Bibliography

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             | Oncology |
| Cardiology                | Pain |
| Clinical Journal of Oncology Nursing | Pain Medicine |
| Clinical Oncology (Royal Coll Rad) | Palliative Medicine |
| CMAJ                      | Palliative and Supportive Care |
| Current Opinion in Supportive and Palliative Care | Pediatric Blood and Cancer |
| Death Studies             | Pediatric Hematology and Oncology |
| Disability and Rehabilitation European Journal of Cancer Care | Psycho-oncology |
| European Journal of Surgical Oncology | Quality of Life Research |
| International Journal of Cancer | Seminars in Oncology Nursing |
| International Journal of Palliative Nursing | Supportive Care in Cancer |
|                           | Thorax |

GENERAL

PPC/GEN1

‘Never waste a good crisis’: A qualitative study of the impact of COVID-19 on palliative care in seven hospitals using the dynamic sustainability framework.

L. M. Holdsworth, H. Z. Mui, M. Winget, et al. (Holdsworth, Laura. Primary Care and Population Health, Department of Medicine, School of Medicine, Stanford University, Stanford, CA, USA. l.holdsworth@stanford.edu)

Palliat Med. 2022:2022163221123966. doi: 10.1177/02692163221123966.

BACKGROUND: The COVID-19 pandemic led to rapid adaptations among palliative care services, but it is unclear how these adaptations vary in relation to their unique organizational contexts. AIM: Understand how the pandemic impacted the implementation of new and existing palliative care programs in diverse hospital systems using the Dynamic Sustainability Framework. DESIGN: Twelve in-depth interviews with 15 key informants representing palliative care programs from seven hospital systems between April and June 2020. SETTING: Public, not-for-profit private, community,
and academic teaching hospitals in the San Francisco Bay Area with existing palliative care programs that were expanding services to new clinical areas (e.g. new outpatient clinic or community-based care).

RESULTS: Six themes characterized how palliative care programs were impacted and adapted during the early stages of the COVID-19 pandemic: palliative care involvement in preparing for surge, increased emphasis on advance care planning, advocating for visitors for dying patients, providing emotional support to clinicians, adopting virtual approaches to care, and gaps in chaplaincy support. There was variation in how new and existing programs were able to adapt to early pandemic stresses; systems with new outpatient programs struggled to utilize their programs effectively during the crisis onset.

CONCLUSIONS: The fit between palliative care programs and practice setting was critical to program resiliency during the early stages of the pandemic. Reconceptualizing the Dynamic Sustainability Framework to reflect a bidirectional relationship between ecological system, practice setting, and intervention levels might better guide implementers and researchers in understanding how ecological/macro changes can influence interventions on the ground.

Is progress being made on Canada’s palliative care framework and action plan? A survey of stakeholder perspectives.

B. Pesut, S. Thorne, A. Huisken, et al. (Pesut, Barbara. University of British Columbia Okanagan. 1147 Research Road, Kelowna, BC, V1V 1V7, Canada. Barb.pesut@ubc.ca) BMC Palliat Care. 2022;21(1):182. doi: 10.1186/s12904-022-01074-4.

BACKGROUND: The legalization of Medical Assistance in Dying in Canada in 2016 provided new impetus for improving palliative care. This commitment to improvement included the development of a National Palliative Care Framework and Action Plan. The purpose of this study was to understand the progress made in palliative care since 2016 from the perspective of persons working and volunteering in palliative care and compare geographic differences. METHODS: A digital survey was developed from goals identified in Canada’s Palliative Care Framework and Action Plan and administered online using Qualtrics. Participants were recruited through national palliative care organizations. The survey included both quantitative survey items designed to evaluate improvements across 5 domains and 29 items and included open-ended questions about impacts, innovations, and ongoing challenges. Descriptive statistics were generated for survey domains, items, and demographic variables. Geographic differences were compared using Independent-Samples Kruskal-Wallis test. Qualitative data was analyzed inductively into themes. RESULTS: One hundred fifty surveys met inclusion criteria and were analysed. Overall, the most improvement was reported in palliative care education and the least improvement was reported in support for family caregivers. Items on which respondents reported the most improvement included healthcare provider education in palliative care, advance care planning, and use of technology. Items on which respondents reported the least improvement were respite for family caregivers, access to bereavement services, and in-home support for family caregivers. Notably, rural participants reported more statistically significant improvements in the domains of education, access, and research and data collection than their urban counterparts. However, rural participants reported less improvement in places to die when home is not preferable. The COVID-19 pandemic was a significant contributor to these perceived improvements and ongoing challenges. CONCLUSION: Canada’s Framework and Action Plan sets out a roadmap for improving palliative care in Canada. Participants in this survey noted significant improvements in key areas, a notable accomplishment amidst the effects of the COVID-19 pandemic. Some improvements were a result of greater use of distance technology. Further leveraging these improvements will make an important contribution to solving some of the rural and remote palliative care issues that have arisen from Canada’s unique geography.

Advance care planning for emergency department patients with COVID-19 infection: An assessment of a physician training program.

M. F. Casey, L. Price, D. Markwalter, et al. (Casey, Martin F. Department of Emergency Medicine, University of North Carolina School of Medicine, Chapel Hill, NC, USA. martin_casey@med.unc.edu) Am J Hosp Palliat Care. 2022;39(11):1358–63. doi: 10.1177/10499091211072850.

OBJECTIVE: Coronavirus Disease 2019 (COVID-19) has heightened the importance of advance care planning (ACP), particularly in the emergency department (ED). The objective of this study was to determine the effect of an educational program for emergency physicians on ACP conversations in the ED during the COVID-19 pandemic. DESIGN: This was an observational pre-/post-interventional study. SETTING: This study was conducted at a Southeastern U.S. academic ED. PARTICIPANTS: 143 patients with confirmed COVID-19 infection in the 2 weeks up to and including the ED encounter of interest (between March 26 and May 25, 2020) were included. INTERVENTIONS: The primary intervention was an ACP training toolkit with three components: (1) an evidence-based guide to COVID-19 risk stratification, (2) education on language
to initiate ACP conversations, and (3) modification of the electronic health record (EHR) to facilitate ACP documentation. Palliative care physicians also delivered a 60-minute ACP educational session for emergency medicine physicians. OUTCOME MEASURES: The primary outcome was a composite of ACP activities including: (1) identification of a healthcare decision-maker (HCDM), (2) an order for a code status, or (3) a documented goals of care conversation. RESULTS: There was a 25.4% (95% CI: 7.0-43.9) increase in the composite outcome of ED-based ACP. After adjustment for patient demographics and triage score, there was a non-statistically significant increase in ACP activity (OR = 2.71, 95% CI: 0.93-8.64; P = .08). CONCLUSION: A rapid and simple physician-facing educational intervention demonstrated a trend, though lacking in statistical significance, towards increased ED-based ACP activities for patients with COVID-19.

**PPC/ADV2**

Prevalence and predictors of advance directive among terminally ill patients in Taiwan before enactment of patient right to autonomy act: A nationwide population-based study.

H. Y. Chang, N. Takemura, P. H. Chau, et al. (Lin, Chia-Chin. School of Nursing, Li Ka Shing Faculty of Medicine, The University of Hong Kong, 5/F, 3 Sassoon Road, Hong Kong, Pokfulam, China. chia.chin.lin@hku.hk)

**BACKGROUND:** Signing advance directives (ADs) among terminally ill patients who receive end-of-life care, according to their wishes, thereby promoting human dignity and sparing them from unnecessary suffering. Despite the enactment of the Hospice Palliative Care Act in Taiwan in 2000, the completion rates of ADs have been found to be low among patients with chronic illness conditions. To date, limited existing research is available regarding the factors associated with AD completion in terminally ill patients in Taiwan. To explore signed AD characteristics, compare differences in signing ADs between patients with and without cancer, and examine the factors associated with signing ADs in terminally ill patients. METHODS: A nationwide study was conducted using data collected via a retrospective review of medical death records from 18 randomly selected hospitals in the northern, central, and southern parts of Taiwan. We collected 200 records, including both cancer and non-cancer-related deaths, from each hospital. Univariate and multivariate logistics regressions were conducted to examine factors associated with signing advance directives among all patients—both with and without cancer. RESULTS: Among the 3004 reviewed medical records, 79% had signed ADs, with most (95%) being signed by patients’ caregivers. A higher education level (OR = 1.52, 95% CI = 1.10, 2.08, p = 0.010); cancer diagnosis (OR = 2.37, 95% CI = 1.79, 3.16, p < 0.001); having family members (OR = 5.62, 95% CI = 2.95, 10.69, p < 0.001), care homes (OR = 4.52, 95% CI = 1.97, 10.38, p < 0.001), friends, or maids (OR = 3.82, 95% CI = 1.76, 8.29, p = 0.001) were associated with a higher likelihood of signing ADs. CONCLUSIONS: Patients with non-malignant chronic illnesses were less likely to have ADs signed by either patients or family caregivers than those with cancer, with the lowest likelihood observed in patients with cardiovascular diseases. Whenever possible, primary caregivers should be involved in discussing ADs with patients, and the importance of truth telling should be reinforced. Following these principles, each patient’s end-of-life care preferences can be respected, thereby promoting quality of care before the patient’s death.

**PPC/ADV3**

Do healthy people engage with education about death, dying and advance care planning? An early evaluation of the Omega Course.

I. Davies, C. Meystre and J. Dale. (Dale, Jeremy. University of Warwick, Coventry, West Midlands, UK. jeremy.dale@warwick.ac.uk)

**Am J Hosp Palliat Care.** 2022:10499091221116794. doi: 10.1177/10499091221116794.

**Background:** Death can be difficult to address personally, to discuss and to plan for. Since 2016 The Omega Course (Omega) has educated local people in Kenilworth, UK, about death and dying; broaching these issues and teaching communication skills whilst enabling social interaction. It aspires to produce practical outcomes with positive implications for end of life (EoL) planning and future neighbourhood care within the town. Aim: To investigate the impact of Omega on the attitudes and actions of participants. Method: Anonymous questionnaires, distributed by Qualtrics, or by post if preferred, were sent to 62 participants of Omega aged 22–94 two and a half years post course institution. Thematic analysis and inferential statistics were used. Results: 23 replies (37%) scored changes across 4 areas; barriers to discussion, ease discussing death, fears about death and future planning capability. All showed a significant beneficial change using a Paired Sample t-test (P < .01). Respondents noted common fears of death and dying, barriers to discussing the topic and planning for it. The course helped to allay fear, enabled discussion and encouraged planning for death and EoL. Respondents rated the course as 9.1/10 for achieving its aims. They appreciated discussing death and dying in a supportive environment and found the approach effective in developing their skills and changing attitudes. Conclusion: Omega has the potential to change attitudes towards death; promoting discussion, planning, and tackling misconceptions.

