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PALLIATIVE CARE BULLETIN

December 2023

Contents

Children

Truth-telling to the seriously ill child - Nurses' experiences, attitudes, and beliefs

Authors: El Ali, M.; Licqurish, S.; O'Neill, J. and Gillam, L.

Journal: Nursing Ethics. (2023)

Abstract:

BACKGROUND: Nurses play an integral role in the care of children hospitalised with a serious illness. Although information about diagnostics, treatments, and prognosis are generally conveyed to parents and caregivers of seriously ill children by physicians, nurses spend a significant amount of time at the child's bedside and have an acknowledged role in helping patients and families understand the information that they have been given by a doctor. Hence, the ethical role of the nurse in truth disclosure to children is worth exploring.

METHODS: A systematic academic database and grey literature search strategy was conducted using CINAHL, Medline Psych Info, and Google Scholar. Keywords used included truth, children, nurse, disclosure, serious illness, and communication. A total of 17 publications of varying types were included in the final data set.

ETHICAL CONSIDERATIONS: As this was a review of the literature, there were no direct human participants. Empirical studies included in the review had received ethics approval.

RESULTS: Of the 17 articles included in the review, only one directly reported on the experiences of nurses asked to withhold the truth from patients. Empirical studies were limited to HIV-positive children and children diagnosed with cancer and the dying child.

CONCLUSION: A paucity of literature exploring the experiences, attitudes, and beliefs of nurses with regard to truth-telling to seriously ill children is evident. Little consideration has been given to the role nurses play in communicating medical information to children in a hospital setting. The 17 articles included in the review focused on cancer, and HIV, diagnosis, and end-of-life care. Further research should be undertaken to explore the experiences and attitudes of nurses to clinical information sharing to children hospitalised with a wide range of serious illnesses and in diverse clinical scenarios.

Full text available online: https://journals.sagepub.com/doi/full/10.1177/09697330231215952

Parents' experiences of being involved in medical decision-making for their child with a life-limiting condition: A systematic review with narrative synthesis

Authors: Polakova, K.; Ahmed, F.; Vlckova, K. and Brearley, S. G.

Journal: Palliative Medicine. (2023)

Abstract:

BACKGROUND: Parental involvement in the decision-making processes about medical treatment for children with life-limiting conditions is recognised as good practice. Previous research

highlighted factors affecting the decision-making process, but little is known about how parents experience their participation.

AIM: To explore how parents experience their participation in the process of decision-making about treatment and future care for their children with life-limiting conditions.

DESIGN: A systematically constructed review using narrative synthesis. The PRISMA guidelines were followed to report the findings. Databases Medline, EMBASE, SCOPUS, CINAHL and PsycINFO were searched up to December 2023. The study protocol was registered at PROSPERO (RN CRD42021215863).

RESULTS: From the initial 2512 citations identified, 28 papers met the inclusion criteria and were included in the review. A wide range of medical decisions was identified; stopping general or life-sustaining treatment was most frequent. Narrative synthesis revealed six themes: (1) Temporal aspects affecting the experience with decision-making; (2) Losing control of the situation; (3) Transferring the power to decide to doctors; (4) To be a 'good' parent and protect the child; (5) The emotional state of parents and (6) Sources of support to alleviate the parental experience.

CONCLUSIONS: Parental experiences with decision-making are complex and multifactorial. Parents' ability to effectively participate in the process is limited, as they are not empowered to do so and the circumstances in which the decisions are taking place are challenging. Healthcare professionals need to support parental involvement in an effective way instead of just formally asking them to participate.

Full text available online: https://journals.sagepub.com/doi/full/10.1177/02692163231214414

Healthy siblings' perspectives about paediatric palliative care: A qualitative systematic review and meta-synthesis

Authors: Rajendran, P.; Jarasiunaite-Fedosejeva, G.; İsbir, G. G. and Shorey, S.

Journal: Palliative Medicine. (2023)

Abstract:

BACKGROUND: Siblings of children requiring palliative care are often forgotten and overlooked, as the focus tends to be on the ill child and their parents. Limited knowledge of non-bereaved siblings' perspectives makes it challenging to provide appropriate support for them. A review of existing literature is thus needed to better understand the experiences of these siblings and to identify research gaps that may require further examination.

AIM: To consolidate the available qualitative evidence on the perspectives of non-bereaved healthy siblings regarding paediatric palliative care.

DESIGN: A qualitative systematic review using a meta-synthesis approach was conducted.

DATA SOURCES: Six electronic databases (PubMed, CINAHL, PsycINFO, Embase, Scopus and ProQuest Dissertations and Theses Global) were searched from each database's inception date until October 2022. The search included qualitative and mixed-method studies that reported the

perceptions and associations of siblings of patients receiving paediatric palliative care. Data were synthesised using thematic analysis.
RESULTS: Eleven studies were included. The overarching theme of the review would be 'A walking shadow: Living in the darkness shaped by the dying sibling', and three key themes and nine subthemes were identified from the included articles: (1) Changing family dynamics; (2) Impact on school and socialisation and (3) Psychological impact and coping.
CONCLUSION: Siblings demonstrated negative psychological impacts and were affected by changing family structure and relationships. However, socialisation with society, and varied coping skills such as cognitive coping and using distraction techniques, were significant for siblings to go through this journey and even led to some positive outcomes for them.

Full text available online: https://journals.sagepub.com/doi/10.1177/02692163231217597

Quality of Care in Pediatric Palliative Care: A Scoping Review

Authors: Ruiz-Gil, T. and Ródenas-Rigla, F.

