

PALLIATIVE CARE BULLETIN

March 2024

Contents

Bereavement.....	2
Children.....	3
Communication.....	5
Ethical and legal issues.....	10
Guidelines and recommendations.....	10
Medicines and treatments.....	12
Place of care.....	14
Quality of care.....	16
Spiritual and psychological care.....	18
Staff.....	18
Technology.....	21

Bereavement

Improving family grief outcomes: A scoping review of family-based interventions before and after the death of a child

Authors: Høeg, B. L.; Guldin, M.; Høgh, J., et al

Journal: Palliative Medicine. (2024)

Abstract:

BACKGROUND: Experiencing the illness and death of a child is a traumatic experience for the parents and the child's siblings. However, knowledge regarding effective grief interventions targeting the whole family is limited, including how to integrate age-appropriate support for siblings.

AIM: We aimed to synthesize the empirical literature regarding grief interventions that target the whole family before and/or after the death of a child.

DESIGN: A scoping review following the Joanna Briggs Institute and Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines. **DATA SOURCES:** We searched PubMed, PsycINFO, Embase, CINAHL, and Scopus covering January 1998-May 2022. We included studies describing any type of structured intervention targeting the whole family (i.e. parents and siblings) before or/and after the death of a child (below 18 years), with pre-post assessments of grief-related symptoms in the family as an outcome.

RESULTS: After removal of duplicates, we screened the titles and abstracts of 4078 publications and identified 30 publications for full-text screening. None of the studies met the inclusion criteria. Most of the studies were excluded because they either did not target the whole family or did not target families who had lost a child below 18 years. Bereavement camps were a popular form of family intervention, but none were evaluated in a pre-post design. No grief interventions offering support pre-death were found.

CONCLUSIONS: There is great need for research to improve bereavement outcomes for the entire family and to potentially integrate this in pediatric palliative care.

Full text available via the library: <https://libkey.io/10.1177/02692163241233958>

Investing in bereavement care as a public health priority

Authors: Lichtenthal, W. G.; Roberts, K. E.; Donovan, L. A., et al

Journal: The Lancet.Public Health. (2024)

Abstract:

Morbidity and mortality associated with bereavement is an important public health issue, yet economic and resource investments to effectively implement and sustain integrated bereavement services are sorely lacking at national and global levels. Although bereavement support is a component of palliative care provision, continuity of care for bereaved individuals is

often not standard practice in palliative and end-of-life contexts. In addition to potentially provoking feelings of abandonment, failure to extend family-centred care after a patient's death can leave bereaved families without access to crucial psychosocial support and at risk for illnesses that exacerbate the already substantial public health toll of interpersonal loss. The effect of inadequate bereavement care disproportionately disadvantages vulnerable groups, including those living in resource-constrained settings. We build on available evidence and previous recommendations to propose a model for transitional care, firmly establishing bereavement care services within health-care institutions, while respecting their finite resources and the need to ultimately transition grieving families to supports within their communities. Key to the transitional bereavement care model is the bolstering of community-based supports through development of compassionate communities and upskilling of professional services for those with more substantial bereavement support needs. To achieve this goal, interprofessional health workers, institutions, and systems must shift bereavement care from an afterthought to a public health priority.

Full text available online: [https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667\(24\)00030-6/fulltext](https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(24)00030-6/fulltext)

Children

Experiences of music therapy in paediatric palliative care from multiple stakeholder perspectives:

A systematic review and qualitative evidence synthesis

Authors: Kammin, V.; Fraser, L.; Flemming, K. and Hackett, J.

Journal: Palliative Medicine. (2024)

Abstract:

BACKGROUND: Children and young people with life-limiting conditions and their families need physical and emotional support to manage the challenges of their lives. There is a lack of synthesised qualitative research about how music therapy is experienced by children, young people and their families supported by paediatric palliative care services.

AIM: To systematically identify and synthesise qualitative research on experiences of music therapy in paediatric palliative care from stakeholder perspectives.

DESIGN: A Qualitative Evidence Synthesis was conducted using Thematic Synthesis. The review protocol was registered in PROSPERO (registration number: CRD42021251025).

DATA SOURCES: Searches were conducted with no dates imposed via the electronic databases PsycINFO, MEDLINE, EMBASE, AMED and CINAHL in April 2021 and updated in April 2022.

Studies were appraised for quality using the Critical Appraisal Skills Programme tool (CASP).

RESULTS: A total of 148 studies were found, 5 studies met the eligibility criteria reporting the experiences of 14 mothers, 24 family members and 4 staff members in paediatric palliative care.

There were five overarching themes: emotional and physical relieve, opportunity for normalised experiences, thriving despite life limited condition, enhance family wellbeing and therapeutic relationship central to outcomes.

CONCLUSION: Music therapy provides unique benefits for this paediatric population particularly in supporting child and family wellbeing. The therapeutic relationship, interpersonal skills of the therapist and experience in paediatric palliative care are perceived as central to these positive outcomes.

Full text available online: <https://journals.sagepub.com/doi/full/10.1177/02692163241230664>

Thirty-day mortality as a metric for palliative radiotherapy in pediatric patients

Authors: Keit, E.; Nanda, R. and Johnstone, P. A. S.

Journal: Current Opinion in Supportive and Palliative Care. (2024)

Abstract:

PURPOSE OF REVIEW: Thirty-day mortality (30DM) is an emerging consideration for determining whether terminally ill adult patients may benefit from palliative radiotherapy (RT). However, the efficacy and ethics of delivering palliative RT at the end of life (EOL) in children are seldom discussed and not well-established.