**Bibliography**

Am J Hosp Palliat Care. 2022:10499091221116794. doi: 10.1177/10499091221116794.
Knowledge and attitudes of allied health professionals towards end-of-life and advance care planning discussions with people with COPD: A cross-sectional survey study.

R. Disler, B. Henwood, T. Luckett, et al. (Disler, Rebecca. Department of Immunology and Pathology, Central Clinical School, Level 4 The Alfred Centre, 99 Commercial Road, Melbourne VIC 3004, Australia. rebecca.disler@monash.edu)

Am J Hosp Palliat Care. 2022;10499091221134777. doi: 10.1177/10499091221134777.

Chronic obstructive pulmonary disease (COPD) is a progressive, life-limiting condition. End-of-life (EOL) and Advance Care Planning (ACP) discussions are essential, yet access and support remain inadequate. Allied health professionals (AHPs) commonly have ongoing relationships with patients and opportunities to discuss care outside acute crises as is considered best practice. Australian and New Zealand AHPs were invited to complete an anonymous, online, cross-sectional survey that aimed to explore knowledge, attitudes and practices, and associated perceived triggers and barriers to EOL and ACP discussions with patients with COPD. Closed survey responses were summarized descriptively and free-text thematically analysed. One hundred and one AHPs (physiotherapists, social workers and occupational therapists) participated. Many held positive attitudes towards ACP but lacked procedural knowledge. Half (50%) of participants routinely discussed EOL care with patients when perceiving this to be appropriate but only 21% actually discussed ACP with the majority of their patients. Many cited lack of training to engage in sensitive EOL discussions, with barriers including: (1) clinician lack of confidence/fear of distressing patients (75%); (2) perceived patient and family reluctance (51%); (3) organizational challenges (28%); and (4) lack of role clarity (39%). AHPs commonly have ongoing relationships with patients with chronic conditions but lack the confidence and role clarity to utilise this position to engage ongoing EOL and ACP discussions. While AHPs may not traditionally consider EOL and ACP discussions as part of their role, it is crucial that they feel prepared to respond if patients broach the topic.

Development of an advance care planning policy within an evidenced-based evaluation framework.

M. Hart, R. Stepita, A. Berall, et al. (Hart, Michelle. Baycrest Health Sciences, 3560 Bathurst Street, Toronto, ON M6A 2E1, Canada. mhart@baycrest.org)

Am J Hosp Palliat Care. 2022;39(12):1389–96. doi: 10.1177/10499091221079057.

Background: As the population is aging and medical advancements enable people to live longer, advance care planning (ACP) becomes increasingly important in guiding future care decisions; however, they are often incomplete or absent from the patient chart. This study describes the development and implementation of an ACP policy in a post-acute care and long-term care setting using a systematic implementation framework. Methods: A process evaluation that parallels the Replicating Effective Programs (REP) framework was used to understand stakeholder experiences with ACP and identify gaps in practice. Physicians, multidisciplinary staff, patients, and substitute decision makers engaged in focus groups and interviews, and completed surveys. A retrospective chart review determined Plan for Life Sustaining Treatment (PLST) form completion rates. Results: Stakeholder feedback identified barriers and facilitators to ACP including a need for staff training, user-friendly resources, and standardization of ACP practice. The PLST form was developed and embedded in the electronic medical record, and had a 92% and an 87% PLST completion rate on 2 pilot units. Conclusion: The study showed the usefulness of the REP model in guiding the evaluation as an effective tool to enhance implementation practices and inform ACP policy development that can be replicated in other organizations.

'SpezPat'- common advance directives versus disease-centred advance directives: A randomised controlled pilot study on the impact on physicians' understanding of non-small cell lung cancer patients' end-of-life decisions.

J. F. L. Koenig, T. Asendorf, A. Simon, et al. (Koenig, Julia. Department of Haematology and Medical Oncology, University Medical Centre, Robert-Koch-Str. 40, Goettingen, Germany. julia.koenig@med.uni-goettingen.de)

BMC Palliat Care. 2022;21(1):167. doi: 10.1186/s12904-022-01057-5.

BACKGROUND: The advance directive represents patients’ health care choices and fosters patients’ autonomy. Nevertheless, understanding patients’ wishes based on the information provided in advance directives remains a challenge for health care providers. Based on the ethical premises of positive obligation to autonomy, an advanced directive that is disease-centred and details potential problems and complications of the disease should help health care providers correctly understand patients’ wishes. To test this hypothesis, a pilot-study was conducted to investigate whether physicians could make the correct end-of-life decision for their patients when patients used a disease-centred advance directive compared to a common advance directive. MATERIAL AND METHODS: A randomised, controlled,
progressive pilot study was designed that included patients with non-small cell lung cancer (NSCLC) stage VI from the Department of Haematology and Medical Oncology, University Medical Centre, Goettingen. Patients were randomised into intervention and control groups. The control group received a common advance directive, and the intervention group received a disease-centred advance directive. Both groups filled out their advance directives and returned them. Subsequently, patients were asked to complete nine medical scenarios with different treatment decisions. For each scenario the patients had to decide whether they wanted to receive treatment on a 5-point Likert scale. Four physicians were given the same scenarios and asked to decide on the treatment according to the patients’ wishes as stated in their advance directives. The answers by patients and physicians were then compared to establish whether physicians had made the correct assumptions. RESULTS: Recruitment was stopped prior to reaching anticipated sample target. 15 patients with stage IV NSCLC completed the study, 9 patients were randomised into the control group and 6 patients in the intervention group. A total of 135 decisions were evaluated. The concordance between physicians’ and patients’ answers, was 0.83 (95%-CI 0.71–0.91) in the intervention group, compared to 0.60 (95%-CI 0.48–0.70) in the control group, and the difference between the two groups was statistically significant ($p = 0.005$). CONCLUSION: This pilot study shows that disease-centred advance directives help physicians understand their NSCLC patients’ wishes more precisely and make treatment choices according to these wishes.

**PPC/ADV**

**Developing a care pathway for hospital-based advance care planning for cancer patients: A modified Delphi study.**

A. J. Pedrosa Carrasco, P. Berlin, L. Betker, et al. (Pedrosa Carrasco, Anna J. Research Group Medical Ethics, Philipps-University Marburg, Baldingerstrasse, 35043 Marburg, Germany. anna.pedrosacarrasco@uni-marburg.de)

_Eur J Cancer Care (Engl). 2022:e13756. doi: 10.1111/ecc.13756._

OBJECTIVES: The objective of this study is to develop a care pathway for a hospital-based advance care planning service for cancer patients. METHODS: A web-based modified Delphi study consulted an expert panel consisting of a convenience sample of stakeholders including professionals with a special interest in advance care planning as well as a ‘public and patient involvement group’. After generating ideas for core elements of a care pathway in the first round, numerical ratings and rankings informed the multi-professional research steering group’s decision process eventually resulting in a final pathway. RESULTS: The 41 participants in the Delphi study identified 177 potential core elements of the pathway in the first round. In two further rounds, consensus was reached on a final version of the pathway with 148 elements covering the 10 domains: prerequisites, organisation and coordination, identification and referral, provision of information, information sources, family involvement, advance care planning discussion, documentation, update and quality assurance. CONCLUSION: We propose a care pathway for advance care planning for hospital patients with cancer based on the results of a Delphi study that reached consensus on an implementation strategy. Our study pioneers the standardisation of the process and provides input for further policy and research with the aim of aligning cancer patients’ care with their preferences and values.

**PPC/ADV**

**National end-of-life-treatment preferences are stable over time: National health and aging trends study.**

L. E. Skolarus, C. C. Lin, A. S. Kelley, et al. (Skolarus, Lesli E. Department of Neurology, Health Services Research Program, University of Michigan Medical School, Ann Arbor, Michigan, USA. lerusche@umich.edu)

_J Pain Symptom Manage. 2022;64(4):e189–e94. doi: 10.1016/j.jpainsymman.2022.06.012._

CONTEXT: Advance Care Planning is a process of understanding and sharing preferences regarding future medical care. OBJECTIVE: To explore individual and national stability of end-of-life treatment preferences among a sample of older adults. METHODS: National Health and Aging Trends Study is a nationally representative sample of older adults. In 2012, a random sample, and in 2018, the entire sample were queried on end-of-life treatment preferences defined as acceptance or rejection of life prolonging treatment (LPT) if they had a serious illness and were at the end of their life and in severe pain or had severe disability. Using a cohort design, we explored individual trends in preferences for LPT among those with responses in both waves (pain scenario: $N = 606$, disability scenario: $N = 628$) and, using a serial cross-sectional design, national trends in LPT among the entire sample (1702 older adults in wave 2 and 4342 in wave 8). RESULTS: In the cohort study, individual preferences were stable over time (overall percent agreement = 86% for disability and 76% for pain scenarios), particularly for older adults who would reject LPT in wave 2 (overall agreement 92% for disability and 86% for pain). In the serial cross-sectional study, national trends in preferences for receipt of LPT were stable over time in the pain (27.4% vs. 27.0%, $P = 0.80$) and disability (15.8% vs. 15.7%, $P = 0.99$) scenarios. CONCLUSIONS: We found that national trends in preferences for end-of-life treatment did not substantially change over time and may be stable within individual older adults.
CARERS & FAMILIES

How caregivers cope and adapt when a family member is diagnosed with a hematologic malignancy: Informing supportive care needs.

T. A. Albrecht, R. Hoppe and M. A. Winter. (Albrecht, Tara A. School of Nursing, Duke University, Durham, North Carolina, USA. tara.albrecht@duke.edu)

Cancer Nurs. 2022;45(6):E849–e55. doi: 10.1097/ncc.0000000000001063.

