Relevant research papers, reviews, letters reporting original research, editorials and case reports are indexed for inclusion. All papers cited are in the English language unless otherwise stated in brackets. Significant papers are cited with full source data and an abstract. Papers are arranged within the headings. The bibliography is intended to be as near comprehensive as possible; the Editorial Board has advised on those journals to be included and a list of those given priority in indexing is given below.

**Priority journals**

The following journals are awarded priority in the compilation of the bibliography:

| AIDS Patient Care and STDs | Internal Medicine Journal |
|--------------------------|--------------------------|
| Acta Oncologica           | Journal of Advanced Nursing |
| AIDS Care                 | Journal of Cancer Research & Clinical Oncology |
| American Journal of Hospice and Palliative Medicine | Journal of Clinical Oncology |
| Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration | Journal of Pain and Palliative Care Pharmacotherapy |
| Annals of Internal Medicine | Journal of Pain and Symptom Management |
| Annals of Oncology        | Journal of Palliative Care |
| Annals of Surgical Oncology | Journal of Palliative Medicine |
| Blood                     | Journal of Social Work in End-of-life and Palliative Care |
| BMC Cancer                | JAMA                     |
| BMC Complementary Medicine and Therapies | Lancet |
| BMC Palliative Care       | Lancet Oncology          |
| BMJ                       | Medical Journal of Australia |
| BMJ Quality and Safety    | New England Journal of Medicine |
| BMJ Supportive and Palliative Care | Nursing Clinics of North America |
| British Journal of Cancer | Nutrition and Cancer     |
| Canadian Oncology Nursing Journal | Omega (Westport) |
| Cancer                    | Oncology Nursing Forum   |
| Cancer Nursing            | Palliative Medicine      |
| Cardiology                | Palliative and Supportive Care |
| Clinical Journal of Oncology Nursing | Pediatric Blood and Cancer |
| Clinical Oncology (Royal Coll Rad) | Pediatric Hematology and Oncology |
| CMAJ                      | Psycho-oncology          |
| Current Opinion in Supportive and Palliative Care | Quality of Life Research |
| Death Studies             | Seminars in Oncology Nursing |
| Disability and Rehabilitation European | Supportive Care in Cancer |
| European Journal of Cancer Care | Thorax |
| European Journal of Surgical Oncology | |
| International Journal of Cancer | |
| International Journal of Palliative Nursing | |
**The ‘surprise question’ in heart failure: A prospective cohort study**

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*BMJ Support Palliat Care*. 2024;14(1):68–75. doi: 10.1136/bmjspcare-2021-003143.

OBJECTIVE: The Surprise Question (SQ) is a prognostic screening tool used to identify patients with limited life expectancy. We assessed the SQ’s performance predicting 1-year mortality among patients in ambulatory heart failure (HF) clinics. We determined that the SQ’s performance changes according to sex and other demographic (age) and clinical characteristics, mainly left ventricular ejection fraction (LVEF) and the New York Heart Association (NYHA) functional classifications.

METHODS: We conducted a prospective cohort study in two HF clinics. To assess the performance of the SQ in predicting 1-year mortality, we calculated the sensitivity, specificity, positive and negative likelihood ratios, and the positive and negative predictive values. To illustrate if the results of the SQ changes the probability that a patient dies within 1 year, we created Fagan’s nomograms. We report the results from the overall sample and for subgroups according to sex, age, LVEF and NYHA functional class.

RESULTS: We observed that the SQ showed a sensitivity of 85% identifying ambulatory patients with HF who are in the last year of life. We determined that the SQ’s performance predicting 1-year mortality was similar among women and men. The SQ performed better for patients aged under 70 years, for patients with reduced or mildly reduced ejection fraction, and for patients NYHA class III/IV.

CONCLUSIONS: We consider the tool an easy and fast first step to identify patients with HF who might benefit from an advance care planning discussion or a referral to palliative care due to limited life expectancy.

**Are surprise questions and probabilistic questions by nurses useful in home palliative care? A prospective study**

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*Am J Hosp Palliat Care*. 2024;41(4):431–41. doi: 10.1177/10499091231187355.

Background: Surprise questions (SQs) are used as screening tools in palliative care. Probabilistic questions (PQs) are more accurate than temporal predictions. However, no study has examined the usefulness of SQs and PQs assessed by nurses. Objectives: To examine the accuracy of nurses’ SQ and PQ assessments in patients with advanced cancer receiving home palliative care. Design: A prospective single-center cohort study. Setting/Subjects: Adult patients with advanced cancer who received palliative care at home in South Korea between 2019 and 2020. Measurements: Palliative care specialized nurses were asked the SQ, “Would you be surprised if the patient died in a specific timeframe?” and PQ, “What is the probability that this patient will be alive (0% to 100%) within a specific timeframe?” at the 1-, 2-, 4-, and 6-week timeframes at enrollment. We calculated the sensitivities and specificities of the SQs and PQs.

Results: 81 patients were recruited with 47 days of median survival. The sensitivity, specificity, and overall accuracy (OA) of the 1-week SQ were 50.0%, 93.2%, and 88.9%, respectively. The accuracies for the 1-week PQ were 12.5%, 100.0%, and 91.3%, respectively. The 6-week SQ showed sensitivity, specificity, and OA of 84.6%, 42.9%, and 62.9%, respectively; the accuracies for the 6-week PQ were 59.0%, 66.7%, and 63.0%, respectively. Conclusion: The SQ and PQ showed acceptable accuracy in home palliative care patients. Interestingly, PQ showed higher specificity than SQ at all timeframes. The SQ and PQ assessed by nurses may be useful in providing additional prognostic information for home palliative care.
Embodied decisions unfolding over time: A meta-ethnography systematic review of people with cancer’s reasons for delaying or declining end-of-life care

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**BMC Palliat Care.** 2024;23(1):45. doi: 10.1186/s12904-024-01342-5.

**BACKGROUND:** Barriers to accessing hospice and palliative care have been well studied. An important yet less researched area is why people approaching the end-of-life decide to decline a referral when they are offered services. This review focused on synthesising literature on patients in the last months of life due to a cancer diagnosis who have declined a referral to end-of-life care. **METHODS:** Six academic databases were systematically searched for qualitative literature published between 2007 and 2021. Two researchers independently reviewed and critically appraised the studies. Using meta-ethnographic methods of translation and synthesis, we set out to identify and develop a new overarching model of the reasons patients decline end-of-life care and the factors contributing to this decision. **RESULTS:** The search yielded 2060 articles, and nine articles were identified that met the review inclusion criteria. The included studies can be reconceptualised with the key concept of ‘embodied decisions unfolding over time’. It emphasises the iterative, dynamic, situational, contextual and relational nature of decisions about end-of-life care that are grounded in people’s physical experiences. The primary influences on how that decision unfolded for patients were (1) the communication they received about end-of-life care; (2) uncertainty around their prognosis, and (3) the evolving situations in which the patient and family found themselves. Our review identified contextual, person and medical factors that helped to shape the decision-making process. **CONCLUSIONS:** Decisions about when (and for some, whether at all) to accept end-of-life care are made in a complex system with preferences shifting over time, in relation to the embodied experience of life-limiting cancer. Time is central to patients’ end-of-life care decision-making, in particular estimating how much time one has left and patients’ embodied knowing about when the right time for end-of-life care is. The multiple and intersecting domains of health that inform decision-making, namely physical, mental, social, and existential/spiritual as well as emotions/affect need further exploration. The integration of palliative care across the cancer care trajectory and earlier introduction of end-of-life care highlight the importance of these findings for improving access whilst recognising that accessing end-of-life care will not be desired by all patients.
PPC/ACC2

Individual socioeconomic factors have a greater impact on end-of-life care outcomes than regional factors

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J Palliat Med. 2024;27(2):160–7. doi: 10.1089/jpm.2023.0163.

Background: End-of-life (EoL) care provided to Americans in urban and rural settings is distinct in terms of both available and delivered services. However, much less is known about which geographic, demographic, and health indicators are associated with disparities in EoL care and how individual versus regional characteristics influence quality of care (QoC). Objective: This study aimed to assess how regionality, rurality, and individual socioeconomic factors are associated with QoC in the last month of life (LML). Design: Nationally representative cross-sectional study using the proxy-completed LML questionnaire as part of the National Health and Aging Trends Study (NHATS). The data were linked at the zip code level to geographic and economic indicators. Settings/Subjects: A total of 2778 NHATS enrollees who died from 2012 to 2020. Measurements: Measurements included population density, socioeconomic indicators, health factors, and health outcomes. The primary independent variable was proxy-reported QoC during the LML (excellent vs. not excellent). Results: In our sample, 52.1% (n=1447) reported not excellent care and 47.9% (n=1331) reported excellent care. These populations varied in their demographic and socioeconomic characteristics. After accounting for survey weighting and design, decedents in the top income quartile had significantly greater odds of receiving excellent care than decedents in the bottom quartile. Decedents in zip codes with top quartile health outcome metrics had significantly greater odds of receiving excellent care (OR: 1.64; 95% CI: 1.17–2.29) than decedents in zip codes with bottom quartile health outcomes. County rurality index and county health factors were not correlated with QoC in the LML. Conclusions: High QoC at the EoL may be more associated with individual socioeconomic factors than regional indicators, including degrees of rurality. Clinicians should strive to recognize the interplay of individual characteristics and regional indicators to provide more personalized care.

PPC/ACC3

Knowledge of palliative care and barriers to access among outpatients with cancer

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J Pain Symptom Manage. 2024;67(2):115–25. doi: 10.1016/j.jpainsymman.2023.10.013.

CONTEXT: Palliative Care (PC) is poorly understood by laypersons. However, little is known about what ambulatory patients with cancer understand about PC or what barriers to access exist. METHODS: Outpatients undergoing cancer treatment completed a survey evaluating their familiarity and knowledge of PC, Palliative Care Knowledge Scale (PaCKS), feelings towards PC (before and after reading a definition of PC), barriers to PC, and prognostic understanding. We summarized responses descriptively and used logistic regression models to examine variables associated with familiarity and interest. RESULTS: The survey response rate was 32%. Of 151 participants, 58.9% reported familiarity with PC. The average PaCKS score was 11.9 out of 13 (standard deviation, 1.4), with 46.4% receiving a perfect score, indicating high knowledge of PC. Patients diagnosed more than one year ago had significantly increased odds of being familiar with PC (OR 2.93; 95% CI 1.37–6.25). More participants reported future interest in PC compared to current interest (74.2% vs 44.4%, respectively). Patients with stage III or IV cancer had significantly increased odds of having a current interest in receiving PC compared to patients with stage I or II disease (OR 2.66; 95% CI: 1.05, 6.76). Participants reported feeling significantly less anxious and more reassured after reading a standardized definition of PC (P<0.05). CONCLUSION: Outpatients with cancer who are being treated at a large academic cancer center exhibit high awareness and knowledge of PC, but anxiety toward PC persists. Factors beyond knowledge may perpetuate the delayed or lack of
involvement with PC. KEY MESSAGE: In this cross-sectional study of outpatients with cancer, findings suggest that high knowledge of PC may co-exist with a lingering uneasiness towards the service. Additionally, factors beyond knowledge, such as logistic barriers, anxiety, and oncologists’ preference may be perpetuating the delay or lack of involvement in PC.

ADVANCE DIRECTIVES

**PPC/ADV**

Digital advance care planning with severe mental illness: A retrospective observational cohort analysis of the use of an electronic palliative care coordination system

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*BMC Palliat Care.* 2024;23(1):56. doi: 10.1186/s12904-024-01381-y.

**BACKGROUND:** People living with severe mental illness (SMI) face significant health inequalities, including in palliative care. Advance Care Planning (ACP) is widely recommended by palliative care experts and could reduce inequalities. However, implementing ACP with this group is challenging. Electronic Palliative Care Coordination Systems such as Coordinate my Care (CMC) have been introduced to support documentation and sharing of ACP records with relevant healthcare providers. This study explores the use of CMC amongst those with SMI and aims to describe how those with a primary diagnosis of SMI who have used CMC for ACP, and makes recommendations for future research and policy.

**METHOD:** A retrospective observational cohort analysis was completed of CMC records created 01/01/2010–31/09/2021 where the service user had a primary diagnosis of SMI, with no exclusions based on comorbidities. Descriptive statistics were used to report on characteristics including: age, diagnosis, individual prognosis and resuscitation status. Thematic analysis was used to report on the content of patients’ statements of preference. RESULTS: 1826 records were identified. Of this sample most (60.1%) had capacity to make treatment decisions, 47.8% were aged under 70, 86.7% were given a prognosis of ‘years’ and most (63.1%) remained for full cardio-pulmonary resuscitation in the event of cardio-pulmonary arrest. Records with completed statements of preferences (20.3%) contained information about preferences for physical and mental health treatment care as well as information about patient presentation and capacity, although most were brief and lacked expression of patient voice. **DISCUSSION:** Compared to usual CMC users, the cohort of interest are relatively able, younger people using CMC to make long-term plans for active physical and mental health treatment. ADM is a service user-driven process, and so it was expected that authentic patient voice would be expressed within statements of preference, however this was mostly not achieved. **CONCLUSIONS:** This digital tool is being used by people with SMI but to plan for more than palliative care. This cohort and supporting professionals have used CMC to plan for longer term physical and mental healthcare. Future research and policy should focus on development of tailored digital tools for people with SMI to plan for palliative, physical and mental healthcare and support expression of patient voice.

**PPC/ADV**

Factors related to advance directives completion among cancer patients: A systematic review

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*BMC Palliat Care.* 2024;23(1):3. doi: 10.1186/s12904-023-01327-w.

