

PALLIATIVE CARE BULLETIN

October 2023

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Carers

Caregiver experiences of hospice dementia care: a systematic review and meta-ethnography

Authors: Bosco, A.; Di Lorito, C.; Yang, Y., et al

Journal: Aging & Mental Health. (2023)

Abstract:

OBJECTIVES: Hospices are regarded as gold standard providers of end-of-life care. The term hospice, however, is broadly used, and can describe a type of care offered in a variety of health care services (e.g. nursing homes). It thus becomes complex for families to decide between services. We aimed to review the evidence around the experience of family carers of people with dementia accessing in-patient hospice settings for end-of-life care.

METHOD: We registered the review protocol on PROSPERO. We used PerSPE(C)TiF to systematically organise our search strategy. The evidence was reviewed across six databases: PubMed, EMBASE, PsycINFO, ASSIA, ISI Web, and CINAHL. We used meta-ethnography as per the eMERGe guidance for data interpretation.

RESULTS: Four studies were included. Two third-order constructs were generated through meta-ethnography: expectations of care and barriers to quality of care. We found that carers had expectations of care, and these could change over time. If discussion was not held with hospice staff early on, the carers could experience reduced care quality due to unmatched expectations. Unmatched expectations acted as barriers to care and these were found in terms of carers not feeling adequately supported, and/or having the person discharged from hospice, which would entail increased care responsibility for carers.

CONCLUSION: In view of an increase in new dementia cases over time and with hospice services being under pressure, integrating palliative care services within community-based models of care is key to reducing the risk of having inadequate and under resourced services for people with dementia.

Full text available via the library: <https://libkey.io/10.1080/13607863.2023.2241027>

Children

Are We on the Same Page? Exploring Pediatric Patients' Involvement With Advance Care Planning

Authors: Aasen, E. R. H. V.; Søvik, M. L.; Størdal, K. and Lee, A.

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

Abstract:

BACKGROUND: According to the UN Convention on the Rights of the Child, children have a right to be heard. This also applies to patients in pediatric palliative care (PPC). The aim of this

literature review was to explore what is known about the involvement of children (<14 years of age), adolescents and young adults (AYAs) in advance care planning (ACP) in PPC.

METHODS: A search was conducted in PubMed including publications from January 1, 2002 until December 31, 2021. The identified citations had to report on ACP or related terms in any PPC context.

RESULTS: A total of n = 471 unique reports were identified. Final inclusion criteria were met by n = 21 reports, including children and AYAs with diagnoses related to oncology, neurology, HIV/AIDS and cystic fibrosis. Nine reports were from randomized controlled studies, investigating ACP methodology. The main findings were: 1) caregivers are included more often than children and adolescents in ACP, 2) some studies indicate an incongruence between AYAs and their caregivers regarding ACP and treatment preferences, 3) although the process evokes a wide range of emotions, ACP is perceived as helpful by many AYAs

CONCLUSION: The majority of studies about ACP in PPC do not include children and AYAs.

Whether incongruence reported in some studies between AYAs and their caregivers regarding treatment preferences could be reduced by ACP should be further explored, including the involvement of children and adolescents in ACP, and the impact of pediatric ACP on patient outcomes in PPC.

Full text available online : [https://www.jpsmjournal.com/article/S0885-3924\(23\)00447-5/fulltext](https://www.jpsmjournal.com/article/S0885-3924(23)00447-5/fulltext)

An agenda to develop Pediatric Palliative care programs to serve children with life-threatening and life-limiting conditions in the Gulf Cooperation Council countries

Authors: Alotaibi, Q. and Siden, H.

Journal: Palliative Care and Social Practice. (2023)

Abstract: Medical advances have increased the number of children living with life-threatening/life-limiting illnesses worldwide, including in Gulf Cooperation Council (GCC) countries. Pediatric palliative care (PPC) is a relatively young subspecialty that cares for children with life-threatening/life-limiting illnesses and their families. PPC aims to alleviate physical, psychological, and social distress in children with life-threatening/life-limiting illnesses and their families and improve their quality of life. PPC is an essential service that should be implemented in all nations, as it is a human right. Moreover, a core value of PPC services is to alleviate children's suffering, irrespective of cure availability. Hence, the global consensus on palliative services must be universal and include developing countries with limited resources. While PPC services are growing internationally, the GCC countries have yet to implement these valuable services in the region. This work aims to define the local base information important to facilitating the PPC program. We explored and identified the information vital for establishing a successful program, which was then categorized and mapped into subgroups. In doing so, we outline a roadmap to facilitate the smooth introduction of PPC in GCC countries to benefit the

lives of children with life-limiting illnesses.

Full text available online: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10542219/>

Pediatric Palliative Care Program Implementation in LMICs: A Systematic Review using SWOT

Analysis

Authors: Kenneson, S. A.; Hughes-Visentin, A.; Wrigley, J., et al

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

Abstract:

CONTEXT: Of the estimated 21 million children world-wide who need access to pediatric palliative care (PPC), about 97% currently reside in low-and middle-income countries (LMIC). Access to PPC programs in LMIC are limited, and successful strategies and barriers to program implementation remain understudied.

OBJECTIVES: We conducted a systematic review to characterize the strengths, weaknesses, opportunities, and threats (SWOT) of PPC program implementation in LMIC.

METHODS: Using PRISMA guidelines, we searched key databases from inception to April 2022 and reviewed references manually. Eligible abstracts and articles included content related to composition, role, function, purpose, development, or implementation of PPC programs in LMIC.

RESULTS: From 7,846 titles and abstracts and 229 full-text articles, we identified 62 eligible abstracts and articles; 16 articles were added following manual searching of references, resulting in 78 items (28 abstracts, 50 articles). A total of 82 unique programs were described, including nine from low-income, 27 from lower-middle income, and 44 from upper-middle income countries. Common strengths included presence of multidisciplinary teams and psychosocial care. Common weaknesses included lack of PPC training and research infrastructure. Common opportunities involved collaboration between institutions, government support, and growth of PPC education. Common threats comprised limited access to PPC services, medications, and other resources.

CONCLUSION: PPC programs are being successfully implemented in resource limited settings. Hospice and palliative medicine organizations should sponsor PPC clinicians to describe and disseminate more detailed descriptions of successes and challenges with program implementation to help build and grow further PPC initiatives in LMICs.

Full text available via the library: <https://libkey.io/10.1016/j.jpainsymman.2023.06.032>

Communication

Interventions to Promote End-of-Life Conversations: A Systematic Review and Meta-Analysis

Authors: Gonella, S.; Dimonte, V.; Arnone, Y., et al

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

Abstract:

CONTEXT: Although several interventions aimed to promote end-of-life conversations are available, it is unclear whether and how these affect delivery of end-of-life conversations. Measuring the processes associated with high-quality end-of-life care may trigger improvement.

OBJECTIVES: To estimate the effect of interventions aimed to promote end-of-life conversations in clinical encounters with patients with advanced chronic or terminal illness or their family, on process indicators of end-of-life conversations.

METHODS: Systematic review with meta-analysis (PROSPERO no. CRD42021289471). Four databases (PubMed, CINAHL, PsycINFO, and Scopus) were searched up to September 30, 2021. The primary outcomes were any process indicators of end-of-life conversations. Results of pairwise meta-analyses were presented as Risk Ratio (RR) for occurrence, standardized mean difference (SMD) for quality and ratio of means (ROM) for duration. Meta-analysis was not performed when fewer than four studies were available.

RESULTS: A total of 4,663 articles were scanned. Eighteen studies were included in the systematic review and 16 entered at least one meta-analysis: documented occurrence (n = 8), patient-reported occurrence (n = 4), patient-reported-quality (n = 4), duration (n = 4). There was significant variability in settings, patients' clinical conditions, and professionals. No significant effect of interventions on documented occurrence (RR 1.54, 95% CI 0.84-2.84; I(2) 91%), patient-reported occurrence (RR 1.52, 95% CI 0.80-2.91; I(2) 95%), patient-reported quality (SMD 0.83, 95% CI -1.06 to 2.71; I(2) 99%), or duration (ROM 1.20, 95% CI 0.95-1.51; I(2) 65%) of end-of-life conversations was found. Data on frequency were conflicting. Interventions targeting multiple stakeholders promoted earlier and more comprehensive conversations.

CONCLUSION: Heterogeneity was considerable, but findings suggest no significant effect of interventions on occurrence, patient-reported quality and duration of end-of-life conversations. Nevertheless, we found indications for interventions targeting multiple stakeholders to promote earlier and more comprehensive conversations.

Full text available via the library: <https://libkey.io/10.1016/j.jpainsymman.2023.05.001>

Development of a Guide to Multidimensional Needs Assessment in the Palliative Care Initial Encounter (MAP)

Authors: Goni-Fuste, B.; Pergolizzi, D.; Monforte-Royo, C., et al

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

Abstract:

CONTEXT: Ensuring patient-centered palliative care requires a comprehensive assessment of needs beginning in the initial encounter. However, there is no generally accepted guide for carrying out this multidimensional needs assessment as a first step in palliative intervention.