RECENT FINDINGS: Palliative RT is perhaps underutilized among patients ≤ 21 years old with rates as low as 11%. While effective when delivered early, clinical benefit decreases when administered within the last 30 days of life. Pediatric 30DM rates vary widely between institutions (0.7-30%), highlighting the need for standardized practices. Accurate prognosis estimation remains challenging and prognostic models specific to palliative pediatric patients are limited. Discordance between provider and patient/parent perceptions of prognosis further complicates decision-making.

SUMMARY: RT offers effective symptom control in pediatric patients when administered early. However, delivering RT within the last 30 days of life may provide limited clinical benefit and hinder optimal EOL planning and care. Early referral for palliative RT, preferably with fewer fractions (five or fewer), along with multidisciplinary supportive care, optimizes the likelihood of maintaining patients' quality of life. Prognosis estimation remains difficult, and improving patient and family understanding is crucial. Further research is needed to refine prognostic models and enhance patient-centered care.

Full text available via the library: <https://libkey.io/10.1097/SPC.0000000000000686>

A Dutch paediatric palliative care guideline: a systematic review and evidence-based recommendations for symptom treatment

Authors: van Teunenbroek, K. C.; Mulder, R. L.; Ahout, I. M. L., et al

Journal: BMC Palliative Care. (2024)

Abstract:

BACKGROUND: Children with life-threatening and life-limiting conditions can experience high levels of suffering due to multiple distressing symptoms that result in poor quality of life and increase risk of long-term distress in their family members. High quality symptom treatment is needed for all these children and their families, even more so at the end-of-life. In this paper, we provide evidence-based recommendations for symptom treatment in paediatric palliative patients to optimize care.

METHODS: A multidisciplinary panel of 56 experts in paediatric palliative care and nine (bereaved) parents was established to develop recommendations on symptom treatment in paediatric palliative care including anxiety and depression, delirium, dyspnoea, haematological symptoms, coughing, skin complaints, nausea and vomiting, neurological symptoms, pain, death rattle, fatigue, paediatric palliative sedation and forgoing hydration and nutrition.

Recommendations were based on evidence from a systematic literature search, additional literature sources (such as guidelines), clinical expertise, and patient and family values. We used the GRADE methodology for appraisal of evidence. Parents were included in the guideline panel to ensure the representation of patient and family values.

RESULTS: We included a total of 18 studies that reported on the effects of specific (non) pharmacological interventions to treat symptoms in paediatric palliative care. A few of these interventions showed significant improvement in symptom relief. This evidence could only (partly) answer eight out of 27 clinical questions. We included 29 guidelines and two textbooks as additional literature to deal with lack of evidence. In total, we formulated 221 recommendations on symptom treatment in paediatric palliative care based on evidence, additional literature, clinical expertise, and patient and family values.

CONCLUSION: Even though available evidence on symptom-related paediatric palliative care interventions has increased, there still is a paucity of evidence in paediatric palliative care. We urge for international multidisciplinary multi-institutional collaboration to perform high-quality research and contribute to the optimization of symptom relief in palliative care for all children worldwide.

Full text available online: <https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-024-01367-w>

Communication

Measuring decision aid effectiveness for end-of-life care: A systematic review

Authors: Hughes, M. C.; Vernon, E.; Egwuonwu, C. and Afolabi, O.

Journal: PEC Innovation. (2024)

Abstract:

OBJECTIVE: To systematically review research analyzing the effectiveness of decision aids for end-of-life care, including how researchers specifically measure decision aid success.

METHODS: We conducted a systematic review synthesizing quantitative, qualitative, and mixed-methods study results using Preferred Reporting Items for Systematic Reviews and Meta-Analysis guidelines. Four databases were searched through February 18, 2023. Inclusion criteria required articles to evaluate end-of-life care decision aids. The review is registered under PROSPERO (#CRD42023408449).

RESULTS: A total of 715 articles were initially identified, with 43 meeting the inclusion criteria. Outcome measures identified included decisional conflict, less aggressive care desired, knowledge improvements, communication improvements, tool satisfaction, patient anxiety and well-being, and less aggressive care action completed. The majority of studies reported positive outcomes especially when the decision aid development included International Patient Decision Aid Standards.

CONCLUSION: Research examining end of life care decision aid use consistently reports positive outcomes.

INNOVATION: This review presents data that can guide the next generation of decision aids for end-of-life care, namely using the International Patient Decision Aid Standards in developing tools and showing which tools are effective for helping to prevent the unnecessary suffering that can result when patients' dying preferences are unknown.

Full text available online:

<https://www.sciencedirect.com/science/article/pii/S2772628224000219>

Shared decision-making in palliative cancer care: A systematic review and metasynthesis

Authors: Rabben, J.; Vivat, B.; Fossum, M. and Rohde, G. E.

Journal: Palliative Medicine. (2024)

Abstract:

BACKGROUND: Shared decision-making is a key element of person-centred care and promoted as the favoured model in preference-sensitive decision-making. Limitations to implementation have been observed, and barriers and limitations, both generally and in the palliative setting, have been highlighted. More knowledge about the process of shared decision-making in palliative cancer care would assist in addressing these limitations.

AIM: To identify and synthesise qualitative data on how people with cancer, informal carers and healthcare professionals experience and perceive shared decision-making in palliative cancer care.

DESIGN: A systematic review and metasynthesis of qualitative studies. We analysed data using inductive thematic analysis.

DATA SOURCES: We searched five electronic databases (MEDLINE, EMBASE, PsycINFO, CINAHL and Scopus) from inception until June 2023, supplemented by backward searches.