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

Abstract:

Palliative care (PC) enhances the quality of life for patients and families facing life-threatening conditions. While PC is well-established for adults, not all practices apply to pediatrics. Consequently, specific quality indicators for Pediatric Palliative Care (PPC) must be identified. This scoping review aimed to identify the variables associated with the quality of care of PPC patients in Spain, focusing specifically on three areas: structure and process of care, psychological aspects of care, and care of patients approaching the end of life. The review was conducted following PRISMA-ScR guidelines. Searches were performed in the PubMed, Scopus, Web of Science, Embase, ProQuest, and Dialnet databases covering the period extending from January 2000 to May 2023. Finally, 35 studies were identified for the complete review. A total of 30 studies include variables associated with the structure and process of care, 20 include variables associated with psychological aspects of care, and 23 studies integrate variables related to patient care at the end of life. Analysis suggests that enhancing professional training in aspects such as communication with patients and families, creating intimate spaces with flexible visiting hours, increasing emotional support, promoting frequent contact with healthcare teams, and transparently communicating about illness and imminent death to both families and minors could improve the quality of PPC.

Full text available online: https://www.mdpi.com/2227-9067/10/12/1922

Parents' hope in perinatal and neonatal palliative care: a scoping review

Authors: Silveira, A. O.; Wernet, M.; Franco, L. F., et al

Journal: BMC Palliative Care. (2023)

Abstract:

BACKGROUND: The diagnosis of a life-limiting condition of a child in the perinatal or neonatal period is a threat to parental hopes. Hope is an interactional and multidimensional construct, and in palliative care, it is a determinant of quality of life, survival, acceptance and peaceful death.
OBJECTIVE: To map scientific evidence on parents' hope in perinatal and neonatal palliative care contexts.
METHOD: a scoping review theoretically grounded on Dufault and Martocchio's Framework, following the Joanna Briggs Institute methodological recommendations. Searches were performed until May 2023 in the MEDLINE, CINAHL and PsycINFO databases. The searches returned 1341 studies.
RESULTS: Eligible papers included 27 studies, most of which were carried out in the United States under a phenomenological or literature review approach. The centrality of women's perspectives in the context of pregnancy and perinatal palliative care was identified. The parental hope experience is articulated in dealing with the uncertainty of information and diagnosis, an approach to which interaction with health professionals is a determinant and potentially distressful element. Hope was identified as one of the determinants of coping and, consequently, linked to autonomy and parenthood. Cognitive and affiliative dimensions were the hope dimensions that predominated in the results, which corresponded to the parents' ability to formulate realistic goals and meaningful interpersonal relationships, respectively.
CONCLUSION: Hope is a force capable of guiding parents along the path of uncertainties experienced through the diagnosis of a condition that compromises their child's life. Health professionals can manage the family's hope by establishing sensitive therapeutic relationships that focus on the dimension of hope. The need for advanced research and intervention in parental and family hope are some of the points made in this study.
Full text available online: https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-023-01324-z

Communication

Anxiety and Depression in Metastatic Cancer: A Critical Review of Negative Impacts on Advance Care Planning and End-of-Life Decision Making With Practical Recommendations

Authors: Arch, J. J.; Bright, E. E.; Finkelstein, L. B., et al
Journal: JCO Oncology Practice. (2023)
Abstract:
PURPOSE: Providers treating adults with advanced cancer increasingly seek to engage patients and surrogates in advance care planning (ACP) and end-of-life (EOL) decision making; however, anxiety and depression may interfere with engagement. The intersection of these two key phenomena is examined among patients with metastatic cancer and their surrogates: the need

to prepare for and engage in ACP and EOL decision making and the high prevalence of anxiety and depression.

METHODS: Using a critical review framework, we examine the specific ways that anxiety and depression are likely to affect both ACP and EOL decision making.

RESULTS: The review indicates that depression is associated with reduced compliance with treatment recommendations, and high anxiety may result in avoidance of difficult discussions involved in ACP and EOL decision making. Depression and anxiety are associated with increased decisional regret in the context of cancer treatment decision making, as well as a preference for passive (not active) decision making in an intensive care unit setting. Anxiety about death in patients with advanced cancer is associated with lower rates of completion of an advance directive or discussion of EOL wishes with the oncologist. Patients with advanced cancer and elevated anxiety report higher discordance between wanted versus received life-sustaining treatments, less trust in their physicians, and less comprehension of the information communicated by their physicians.

CONCLUSION: Anxiety and depression are commonly elevated among adults with advanced cancer and health care surrogates, and can result in less engagement and satisfaction with ACP, cancer treatment, and EOL decisions. We offer practical strategies and sample scripts for oncology care providers to use to reduce the effects of anxiety and depression in these contexts.

Full text available via the library: https://libkey.io/10.1200/OP.23.00287

How clinicians recognise people who are dying: An integrative review

Authors: Colquhoun-Flannery, E.; Goodwin, D. and Walshe, C.

Journal: International Journal of Nursing Studies. (2023)

Abstract:

BACKGROUND: Timely recognition of dying is important for high quality end-of-life care however, little is known about how clinicians recognise dying. Late recognition is common and can lead to futile treatment that can prolong or increase suffering and prevent a change in the focus of care.

AIM: To explore how clinicians caring for dying people recognise that they are in the last days or hours of life, as well as the factors that influence the recognition of dying.

DESIGN: A systematically constructed integrative review of the literature.