OBJECTIVES: To develop an expert panel-endorsed interview guide that would enable proactive

and systematic Multidimensional needs Assessment in the Palliative care initial encounter (MAP).

METHODS: A preliminary version of the MAP guide was drafted based on a published literature review, published semistructured interviews with 20 patients, 20 family carers, and 20 palliative care professionals, and a nominal group process with palliative care professionals and a representative of the national patient's association. Consensus regarding its content was obtained through a modified Delphi process involving a panel of palliative care physicians from across Spain.

RESULTS: The published systematic literature review and qualitative study resulted in the identification of 55 needs, which were sorted and grouped by the nominal group. Following the Delphi process, the list of needs was reduced to 47, linked to six domains: Clinical history and medical conditions (n = 8), Physical symptoms (n = 17), Functional and cognitive status (n = 4), Psycho-emotional symptoms (n = 5), Social issues (n = 8), and Spiritual and existential concerns (n = 5).

CONCLUSION: MAP is an expert panel-endorsed semi-structured clinical interview guide for the comprehensive, systematic, and proactive initial assessment to efficiently assess multiple domains while adjusting to the needs of each patient. A future study will assess the feasibility of using the MAP guide within the timeframe of the palliative care initial encounter.

Full text available online: www.sciencedirect.com/science/article/pii/S0885392423005961

Barriers to and facilitators of advance care planning implementation for medical staff after the COVID-19 pandemic: an overview of reviews

Authors: Inokuchi, R.; Hanari, K.; Shimada, K., et al

Journal: BMJ Open. (2023)

Abstract:

OBJECTIVE: The COVID-19 pandemic has impacted the capacity for advance care planning (ACP) among patients, families and healthcare teams. We sought to identify and review the barriers to and facilitators of ACP implementation for medical staff in different settings (eg, hospitals, outpatient palliative care, nursing and care homes) during the pandemic.

DESIGN: This study employed an overview of reviews design. We searched the MEDLINE, CENTRAL, Web of Science and Embase databases for studies published between 8 December 2019 and 30 July 2023. We used AMSTAR 2 to assess the risk of bias.

RESULTS: We included seven reviews. Common barriers to ACP implementation included visitation restrictions, limited resources and personnel and a lack of coordination among healthcare professionals. In care and nursing homes, barriers included a dearth of palliative care physicians and the psychological burden on facility staff. Using telemedicine for information sharing was a common facilitator across settings. In hospitals, facilitators included short-term

training in palliative care and palliative care physicians joining the acute care team. In care and nursing homes, facilitators included ACP education and emotional support for staff.

CONCLUSIONS: Visitation restrictions and limited resources during the pandemic posed obstacles; however, the implementation of ACP was further hindered by insufficient staff education on ACP in hospitals and facilities, as well as a scarcity of information sharing at the community level. These pre-existing issues were magnified by the pandemic, drawing attention to their significance. Short-term staff training programmes and immediate information sharing could better enable ACP.

Full text available online: <https://bmjopen.bmj.com/content/13/10/e075969>

Motivational interviews to enhance advance care plans in older adults: systematic review

Authors: Wang, T.; Ho, M.; Xu, X., et al

Journal: BMJ Supportive & Palliative Care. (2023)

Full text available online: <https://spcare.bmj.com/content/early/2023/10/06/spcare-2023-004424>

Conditions

Multilevel Determinants of Palliative Care Referral in Women with Advanced Ovarian Cancer: A Scoping Review

Authors: Cho, S.; Goff, B. A. and Berry, D. L.

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

Abstract:

CONTEXT: Receipt of palliative care (PC) has long been suggested in practice for patients with advanced cancer for improved quality of life, mood, and prolonged survival. However, PC referrals in women with ovarian cancer remain suboptimal.

OBJECTIVE: To consolidate existing literature on the multiple factors associated with PC referrals in women with advanced ovarian cancer to better understand the contextual factors of PC referrals and frame receipt of PC using a socioecological model.

METHODS: A search of scientific databases was conducted, including PubMed, Embase, CINAHL Complete, and PsycINFO. Key search terms included "ovarian cancer" and "palliative care," and later refined to include advanced stages of the diagnosis. The reviewed articles included a focus on advanced ovarian cancer and reported demographic, medical/clinical, support, or system-level factors examined in the PC referral process.

RESULTS: Thirteen articles focused on the factors directly associated with PC referrals. Factors were categorized into different socioecological levels: tumor-level, intrapersonal, interpersonal, and environmental. Factors included tumor characteristics, age, marital status, medical condition, performance status, psychosocial status, support system, provider, and infrastructure.

The patient's medical condition was the major component considered in PC referral and care transition.

CONCLUSION: Various factors in the socioecological framework suggest that the decision for PC referral could be multifactorial and influenced by factors beyond the medical condition and status. Future research should aim to understand the impact of various socioecological factors on PC referral and examine PC referral experiences from the patient's perspective.

Full text available via the library: <https://libkey.io/10.1016/j.jpainsymman.2023.09.019>

Expanding the Paradigm for Cardiovascular Palliative Care

Authors: Godfrey, S.; Kirkpatrick, J. N.; Kramer, D. B. and Sulistio, M. S.

Journal: Circulation. (2023)

Abstract:

Cardiovascular disease (CVD) is the leading cause of death worldwide. Despite medical advances, patients with CVD experience high morbidity and mortality rates, affecting their quality of life and death. Among CVD conditions, palliative care has been studied mostly in patients with heart failure, where palliative care interventions have been associated with improvements in patient-centered outcomes, including quality of life, end-of-life care, and health care use.

Although palliative care is now incorporated into the American Heart Association/American College of Cardiology/Heart Failure Society of America guidelines for heart failure, the role of palliative care for non-heart failure CVD remains uncertain. Across all causes of CVD, palliative care can play an important role in all domains of CVD care from initial diagnosis to terminal care. In addition to general cardiovascular palliative care practices applicable to all areas, disease-specific palliative care needs may warrant individualized palliative care models. In this review, we discuss the role of cardiovascular palliative care for ischemic heart disease, valvular disease, arrhythmias, peripheral artery disease, and adult congenital heart disease. Although there are multiple barriers to cardiovascular palliative care, we recommend a framework for studying and developing cardiovascular palliative care models to improve patient-centered goal-concordant care for this underserved patient population.

Full text available via NHS OpenAthens:

<https://libkey.io/10.1161/CIRCULATIONAHA.123.063193>

Uncovering Methods and Outcomes of Palliative Care for Geriatric Patients: A Scoping Review

Authors: Haroen, H.; Harun, H.; Sari, C. W. M. and Witdiawati, W.

Journal: Journal of Multidisciplinary Healthcare. (2023)

Abstract:

BACKGROUND: Palliative care is an integral part of care for patients with life-limited diseases that focuses on reducing symptoms and maintaining and increasing the quality of life (QoL) for

patients and their families. Geriatric patients were more likely to receive palliative care and had unique needs compared to the general population. To improve the quality of palliative care, especially for geriatric patients, it is necessary to have a better understanding of methods and outcomes for geriatric patients when delivering palliative care.

OBJECTIVE: This study aims to identify the methods and outcomes of palliative care in geriatric patients across the globe.

METHODS: This scoping review was guided by Arksey and 'O Malley's framework and utilized the Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) checklist for providing transparent reporting to the readers. EBSCO, PubMed, and Scopus databases were used to search the relevant articles with a publication range of 2013-2023. Thematic analysis was used to identify and summarize palliative care methods and outcomes for geriatric patients in this review.

RESULTS: Twenty-one studies were included in this review, and it was found that there were many types of methods for delivering palliative care to geriatric patients. In both acute care settings and community settings, a wide range of methods for delivering palliative care to geriatric patients were identified. Outcomes of palliative care in geriatric patients in hospitals and community settings, were reduced pain, depressive symptoms and anxiety, edema, constipation, odds of in-hospital death, and increased spiritual well-being, QoL and well-being, being comfortable, patient readiness, place of death, sleep quality, and quality of dying.

CONCLUSION: Geriatric patients had a variety of methods and outcomes in palliative care. This study suggests that outcomes should be evaluated continuously after implementing methods for delivering palliative care to geriatric patients.

Full text available online: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10544005/>

Experience of Care Among Adults With Acute Leukemia Near the End of Life: A Scoping Review

Authors: Malakian, A.; Rodin, G.; Widger, K., et al

Journal: Journal of Palliative Medicine. (2023)

Abstract:

BACKGROUND: Acute leukemia is a cancer of the blood and bone marrow with a high symptom burden and a high mortality rate in adults. The quality of end-of-life care among this patient population is deemed to be low based on health care administrative data, though the patient experience is not included in this evaluation.

OBJECTIVE: This scoping review aims at exploring and mapping the current research literature on the experience of care among adults with incurable acute leukemia near the end of life.