BACKGROUND: Informal family caregivers (FCs) of adults with various diseases including hematologic malignancy (HM) experience low quality of life and psychological well-being. Although HMs are life-threatening cancers associated with high mortality, numerous symptoms, and lengthy hospitalizations and are therefore likely to be challenging for FCs to cope with, there is scant research exploring FC experiences. OBJECTIVE: The aim of this study was to describe the coping and adaptation of FCs of patients during diagnosis and treatment of HM. METHODS: This study used a qualitative descriptive design to analyze semi-structured interview responses from FCs (N = 28) within 3 months of the patients’ HM diagnosis. A content analysis was conducted to generate common themes. RESULTS: Family caregivers endorsed adaptive and maladaptive coping. Adaptive strategies included taking one day at a time, spirituality, engaging in pastimes, and utilizing emotional and instrumental family and community support. Maladaptive coping included wishful thinking, harmful habits, avoidance, and lacking or being unable to accept family and community support. CONCLUSIONS: Findings highlight the complexities of caregiver burden as they support their loved ones with HM. IMPLICATIONS FOR PRACTICE: Family caregivers would benefit from receiving an interdisciplinary family-centered approach as their HM person is initiating treatment. Nurses should consider assessing the FCs’ psychosocial needs to help facilitate appropriate services, such as palliative care consultations, social work referrals, support groups, and/or counseling.

Problem-solving dimensions among caregivers of people with cancer receiving outpatient palliative care.

A. E. Bruton, L. R. Debosik, K. A. Pitzer, et al. (Bruton, Adrian E. School of Social Work, University of Alabama, Tuscaloosa, Alabama, USA. Brutoon01@crimson.ua.edu)

J Soc Work End Life Palliat Care. 2022;1–10. doi: 10.1080/15524256.2022.2139333.

Family caregivers of people with cancer encounter a wide range of problems including challenges managing patients’ symptoms, difficulties navigating complex healthcare systems, and financial stressors associated with caregiving. Outpatient palliative care teams are ideally positioned to help caregivers respond to these challenges; however, little evidence is available to inform problem-solving support for caregivers in this setting. This article presents results from a secondary analysis of data obtained as part of a randomized clinical trial of a problem-solving intervention for family caregivers of people with cancer receiving outpatient palliative care. It describes the extent to which caregivers report adoption of positive and negative problem orientations and use of rational, impulsive, and avoidant problem-solving styles, and examines whether these problem-solving dimensions differ by age and gender. Results reveal statistically significant negative correlations between caregiver age and positive and negative problem orientations and use of a rational problem-solving style, and statistically significant gender differences with regard to negative problem orientation and use of an impulsive problem-solving style. Findings from this exploratory study highlight unique potential strengths and needs of caregivers, and set the stage for future research on problem-solving among cancer caregivers in the growing field of outpatient palliative care.
review. These instruments varied significantly in terms of contents, constructs, scoring methods, and applicability. Three of these instruments were developed to assess the comprehensive supportive care needs of family caregivers, while one was specifically developed to assess the spiritual needs of family caregivers. With respect to psychometric properties, none of the instruments identified met all the criteria. Three major shortcomings were identified, namely, lack of longitudinal validity, lack of a strategy for interpreting missing data, and lack of a description of the literacy level required to understand the questions. Additionally, the instrument development processes assessed in this study lacked qualitative elements. CONCLUSIONS: End-users need to consider contents, psychometric properties, and applicability when choosing an appropriate needs assessment instrument according to individual purpose and context. Further evaluation or development of needs assessment for the family caregivers of palliative cancer patients is needed, with a particular emphasis on caregivers’ perspectives.

**PPC/CAR4**

**Benefits of supportive strategies for carers of people with high-grade glioma: A systematic review. Strategies for addressing the needs of high-grade glioma carers.**

D. Jones, M. B. Pinkham, M. P. Wallen, et al. (Chan, Raymond. Caring Futures Institute, College of Nursing and Health Sciences, Flinders University, Sturt Road, Bedford Park, Adelaide, SA, 5042, Australia. raymond.chan@flinders.edu.au)

Support Care Cancer. 2022. doi: 10.1007/s00520-022-07419-2.

**PURPOSE:** To systematically review and examine current evidence for the carer-reported benefits of supportive care strategies for carers of adults with high-grade glioma (HGG). **METHODS:** Four databases (CINAHL, EMBASE, PubMed, PsycINFO) were searched for articles published between January 2005 and April 2022 that assessed strategies for addressing the supportive care needs of carers of adults with HGG (WHO grade 3–4). Study selection and critical appraisal were conducted independently by three authors (DJ/ MC. 2021: DJ/RJ 2022). Data extraction was conducted by one author (DJ) and checked by a second author (RJ). Results were synthesised narratively. **RESULTS:** Twenty-one studies consisting of two categories: ‘restricted communication’ and ‘abortive communication.’ CONCLUSION: The results of this study highlight the need to increase the professional and ethical sensitivity of nurses in dealing with patients’ families at the end-of-life.

**PPC/CAR5**

**Nurses’ communication with the families of patients at the end-of-life.**

R. Norouzadeh, M. Anoosheh and F. Ahmadi. (Anoosheh, Monireh, Department of Nursing, Faculty of Medical Sciences, Tarbiat Modares University, Jalal AleHmad, Nasr, P. O. Box 14115-111, Tehran, I. R. Iran. anoosheh@modares.ac.ir)

Omega (Westport). 2022;86(1):119–34. doi: 10.1177/0030222820959933.

**BACKGROUND:** Effective communication is important in providing quality care to families at the end-of-life. In the end-of-life situations, the nurses’ views on how to communicate with the family are not well understood. **AIM:** This study was conducted to explore the nurses’ experiences of their communication with families of patients at the end-of-life situations. **METHODS:** The authors used standards for reporting qualitative research. The data were analyzed by conventional content analysis. Semi-structured interviews were conducted with 24 Iranian nurses who had the experiences of dealing with patients’ families at the end-of-life. **RESULTS:** Nurses’ perceptions of communication with families emerged base on the main theme: ‘Disrupted communication’ consisting of two categories: ‘restricted communication’ and ‘abortive communication.’ **CONCLUSION:** The results of this study highlight the need to increase the professional and ethical sensitivity of nurses in dealing with patients’ families at the end-of-life.

**PPC/CAR6**

**Quality of life of family caregivers and survival of head and neck cancer patients in palliative care.**

D. P. Pequeno, J. Carron, K. C. Gaspar, et al. (Lourenço, Gustavo Jacob. Laboratory of Cancer Genetics, School of Medical Sciences, University of Campinas, 50 Vital Brasil Street, Barão Geraldo, Campinas, São Paulo, 13083-888, Brazil. guslour@unicamp.br)

Eur J Cancer Care (Engl). 2022;e13731. doi: 10.1111/ecc.13731.

**OBJECTIVE:** The aim of this study is to assess the effect of sociodemographic and genetic features on through peer support. Supportive and early palliative care programmes have potential to reduce unmet carer needs while providing ongoing carer support. **CONCLUSION:** Strategies incorporating an educational component, emotional support, and a regular needs assessment with corresponding tailored support are most valued by carers. Future practice development research should adopt a value-based approach and exceed evaluation of efficacy outcomes to incorporate evaluation of the experience of patients, carers, and staff, as well as costs.
the quality of life (QoL) of family caregivers (FCGs) of patients with head and neck cancer (HNC) in palliative care (PC) and the effect of QoL of FCGs on patients’ survival. METHODS: A questionnaire was applied to obtain sociodemographic information of 100 FCGs of patients with HNC in PC. The WHOQoL-bref questionnaire was used to measure QoL. Genotypes were identified using real-time PCR. Differences between groups were assessed by linear regression. Event-free survival (EFS) and overall survival (OS) were calculated by the Cox proportional hazard ratio (HR) regression. RESULTS: Worse QoL in the overall QoL (p = 0.04), physical health (p = 0.04), psychological (p = 0.005), and environment (p = 0.02) domains was associated to employed caregivers. Collective transport was related to worse QoL of the FCGs in the general health (p = 0.02) and psychological (p = 0.01) domains. Lower levels of QoL of FCGs in the social relationships domain were predictive of a decrease in EFS (HR: 1.98, p = 0.01) and OS (HR: 2.01, p = 0.01) of the patients. CONCLUSION: The results suggest that employment status and means of transportation may impair the QoL of FCGs. Lower levels of QoL of FCGs in the social relationships domain could decrease patients’ survival.

PPC/CAR,

'It was terrible, I didn’t sleep for two years': A mixed methods exploration of sleep and its effects among family caregivers of in-home hospice patients at end-of-life.

L. T. Starr, K. T. Washington, M. V. McPhillips, et al. (Starr, Lauren T. NewCourtland Center for Transitions and Health, University of Pennsylvania School of Nursing, 418 Curie Blvd., Philadelphia, PA 19104, USA. ltstarr@nursing.upenn.edu) Palliat Med. 2022:26921632211122956. doi: 10.1177/02692163221122956.

BACKGROUND: Due to overnight caregiving demands; exacerbation of high rates of anxiety, depression, and distress; and inadequate support, millions of family caregivers of patients receiving in-home hospice are at risk of poor sleep and negative health effects. AIM: To describe sleep experiences of family caregivers of in-home hospice patients and perceptions of these experiences on caregivers’ wellbeing in the context of caregiver health and live-in status. DESIGN: Developed using the Symptom Management Model, this mixed methods study featured a concurrent nested design prioritizing qualitative reflexive thematic analysis. SETTING/ PARTICIPANTS: About 47 family caregivers of in-home hospice patients from two randomized clinical trials (NCT03712410, NCT02929108) were interviewed (United States, 2021). Anxiety (GAD-7), depression (PHQ-9), quality-of-life (QOL) (CQLI-R), and self-rated health and energy were reported prior to interviews. RESULTS: Qualitative analysis revealed three themes: compromised sleep quality, factors influencing sleep, effects of sleep. 72.5% of hospice family caregivers described ‘fair’ or ‘poor’ sleep quality, with ‘interrupted’ sleep and frequent night-waking due to ‘on-call’ vigilance and anxiety. Negative effects included exhaustion, mental and physical health decline, and reduced caregiver function. Live-in caregivers reported higher mean depression scores (8.4 vs 4.3, p = 0.08), higher mean anxiety scores (7.7 vs 3.3, p = 0.06), and lower mean QOL scores (24.8 vs 33.6, p < 0.001) than live-out caregivers. Anxiety, depression, and QOL worsened as self-reported caregiver sleep quality decreased. Few caregivers had adequate support. CONCLUSION: End-of-life family caregivers experience disrupted sleep with negative effects and inadequate support. Clinicians must assess sleep, offer sleep interventions, and provide more supports to hospice family caregivers.

DEATH

PPC/DEA,

End of life in general practice: Trends 2009–2019.