METHODS: Medline, Scopus, Cumulative Index to Nursing and Allied Health Literature, PsycInfo and Allied and Complementary Medicine were searched in July 2022. Papers were included if they were original research, discussed how clinicians recognise dying, available in English language and published in 2012 or later. A constant comparison approach was applied to the analysis and synthesis of the literature.

RESULTS: 24 papers met the inclusion criteria. There were 3 main categories identified: 'Clues and signals' refers to prompts and signs that lead a clinician to believe a person is dying,

incorporating the sub-categories 'knowing the patient over time', and 'intuition and experience'. 'Recognition by others' is where clinicians come to recognise someone is dying through others. This can be through a change in the context of care such as a tool or care plan or by communication with the team. 'Culture, system and practice' refers to the cultural beliefs of a setting that influences awareness of dying and denial of death as a possibility and avoidance of naming death and dying directly. System and practice of the setting also impact on recognition of dying. This involves work pace and intensity, shift systems and timing of senior reviews of patients. Uncertainty and its impact on recognition of dying are evident throughout the findings of this review. The seeking of certainty and the absence of the possibility of dying contributes to late recognition of dying.

DISCUSSION: Recognition of dying is a complex process that occurs over time, involving a combination of intuition and gathering of information, that is influenced by contextual factors. A culture where dying is not openly acknowledged or even named explicitly contributes to late recognition of dying. A shared language and consistent terminology for explicitly naming dying are needed. Uncertainty is intrinsic to the recognition of dying and therefore a shift to recognising the possibility of dying rather than seeking certainty is needed.

Full text available online:

https://www.sciencedirect.com/science/article/pii/S0020748923002316

Barriers and facilitators that hospital clinicians perceive to discuss the personal values, wishes, and needs of patients in palliative care: a mixed-methods systematic review

Authors: de Vries, S.; Verhoef, M.; Vervoort, S. C. J. M., et al

Journal: Palliative Care and Social Practice. (2023)

Abstract:

BACKGROUND: The exploration and monitoring of the personal values, wishes, and needs (VWN) of patients in the palliative phase by hospital clinicians is essential for guiding appropriate palliative care.

OBJECTIVE: To explore the barriers and facilitators concerning communication with patients in the palliative phase about their VWN as perceived by hospital clinicians.

DESIGN: A mixed-methods systematic review following the Joanna Briggs Institute guidelines for mixed-method systematic reviews and Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines was conducted.

DATA SOURCES AND METHODS: Eight databases, including PubMed, Embase, and CINAHL, were searched without time restrictions. The search string was built using the search Palliative cAre Literature rEview iTeraTive mEthod (PALETTE) framework. Eligible studies focused on (1) hospital clinicians and (2) perceived barriers and facilitators regarding the exploration and monitoring of the VWN of adult patients in the palliative phase. Two researchers independently selected articles and evaluated the quality. Findings were synthesized using a convergent integrated approach.

RESULTS: In total, 29 studies were included: 14 quantitative, 13 qualitative, and 2 mixed methods. Five synthesized findings were identified: (1) the clinician's professional manners, (2) the image formed of the patient and loved ones, (3) the human aspect of being a clinician, (4) the multidisciplinary collaboration, and (5) the contextual preconditions. Most studies seemed focused on communication about treatment decision making.

CONCLUSION: A patient-centered approach seems lacking when clinicians discuss the patient's VWN, since most studies focused on treatment decision making rather than on the exploration and monitoring of the multidimensional well-being of patients. This review emphasizes the need for the development and integration of a systematic approach to explore and monitor the patients' VWN to improve appropriate palliative care in hospitals.

Full text available online: https://journals.sagepub.com/doi/10.1177/26323524231212510

The Next Best Thing: Three Key Conversations to Convey Prognosis Over the Course of an Incurable Cancer

Authors: Gage, L. and Teply, M.

Journal: Clinical Colorectal Cancer. (2023)

Abstract:

INTRODUCTION: Waiting until a person is very near end of life to discuss limited life expectancy risks lower goal-concordant care and increased utilization of medical interventions with lower likelihood of benefit at the end of life. Medical training on communication skills in serious illness often focuses on early and late conversations regarding prognosis, with no guidance on navigating the conversations occurring in the middle of the illness course.

GOAL OF THE REVIEW: We propose a new framework for identifying and discussing prognosis at various points along the cancer course, as a continuum from beginning to end, that is prompted by changes in clinical status and number of available remaining cancer directed interventions.

DISCUSSION: SPIKES is a framework utilized for early conversations in a cancer course. REMAP is a framework utilization for late conversations in a cancer course. There is a gap in guidance on how to navigate conversations that occur between the early and late phases of a cancer course. We describe 3 general phases of care during a cancer course ("early," "middle," and "late"), with each phase warranting specific communication skills in order to improve patient understanding of prognosis, goal concordant care, and best practices for healthcare utilization in the acute and end of life care settings.

CONCLUSION: Framing prognosis by available medical interventions through a framework of "early," "middle," and "late" adds clarity to the phase of illness, expectations around delivery of information to the patient, and framing of recommendations at each given phase.

Full text available via the library: https://libkey.io/10.1016/j.clcc.2023.07.002

A Systematic Scoping Review on Dignity Assessment Tools

Authors: Lim, Y. X.; Quah, E. L. Y.; Chua, K. Z. Y., et al

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

Abstract:

CONTEXT: The provision of person-centered dignity-conserving care is central to palliative care. It is important to reevaluate current methods of assessing dignity as the concept of dignity is multi-faceted.

OBJECTIVES: The aim of this study is to understand the tools which are used to assess a patient's dignity and the elements of dignity evaluated in these tools.