RESULTS: We identified and included 23 studies, reported in 26 papers. Our analysis produced four analytical themes; (1) Overwhelming situation of 'no choice', (2) Processes vary depending on the timings and nature of the decisions involved, (3) Patient-physician dyad is central to decision-making, with surrounding support and (4) Level of involvement depends on interactions between individuals and systems.

CONCLUSION: Shared decision-making in palliative cancer care is a complex process of many decisions in a challenging, multifaceted and evolving situation where equipoise and choice are limited. Implications for practice: Implementing shared decision-making in clinical practice requires (1) clarifying conceptual confusion, (2) including members of the interprofessional team in the shared decision-making process and (3) adapting the approach to the ambiguous, existential situations which arise in palliative cancer care.

Full text available online: <https://journals.sagepub.com/doi/full/10.1177/02692163241238384>

Stages of readiness for advance care planning: Systematic review and meta-analysis of prevalence rates and associated factors

Authors: Tan, M.; Ding, J.; Johnson, C. E., et al

Journal: International Journal of Nursing Studies. (2024)

Abstract:

BACKGROUND: Advance care planning has been widely recommended to respect the medical care preferences of patients in the final stages of life. However, uptake of advance care planning in healthcare settings remains suboptimal. It may be beneficial to take into account individuals' readiness for advance care planning based on the stages to change identified in the Transtheoretical Model.

OBJECTIVE: To identify the measurements used to assess readiness of advance care planning based on the Transtheoretical Model, to pool the prevalence of readiness stages, and to summarize the factors affecting people's readiness for advance care planning. DESIGN: Systematic review and meta-analysis.

METHODS: We systematically searched the databases of PubMed, EMBASE, The Cochrane Library, CINAHL, and Web of Science for relevant studies from inception to February 2023. A random effects model was used to estimate the pooled prevalence. And a narrative review on the factors associated with stages of readiness was conducted.

RESULTS: This meta-analysis included 25 studies involving a total of 4237 individuals. The precontemplation stage was the most commonly identified stage of readiness among advance care planning behaviors (26-72 %). The prevalence of readiness stages for advance care planning varied among different types of behavior. The behavior of "talking to health care

proxy/family/loved ones about thoughts on quality versus quantity of life" had the highest level of readiness among all listed behaviors, followed by "talking to health care proxy/family/loved ones about living will", "signing a health care proxy form" and "signing a living will", "signing an advance directive", as well as "talking to doctors about living will". Regarding to influencing factors, a majority of sociodemographic and clinical factors did not show consistent associations with readiness, but some studies did suggest potential links with age, health status, countries, type of assessment, core structures of the Transtheoretical Model, and intervention modalities.

CONCLUSIONS: A majority of individuals were unaware of advance care planning. There is an urgent need to promote readiness for such planning. Starting with preliminary activities such as "talking to health care proxy/family/loved ones about thoughts on quality versus quantity of life" can help initiate advance care planning. Better integration of the Transtheoretical Model and interventions into the research of advance care planning readiness are needed.

Full text available via NHS OpenAthens: <https://libkey.io/10.1016/j.ijnurstu.2023.104678>

Question prompt list intervention for patients with advanced cancer: a systematic review and meta-analysis

Authors: Wang, S.; Hu, W. and Chang, Y.

Journal: Supportive Care in Cancer : Official Journal of the Multinational Association of Supportive Care in Cancer. (2024)

Abstract:

BACKGROUND: Enhanced communication in end-of-life care (EOL) improves preparation and treatment decisions for patients with advanced cancer, affecting their quality of life at the end of life. Question prompt list (QPL) has been shown to enhance physician-patient communication in patients with cancer, but there is a lack of systematic review and meta-analysis for those with advanced cancer. Enhanced communication in end-of-life care improves preparation and treatment decisions for patients with advanced cancer, affecting their quality of life at the end of life.

OBJECTIVE: To review the effectiveness of QPL intervention on physician-patient communication and health outcomes during consultation in patients with advanced cancer.

METHODS: CINAHL, Embase, Scopus, and PsycINFO databases were undertaken using inclusion criteria for relevant articles up to August 2021. Pooled standardized mean difference (SMD) and 95% confidence intervals (CIs) were calculated using random-effects models. We used the Cochrane risk-of-bias assessment tool and modified Jadad scale to assess the quality of the studies.

RESULTS: Seven RCTs with 1059 participants were included, of which six studies were eligible for the meta-analysis. The pooled meta-analysis results indicated that QPL in patients with

advanced cancer had a significant positive effect on the total number of questions asked (SMD, 0.73; 95% CI, 0.28 to 1.18; I(2) = 83%) and on the patients' expectations for the future (SMD, 0.67; 95% CI, 0.08 to 1.25; I(2) = 88%). There were no significant improvements in health-related outcomes such as end of life, anxiety, and quality of life.

CONCLUSIONS: Using QPL in advanced cancer consultations boosts patient questions which helps communication but not health-related indicators. Optimal results depend on full reading, but timing varies. Future research should examine the relationship between communication and health outcomes, including patient/physician behavior and social context.

Full text available via the library: <https://libkey.io/10.1007/s00520-024-08432-3>

Implementing advance care planning in palliative and end of life care: a scoping review of community nursing perspectives

Authors: Wilkin, K.; Fang, M. L. and Sixsmith, J.