DESIGN: The JBI framework guided our scoping review, and the protocol was prospectively registered in the Open Science Forum.

RESULTS: A total of 5661 unique articles were screened for title and abstract, and 44 were selected for full text. After a manual search, five studies published in seven articles were selected for data extraction, including three qualitative and two quantitative studies. Two studies used family caregivers as patient proxies, two studies engaged patients directly, whereas one study obtained data from patients and family caregivers. Patient care in acute settings was reported in all studies, with most patients dying in acute care settings. Patients and family caregivers often valued an open and honest approach, with sufficient time for dialogue with their providers. Discussions about prognosis, palliative care, and hospice care were often late or incomplete. The medicalization of end-of-life care, including intensive care unit admissions and invasive medical procedures, were viewed as the norm by some providers, though perceived as distressing for both patients and their loved ones.

CONCLUSIONS: Adults with acute leukemia face significant challenges in accessing high-quality end-of-life care brought about by the complex nature of their disease and its treatment. A systematic exploration of the end-of-life experience among these patients through direct patient engagement or by way of patient reporting proxies is needed.

Full text available via the library: <https://libkey.io/10.1089/jpm.2023.0130>

Access to palliative care in patients with advanced cancer of the uterine cervix in the low- and middle-income countries: a systematic review

Authors: Ooko, F.; Mothiba, T.; Van Bogaert, P. and Wens, J.

Journal: BMC Palliative Care. (2023)

Abstract:

BACKGROUND: Women with advanced uterine cervical cancer suffer from a combination of moderate to severe physical, psychological, social, and spiritual distress due to their disease and are in need of palliative care to improve their quality of life. Approximately 85% of the women live in the low- and middle-income countries. Whether these women and their families access palliative care is not known.

OBJECTIVES: To understand the geographic accessibility, availability, financial accessibility, and acceptability of palliative care by patients with advanced cervical cancer and their families.

METHODS: We conducted a Systematic review following PRISMA guidelines in CINAHL, Cochrane Central Register of Controlled Trials, MEDLINE, PsychINFO, PubMed and Scopus for the core concepts: palliative care, access, advanced uterine cervical cancer. Eligible articles were published in English, contained original data on experiences of patients and/or caregivers including symptoms management, and discussed available resources, communication, satisfaction, and healthcare utilization.

RESULTS: Overall there was limited access to palliative care with the few available facilities located in cities, far from the rural areas where most women lived. Pervasive poverty was

common with poor affordability of healthcare, travelling, accommodation, and subsistence expenses. Misconceptions and poor knowledge of the disease, cultural beliefs and attitudes, and other health system insufficiencies also presented challenges for access.

CONCLUSION: Concerted effort should be made to improve availability of palliative care facilities. Health education to address misconceptions and other cognitive barriers that limit access among cervical cancer patients and their families should be urgently undertaken in the LMICs.

Full text available online:

<https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-023-01263-9>

Incorporation of Palliative Care in Gynecologic Oncology

Authors: Persenaire, C.; Spinosa, D. L.; Brubaker, L. W. and Lefkowitz, C. J.

Journal: Current Oncology Reports. (2023)

Abstract:

PURPOSE OF REVIEW: This review serves to provide clarity on the nature, scope, and benefits of early palliative care integration into the management of patients with gynecologic malignancies.

RECENT FINDINGS: There is increased recognition that timely referral to palliative care improves quality of life for patients and their families by providing goal-concordant care that reduces physical and emotional suffering and limits futile and aggressive measures at the end of life. Palliative care services rendered throughout the continuum of illness ultimately increase engagement with hospice services and drive down health expenditures. Despite these myriad benefits, misconceptions remain, and barriers to and disparities in access to these services persist and warrant continued attention. Palliative care should be offered to all patients with advanced gynecologic cancers early in the course of their disease to maximize benefit to patients and their families.

Full text available online: <https://link.springer.com/article/10.1007/s11912-023-01457-7>

Consensus-based guidelines for the provision of palliative and end-of-life care for people living with epidermolysis bullosa

Authors: Popenhagen, M. P.; Genovese, P.; Blishen, M., et al

Journal: Orphanet Journal of Rare Diseases. (2023)

Abstract:

BACKGROUND: Inherited epidermolysis bullosa (EB) is a cluster of rare, genetic skin and mucosal fragility disorders with multi-system and secondary effects, in which blistering and erosions occur in response to friction/mechanical trauma. Considering the incurable and potentially life-limiting nature of the condition and the challenges posed by its symptoms, a palliative approach to EB-related care is necessary. However, knowledge and experience related

to the provision of EB palliative care is minimal. Evidence-based, best care guidelines are needed to establish a base of knowledge for practitioners to prevent or ease suffering while improving comfort at all stages of the illness, not just the end of life.

METHODS: This consensus guideline (CG) was begun at the request of DEBRA International, an international organization dedicated to improvement of care, research, and dissemination of knowledge for EB patients, and represents the work of an international panel of medical experts in palliative care and EB, people living with EB, and people who provide care for individuals living with EB. Following a rigorous, evidence-based guideline development process, the author panel identified six clinical outcomes based on the results of a survey of people living with EB, carers, and medical experts in the field, as well as an exhaustive and systematic evaluation of literature. Recommendations for the best clinical provision of palliative care for people living with EB for each of the outcomes were reached through panel consensus of the available literature.

RESULTS: This article presents evidence-based recommendations for the provision of palliative healthcare services that establishes a base of knowledge and practice for an interdisciplinary team approach to ease suffering and improve the quality of life for all people living with EB. Any specific differences in the provision of care between EB subtypes are noted.

CONCLUSIONS: Because there is yet no cure for EB, this evidence-based CG is a means of optimizing and standardizing the IDT care needed to reduce suffering while improving comfort and overall quality of life for people living with this rare and often devastating condition.

Full text available online: <https://ojrd.biomedcentral.com/articles/10.1186/s13023-023-02870-8>

Palliative Care in Neuro-oncology: an Update

Authors: Rhee, J. Y.; Strander, S.; Podgurski, A., et al

Journal: Current Neurology and Neuroscience Reports. (2023)

Abstract:

PURPOSE OF REVIEW: While the benefits of palliative care for patients with cancer are well established, palliative care in neuro-oncology is still in its early stages. However, in recent years, there has been increasing attention drawn to the need for better palliative care for patients with brain tumors.

RECENT FINDINGS: There is a growing body of literature demonstrating the high symptom burden and significant supportive care and information needs of these patients and their caregivers. In the area of caregiver needs, the last 3 years has seen a more rapid growth in recognizing and characterizing these needs. However, there remains a knowledge gap regarding the optimal means of addressing these needs. In this article, we outline important recent advances in the literature on palliative care for patients with brain tumors and highlight areas in need of greater attention and investigation.

Full text available via the library: <https://libkey.io/10.1007/s11910-023-01301-2>

An evidence-base for the implementation of hospital-based palliative care programs in routine cancer practice: A systematic review

Authors: Rizvi, F.; Wilding, H. E.; Rankin, N. M., et al

Journal: Palliative Medicine. (2023)

Abstract:

BACKGROUND: Despite global support, there remain gaps in the integration of early palliative care into cancer care. The methods of implementation whereby evidence of benefits of palliative care is translated into practice deserve attention.

AIM: To identify implementation frameworks utilised in integrated palliative care in hospital-based oncology services and to describe the associated enablers and barriers to service integration.

DESIGN: Systematic review with a narrative synthesis including qualitative, mixed methods, pre-post and quasi experimental designs following the guidance by the Centre for Reviews and Dissemination (PROSPERO registration CRD42021252092).

DATA SOURCES: Six databases searched in 2021: EMBASE, EMCARE, APA PsycINFO, CINAHL, Cochrane Library and Ovid MEDLINE searched in 2023. Included were qualitative or quantitative studies, in English language, involving adults >18 years, and implementing hospital-based palliative care into cancer care. Critical appraisal tools were used to assess the quality and rigour.

RESULTS: Seven of the 16 studies explicitly cited the use of frameworks including those based on RE-AIM, Medical Research Council evaluation of complex interventions and WHO constructs of health service evaluation. Enablers included an existing supportive culture, clear introduction to the programme across services, adequate funding, human resources and identification of advocates. Barriers included a lack of communication with the patients, caregivers, physicians and palliative care team about programme goals, stigma around the term 'palliative', a lack of robust training, or awareness of guidelines and undefined staff roles.

CONCLUSIONS: Implementation science frameworks provide a method to underpin programme development and evaluation as palliative care is integrated within the oncology setting.

Full text available online: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10548767/>

Palliative care interventions in chronic respiratory diseases: A systematic review

Authors: Santos, M. F. and Reis-Pina, P.

Journal: Respiratory Medicine. (2023)

Abstract:

INTRODUCTION: Chronic respiratory diseases represent a significant burden of disease globally, with high morbidity and mortality. Individuals living with these conditions, as well as their

families, face considerable physical, emotional and social challenges. Palliative care might be a valuable approach to address their complex needs, but evidence to prove this is still scarce.