METHODS: Two independent and concurrent Systematic Evidence-Based Approach guided systematic scoping reviews (SSR in SEBA) on existing dignity assessment tools and on accounts of assessments of dignity were carried out. The SSR in SEBA on dignity assessment tools involving PubMed, Embase, PsycINFO, Cochrane Database of Systematic Reviews, Scopus, and CINAHL databases saw 22 full-text articles included from the 645 articles reviewed. The SSR in SEBA on accounts of assessments of dignity featured in the PubMed database identified 102 full-text articles which saw 46 articles included.

RESULTS: domains identified were factors affecting patient's definition of dignity; elements of dignity conserving care; and components of effective tools.

CONCLUSION: Current accounts to assess dignity and assessment tools fail to capture shifting self-concepts of dignity holistically. A portfolio-like appraisal of dignity is proposed to achieve assessments which are timely, longitudinal, and patient-specific. Portfolio-based assessments by members of the multidisciplinary team will better direct timely evaluations of relevant aspects of changing concepts of dignity, without losing the patient's holistic perception of dignity.

Full text available online: https://www.jpsmjournal.com/article/S0885-3924(23)00831-X/fulltext

The role of patients' stories in medicine: a systematic scoping review

Authors: Quah, E. L. Y.; Chua, K. Z. Y.; Lin, C. K. R., et al

Journal: BMC Palliative Care. (2023)

Abstract:

BACKGROUND: Patients' stories provide Palliative Care physicians with a glimpse into the former's lives and their psycho-emotional, sociocultural, and contextual considerations. Yet, few physicians are trained to interpret and apply patients' stories in their practice. Inherent variability in how stories are transmitted and interpreted raises questions over their potential effects on care. Amidst a dearth of accounts in Palliative Care, we map current use of patient stories to guide the training, assessment, and oversight of this 'care influencing' practice in medicine.

METHODS: This systematic scoping review was guided by the Systematic Evidence-Based Approach (SEBA) to ensure a reproducible and structured approach. The themes and categories identified through the Split Approach's concurrent and independent thematic and directed content analyses provided a comprehensive sketch of the included articles. The Jigsaw Perspective combined the themes and categories identified. The last stage of SEBA compared these results with two recent reviews of storytelling to ensure consistency of the domains created that guided the discussion.

RESULTS: Ten thousand two hundred seven articles were reviewed, 963 full text articles were evaluated, and 199 articles were included. The four domains identified were study characteristics, benefits, approaches, and positive effects and concerns.

CONCLUSION: Stories support patient-centered, personalized, and holistic clinical care. However, variability in the stories, their interpretations and use in care decisions underscore the need for further study on the structuring, teaching, assessing, and delivery of this 'care influencing' practice.

Full text available online: https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-023-01319-w

Conditions

A systematic practice review: Providing palliative care for people with Parkinson's disease and their caregivers

Authors: Garon, M.; Weck, C.; Rosqvist, K., et al

Journal: Palliative Medicine. (2023)

Abstract:

BACKGROUND: People with Parkinson's disease has significant and increasing physical, psychosocial and spiritual needs, as well as problems with coordination and continuity of care. Despite the benefits that palliative care could offer, there is no consensus on how it should be delivered.

AIM: The aim of this study is to provide a pragmatic overview of the evidence to make clinical recommendations to improve palliative care for people with Parkinson's disease and their caregivers.

DESIGN: A systematic review method was adopted to determine the strength of evidence, supported by feedback from an expert panel, to generate the 'do', 'do not do' and 'do not know' recommendations for palliative care.

DATA SOURCES: Searches were conducted via OVID to access CINAHL, MEDLINE, EMBASE and the Cochrane Library from 01/01/2006 to 31/05/2021. An additional search was conducted in

December 2022. The search was limited to articles that included empirical studies of approaches to enabling palliative care.

RESULTS: A total of 62 studies met inclusion criteria. There is evidence that education about palliative care and movement disorders is essential. palliative care should be multi-disciplinary, individualised and coordinated. Proactive involvement and support of caregivers throughout the illness is recommended. Limited data provide referral indicators for palliative care integration. Discussions about advance care planning should be held early.

CONCLUSIONS: Consideration of palliative care integration based on symptom burden and personal preferences, coordination and continuity of care are needed to maintain the quality of life of people with Parkinson's disease and their caregivers.

Full text available online: https://journals.sagepub.com/doi/full/10.1177/02692163231214408

Integrating palliative care and heart failure: a systematic realist synthesis (PalliatHeartSynthesis)

Authors: McConnell, T.; Blair, C.; Burden, J., et al

Journal: Open Heart. (2023)

Abstract:

OBJECTIVES: (1) Develop a programme theory of why, for whom and in what contexts integrated palliative care (PC) and heart failure (HF) services work/do not work; (2) use the programme theory to co-produce with stakeholders, intervention strategies to inform best practice and future research.

METHODS: A systematic review of all published articles and grey literature using a realist logic of analysis. The search strategy combined terms significant to the review questions: HF, PC and end of life. Documents were included if they were in English and provided data relevant to integration of PC and HF services. Searches were conducted in November 2021 in EMBASE, MEDLINE, PsycINFO, AMED, HMIC and CINAHL. Further relevant documents were identified via monthly alerts (up until April 2023) and the project stakeholder group (patient/carers, content experts and multidisciplinary practitioners).