Journal: BMC Geriatrics. (2024)

Abstract:

BACKGROUND: Advance care planning (ACP) is a priority within palliative care service provision. Nurses working in the community occupy an opportune role to engage with families and patients in ACP. Carers and family members of palliative patients often find ACP discussions difficult to initiate. However, community nurses caring for palliative patients can encourage these discussions, utilising the rapport and relationships they have already built with patients and families. Despite this potential, implementation barriers and facilitators continue to exist. To date, no research synthesis has captured the challenges community nurses face when implementing ACP, nor the facilitators of community nurse-led ACP. Considering this, the review question of: 'What factors contribute to or hinder ACP discussion for nurses when providing care to palliative patients?' was explored.

METHOD: To capture challenges and facilitators, a global qualitative scoping review was undertaken in June 2023. The Arksey and O'Malley framework for scoping reviews guided the review methodology. Six databases were searched identifying 333 records: CINAHL (16), MEDLINE (45), PUBMED (195), EMBASE (30), BJOCN (15), IJOPN (32). After de-duplication and title and abstract screening, 108 records remained. These were downloaded, hand searched (adding 5 articles) and subject to a full read. 98 were rejected, leaving a selected dataset of 15 articles. Data extracted into a data extraction chart were thematically analysed.

RESULTS: Three key themes were generated: 'Barriers to ACP', 'Facilitators of ACP' and 'Understanding of professional role and duty'. Key barriers were - lack of confidence, competence, role ambiguity and prognostic uncertainty. Key facilitators concerned the pertinence of the patient-practitioner relationship enabling ACP amongst nurses who had both competence and experience in ACP and/or palliative care (e.g., palliative care training). Lastly,

nurses understood ACP to be part of their role, however, met challenges understanding the law surrounding this and its application processes.

CONCLUSIONS: This review suggests that community nurses' experience and competence are associated with the effective implementation of ACP with palliative patients. Future research is needed to develop interventions to promote ACP uptake in community settings, enable confidence building for community nurses and support higher standards of palliative care via the implementation of ACP.

Full text available online: <https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-024-04888-4>

Ethical and legal issues

Ethical dilemmas for palliative care nurses: systematic review

Authors: Geng, S.; Zhang, L.; Zhang, Q. and Wu, Y.

Journal: BMJ Supportive & Palliative Care. (2024)

Abstract:

BACKGROUND: Nurses play a unique and critical role in palliative care, and it is noteworthy that nurses often encounter ethical dilemmas in this field.

OBJECTIVE: This review aims to conduct a summarised synthesis of the latest research on the ethical considerations nurses faced in palliative care.

METHODS: We conducted a rigorous systematic review of relevant existing studies published in high-quality English peer-reviewed journals from January 2017 to July 2023. We identified a total of 4492 articles (1029 in Web of Science, 1570 in PubMed and 1893 in Science Direct). Out of these, only 13 studies met the inclusion criteria.

RESULTS: Following the thematic analysis, the ethical considerations reported in these 13 studies were grouped into three main themes and four subthemes: ethical issues in communication (ethical issues in communication with patients, ethical issues in communication with families), ethical issues in decision-making (autonomy, dignity) and moral distress in palliative care.

CONCLUSION: This study elaborated on the ethical challenges faced by nurses in their communication with patients and families as well as decision-making and analysed the causes and effects of ethical distress, hoping to give a hand to ethical issues for nurses' work in palliative care.

Full text available via NHS OpenAthens: <https://libkey.io/10.1136/spcare-2023-004742>

Guidelines and recommendations

Medication review and deprescribing in different healthcare settings: a position statement from an Italian scientific consortium

Authors: Carollo, M.; Boccardi, V.; Crisafulli, S., et al

Journal: Aging Clinical and Experimental Research. (2024)

Abstract:

Recent medical advancements have increased life expectancy, leading to a surge in patients affected by multiple chronic diseases and consequent polypharmacy, especially among older adults. This scenario increases the risk of drug interactions and adverse drug reactions, highlighting the need for medication review and deprescribing to reduce inappropriate medications and optimize therapeutic regimens, with the ultimate goal to improving patients' health and quality of life. This position statement from the Italian Scientific Consortium on medication review and deprescribing aims to describe key elements, strategies, tools, timing, and healthcare professionals to be involved, for the implementation of medication review and deprescribing in different healthcare settings (i.e., primary care, hospital, long-term care facilities, and palliative care). Challenges and potential solutions for the implementation of medication review and deprescribing are also discussed.

Full text available online: <https://link.springer.com/article/10.1007/s40520-023-02679-2>

Multinational Association of Supportive Care in Cancer (MASCC) expert opinion/guidance on the use of clinically assisted hydration in patients with advanced cancer

Authors: Hayes, J.; Bruera, E.; Crawford, G., et al

Journal: Supportive Care in Cancer : Official Journal of the Multinational Association of Supportive Care in Cancer. (2024)

Abstract:

PURPOSE: The provision of clinically assisted hydration (CAH) in patients with advanced cancer is controversial, and there is a paucity of specific guidance and so a diversity in clinical practice. Consequently, the Palliative Care Study Group of the Multinational Association of Supportive Care in Cancer (MASCC) formed a sub-group to develop evidence-based guidance on the use of CAH in patients with advanced cancer.

METHODS: This guidance was developed in accordance with the MASCC Guidelines Policy. A search strategy for Medline was developed, and the Cochrane Database of Systematic Reviews and the Cochrane Central Register of Controlled Trials were explored for relevant reviews/trials, respectively.

RESULTS: Due to the paucity of evidence, the sub-group was not able to develop a prescribed guideline, but was able to generate a number of "expert opinion statements": these statements

relate to assessment of patients, indications for CAH, contraindications for CAH, procedures for initiating CAH, and reassessment of patients.