**INTRODUCTION:** Advance directives (ADs) has recently been considered as an important component of palliative care for patients with advanced cancer and is a legally binding directive regarding a person’s future medical care. It is used when a person is unable to participate in the decision-making process about their own care. Therefore, the present systematic review investigated the factors related to ADs from the perspective of cancer patients. **METHODS:** A systematic review study was searched in four scientific databases: PubMed, Medline, Scopus, Web of Science, and ProQuest using with related keywords and without date restrictions. The quality of the studies was assessed using the Hawker criterion. The research papers were analyzed as directed content analysis based on the theory of planned behavior. **RESULTS:** Out of 5900 research papers found, 22 were included in the study. The perspectives of 9061 cancer patients were investigated, of whom 4347 were men and 4714 were women. The
Bibliography

According to TPB, factors affecting ADs were categorized into four categories, including attitude, subjective norm, perceived behavioral control, and external factors affecting the model. The attitude category includes two subcategories: “Lack of knowledge of the ADs concept” and “Previous experience of the disease”. The subjective norm category includes three subcategories: “Social support and interaction with family”, “Respecting the patient’s wishes” and “EOL care choices”. Also, the category of perceived control behavior was categorized into two subcategories: “Decision-making” and “Access to the healthcare system”, as well as external factors affecting the model, including “socio-demographic characteristics”. CONCLUSION: The studies indicate that attention to EOL care and the wishes of patients regarding receiving medical care and preservation of human dignity, the importance of facilitating open communication between patients and their families, and different perspectives on providing information, communicating bad news and making decisions require culturally sensitive approaches. Finally, the training of cancer care professionals in the palliative care practice, promoting the participation of health care professionals in ADs activities and creating an AD-positive attitude should be strongly encouraged.

**PPC/ADV**

The impact of advance care planning on healthcare professionals' well-being: A systematic review

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J Pain Symptom Manage. 2024;67(2):173–87. doi: 10.1016/j.jpainsymman.2023.09.026.

CONTEXT: Advance care planning (ACP) improves care for patients with chronic illnesses and reduces family stress. However, the impact of ACP interventions on healthcare professionals’ well-being remains unknown. OBJECTIVE: To systematically review the literature evaluating the impact of ACP interventions on healthcare professionals’ well-being. METHODS: We followed the Joanna Briggs Institute methodology for systematic reviews and registered the protocol in PROSPERO (CRD42022346354). We included primary studies in all languages that assessed the well-being of healthcare professionals in ACP interventions. We excluded any studies on ACP in psychiatric care and in palliative care that did not address goals of care. Searches were conducted on April 4, 2022, and March 6, 2023 in Embase, CINAHL, Web of Science, and PubMed. We used the Mixed Methods Appraisal Tool for quality analysis. We present results as a narrative synthesis because of their heterogeneity. RESULTS: We included 21 articles published in English between 1997 and 2021 with 17 published after 2019. All were conducted in high-income countries, and they involved a total of 1278 participants. Three reported an interprofessional intervention and two included patient partners. Studies had significant methodological flaws but most reported that ACP had a possible positive impact on healthcare professionals’ well-being. CONCLUSION: This review is the first to explore the impact of ACP interventions on healthcare professionals’ well-being. ACP interventions appear to have a positive impact, but high-quality studies are scarce. Further research is needed, particularly using more rigorous and systematic methods to implement interventions and report results.

**PPC/ADV**

Co-designing a culturally-sensitive theory-driven advance care planning game with Chinese older adults and healthcare providers

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Palliat Med. 2024;2692163231222776. doi: 10.1177/02692163231222776.

BACKGROUND: Advance care planning can be challenging because discussing end-of-life care often has negative connotations. Gamification is a novel approach to encourage advance care planning conversations in Western culture. AIM: To co-design a game with multiple stakeholders to promote advance care planning in Chinese communities. DESIGN: A two-phase design guided by the Medical Research Council framework for developing complex interventions was adopted between May 2019 and August 2020. In phase I, a game prototype was developed based on literature review, expert consultation and end-user consultation. In Phase II, the game prototype was tested among end-users and refined according to their feedback and expertise of a multi-
disciplinary team through an iterative process. SETTING/PARTICIPANTS: Experts in the field of aged care, palliative care, life education and game development and Chinese community-dwelling adults aged 60 years or older. RESULTS: A board game called ‘The Five Tastes Found in a Grocery Store’ was developed. The game design was shaped by Bandura’s Self-efficacy theory and feedback from experts and end-users. The participants generally found the gaming experience enjoyable and appreciated the opportunity to discuss end-of-life care openly. CONCLUSIONS: This study is the first to develop an evidence-informed, theory-based, culturally sensitive game for promoting advance care planning in the Chinese community using a co-design approach.

PPC/ADV5
The perspectives of people with dementia and their supporters on advance care planning: A qualitative study with the European working group of people with dementia
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Palliat Med. 2024:2692163231219915. doi: 10.1177/02692163231219915.

BACKGROUND: Advance care planning has been defined in an international consensus paper, supported by the European Association for Palliative Care. There are concerns that this definition may not apply to dementia. Moreover, it is not informed by input from people with dementia. AIM: To gather the perspective of the European Working Group of People with Dementia and their supporters on how advance care planning is defined and develop recommendations for changes to the definition. DESIGN: An in-depth qualitative study was conducted, analysing online focus groups and interviews using thematic analysis. SETTING/PARTICIPANTS: We included 12 people with dementia and 9 supporters. RESULTS: Participants suggested several changes to the current advance care planning definition: mentioning people with decreasing decisional capacity; better reflecting the role of family and/or trust-based relationships; reducing focus on end-of-life/medical decisions; strengthening focus on social aspects of care. Elements of the current definition that participants suggested keeping and highlighting include the framing of advance care planning as a continuous process, that is also optional; mention of communication next to documentation of decisions; and the importance of proxy decision makers. Based on this input, we developed three overarching and 16 specific recommendations for a modified definition of advance care planning that is inclusive of people with dementia. CONCLUSIONS: The perspectives of the European Working Group of People with Dementia and their supporters highlighted the need for a person-centred and dementia-inclusive advance care planning definition. We provide tangible recommendations for future adaptations of the definition that reflect these perspectives.

PPC/ADV6
A survey of state correctional health care providers on advance care planning: Opportunity for collaboration with corrections
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Prison populations are rapidly aging. Persons in prison age quicker and suffer more chronic illness and disability than their nonincarcerated peers, posing challenges to caring for prisoners who are chronically ill and dying. The goal of our study was to describe state prisons’ practices and policies addressing persons in prison with advanced chronic and life limiting illness through a national web-based survey of state-level prison health care professionals. In particular, we focused on advanced care planning, use of health care directives, decision-making about goals of care, including life sustaining treatments. The response rate was 22% for a sample size 152 completed surveys. The average age of respondent was 52 years; majority were female and Caucasian, and had worked in corrections more than 8 years. Nearly half were registered nurses. Most reported their prison did not have a dedicated end-of-life care program and only 11% offered a peer-care program. However, two-thirds indicated their facility provided the opportunity to designate a health care agent with physicians most likely responsible for facilitating completion of a health care directive. It is evident the care of persons aging and dying in prison is complex and requires further investigation addressing staff and prison population education,
ethics guidelines for care, compassionate release, and advance care planning. This study suggests that hospice and palliative care professionals could collaborate with corrections professionals and national organizations to provide innovative education and support to enhance the humane care of this vulnerable population.

**Advance care planning among patients with amyotrophic lateral sclerosis: Patient perspectives on goals of care conversations**

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*Am J Hosp Palliat Care*. 2024;41(3):295–301. doi: 10.1177/10499091231172901.

**INTRODUCTION:** Little is known regarding circumstances surrounding advanced care planning (ACP) for patients with amyotrophic lateral sclerosis (ALS). We aim to describe preferences, and perspectives surrounding ACP in patients with ALS.

**METHODS:** We conducted a survey of patients with ALS. Survey questions were related to advance directive completion and ACP discussions regarding end-of-life (EoL) choices. **RESULTS:** 49 surveys were included. Patients have given thought to advance directives, goals of care, and EoL treatments within months of diagnosis (Median: 1 month; IQR: .6 – 3 months). Twenty-seven opened dialogue with spouses, 24 with family members, 19 with health professionals and 16 with their lawyer. Eighty percent were comfortable discussing advance directives and power of attorney while fewer (70%) are less comfortable regarding specific aspects of care such as CPR or invasive ventilation. Only one barrier to discussion was identified with one patient reporting they did not wish to talk about the topic. There was no significant correlation between timing of diagnosis and whether an EoL discussion had occurred (τ(b)=.23, P=.14; n=42). Level of feeling informed was significantly associated with making EoL decisions for CPR, legal arrangements for a decision maker and completion of living will or AD. **CONCLUSION:** In this small cohort, a substantial proportion of ALS patients initiated EoL conversations early. When feeling informed, patients were more likely to make specific EoL choices. Findings suggest an opportunity for providers to help facilitate conversations, ensuring patient wishes.

**When and how to discuss about palliative care and advance care planning with cancer patients: A mixed-methods study**

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*Palliat Support Care*. 2024;22(2):387–95. doi: 10.1017/s1478951523001517.

**OBJECTIVES:** To identify the patients who are most likely to participate in discussions about palliative care (PC) and advance care planning (ACP), and to determine their preferred timing and approach of discussion.

**METHODS:** The study included women aged 18–75 years diagnosed with breast cancer. In the quantitative phase, sociodemographic and clinical characteristics, knowledge, decision-making, and stigmas were evaluated. The qualitative phase included questions about patients’ understanding, timing, and method of discussing PC and ACP, which were analyzed by Bardin’s content analysis.

**RESULTS:** In Phase 1, a total of 115 participants were included, with 53.04% completing both phases and 46.96% declining further participation. Those who completed both phases exhibited higher rates of marriage and educational attainment, while those who declined Phase 2 had a higher prevalence of advanced-stage cancer and palliative treatment. Completion of both phases was associated with a greater knowledge of reality and increased awareness of PC and ACP. Furthermore, the qualitative analysis revealed 5 convergent themes: timing, demystification, patient empowerment, misconception elimination, and open communication. These themes informed the development of a conceptual model that provides a framework for discussing PC and ACP with patients at different stages of cancer diagnosis and treatment, highlighting appropriate and inappropriate approaches and timing.

**SIGNIFICANCE OF RESULTS:** Early discussion is beneficial, but withholding information or infringing on autonomy should be avoided. The study reveals that married and highly educated individuals tend to be more receptive to these discussions. However, patients with late-stage cancer tend to decline participation. Patients value open communication, demystification of PC, and empowering discussions that eliminate misunderstandings. Efforts should be made to reach patients with limited familiarity, particularly those...
with late-stage cancer, to increase their receptiveness to enable well-informed decision-making.

**CARERS & FAMILIES**

**PPC/CAR 1**

**Intensive caring: Reminding families they matter**

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Families often struggle with feelings of helplessness and futility in supporting suffering loved ones. Healthcare providers face similar struggles when patients’ ailments aren’t readily fixable. Intensive Caring describes an approach to being with suffering, inspired by the words of Dame Cicely Saunders who said ‘you matter because you are you, and you matter to the last moment of your life. Intensive Caring describes how to affirm patients matter, comprised of non-abandonment, taking an interest in the patient as a person, containing hope, guiding families towards viable opportunities, dignity affirming tone, and therapeutic humility. While originally conceived for healthcare providers, its applications for families supporting suffering loved ones remains to be explored.

**PPC/CAR 2**

**Music therapy for supporting informal carers of adults with life-threatening illness pre- and post-bereavement: A mixed-methods systematic review**

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*BMC Palliat Care.* 2024;23(1):55. doi: 10.1186/s12904-024-01364-z.

**BACKGROUND:** Music therapy interventions with informal carers of individuals with life-threatening illness at pre- and post-bereavement is an increasingly important clinical area. This systematic review is the first to synthesise and critically evaluate the international evidence associated with music therapy with adult informal carers pre- and post-bereavement. Specifically, the objectives were: (i) to describe the characteristics and effectiveness of music therapy interventions which aim to improve health-related outcomes for adult informal carers of adults with life-threatening illness (pre- and post-bereavement), and (ii) to describe the experience of music therapy for adult informal carers of adults with life-threatening illness (pre- and post-bereavement).

**METHODS:** Eligibility: adult informal carers of adults at end of life or bereaved; music therapy interventions for improving health-related outcomes; qualitative; mixed-method; and quantitative studies including comparators of any other intervention; published in English from 1998 onwards. Six databases were searched up to July 2022. A JBI mixed-methods systematic review approach was followed throughout, including quality appraisal, data extraction and a convergent segregated approach to synthesis and integration.

**RESULTS:** A total of 34 studies were included, published between 2003 and 2022. Most were conducted in North America (n=13), Australia (n=10), or Europe (n=8). No studies were conducted in low- and middle-income countries or in the UK. The majority were qualitative (n=17), followed by quasi-experimental (n=8), mixed-methods (n=7) and two RCTs. The majority focused on carers of individuals with dementia (n=21) or advanced cancer (n=7). Seventeen studies were purely quantitative or included a quantitative component. During meta-synthesis, findings were aligned to core outcomes for evaluating bereavement interventions in palliative care and previously identified risk factors for complicated grief. Commonly targeted outcomes in quantitative studies included quality of life and mental wellbeing, showing equivocal effectiveness of music therapy with significant and non-significant results. Twenty-two studies either purely qualitative or with a qualitative component underwent meta synthesis and suggested a diverse range of improved pre- and post-bereavement outcomes for informal carers across all core outcomes, and across all risk and protective factors, including psychological, spiritual, emotional, and social outcomes. **CONCLUSIONS:** Qualitative studies provide moderate to strong evidence for improved health-related outcomes for adult informal carers of adults with life-threatening illness pre-bereavement. Limited studies including those bereaved negates conclusions for the bereavement phase. Comparisons and explanations for effectiveness across quantitative and qualitative studies are equivocal, with a high risk of bias and small
samples in the limited number of quantitative studies, demonstrating a need for high-quality RCTs.

**PPC/CAR₃**

**Knowledge gaps in end-of-life family caregiving for persons living with dementia: A study of hospice clinician perspectives**

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*Am J Hosp Palliat Care.* 2024;41(3):270–80. doi: 10.1177/10499091231176298.

**INTRODUCTION:** More than 35% of hospice care recipients 65 and older have a dementia diagnosis. Yet family care partners of persons living with dementia report feeling unprepared to address their hospice recipient’s changing needs nearing end of life. Hospice clinicians may have unique insight into the knowledge needs of family care partners and strategies for end-of-life dementia caregiving. METHODS: Semi-structured interviews were conducted with 18 hospice physicians, nurse practitioners, nurses, and social workers. Interview transcripts were deductively analyzed using thematic analysis to examine clinicians’ perspectives on gaps and strategies related to family care partner knowledge about end-of-life dementia caregiving. RESULTS: We identified 3 themes related to gaps in family care partners’ knowledge: dementia is a progressive, fatal disease; end-of-life symptoms and symptom management in persons living with advanced dementia; and understanding hospice goals and guidelines. Three themes related to clinicians’ strategies to increase knowledge included: providing education; teaching strategies to facilitate coping and preparedness for end-of-life care; and communicating with empathy. DISCUSSION: Clinicians perceive gaps in knowledge specific to dementia and end of life among family care partners. These gaps include a lack of understanding of Alzheimer’s symptom progression and strategies to manage common symptoms. Recommendations for approaches to reduce knowledge gaps include providing education and strategies delivered with empathy toward the family care partner experience. CONCLUSION: Clinicians who work with persons living with dementia receiving hospice care have valuable insights regarding family care partners’ gaps in knowledge. Implications on the training and preparation of hospice clinicians working with this care partner population are discussed.