OBJECTIVES: This systematic review aimed to study the effectiveness of palliative care interventions in health-related outcomes (quality of life, symptom control, symptom burden, psychological well-being, advance care planning, use of health services, and survival) in chronic respiratory patients.

METHODS: Pubmed, Cochrane and Web of Science were searched for trials published in the last 10 years, comparing palliative care interventions to usual care, in patients with chronic respiratory diseases. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines were followed.

RESULTS: Eight studies were included, seven randomized controlled trials and one cluster-controlled trial; the former with moderate risk of bias and the latter with high risk of bias. Findings revealed that palliative interventions improve breathlessness control and advance care planning. There were no significant differences for the other outcomes.

CONCLUSIONS: Palliative care appears to have a beneficial effect on breathlessness, one of the most distressing symptoms in patients suffering from chronic respiratory diseases and allows for advanced care planning. Additional research, with more robust trials, is needed to draw further conclusions about other health-related outcomes.

Full text available via the library: <https://libkey.io/10.1016/j.rmed.2023.107411>

Swallowing disorders and mortality in adults with advanced cancer outside the head and neck and upper gastrointestinal tract: a systematic review

Authors: Silva, D. N. M.; Vicente, L. C. C.; Glória, V. L. P. and de Lima Friche, A. A.

Journal: BMC Palliative Care. (2023)

Abstract:

BACKGROUND: Although oncological palliative care is increasingly being offered by multidisciplinary teams, there is still a lack of data about some symptoms handled by these teams, such as dysphagia, in patients with advanced cancer outside swallow regions. This study aimed to estimate the occurrence of dysphagia in prognosis studies of adults with advanced cancer outside the head, neck, and upper gastrointestinal tract, and to determine if there is an association with mortality.

METHODS: A systematic review of studies that evaluated dysphagia and mortality was conducted (PROSPERO: CRD42021257172). **DATA SOURCES:** BVS, PubMed, CINAHL, Web of Science, and Scopus. Data between 2011 and 2023 were selected.

RESULTS: Among the 608 articles screened, only 14 were included, which covered different types of cancer, primarily Lung, and Genitourinary, Skin, Hematological, and Central Nervous System as well. Dysphagia demonstrated a variable frequency, and almost half of the studies found a

percentage of dysphagia above 60%, appearing most as a symptom that affects health-related quality of life and prove to be a toxicity of treatment. The association between dysphagia and mortality was only evaluated in three articles that studied advanced lung cancer, in which, after controlling for covariates, swallowing disorders were associated with worse survival, with prevalences of dysphagia and hazard ratios of 78.5% (1.12 [1.04-1.20]), 4% (1.34 [1.28-1.35]), and 3% (1.40 [1.07-1.81]), respectively.

CONCLUSIONS: The occurrence of dysphagia in advanced cancer outside the head, neck, and upper GI tract is common, and there seems to be an association with significantly decreased survival in patients with advanced lung cancer.

Full text available online:

<https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-023-01268-4>

Performance of the Palliative Prognostic Index for cancer patients: A systematic review and meta-analysis

Authors: Yoong, S. Q.; Porock, D.; Whitty, D., et al

Journal: Palliative Medicine. (2023)

Abstract:

BACKGROUND: Clinician predicted survival for cancer patients is often inaccurate, and prognostic tools may be helpful, such as the Palliative Prognostic Index (PPI). The PPI development study reported that when PPI score is greater than 6, it predicted survival of less than 3 weeks with a sensitivity of 83% and specificity of 85%. When PPI score is greater than 4, it predicts survival of less than 6 weeks with a sensitivity of 79% and specificity of 77%. However, subsequent PPI validation studies have evaluated various thresholds and survival durations, and it is unclear which is most appropriate for use in clinical practice. With the development of numerous prognostic tools, it is also unclear which is most accurate and feasible for use in multiple care settings.

AIM: We evaluated PPI model performance in predicting survival of adult cancer patients based on different thresholds and survival durations and compared it to other prognostic tools.

DESIGN: This systematic review and meta-analysis was registered in PROSPERO (CRD42022302679). We calculated the pooled sensitivity and specificity of each threshold using bivariate random-effects meta-analysis and pooled diagnostic odds ratio of each survival duration using hierarchical summary receiver operating characteristic model. Meta-regression and subgroup analysis were used to compare PPI performance with clinician predicted survival and other prognostic tools. Findings which could not be included in meta-analyses were summarised narratively.

DATA SOURCES: PubMed, ScienceDirect, Web of Science, CINAHL, ProQuest and Google Scholar were searched for articles published from inception till 7 January 2022. Both retrospective and

prospective observational studies evaluating PPI performance in predicting survival of adult cancer patients in any setting were included. The Prediction Model Risk of Bias Assessment Tool was used for quality appraisal.

RESULTS: Thirty-nine studies evaluating PPI performance in predicting survival of adult cancer patients were included (n = 19,714 patients). Across meta-analyses of 12 PPI score thresholds and survival durations, we found that PPI was most accurate for predicting survival of 6 (pooled sensitivity = 0.68, 95% CI 0.60-0.75, specificity = 0.80, 95% CI 0.75-0.85). Survival prediction of 4 (pooled sensitivity = 0.72, 95% CI 0.65-0.78, specificity = 0.74, 95% CI 0.66-0.80). Comparative meta-analyses found that PPI performed similarly to Delirium-Palliative Prognostic Score and Palliative Prognostic Score in predicting 4 (pooled sensitivity = 0.72, 95% CI 0.65-0.78, specificity = 0.74, 95% CI 0.66-0.80). Comparative meta-analyses found that PPI performed similarly to Delirium-Palliative Prognostic Score and Palliative Prognostic Score in predicting 4 (pooled sensitivity = 0.72, 95% CI 0.65-0.78, specificity = 0.74, 95% CI 0.66-0.80). Comparative meta-analyses found that PPI performed similarly to Delirium-Palliative Prognostic Score and Palliative Prognostic Score in predicting 4 (pooled sensitivity = 0.72, 95% CI 0.65-0.78, specificity = 0.74, 95% CI 0.66-0.80). Comparative meta-analyses found that PPI performed similarly to Delirium-Palliative Prognostic Score and Palliative Prognostic Score in predicting 6 should be used for 4 for <6-week survival. PPI is easily scored and does not require invasive tests, and thus would be easily implemented in multiple care settings. Given the acceptable accuracy of PPI in predicting <3- and <6-week survival and its objective nature, it could be used to cross-check clinician predicted survival especially when clinicians have doubts about their own judgement, or when clinician estimates seem to be less reliable. Future studies should adhere to the reporting guidelines and provide comprehensive analyses of PPI model performance.

Full text available via the library: <https://libkey.io/10.1177/02692163231180657>

COVID-19

Palliative care for cancer patients during the COVID-19 pandemic: A narrative synthesis from 36 studies of 16 countries

Authors: Zhao, D.; Hu, S.; Hu, F., et al

Journal: Journal of Clinical Nursing. (2023)

Abstract:

BACKGROUND: During the COVID-19 epidemic, palliative care has become even more indispensable for cancer patients. **AIM:** To identify the changes in palliative care for cancer patients and improvements in palliative care quality during the COVID-19 pandemic.

DESIGN: A systematic review and narrative synthesis was conducted in PubMed, Embase and Web of Science. An evaluation tool using mixed methods was used to assess the quality of the

study. The main relevant themes identified were used to group qualitative and quantitative findings.

RESULTS: A total of 36 studies were identified, primarily from different countries, with a total of 14,427 patients, 238 caregivers and 354 health care providers. Cancer palliative care has been experiencing several difficulties following the COVID-19 pandemic, including increased mortality and infection rates as well as delays in patient treatment that have resulted in poorer prognoses. Treatment providers are seeking solutions such as electronic management of patients and integration of resources to care for the mental health of patients and staff. Telemedicine plays an important role in many ways but cannot completely replace traditional treatment. Clinicians strive to meet patients' palliative care needs during special times and improve their quality of life.

CONCLUSIONS: Palliative care faces unique challenges during the COVID-19 epidemic. With adequate support to alleviate care-related challenges, patients in the home versus hospital setting will be able to receive better palliative care. In addition, this review highlights the importance of multiparty collaboration to achieve personal and societal benefits of palliative care.

Full text available via the library: <https://libkey.io/10.1111/jocn.16742>

Equality and diversity

Matters of care and the good death - rhetoric or reality?

Authors: Collier, A. and Chapman, M.

Journal: Current Opinion in Supportive and Palliative Care. (2023)

Abstract:

PURPOSE OF REVIEW: The notion of a 'good death' is central to hospice and palliative care philosophy. This review interrogates social imaginaries of the 'good death' in the context of current global, health and sociopolitical challenges.