CONCLUSIONS: This guidance provides a framework for the use of CAH in advanced cancer, although every patient requires individualised management.

Full text available online: <https://link.springer.com/article/10.1007/s00520-024-08421-6>

Medicines and treatments

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

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

Journal: Farmacia Hospitalaria : Organo Oficial De Expresion Cientifica De La Sociedad Espanola De Farmacia Hospitalaria. (2024)

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 two independent researchers. Experimental and observational studies were eligible for inclusion.

RESULTS: Out of the 5,791 studies retrieved, after excluding duplicates (n = 1,050), conducting title/abstract screening (n = 4,741), and full reading (n = 41), only one 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 two 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 one 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>

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

Authors: Jenkins, G.

Journal: Journal of Pain & Palliative Care Pharmacotherapy. (2024)

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>

State-of-the-Art Review: Use of Antimicrobials at the End of Life

Authors: Karlin, D.; Pham, C.; Furukawa, D., et al

Journal: Clinical Infectious Diseases : An Official Publication of the Infectious Diseases Society of America. (2024)

Abstract:

Navigating antibiotics at the end of life is a challenge for infectious disease (ID) physicians who remain deeply committed to providing patient-centered care and engaging in shared decision making. ID physicians, who often see patients in both inpatient and outpatient settings and maintain continuity of care for patients with refractory or recurrent infections, are ideally situated to provide guidance that aligns with patients' goals and values. Complex communication skills, including navigating difficult emotions around end-of-life care, can be used to better direct

shared decision making and assist with antibiotic stewardship.

Full text available online: <https://academic.oup.com/cid/article/78/3/e27/7596076>

Subcutaneous sodium valproate in palliative care: A systematic review

Authors: Tan, S.; Ng, J. S.; Tang, C., et al

Journal: Palliative Medicine. (2024)

Abstract:

BACKGROUND: Seizures are an important palliative symptom, the management of which can be complicated by patients' capacity to swallow oral medications. In this setting, and the wish to avoid intravenous access, subcutaneous infusions may be employed. Options for antiseizure medications that can be provided subcutaneously may be limited. Subcutaneous sodium valproate may be an additional management strategy.

AIM: To evaluate the published experience of subcutaneous valproate use in palliative care, namely with respect to effectiveness and tolerability.

DESIGN: A systematic review was registered (PROSPERO CRD42023453427), conducted and reported according to PRISMA reporting guidelines.

DATA SOURCES: The databases PubMed, EMBASE and Scopus were searched for publications until August 11, 2023.

RESULTS: The searches returned 429 results, of which six fulfilled inclusion criteria. Case series were the most common study design, and most studies included <10 individuals who received subcutaneous sodium valproate. There were three studies that presented results on the utility of subcutaneous sodium valproate for seizure control, which described it to be an effective strategy. One study also described it as an effective treatment for neuropathic pain. The doses were often based on presumed 1:1 oral to subcutaneous conversion ratios. Only one study described a local site adverse reaction, which resolved with a change of administration site.

CONCLUSIONS: There are limited data on the use of subcutaneous sodium valproate in palliative care. However, palliative symptoms for which subcutaneous sodium valproate have been used successfully are seizures and neuropathic pain. The available data have described few adverse effects, supporting its use with an appropriate degree of caution.

Full text available online: <https://journals.sagepub.com/doi/full/10.1177/02692163241234597>

Place of care

The determinants of actual place of death among noncancer patients with end-stage chronic health conditions: a scoping review

Authors: Ginggeaw, S. and LeBlanc, R.

Journal: Palliative Care and Social Practice. (2024)

Abstract:

A home is a preferred place of death by most people. Nurses play a key role in supporting end-of-life home care, yet less is known about the factors that determine home as a place of death. This scoping review describes the percentage of actual places of death and determines social factors related to home as the place of death among noncancer patients with end-stage chronic health conditions. Inclusion criteria included (1) noncancer chronic illness conditions, (2) outcomes of place of death, and (3) factors that determine home as a place of death. Sources of evidence included PubMed, CINAHL, and Web of Science databases, which were searched in May 2022, and additional searches from May 2022 to November 2023. The JBI scoping review guide (2020) and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Scoping Review extension were used. Twenty-eight studies were included in this analysis. The range of percentages is varied within the same place of death among the sample. Two major constructs that determine a home as a place of death were identified: preceding factors and social capital. The results suggest that the place of death among noncancer patients with end-stage chronic health conditions should be continued to be understood. Two constructs determined home as a place of death and are considered as a fundamental to increasing equal accessibility in the initiation of palliative care services to promote home death and meet end-of-life care goals.

Full text available online: <https://journals.sagepub.com/doi/10.1177/26323524241236964>

Palliative Care Costs in Different Ambulatory-Based Settings: A Systematic Review

Authors: Perea-Bello, A. H.; Trapero-Bertran, M. and Dürsteler, C.

Journal: PharmacoEconomics. (2024)

Abstract:

BACKGROUND: Cost-of-illness studies in palliative care are of growing interest in health economics. There is no standard methodology to capture direct and non-direct healthcare and non-healthcare expenses incurred by health services, patients and their caregivers in the course of the ambulatory palliative care process.

OBJECTIVE: We aimed to describe the type of healthcare and non-healthcare expenses incurred by patients with cancer and non-cancer patients and their caregivers for palliative care in ambulatory-based settings and the methodology used to capture the data.