T. D. Bergman, H. R. W. Pasman, J. M. Hendriksen, et al. (Bergman, Tessa. Department of Public and Occupational Health, Amsterdam UMC Locatie VUmc, 1081 BT Amsterdam, The Netherlands. t.bergman@amsterdamumc.nl) BMJ Support Palliat Care. 2022. doi: 10.1136/spcare-2022-003609.

OBJECTIVES: To assess possible trends between 2009 and 2019 in the Netherlands of palliative care indicators: the provision of palliative care or treatment, hospitalisations in the last month before death, use of specialised palliative care services and place of death. METHODS: The study design was a repeated retrospective cross-sectional design with questionnaires filled in by general practitioners within a clustered sample of 67 Sentinel practices. Patients whose death was non-sudden, and thus could have received palliative care, between 1 January 2009 and 31 December 2019 were included in the study, resulting in 3121 patients. RESULTS: Between 2009 and 2019, there is a significant increase in the number of people who receive palliative care or treatment alongside life-prolonging or curative treatment and the number of people who die at home, while the number of hospitalisations in the last month before death and the number of people dying in hospital shows a significant decrease. However, there is no trend in the involvement of specialised palliative care services or people receiving solely palliative care or treatment. CONCLUSION: This study suggests improvements in end-of-life care provided in primary care in the Netherlands. Trends
coincided with increased attention to palliative care both in practice and policy. Yet, there is still considerable room for improvement as there is no significant increase in people solely receiving palliative care or treatment and the involvement of specialised palliative care services.

**PPC/DEA**

**Nursing home staff members’ experiences with and beliefs about unusual end-of-life phenomena.**

S. Claxton-Oldfield and N. Richard. (Claxton-Oldfield, Stephen. Psychology Department, Mount Allison University, 49A York Street, Sackville, New Brunswick, Canada E4L 1C7. sclaxton@mta.ca)

Omeg (Westport). 2022;86(2):609–23. doi: 10.1177/0030222820981238.

Twenty-two members of a nursing home took part in a study examining their experiences with and beliefs about unusual end-of-life phenomena (EOLP). Nearly all the staff members had witnessed and/or been told about residents holding on for someone to arrive or for a specific event to occur before dying (95% and 91%, respectively). Other commonly witnessed/reported EOLP included residents having sudden, unexpected moments of lucidity, sensing or feeling the presence of deceased residents, residents’ dreaming about deceased relatives, friends or pets, and deathbed visions. More than three-quarters of the staff members regarding EOLP as transpersonal experiences, as comforting to dying residents and their family members, and as part of the dying process. Fourteen staff members described experiences they had had with EOLP in the nursing home. The most frequently described experiences involved the appearance of apparitions. Seventy-seven percent of the staff members expressed an interest in learning more about EOLP.

**PPC/DEA**

**Patients’ dying process from the point of view of family and hospice team: A qualitative exploration of family member and hospice team experiences with hospice in Korea.**

S. K. Han and Y. Eo. (Eo,Yugeo. Department of Social Services Policy Research, Korea Institute for Health and Social Affairs, 309ho, Building D, 370 Sicheong-daero, Sejong City 30147, Korea. ygeo@kihasa.re.kr)

Omega (Westport). 2022;86(2):533–52. doi: 10.1177/0030222820976428.

The aim of this study is to analyze the experiences of family members and hospice teams regarding hospice care in Korea where culture and institution for well-dying is in the early stage. The study was conducted through in-depth interviews based on the grounded theory method. The participants were 12 individuals, 5 family members and 7 individuals from the hospice team. 133 concepts, 34 subcategories, and 11 categories were derived. The core phenomenon was ‘maintaining balance by becoming a ballast in the journey toward death’. From the analysis of paradigm model, this phenomenon was caused to the medical-centered hospice service, the negative social and cultural context of death. It was strategically responded to the scope and contents of the interventions by the hospice team. Systematic, policy, and implementation plans that could improve the quality of hospice care were discussed.

**PPC/DEA**

**End-of-life decisions of intracranial hemorrhage patients successfully weaned from prolonged mechanical ventilation.**

C. Huang, T. H. Wu and J. C. Chen. (Wu, Tsung-Hsien. Department of Surgery, Min-Sheng Road. Dalin Town, Chiayi County, 60047, Taiwan. q21200@ttu.tuchii.com.tw)

Am J Hosp Palliat Care. 2022;39(11):1342–9. doi: 10.1177/10499091221074636.

Factors related to the end-of-life decisions of patients with intracranial hemorrhage who were successfully weaned from prolonged mechanical ventilation remain unclear. This study aimed to evaluate factors that influence the end-of-life decisions of these patients.

**METHODS:** This retrospective study examined patients with intracranial hemorrhage successfully weaned from prolonged mechanical ventilation between January 2012 and December 2017. The following data was collected and analyzed: age, gender, comorbidities, Glasgow Coma Scale scores, receipt or non-receipt of intracranial hemorrhage surgery, discharge status, and end-of-life decisions.

**RESULTS:** In total, 91 patients with intracranial hemorrhage were successfully weaned from prolonged mechanical ventilation. The families of 62 (68.1%) patients signed the do-not-resuscitate order. A Glasgow Coma Scale score of ≥10 at discharge from the respiratory care center and zero comorbidities were the influencing factors between patients whose do-not-resuscitate orders were signed and those whose orders were not signed. Patients with intracranial hemorrhage successfully weaned from prolonged mechanical ventilation had chronic kidney disease comorbidity and Glasgow Coma Scale score of <7 on admission to respiratory care center with a general ward mortality rate of 83.3%. **CONCLUSIONS:** The families of intracranial hemorrhage patients with multiple comorbidities and higher neurologic impairment after successful weaning from the ventilator believed that palliative therapy would provide a greater benefit. Patients with intracranial hemorrhage successfully weaned from prolonged mechanical ventilation with chronic kidney disease comorbidity and Glasgow Coma Scale score of <7 on admission to respiratory care center are...
candidates for the consideration of hospice care with ventilator withdrawal.

**PPC/DEA**

Admission code status and end-of-life care for hospitalized patients with COVID-19.
W. A. Kiker, S. Cheng, L. R. Pollack, et al. (Kiker, Whitney A. Box 356222, BB1226 Health Sciences Building, University of Washington, Seattle, 98195 WA, USA. wkiker@uw.edu)

*J Pain Symptom Manage.* 2022;64(4):359–69. doi: 10.1016/j.jpainsymman.2022.06.014.

**CONTEXT:** The COVID-19 pandemic has highlighted variability in intensity of care. We aimed to characterize intensity of care among hospitalized patients with COVID-19. **OBJECTIVES:** Examine the prevalence and predictors of admission code status, palliative care consultation, comfort-measures-only orders, and cardiopulmonary resuscitation (CPR) among patients hospitalized with COVID-19. **METHODS:** This cross-sectional study examined data from an international registry of hospitalized patients with COVID-19. A proportional odds model evaluated predictors of more aggressive code status (i.e., Full Code) vs. less (i.e., Do Not Resuscitate, DNR). Among decedents, logistic regression was used to identify predictors of palliative care consultation, comfort measures only, and CPR at time of death. **RESULTS:** We included 29,923 patients across 179 sites. Among those with admission code status documented, Full Code was selected by 90% (n = 15,273). Adjusting for site, Full Code was more likely for patients who were of Black or Asian race (ORs 1.82, 95% CIs 1.5–2.19; 1.78, 1.15–3.09 respectively, relative to White race), Hispanic ethnicity (OR 1.89, CI 1.35–2.32), and male sex (OR 1.16, CI 1.0–1.33). Of the 4951 decedents, 29% received palliative care consultation, 59% transitioned to comfort measures only, and 29% received CPR, with non-White racial and ethnic groups less likely to receive comfort measures only and more likely to receive CPR. **CONCLUSION:** In this international cohort of patients with COVID-19, Full Code was the initial code status in the majority, and more likely among patients who were Black or Asian race. Hispanic ethnicity or male. These results provide direction for future studies to improve these disparities in care.

**ECONOMICS**

**PPC/ECO**

End of life cost savings in the palliative care unit compared to other services.
M. H. Abian, C. Antón Rodríguez and A. Noguera. (Antón Rodríguez, Cristina. Unidad de Apoyo a la Investigación, Facultad de Medicina, Universidad Francisco de Vitoria, Madrid, Spain. c.anton@ufv.es)

*J Pain Symptom Manage.* 2022;64(5):495–503. doi: 10.1016/j.jpainsymman.2022.06.016.

**CONTEXT:** Hospital deaths carry a significant healthcare cost that has been confirmed to be lower when palliative care units (PCUs) are available. **OBJECTIVES:** To compare the last admission hospital health care cost of dying in a first-level hospital between the PCU and the rest of the hospital services. **METHODS:** A retrospective, comparative, observational study evaluating costs from the payer perspective on treatments and diagnostic-therapeutic tests performed on patients who die in first-level hospital, comparing whether they were treated by the PCU or another unit (Non-PCU). Patients with a mortality risk >2 were included according to the Severity of Illness Index (SOI) and Risk of Mortality (MOR). All cost express in €, median per patient and inter-quartile range (IQR). **RESULTS:** From 1,833 patients who died, 1,389 were included, 442 (31.1%) treated by PCU and 928 (68.9%) Non-PCU. Statistical differences were found for the last admission total cost (€262.8 (€470.1) for PCU versus €515.3 (€980.48) in Non-PCU), daily total cost (€74.27 (€127.4) vs €115.8 (€142.4) Non-PCU). Savings were maintained when the sample was broken down by diagnosis-related group (DRG) and a multivariate analysis was performed to determine how the different patients baseline characteristics between PCU and Non-PCU patients influenced the results obtained. **CONCLUSIONS:** Data from this study show that cost is significantly lower when the patients are treated by a PCU during their last hospital stay when they pass away.

**PPC/ECO**

The end of life experiences of people living with socio-economic deprivation in the developed world: An integrative review.
S. P. Bowers, M. Chin, M. O’Riordan, et al. (Bowers, Sarah. NHS Tayside and University of Dundee, Ninewells Hospital, Dundee, DD1 9SY, UK. Sarah.Bowers3@nhs.scot)

*BMC Palliat Care.* 2022;21(1):193. doi: 10.1186/s12904-022-01080-6.