RECENT FINDINGS: Research literature and policy documents across fields continue to place emphasis on the 'good death'. As part of the equity turn in palliative care, there is a growing body of work highlighting the diverse perspectives of people whose voices were heretofore not understood. Inequities are evident not only in terms of who has access to a 'good death' but also related to the effects of the dominant 'good death' script itself.

SUMMARY: There is increasing evidence that pursuit of the 'good death' narrative may be counter to supporting people as they are living and dying. The authors instead argue for a research, policy and practice shift to 'matters of care'.

Full text available via the library: <https://libkey.io/10.1097/SPC.0000000000000663>

How do cultural factors influence the provision of end-of-life care? A narrative review

Authors: Glyn-Blanco, M. B.; Lucchetti, G. and Badanta, B.

Journal: Applied Nursing Research : ANR. (2023)

Abstract:

BACKGROUND: Culture influences the way in which patients, families and professionals provide care and undergo decision-making at the end of life.

OBJECTIVE: Therefore, our research questions were: How do cultural aspects influence the needs, perceptions, and experiences of patients and their families in end-of-life care? What implications does cultural diversity have for professionals who care for individuals at the end of life?

METHODS: A narrative review was conducted between June and July 2022. Articles published between 2017 and 2022 in peer-reviewed journals were included.

RESULTS: A total of 43 studies were included. Our findings were grouped into four themes: 1) places to die and preferences about healthcare interventions (e.g. parts of the immigrant population tend to receive more aggressive and invasive interventions); 2) advance care planning and verbalization of death (e.g. less use of ACP in some minority groups); 3) rituals and family involvement during healthcare; 4) professionals addressing multiculturalism in care at the end of life (e.g. lack of training in addressing the context of multiculturalism).

CONCLUSIONS: These findings could contribute to making professionals more aware of cultural aspects that influence the process of death and highlight the need for further training in the handling of such situations.

Full text available online:

<https://www.sciencedirect.com/science/article/pii/S089718972300054X>

Families

Memory making in critical care: A qualitative thematic synthesis

Authors: MacEachen, D.; Johnston, B. and McGuire, M.

Journal: Nursing in Critical Care. (2023)

Abstract:

BACKGROUND: Caring for bereaved families is an important aspect of the nursing role in critical care. Memory making practices are one way in which dying, death and bereavement can be acknowledged and supported within critical care. Memory making was introduced into the care of stillborn babies and neonatal deaths to improve parents' experiences of bereavement, and has since become common practice in adult critical care.

AIMS: The aim of this qualitative thematic synthesis was to explore families' experiences of memory making in critical care, with a view of gaining greater understanding of the ways in which memory making impacts bereaved families.

METHODS: A systematic search strategy was developed, and five databases were searched (Medline, CINAHL, PsychINFO, Embase and ASSIA). Seven qualitative studies were included: four were conducted in adult and three in paediatric critical care settings in which memory making was initiated between 2014 and 2020. Memory making practices included, patient diaries, general keepsakes, word clouds and photography.

RESULTS: The thematic synthesis generated four main themes to describe families' experience of memory making in critical care: 'connection', 'compassion', 'engagement and creation' and 'continuation'.

CONCLUSIONS: Memory making is a meaningful activity for families whose loved one dies in critical care; it brings focus and meaning during a devastating process in a highly technical environment. Families rely heavily on nursing staff for support and guidance. The creation of memories and/or keepsakes can have a positive impact on the bereavement experience for families and can facilitate a continuing bond with their loved one.

RELEVANCE TO CLINICAL PRACTICE: Memory making is a worthwhile practice to support and guide family bereavement within critical care. It can provide structure and purpose during an emotionally challenging transition, by supporting families to focus on a meaningful activity during a devastating time.

Full text available online: <https://onlinelibrary.wiley.com/doi/10.1111/nicc.12983>

Guidelines and recommendations

A Core Outcome Set for Interventions to Prevent and/or Treat Delirium in Palliative Care

Authors: Bryans, A.; Siddiqi, N.; Burry, L., et al

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

Abstract:

CONTEXT: Delirium is a serious neurocognitive syndrome which is highly prevalent in people approaching the end of life. Existing trials of interventions to prevent or treat delirium in adults receiving palliative care report heterogeneous outcomes.

OBJECTIVES: To undertake an international consensus process to develop a core outcome set for trials of interventions, designed to prevent and/or treat delirium, for adults receiving palliative care.

METHODS: The core outcome set development process included a systematic review, qualitative interviews, modified Delphi method and virtual consensus meetings using nominal group

technique. Participants included family members, clinicians, and researchers with experience of delirium in palliative care.

RESULTS: Forty outcomes were generated from the systematic review and interviews informing the Delphi Round one survey. The international Delphi panel comprised 92 participants including clinicians (n = 71, 77%), researchers (n = 13, 14%), and family members (n = 8, 9%). Delphi Round two was completed by 77 (84%) participants from Round one. Following the consensus meetings, four outcomes were selected for the core outcome set: 1) delirium occurrence (incidence and prevalence); 2) duration of delirium until resolution defined as either no further delirium in this episode of care or death; 3) overall delirium symptom profile (agitation, delusions or hallucinations, delirium symptoms and delirium severity); 4) distress due to delirium (person with delirium, and/or family and/or carers [including healthcare professionals]).

CONCLUSION: Using a rigorous consensus process, we developed a core outcome set comprising four delirium-specific outcomes for inclusion in future trials of interventions to prevent and/or treat delirium in palliative care.

Full text available via : <https://www.sciencedirect.com/science/article/pii/S0885392423005213>

Recommendations on palliative care aspects in intensive care medicine

Authors: Michels, G.; Schallenburger, M.; Neukirchen, M. and ICU Palliative Study Group

Journal: Critical Care (London, England). (2023)

Abstract:

BACKGROUND: The timely integration of palliative care is important for patients suffering from various advanced diseases with limited prognosis. While a German S-3-guideline on palliative care exists for patients with incurable cancer, a recommendation for non-oncological patients and especially for integration of palliative care into intensive care medicine is missing to date.

METHOD: Ten German medical societies worked on recommendations on palliative care aspects in intensive care in a consensus process from 2018 to 2023.

RESULTS: Based on the German consensus paper, the palliative care aspects of the respective medical disciplines concerning intensive care are addressed. The recommendations partly refer to general situations, but also to specific aspects or diseases, such as geriatric issues, heart or lung diseases, encephalopathies and delirium, terminal renal diseases, oncological diseases and palliative emergencies in intensive care medicine. Measures such as non-invasive ventilation for symptom control and compassionate weaning are also included.

CONCLUSION: The timely integration of palliative care into intensive care medicine aims to improve quality of life and symptom control and also takes into account the often urgently needed support for patients' highly stressed relatives.

Full text available online: <https://ccforum.biomedcentral.com/articles/10.1186/s13054-023-04622-3>

Medicines and treatments

Radiotherapy of orbital metastases: a systematic review of management and treatment outcomes on behalf of palliative care study group of Italian association of radiotherapy and clinical oncology (AIRO)

Authors: Pezzulla, D.; Di Franco, R.; Zamagni, A., et al

Journal: The British Journal of Radiology. (2023)

Abstract:

OBJECTIVES: We search the current literature on data regarding the role of RT in OM treatment, focusing on the improvement of symptoms and patient quality of life.

METHODS: This systematic review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) recommendations.

RESULTS: From 340 citations, 60 papers were finally selected: 45 case reports and 15 case series. The case reports accounted for 47 patients. In 37/39 cases (95%), EBRT was done. Patients were mainly treated with 3DCRT, IMRT, and with SBRT. The most used RT regimens were 30 Gy in 10 fractions (23%) and 20-25 Gy in 5 fx (13%). No severe toxicity was reported. A median LC of 11 months (range 1-54 months) and a median OS of 12 months (range 1-54 months) were registered. Among the case series, a total of 457 patients were examined, 227 of whom underwent RT. The main used techniques were 3DCRT, CK, GK, SBRT, and BRT. RT doses could vary from 30 Gy/10 fractions to 60 Gy/30 fractions, 50 Gy/5 fractions, or 16.5-21 Gy in single fraction. No toxicity above G2 was reported. ORR could vary between 75 and 100%. Only two study provided information on response duration: a mean LC time of 22.8 months and a mean time to local progression of 5 months (range: 3-7). Regarding OS, the data were heterogeneous, ranging between 1 and 54 months.

CONCLUSIONS: RT for OM seems to be a safe and feasible option. More information on the RT ideal techniques and dose are still needed.

ADVANCES IN KNOWLEDGE: This paper tried to sum up the few and fragmented data on the use of radiotherapy for orbital metastases: the possible option ranged from 3D- and 2D-CRT to SBRT, CK, and GK, with different possible fractionations (30Gy in 10 fractions, 60 Gy/30 fractions, 20-50 Gy/5 fractions, or 16.5-21 Gy in single fraction). Regardless of the chosen approach, almost all treated patients experienced a benefit after RT in terms of OM-related symptom intensity reduction and a good acute and late toxicity profile.