METHODS: We conducted a systematic review of studies on the costs of ambulatory-based palliative care in patients with cancer (breast, lung, colorectal) and non-cancer conditions (chronic heart failure, chronic obstructive pulmonary disease, dementia) found in six bibliographic databases (PubMed, EMBASE [via Ovid], Cochrane Database of Systematic Reviews, EconLit, the National Institute for Health Research Health Technology Assessment Database and the National Health Service Economic Evaluation Database at the University of York, and Google Scholar). The studies were published between January 2000 and December 2022. We followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses

(PRISMA) methodology for study selection and assessed study quality using the Quality of Health Economic Studies instrument. The study was registered in PROSPERO (CRD42021250086).

RESULTS: Of 1434 identified references, 43 articles met the inclusion criteria. The primary data source was databases. More than half of the articles presented data from public healthcare systems (65.12%) were retrospective (60.47%), and entailed a bottom-up costing analysis (93.2%) made from a healthcare system perspective (53.49%). The sociodemographic characteristics of patients and families/caregivers were similar across the studies. Cost outcomes reports were heterogeneous; almost all of the studies collected data on direct healthcare costs (97.67%). The main driver of costs was inpatient care (55.81%), which increased during the end-of-life period. Nine studies (20.97%) recorded costs due to productivity losses for caregivers and three recorded such costs for patients. Caregiving costs were explored through an opportunity cost analysis in all cases, based on interviews conducted with and questionnaires administered to patients and caregivers, mainly via telephone calls (23.23%).

CONCLUSIONS: This systematic review reveals that studies on the costs of ambulatory-based palliative care are increasing. These studies are mostly conducted from a healthcare system perspective, which leaves out costs related to patients'/caregivers' economic burden. There is a need for prospective studies to assess this financial burden and evaluate, with strong evidence, the interventions and actions designed to improve the quality of life of palliative care patients. Future studies should propose cost calculation approaches using a societal perspective to better estimate the economic burden imposed on patients in ambulatory-based palliative care.

Full text available online: <https://link.springer.com/article/10.1007/s40273-023-01336-w>

Quality of care

Outcomes of care during the last month of life: a systematic review to inform the development of a core outcome set

Authors: González-Jaramillo, V.; Luethi, N.; Egloff, M., et al

Journal: Annals of Palliative Medicine. (2024)

Abstract:

BACKGROUND: To date, there is a lack of standardization and consensus on which outcomes are central to assess the care provided to patients in the last month of life. Therefore, we aimed to conduct a systematic review to identify relevant outcomes to inform the development of a core outcome set for the best care for the dying person.

METHODS: We conducted a systematic review of outcomes reported in the scientific literature about the care for the dying person in the last month of life. We searched for peer-reviewed studies published before February 2022 in four electronic databases. To categorise the

outcomes, we employed the taxonomy developed by the "Core Outcome Measures in Effectiveness Trials" collaboration.

RESULTS: Out of the 2,933 articles retrieved, 619 were included for analyses. The majority of studies (71%) were retrospective and with data extracted from chart reviews (71%) . We extracted 1,951 outcomes in total, from which, after deletion of repeated outcomes, we identified 256 unique ones. The most frequently assessed outcomes were those related to medication or therapeutic interventions and those to hospital/ healthcare use. Outcomes related to psychosocial wellbeing were rarely assessed. The closer to death, the less frequently the outcomes were studied.

CONCLUSIONS: Most outcomes were related to medical interventions or to hospital use. Only a few studies focused on other components of integrated care such as psychosocial aspects. It remains to be defined which of these outcomes are fundamental to achieve the best care for the dying.

Full text available online: <https://apm.amegroups.org/article/view/122297/html>

Enhanced supportive care

Authors: Monnery, D. and Droney, J.

Journal: British Journal of Hospital Medicine (London, England : 2005). (2024)

Abstract:

Enhanced supportive care is a care model providing earlier access to multiprofessional, coordinated care for patients from the point of cancer diagnosis. As a proactive model of care, it stands as a contrast to providing access to a multidisciplinary team once a patient has hit a crisis point, or when their prognosis has become sufficiently poor that they are able to access traditional end-of-life services. Its arrival in the UK through palliative care teams working in cancer care has led to enhanced supportive care being synonymous with early palliative care. While enhanced supportive care has enabled early palliative care, as it has become more embedded in the UK, it has taken on a wider remit for patients living longer with cancer and the management of side effects. Enhanced supportive care services have also begun to provide care for cancer survivors. Enhanced supportive care services have a key role in modern cancer care in maintaining and improving patients' quality of life alongside cancer treatment and ensuring that patients' priorities and preferences for treatment are considered. Furthermore, enhanced supportive care has been shown to support the wider healthcare system by creating capacity within the NHS, reducing demand on hospital services and saving money. As enhanced supportive care services continue to grow and venture into the care and support of cancer survivors and those receiving potentially curative treatments, ongoing work is needed to determine how these services can be made available throughout the NHS and how a shared

vision of the way enhanced supportive care operates can be realised.

Full text available NHS OpenAthens: <https://libkey.io/10.12968/hmed.2023.0416>

Spiritual and psychological care

Effects of different psychosocial interventions on death anxiety in patients: a network meta-analysis of randomized controlled trials

Authors: Lu, J.; Yang, Y.; Chen, H., et al

Journal: Frontiers in Psychology. (2024)

Abstract:

OBJECTIVE: This research intended to assess and compare influence of psychosocial interventions in death anxiety in patients, providing evidence-based guidance for both patients and healthcare providers.

DESIGN: The present study exclusively gathered randomized controlled trials by comprehensively searching across multiple databases, comprising of PubMed, Embase, Cochrane Library, Web of Science, and Scopus. The methodological quality of the enrolled studies involved in the analysis was assessed using the Cochrane bias risk assessment tool, and data analysis was performed utilizing appropriate software.

