. (2023)

Abstract:

Acute care surgeons encounter patients experiencing surgical emergencies related to advanced malignancy, catastrophic vascular events, or associated with multisystem organ failure. The acute nature is a factor in establishing a relationship between surgeon, patient, and family. Surgeons must use effective communication skills, empathy, and a knowledge of legal and ethical foundations. Training in palliative care principles is limited in many medical school and residency curricula. We offer examples of clinical situations facing acute care surgeons and discuss evidence-based recommendations to facilitate successful treatment and outcomes.

Full text available via the library: <https://libkey.io/10.1016/j.suc.2023.06.005>

Patient experience

The experiences of people with liver disease of palliative and end-of-life care in the United Kingdom-A systematic literature review and metasynthesis

Authors: Beresford, C. J.; Gelling, L.; Baron, S. and Thompson, L.

Journal: Health Expectations : An International Journal of Public Participation in Health Care and Health Policy. (2023)

Abstract:

BACKGROUND: Liver disease is a growing health concern and a major cause of death. It causes multiple symptoms, including financial, psychological and social issues. To address these challenges, palliative care can support people alongside active treatment, and towards the end of life, but little is known about the care experiences of individuals with liver disease in the United Kingdom. This review aimed to explore the palliative and end-of-life care experiences of people with liver disease in the United Kingdom.

METHOD: A systematic review was conducted using a five-stage process and following Preferred Reporting Items for Systematic Reviews and Meta Analyses guidelines. Searches were across Web of Science, Scopus, EBSCO and grey literature until 10 May 2023. The review was registered through International Prospective Register of Systematic Reviews (PROSPERO). NVivo 12.5 was used to facilitate data analysis .

RESULTS: Of 6035 papers (excluding duplicates) found from searches, five met the inclusion criteria of primary research related to adults with liver disease receiving palliative and/or end-of-life care in the United Kingdom, published in English. Reflexive thematic analysis of the data was conducted. The themes identified were the experiences of people with liver disease of relating to healthcare professionals, using services, receiving support, and experiences of information and communication. These were connected by an overarching concept of disempowerment versus empowerment, with the notion of person-centred care as an important feature.

CONCLUSION: This review has found variations in the care experiences of people with advanced liver disease towards the end of life and an overall lack of access to specialist palliative care services. Where services are designed to be person-centred, experiences are more empowering. Further research is needed but with recognition that it is often unclear when care for people with liver disease is palliative or end-of-life.

PATIENT AND PUBLIC CONTRIBUTION: An online public involvement workshop was held on 18 April 2023 through Voice (2023). This included four people with liver disease and four carers to discuss the review findings and to design a qualitative research study to further explore the topic.

Full text available online: <https://onlinelibrary.wiley.com/doi/10.1111/hex.13893>

Older persons' perceptions and experiences of community palliative care: a systematic review of qualitative evidence

Authors: Cotton, A.; Sayers, J.; Green, H., et al

Journal: JBI Evidence Synthesis. (2023)

Abstract:

OBJECTIVE: The objective of this review was to critically appraise and synthesize qualitative evidence of older persons' perceptions and experiences of community palliative care.

INTRODUCTION: Palliative care focuses on the relief of symptoms and suffering at the end of life and is needed by approximately 56.8 million people globally each year. An increase in aging populations coupled with the desire to die at home highlights the growing demand for community palliative care. This review provides an understanding of the unique experiences and perceptions of older adults receiving community palliative care.

INCLUSION CRITERIA: This review appraised qualitative studies examining the perceptions and experiences of older adults (65 years or older) receiving community palliative care. Eligible research designs included, but were not limited to, ethnography, grounded theory, and phenomenology.

METHODS: A search of the literature across CINAHL (EBSCOhost), MEDLINE (Ovid), Embase (Ovid SP), Web of Science Core Collection, and Scopus databases was undertaken in July 2021 and updated November 1, 2022. Included studies were published in English between 2000 and 2022. The search for unpublished studies included ProQuest Dissertations and Theses. Study selection, quality appraisal, and data extraction were performed by 2 independent reviewers. Findings from the included studies were pooled using the JBI meta-aggregation method.

RESULTS: Nine qualitative studies involving 98 participants were included in this review. A total of 100 findings were extracted and grouped into 14 categories. Four synthesized findings evolved from these categories: i) Older persons receiving palliative care in the community recognize that their life is changed and come to terms with their situation, redefining what is normal, appreciating life lived, and celebrating the life they still have by living one day at a time; ii) Older persons receiving palliative care in the community experience isolation and loneliness exacerbated by their detachment and withdrawal from and by others; iii) Older persons receiving palliative care in the community face major challenges managing prevailing symptoms, medication management difficulties, and costs of medical care and equipment; and iv) Older persons want to receive palliative care and to die at home; however, this requires both informal and formal supports including continuity of care, good communication, and positive relationships with health care providers.