RESULTS: 130 documents were included (86 research, 22 literature reviews, 22 grey literature). The programme theory identified intervention strategies most likely to support integration of PC and HF services. These included protected time for evidence-based PC and HF education from undergraduate/postgraduate level and continuing professional practice; choice of educational setting (eg, online, face-to-face or hybrid); increased awareness and seeing benefits of PC for HF management; conveying the emotive and intellectual need for integrating PC and HF via credible champions; and prioritising PC and HF guidelines in practice.

CONCLUSIONS: The review findings outline the required steps to take to increase the likelihood that all key players have the capacity, opportunity and motivation to integrate PC into HF management.

Full text available online: https://openheart.bmj.com/content/10/2/e002438

Palliative care in the treatment of women with breast cancer: A scoping review

Authors: Velasco Yanez, R. J.; Carvalho Fernandes, A. F.; de Freitas Corpes, E., et al

Journal: Palliative & Supportive Care. (2023)

Abstract:

OBJECTIVES: Recent studies on the quality of life in women with breast cancer show a high prevalence of signs and symptoms that should be the focus of palliative care (PC), leading us to question the current role they play in addressing breast cancer. Therefore, the objective of this review is to map the scope of available literature on the role of PC in the treatment of women with breast cancer.

METHODS: This is a methodologically guided scoping review by the Joanna Briggs Institute and adapted to the PRISMA Extension for Scoping Reviews (PRISMA-ScR) Checklist for report writing. Systematic searches were conducted in 8 databases, an electronic repository, and gray literature. The searches were conducted with the support of a librarian. The study selection was managed through the RAYYAN software in a blind and independent manner by 2 reviewers. The extracted data were analyzed using the qualitative thematic analysis technique and discussed through textual categories.

RESULTS: A total of 9,812 studies were identified, of which only 136 articles and 3 sources of gray literature are included in this review. In terms of general characteristics, the majority were published in the USA (35.7%), had a cross-sectional design (44.8%), and were abstracts presented at scientific events (19.6%). The majority of interventions focused on palliative radiotherapy (13.6%). Thematic analysis identified 14 themes and 12 subthemes.

SIGNIFICANCE OF RESULTS: Our findings offer a comprehensive view of the evidence on PC in the treatment of breast cancer. Although a methodological quality assessment was not conducted, these results could guide professionals interested in the topic to position themselves in the current context. Additionally, a quick synthesis of recommendations on different palliative therapies is provided, which should be critically observed. Finally, multiple knowledge gaps are highlighted, which could be used for the development of future studies in this field.

Full text available via the library: https://libkey.io/10.1017/S1478951523001840

Equality and diversity

Healthcare practitioners' perspectives of providing palliative care to patients from culturally diverse backgrounds: a qualitative systematic review

Authors: Burke, C.; Doody, O. and Lloyd, B.

Journal: BMC Palliative Care. (2023)

Abstract:

BACKGROUND: Palliative care practitioners are increasingly caring for patients and families from diverse cultural backgrounds. There is growing awareness of the influence of culture on many aspects of care in the palliative phase of an illness. However, disparities have been noted in the provision of palliative care to patients from culturally diverse backgrounds and challenges have been reported in meeting their needs and those of their families.

METHOD: A qualitative systematic review of research papers identified through searching four databases. Papers were screened against inclusion criteria within the timeframe of January 2012 to March 2022. Data was extraction from all included studies and methodological quality assessed utilising the Critical Appraisal Skills Programme Tool. Thematic analysis followed Braun and Clarke's framework and the review is reported in line with PRISMA guidelines.

FINDINGS: The search yielded 1954 results of which 26 were included for appraisal and review. Four themes were identified: communication and connection, the role of the family in death and dying, the role of education in addressing uncertainty, and institutional and societal factors. The findings highlighted challenges of communication and a fear of acting in a culturally insensitive way, the pivotal role of the family, the need for an individualised approach to care, the universality of needs when approaching end of life and the need for education of practitioners.

CONCLUSION: These findings suggest that healthcare practitioners draw on their existing skills to adapt their practice to meet the needs of patients from culturally diverse backgrounds. However, results also indicate a need for further education and identification of educational approaches best suited to supporting healthcare professionals in practice.

Full text available online: https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-023-01285-3

Applied patient-level palliative care interventions designed to meet the needs of sexual and gender minorities: A scoping review and qualitative content analysis of how to support sexual and gender minorities at end of life

Authors: Robinson, L. and Matamoros, C.

Journal: Palliative Medicine. (2023)

Abstract:

BACKGROUND: Sexual and gender minorities experience considerable health disparities across the life span. End of life presents unique challenges for this population, further exacerbating existing disparities.

AIM: We aimed to identify applied patient-level palliative care interventions for sexual and gender minorities and describe how said interventions met the needs of these populations at end of life.

DESIGN: We conducted a scoping review in keeping with the updated Arksey and O'Malley Framework. All included reports were analyzed qualitatively to describe the intervention and summarize thematically how it met the needs of sexual and gender minorities at end of life.
DATA SOURCES: We conducted searches in MEDLINE, EMBASE, PsychInfo, and CINAHL from 1946 to June 10, 2023. Reports were eligible for inclusion if they described a palliative care intervention delivered to sexual and gender minorities, and if the palliative care intervention responded to at least one specific need of the sexual and gender minority population(s) in question.
RESULTS: We included and summarized 27 reports. We identified three overarching themes describing how palliative care interventions responded to the needs of sexual and gender minorities at end of life.
CONCLUSIONS: This review responds to a need to improve palliative care delivery for sexual and gender minorities. Recommendations derived from these interventions, including how to center and advocate for sexual and gender minorities at end of life, can be applied by any interdisciplinary palliative care provider.
Full text available online: https://journals.sagepub.com/doi/full/10.1177/02692163231214123

Medicines and treatments

Medically assisted hydration for adults receiving palliative care

Authors: Buchan, E. J.; Haywood, A.; Syrmis, W. and Good, P.