Full text available via the library: <https://libkey.io/10.1259/bjr.20230124>

Complications of Central Venous Access Devices Used in Palliative Care Settings for Terminally Ill Cancer Patients: A Systematic Review and Meta-Analysis

Authors: Wong, C. C.; Choi, H. C. and Lee, V. H.

Journal: Cancers. (2023)

Abstract:

BACKGROUND: Central venous access devices (CVADs) have been commonly employed during various courses of anticancer treatment. Currently, there are a few types of clinically available CVADs, which are associated with short-term and long-term complications. However, little is known about the complication rates when CVADs are used only in palliative care settings. We therefore performed a systematic review and meta-analysis of all the published literature to evaluate the complication rates of CVADs in this clinical setting.

METHODS: A systematic review and meta-analysis were conducted to identify publications from PubMed/MEDLINE, Embase (Ovid), Scopus, Cochrane Library, CINAHL, Google Scholar, and trial registries. Publications reporting the complication rates of PICCs, central lines, and PORTs in palliative settings for terminally ill cancer patients were included, while those on the use of systemic anticancer therapy and peripheral venous catheters were excluded. The outcome measures included overall complication rate, rate of catheter-related bloodstream infection (CRBSI), and rate of thromboembolism (TE). This systematic review was registered with PROSPERO (CRD42023404489).

RESULTS: Five publications with 327 patients were analyzed, including four studies on PICCs and one study on central lines. No studies on PORTs were eligible for analysis. The overall complication rate for PICCs (pooled estimate 7.02%, 95% CI 0.27-19.10) was higher than that for central lines (1.44%, 95% CI 0.30-4.14, $p = 0.002$). The risk of CRBSI with PICCs (2.03%, 95% CI 0.00-9.62) was also higher than that with central lines (0.96%, 95% CI 0.12-3.41, $p = 0.046$). PICCs also had a trend of a higher risk of TE (2.10%, 95% CI 0.00-12.22) compared to central lines (0.48%, 95% CI 0.01-2.64, $p = 0.061$).

CONCLUSIONS: PICCs for palliative cancer care were found to have greater complications than central lines. This might aid in the formulation of future recommendation guidelines on the choice of CVAD in this setting.

Full text available online: <https://www.mdpi.com/2072-6694/15/19/4712>

Patient experience

Patients' perception of hope in palliative care: A systematic review and narrative synthesis

Authors: Velić, S.; Qama, E.; Diviani, N. and Rubinelli, S.

Journal: Patient Education and Counseling. (2023)

Abstract:

OBJECTIVE: The aim of this study was to systematically review and synthesize the literature on patients' perceptions of hope in palliative care.

METHODS: PubMed, Scopus, SocINDEX, Cochrane, and Web of Science were screened against the eligibility criteria. After familiarization with the data and conduction of the coding process, studies were thematically analyzed using Braun and Clarke's methodology. The research question guiding our analysis was: what is said about hope from patients in PC?

RESULTS: The database searches yielded 24 eligible studies. Three main themes emerged from the studies: Hope beliefs (encompassing patients' understanding of hope and characteristics assigned to it), Hope functions (including the role that hope plays for patients) and Hope work (highlighting aspects that in patients' perspective cultivate hope).

CONCLUSION: This review emphasizes the importance of acknowledging patients' understanding of hope, its role, and the efforts required to sustain it. In particular, it suggests that hope serves as a valuable strategy, fostering meaningful personal relationships towards end of life.

PRACTICE IMPLICATIONS: In order to address communication challenges in clinical practice, a potential fruitful strategy for nurturing hope could involve engaging family and friends in hope interventions facilitated by healthcare professionals.

Full text available online:

<https://www.sciencedirect.com/science/article/pii/S0738399123002598>

Place of care

Easing Suffering for ICU Patients and Their Families: Evidence and Opportunities for Primary and Specialty Palliative Care in the ICU

Authors: Doherty, C.; Feder, S.; Gillespie-Heyman, S. and Akgün, K. M.

Journal: Journal of Intensive Care Medicine. (2023)

Abstract:

Intensive care unit (ICU) admissions are often accompanied by many physical and existential pressure points that can be extraordinarily wearing on patients and their families and surrogate decision makers (SDMs). Multidisciplinary palliative support, including physicians, advanced practice nurses, nutritionists, chaplains and other team members, may alleviate many of these sources of potential suffering. However, the palliative needs of ICU patients undoubtedly exceed the bandwidth of current consultative specialty palliative medicine teams. Informed by standard-of-care palliative medicine domains, we review common ICU symptoms (pain, dyspnea and thirst) and their prevalence, sources and their treatment. We then identify palliative needs and impacts in the domains of communication, SDM support and transitions of care for patients and their families through their journey in the ICU, from discharge and recovery at home to chronic

critical illness, post-ICU disability or death. Finally, we examine the evidence for strategies to incorporate specialty palliative medicine and palliative principles into ICU care for the improvement of patient- and family-centered care. While randomized controlled studies have failed to demonstrate measurable improvement in pre-determined outcomes for patient- and family-relevant outcomes, embracing the principles of palliative medicine and assuring their delivery in the ICU is likely to translate to overall improvement in humanistic, person-centered care that supports patients and their SDMs during and following critical illness.

Full text available via the library: <https://libkey.io/10.1177/08850666231204305>

A Rapid Review of Uses and Outcomes of Telehealth Care in Rural and Remote Regions in the United States

Authors: Fasolino, T.; Koci, A.; Huggins, J. and Lindell, K.

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

Abstract:

As telehealth expands and becomes an increasingly important provision of palliative care and hospice services, the understanding of the uses and outcomes of this care delivery platform in rural communities is warranted. This rapid review aims to highlight the practice, policy, and research implications of telehealth in rural regions. Using a systematic approach for accessing and synthesizing available publications, this review included 22 articles published between January 2020 and January 2023. Telehealth was used with adult and pediatric populations diagnosed with serious illnesses. Acceptance of this type of care delivery was noted in adults and children, but not all found telehealth a valuable mechanism for care. Telehealth services included but were not limited to direct communication between the provider and the patient/caregiver, medication management, and a peer-to-peer consultant role for rural palliative care and hospice teams. Of those studies addressing provider-centered outcomes, noise level, interruptions, missed appointments, and challenges with providing emotional support were reported. Organizational barriers, such as the lack of financial support, were noted for pediatric hospices. Individuals living in rural communities require more frequent, immediate, and specialized attention over their illness trajectory. Practice, policy, and research implications are identified to consider the next steps for telehealth delivery of palliative care.

Full text available via the library: <https://libkey.io/10.1097/NJH.0000000000000964>

The effectiveness of community-based palliative care programme components: a systematic review

Authors: Hughes, M. C.; Vernon, E. and Hainstock, A.

Journal: Age and Ageing. (2023)

Abstract:

BACKGROUND: There is evidence that community-based palliative care programmes can improve patient outcomes and caregiver experiences cost-effectively. However, little is known about which specific components within these programmes contribute to improving the outcomes.

AIM: To systematically review research that evaluates the effectiveness of community-based palliative care components.

DESIGN: A systematic mixed studies review synthesising quantitative, qualitative and mixed-methods study findings using Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines. PROSPERO: ID # CRD42022302305.

DATA SOURCES: Four databases were searched in August 2021 (CINAHL, Web of Science, ProQuest Federated and PubMed including MEDLINE) and a close review of included article references. Inclusion criteria required articles to evaluate a single, specific component of a community-based palliative care programme either within an individual programme or across several programmes.

RESULTS: Overall, a total of 1,674 articles were identified, with 57 meeting the inclusion criteria. Of the included studies, 21 were qualitative, 25 were quantitative and 11 had mixed methods. Outcome measures consistently examined included patient/caregiver satisfaction, hospital utilisation and home deaths. The components of standardised sessions (interdisciplinary meetings about patients), volunteer engagement and early intervention contributed to the success of community-based palliative care programmes.

CONCLUSIONS: Certain components of community-based palliative care programmes are effective. Such components should be implemented and tested more in low- and middle-income countries and key and vulnerable populations such as lower-income and marginalised racial or ethnic groups. In addition, more research is needed on the cost-effectiveness of individual programme components.

Full text available online: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10517647/>

Quality of health care

Challenges and opportunities for improvement when people with an intellectual disability or serious mental illness also need palliative care: A qualitative meta-ethnography

Authors: Ashok, N.; Hughes, D. and Yardley, S.

Journal: Palliative Medicine. (2023)

Abstract:

BACKGROUND: People with diagnoses of intellectual disability or serious mental illness have higher mortality rates due to physical comorbidities; better understanding is needed to guide best practice in provision of palliative care for these populations.

AIMS: To identify multivoiced perspectives, drawn from lived experience of: what works, and what does not, in palliative care for people with intellectual disability or serious mental illness; challenges in, and opportunities to improve, palliative care.

DESIGN: A systematically constructed qualitative meta-ethnography. Protocol published (PROSPERO: CRD42021236616).