CONCLUSIONS: Experiences and perceptions of community palliative care vary among older adults. These are influenced by the individual's expectations and needs, available services, and cost. Older adults' input into decision-making about their care is fundamental to their needs

being met and is contingent on effective communication between the patient, family, and staff across services. Policy that advocates for trained palliative care staff to provide care is necessary to optimize care outcomes, while collaboration between staff and services is critical to enabling holistic care, managing symptoms, and providing compassionate care and support.

Full text available online:

https://journals.lww.com/jbisrir/fulltext/9900/older_persons_perceptions_and_experiences_of_233.aspx

Place of care

Best Practices in End of Life and Palliative Care in the Emergency Department

Authors: Prachanukool, T.; George, N.; Bowman, J., et al

Journal: Clinics in Geriatric Medicine. (2023)

Abstract:

Three-quarters of patients over the age of 65 visit the emergency department (ED) in the last six months of their lives. Approximately 20% of hospice residents have ED visits. These patients must decide whether to receive emergency care that prioritizes life support, which may not achieve their desired outcomes and might even be futile. The patients in these end-of-life stages could benefit from early palliative care or hospice consultation before they present to the ED. Furthermore, early integration of palliative care at the time of ED visits is important in establishing the goals of the entire treatment.

Full text available via NHS OpenAthens: <https://libkey.io/10.1016/j.cger.2023.05.011>

Staff

Nurse-led adult palliative care models in low- and middle-income countries: A scoping review

Authors: Bassah, N.; Vaughn, L. and Santos Salas, A.

Journal: Journal of Advanced Nursing. (2023)

Abstract:

AIMS: To map evidence on the nature and extent of use of nurse-led palliative care models in low- and middle-income countries serving adults with life-limiting conditions. **DESIGN:** A scoping review of the literature was undertaken.

DATA SOURCES: A systematic search was performed from database inception to March 2022 in: Medline, EMBASE, CINAHL, Wiley Cochrane Library, SCOPUS, Web of Science, SciELO and Global Health. Main search terms included: Nurse-led AND Palliative care AND Low-and middle-income countries. Grey literature was searched from Proquest Dissertations and Theses Global, the

World Health Organization and selected palliative care websites. We searched the reference list of included articles for additional studies.

REVIEW METHODS: We used the framework by Arksey and O'Malley and the PRISMA-ScR guidelines. Titles and abstracts were screened by one reviewer and full text by two reviewers. Thematic analysis was used to synthesize data and results are presented descriptively using themes and categories.

RESULTS: Eighteen studies were included, with majority from Sub-Saharan Africa (10/20). Three nurse-led palliative care models emerged: nurse-led empowering care, nurse-led symptom control and nurse-led multicomponent palliative care. They served particularly cancer and HIV patients and were delivered in person or by telehealth care. Reported outcomes were adherence to therapy, improved self-care ability, improved quality of life and increased access to palliative.

CONCLUSIONS: The use of nurse-led palliative care in low- and middle-income countries is in its developing stages and seems feasible. Nursing roles in low- and middle-income countries need to be expanded by developing advanced practice nurses and nurse practitioner programmes, with palliative care content. More impact evaluation studies on the use of nurse-led palliative care models in these countries are needed.

IMPACT: This review highlights nurse-led care models that can enhance access and quality of life of patients with life-limiting conditions in low- and middle-income countries.

Full text available online: <https://onlinelibrary.wiley.com/doi/10.1111/jan.15646>

The roles and experiences of medical interpreters in palliative care: A narrative review

Authors: Slusarz, C.

Journal: Palliative & Supportive Care. (2023)

Abstract:

OBJECTIVES: Skilled medical interpreters are essential to providing high-quality, culturally sensitive palliative care and addressing health-care disparities for patients with limited English proficiency (LEP). While the benefits of utilizing medical interpreters are well documented, interpreter roles and experiences in palliative care are unique and poorly defined. This narrative review examines the extant literature on medical interpreters in palliative care to define their unique roles and describe their experiences and recommendations.

METHODS: A narrative literature review was completed through systematically searching the following databases: Medline, Embase, Web of Science, and CINAHL. Title and abstract screening was completed, followed by full-text review.

RESULTS: Ten articles met inclusion criteria and were included in the review. Medical interpreters play several roles in palliative care for patients with LEP including interpreting language and meaning, acting as a cultural broker, and advocating for patients and families. Medical interpreters report being comfortable interpreting palliative care discussions; however, they face

challenges in navigating their complex roles and the emotional impact of palliative care encounters. Their recommendations to improved palliative care encounters involving medical interpreters are careful language choice, holding pre- and post-meetings, education for interpreters and health-care professionals, and further integrating the medical interpreter into the interprofessional team.