RESULTS: This research, encompassing 15 randomized controlled trials with a cumulative sample size of 926 patients, spanned from the earliest possible date to December 2023. The findings of network meta-analysis unveiled that the Rational-Emotive Hospice Care Therapy significantly reduced death anxiety among patients (Sequentially Updated Cumulative Ranking Analysis: 100%).

CONCLUSION: The ranking plot of the network suggested that the rational-emotive hospice care therapy exhibited superior efficacy as a psychological treatment for reducing the death anxiety of patients.

Full text available via NHS OpenAthens: <https://libkey.io/10.3389/fpsyg.2024.1362127>

Staff

Beliefs, practices, perceptions and motivations of healthcare professionals on medication deprescribing during end-of-life care: A systematic review

Authors: Hickman, E.; Almaqhaw, A.; Gillies, C., et al

Journal: Primary Care Diabetes. (2024)

Abstract:

AIM: Conduct a systematic review to investigate current beliefs, practices, perceptions, and motivations towards deprescribing practices from the healthcare professional perspective in

older adults residing in long term care facilities with cardiometabolic conditions, using a narrative approach.

METHODS: Studies were identified using a literature search of MEDLINE, CINAHL and Web of Science from inception to June 2023. Two reviewers (EH and AA) independently extracted data from each selected study using a standardised self-developed data extraction proforma. Studies reviewed included cross-sectional and observational studies. Data was extracted on baseline characteristics, motivations and beliefs and was discussed using a narrative approach.

RESULTS: Eight studies were identified for inclusion. Deprescribing approaches included complete withdrawal, dose reduction, or switching to an alternative medication, for at least one preventive medication. Most healthcare professionals were willing to initiate deprescribing strategies and stated the importance of such interventions, however many felt inexperienced and lacked the required knowledge to feel comfortable doing so.

CONCLUSION: Deprescribing is a key strategy when managing older people with cardiometabolic and multiple long term conditions (MLTC). Overall, HCPs including specialists, were happy to explore deprescribing strategies if provided with the relevant training and development to do so. Barriers that still exist include communication and consultation skills, a lack of evidence-based guidance and trust based policies, and a lack of MDT communications and involvement.

Full text available online:

<https://www.sciencedirect.com/science/article/pii/S1751991824000408>

Nursing activities for health promotion in palliative home care: an integrative review

Authors: Leclerc-Loiselle, J.; Gendron, S. and Daneault, S.

Journal: Palliative Care and Social Practice. (2024)

Abstract:

Palliative care in community contexts is undergoing significant change as a result of public policy and new models of care, which link health promotion principles with palliative care practices. These models support the creation of partnerships between formal care structures and the communities in which care is provided. Given the central role of nurses in the institutional delivery of palliative care, particularly in the home, it is important to provide a systematic description of the activities of nurses that fall within the principles of health promotion. The objective was to describe the diverse range of nursing activities for health promotion that are provided in the palliative home care setting. This is an integrative review. Fifty-five studies listed in the MEDLINE, CINAHL and EMBASE databases, and published between 1999 and December 2022, were identified. Data analysis and presentation of the results were guided by Kellehear's Health-Promoting Palliative Care (HPPC) model. Six themes were identified to describe nursing activities for health promotion in the context of palliative home care: creating a meaningful relationship, supplying medical information, promoting self-care throughout the

trajectory, providing emotional support, involving professional or community services and supporting change. The findings point to nurses focusing more on the individual context and on direct care. The relationship with communities in which they work remains unidirectional. However, some HPPC principles are relevant to nursing activities through the contextualization of nurses' actions and their moral responsibility to work towards the respect of patient's values. Being poorly described, how nurses can truly engage their practice towards health-promoting principles, such as the enhancement of support and control over their lives for people living with serious illness, still requires further empirical research.

Full text available online: <https://journals.sagepub.com/doi/10.1177/26323524241235191>

Core components of end-of-life care in nursing education programs: a scoping review

Authors: Taheri-Ezbarami, Z.; Jafaraghaee, F.; Sighlani, A. K. and Mousavi, S. K.

Journal: BMC Palliative Care. (2024)

Abstract:

BACKGROUND: So far, there have been many studies on end-of-life nursing care education around the world, and in many cases, according to the cultural, social, and spiritual contexts of each country, the results have been different. The present study intends to gain general insight into the main components of end-of-life care in nursing education programs by reviewing scientific texts and the results of investigations.

METHODS: This study was a scoping review conducted with the Arksey and O'Malley methodology updated by Peters et al. First, a search was made in Wos, ProQuest, Scopus, PubMed, Science Direct, Research Gate, and Google Scholar databases to find studies about end-of-life care education programs. Then, the screening of the found studies was done in four stages, and the final articles were selected based on the inclusion and exclusion criteria of the studies. Due to the nature of the research, editorials, letters, and commentaries were excluded. The screening steps are shown in the PRISMA-ScR diagram.

RESULTS: 23 articles related to end-of-life care education programs were reviewed. The studies included eleven descriptive and cross-sectional studies, two qualitative studies, eight interventional studies, one concept analysis article, and one longitudinal study. By summarizing the data from the studies, six themes were obtained as the main components of end-of-life care education: principles of end-of-life care, communication skills, physical considerations, psychosocial and spiritual considerations, ethical considerations, and after-death care.