**PPC/CAR₄**

**Caregivers’ concerns through health professionals’ eyes**

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*Palliat Support Care.* 2024:1–12. doi: 10.1017/s1478951523001864.

**OBJECTIVES:** Advancements in medicine and science have enabled more and more people to live longer with a chronic medical condition, namely cancer. Nevertheless, the palliative care (PC) approach continues to be introduced and incorporated later in the lives of patients and families dealing with such conditions. Thus, the need for individuals to care for this population in our society is increasing, giving rise to the so-called “informal caregivers.” The present study intends to examine the main obstacles faced by informal caregivers taking care of a cancer patient receiving PC based on what health professionals working in these settings perceive and write down. To achieve this goal, the written files of 2 Portuguese palliative care institutions were analyzed. METHODS: An inductive thematic analysis was conducted, focusing on the contact between health professionals and family caregivers and based on the notes taken by health professionals. RESULTS: Three main overarching themes were identified: (1) burden, (2) intra-family impact of the illness, and (3) network vulnerabilities. Included in this are the emphasis on the role of the family and social support, the high levels of psychological morbidity and caregiver burden present over this period, and a great need for information about the illness. SIGNIFICANCE OF RESULTS: This study provided a broader awareness regarding the daily struggle experienced by family caregivers, particularly those who juggle between “roles.” It is vital to understand the scope of the obstacles experienced by caregivers during the terminal phase of their loved one’s illness, given how important it is to address the family’s needs. Future studies and practitioners should consider these observations and topics when considering new approaches for this population, as they ought to be quite focused and short in time in order to meet people’s needs.
COMMUNICATION
PPC/COM1

Qualitative analysis of expressions used in the end-of-life discussions and their associated factors
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Palliat Support Care. 2024;22(2):374–80. doi: 10.1017/s1478951523001396.

OBJECTIVES: Discussing end-of-life (EOL) issues with patients remains challenging for health professionals. Physicians may use various expressions, including euphemistic ones, when disclosing the prognosis to their patients to reduce their psychological impact. However, the actual expressions of EOL disclosure in clinical practice are unclear. This study aims to investigate the expressions used in EOL disclosures and explore their associated factors.

METHODS: A retrospective chart review was conducted enrolling all the patients who died in a university-affiliated hospital. Expressions used in the EOL disclosure were qualitatively analyzed. The patients’ participation rate and length from the discussion to death were investigated.

RESULTS: EOL disclosures were observed in 341 of 358 patients. The expressions used by the physicians were categorized into 4 groups; Group 1: Clear presentation of life expectancy \((n=106; 31.1\%)\), Group 2: Euphemistic presentation of life expectancy \((n=24; 7.0\%)\), Group 3: Presentation of risk of sudden death \((n=147; 43.1\%)\), Group 4: No mention on life expectancy \((n=64; 18.8\%)\). The proportion of male patients was higher in Group 2 (79%) and lower in Group 4 (56%). Patients with cancer accounted for approximately 70% of Groups 1 and 4, but only approximately 30% of Group 3. The patient participation rate was highest in Group 4 (84.4%), followed by Group 2 (50.0%). The median time from EOL disclosure to death was longer in Groups 1 and 4 (26 and 29.5 days, respectively), compared to Groups 2 and 3 (18.5 and 16 days, respectively).

SIGNIFICANCE OF RESULTS: A variety of expressions are used in EOL disclosure. Patterns of communication are influenced by patients’ gender and type of illness (cancer or noncancer). Euphemisms do not seem to facilitate timely disclosure of life expectancy or patient participation. For health professionals, not only devising the expressions to alleviate their patients’ distress when breaking bad news but also considering the communication process and patient background are essential.

PPC/COM2

Family caregiver communication and perceptions of involvement in hospice care
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J Palliat Med. 2024. doi: 10.1089/jpm.2023.0576.

Background: The burden of caregiving for family members is significant and becomes particularly challenging at end of life, with negative effects on mental health, including anxiety and depression. Research has shown caregivers need better communication with their health care team. Objectives: To evaluate the relationship between hospice team communication with caregivers and caregiver involvement in care. Methods: The purpose of this secondary analysis of data collected from a U.S.-based cluster crossover randomized trial was to evaluate whether caregiver-centered communication (Caregiver-Centered Communication Questionnaire) is associated with a caregiver’s perceptions of involvement in care (Perceived Involved in Care Scale). A block-wise approach was used to estimate linear models, which were created using total scores and subscale scores. Results: Caregiver-centered communication was positively associated with perceptions of involvement in care. Conclusion: Skilled communication between hospice clinicians and family caregivers is critical in helping family members perception they are involved in the care of their loved one. There could be similar benefit in caregiver-centered communication during cancer treatment as well.

PPC/COM3

Communication strategies for adults in palliative care: The speech-language therapists’ perspective
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BMC Palliat Care. 2024;23(1):49. doi: 10.1186/s12904-024-01382-x.

BACKGROUND: Communication disorders are a challenge that many patients in palliative care (PC)
may encounter. This intervention area is emerging for the speech-language therapist (SLT), the professional who works in preventing, assessing, diagnosing, and treating human communication disorders. This study aims to identify and classify the communication strategies considered most important by SLTs for use in PC and evaluate whether there are any differences in perception regarding the importance of strategies between SLTs with and without PC experience.

METHODS: This cross-sectional quantitative study was conducted using a survey, which employed a well-structured, self-completion questionnaire previously validated by a panel of experts with over six years of PC experience. RESULTS: The strategies rated as most important within each group were the following: (i) adjust the patient’s position and minimise environmental noise; (ii) establish eye contact and adjust the pace of speech; (iii) adjust the language level and raise one topic at a time; (iv) use images of the patient’s interests and their personal objects; (v) use orality and multimodal form; (vi) use simplified language and structured pauses; and (vii) use tables with images and books with pictures. CONCLUSIONS: Verbal and non-verbal strategies were rated as highly important. There was no evidence of differences in perception in terms of importance between the SLTs with or without experience in PC, but more studies are needed to support this aspect. The patient’s communication ability is one of the cornerstones of PC quality. Through their actions, speech-language professionals could empower the patient with strategies so that they can autonomously and self-determinedly express their experiences and most significant needs.

**PPC/COM₄**

**End-of-life conversations about death and dying from volunteer perspectives: A qualitative study**

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*Palliat Support Care*. 2024;1–9. doi: 10.1017/s147895152300189x.

OBJECTIVES: Although often unrecognized, volunteers fulfill many essential roles in hospices and other end-of-life care settings. Volunteers complement the actions of professionals in fulfilling many extra care needs, such as delivering newspapers and tidying bedsides. We explored end-of-life conversations about death and dying between hospice volunteers and terminally ill people, with a particular emphasis on any expressed desire to die. Our 2 research questions were as follows: (1) What is the nature of end-of-life conversations between hospice patients and hospice volunteers? and (2) How do hospice volunteers experience conversations about death and dying with patients who are at the end-of-life? METHODS: We conducted semi-structured interviews using an interpretive phenomenological analysis. We recruited hospice volunteers from 4 hospices in Calgary, Edmonton, and Red Deer; 3 larger cities in the province of Alberta, Canada. RESULTS: We interviewed 12 participants to saturation. Four themes emerged: (1) trusting conversations about death and dying in the context of a safe place; (2) normalcy of conversations about death and dying; (3) building meaningful relationships; and (4) end-of-life conversations as a transformative experience. Our results emphasize the importance of preparing volunteers for conversations about death and dying, including the desire to die. SIGNIFICANCE OF RESULTS: The safe environment of the hospice, the commitment to patient confidentiality, and the ability of volunteers to meet the basic and emotional needs of dying people or simply just be present without having formal care duties that need to be completed contribute to volunteers being able to participate in timely and needed conversations about death and dying, including the desire to die. In turn, hospice experiences and end-of-life conversations provide a transformative experience for volunteers.

**PPC/COM₅**

**Some differences between social work, spiritual care, and psychology: Content variance in end-of-life conversations**

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*Palliat Support Care*. 2024;22(2):306–13. doi: 10.1017/s1478951523000652.

OBJECTIVES: Within the multidisciplinary team, there can sometimes be lack of clarity as to the specific different contributions of each of the psycho-social-spiritual professionals: social workers, psychologist, and spiritual caregivers. This study examined the content of their end-of-life conversations with patients. METHODS: A total of 180 patients with terminal cancer received standard multidisciplinary care, including conversations with a social worker, psychologist, and spiritual caregiver. After each patient’s death, these professionals
reported using a structured tool which content areas had arisen in their conversations with that patient.

RESULTS: Across all content areas, there were significant differences between social work and spiritual care. The difference between social work and psychology was slightly smaller but still quite large. Psychology and spiritual care were the most similar, though they still significantly differed in half the content areas. The differences persisted even among patients who spoke with more than 1 kind of professional. The 6 content areas examined proved to subdivide into 2 linked groups, where patients speaking about 1 were more likely to speak about the others. One group, “reflective” topics (inner and transpersonal resources, interpersonal relationships, one’s past, and end of life), included all those topics which arose more often with spiritual caregivers or psychologists. The second group, “decision-making” topics (medical coping and life changes), was comprised of those topics which arose most commonly with social workers, bridging between the medical and personal aspects of care and helping patients navigate their new physical, psychological, and social worlds.

SIGNIFICANCE OF RESULTS: These findings help shed light on the differences, in practice, between patients’ conversations with social workers, psychologists, and spiritual caregivers and the roles these professionals are playing; can aid in formulating individualized care plans; and strengthen the working assumption that all 3 professions contribute in unique, complementary ways to improving patients’ and families’ well-being.

PPC/COM6

Resident and caregiver dyads talk about death and dying in assisted living: A typology of communication behaviors
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Am J Hosp Palliat Care. 2024;10499091231225960. doi: 10.1177/10499091231225960.

BACKGROUND: In the U.S., assisted living (AL) is increasingly a site of death, and anxiety about dying has been identified in long-term care residents and their caregivers. Communication about death and dying is associated with better quality of life and care at end of life (EOL). OBJECTIVE: To understand communication behaviors used by AL residents and their informal caregivers (i.e., family members or friends) related to death and dying, and address communication needs or opportunities applicable to EOL care in AL. DESIGN: A thematic analysis of in-depth interviews and fieldnotes from a subsample of data from a 5-year NIA-funded study. SETTING/SUBJECTS: Participants included 15 resident-caregiver dyads from three diverse AL communities in Atlanta, Georgia in the U.S. MEASUREMENTS: Interview transcripts were coded for communication behavior. Concordances and discordances within dyads were examined. RESULTS: We identified a typology of four dyadic communication behaviors: Talking (i.e., both partners were talking with each other about death), Blocking (i.e., one partner wanted to talk about death but the other did not), Avoiding (i.e., each partner perceived that the other did not want to communicate about death), and Unable (i.e., dyads could not communicate about death because of interpersonal barriers). CONCLUSIONS: Older residents in AL often want to talk about death but are blocked from doing so by an informal caregiver. Caregivers and AL residents may benefit from training in death communication. Recommendations for improving advance care planning and promoting better EOL communication includes timing these conversations before the opportunity is lost.

DEATH
PPC/DEA1

Can we make more accurate prognoses during last days of life?
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J Palliat Med. 2024. doi: 10.1089/jpm.2023.0675.

Background: Life expectancy prediction is important for end-of-life planning. Established methods (Palliative Performance Scale [PPS], Palliative Prognostic Index [PPI]) have been validated for intermediate- to long-term prognoses, but last-weeks-of-life prognosis has not been well studied. Patients admitted to a palliative care facility often have a life expectancy of less than three weeks. Reliable last-weeks-of-life prognostic tools are needed. Objective: To improve short-term survival prediction in terminally ill patients. Method: This prospective study
included all patients admitted to a palliative care facility in Montreal, Canada, over one year. PPS and PPI were assessed until patients’ death. Seven prognostic clinical signs of impending death (Short-Term Prognosis Signs [SPS]) were documented daily. Results: The analyses included 273 patients (76% cancer). The median survival time for a PPS ≤20% was 2.5 days, while for a PPS ≥50% it was 44.5 days, for a PPI >8 the median survival was 3.5 days and for a PPI ≤4 it was 38.5 days. Receiver operating characteristic curves showed a high accuracy in predicting survival. Median survival after the first occurrence of any SPS was below one week. Conclusions: This study demonstrated that the PPS and PPI perform well between one week and three months extending their usefulness to shorter term survival prediction. SPS items provided survival information during the last week of life. Using SPS along with PPS and PPI during the last weeks of life could enable a more precise short-term survival prediction across various end-of-life diagnoses. The translation of this research into clinical practice could lead to a better adapted treatment, the identification of a most appropriate care setting for patients, and improved communication of prognosis with patients and families.

**PPC/DEA₂**

**Place of death and place of care at the end of life: Are they correlated? A retrospective cohort study of Ontario decedents**

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*J Palliat Med.* 2024;27(2):224–30. doi: 10.1089/jpm.2023.0167.

Background: Dying in nonpalliative acute care is generally considered inappropriate and avoidable. Place of death, a commonly reported big-dot indicator of end-of-life care quality, is often used as a proxy for place of care despite no empirical evidence for their correlations. Thus, we examined the correlations between place of death and place of care in the last month of life. We also investigated anecdotal claims that individuals cared in acute care often get discharged to die at home, and vice versa. Methods: We conducted a retrospective cohort study of Ontario decedents (18+) who died between January 1, 2015 and December 31, 2017. We identified individuals who died in nonpalliative acute care, palliative care unit, subacute care, long-term care (LTC), and the community. We calculated the number of days decedents spent in each setting in their last month of life, and used descriptive analyses to investigate their correlations. Results: Decedent’s place of death generally correlated with their place of care in the last month of life—individuals who died in a particular setting spent more time in that setting than individuals who died elsewhere. Furthermore, 75.0% of individuals who spent more than two weeks of their last month in acute care died in acute care. Among individuals who died in the community and in LTC, 65.4% and 75.0%, respectively, spent zero days in acute care. Interpretation: We showed that place of death can be a useful high-level performance indicator, by itself and as a proxy for place of care, to gauge end-of-life quality and service provision/implementation.