DATA SOURCES: MEDLINE, PsychINFO, CINAHL PLUS and Embase used without date limitations. Papers published in English, containing qualitative data on palliative care provision for people with a diagnosis of intellectual disability or serious mental illness were included. Global five-point strength score applied for relevance/quality appraisal.

RESULTS: Familiarity (of location, people and/or things) is important for good palliative care. Assumptions and misunderstandings about the role of mental capacity assessment to appropriately involve the patient in decision-making are common. Adapting training for palliative care staff to address concerns and beliefs about mental illness is one of the methods that helps avoid diagnostic overshadowing. Proactive identification of service arrangements to meet needs of persons with personality, psychotic, delusional and bipolar affective disorders will help optimise care.

CONCLUSIONS: Evidence, including the voices of people with intellectual disability or serious mental illness is urgently needed to guide efforts to improve their access to and experience of palliative care. More evidence is especially needed to understand, develop and implement best practice for people with psychosis, bipolar affective disorder, mania and personality disorder.

Full text available online: <https://journals.sagepub.com/doi/full/10.1177/02692163231175928>

Validated medication deprescribing instruments for patients with palliative care needs a systematic review

Authors: de Andrade, F. K.; Nunes, R. P. I.; Zanetti, M. O. B., et al

Journal: Farmacia Hospitalaria : Organo Oficial De Expresion Cientifica De La Sociedad Espanola De Farmacia Hospitalaria. (2023)

Abstract:

OBJECTIVES: Patients with life-limiting illnesses are prone to unnecessary polypharmacy. Deprescribing tools may contribute to minimizing negative outcomes. Thus, the aims of the study were to identify validated instruments for deprescribing inappropriate medications for patients with palliative care needs and to assess the impact on clinical, humanistic, and economic outcomes.

METHODS: A systematic review was conducted in LILACS, PUBMED, EMBASE, COCHRANE, and WEB OF SCIENCE databases (until May 2021). A manual search was performed in the references of enrolled articles. The screening, eligibility, extraction, and bias risk assessment were carried

out by 2 independent researchers. Experimental and observational studies were eligible for inclusion.

RESULTS: Out of the 5791 studies retrieved, after excluding duplicates (n = 1050), conducting title/abstract screening (n = 4741), and full reading (n = 41), only 1 study met the inclusion criteria. In this included study, a randomized controlled trial was conducted, which showed a high level of bias risk overall. Adults 75 years or older (n = 130) with limited life expectancy and polypharmacy were allocated to 2 groups [intervention arm (deprescribing); and control arm (usual care)]. Deprescribing was performed with the aid of the STOPPFrail tool. The mean number of inappropriate medications and monthly medication costs were significantly lower in the intervention arm. No statistically significant differences were found in terms of unscheduled hospital presentations, falls, fractures, mortality, and quality of life.

CONCLUSIONS: Despite the availability of several instruments to support deprescribing in patients with palliative care needs, only 1 of them has undergone validation and robust assessment for effectiveness in clinical practice. The STOPPFrail tool appears to reduce the number of inappropriate medications for older people with limited life expectancy (and probably palliative care needs) and decrease the monthly costs of pharmacotherapy. Nevertheless, the impact on patient safety and humanistic outcomes remain unclear.

Full text available online:

<https://www.sciencedirect.com/science/article/pii/S1130634323001253>

Documentation of Sedation in Palliative Care: A Scoping Review of Requirements,

Recommendations, and Templates

Authors: Kauzner, S.; Heckel, M.; Ostgathe, C., et al

Journal: Journal of Palliative Medicine. (2023)

Abstract:

OBJECTIVE: To identify and describe requirements, recommendations, and templates for the documentation of sedation in adult palliative care. **Introduction:** International literature shows inconsistency in clinical practice regarding sedation in palliative care accompanied by legal, ethical, and medical uncertainties. Documentation in general serves as proof for previous treatments. In the context of intentional sedation to relieve suffering at the end of life, documentation provides a clear demarcation against practices of euthanasia.

INCLUSION CRITERIA: Articles with full-text version published in English or German since 2000, covering documentation requirements, recommendations, monitoring parameters or templates for sedation in adult palliative care were included.

METHODS: Scoping review following the JBI methodology. Search in online databases, websites of professional associations in palliative care, reference lists of relevant publications, the archive of the German "Journal of Palliative Medicine" and databases for unpublished literature were

used. Search terms included "palliative care," "sedation," and "documentation." The search was conducted from January 2022 to April 2022 with an initial hand search in November 2021. Data were screened and charted by one reviewer after conducting a pilot test of the criteria.

RESULTS: From the initial 390 articles (database search), 22 articles were included. In addition, 15 articles were integrated from the hand search. The results can be clustered in two sets of items, regarding either the documentation before or during sedation. The documentation requirements referred both to inpatient and homecare settings but in many cases, a clear assignment was missing.

CONCLUSIONS: The guidelines analyzed in this study rarely cover setting-specific differences in documentation and often treat documentation as minor topic. Further research is needed addressing legal and ethical concerns of health care teams and, therefore, help to improve treatment of patients suffering from otherwise intractable burden at the end of life.

Full text available via the library: <https://libkey.io/10.1089/jpm.2022.0476>

Barriers for adult patients to access palliative care in hospitals: A mixed methods systematic review

Authors: Pitzer, S.; Kutschar, P.; Paal, P., et al

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

Abstract:

BACKGROUND: Access to palliative care services is variable, and many inpatients do not receive palliative care. An overview of potential barriers could facilitate the development of strategies to overcome factors that impede access for patients with palliative care needs.

AIM: To review the current evidence on barriers that impair, delay, or prohibit access to palliative care for adult hospital inpatients.

DESIGN: A mixed methods systematic review was conducted using an integrated convergent approach and thematic synthesis (PROSPERO ID: CRD42021279477).

DATA SOURCES: The Cochrane Library, MEDLINE, CINAHL, and PsycINFO were searched from 10/2003 to 12/2020. Studies with evidence of barriers for inpatients to access existing palliative care services were eligible and reviewed.

RESULTS: After an initial screening of 3,359 records and 555 full-texts, 79 studies were included.

Thematic synthesis yielded 149 access-related phenomena in 6 main categories: (1)

Sociodemographic characteristics, (2) Health-related characteristics, (3) Individual beliefs and attitudes, (4) Inter-individual cooperation and support, (5) Availability and allocation of resources, and (6) Palliative care-specific challenges. While evidence was inconclusive for most socio-demographic factors, the following barriers emerged: having a non-cancer condition or a low symptom burden, the focus on cure in hospitals, non-acceptance of terminal prognosis, negative perceptions of palliative care, misleading communication and conflicting care preferences, lack

of resources, poor coordination, insufficient expertise, and clinicians' emotional discomfort and difficult prognostication.

CONCLUSION: Hospital inpatients face multiple barriers to accessing palliative care. Strategies to address these barriers need to take into account their multidimensionality and long-standing persistence.

Full text available online:

<https://www.sciencedirect.com/science/article/pii/S0885392423006826>

Spiritual and psychological care

Effectiveness of dignity therapy in the context of culturally competent care in people with palliative care needs: a systematic review of systematic reviews

Authors: Johnston, B.; Dönmez, C. F. and Julião, M.

Journal: Current Opinion in Supportive and Palliative Care. (2023)

Abstract:

PURPOSE OF REVIEW: This review aims to synthesise the evidence from systematic reviews and meta-analyses on the efficacy of dignity therapy (DT) in relation to psychosocial and spiritual outcomes in the context of person-centred and culturally competent care for people with supportive and palliative care needs.

RECENT FINDINGS: Thirteen reviews were found, including seven conducted by nurses. Most reviews were of high quality, including various study populations such as cancer, motor neurone disease and non-malignant conditions. Six psychosocial and spiritual outcomes were identified: quality of life, anxiety, depression, hopefulness, meaning and purpose in life, and suffering based on the cultural variations in the implementation of DT.

SUMMARY: DT has a positive impact on anxiety, depression, suffering, and meaning and purpose in life for people with palliative care needs, but the evidence is somewhat conflicted as to whether DT is effective in improving hope, quality of life and spiritual outcomes in the context of culturally competent care. Nurse-led DT seems desirable given its pivotal role when caring for people with palliative care needs. More randomised controlled trials should be conducted for people with different cultural backgrounds to provide person-centred, culturally competent supportive and palliative care.

Full text available via the library: <https://libkey.io/10.1097/SPC.0000000000000664>

Staff

Compassion fatigue in the community nursing workforce: a scoping review

Authors: Adia, R.

Journal: British Journal of Community Nursing. (2023)

Abstract:

BACKGROUND: compassion fatigue is a phenomenon in areas of nursing practice such as oncology, ICU, palliative care, hospice, and dementia care, but less so among community nurses (Joinson, 1992). A gap in enquiry exists around CN and compassion fatigue around end-of-life patient care.

METHODS: a scoping review with narrative analysis of selected literature on compassion fatigue in nursing using CINAHL, ProQuest, Science Direct, and the Cochrane Library.