CONCLUSION: End-of-life care is one of the most challenging nursing care in the world. Since many nurses are not prepared to provide such care, the information obtained from this review can help nursing education and treatment managers develop more comprehensive training programs to improve the quality of end-of-life care.

Full text available online: <https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-024-01398-3>

Technology

Electronic Health Record Tracking of Psychosocial Care in the Context of Serious Illness: A

Narrative Review

Authors: Cammy, R.

Journal: Journal of Palliative Medicine. (2024)

Abstract:

OBJECTIVE: The electronic health record (EHR) has emerged as a fundamental tool but has focused on physical care delivery. Psychosocial screenings and interventions are central to palliative care that supports whole person care models; however, EHR innovations to capture psychosocial care have not been optimized.

MATERIAL AND METHODS: A narrative review was conducted from 2009 to March 2023. EMBASE, PubMed, and PsychINFO were queried to identify articles that discussed EHR tracking of psychosocial care in palliative care. **Results:** Eight articles met inclusion criteria representing a broad range of works in palliative care. Three themes emerged in the narrative review: (a) quality improvement strategy to support EHR tracking in collaboration with key stakeholders, (b) clarification of psychosocial domains for documentation and measurement, and (c) lack of standardization in data collection tools and processes.

DISCUSSION: This narrative review contributes to a limited body of literature on EHR extraction of complex sources of distress in palliative care. The designation of four domains (social history and distress, psychological symptoms, spiritual needs, and patients' goals and preferences) defines psychosocial practice aligned with palliative care quality metrics. Recommendations highlight the importance of shared priorities and collaboration with key stakeholders to fully execute on the clinical utility of EHRs. Future work will continue to evaluate data collection tools and systematic approaches to capture psychological needs and social environment and its impact on health outcomes and quality of life.

CONCLUSION: This review will expand on opportunities for automated reporting of psychosocial care in the context of seriously ill.

Full text available via the library: <https://libkey.io/10.1089/jpm.2023.0514>

Consumer satisfaction, palliative care and artificial intelligence (AI)

Authors: Nair, D. and Raveendran, K. U.

Journal: BMJ Supportive & Palliative Care. (2024)

Abstract:

The scope of artificial intelligence (AI) in healthcare is promising, and AI has the potential to

revolutionise the field of palliative care services also. Consumer satisfaction in palliative care is a critical aspect of providing high-quality end-of-life support. It encompasses various elements that contribute to a positive experience for both patients and their families. AI-based tools and technologies can help in early identification of the beneficiaries, reduce the cost, improve the quality of care and satisfaction to the patients with chronic life-limiting illnesses. However, it is essential to ensure that AI is used ethically and in a way that complements, rather than replaces, the human touch and compassionate care, which are the core components of palliative care. This article tries to analyse the scope and challenges of improving consumer satisfaction through AI-based technology in palliative care services.

Full text available via NHS OpenAthens: <https://libkey.io/10.1136/spcare-2023-004634>

Noninvasive monitoring technologies to identify discomfort and distressing symptoms in persons with limited communication at the end of life: a scoping review

Authors: Xu, J.; Smaling, H. J. A.; Schoones, J. W., et al

Journal: BMC Palliative Care. (2024)

Abstract:

BACKGROUND: Discomfort and distressing symptoms are common at the end of life, while people in this stage are often no longer able to express themselves. Technologies may aid clinicians in detecting and treating these symptoms to improve end-of-life care. This review provides an overview of noninvasive monitoring technologies that may be applied to persons with limited communication at the end of life to identify discomfort.

METHODS: A systematic search was performed in nine databases, and experts were consulted. Manuscripts were included if they were written in English, Dutch, German, French, Japanese or Chinese, if the monitoring technology measured discomfort or distressing symptoms, was noninvasive, could be continuously administered for 4 hours and was potentially applicable for bed-ridden people. The screening was performed by two researchers independently. Information about the technology, its clinimetrics (validity, reliability, sensitivity, specificity, responsiveness), acceptability, and feasibility were extracted.

RESULTS: Of the 3,414 identified manuscripts, 229 met the eligibility criteria. A variety of monitoring technologies were identified, including actigraphy, brain activity monitoring, electrocardiography, electrodermal activity monitoring, surface electromyography, incontinence sensors, multimodal systems, and noncontact monitoring systems. The main indicators of discomfort monitored by these technologies were sleep, level of consciousness, risk of pressure ulcers, urinary incontinence, agitation, and pain. For the end-of-life phase, brain activity monitors could be helpful and acceptable to monitor the level of consciousness during palliative sedation. However, no manuscripts have reported on the clinimetrics, feasibility, and acceptability of the other technologies for the end-of-life phase.

CONCLUSIONS: Noninvasive monitoring technologies are available to measure common symptoms at the end of life. Future research should evaluate the quality of evidence provided by existing studies and investigate the feasibility, acceptability, and usefulness of these technologies in the end-of-life setting. Guidelines for studies on healthcare technologies should be better implemented and further developed.

Full text available online: <https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-024-01371-0>

Need further help? The outreach team at the Bodleian Health Care Libraries is here to support the information needs of all OUH Trust staff.

We're happy to help you with literature searches, search skills training and advice, keeping you up to date, and general references enquiries.

Contact us:

hcl-enquiries@bodleian.ox.ac.uk

www.bodleian.ox.ac.uk/nhs

Register for OpenAthens to access e-resources:

<https://openathens.nice.org.uk/>

To subscribe/unsubscribe from this bulletin please email hcl-enquiries@bodleian.ox.ac.uk or reply to this email. Please see our privacy notice https://libguides.bodleian.ox.ac.uk/Keeping_up_to_date/privacynotice