**PPC/DEA₃**

**Children’s understanding of dying and death: A multinational grounded theory study**

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*Palliat Support Care.* 2024;22(2):213–20. doi: 10.1017/s1478951523000287.

OBJECTIVES: The ways in which children understand dying and death remain poorly understood; most studies have been carried out with samples other than persons with an illness. The objective of this study was to understand the process by which children directly involved with life-limiting conditions understand dying and death. METHODS: This qualitative study obtained interview data from N=44 5–18-year-old children in the USA, Haiti, and Uganda who were pediatric palliative care patients or siblings of patients. Of these, 32 were children with a serious condition and 12 were siblings of a child with a serious condition. Interviews were recorded, transcribed, verified, and analyzed using grounded theory methodology. RESULTS: Loss of normalcy and of relationships emerged as central themes described by both ill children and siblings. Resilience, altruism, and spirituality had a bidirectional relationship with loss, being strategies to manage both losses and anticipated death, but also being affected by losses. Resiliency and spirituality, but not altruism, had a bidirectional relationship with anticipating death. Themes were consistent across the 3 samples,
although the beliefs and behaviors expressing them varied by country. **SIGNIFICANCE OF RESULTS:** This study partially fills an identified gap in research knowledge about ways in which children in 3 nations understand dying and death. While children often lack an adult vocabulary to express thoughts about dying and death, results show that they are thinking about these topics. A proactive approach to address issues is warranted, and the data identify themes of concern to children.

**PPC/DEA4**

**Patient and family preferences about place of end-of-life care and death: An umbrella review**

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*J Pain Symptom Manage*. 2024. doi: 10.1016/j.jpainsymman.2024.01.014.

In this umbrella review we examine and synthesized evidence regarding preferences about place of end-of-life care and death of patients with life-threatening illnesses and their families. Following the Joanna Briggs Institute methodology, we conducted a comprehensive search for systematic reviews in PsycINFO, MEDLINE, EMBASE, CINAHL, Epistemonikos, and PROSPERO without language restrictions. The search identified 15 reviews (10 high-quality, 3 with meta-analysis), covering 229 non-overlapping primary studies. Home is the most preferred place of end-of-life care for both patients (11–89%) and family members (23–84%). It is also the most preferred place of death (patient estimates from two meta-analyses: 51–55%). Hospitals and hospice/palliative care facilities are preferred by substantial minorities. Reasons and factors affecting preferences include illness-related, individual, and environmental. Differences between preferred places of care and death are underexplored and the evidence remains inconclusive about changes over time. Congruence between preferred and actual place of death ranges 21–100%, is higher in studies since 2004 and a meta-analysis shows non-cancer patients are at higher risk of incongruence than cancer patients (OR 1.23, 95%CI 1.01–1.49, I²=62%). These findings are a crucial starting point to address gaps and enhance strategies to align care with patient and family preferences.

**PPC/ECO1**

**Cost and utilization implications of a health plan’s home-based palliative care program**

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*J Palliat Med*. 2024. doi: 10.1089/jpm.2023.0401.

Background: A California-based health plan offered home-based palliative care (HBPC) to members who needed support at home but did not yet qualify for hospice. Objectives: This study compares hospital and emergency department (ED) utilization and costs and mortality for individuals receiving HBPC to a cohort not receiving palliative care services (Usual Care). Design: This is an observational retrospective study using claims data covering a prestudy period and a study period during which time half of the study population received HBPC services. Setting/Subjects: Seriously ill individuals who received HBPC were matched with those receiving Usual Care using a propensity-based matching algorithm. Intervention: Interdisciplinary teams from home health and hospice agencies provided HBPC services. Measurements: Outcome measures included hospital and ED utilization and cost before and during the study period and mortality during the study period. Results: For both groups, hospital and ED utilization and associated costs were higher during the prestudy period than during the study period. No differences were found in outcome measures between groups during the study period. Average time in the study period was longer for the HBPC group than that in the Usual Care group, indicating that they lived longer or transitioned to hospice later. Conclusion: Although individuals in both groups were living with serious illnesses for which worsening health and increased acute care utilization are expected over time, both groups had reduced acute care utilization and costs during the study period compared with the prestudy period. Reduced utilization and costs were equivalent for both groups.

**PPC/ECO2**

**Financial hardship for patients with cancer and caregivers at end of life in the USA: Narrative review**

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OBJECTIVE: To assess the degree of openness of communication about illness and death between patients with advanced cancer and their relatives during the last three months of the patient’s life, and its association with relatives’ characteristics and bereavement distress. METHODS: We used data from bereaved relatives of patients with advanced cancer from the prospective, longitudinal, multicenter, observational eQuipe study. Univariate and multivariable linear regression analyses were used to assess the association between the degree of openness of communication (measured using the validated Caregivers’ Communication with patients about Illness and Death scale), the a priori defined characteristics of the relatives, and the degree of bereavement distress (measured using the Impact of Event Scale). RESULTS: A total of 160 bereaved relatives were included in the analysis. The average degree of open communication about illness and death between patients with advanced cancer and their relatives was 3.86 on a scale of 1 to 5 (SE=0.08). A higher degree of open communication was associated with a lower degree of bereavement distress (p=0.003). No associations were found between the degree of open communication and the relatives’ age (p=0.745), gender (p=0.196), level of education (p>0.773), (religious) worldview (p=0.435), type of relationship with the patient (p=0.548), or level of emotional functioning before the patient’s death (p=0.075). CONCLUSIONS: Open communication about illness and death between patients and relatives seems to be important, as it is associated with a lower degree of bereavement distress. Healthcare professionals can play an important role in encouraging the dialogue. However, it is important to keep in mind that some people not feel comfortable talking about illness and death.

Long-term bereavement outcomes in family members of those who died in acute care hospitals before and during the first wave of COVID-19: A cohort study

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Palliat Med. 2024;2692163231223394. doi: 10.1177/02692163231223394.

BACKGROUND: Severe grief is highly distressing and prevalent up to 1 year post-death among people who have experienced the death of a loved one.
bereaved during the first wave of COVID-19, but no study has assessed changes in grief severity beyond this timeframe. AIM: Understand the trajectory of grief during the pandemic by reassessing grief symptoms in our original cohort 12–18 months post-death.

DESIGN: Prospective matched cohort study.

SETTINGS/PARTICIPANTS: Family members of decedents who died in an acute care hospital between November 1, 2019 and August 31, 2020 in Ottawa, Canada. Family members of patients who died of COVID (COVID +ve) were matched 2:1 with those who died of non-COVID illness (COVID −ve) during pandemic wave 1 or immediately prior to its onset (pre-COVID). Grief was assessed using the Inventory of Complicated Grief (ICG).

RESULTS: Follow-up assessment was completed by 92% (111/121) of family members in the initial cohort. Mean ICG score on the 12–18-month assessment was 19.9 (SD = 11.8), and severe grief (ICG >25) was present in 28.8% of participants. One-third (33.3%) had either a persistently high (>25) or worsening ICG score (≥4-point increase between assessments). Using a modified Poisson regression analysis, persistently high or worsening ICG scores were associated with endotracheal intubation in the deceased, but not cause of death (COVID +ve, COVID −ve, pre-COVID) or physical presence of the family member in the final 48h of life.

CONCLUSIONS: Severe grief is a substantial source of psychological morbidity in the wake of the COVID-19 pandemic, persisting more than a year post-death. Our findings highlight an acute need for effective and scalable means of addressing severe grief.

Pain Management

PPC/PAI1

Caring for patients with opioid misuse or substance use disorders in hospice: A national survey

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J Palliat Med. 2024;27(2):209–15. doi: 10.1089/jpm.2023.0082.

Background: Opioid misuse and substance use disorders (SUDs) including opioid use disorder (OUD) are common and negatively impact quality of life. Hospice clinicians’ experiences with these conditions have not been well described. Objectives: We sought to explore hospice clinicians’ knowledge, practices, and comfort caring for patients with opioid misuse (e.g., a pattern of unsanctioned opioid use escalation, or concurrent illicit substance use) and SUDs. Design:
We recruited hospice clinicians in the United States via national hospice and palliative care organizations to complete an online survey designed by the study authors and pilot tested with an interdisciplinary group of current/former hospice clinicians. Results: One hundred seventy-five clinicians (40% nurses, 40% physicians, 16% nurse practitioners) responded to the survey; most had cared for two or more hospice patients with opioid misuse or SUD in the past month. The majority felt confident identifying opioid misuse (94%) and taking SUD histories (79%). Most (62%) felt it is their role to treat hospice patients for SUD, though 56% lacked comfort in using buprenorphine for OUD treatment. While the majority felt it is their role to treat pain in hospice patients with SUDs (94%), many were not comfortable managing pain in patients taking buprenorphine (45%) or naltrexone (49%) for SUDs. Most felt comfortable managing pain in patients taking methadone for SUD (73%). Conclusions: Opioid misuse and SUD are common in hospice. Though clinicians are comfortable taking relevant histories, they feel less comfortable managing patients’ opioid misuse or SUD, or these patients’ pain.

**PPC/PAT**

**Routine monitoring of QTc interval as a barrier for efficient use of methadone in palliative care**

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*J Pain Symptom Manage*. 2024;67(2):e147-e50. doi: 10.1016/j.jpainsymman.2023.10.018.

**BACKGROUND:** Methadone is a commonly prescribed opioid amongst cancer patients. It has unique pharmacological properties which can benefit in treating complex pain syndromes and neuropathic pain. However, strict guidelines have been created in a generalized manner for chronic pain and long-term survival patients. These guidelines, such as QT interval monitoring can lead to limitations for methadone use in patients with comfort-associated goals. We present two cases of patients with metastatic cancer who were treated for pain with methadone and had to undergo opioid rotation due to abnormal QT intervals. **CASE DESCRIPTION:** Case one was a female with open ulcerated wounds due to metastatic breast cancer who presented with uncontrolled pain on her current opioid regimen. She achieved pain relief when rotated to methadone but a repeat electrocardiogram a few months later showed QTc prolongation. She underwent opioid rotation with different medications, but her pain remained poorly controlled. Case two was a female with poorly controlled pain in the setting of bilateral breast cancer. She presented with concerns for opioid-induced neurotoxicity and was rotated to methadone. She achieved optimal pain relief. A few weeks later, her machine read QT interval was prolonged and she was rotated off methadone. The electrocardiogram was manually read which showed a normal QT interval and she was restarted on methadone with pain relief. **CONCLUSION:** In the palliative care setting, monitoring QTc per chronic pain guidelines may lead to uncontrolled pain and a significant impact on quality of life.

**PPC/PAT**

**Specialist palliative care use and end-of-life care in patients with metastatic cancer**

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*J Pain Symptom Manage*. 2024. doi: 10.1016/j.jpainsymman.2024.01.029.

**CONTEXT:** For patients with advanced cancer, high intensity treatment at the end of life is measured as a reflection of the quality of care. Use of specialist palliative care has been promoted to improve care quality, but whether its use is associated with decreased treatment intensity on a population-level is unknown. **OBJECTIVES:** To determine whether receipt of specialist palliative care use is associated with differences in end-of-life quality metrics in patients with metastatic cancer. **METHODS:** Retrospective propensity-matched cohort of patients age ≥65 who died with metastatic cancer in U.S. hospitals with palliative care programs that participated in the National Palliative Care Registry in 2018–2019. Cox proportional hazards regression was used to assess the impact of specialist palliative care on use of chemotherapy in the last 14 days of life, use of intensive care unit (ICU) in the last 30 days of life, use of hospice, and hospice enrollment ≥3 days. **RESULTS:** AFTER 1: 2 matching, our cohort consisted of 15,878 exposed and 31,756 unexposed patients. Receipt of specialist palliative care was associated with a decrease in use of chemotherapy...
(adjusted hazard ratio (aHR) 0.59 [0.50–0.70]) and ICU at the end of life (aHR 0.86 [0.80–0.92]), and an increase in hospice use (aHR 1.92 [1.85–1.99]) and hospice enrollment for ≥3 days (aHR 2.00 [1.93–2.07]). CONCLUSIONS: On a population-level, use of specialist palliative care was associated with improved metrics for quality end-of-life care for patients dying with metastatic cancer, underscoring the importance of its integration into cancer care.

**PPC/PAT**

**Experience of care among adults with acute leukemia near the end of life: A scoping review**

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Background: Acute leukemia is a cancer of the blood and bone marrow with a high symptom burden and a high mortality rate in adults. The quality of end-of-life care among this patient population is deemed to be low based on health care administrative data, though the patient experience is not included in this evaluation. Objective: This scoping review aims at exploring and mapping the current research literature on the experience of care among adults with incurable acute leukemia near the end of life. Design: The JBI framework guided our scoping review, and the protocol was prospectively registered in the Open Science Framework. Results: A total of 5661 unique articles were screened for title and abstract, and 44 were selected for full text. After a manual search, five studies published in seven articles were selected for data extraction, including three qualitative and two quantitative studies. Two studies used family caregivers as patient proxies, two studies engaged patients directly, whereas one study obtained data from patients and family caregivers. Patient care in acute settings was reported in all studies, with most patients dying in acute care settings. Patients and family caregivers often valued an open and honest approach, with sufficient time for dialogue with their providers. Discussions about prognosis, palliative care, and hospice care were often late or incomplete. The medicalization of end-of-life care, including intensive care unit admissions and invasive medical procedures, were viewed as the norm by some providers, though perceived as distressing for both patients and their loved ones. Conclusions: Adults with acute leukemia face significant challenges in accessing high-quality end-of-life care brought about by the complex nature of their disease and its treatment. A systematic exploration of the end-of-life experience among these patients through direct patient engagement or by way of patient reporting proxies is needed.

**PPC/PAT**

**Potentially burdensome care at the end-of-life for cancer decedents: A retrospective population-wide study**

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*BMC Palliat Care* 2024;23(1):32. doi: 10.1186/s12904-024-01358-x.