**BACKGROUND:** Those experiencing socio-economic deprivation have poorer quality of health throughout their life course which can result in poorer quality of death - with decreased access to palliative care services, greater use of acute care, and reduced access to preferred place of care compared with patients from less deprived populations. **AIM:** To summarise the current global evidence from developed countries on end-of-life experience for those living with socio-economic deprivation. **DESIGN:** Integrative review in accordance with PRISMA. A thorough search of major databases from 2010 to 2020, using clear definitions of end-of-life care and well-established proxy indicators of socio-economic
deprivation. Empirical research describing experience of adult patients in the last year of life care were included. RESULTS: Forty studies were included from a total of 3508 after screening and selection. These were deemed to be of high quality; from a wide range of countries with varying healthcare systems; and encompassed all palliative care settings for patients with malignant and non-malignant diagnoses. Three global themes were identified: (1) multi-dimensional symptom burden, (2) preferences and planning and (3) health and social care interactions at the end of life. CONCLUSIONS: Current models of healthcare services are not meeting the needs of those experiencing socioeconomic deprivation at the end-of-life. Further work is needed to understand the disparity in care, particularly around ensuring patients voices are heard and can influence service development and delivery.

**PPC/ECO3**

**Pediatric concurrent hospice care: Cost implications of a hybrid payment model.**

M. J. Cozad, R. Svyarenko, P. S. Hinds, et al. (Cozad, Melanie J. Department of Health Services Research and Administration, University of Nebraska Medical Center, 42nd and Emile Streets, Omaha, NE 68198, USA. mcozad@mailbox.sc.edu)

Am J Hosp Palliat Care. 2022;39(12):1436–42. doi: 10.1177/10499091221089337.

BACKGROUND: Implementation of concurrent hospice care led to a new hybrid payment model that combines hospice payments with payments for non-hospice medical care. Little is known about the cost implications of this new hybrid payment model. OBJECTIVE: The purpose was to identify costs and compare concurrent care and standard hospice care costs by estimating the average incremental Medicaid cost of care over time. METHODS: Using national Medicaid data of 18 147 hospice children and a multilevel generalized linear model, we calculated the incremental costs of receiving concurrent vs standard hospice care. We used the total cost of care over the last year of life. Increments for the analysis were hospice length of stay, stratified to 1 day, 2–14 days, and 15 + days. RESULTS: Overall, compared to standard hospice care, enrollment in concurrent hospice care was significantly associated with an increase in outpatient care and prescription drug costs. For a stay of 1 day, concurrent hospice care decreased inpatient costs and increased costs of prescription drugs. For stays between 2 and 14 days, concurrent hospice decreased total costs and inpatient costs, but increased prescription drug costs. With a hospice stay of 15 + days, concurrent hospice had significantly higher costs across all measures, including total costs, inpatient costs, outpatient costs, and prescription drug costs. CONCLUSION: This study provides critical insight into incremental costs of receiving concurrent vs standard hospice care. More research is needed to understand how concurrent hospice lengthy hospice stays are associated with increases of costs.

**PPC/ECO4**

**Optimising the management of patients with multiple myeloma in Spain: A measurement of the social return on investment.**

M. Merino, Y. Ivanova, P. Maravilla-Herrera, et al. (Merino, María. Calle Moreto, 17, 5D, Madrid 28014, Spain. maria.merino@weber.org.es)

Eur J Cancer Care (Engl). 2022:e13706. doi: 10.1111/ecc.13706.

OBJECTIVE: The aim of this study was to reach a consensus on a set of proposals to optimise the disease management of Multiple myeloma (MM) within the Spanish National Health System (SNHS) and to apply the Social Return on Investment (SROI) method to estimate their social impact. METHODS: A Multidisciplinary Working Team (MWT) including MM main stakeholders was organised. A survey was administered to gather information from patients regarding the impact of MM on different life domains. A forecast-type SROI analysis, with a 1-year timeframe, was applied. RESULTS: Fifteen proposals were selected, to optimise MM management, including actions for early diagnosis, psychological support, improvement of information for patients and quick access to palliative care, among others. The implementation of these proposals would benefit patients, their informal caregivers and the SNHS. The investment required would amount to 10.32 million euros with a social return of 43.31 million euros: 4.2 euros for each euro invested. According to the sensitivity analysis, this ratio could range from 3.38 to 5.20 euros from the worst to the best-case scenario. CONCLUSIONS: The current management of MM could be optimised by implementing a set of proposals that would most likely result in an overall positive social return.

**PPC/LOS1**

**Bereavement support effectiveness for parents of infants and children: A systematic review.**

T. Ainscough, L. Fraser, J. Taylor, et al. (Fraser, Lorna. Department of Health Sciences, University of York, York Y010 5DD, UK. lorna.fraser@york.ac.uk)

BMJ Support Palliat Care. 2022;12(e5):e623–e31. doi: 10.1136/bmjpsychcare-2019-001823.

OBJECTIVES: This systematic review aims to assess the effectiveness of bereavement support interventions (BSIs) for parents of an infant or a child who has died...
from a medical condition or in unforeseen circumstances. METHODS: A systematic search of MEDLINE, PsycINFO, Embase and CINAHL (1980 to January 2018) was performed to identify studies investigating BSIs for the parents of children who died between the ages of 24 weeks gestation and 30 years. Due to significant clinical and methodological heterogeneity between studies, a narrative synthesis was performed. RESULTS: The database searches returned 24,550 records, with a further 6 identified through other sources. Of these, eight studies, reported in nine papers, met the inclusion criteria. Most studies were conducted in the USA (n = 5) and in perinatal/neonatal deaths (n = 6). Five of the included studies were randomised controlled trials and three were non-randomised comparative studies. Interventions were delivered to groups, individuals or families. Outcomes of interest were grief, mental health, physical health and ‘others’. There were major concerns over the quality of study methods and reporting. Only three of the nine studies reported a significant difference between experimental and control arm participants in any outcomes, despite a total of 23 outcomes being measured. CONCLUSIONS: Poor methodology and reporting of the few studies which have assessed BSIs for parents limit any conclusions on their effectiveness. Agreement on core outcomes and more robust study methodology are required in this neglected area of research.

**PPC/LOS2**

**End-of-life-related factors associated with posttraumatic stress and prolonged grief in parentally bereaved adolescents.**

M. W. Falk, A. Alvariza, U. Kreicbergs, et al. (Falk, Megan Weber. Palliative Research Centre, Department of Caring Sciences, Ersta Sköndal Bräcke University College, P.O. Box 11189, Stockholm SE-10061, Sweden. megan.weber@esh.se)

Omega (Westport). 2022;86(1):174–86. doi: 10.1177/003022820963768.

Posttraumatic stress disorder (PTSD) and prolonged grief disorder (PGD) are well-documented in parentally bereaved adolescents. Whether or not the parent’s death is perceived as traumatic may be influenced by several end-of-life-related factors. This study aimed to examine the associations between end-of-life-related factors, symptoms of posttraumatic stress disorder (PTSD), symptoms of prolonged grief disorder and PGD, and the association between PTSD and PGD. Mann-Whitney U tests and Spearman correlation were used to analyze the relationships between end-of-life-related factors, PTSD, and PGD. Regrettin one’s decision to be present or not present at the time of death resulted in a significant difference in self-reported scores for PTSD, but not PGD.

**PPC/LOS3**

**Mental wellbeing in bereaved carers: A health survey for England population study.**

F. Hodiamont, V. Allgar, D. C. Currow, et al. (Johnson, Miriam J. Wolfson Palliative Care Research Centre, Hull York Medical School, University of Hull, Hull HU6 7RX, UK. miriam.johnson@hyms.ac.uk)

BMJ Support Palliat Care. 2022;12(e4):e592–e8. doi: 10.1136/bmjspcare-2019-001957.

OBJECTIVES: The experience of caregiving may affect carers’ well-being into bereavement. We explored associations between mental well-being and previous experience of bereavement of, and caring for, someone close at the end-of-life. METHODS: An end-of-life set of questions was included in population-based household survey administered to adults (age 16 years and above). We used univariable regression to explore the cross-sectional relationship between our primary outcome (Warwick-Edinburgh Mental Well-being Scale (WEMWS)) and possible explanatory variables: sociodemographic; death and bereavement including ability to continue with their life; disease and carer characteristics; service use and caregiving experience. RESULTS: The analysis dataset included 7606 on whom 5849 (77%) were not bereaved, 1174 (15%) were bereaved but provided no care and 583 (8%) were bereaved carers. WEMWS was lower in the oldest age class (85 years and above) in both bereaved groups compared with not bereaved (p < 0.001). The worst WEMWS scores were seen in the ‘bereaved but no care’ group who had bad/very bad health self-assessed general health (39.8 (10.1)) vs 41.6 (9.5) in those not bereaved and 46.4 (10.7) in bereaved carers. Among the bereaved groups, those who would not be willing to care again had lower WEMWS scores than those who would (48.3 (8.3) vs 51.4 (8.4), p = 0.024).

CONCLUSION: Mental well-being in bereavement was worse in people with self-reported poor/very poor general health and those with a worse caregiving experience. Although causality cannot be assumed, interventions to help people with worse mental and physical health to care, so that their experience is as positive as possible, should be explored prospectively.

**PPC/LOS4**

**Low rates of grief and bereavement support pre- and post-death for those who died within 72 hours of admission to a quaternary teaching hospital.**

N. T. Katz, C. Coleman and C. Corbett. (Katz, Naomi T. Palliative Care Service, Alfred Health, 55 Commercial Rd, Melbourne, VIC 3181, Australia. n.katz@alfred.org.au)

Am J Hosp Palliat Care. 2022;10499091221137744. doi: 10.1177/10499091221137744.
Grief and bereavement support are crucial to good palliative and end-of-life care. Support models differ between and within services. In addition, while patient and family needs vary based on risk and resilience factors, acute or unexpected death is associated with complicated grief. Our study was a retrospective review of 159 patients who died within 72 hours of hospital admission. We found a high proportion of unexpected and traumatic deaths and low grief and bereavement support rates. Further work is needed to streamline policies to optimize patient and family-centred grief and bereavement support in the acute hospital setting.

Predictors of complicated grief in caregivers of palliative care patients.

Y. López Pérez, J. A. Cruzado, M. A. Lacasta Reverte, et al. (Cruzado, Juan Antonio. Facultad de Psicología. Universidad Complutense de Madrid. Ciudad Universitaria, Campus de Somosaguas, s/n, Pozuelo de Alarcón, Madrid 28223, Spain. jacruzad@ucm.es)

Omega (Westport). 2022;302228221133437. doi: 10.1177/00302228221133437.