SIGNIFICANCE OF RESULTS: Medical interpreters play several complex roles when participating in palliative care encounters for patients with LEP. Understanding these roles and the experiences allows medical interpreters to be better integrated into the interprofessional team and enhances the ability to provide quality, culturally sensitive palliative care for patients with LEP. Further research is required to understand how implementing the recommendations of medical interpreters impacts patient outcomes.

Full text available via NHS OpenAthens: <https://libkey.io/10.1017/S1478951523001505>

Burnout among palliative care providers

Authors: Zogby, C. B.

Journal: Journal of the American Association of Nurse Practitioners. (2023)

Abstract:

BACKGROUND: Burnout among health care professionals contributes to high job turnover. Within the United States, burnout among specialty palliative care (PC) providers will accentuate provider shortage problems.

OBJECTIVES: This systematic review was conducted to answer the question "what is known about burnout among specialty PC providers practicing in the United States?" More specifically, it was designed to identify the rate of burnout and factors that influence or mitigate it among PC nurse practitioners (NPs), physician assistants (PA), and physicians and to inform future research.

DATA SOURCES: An electronic literature search of studies conducted in the United States between 2012 and September 2022 was completed in Embase, PubMed, CINAHL, and PsycINFO.

CONCLUSIONS: Analysis of 14 studies showed that there are five primary themes related to burnout among PC providers: (1) the rate of burnout, (2) the physical, psychological, and clinical manifestations of burnout, (3) predictors of burnout, (4) factors of resiliency, and (5) interventions piloted to decrease burnout. The majority of studies have delineated the physician role but have failed to determine the rate and factors of burnout among PC NPs and PAs.

IMPLICATIONS FOR PRACTICE: As NPs and PAs are integral to the PC provider workforce, future research should be designed to understand more clearly how burnout affects these two PC roles to inform efforts to sustain the PC workforce.

Full text available via the library: <https://libkey.io/10.1097/JXX.0000000000000912>

Symptoms

Review article: Thalidomide for the management of gastrointestinal bleeding in a palliative care setting

Authors: Fabian, E.; Königsbrügge, O.; Krejs, G. J. and Unsel, M.

Journal: Digestive Diseases (Basel, Switzerland). (2023)

Abstract:

BACKGROUND: Palliative care patients frequently present with clinically significant gastrointestinal bleeding. Due to the existence of confounding comorbidities and an often remarkably reduced state of general health, the management of gastrointestinal bleeding in this population is often challenging.

SUMMARY: This review summarises and discusses the role of thalidomide in gastrointestinal bleeding with a special focus on palliative care patients. In addition, an illustrative case report is presented. Thalidomide may be beneficial in gastrointestinal bleeding by exerting antiangiogenic effects. The drug has an acceptable safety profile. Given its teratogenicity, thalidomide should not be administered to women of childbearing potential who are not using adequate contraception. Other side effects of thalidomide like neurotoxicity may limit its use, but can be monitored safely. Due to thalidomide's thrombin generating potential, patients managed with thalidomide-containing regimes should be closely monitored for deep venous thrombosis.

KEY MESSAGE: Physicians caring for patients in a palliative care setting should be aware of thalidomide as an effective therapeutic option when endoscopy fails to find a bleeding source or for those patients who cannot or refuse to undergo endoscopy but present with recurrent or obscure gastrointestinal bleeding.

Full text available online:

<https://karger.com/ddi/article/doi/10.1159/000533437/868537/Thalidomide-for-the-Management-of-Gastrointestinal>

Nursing support for breathlessness in patients with cancer: a scoping review

Authors: Kako, J.; Morikawa, M.; Kobayashi, M., et al

Journal: BMJ Open. (2023)

Abstract:

OBJECTIVE: To identify nursing support provided for the relief of breathlessness in patients with cancer.

DESIGN: A scoping review following a standard framework proposed by Arksey and O'Malley.

STUDY SELECTION: Electronic databases (PubMed, CINAHL, CENTRAL and Ichushi-Web of the Japan Medical Abstract Society Databases) were searched from inception to 31 January 2022.

Studies reporting on patients with cancer (aged ≥ 18 years), intervention for relief from breathlessness, nursing support and quantitatively assessed breathlessness using a scale were included.

RESULTS: Overall, 2629 articles were screened, and 27 were finally included. Results of the qualitative thematic analysis were categorised into 12 nursing support components: fan therapy, nurse-led intervention, multidisciplinary intervention, psychoeducational programme, breathing technique, walking therapy, inspiratory muscle training, respiratory rehabilitation, yoga, acupuncture, guided imagery and abdominal massage.