Journal: The Cochrane Database of Systematic Reviews. (2023)

Abstract:

BACKGROUND: Many people receiving palliative care have reduced oral intake during their illness, and particularly at the end of their life. Management of this can include the provision of medically assisted hydration (MAH) with the aim of improving their quality of life (QoL), prolonging their life, or both. This is an updated version of the original Cochrane Review published in Issue 2, 2008, and updated in February 2011 and March 2014.
OBJECTIVES: To determine the effectiveness of MAH compared with placebo and standard care, in adults receiving palliative care on their QoL and survival, and to assess for potential adverse events.
SEARCH METHODS: We searched for studies in the Cochrane Central Register of Controlled Trials (CENTRAL), MEDLINE, Embase, CINAHL, CANCERLIT, CareSearch, Dissertation Abstracts, Science Citation Index and the reference lists of all eligible studies, key textbooks, and previous systematic reviews. The date of the latest search conducted on CENTRAL, MEDLINE, and Embase was 17 November 2022.

SELECTION CRITERIA: We included all relevant randomised controlled trials (RCTs) of studies of MAH in adults receiving palliative care aged 18 and above. The criteria for inclusion was the comparison of MAH to placebo or standard care.
DATA COLLECTION AND ANALYSIS: Three review authors independently reviewed titles and abstracts for relevance, and two review authors extracted data and performed risk of bias assessment. The primary outcome was QoL using validated scales; secondary outcomes were survival and adverse events. For continuous outcomes, we measured the arithmetic mean and standard deviation (SD), and reported the mean difference (MD) with 95% confidence interval (CI) between groups. For dichotomous outcomes, we estimated and compared the risk ratio (RR) with 95% CIs between groups. For time-to-event data, we planned to calculate the survival time from the date of randomisation and to estimate and express the intervention effect as the hazard ratio (HR). We assessed the certainty of evidence using GRADE and created two summary of findings tables.
MAIN RESULTS: We identified one new study (200 participants), for a total of four studies included in this update (422 participants). All participants had a diagnosis of advanced cancer. With the exception of 29 participants who had a haematological malignancy, all others were solid organ cancers. Two studies each compared MAH to placebo and standard care. There were too few included studies to evaluate different subgroups, such as type of participant, intervention, timing of intervention, and study site. We considered one study to be at high risk of performance and detection bias due to lack of blinding; otherwise, risk of bias was assessed as low or unclear. MAH compared with placebo Quality of life One study measured change in QoL at one week using Functional Assessment of Cancer Therapy - General (FACT-G) (scale from 0 to 108; higher score = better QoL). No data were available from the other study. We are uncertain whether MAH improves QoL (MD 4.10, 95% CI -1.63 to 9.83; 1 study, 93 participants, very low-certainty evidence). Survival One study reported on survival from study enrolment to last date of follow-up or death. We were unable to estimate HR. No data were available from the other study. We are uncertain whether MAH improves survival (1 study, 93 participants, very low-certainty evidence). Adverse events One study reported on intensity of adverse events at two days using a numeric rating scale (scale from 0 to 10; lower score = less toxicity). No data were available from the other study. We are uncertain whether MAH leads to adverse events (injection site pain: MD 0.35, 95% CI -1.19 to 1.89; injection site swelling MD -0.59, 95% CI -1.40 to 0.22; 1 study, 49 participants, very low-certainty evidence). MAH compared with standard care Quality of life No data were available for QoL. Survival One study measured survival from randomisation to last date of follow-up at 14 days or death. No data were available from the other study. We are uncertain whether MAH improves survival (HR 0.36, 95% CI 0.22 to 0.59; 1 study, 200 participants, very low-certainty evidence). Adverse events Two studies measured adverse events

at follow-up (range 2 to 14 days). We are uncertain whether MAH leads to adverse events (RR 11.62, 95% CI 1.62 to 83.41; 2 studies, 242 participants, very low-certainty evidence).
AUTHORS' CONCLUSIONS: Since the previous update of this review, we have found one new study. In adults receiving palliative care in the end stage of their illness, there remains insufficient evidence to determine whether MAH improves QoL or prolongs survival, compared with placebo or standard care. Given that all participants were inpatients with advanced cancer at end of life, our findings are not transferable to adults receiving palliative care in other settings, for non-cancer, dementia or neurodegenerative diseases, or for those with an extended prognosis. Clinicians will need to make decisions based on the perceived benefits and harms of MAH for each individual's circumstances, without the benefit of high-quality evidence to guide them.