Introduction: It is important to identify the factors associated with complicated grief (CG) in order to prevent it. Objective: To determine the factors associated with CG in the end-of-life phase within the palliative care context. Method: The PRISMA model was followed for the review. We accessed the following databases: PUBMED, SCOPUS, and PsycINFO, to review publications from 2006. Results: A total of 17 studies were obtained. A direct relationship between factors prior to bereavement and CG is established: intensity of anticipated grief, previous mental and physical health of the caregiver, social support; quality of patient care, communication at the end-of-life, preparation for death, spirituality, and sociodemographic factors. Conclusions: Previous mental health and level of anticipatory grief in the main caregiver are shown to be the most powerful predictors of CG. Patient age and quality of care are factors considered as strong predictors of CG in almost every study.

Family caregiver challenges in pain management for patients with advanced illnesses: A systematic review.

N. C. Chi, Y. K. Fu, L. Nakad, et al. (Chi, Nai-Ching. College of Nursing, University of Iowa, Iowa City, Iowa, USA. nai-ching-chi@uiowa.edu)

J Palliat Med. 2022. doi: 10.1089/jpm.2020.0806.

Although pain management is integral to the caregiving role, there is a paucity of evidence synthesizing specific challenges family caregivers (FCs) face when...
managing pain for their care partners. This review comprehensively identified and summarized such challenges in the setting of advanced illnesses. Electronic databases (PubMed, CINAHL, PsycINFO, Scopus, and Health and Psychosocial Instruments) were searched using index and keyword methods for all articles published before April 2021. Fifty-five studies were included in this review. Most articles were published within the last 10 years (54%) in community settings, with home hospice care comprising the majority (50%). Most studies included patients with an advanced cancer diagnosis (84%), and 16% of the studies included patients with a non-cancer diagnosis. Four major categories of challenges were identified: (1) caregiver-related issues (e.g., fears, beliefs, function), (2) caregivers’ limited knowledge and skills in pain management (e.g., verbal and non-verbal pain assessment skills, pharmacological knowledge, documentation, safe management of medication), (3) communication challenges with health care providers, and (4) patient-related issues (e.g., inability to report pain). Many of these challenges have not been fully addressed in prior literature. Thus, this review provides a framework for needed future research to develop interventions that target FCs’ specific challenges in providing pain management. The results also highlight a significant lack of research surrounding challenges faced by caregivers of care partners having a noncancer, dementia, or multimorbidity diagnosis.

Virtual reality reduces pain in palliative care—a feasibility trial.

M. Guenther, D. Görlich, F. Bernhardt, et al. (Lenz, Philipp. Department of Palliative Care, University Hospital Muenster, Albert-Schweitzer-Campus 1, Building W 30, D-48149 Muenster, Germany. lenzph@uni-muenster.de)

BMC Palliat Care. 2022;21(1):169. doi: 10.1186/s12904-022-01058-4.

BACKGROUND: Effective symptom control is a stated goal of palliative care (PC) to improve quality of life for terminally ill patients. Virtual reality (VR) provides temporary escapes from pharmacologically resistant pain and allows for experiences and journeys patients may not access in any other way. Enabling wishes through virtual worlds may also offer additional benefits such as controlling psychological and physical symptoms. AIMS: We investigated the feasibility of a single VR experience as a viable, satisfying, and effective tool for end-of-life pain relief for inpatients presenting palliative needs. DESIGN: This is an observational, single-arm and national single-center feasibility trial. METHODS: A one-time VR experience with a selection of several videos and games was offered to 45 inpatients receiving PC at Muenster University Hospital. Patients with brain tumors, brain metastases, seizures, motion sickness, claustrophobia, vertigo, hearing or visual impairment, or unable to consent were excluded. Primary outcome measured patient reported pain on a visual analogue scale (VAS). We also measured Karnofsky performance status, health-related quality of life (HRQOL) using the EQ-5D-3 L questionnaire, and the Pain Out Questionnaire for postoperative pain. RESULTS: We analyzed data from 21 women (52.5%) and 19 men (47.5%) at an average age of 51.9 (SD: 15.81) years. The mean Karnofsky score among the sample was 45.5 (SD: 14.97) and the HRQOL was 41.9 (SD: 23.08). While no serious side effects were reported during the intervention, three patients experienced nausea (7%), two headaches (5%), and three reported dry eyes (7%) afterwards. Significant pain reduction (baseline VAS 2.25 (SD: 0.4399)) was demonstrated during (VAS 0.7 (SD: 0.2983, p < 0.0001)), immediately after (VAS 0.9 (SD: 0.3354, p = 0.0001)) and one hour after the intervention (VAS 1.15 (SD: 0.4163, p = 0.0004)). More than 80% rated the VR experience as very good or good (85%, n = 34) and intended to make use of the device again (82.5%, n = 33). However, two participants (5%) also expressed sadness by becoming aware of old memories and previous opportunities that are gone. DISCUSSION: The present pilot study suggests that VR seems to be a feasible and effective tool for pain relief in PC. Its use encompasses the approach of a total pain and symptom therapy and enhances patients’ dignity and autonomy. Future research ought to include if and to what extent VR could reduce the necessity of pharmacological pain relief.

‘Knock me out’: The challenges of managing pain due to cutaneous T cell lymphomas: A case report.

S. Pandey, A. Dolan, M. Norton-Westbrook, et al. (Pandey, Shila. Supportive Care Service, Memorial Sloan Kettering Cancer Center, New York, New York 10065, USA. pandeys@mskcc.org)

J Palliat Med. 2022;25(11):1740–6. doi: 10.1089/jpm.2021.0561.

Cutaneous T cell lymphomas are associated with distressing symptoms, including pain and pruritus that negatively impact quality of life. Early involvement of palliative care can provide relief of symptoms and address multifaceted distress. This case highlights the complex management of cutaneous T cell lymphoma pain and associated symptoms, including existential and psychosocial distress. Our patient required frequent titration and rotation of high-dose opioids and adjuvant analgesics, ultimately requiring transfer to the intensive care unit for analgesedation. Total skin loss and disease complications led to his death after a compassionate withdrawal of life support. Cutaneous T cell lymphoma pain can be successfully
managed with an interdisciplinary approach, early palliative care, and aggressive pain management. Complications from advanced disease, superinfection, and multidimensional distress complicate the efficacy of a multimodal analgesic approach. Further research is needed to deepen our understanding of how to optimally alleviate suffering within this vulnerable population.

**Health and disability care providers’ experiences and perspectives on end-of-life care needs of individuals with long-standing physical disability: A qualitative interview study.**

I. Belperio, K. Devery, D. D. Morgan, et al. (Walker, Ruth. Disability and Community Inclusion, College of Nursing and Health Sciences, Flinders University, Adelaide, South Australia. ruth.walkler@flinders.edu.au)

*Palliat Med.* 2022;2692163221128702. doi: 10.1177/02692163221128702.

**BACKGROUND:** Little is known about the specific needs and experiences of individuals with long-standing physical disability at end of life. **AIM:** To explore health and disability care providers perspectives and experiences in relation to end-of-life care needs of individuals with long-standing physical disability. **DESIGN:** Qualitative study using reflexive thematic analysis. **SETTING/PARTICIPANTS:** Semi-structured interviews were conducted with nine health and disability care providers from two Australian states. **RESULTS:** Five themes were constructed from the data: (1) The significance of place. All participants described how the end-of-life care experience was significantly impacted by the place in which dying occurred. (2) Knowing the person and their needs. Knowledge and familiarity with the individual with long-standing disability were seen as invaluable in terms of providing continued high-quality care. (3) Navigating a new care landscape. For disability support workers, struggling to adapt from providing disability support to end-of-life care was difficult. (4) Complexities of family involvement. Past experiences of families within the healthcare system had resultant impacts on care received by the individual with long-standing disability. (5) Being prepared. Participants felt more was needed in terms of end-of-life planning and discussions around end of life for this cohort. **CONCLUSIONS:** This research highlights a significant lack of continuity of care and problems at the intersection of the disability and health systems when providing end-of-life care for this cohort. Suggested areas for improvement include team approaches to enable continuity of care and dying in place, and a need for knowledge and skills in this area for all stakeholders.
PC was delivered to veterans at risk for homelessness received PC services similarly (adjusted OR adjusted for IPTW, those at risk for homelessness 6249, 9.6%). Relative to the stably housed and 1967, 2.8%) and stably housed (n = 64,843, 91.5%). PC was delivered to veterans at risk for homelessness (n = 484, 12.0%), veterans experiencing homelessness, (n = 161, 8.2%) and patients with stable housing (n = 6249, 9.6%). Relative to the stably housed and adjusted for IPTW, those at risk for homelessness received PC services similarly (adjusted OR = 1.06, 95% CI 0.94,1.19) and those experiencing homelessness were at lower odds of receiving PC services (adjusted OR = 0.62, 95% CI 0.52,0.75).

CONCLUSION: Housing stability may be a factor in Veterans receiving PC during hospitalization for heart failure. While the logistical challenges of delivering PC and hospice to people experiencing homelessness are daunting, advocating for these services shows commitment to reducing suffering in life-limiting Illness.

**PPC/PAT₄**

Implementation of a threefold intervention to improve palliative care for persons experiencing homelessness: A process evaluation using the RE-AIM framework.

H. T. Klop, A. J. E. de Veer, J. R. G. Gootjes, et al. (Klop, Hanna T. Department of Public and Occupational Health, Amsterdam UMC, Vrije Universiteit Amsterdam, Amsterdam Public Health research institute (APH), De Boelelaan 1117, Amsterdam, Netherlands. j.klop@amsterdamumc.nl)

*BMC Palliat Care*. 2022;21(1):192. doi: 10.1186/s12904-022-01083-3.

**BACKGROUND:** Palliative care provision for persons experiencing homelessness is often poor. A threefold consultation service intervention was expected to increase knowledge of palliative care and multidisciplinary collaboration, and improve palliative care for this population. This intervention comprised: (1) consultation of social service professionals by palliative care specialists and vice versa; (2) multidisciplinary meetings with these professionals; and (3) training and education of these professionals. We aimed to evaluate the implementation process and its barriers and facilitators of this service implemented within social services and healthcare organizations in three Dutch regions. **METHODS:** A process evaluation using structured questionnaires among consultants, semi-structured individual and group interviews among professionals involved, and (research) diaries. Qualitative data were analysed using thematic analysis. The process evaluation was structured using the Reach, Adoption, Implementation and Maintenance dimensions of the RE-AIM framework. **RESULTS:** All three regions adopted all three activities of the intervention, with differences between the three regions in the start, timing and frequency. During the 21-month implementation period there were 34 consultations, 22 multidisciplinary meetings and 9 training sessions. The professionals reached were mainly social service professionals. Facilitators for adoption of the service were a perceived need for improving palliative care provision and previous acquaintance with other professionals involved, while professionals’ limited skills in recognizing, discussing and prioritizing palliative care hindered adoption. Implementation was facilitated by a consultant’s expertise in advising professionals and working with persons experiencing homelessness, and hindered by COVID-19 circumstances, staff shortages and lack of knowledge of palliative care in social service facilities. Embedding the service in regular, properly funded meetings was expected to facilitate maintenance, while the limited number of persons involved in this small-scale service was expected to be an obstacle. **CONCLUSIONS:** A threefold intervention aimed at improving palliative care for persons experiencing homelessness is evaluated as being most usable when tailored to specific regions, with bedside and telephone consultations and a combination of palliative care consultants and teams of social service professionals. It is recommended to further implement this region-tailored intervention with palliative care consultants in the lead, and to raise awareness and to remove fear of palliative care provision.