CONCLUSIONS: We identified 12 components of nursing support for breathlessness in patients with cancer. The study results may be useful to understand the actual state of nursing support provided for breathlessness in patients with terminal cancer and to consider possible support that can be implemented.

Full text available online: <https://bmjopen.bmj.com/content/13/10/e075024>

Xerostomia in patients with advanced cancer: a scoping review of clinical features and complications

Authors: Walsh, M.; Fagan, N. and Davies, A.

Journal: BMC Palliative Care. (2023)

Abstract:

BACKGROUND: The aim of this project was to review the literature on dry mouth / xerostomia in patients with advanced cancer, with the objectives being to determine its prevalence, clinical features, and complications.

METHODS: Standard methodology was used to conduct this scoping review. Detailed searches of the Medline, Embase, CINAHL, and PsycInfo databases were conducted to identify relevant studies: eligible studies had to include patients with advanced cancer, and to contain details of clinical features and/or complications of xerostomia. Commercial bibliographic / systematic review software was used to support the process.

RESULTS: Forty-three studies were discovered from the database and hand searches. The studies included 23 generic symptom studies, eight "symptom cluster" studies, nine oral symptom / problem studies, and three xerostomia-specific studies. In depth data is described on the clinical features and complications of xerostomia, and on the "symptom clusters" including xerostomia, in this cohort of patients.

CONCLUSION: This review discovered a relatively small number of focused studies (involving a similarly small number of patients). Nonetheless, it demonstrates that xerostomia is a very common problem in patients with advanced cancer and is often associated with significant morbidity (and impairment of quality of life).

Full text available online: <https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-023-01276-4>

Technology

Virtual reality use and patient outcomes in palliative care: A scoping review

Authors: Moloney, M.; Doody, O.; O'Reilly, M., et al

Journal: Digital Health. (2023)

Abstract:

OBJECTIVE: Virtual reality is increasingly used in healthcare settings. Potentially, its use in palliative care could have a positive impact; however, there is limited evidence on the scope, purpose and patient outcomes relating to virtual reality use in this context. The objective of this scoping review is to chart the literature on virtual reality use in palliative care, identifying any evidence relating to biopsychosocial patient outcomes which could support its use in practice.

METHODS: A scoping review of the literature, involving a systematic search across 10 electronic bibliographic databases in December 2021. Eligibility criteria were primary research studies, of any research design within a 10-year timeframe, which reported on virtual reality use and patient outcomes in palliative care. A total of 993 papers were identified, and comprehensive screening resulted in 10 papers for inclusion.

RESULTS: This scoping review identified 10 papers addressing virtual reality in palliative care, published within a three-year timeframe 2019-2021. Research methodologies included mixed methods, quantitative and qualitative. The evidence highlights virtual reality use with patients receiving palliative care in a variety of settings, and data around usability, feasibility and acceptability is positive. However, the evidence regarding biopsychosocial patient outcomes linked to virtual reality use is limited.

CONCLUSION: Virtual reality is gathering momentum in palliative care and is potentially a helpful intervention; however more research is needed to underpin the evidence base supporting its application, particularly in understanding the impact on biopsychosocial patient outcomes and ascertaining the best approach for measuring intervention effectiveness.

Full text available online: <https://journals.sagepub.com/doi/10.1177/20552076231207574>

A Rapid Review of the Role of Virtual Reality in Care Delivery of Palliative Care and Hospice

Authors: Moutogiannis, P. P.; Thrift, J.; Pope, J. K., et al

Journal: Journal of Hospice and Palliative Nursing : JHPN : The Official Journal of the Hospice and Palliative Nurses Association. (2023)

Abstract:

Virtual reality (VR) is an emerging technology that can provide a nonpharmacological approach

to symptom management for those with serious illnesses. The VR platform offers a unique perspective to connect patients with places and experiences they might otherwise miss. This rapid review aims to present the current literature on the uses and benefits of VR for palliative care and hospice patients. Through a systematic process, we identified 14 articles published between 2018 and 2023 that used VR as an interventional strategy for symptom management. The VR equipment includes a head-mounted display, such as the Oculus Go, and sometimes requires hand controllers or joysticks. Virtual reality software was contained exclusively in the head-mounted displays or required a laptop. Nature scenes, memorable locations, and the solar system are examples of options patients could select for the VR experience. Assessments of the intervention were measured before, during, after, and several hours afterward to evaluate benefits and potential adverse effects. Pain was the predominant symptom assessed in the studies. Overall, most of the studies focused on establishing the safety, efficacy, and feasibility of VR using a single-arm interventional method. Future research should implement randomized controlled trials, increase sample size, and expand to pediatric populations.

Full text available via the library: <https://libkey.io/10.1097/NJH.0000000000000983>

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