BACKGROUND: Variation persists in the quality of end-of-life-care (EOLC) for people with cancer. This study aims to describe the characteristics of, and examine factors associated with, indicators of potentially burdensome care provided in hospital, and use of hospital services in the last 12 months of life for people who had a death from cancer. METHOD: A population-based retrospective cohort study of people aged ≥20 years who died with a cancer-related cause of death during 2014–2019 in New South Wales, Australia using linked hospital, cancer registry and mortality records. Ten indicators of potentially burdensome care were examined. Multinominal logistic regression examined predictors of a composite measure of potentially burdensome care, consisting of >1 ED presentation or >1 hospital admission or ≥1 ICU admission within 30 days of death, or died in acute care. RESULTS: Of the 80,005 cancer-related deaths, 86.9% were hospitalised in the 12 months prior to death. Fifteen percent had >1 ED presentation, 9.9% had >1 hospital admission, 8.6% spent ≥14 days in hospital, 3.6% had ≥1 intensive care unit admission, and 1.2% received mechanical ventilation on ≥1 occasion in the last 30 days of life. Seventeen percent died in acute care. The potentially burdensome care composite measure identified 20.0% had 1 indicator, and 10.9% had ≥2 indicators of potentially burdensome care. Compared to having no indicators of potentially burdensome care, people who smoked, lived in rural areas, were most socially economically disadvantaged,
and had their last admission in a private hospital were more likely to experience potentially burdensome care. Older people (≥55 years), females, people with 1 or ≥2 Charlson comorbidities, people with neurological cancers, and people who died in 2018–2019 were less likely to experience potentially burdensome care. Compared to people with head and neck cancer, people with all cancer types (except breast and neurological) were more likely to experience ≥2 indicators of potentially burdensome care versus none. CONCLUSION: This study shows the challenge of delivering health services at end-of-life. Opportunities to address potentially burdensome EOLC could involve taking a person-centric approach to integrate oncology and palliative care around individual needs and preferences.

**PPC/PAT4**

**Improving end-of-life care for people with dementia: A mixed-methods study**

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*BMC Palliat Care.* 2024;23(1):30. doi: 10.1186/s12904-023-01335-w.

**BACKGROUND:** Improving palliative and end-of-life care for people with dementia is a growing priority globally. This study aimed to integrate multiple perspectives on end-of-life care for people with dementia and carers, to identify clinically relevant areas for improvement. **METHODS:** The mixed-methods study involved surveys, interviews, and workshops with two participant groups: healthcare professionals and carers (individuals who provided care and support to a family member or friend). Healthcare professionals were invited to complete an online adapted version of the Australian Commission on Safety and Quality in Health Care, End-of-Life Care Toolkit: Clinician Survey Questions. Carers completed a hard copy or online adapted version of the Views of Informal Carers-Evaluation of Services (Short form) (VOICES-SF) questionnaire. Interview schedules were semi-structured, and workshops followed a co-design format. Findings were integrated narratively using a weaving approach. **RESULTS:** Participants described that the essence of spiritual support was “in every detail” throughout pediatric palliative care. Four major themes and eleven subthemes were identified. (1) Assessing spiritual needs: paying attention to different perspectives; considering religion, tradition, and culture; discovering spiritual needs behind other needs. (2) Facilitating spiritual exploration: being with the family; providing resources; guiding by providers’ own faith; (3) Supporting connections: encouraging the building of personal bonds; facilitating the establishment of spiritual connections. (4) Relieving spiritual suffering: facilitating a family review of child’s life; supporting building meaning in daily life; assisting in leaving a legacy for the child. **CONCLUSION:** This study illustrated that current spiritual support was provided “in every detail” throughout pediatric palliative care. Four major themes and eleven subthemes were identified. (1) Assessing spiritual needs: paying attention to different perspectives; considering religion, tradition, and culture; discovering spiritual needs behind other needs. (2) Facilitating spiritual exploration: being with the family; providing resources; guiding by providers’ own faith; (3) Supporting connections: encouraging the building of personal bonds; facilitating the establishment of spiritual connections. (4) Relieving spiritual suffering: facilitating a family review of child’s life; supporting building meaning in daily life; assisting in leaving a legacy for the child. **CONCLUSIONS:** There are multiple areas where we can improve the quality of end-of-life care people with dementia receive. The findings demonstrate that the heterogeneous and challenging experiences of living with and caring for people with dementia necessitate a multidisciplinary, multifaceted approach to end-of-life care. The identified solutions, including care coordination, can guide local development of co-designed models of end-of-life care for people with dementia.

**PPC/PED1**

**In every detail: Spiritual care in pediatric palliative care perceived by healthcare providers**

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*J Pain Symptom Manage.* 2024;67(2):167–72. doi: 10.1016/j.jpainsymman.2023.11.005.

**CONTEXT:** Spiritual care is an essential domain of pediatric palliative care. The current mainland China faces a lack of national guidance and a shortage of specialized personnel to provide spiritual care in a traditional developing country. **OBJECTIVES:** To identify spiritual care in pediatric palliative care services in mainland China from the perspective of healthcare professionals. **METHODS:** A qualitative descriptive interview study was conducted individually with 27 participants: 14 physicians, seven nurses, and six social workers. The data were analyzed using thematic analysis. **RESULTS:** Participants described that the essence of spiritual support was provided “in every detail” throughout pediatric palliative care. Four major themes and eleven subthemes were identified. (1) Assessing spiritual needs: paying attention to different perspectives; considering religion, tradition, and culture; discovering spiritual needs behind other needs. (2) Facilitating spiritual exploration: being with the family; providing resources; guiding by providers’ own faith; (3) Supporting connections: encouraging the building of personal bonds; facilitating the establishment of spiritual connections. (4) Relieving spiritual suffering: facilitating a family review of child’s life; supporting building meaning in daily life; assisting in leaving a legacy for the child. **CONCLUSION:** This study illustrated that current spiritual support, though not formally organized, is provided individually in pediatric palliative care.
palliative care services in mainland China. Strategies for a practice guide, education and training for professionals, and cultural building need to be rationally developed to strengthen and structure spiritual support integrated into pediatric palliative care.

**PPC/PED**

**Experiences of music therapy in paediatric palliative care from multiple stakeholder perspectives: A systematic review and qualitative evidence synthesis**

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**Palliat Med. 2024;2692163241230664. doi: 10.1177/02692163241230664.**

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 reprieve, 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.

**PPC/PED**

**Factors influencing parents’ choice of palliative treatment goals for children with relapsed or refractory neuroblastoma: A multi-site longitudinal survey study**

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Cancer. 2024;130(7):1101–11. doi: 10.1002/cncr.35149.

BACKGROUND: Many parents of children with advanced cancer report curative goals and continue intensive therapies that can compound symptoms and suffering. Factors that influence parents to choose palliation as the primary treatment goal are not well understood. The objective of this study was to examine experiences impacting parents’ report of palliative goals adjusted for time. The authors hypothesized that awareness of poor prognosis, recall of oncologists’ prognostic disclosure, intensive treatments, and burdensome symptoms and suffering would influence palliative goal-setting. METHODS: The authors collected prospective, longitudinal surveys from parents of children with relapsed/refractory neuroblastoma at nine pediatric cancer centers across the United States, beginning at relapse and continuing every 3 months for 18 months or until death. Hypothesized covariates were examined for possible associations with parental report of palliative goals. Generalized linear mixed models were used to evaluate factors associated with parents’ report of palliative goals at different time points. RESULTS: A total of 96 parents completed surveys. Parents were more likely to report a primary goal of palliation when they recalled communication about prognosis by their child’s oncologist (odds ratio [OR], 52.48; p=.010). Treatment intensity and previous ineffective therapeutic regimens were not associated with parents’ report of palliative goals adjusted for time. A parent who reported new suffering for their child was less likely to report palliative goals (OR, 0.13; p=.008). CONCLUSIONS: Parents of children with poor prognosis cancer may not report palliative goals spontaneously in the setting of treatment-related suffering. Prognostic communication, however, does influence palliative goal-setting. Evidence-based interventions are needed to encourage timely, person-centered prognostic disclosure in the setting of advanced pediatric cancer. PLAIN LANGUAGE SUMMARY: Many parents of
children with poor-prognosis cancer continue to pursue curative treatments that may worsen symptoms and suffering. Little is known about which factors influence parents to choose palliative care as their child’s main treatment goal. To explore this question, we asked parents of children with advanced neuroblastoma across the United States to complete multiple surveys over time. We found that the intensity of treatment, number of treatments, and suffering from treatment did not influence parents to choose palliative goals. However, when parents remembered their child’s oncologist talking about prognosis, they were more likely to choose palliative goals of care.

**PPC/PED4**

Interventions performed in children with immunocompromised conditions in the pediatric intensive care unit within 48 hours of death

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Background: Understanding interventions preceding death in children with immunocompromised conditions is important to ensure a peaceful and dignified perideath experience. The aim of this study was to describe the number of interventions performed in the pediatric intensive care unit (PICU) within the 48 hours before death in this population. Methods: This was a single-center, retrospective cohort study of all children with an underlying oncologic, hematologic, or immunologic diagnosis admitted to the PICU for at least 72 hours between 2014 and 2021. Medical records were reviewed for interventions within 48 hours preceding death and for palliative care involvement. Interventions were defined as new or escalations in respiratory support, cardiopulmonary resuscitation (CPR), vascular access, drains, and radiographic studies. Associations were evaluated using simple logistic regression. Results: A total of 55 patients were included in this study. The predominant PICU admission diagnoses were respiratory (51%), followed by shock (25%), and neurologic diagnoses (9%). These predominant diagnoses were similar perideath. At PICU admission, only 1 patient had a do-not-resuscitate (DNR) order. Forty-six percent had a DNR order 48 hours preceding death, and 91% had DNR orders in place at time of death. During the 48-hour period preceding death, 80% of children received at least one intervention. Radiographic studies were the most common, used in 78% of children, followed by respiratory (20%), vascular (16%), CPR (13%), and drain placement (7%). Palliative care was involved in 38% of cases and was associated with a decrease in the number of radiologic interventions ($p=0.028$) and CPR ($p=0.026$). Conclusions: Children in the PICU with underlying immunocompromised conditions frequently receive interventions within the 48-hour period preceding death. Palliative care involvement was associated with fewer radiographic studies and fewer occurrences of CPR. The impact of interventions on the dying experience warrants further investigation.

**PPC/PED5**

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

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*Curr Opin Support Palliat Care*. 2024;18(1):65–9. doi: 10.1097/spc.0000000000000686.

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.

Improving prenatal palliative care consultation using diagnostic trigger criteria
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BACKGROUND: Three percent of pregnancies are complicated by congenital anomalies. Prenatal integration of pediatric palliative care (PPC) may be hindered by non-standardized PPC referral processes. This quality improvement (QI) project aimed to improve prenatal PPC consultation using a diagnostic trigger list. MEASURES: Main outcome measure was the percentage of prenatal PPC consultations completed based on diagnostic trigger list eligibility. Balancing measures included stakeholder perspectives on PPC consults and products. INTERVENTION: Interventions included creation and implementation of a diagnostic trigger list for prenatal PPC consultation, educational initiatives with stakeholders, and iterative modifications of our prenatal consultation process. OUTCOMES: Interventions increased consultation rates ≥80% during the first six months of QI implementation (baseline vs. post-interventions) although this increase was not consistently sustained over a 12-month period. CONCLUSIONS/LESSONS LEARNED: Diagnostic trigger lists improve initial rates of prenatal PPC consultation and additional interventions are likely needed to sustain this increase.

How do children with medical complexity die? A scoping review
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Introduction: Advancement in medical expertise and technology has led to a growing cohort of children with medical complexity (CMC), who make up a rising proportion of childhood deaths. However, end of life in CMC is poorly understood and little is known about illness trajectories, communication, and decision-making experiences. Objective: To synthesize existing literature and characterize the end-of-life experience in CMC. Methods: A literature search of MEDLINE, CINAHL, PsycINFO, Scopus, Embase, and Google Scholar was conducted up to August 26, 2021. Studies reporting CMC at end of life were included and the extracted data were analyzed descriptively. Findings: Of 1535 publications identified, 23 studies were included. Most studies (15/23 [65%]) were published from 2015 to 2021 and were quantitative in nature (20/23 [87%]). The majority of studies that extracted data from a single country (18/20 [90%]) originated from North America. Study outcomes were categorized into four main domains: (1) place of death (2) health care use (3) interventions received or withdrawn (4) communication, and end-of-life experiences. The weighted percentage of in-hospital CMC deaths was 80.6%. Studies reported that CMC had increased health care use and were subjected to more intensive interventions at end of life compared with non-CMC. Qualitative studies highlighted the following themes: Intrinsic prognostic uncertainty, differing perspectives of the child’s quality of life, the chronic illness experience, a desire to have parental expertise acknowledged, surprise at the terminal event, the experience of multiple losses, with an overarching theme of the need for compassionate care at end of life. Conclusions: This scoping review highlighted important characteristics of end of life in CMC, outlining the emerging evidence and knowledge gaps on this topic. A better understanding of this cohort of seriously and chronically ill children would serve to inform clinical practice, service development, and future research.

Pediatric oncology hospice: A comprehensive review
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Am J Hosp Palliat Care. 2024;10499091241227609. doi: 10.1177/10499091241227609.
Pediatric hospice is a new terminology in current medical literature. Implementation of pediatric hospice care in oncology setting is a vast but subspecialized field of research and practice. However, it is accompanied by substantial uncertainties, shortages and unexplored sections. The lack of globally established definitions, principles, and guidelines in this field has adversely impacted the quality of end-of-life experiences for children with hospice needs worldwide. To address this gap, we conducted a comprehensive review of scientific literature, extracting and compiling the available but sparse data on pediatric oncology hospice from the PubMed database. Our systematic approach led to development of a well-organized structure introducing the foundational elements, highlighting complications, and uncovering hidden gaps in this critical area. This structured framework comprises nine major categories including general ideology, population specifications, role of parents and family, psychosocial issues, financial complications, service locations, involved specialties, regulations, and quality improvement. This platform can serve as a valuable resource in establishing a scientifically reliable foundation for future experiments and practices in pediatric oncology hospice.