**PEDIATRIC ISSUES**

**PPC/PED₁**

Charting a path to high-quality end-of-life care for children with cancer.

P. Ananth, J. Wolfe and E. E. Johnston. (Johnston, Emily. E. 1600 7th Ave S, Birmingham, AL 35233, USA. eejohnston@uabmc.edu)

*Cancer*. 2022;128(20):3586–92. doi: 10.1002/cncr.34419.

There are currently no quality measures for end-of-life (EOL) care for children with cancer. In this commentary, we address why it is essential that we develop quality measures for EOL care for children with cancer, review the progress made to date, and chart the course for future work in this area.

**PPC/PED₂**

Analysis of health administration data to inform health service planning for paediatric palliative care.

A. P. Bowers, N. Bradford, R. J. Chan, et al. (Bowers, Alison. Queensland University of Technology (QUT), Brisbane, Queensland, Australia. ap.bowers@qut.edu.au)
BACKGROUND: Health service planning in paediatric palliative care is complex, with the diverse geographical and demographic characteristics adding to the challenge of developing services across different nations. Accurate and reliable data are essential to inform effective, efficient and equitable health services.

AIM: To quantify health service usage by children and young people aged 0–21 years with a life-limiting condition admitted to hospital and health service facilities in Queensland, Australia during the 2011 and 2016 calendar years, and describe the clinical and demographic characteristics associated with health services usage.

DESIGN: Retrospective health administrative data linkage of clinical and demographic information with hospital admissions was extracted using International Statistical Classification of Diseases and Related Health Problems, Tenth Revision Australian Modification (ICD-10-AM) diagnostic codes. Data were analysed using descriptive statistics.

SETTING/PARTICIPANTS: Individuals aged 0–21 years with a life-limiting condition admitted to a Queensland Public Hospital and Health Service or private hospital.

RESULTS: Hospital admissions increased from 17,955 in 2011 to 23,273 in 2016, an increase of 5,318 (29.6%). The greatest percentage increase in admissions were for those aged 16–18 years (58.1%, n = 1,050), and those with non-oncological conditions (36.2%, n = 4,256). The greatest number of admissions by ICD-10-AM chapter for 2011 and 2016 were by individuals with neoplasms (6,174, 34.4% and 7,206, 31.0% respectively). Overall, the number of admissions by Indigenous children and young people increased by 70.2% (n = 838).

CONCLUSIONS: Administrative data are useful to describe clinical and demographic characteristics and quantify health service usage. Available data suggest a growing demand for health services by children eligible for palliative care that will require an appropriate response from health service planners.

Multidisciplinary health care professionals’ perceptions about pediatric end of life discussions: A cross-sectional survey and needs analysis.

A. G. Georgadarellis, T. C. Chu and K. E. Mason (Mason, Katherine E. Division of Pediatric Critical Care Potter Building 115, Hasbro Children’s Hospital, 593 Eddy Street, Providence, RI, 02903, USA)

Am J Hosp Palliat Care. 2022;39(12):1428–35. doi: 10.1177/10499091221091294.

BACKGROUND: Pediatric end of life (EOL) care involves complex coordination of providers from multiple disciplines. Many of these providers’ experiences have not been completely described. AIM: This study aims to explicate the alignment and divergence of health care professionals’ perceptions of the training, timelines, comfort, and effectiveness of pediatric EOL discussions as well as identify methods to improve medical education training.

DESIGN: A cross-sectional survey was conducted. Analyses included Fisher’s exact and post-hoc tests for all pairwise comparisons.

SETTING/PARTICIPANTS: A total of 160 of 508 eligible participants at a single academic Department of Pediatrics completed the survey (response rate 31%). Participants included attending physicians, fellows, residents, mid-level providers, nurses, and social workers.

RESULTS: Sixty percent thought EOL discussions occurred late and 70% thought discussions should occur earlier. Attending physicians were more likely to think discussions occurred late and should occur earlier (P < .01). Residents and fellows were more likely to think participating in and leading discussions was stressful (P < .02 and P < .01, respectively). Respondents that were female, younger than forty years old, had been in their provider role less than five years, or were residents and fellows were more likely to agree that these discussions led to changes in plan of patient care (P < .05).

CONCLUSIONS: The majority of multidisciplinary pediatric health care professionals believe pediatric EOL discussions are stressful, occur too late, and should occur earlier. Future efforts in medical education should prioritize curriculum development focusing on workshops and simulations.

Defining neonatal serious illness.

K. Guttmann, A. Kelley, A. Weintraub, et al. (Guttmann, Katherine. Division of Newborn Medicine, Department of Pediatrics, Icahn School of Medicine at Mount Sinai, New York, New York, USA.

Katherine.guttmann@mssm.edu)

J Palliat Med. 2022;25(11):1655–60. doi: 10.1089/jpm.2022.0033.

Background: One major challenge to the conduct of rigorous neonatal palliative care research is the lack of robust universally agreed upon definitions of key concepts central to pediatric and neonatal palliative care. Objective: We sought to define neonatal serious illness as a foundational concept for neonatal palliative care. Design: Survey study. Setting/Subjects: Practitioners in the United States with expertise in neonatal serious illness. Measurements: Participants ranked 15 components according to how important each would be to include in a conceptual definition of neonatal serious illness. Based on rankings and free text responses, a working definition was created and a follow-up survey was circulated. Participants then ranked the extent to which the proposed definition comprehensively defines neonatal serious illness. The definition was further refined based on responses to the second survey. Results: Eighty experts responded.
Empowering pediatric palliative homecare patients and caregivers with symptom management plans.

A. Larrow, A. Doshi, E. Fisher, et al. (Larrow, Annie. Rady Children’s Hospital, 3020 Children’s Way, MC 5064, San Diego, CA 92123, USA. alarrow@rchsd.org)

J Pain Symptom Manage. 2022;64(4):340–8. doi: 10.1016/j.jpainsymman.2020.06.015.

Palliative care in a tertiary neonatal intensive care unit: A 10-year review.

S. K. F. Ng, N. Keenan, S. Swart, et al. (Ng, Stanley Ka Fai. Department of Paediatrics and Child Health, Nelson Marlborough District Health Board, Nelson Hospital, Nelson 7042, New Zealand. stanleyfng@gmail.com)

BMJ Support Palliat Care. 2022;12(e5):e641–e5. doi: 10.1136/bmjspcare-2018-001538.

OBJECTIVES: When active treatment is no longer in the best interests of the patient, redirection of care to palliation is an important transition. We review, within a tertiary neonatal intensive care unit (NICU), the journey leading to the decision to redirect care, the means of symptom control and the provision of psychosocial supports. METHODS: A retrospective review of all 166 deaths of NICU-affiliated patients during a 10-year epoch. Medical notes were reviewed, and the provision and type of, or barriers to, effective palliative care was defined. RESULTS: Extreme prematurity accounted for 71/145 (49%) of deaths with relatively high proportions of Māori 17/71 (25%) and Pacific Islanders 9/71 (13%). Almost all eligible infants received some form of palliation. Transition from curative to palliative care was refused by the family in a single case. Median time from decision to redirect care until first recorded action was 80 min, and median time from action until death was 60 min. The majority of infants received some form of comfort cares, (128/166) most commonly morphine (94/128, 73%). Three infants had documented seizure activity or respiratory distress but did not receive any pharmacological intervention. Psychosocial supports were offered in 98/145 (67%) of cases, but only 71/145 (49%) of families were formally offered an opportunity to discuss the infant’s clinical course after their death. CONCLUSIONS: Clinical documentation of care plans was often incomplete, potentially leading to inconsistent delivery of care, increased risk of symptom breakthrough and/or inadequate psychosocial supports for family. Formal individualised palliative care plans are under development to standardise documentation and improve therapeutic and psychosocial interventions available to the infant and their family.
Patterns of healthcare services among children with advanced cancer in concurrent hospice care.

R. Svynarenko, L. C. Lindley, K. Mooney-Doyle, et al. (Svynarenko, Radion. College of Nursing, University of Tennessee, 1200 Volunteer Blvd., Knoxville, TN 37996 USA. rsynarel@utk.edu)

Cancer Nurs. 2022;45(6):E843–e8. doi: 10.1097/ncn.0000000000001067.

BACKGROUND: Children with advanced cancer have access to comprehensive cancer care and hospice care if they enroll in concurrent hospice care. However, little is known about the patterns of nonhospice healthcare services used by these children. OBJECTIVE: The aim of this study was to examine the patterns of nonhospice healthcare services among children with cancer in concurrent hospice care. METHODS: This study was a retrospective cohort analysis of 2011–2013 Medicaid claims data from 862 pediatric cancer patients. Data were analyzed using descriptive statistics and latent class analysis (LCA). RESULTS: Children used 120,388 healthcare services, including inpatient and outpatient hospital services, laboratories and x-rays, durable medical equipment, medications, and others. These services clustered into 2 classes with moderate-intensity (57.49%) and high-intensity (42.50%) healthcare service use. Children in the high-intensity cluster were more likely to reside in the South with comorbidities, mental/behavioral health conditions, and technology dependence and were less likely to have solid tumors, compared with the moderate-intensity group. CONCLUSIONS: Nonhospice healthcare services clustered together in 2 distinct classes, providing critical insight into the complexity of the healthcare use among children with cancer in concurrent hospice care. IMPLICATIONS FOR PRACTICE: Understanding that pediatric patients in concurrent care may have different healthcare service patterns may assist oncology nurses caring for children with advanced cancer. These findings also have policy implications.

PROFESSIONAL ISSUES

Views of general practitioners on end-of-life care learning preferences: A systematic review.