Full text available online:
https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD006273.pub4/full

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. (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 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

Patient experience

The Validity of Patient-Reported Outcome Measures of Quality of Life in Palliative Care: A Systematic Review

Authors: Li, Y.; Hung, V.; Ho, K., et al

Journal: Journal of Palliative Medicine. (2023)

Abstract:

Importance: A recent systematic review and meta-analysis found that palliative care was not associated with improvement in quality of life (QOL) in terminal noncancer illness. Among potential reasons for a null effect, it is unclear if patient-reported outcome measures (PROMs) measuring QOL were derived or validated among populations with advanced life-limiting illness (ALLI). Objective: To systematically review the derivation and validation of QOL PROMs from a recent meta-analysis of randomized controlled trials (RCT) of palliative care interventions in people with terminal noncancer illness. Evidence Review: EMBASE, MEDLINE, and PsycINFO were searched from inception to January 8, 2023 for primary validation studies of QOL PROMs in populations with ALLI, defined as adults with a progressive terminal condition and an estimated median survival of less than or equal to one year. The primary outcome was the proportion of PROMs that were derived or validated in ≥1 ALLI population. Findings: Twenty-one unique studies of derivation (n = 13) and validation (n = 11, 3 studies evaluated both) provided data on 9657 participants (mean age 63 years, 50% female) across 15 unique QOL PROMs and subscales. Among studies of validation, 9 were in people with cancer (n = 2289, n = 5 PROMs), 1 in neurodegenerative disease (n = 23, n = 1 PROM), and 1 with mixed diseases (n = 248, n = 1 PROM). Across 15 QOL PROMs and subscales, 47% (n = 7) were derived or validated in an ALLI population. The majority of these seven PROMs were exclusively derived or validated among people with cancer (57%, n = 4). QOL PROMs such as Quality of Life at End of Life, EuroQoL-5 Dimension 5-level, and 36-item Short Form Survey demonstrated validity in more than one terminal noncancer illness. Conclusions: Most QOL PROMs that measured the effect of palliative care on QOL in RCTs were neither derived nor validated in an ALLI population. These findings raise questions about the inferences that palliative care does not improve QOL among people with terminal noncancer illness.

Full text available via the library: https://libkey.io/10.1089/jpm.2023.0294

Preferences for Palliative and End-of-Life Care: A Systematic Review of Discrete Choice Experiments

Authors: Xia, Q.; Kularatna, M.; Virdun, C., et al

Journal: Value in Health : The Journal of the International Society for Pharmacoeconomics and Outcomes Research. (2023)

Abstract:

OBJECTIVES: Understanding what matters most to patients and their caregivers is fundamental to delivering high-quality care. This systematic review aimed to characterize and appraise the evidence from discrete choice experiments eliciting preferences for palliative care.

METHODS: A systematic literature search was undertaken for publications up until August 2022. Data were synthesized narratively. Thematic analysis was applied to categorize attributes into groups. Attribute development, frequency, and relative importance were analyzed. Subgroup analyses were conducted to compare outcomes between patient and proxy respondents.

RESULTS: Seventeen studies spanning 11 countries were included; 59% of studies solely considered preferences for patients with cancer. A range of respondent groups were represented including patients (76%) and proxies (caregivers [35%], health providers [12%], and the public [18%]). A total of 117 individual attributes were extracted and thematically grouped into 8 broad categories and 21 subcategories. Clinical outcomes including quality of life, length of life, and pain control were the most frequently reported attributes, whereas attributes relating to psychosocial components were largely absent. Both patients and proxy respondents prioritized pain control over additional survival time. Nevertheless, there were differences between respondent cohorts in the emphasis on other attributes such as access to care, timely information, and low risk of adverse effects (prioritized by patients), as opposed to cost, quality, and delivery of care (prioritized by proxies).

CONCLUSIONS: Our review underscores the vital role of pain control in palliative care; in addition, it shed light on the complexity and relative strength of preferences for various aspects of care from multiple perspectives, which is useful in developing personalized, patient-centered models of care for individuals nearing the end of life.

Full text available online: https://www.valueinhealthjournal.com/article/S1098-3015(23)03071-1/fulltext

Physical and occupational therapy

The importance of a continuum of rehabilitation from diagnosis of advanced cancer to palliative care

Authors: Rezende, G.; Gomes-Ferraz, C. A.; Bacon, I. G. F. I. and De Carlo, Marysia Mara Rodrigues do Prado

Journal: Disability and Rehabilitation. (2023)

Abstract:

PURPOSE: Identifying the evidence found in the international scientific literature, referring to the concept of rehabilitation in the setting of oncologic palliative care.

METHODS: Integrative literature review based on articles published in indexed journals on the electronic databases: LILACS, CINAHL and PubMed/MEDLINE, WEB OF SCIENCE, OTSEEKER and PEDRO, following the PRISMA criteria. The quantitative articles were evaluated using the McMaster form for quantitative studies and the qualitative studies were assessed by the Critical Appraisal Skills Program. The studies were inserted in the Rayyan™ application.

RESULTS: The final sample was composed of 21 qualitative and quantitative articles published in the period from 2004 to 2021, in nine different countries. Three thematic units were defined addressing the interface between palliative care and rehabilitation, the concept of palliative rehabilitation and the barriers to its implementation. The quality of the articles reviewed varied from 31% to 100% of the criteria met.

CONCLUSION: The international scientific production reinforces the importance of including rehabilitation in care in oncologic palliative care, highlighting the concept of palliative rehabilitation, but there is a need for expanding and divulging new research on the theme and the results.

IMPLICATIONS FOR REHABILITATION: Palliative care services and rehabilitation services should take and create opportunities to promote rehabilitation for people living with incurable cancer. Palliative rehabilitation has an important role in the treatment of people with advanced cancer, helping increase the quality of life, relief of pain, symptoms, and distress. It is considered an integral part of palliative care, given that rehabilitation and palliative care are related to the continuum of care. It is important to understand this gap in the international literature on the continuum between rehabilitation and palliative rehabilitation to improve the provision of this approach in both rehabilitation and palliative care services.