PROFESSIONAL ISSUES

Default palliative care consultation for seriously ill hospitalized patients: A pragmatic cluster randomized trial

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JAMA. 2024;331(3):224–32. doi: 10.1001/jama.2023.25092.

IMPORTANCE: Increasing inpatient palliative care delivery is prioritized, but large-scale, experimental evidence of its effectiveness is lacking. OBJECTIVE: To determine whether ordering palliative care consultation by default for seriously ill hospitalized patients without requiring greater palliative care staffing increased consultations and improved outcomes. DESIGN, SETTING, AND PARTICIPANTS: A pragmatic, stepped-wedge, cluster randomized trial was conducted among patients 65 years or older with advanced chronic obstructive pulmonary disease, dementia, or kidney failure admitted from March 21, 2016, through November 14, 2018, to 11 US hospitals. Outcome data collection ended on January 31, 2019. INTERVENTION: Ordering palliative care consultation by default for eligible patients, while allowing clinicians to opt-out, was compared with usual care, in which clinicians could choose to order palliative care. MAIN OUTCOMES AND MEASURES: The primary outcome was hospital length of stay, with deaths coded as the longest length of stay, and secondary end points included palliative care consult rate, discharge to hospice, do-not-resuscitate orders, and in-hospital mortality. RESULTS: Of 34,239 patients enrolled, 24,065 had lengths of stay of at least 72 hours and were included in the primary analytic sample (10,313 in the default order group and 13,752 in the usual care group; 13,338 [55.4%] women; mean age, 77.9 years). A higher percentage of patients in the default order group received palliative care consultation than in the standard care group (43.9% vs 16.6%; adjusted odds ratio [aOR], 5.17 [95% CI, 4.59–5.81]) and received consultation earlier (mean [SD] of 3.4 [2.6] days after admission vs 4.6 [4.8] days; P < .001). Length of stay did not differ between the default order and usual care groups (percent difference in median length of stay, −0.53% [95% CI, −3.51% to 2.53%]). Patients in the default order group had higher rates of do-not-resuscitate orders at discharge (aOR, 1.40 [95% CI, 1.21–1.63]) and discharge to hospice (aOR, 1.30 [95% CI, 1.07–1.57]) than the usual care group, and similar in-hospital mortality (4.7% vs 4.2%; aOR, 0.86 [95% CI, 0.68–1.08]). CONCLUSIONS AND RELEVANCE: Default palliative care consult orders did not reduce length of stay for older, hospitalized patients with advanced chronic illnesses, but did improve the rate and timing of consultation and some end-of-life care processes.

Burnout and attachment in oncology and palliative care healthcare professionals

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BMJ Support Palliat Care. 2024. doi: 10.1136/spcare-2023-004694.

OBJECTIVES: Examine the prevalence of burn-out in health professionals working in a hospital dedicated to patients with cancer. Explore the relationship
between attachment style and burn-out in healthcare professionals working in Oncology and Palliative Care. METHODS: Cross-sectional descriptive and correlational study with a sample of 337 health professionals working in a tertiary hospital dedicated to oncology care. The evaluation protocol included a sociodemographic questionnaire, two burn-out (Copenhagen Burnout Inventory (CBI) and Maslach Burnout Inventory) and attachment (Adult Attachment Scale) scales. Statistical analysis was performed by IBM SPSS Statistics V.25. The tests were performed at a significance level of 5%. RESULTS: In the sample, there is a predominance of professionals working in oncology services (76.8%). Comparing professionals who work in oncology services and palliative care, it appears that just over half have high levels of personal burn-out, however the groups do not differ significantly (53.5% vs 56.8%, p=0.619); the same is observed in work-related (p=0.626) and patient-related burn-out (p=0.672). The number of hours per week in which one has the perception that is exposed to suffering is positively correlated with personal, work-related burn-out and exhaustion (p<0.05). Correlating the two burn-out scales in the sample, it is observed that higher levels of personal, work-related and patient-related burn-out are associated with higher levels of emotional exhaustion and depersonalisation, as well as lower levels of personal accomplishment (p<0.001). Considering the correlation between the burn-out dimensions and attachment scale, it appears that high levels of exhaustion, depersonalisation, personal, work-related and patient-related burn-out were associated with higher levels of anxiety (p<0.001). Similar results were found in the palliative care professional’s sample. CONCLUSIONS: The constant exposure to the suffering of others places high emotional demands on oncology and palliative care professionals, making them vulnerable to burn-out. Burn-out is a multifactorial process, that involves individual characteristics with environmental effects. There are no significant differences between Oncology and Palliative Care professionals. Higher levels of personal, work-related and patient-related burn-out are associated with higher levels of anxiety. These results suggest that an anxious attachment style increases the risk of burn-out. In the sample, the most important predictor of burn-out was the number of hours per week exposed to suffering. In order to prevent burn-out, there is growing evidence that suggests mindfulness, exercise, high-quality sleep and pursuit of happiness can improve burn-out in healthcare professionals. This work brings the advantage of using two burn-out assessment scales (particularly CBI scale), in addition to trying to correlate the level of burn-out and attachment in professionals exposed to suffering.

PPC/PRO

Nurses’ encounters with patients having end-of-life dreams and visions in an acute care setting - a cross-sectional survey study

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AIM: This study aimed to estimate the proportion of acute care nurses witnessing end-of-life dreams and visions or having these reported by a patient or relative, and to canvass their related attitudes and beliefs. DESIGN: A cross-sectional survey study was conducted from February 2023 to May 2023. SETTING/PARTICIPANTS: Participants were medical and surgical nurses from a 200-bed acute care hospital in metropolitan Australia. RESULTS: Fifty-seven nurses participated from a workforce of 169 (34% response rate), of whom 35 (61%) reported they had encountered end-of-life dreams and visions. The nature of end-of-life dreams and visions encountered was similar to those reported in previous studies by patients and clinicians. Nurses generally held positive attitudes towards end-of-life dreams and visions but identified an unmet need for education and training on this aspect of end-of-life care. CONCLUSION: Our results suggest that nurses in acute care encounter end-of-life dreams and visions in a similar proportion to oncology and long-term care but lower than in palliative care settings. Education and training regarding end-of-life dreams and visions are needed to ensure the provision of comprehensive, patient-centred end-of-life care. PATIENT OR PUBLIC CONTRIBUTION: No patient or public contribution. IMPACT: Research in sub-acute and long-term care settings suggests that end-of-life dreams and visions are a common accompaniment to the dying process. No research has yet focused on the acute care setting, despite this being the place of death for the majority of people in most high-income countries. This study demonstrates that acute care nurses encounter end-of-life dreams and visions in similar proportions to oncology and long-term care nurses but lower than palliative care
nurses. Acute care nurses would benefit from education and training regarding end-of-life dreams and visions to enable the provision of holistic person-centred end-of-life care. REPORTING METHOD: This study was reported using the STROBE Checklist for cross-sectional studies.

PPC/PRO4

Online modules to alleviate burnout and related symptoms among interdisciplinary staff in long-term care: A pre-post feasibility study
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Am J Hosp Palliat Care. 2024;41(3):329–39. doi: 10.1177/10499091231174448.

BACKGROUND: The rising trend of providing palliative care to residents in Canadian long-term care facilities places additional demands on care staff, increasing their risk of burnout. Interventions and strategies to alleviate burnout are needed to reduce its impact on quality of patient care and overall functioning of healthcare organizations. AIM: To examine the feasibility of implementing online modules with the primary goal of determining recruitment and retention rates, completion time and satisfaction with the modules. A secondary goal was to describe changes in burnout and related symptoms associated with completing the modules. SETTING: This single-arm, nonrandomized feasibility study was conducted in five long-term care sites of a publicly-funded healthcare organization in Vancouver, British Columbia, Canada. Eligible participants were clinical staff who worked at least 1 day per month. RESULTS: A total of 103 study participants consented to participate, 31 (30.1%) of whom were lost to follow-up. Of the remaining 72 participants, 64 (88.9%) completed the modules and all questionnaires. Most participants completed the modules in an hour (89%) and found them easy to understand (98%), engaging (84%), and useful (89%). Mean scores on burnout and secondary traumatic stress decreased by .9 (95% CI: -.1–1.8; d=.3) and 1.4 (95% CI: -.4–2.4; d=.4), respectively; mean scores on compassion satisfaction were virtually unchanged. CONCLUSIONS: Modules that teach strategies to reduce burnout among staff in long-term care are feasible to deliver and have the potential to reduce burnout and related symptoms. Randomized controlled trials are needed to assess effectiveness and longer-term impact.

PPC/PRO5

From comfort zone to front-line care: Perspectives and reflections of community pharmacists entering home-based palliative care
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BMC Palliat Care. 2024;23(1):4. doi: 10.1186/s12904-023-01332-z.

BACKGROUND: Palliative care requires a multidisciplinary team to assist patients and their families to obtain good quality care at the end of life. Typically, community pharmacists have fewer opportunities to provide services for patients with palliative care needs than hospital pharmacists. Moreover, home-based palliative care (HBPC) by pharmacists remains low and there is a lack of research regarding HBPC provided by pharmacists. Therefore, this study sought to understand the views and reflections of community pharmacists in the clinical frontline providing palliative home services. METHODS: Purposive sampling was used to recruit six community pharmacists for one-on-one, in-depth, semi-structured interviews and the data were analysed using thematic analysis. RESULTS: Five major themes emerged: [1] Engagement, [2] Challenge, [3] Mission, [4] Career metamorphosis, and [5] Outlook. The pharmacists described how they engaged in HBPC and faced the challenges. They regarded opioid management as a burden. Moreover, some mentioned that reimbursement for palliative home care is low or non-profitable. They suggested building a platform to exchange advice and legislation adjustments so that they could pass on their experiences to less experienced pharmacists in HBPC. CONCLUSIONS: The involvement of pharmacists is crucial to provide better palliative care. Although the present study was small and might not fully represent the whole situation, the findings could still inform future education, training, and policy planning to promote pharmacists’ participation in palliative care to generalise community palliative care.
**PPC/PSY**

**Top ten tips palliative care clinicians should know about the psychological aspects of palliative care encounters**

D. Chammas, K. O. Brenner, A. Gamble, et al.

PTC/PSY1

Palliative care clinicians enhance the illness experiences of patients and their families through building therapeutic relationships. Many psychological concepts underlie a clinician’s approach to a specific patient. Through high-yield tips, this article highlights ten selected psychological elements that palliative care clinicians often use to support patients. As we all (both clinicians and patients) bring our own histories and unique biographies to the work of palliative care, a more explicit focus on the psychological aspects of this work can enhance our own experience and efficacy as providers. With a thoughtful focus on the psychological aspects of how we engage with patients, palliative care clinicians can offer a more meaningful therapeutic encounter.

**PPC/PSY2**

**The gift of here and now at the end of life: Mindful living and dignified dying among Asian terminally ill patients**

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J Palliat Med. 2024;27(2):251–4. doi: 10.1089/jpm.2023.0390.

OBJECTIVES: In Chochinov’s dignity model, living in the here and now (mindful living) is explicitly stated as a dignity-conserving practice. However, what facilitates mindful living remain unclear. This study aims to investigate the mechanisms of mindful living among Asian terminally ill patients.

METHODS: This interpretative phenomenological analysis comprised patients aged 50 and above with a prognosis of less than 12 months. Fifty interview transcripts from a larger Family Dignity Intervention study conducted in Singapore were used for the analysis. RESULTS: Findings revealed 12 themes that were organized into 3 axioms of mindful living for dignified dying: (a) purposive self-awareness, (b) family-centered attention, and (c) attitudes of mortality acceptance. Through purposive self-awareness, patients introspected their lived experience with illness and anticipated death to find resilience and contentment. Patients’ conscious family-centered attention revolved around their relationships, achievements, and legacy within the family, leading to a deepened sense of interconnectedness with self and beloved others at life’s end. Lastly, patients adopted nonjudgmental attitudes of mortality acceptance as they made necessary arrangements in preparation for their death, allowing them to treasure every living moment and obtain a closure in life. An empirical model of mindful living for dignified dying was developed based on these emerging themes, illustrating the interweaving of intention, attention, and attitude for facilitating meaningful living in the face of mortality. SIGNIFICANCE OF RESULTS: Mindful living is a dignity-preserving practice, which helps terminally ill patients to find tranquillity in each present moment despite their impending death. The identified mechanisms of mindful living lay important groundwork for a new understanding and possible directions for culture-specific, mindfulness-based, family-centered interventions suited to terminally ill patients in the Asian context.

**PPC/PSY3**

**Comparison of anxiety and depression levels in caregivers of patients with percutaneous endoscopic gastrostomy for home enteral tube feeding against other enteral nutrition methods**

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BMC Palliat Care. 2024;23(1):20. doi: 10.1186/s12904-024-01360-3.

BACKGROUND: The aim of the study was to demonstrate whether the care burden of caregivers of bedridden patients, who experience feeding difficulties, decreases according to the Hospital Anxiety and Depression Scale (HADS) (1) after the patient has undergone PEG (Percutaneous Endoscopic Gastrostomy). The hypothesis of the study was that the levels of anxiety and depression of caregivers for patients fed via PEG decrease more than those for
caregivers of patients fed through other enteral methods. Based on this, the goal is to recommend to palliative care and home care professionals the type of feeding method for bedridden patients that will create less burden on their relatives. METHODS: A comparison was made of the Hospital Anxiety and Depression Scale (HADS) scores among caregivers of patients receiving PEG and other enteral nutrition, focusing on changes between hospital admission and discharge. These changes were analyzed based on the caregiver’s age, gender, and the duration of the patient’s hospital stay. METHODS: This study conducted a comparative analysis of the Hospital Anxiety and Depression Scale (HADS) scores among caregivers of patients receiving Percutaneous Endoscopic Gastrostomy (PEG) versus other forms of enteral nutrition. The focus was on the variation in these scores from the time of the patients’ hospital admission to their discharge. This analysis incorporated an examination of how these changes correlated with the caregiver’s age and gender, as well as the duration of the patient’s hospitalization. RESULTS: Despite longer hospital stays, a decrease in anxiety and depression was observed in caregivers of patients receiving PEG compared to the other group (\(p=0.078\)). It was found that the decrease in anxiety and depression levels was less pronounced with increasing age of the caregiver (\(r=-0.202, p=0.038\)). Hospital stay duration for patients receiving PEG was significantly longer than for those receiving other enteral nutrition methods (\(p=0.017\)). CONCLUSIONS: We believe that Percutaneous Endoscopic Gastrostomy (PEG) should be the preferred method for long-term enteral nutrition due to its facilitation of effective and comfortable feeding and medication administration by caregivers. In palliative care services, for patients requiring long-term nutrition, PEG should be considered more prominently than other enteral feeding methods to reduce the anxiety of caregivers.