FINDINGS: whilst no specific studies were located on compassion fatigue and UK community nurses. Australian, Spanish, and Taiwanese studies report of environment, care relationship duration, resources and poor organisational support being linked to a likelihood of developing compassion fatigue.

CONCLUSION: compassion fatigue is under-researched in community nursing and merits further enquiry to understand the challenges posed by providing end-of-life care.

Full text available via NHS OpenAthens: <https://libkey.io/10.12968/bjcn.2023.28.9.456>

Education About Specialty Palliative Care Among Non-Healthcare Workers: A Systematic Review

Authors: Smith, G. M.; Singh, N.; Hui, F., et al

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

Abstract:

CONTEXT: Despite the expansion of palliative care (PC) services, the public has little knowledge and holds misperceptions about PC, creating barriers to accessing timely specialty PC.

OBJECTIVES: To systematically review the evidence regarding the efficacy of educational interventions to improve knowledge and attitudes about PC among non-healthcare workers.

METHODS: We searched five databases (PubMed/MEDLINE, Embase, CINAHL, Web of Science, and Scopus) for studies investigating educational interventions about specialty PC in adults who identified as patients, caregivers, or members of the public. We included studies that were available in English and had a comparator group. We excluded studies that only sampled health professionals or children. We used the Mixed Methods Appraisal Tool to assess quality and risk of bias.

RESULTS: Of 12,420 records identified, we screened 5,948 abstracts and assessed 526 full texts for eligibility. 21 articles were extracted for analysis, representing 20 unique educational interventions. Common methodologies included quasi-experimental (9, 45%), randomized controlled trial (4, 20%), and non-randomized trial (2, 10%). Common components of the educational interventions included video presentations (9, 45%), written materials (8, 40%), and lectures (4, 20%). Content included definition (14, 70%) and philosophy (14, 70%) of PC, distinctions between PC and hospice (11, 55%), and eligibility for PC (11, 55%). Fourteen (70%)

interventions showed statistically significant positive differences in either knowledge or attitudes about PC.

CONCLUSIONS: While educational interventions can positively impact knowledge and attitudes about PC among non-healthcare workers, more research is needed to inform the design, delivery, and evaluation of interventions to increase knowledge and attitudes about PC.

Full text available via the library: <https://libkey.io/10.1016/j.jpainsymman.2023.09.023>

The Impact of Advance Care Planning on Healthcare Professionals' Well-being: A Systematic

Review

Authors: Souza, L. G.; Bouba, D. A.; Corôa, R. d. C., et al

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

Abstract:

CONTEXT: Advance care planning (ACP) improves care for patients with chronic illnesses and reduces family stress. However, the impact of ACP interventions on healthcare professionals' well-being remains unknown.

OBJECTIVE: To systematically review the literature evaluating the impact of ACP interventions on healthcare professionals' well-being.

METHODS: We followed the Joanna Briggs Institute methodology for systematic reviews and registered the protocol in PROSPERO (CRD42022346354). We included primary studies in all languages that assessed the well-being of healthcare professionals in ACP interventions. We excluded any studies on ACP in psychiatric care and in palliative care that did not address goals of care. Searches were conducted on April 4, 2022, and March 6, 2023 in Embase, CINAHL, Web of Science, and PubMed. We used the Mixed Methods Appraisal Tool for quality analysis. We present results as a narrative synthesis because of their heterogeneity.

RESULTS: We included 21 articles published in English between 1997 and 2021 with 17 published after 2019. All were conducted in high-income countries, and they involved a total of 1278 participants. Three reported an interprofessional intervention and two included patient partners. Studies had significant methodological flaws but most reported that ACP had a possible positive impact on healthcare professionals' well-being.

CONCLUSION: This review is the first to explore the impact of ACP interventions on healthcare professionals' well-being. ACP interventions appear to have a positive impact, but high-quality studies are scarce. Further research is needed, particularly, using more rigorous and systematic methods to implement interventions and report results.

Full text available via the library: <https://libkey.io/10.1016/j.jpainsymman.2023.09.026>

A global exploration of palliative community care literature: An integrative review

Authors: Weston, E. J.; Jefferies, D.; Stulz, V., et al

Journal: Journal of Clinical Nursing. (2023)

Abstract:

AIM: This review sought to discover how community nurses globally provide palliative care, with specific focus on how they manage the personal and professional stressors associated with caring for dying clients in the home.

DESIGN: An integrative review methodology was used to gain insight into how community palliative care is delivered worldwide.

BACKGROUND: The provision of home palliative care by community nurses gives clients the ability to spend their final days in familiar surroundings. Research has focussed on the provision of palliative care in the inpatient setting, with little known about the community setting.

METHODS: Data were collected through a literature search, then a critical analysis approach was used to evaluate the strengths of palliative care literature by analysing recurrent themes to stimulate further research on the topic.

DATA SOURCES: The following databases were used to conduct the literature search: CINAHL, Medline, Pubmed, Scopus, Ovid.

RESULTS: The results highlighted the importance of building a skilled palliative community nursing workforce and the need to offer specialised palliative care training to nurses, particularly around difficult conversations and service coordination.

CONCLUSION: The literature identified the challenges implicit within the community nursing role in delivering palliative care, but it did not identify the factors that enhance the nurses' ability to manage the stressors associated with this role. The input of nurses must be sought to understand the development of resilience. **IMPLICATIONS FOR THE PROFESSION:** Community palliative care nursing requires time spent with clients and family members who are suffering, therefore predisposing nurses to stress. Effort must be made to provide palliative care nurses with support to enhance professional resilience.

Full text available via the library: <https://libkey.io/10.1111/jocn.16707>

The experiences and needs of nurses providing home-based palliative care: A qualitative meta-synthesis

Authors: Wu, Y.; Hsieh, H.; Kuo, Y. and Wu, C.

Journal: Journal of Palliative Care. (2023)

Abstract:

OBJECTIVES: We conducted a qualitative meta-synthesis of qualitative studies on nurses' experiences when caring for palliative patients to (1) identify the needs of nurses and (2) describe their experiences to provide more in-depth information.

METHODS: Qualitative articles published in English from 2000 to 2022 were identified from several databases through a searching strategy. Authors screened through the title, abstract, and full text of relevant studies. Articles were read repeatedly and discussed. The thematic analysis methodology was adopted to analyze the data.

RESULTS: Of 967 articles, 22 were included in our review. Notions reflecting community nurses providing palliative home care were clustered into four themes: (1) nature of community-based palliative nursing, (2) teamwork, (3) relationship with patient and family, and (4) resources.

Findings also suggest establishing a sound support system, strengthening palliative education, and creating more decisive referral criteria and systems.

CONCLUSIONS: The growing need for palliative home care has become challenging for community health care systems. Our study summarized various aspects of nurses providing home-based palliative care. The findings provide information for health care and education settings to improve home care systems and recruit more staff to meet the needs.

Full text available via the library: <https://pubmed.ncbi.nlm.nih.gov/35642265/>

Symptoms

Opioid-induced Neurotoxicity in Patients with Cancer Pain

Authors: Mercadante, S.

Journal: Current Treatment Options in Oncology. (2023)

Abstract:

Opioid-induced neurotoxicity (OINT) is a neuropsychiatric syndrome observed with opioid therapy. The mechanism of OINT is thought to be multifactorial, and many risk factors may facilitate its development. If symptoms of OINT are seen, the prescriber should consider hydration, discontinuation of the offending opioid drug, or switching of opioid medication, or the use of some adjuvants. Multiple factors like inter- and intraindividual differences in opioid pharmacology may influence the accuracy of dose calculations for opioid switching. Experience and clinical judgment in a specialistic palliative care setting should be used and individual patient characteristics considered when applying any conversion table.

Full text available via the library: <https://libkey.io/10.1007/s11864-023-01117-9>

Vital Signs in Palliative Care: A Scoping Review

Authors: Power, J.; Gouldthorpe, C. and Davies, A.

Journal: Cancers. (2023)

Abstract:

Vital signs are routinely measured in secondary healthcare settings and can be used to detect clinical problems, guide treatment, and monitor response to treatment. Vital signs are less

frequently measured in palliative care settings. Reasons for this are unclear. This scoping review aimed to assess the generic use of vital signs in palliative care, and its role in prognostication for adult patients with cancer receiving palliative care. Medline, Embase, and CINAHL were searched for articles involving adult patients with advanced cancer receiving palliative care who had their vital signs measured. Twenty-six articles were identified in which one or a combination of vital signs, with or without other clinical parameters, was used to prognosticate for patients. An additional three articles investigated the generic use of vital signs in patients with advanced cancer. There was significant heterogeneity between identified studies, with some indication that changes in vital signs may indicate that a patient is close to death. However, other studies suggested that patients may maintain normal vital signs until the time of death. Further studies are needed to explore whether abnormal vital signs may be used as a prognostic indicator for patients with cancer receiving palliative care.

Full text available online: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10527359>

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