Full text available via the library: https://libkey.io/10.1080/09638288.2022.2140456

Place of care

Patient and families' perspectives on telepalliative care: A systematic integrative review

Authors: Hayes Bauer, E.; Schultz, A. N. Ø; Brandt, F., et al

Journal: Palliative Medicine. (2023)

Abstract:

BACKGROUND: Telepalliative care is increasingly used in palliative care, but has yet to be examined from a patient and family perspective. A synthesis of evidence may provide knowledge on how to plan and provide telepalliative care that caters specifically to patients and families' needs.

OBJECTIVE: To synthesise evidence on patients and families' perspectives on telepalliative care.

DESIGN: A systematic integrative review (PROSPERO #CRD42022301206) reported in accordance with PRISMA 2020 guidelines. Inclusion criteria; primary peer-reviewed studies published 2011-2022, patient and family perspective, >18 years, telepalliative care and English/Danish language. Quality was appraised using the mixed-methods appraisal tool, version 2020. Guided by Toronto and Remington, data were extracted, thematically analysed and synthesised.

DATA SOURCES: MEDLINE, EMBASE, PsycINFO and CINAHL were searched in March 2022 and updated in February 2023. RESULTS: Forty-four studies were included. Analysis revealed five themes; the effect of the Covid-19 pandemic on telepalliative care, adding value for patients and families, synchronous and asynchronous telepalliative care, the integration of telepalliative care with other services and the tailoring and timing of telepalliative care.

CONCLUSION: Enhanced access to care and convenience, as attributes of telepalliative care, are highly valued. Patients and families have varying needs during the illness trajectory that may be addressed by early integration of telepalliative care based on models of care that are flexible and combine synchronous and asynchronous solutions. Further research should examine telepalliative care in a post-pandemic context, use of models of care and identify meaningful outcome measures from patient and family perspectives for evaluation of telepalliative care.

Full text available online: https://journals.sagepub.com/doi/10.1177/02692163231217146

Spiritual and psychological care

Spiritual healing in palliative care with clinical hypnosis: neuroscience and therapy

Authors: Brugnoli, M. P.

Journal: The American Journal of Clinical Hypnosis. (2023)

Abstract:

The neuroscientific features of inner consciousness, including its role in suffering and in accessing states of mind that relieve suffering; details salient meditative and hypnotic approaches appropriate for palliative settings of care; discusses core principles and orientations shared by effective approaches; and proposes early integration of hypnotic training as a coping

skill and a platform for spiritual exploration, as desired.

Full text available via the library: https://libkey.io/10.1080/00029157.2023.2281466

Effects of Music Therapy on Spiritual Well-Being among Patients with Advanced Cancer in Palliative Care: A Meta-Analysis of Randomized Controlled Trials

Authors: Huda, N.; Banda, K. J.; Liu, A. and Huang, T.

Journal: Seminars in Oncology Nursing. (2023)

Abstract:

PURPOSE: Patients with advanced cancer in palliative care often experience physical and psychological symptoms that negatively impact their quality of life (QoL) and spiritual well-being. Music therapy can be used for symptom management in these patients. However, the effectiveness is uncertain. To determine the effectiveness of music therapy on spiritual well-being, QoL, pain, and psychological distress using randomized controlled trials (RCTs).
DATA SOURCE: A systematic search was conducted in EMBASE, PubMed, Cochrane Library, CINAHL, Web of Science, and the ClinicalTrial.gov registry up to September 2022.
CONCLUSION: The meta-analysis included seven RCTs with a total of 747 advanced cancer patients. Music therapy was found to significantly improve spiritual well-being with a mean difference of 0.43 (95% CI: 0.25 to 0.61, P < .001) in the intervention group compared to the control group. However, no significant group differences were found between the intervention and control groups for QoL (SMD: 0.53, 95% CI: -0.12 to 1.13, P = .11), pain (MD: -0.81, 95% CI: -2.06 to 0.44, P = .20), and psychological distress (SMD: -0.05, 95% CI: -0.41 to 0.32, P = .81). Music therapy can effectively improve the spiritual well-being of palliative care patients. However, its beneficial effects on QoL, pain, and psychological distress were minimal.
IMPLICATIONS FOR NURSING PRACTICE: Music therapy interventions can be introduced to help patients deal with spiritual/existential needs. Future studies should identify optimal characteristics of music therapy interventions to aid in enhancing the quality of palliative care for patients with advanced cancer.

Full text available via NHS OpenAthens: https://libkey.io/10.1016/j.soncn.2023.151481

Spiritual Care Guide in Hospice. Palliative Care

Authors: Kang, K.; Kim, D.; Koh, S., et al

Journal: Journal of Hospice and Palliative Care. (2023)

Abstract:

The Spiritual Care Guide in Hospice. Palliative Care is evidence-based and focuses on the universal and integral aspects of human spirituality-such as meaning and purpose, interconnectedness, and transcendence-which go beyond any specific religion. This guide was crafted to improve the spiritual well-being of adult patients aged 19 and older, as well as their families, who are receiving end-of-life care. The provision of spiritual care in hospice and palliative settings aims to assist patients and their families in finding life's meaning and purpose, restoring love and relationships, and helping them come to terms with death while maintaining hope. It is recommended that spiritual needs and the interventions provided are periodically reassessed and evaluated, with the findings recorded. Additionally, hospice and palliative care teams are encouraged to pursue ongoing education and training in spiritual care. Although challenges exist in universally applying this guide across all hospice and palliative care organizations in Korea-due to varying resources and the specific environments of medical institutions-it is significant that the Korean Society for Hospice and Palliative Care has introduced a spiritual care guide poised to enhance the spiritual well-being and quality of care for hospice and palliative care patients.

Full text available online: https://www.e-jhpc.org/journal/view.html?uid=527&vmd=Full

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