**PPC/PSY**

**Social acceptability of psilocybin-assisted therapy for existential distress at the end of life: A population-based survey**

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**BACKGROUND:** Internationally, there is a growing interest in the potential benefits of psilocybin-assisted therapy to treat existential distress at the end of life. However, the social acceptability of this therapy is not yet well known. AIM: This study assesses the social acceptability of the medical use of psilocybin to treat existential distress at the end of life. DESIGN: An online survey was conducted in Canada between November 23 and December 4, 2022. The questionnaire included items pertaining to perceptions, attitudes and concerns towards psilocybin-assisted therapy to treat existential distress at the end of life. PARTICIPANTS: The sample (\(n=2800\)) was stratified by province, age and sex. Participants were adults from four provinces of Canada: Québec, Ontario, Alberta and British Columbia. RESULTS: Overall, 79.3% considered psilocybin-assisted therapy a reasonable medical choice for a patient suffering from existential distress at the end of life, 84.8% agreed that the public health system should cover the costs of the intervention and 63.3% would welcome the legalisation of psilocybin for medical purposes. Previous psilocybin use (\(p<0.0001\), for all dependent variables), exposure to palliative care (\(p<0.05\), for all dependent variables) and a progressive political orientation (\(p<0.05\), for all dependent variables) were associated with more favourable attitudes towards psilocybin-assisted therapy at the end of life. CONCLUSION: The social acceptability of psilocybin-assisted therapy for existential distress at the end of life is rather high in Canada. These findings may contribute to efforts to mobilise resources and improve access to this emerging therapy in palliative care settings.

**QUALITY OF LIFE**

**PPC/QOL**

**Nurse and social worker palliative telecare team and quality of life in patients with COPD, heart failure, or interstitial lung disease: The ADAPT randomized clinical trial**

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*JAMA.* 2024;331(3):212–23. doi: 10.1001/jama.2023.24035.

**IMPORTANCE:** Many patients with chronic obstructive pulmonary disease (COPD), heart failure (HF), and interstitial lung disease (ILD) endure poor quality of life despite conventional therapy.
Palliative care approaches may benefit this population prior to end of life. OBJECTIVE: Determine the effect of a nurse and social worker palliative telecare team on quality of life in outpatients with COPD, HF, or ILD compared with usual care. DESIGN, SETTING, AND PARTICIPANTS: Single-blind, 2-group, multisite randomized clinical trial with accrual between October 27, 2016, and April 2, 2020, in 2 Veterans Administration health care systems (Colorado and Washington), and including community-based outpatient clinics. Outpatients with COPD, HF, or ILD at high risk of hospitalization or death who reported poor quality of life participated. INTERVENTION: The intervention involved 6 phone calls with a nurse to help with symptom management and 6 phone calls with a social worker to provide psychosocial care. The nurse and social worker met weekly with a study primary care and palliative care physician and as needed, a pulmonologist, and cardiologist. Usual care included an educational handout developed for the study that outlined self-care for COPD, ILD, or HF. Patients in both groups received care at the discretion of their clinicians, which could include care from nurses and social workers, and specialists in cardiology, pulmonology, palliative care, and mental health. MAIN OUTCOMES AND MEASURES: The primary outcome was difference in change in quality of life from baseline to 6 months between the intervention and usual care groups (FACT-G score range, 0–100, with higher scores indicating better quality of life, clinically meaningful change ≥4 points). Secondary quality-of-life outcomes at 6 months included disease-specific health status (Clinical COPD Questionnaire; Kansas City Cardiomyopathy Questionnaire-12), depression (Patient Health Questionnaire-8), anxiety (Generalized Anxiety Disorder-7) symptoms. RESULTS: Among 306 randomized patients (mean [SD] age, 68.9 [7.7] years; 276 male [90.2%], 30 female [9.8%]; 245 White [80.1%], 177 [57.8%] had COPD, 67 [21.9%] HF, 49 [16%] both COPD and HF, and 13 [4.2%] ILD. Baseline FACT-G scores were similar (intervention, 52.9; usual care, 52.7). FACT-G completion was 76% (intervention, 117 of 154; usual care, 116 of 152) at 6 months for both groups. Mean (SD) length of intervention was 115.1 (33.4) days and included a mean of 10.4 (3.3) intervention calls per patient. In the intervention group, 112 of 154 (73%) patients received the intervention as randomized. At 6 months, mean FACT-G score improved 6.0 points in the intervention group and 1.4 points in the usual care group (difference, 4.6 points [95% CI, 1.8–7.4]; \( P = .001 \); standardized mean difference, 0.41). The intervention also improved COPD health status (standardized mean difference, 0.44; \( P = .04 \)), HF health status (standardized mean difference, 0.41; \( P = .01 \)), depression (standardized mean difference, −0.50; \( P < .001 \)), and anxiety (standardized mean difference, −0.51; \( P < .001 \)) at 6 months. CONCLUSIONS AND RELEVANCE: For adults with COPD, HF, or ILD who were at high risk of death and had poor quality of life, a nurse and social worker palliative telecare team produced clinically meaningful improvements in quality of life at 6 months compared with usual care. TRIAL REGISTRATION: ClinicalTrials.gov Identifier: NCT02713347.

**Nursing care for spiritual pain in terminal cancer patients: A non-randomized controlled trial**

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*J Pain Symptom Manage.* 2024;67(2):126–37. doi: 10.1016/j.jpainsymman.2023.10.016.

CONTEXT: Spiritual well-being is important for terminal cancer patients; however, appropriate interventions remain to be established. OBJECTIVES: To evaluate the effectiveness of nursing care to alleviate spiritual pain in daily clinical practice using a Spiritual Pain Assessment Sheet-based spiritual care program for nurses (SpiPas-SCP-N). METHODS: A nonrandomized controlled trial was conducted in five palliative care units in Japan. The intervention group received spiritual care based on SpiPas-SCP-N by ward nurses. The primary outcome was the Functional Assessment of Chronic Illness Therapy-Spiritual (FACT-Sp). Secondary outcomes included: Hospital Anxiety and Depression Scale (HADS), Comprehensive Quality of life Outcome (CoQoLo), and the Japanese version of the M.D. Anderson Symptom Inventory (MDASI-J). Propensity score matching was used for adjustment. RESULTS: Terminal cancer patients were assigned to the control and intervention groups (\( n = 140 \) and 157, respectively); of whom, 97 (69.8%) and 106 (68.0%), respectively, completed two weeks. Seventy-three patients were matched in each group. The total score of FACT-Sp increased in the intervention group and decreased in the control group; however, there was no significant difference (95% CI, −3.98, 1.41,
HADS total score significantly increased (95% CI, 0.15, 3.87, \( P = 0.035 \)), whereas there were no significant changes in CoQoLo and MDASI-J scores. The effect size of changes in FACIT-Sp subscales were 0.25 in the meaning/peace subscale and 0.04 in the faith subscale. CONCLUSION: SpiPas-SCP-N for spiritual pain may have a positive impact on terminal cancer patients. Future research using larger samples, randomized design, and the meaning/peace subscale of FACIT-Sp as the primary outcome is necessary as well as supervision and continuous training in daily nursing practice.

**PPC/QOL3**

The impact of an integrated early palliative care telehealth intervention on the quality of life of heart failure patients: A randomized controlled feasibility study

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*BMC Palliat Care*. 2024;23(1):22. doi: 10.1186/s12904-024-01348-z.

**BACKGROUND:** While palliative care for patients with heart failure has gained global attention, in Iran most palliative care interventions have focused only on cancer patients. The purpose of this study is to determine the feasibility and acceptability of a telehealth palliative care intervention to improve the quality of life in patients with heart failure in Iran. **METHODS:** This single-site, pilot randomized controlled trial of a telehealth palliative care intervention versus usual care was conducted on patients with New York Heart Association class II/III heart failure recruited from a heart failure clinic in Iran. Under the supervision of a nurse interventionist, intervention participants received 6 weekly educational webinars and concurrent WhatsApp® group activities, with 6 weeks of follow-up. Feasibility was assessed by measuring recruitment, attrition, and questionnaire completion rates; acceptability was assessed via telephone interviews asking about satisfaction and attitudes. Secondary outcomes measured at baseline and 6 weeks included quality of life (PKCCQ and FACIT-Pal-14), anxiety and depression (HADS), and emergency department visits. **RESULTS:** We recruited and randomized 50 patients (mean age 47.5 years, 60% men). Among those approached for consent, 66% of patients agreed to participate and total study attrition was 10%. Also 68% of patients successfully completed at least 4 out of the 6 webinar sessions. **CONCLUSION:** This nurse-led, early telehealth-palliative care intervention demonstrated evidence of feasibility, acceptability, and potential improvement on quality of life in patients with heart failure in Iran. **TRIAL REGISTRATION:** The study was registered at the Iranian Registry of Clinical Trials (IRCT) at 14 November, 2021, and can be found on the Iranian Registry of Clinical Trials Platform. IRCT registration number: IRCT2010072500443N29.

**PPC/QOL4**

Psychological symptom burden associated with malignant wounds: Secondary analysis of a prospective cohort study

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*Palliat Support Care*. 2024;22(2):396–403. doi: 10.1017/s1478951523000536.

**OBJECTIVES:** Patients with malignant wounds suffer from physical and psychological symptom burden. Despite psychological support being required, the impact of malignant wounds on patients’ psychological distress is poorly investigated. We evaluated psychological distress associated with malignant wounds for patients at their end of life. **METHODS:** This study used the secondary analysis of the results of a large prospective cohort study, which investigated the dying process among patients with advanced cancer in 23 palliative care units in Japan. The primary outcome of this study was the prevalence of moderate to severe psychological symptom burden, evaluated by the Integrated Palliative Care Outcome Scale (IPOS)-feeling at peace scores of 2–4. In addition, the factors affecting psychological symptoms were investigated. The quality of death was also evaluated upon death using the Good Death Scale score. **RESULTS:** Out of the total 1896 patients, 156 had malignant wounds (8.2%). Malignant wounds were more
common in female and young people. The breast, head, and neck were the most prevalent primary sites. More patients with malignant wounds had IPOS-feeling at peace scores of 2–4 than patients without malignant wounds (41.0% vs. 31.3%, p = 0.024). Furthermore, psychological distress was associated with moderate to severe IPOS-pain and the frequency of dressing changes. The presence of malignant wounds did not affect the quality of death. SIGNIFICANCE OF RESULTS: This study showed increased psychological distress due to malignant wounds. Patients with malignant wounds require psychological support in addition to the treatment of physical symptoms for maintaining their quality of life.

**PPC/QOL5**

*Optimizing quality of life: Integrating palliative care for patients with hand-foot syndrome in oncology practice*

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*BMJ Support Palliat Care*. 2024. doi: 10.1136/spcare-2024-004786.

Hand-foot syndrome (HFS) emerges as one of the common dermatological side effects associated with anticancer medications such as 5-fluorouracil (5-FU), capecitabine and docetaxel. This condition can be notably debilitating, exerting a predominant impact on the clinical, functional and psychosocial domains of health. With prevalence rates of HFS, ranging from 43% to 71%, there exists an unmet need among palliative care physicians to comprehend this syndrome in addressing physical, psychological dimensions and its integrated management within healthcare. This understanding enables them to adopt diverse approaches aimed at preserving the quality of life for patients, by enhancing the overall healthcare experience. Our primary objective is to underscore the imperative for the high-quality integration of palliative care with respect to HFS in contemporary oncology practices. We aim to achieve this by providing evidence-based insights to enhance patient outcomes. The intent of this study: (1) The article delves into the range of symptoms linked to HFS, and stresses the necessity of a holistic strategy and the difference that a palliative physician can contribute during cancer treatment-in picking up certain intricate aspects of patient care and addressing them. (2) The article also highlights the comprehensive approach through the incorporation of quality-of-life assessments, with the goal of enhancing patient outcomes, overall care experience within an integrated healthcare framework.

**SYMPTOM MANAGEMENT**

**PPC/SYM1**

*Methylphenidate for treating fatigue in palliative cancer care - effect and side effects in real-world data from a palliative care unit*

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BACKGROUND: Methylphenidate can be used for the treatment of cancer-related fatigue (CRF), although randomized controlled trials have shown conflicting results. The aim of this study was to use ‘real-world’ data to evaluate the effect and side effects of using methylphenidate in palliative cancer care with a focus on the late palliative phase and dose-response. METHOD: A retrospective review of medical records from a palliative care unit in Sweden was performed to evaluate the effect and adverse events (AEs) of using methylphenidate to treat CRF. Univariable and multivariable regression was performed and odds ratio (OR) calculated. Adjustments were made for sex, age, cancer type, dose and starting treatment <4 weeks before death. RESULTS: Of the 2,419 screened patients, 112 had been treated with methylphenidate for CRF. The treatment was assessed as being effective in 51 patients (46%). Twenty-six patients (23%) experienced AEs that were generally mild, including anxiety, palpitations, and insomnia. Patients starting the treatment <4 weeks before death (n = 54) were less likely to have an effect from treatment compared to those starting earlier; adjusted OR 0.24 (95% CI 0.10–0.55). Doses of 20 mg and above were well-tolerated and had a higher frequency of effect in the crude data but not after adjustment for confounding factors. CONCLUSION: Methylphenidate is generally effective and well-tolerated for the treatment of CRF in palliative care. However, patients with a short life expectancy (<4 weeks) seem to benefit
Background: The transition to spontaneous breathing puts patients who are undergoing ventilator withdrawal at high risk for developing respiratory distress. A patient-centered algorithmic approach could standardize this process and meet unique patient needs because a single approach (weaning vs. one-step extubation) does not capture the needs of a heterogenous population undergoing this palliative procedure.

Objectives: (1) Demonstrate that the algorithmic approach can be effective to ensure greater patient respiratory comfort compared to usual care; (2) determine differences in opioid or benzodiazepine use; (3) predict factors associated with duration of survival. Design/Settings/Measures: A stepped-wedge cluster randomized design at five sites was used. Sites crossed over to the algorithm in random order after usual care data were obtained. Patient comfort was measured with the Respiratory Distress Observation Scale© (RDOS) at baseline, at ventilator cessation; 58% of patients in the algorithm arm were weaned over an average of 18±27 minutes as prescribed in the algorithm. Patients had significantly less respiratory distress in the intervention arm (F=10.41, p=0.0013, effective size [es]=0.49). More opioids (t=−2.30, p=0.023) and benzodiazepines (t=−2.08, p=0.040) were given in the control arm. Conclusions: The algorithm was effective in ensuring patient respiratory comfort. Surprisingly, more medication was given in the usual care arm; however, less may be needed when distress is objectively measured (RDOS), and treatment is initiated as soon as distress develops as in the algorithm. Clinical Trial Registration number: NCT03121391.

Background: Patients with life-limiting illnesses receiving palliative care have a high symptom burden that can be challenging to manage. Guided imagery (GI), a complementary and integrative therapy in which patients are induced to picture mental images with sensory components, has proven in quasi-experimental studies to be effective as a complementary therapy for symptom management. Objective: To systematically review randomized controlled trials that report evidence of guided imagery for symptom management in patients with life-limiting illnesses. Methods: The Preferred Reporting Items for Systematic Reviews and Meta-Analyses guideline was followed for this review and the search strategy was applied in Medline, CINHAL, and Web of Science. The quality of articles was evaluated using the Cochrane Collaboration’s Risk-of-Bias Tool 2 (RoB 2). The results are presented using the Guidance on the Conduct of Narrative Synthesis in Systematic Reviews. Results: A total of 8822 studies were initially identified through the search strategy, but after applying exclusion criteria, 14 randomized controlled trials were included in this review. The quality assessment revealed that four studies had a high risk of bias, nine had some concerns, and one had a low risk of bias. Out of the 14 studies, 6 evaluated oncological diagnosis, while the remaining 8 focused on nononcological diagnoses across 6 different diseases. GI was found to be effective in managing symptoms in 10 out of the 14 studies. Regardless of the disease stage, patients who received guided imagery experienced relief from anxiety, depression, pain, sleep disturbances, and fatigue. Conclusion: GI therapy has shown promising results regarding symptom management in palliative care patients with life-limiting illnesses at different stages.
Transdermal rotigotine at end-of-life for Parkinson’s disease: Association with measures of distress

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BACKGROUND: End-of-life (EOL) care for Parkinson’s disease (PD) can be challenging when oral medications are no longer tolerated. MEASUREMENTS: To assess EOL prescribing for people with PD (PWP), focusing on rotigotine dosing and proxy measures of distress: benzodiazepine and opioid use. INTERVENTION: A retrospective audit of patient records from PWP who died between January 2019 and May 2022 at the Royal Hobart Hospital (RHH), Australia, was conducted. Data was systematically collated on demographics, symptoms, levodopa equivalent daily dose (LEDD) and rotigotine, oral morphine equivalent (OME) and benzodiazepine doses in the last 72 hours of life. OUTCOMES: Pain (72%), respiratory secretions (66%) and agitation (66%) were the most documented EOL symptoms. 83% (n=52) of PWP were eligible for rotigotine and, of those, 13% (n=7) received the correct dose, 38% (n=20) a lower dose, 12% (n=6) a higher dose and 37% (n=19) did not receive any. Rotigotine dose was positively associated with total (P=0.016) and PRN (P=0.037) benzodiazepine dose. LEDD was positively associated with total benzodiazepine (P=0.018) and total OME dose (P=0.046). Contraindicated dopamine antagonists were prescribed for 43% of PWP and administered in 31% of those cases. CONCLUSIONS: Rotigotine dose and admission LEDD were both associated with proxy measures of distress in the last 72 hours of life. This suggests caution use of rotigotine at EOL. LEDD may help identify patients at risk of distress. Rates of inappropriate prescribing and symptom prevalence were high, indicating a need for further staff education to optimize the care of PWP.

Perceptions on use of opioids in palliative care of dyspnoea in patients with fibrotic interstitial lung disease and chronic obstructive pulmonary disease: A qualitative study

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BACKGROUND: Many patients with chronic obstructive pulmonary disease and fibrotic interstitial lung disease suffer from severe dyspnea and reduced quality of life, despite receiving optimal disease-modifying treatment for their illness. Studies have suggested that these patients may benefit from treatment with low-dose opioids. However, many patients decline opioid treatment. This has led to patients not receiving proper palliative treatment of their lung disease. AIM: To identify potential barriers that prevent patients from receiving adequate palliative care with opioids and enable doctors to address patients’ concerns. DESIGN: A qualitative study based on semi-structured interviews. Interviews were transcribed and thematic analysis was done using NVivo. SETTING/PARTICIPANTS: Patients were recruited when scheduled for out-patient follow-up at Center for Rare Lung Diseases or at the COPD clinic, Aarhus University Hospital. Eligible patients were 18 years of age, did not currently receive opioids or had ever received opioids for dyspnea. RESULTS: A total of 28 patients participated. One patient was excluded before final analysis of 27 patients. Four themes were identified: Fear of side-effects, Need for more information, Stigma of opioids association with severe illness and dying, and No discernible barriers. Furthermore, three sub-themes to Fear of side-effects were identified: Fear of addiction, concern for sedative effect, and fear for loss of mobility due to inability to drive a car. The most expressed concern was Fear of side-effects, especially addiction. CONCLUSIONS: Pre-conceived notions about opioids prevent some patients with chronic obstructive lung disease or interstitial lung disease from receiving palliative care for breathlessness.

Comparison of pharmacological treatments for agitated delirium in the last days of life

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CONTEXT: Antipsychotics are often used in managing symptoms of terminal delirium, but evidence is limited. OBJECTIVES: To explore the comparative effectiveness of haloperidol with as-needed benzodiazepines (HPD) vs. chlorpromazine (CPZ) vs. levomepromazine (LPZ) for agitated delirium in the last days. METHODS: A prospective observational study was conducted in two palliative care units in Japan. Adult cancer patients who developed agitated delirium with a modified Richmond Agitation-Sedation Scale (RASS-PAL) of one or more were included; palliative care specialist physicians determined that the etiology was irreversible; and estimated survival was 3 weeks or less. Patients treated with HPD, CPZ, or LPZ were analyzed. We measured RASS, NuDESC, Agitation Distress Scale (ADS), and Communication Capacity Scale (CCS) on Days 1 and 3. RESULTS: A total of 277 patients were enrolled, and 214 were analyzed (112 in HPD, 50 in CPZ, and 52 in LPZ). In all groups, the mean RASS-PAL score significantly decreased on Day 3 (1.37 to $-1.01$, 1.87 to $-1.04$, 1.79 to $-0.62$, respectively; $P < 0.001$); the NuDESC and ADS scores also significantly decreased. The percentages of patients with moderate to severe agitation and those with full communication capacity on Day 3 were not significantly different. The treatments were well-tolerated. While one-fourth of HPD group changed antipsychotics, 88% or more of CPZ and LPZ groups continued the initial antipsychotics. CONCLUSION: Haloperidol with as-needed benzodiazepine, chlorpromazine, or levomepromazine may be effective and safe for terminal agitation. Chlorpromazine and levomepromazine may have an advantage of no need to change medications.

A randomized controlled trial of betamethasone on fatigue in patients with advanced cancer
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CONTEXT: Fatigue is one of the most uncomfortable physical symptoms seen in patients with advanced cancer. Previous studies have reported on the efficacy of corticosteroids from Western countries. OBJECTIVES: To assess the effectiveness of 4mg betamethasone improving fatigue among Japanese patients with advanced cancer. METHODS: A randomized, double-blind, placebo-controlled trial enrolled eligible patients with advanced cancer expected to survive 1–2 months, with an Eastern Cooperative Oncology Group Performance Status of 2–3, and experiencing fatigue according to the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core-15-palliative criteria. Participants received twice-daily oral administration of 2 mg betamethasone (4 mg/d) or placebo for seven days, with fatigue assessed using EORTC QLQ-C15-PAL subscale and numerical rating scale (NRS) score (at baseline and day seven). The trial was registered under the University Hospital Medical Information Network (UMIN)000011913. RESULTS: Among the 267 screened patients, 81 were eligible, of which 70 were evaluable (betamethasone, 33; placebo, 37). The mean difference in the EORTC-QLQ-C15-PAL fatigue subscale was $-8.2$ (95% CIs: $-22.3$, 0.0; $P = 0.178$) and in a NRS for fatigue was $-1.2$ (95% CIs: $-2.5$, $-0.01$; $P = 0.048$), respectively. Emotional function, appetite loss, and global-health were slightly better in the betamethasone group than in the placebo group. CONCLUSION: The impact of betamethasone 4 mg/d on alleviating fatigue in patients with advanced cancer in the last weeks of life did not reach statistical significance in the EORTC-QLQ-C15-PAL as the primary endpoint, however, it was significant in the NRS, the secondary endpoint.

Symptoms and problems reported by patients with non-cancer diseases through open-ended questions in specialist palliative care: A national register-based study
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PURPOSE: Since 2010, a comprehensive symptom/problem (S/P) assessment has been carried out in Danish specialist palliative care using the EORTC QLQ-C15-PAL questionnaire and the open-ended “Write In three Symptoms/Problems” (WISP) instrument. On WISP patients can report up to three S/Ps not included in the EORTC QLQ-C15-PAL. However, little is known about which S/Ps patients with non-cancer diseases report using WISP. Therefore, we investigated the prevalence and severity of S/Ps reported on WISP by non-cancer patients in specialist palliative care and compared these S/Ps with those previously reported by cancer patients.

METHODS: This register-based study collected data from the Danish Palliative Care Database. We included adult patients with non-cancer diseases answering the EORTC QLQ-C15-PAL at admittance to specialist palliative care between 2016 and 2021. WISP responses were qualitatively categorized, and their prevalence and severity calculated. RESULTS: Of the 2323 patients with non-cancer diseases answering the EORTC QLQ-C15-PAL, 812 (34.9%) reported at least one S/P using WISP. A total of 1340 S/Ps were reported on WISP, of which 56.7% were not included in the EORTC QLQ-C15-PAL (i.e., were new). Edema, existential problems, dizziness, cough, and dysphagia were the most prevalent new S/Ps. Overall, 88.7% of the S/Ps were scored as moderate-severe. The prevalence of S/Ps reported on WISP did not significantly differ between cancer and non-cancer patients, except for existential problems, dysphagia, myoclonus, speaking problems, sweats, and vomiting. CONCLUSION: The similarities and differences in the prevalence of the most common S/Ps reported on WISP confirm that WISP improves symptom assessment regardless of patient diagnosis.

Non-invasive ventilation in the care of patients with chronic obstructive pulmonary disease with palliative care needs: A scoping review

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BACKGROUND: Patients with severe chronic obstructive pulmonary disease (COPD) may have palliative care (PC) needs because of unmet needs such as dyspnoea. This may lead to anxiety and may have an impact on patients’ ability to perform daily activities of living. PC can be started when patients with COPD have unmet needs and can be provided alongside disease-modifying therapies. Non-invasive ventilation (NIV) could be an important measure to manage dyspnoea in patients with COPD in need of PC. A scoping review was conducted to gain an overview of the existing research and to identify knowledge gaps. The aim of this scoping review was to systematically map published studies on the use of NIV in patients with COPD with PC needs, including the perspectives and experiences of patients, families, and healthcare professionals (HCPs).

METHODS: This review was conducted following the framework of Arksey and O’Malley. The reporting of the review was guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews checklist. The review protocol was published. AMED, CINAHL, Embase, MEDLINE, PEDro, and PsycInfo were searched from inception to November 14, 2022. The included studies had to report the perspectives and experiences of COPD patients, relatives, and HCPs regarding NIV in the care of patients with COPD with PC needs. In pairs, the authors independently assessed studies’ eligibility and extracted data. The data were organised thematically. The results were discussed in a consultation exercise. RESULTS: This review included 33 papers from 32 studies. Four thematic groupings were identified: preferences and attitudes towards the use of NIV; patient participation in the decision-making process of NIV treatment; conflicting results on the perceived benefits and burdens of treatment; and heterogenous clinical outcomes in experimental studies. Patients perceived NIV as a ‘life buoy’ to keep them alive. Many patients wanted to take part in the decision-making process regarding NIV treatment but expressed varying degrees of inclusion by HCPs in such decision-making. Conflicting findings were identified regarding the perceived benefits and burdens of NIV treatment. Diversity in heterogeneous clinical outcomes were reported in experimental studies. CONCLUSIONS: There is a need for more studies designed to investigate the effectiveness of NIV as a palliative measure for patients with COPD with PC needs using comprehensive outcomes. It is especially important to gain more knowledge on the experiences of all stakeholders in the use of home-based NIV treatment to these patients.
Trajectories of health-related quality of life and symptom burden in patients with advanced cancer towards the end of life: Longitudinal results from the eQuipe study
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BACKGROUND: Support for health-related quality of life (HRQOL) is an essential part of cancer care in the final stages of life, yet empirical guidance regarding HRQOL and symptom trajectories is lacking. AIM: To assess the change in HRQOL and symptom burden in the last year of life in patients with advanced cancer and its association with health care-related factors, cancer-specific treatment, and comorbidity. METHODS: A prospective, multicenter, observational study in patients with advanced cancer (eQuiPe). Three monthly questionnaires included European Organization for Research and Treatment of Cancer Quality of Life-C30 and reported continuity of care. Multivariable mixed-effects analysis was used to assess the association between HRQOL and health care-related factors. RESULTS: A total of 762 deceased patients were included with a mean age of 66 (SD, 10) years and 52% were male. The most common primary tumors were lung (29%), colorectal (20%), and breast cancer (13%). Mean overall HRQOL decreased in the last 9 months of life, with the greatest decrease in the last 3 months (β = 16.2). Fatigue, pain, appetite loss, dyspnea, constipation, and nausea worsened significantly in the last year of life. Multimorbidity (β = 7.5) and a better reported continuity of care (β = 0.7) were both significantly associated with the trajectory of HRQOL. CONCLUSION: Mean overall HRQOL begins to decline 9 months before death, highlighting the need for early identification and (re)assessment of different symptoms as aspects of HRQOL follow different trajectories. Multimorbidity and reported continuity of care may be associated with the trajectory of HRQOL.