S. Atreya, S. S. Datta and N. Salins. (Salins, Naveen. Department of Palliative Medicine and Supportive Care, Kasturba Medical College, Manipal Academy of Higher Education, Manipal, India. naveen.salins@manipal.edu.)

BMC Palliat Care. 2022;21(1):162. doi: 10.1186/s12904-022-01053-9.

BACKGROUND: General practitioners (GPs) play a pivotal role in providing end-of-life care in the community. Although they value end-of-life care, they have apprehensions about providing care in view of the limitations in knowledge and skills in end-of-life care. This review aimed to explore, synthesize, and analyze the views of general practitioners on end-of-life care learning preferences. METHODS: MEDLINE, CINAHL, PsycINFO, EMBASE, Scopus, Web of Science, and Cochrane were searched for literature on the views of general practitioners on end-of-life care learning preferences from 01/01/1990 to 31/05/2021. Methodological quality was reported. RESULTS: Of the 10,037 articles identified, 23 were included for the review. Five themes developed from the review. The desire to provide palliative care, as well as self-actualisation needs, relevance to practice,
a sense of responsibility, and a therapeutic bond, motivates general practitioners to learn end-of-life care. Some of the learning needs expressed were pain and symptom management, communication skills, and addressing caregiver needs. Experiential learning and pragmatist learning styles were preferred learning styles. They perceived the need for an amicable learning environment in which they could freely express their deficiencies. The review also identified barriers to learning, challenges at personal and professional level, feelings of disempowerment, and conflicts in care.

CONCLUSION: GPs’ preference for learning about end-of-life care was influenced by the value attributed to learning, context and content, as well as preference for learning styles and the availability of resources. Thus, future trainings must be in alignment with the GPs’ learning preferences.

**PPC/PRO**

**The buddy system: An intervention to reduce distress and compassion fatigue and promote resilience on a palliative care team during the COVID-19 pandemic.**

N. McCool, J. Reidy, S. Steadman, et al. (McCool, Nancy. Division of Palliative Care, UMass Chan Medical School, UMass Memorial Health, Worcester, MA, USA. nancy.mccool@umassmemorial.org)

*J Soc Work End Life Palliat Care. 2022;1:23. doi: 10.1080/15524256.2022.2122650.*

The SARS-CoV-2 pandemic (COVID-19) dramatically increased the number of stressors on healthcare workers, including palliative care practitioners. Restrictions and increased demands on time made it difficult for the UMass Memorial Health palliative care team to utilize preexisting wellness strategies. In response to team members’ stress reactions, a buddy system intervention was conceived and implemented to restore a sense of connection and self-efficacy (Phase 1). Our objective with this quality improvement project was to assess the feasibility and effectiveness of the buddy system and evaluate staff attitudes toward this intervention. After four months, feedback from team members informed redesign to a more structured buddy system (Phase 2). A mixed-methods design of this project included a qualitative online survey along with quantitative data collection with the Professional Quality of Life Scale V (ProQOL V) and the Brief Resilience Scale (BRS) during Phase 1. Phase 2 was also evaluated quantitatively with ProQOL V and BRS. Semi-structured interviews were conducted at the end of this project to enhance qualitative data on staff attitudes and beliefs. Of the 12 study participants, 10 completed all phases of the study. Participants reported the buddy system was a useful, easy-to-implement intervention for mitigating personal distress and compassion fatigue (CF) by providing a strong sense of support and connection to team members.

**PPC/PRO**

**Stories of paediatric palliative care: A qualitative study exploring health care professionals’ understanding of the concept.**

K. Riiser, H. Holmen, A. Winger, et al. (Riiser, Kirsti. Department of Rehabilitation Science and Health Technology, Faculty of Health Sciences, OsloMet - Oslo Metropolitan University, St. Olavs plass, NO-0130, Oslo, PO Box 4, Norway. kiri@oslomet.no)

*BMC Palliat Care. 2022;21(1):187. doi: 10.1186/s12904-022-01077-1.*

**BACKGROUND:** By sharing patient stories, health care professionals (HCPs) may communicate their attitudes, values and beliefs about caring and treatment. Previous qualitative research has shown that HCPs usually associate paediatric palliative care (PPC) with death or dying and that they find the concept challenging to understand and difficult to implement. Attending to HCPs’ stories may provide a richer account of their understanding of PPC. Thus, the aim of this study was to explore PPC stories narrated by HCPs to gain increased insight into their understanding of what PPC entails. METHODS: This qualitative study collected data from four focus group interviews with 21 HCPs from different units in two Norwegian hospitals. Stories told by the HCPs to illustrate their comprehension of PPC were analysed following thematic analysis procedures. RESULTS: Four themes were identified illustrating what PPC meant to the participants: creating spaces for normality, providing tailored support for the family, careful preparations for saying goodbye and experiencing dilemmas and distress. The stories centred on family care, particularly relating to dramatic or affective situations when the death of a child was imminent. CONCLUSION: The stories reflect how the HCPs view PPC as a specific field of health care that requires particular professional sensitivity, including good communication, collaboration and planning. Thus, the HCPs in this study demonstrated knowledge about the core qualities needed to succeed in PPC. However, similar to previous research, the stories illustrate that how HCPs speak about PPC is strongly associated with end-of-life care, and by that the HCPs do not capture the breadth of the PPC concept. The findings highlight the importance of increasing knowledge about the meaning and content of PPC among HCPs in order to maintain quality of life for all children with life-limiting or life-threatening conditions throughout their illness trajectory.

**PPC/PRO**

**When cultural values meets professional values: A qualitative study of Chinese nurses’ attitudes and experiences concerning death.**

J. Tu, M. Shen and Z. Li. (Tu, Jiong. School of Sociology and Anthropology, Sun Yat-sen University, Guangzhou, China. tujiong@mail.sysu.edu.cn)
BACKGROUND: In China, there is a culture of death-avoidance and death-denying. Influenced by this distinctive socio-cultural views surrounding death, nurses often find it challenging to handle death and care for dying patients. This study explores the nurses’ attitudes and coping strategies concerning death and caring for dying patients in a cultural context of death taboo. METHODS: This research is a qualitative study that employs in-depth, semi-structured interviews with nurses from two major hospitals in Guangzhou, China. Overall, 28 nurses from four departments with high patient death rate were recruited and interviewed. All of the interviews were analyzed thematically. RESULTS: The nurses who participated in this study expressed attitudes toward death and caring for dying patients from both a personal dimension and a professional dimension. The personal dimension is influenced by traditional culture and societal attitudes towards death and dying, while their professional dimension is congruent with the nursing and palliative care values concerning death and dying. With an obvious discrepancy between these two dimensions, Chinese nurses adopt three strategies in their practice to solve this tension: boundary-drawing to separate their personal and professional life, complying with the existing cultural values at work, and constructing positive meanings for end-of-life care. CONCLUSION: In a society that traditionally avoids making any reference to death, it is useful to reduce cultural taboo and construct positive meanings in end-of-life care, death education and the development of palliative care. Meanwhile, nurses also need institutional support, education and training to transition smoothly from a novice to a mature professional when handling patient death.

Low-cost, low-resource training model to enhance and sustain serious illness conversation skills for internal medicine residents.

M. T. Vergo, A. Cullinan, M. Wilson, et al. (Vergo, Maxwell. Section of Palliative Medicine, Geisel School of Medicine at Dartmouth, 1 Medical Center Drive, Lebanon, NH 03750, USA. maxwell.t.vergo@hitchcock.org)

J Palliat Med. 2022;25(11):1708–14. doi: 10.1089/jpm.2022.0247.

Background: Funding and limited resources are barriers to required training of residents in serious illness conversation (SIC) skills. Objectives: To examine the effectiveness of a low-cost, low-resource (LCLR) SIC training embedded within a required palliative care rotation. Design: Pre-post prospective cohort study design. Setting/Subjects: Second year internal medicine (IM) residents received an LCLR three-hour training in the SIC Guide (SICG) with a single-faculty member and paired-participant practice replacing actors during a required two-week palliative medicine rotation. Measures: SIC competence checklist measured within simulated patient encounters longitudinally. Results: Twenty resident average SIC checklist scores improved from 11 (95% confidence interval [CI] 9–13) at the beginning of rotation to 19 (95% CI 17–20) at the end of rotation and 18 (95% CI 16–20) at six months after the rotation. Conclusions: LCLR SIC training for IM residents significantly increased the sustained use of basic SIC skills, but was less effective for more complex skills.

UK palliative medicine trainees and multisource communication skills feedback: An educational tool?

K. Webber and R. Selman. (Webber, Katherine. Department of Supportive and Palliative Care, Royal Surrey County Hospital NHS Foundation Trust, Guildford GU2 7XX, UK. kwebber1@nhs.net)

BMJ Support Palliat Care. 2022;12(e4):e485–e8. doi: 10.1136/bmjspcare-2019-002133.

BACKGROUND: Multisource feedback provides ratings of a trainee doctor’s performance from a range of assessors and enables 360 degree feedback on communication skills and team working behaviours. It is a tool used throughout palliative medicine training in the UK. There are limited data on the value of multisource feedback from a palliative medicine trainee perspective. AIM: To study the views of palliative medicine trainees regarding multisource feedback as an educational tool to develop communication skills. DESIGN: A multimodal study encompassing a focus group and questionnaire mailed to all deanery palliative doctors. SETTING/PARTICIPANTS: All palliative medicine trainees within a UK training deanery. RESULTS: Over half of responding trainees thought multisource feedback had little or no impact on their clinical practice. Improvements in delivery of multisource feedback to maximise learning were identified, including skilled feedback and facilitation by educational supervisors. CONCLUSIONS: Despite multisource feedback currently having limited benefits, a number of recommendations are suggested to improve this.

A qualitative exploration of the feasibility and acceptability of meaning-centered psychotherapy for cancer caregivers.

A. J. Applebaum, K. E. Roberts, K. Lynch, et al. (Applebaum, Allison. Caregivers Clinic, Department of Psychiatry and Behavioral Sciences, Memorial Sloan Kettering Cancer Center)
OBJECTIVE: Caregivers of patients with cancer are at significant risk for existential distress. Such distress negatively impacts caregivers’ quality of life and capacity to serve in their role as healthcare proxies, and ultimately, contributes to poor bereavement outcomes. Our team developed Meaning-Centered Psychotherapy for Cancer Caregivers (MCP-C), the first targeted psychosocial intervention that directly addresses existential distress in caregivers. METHOD: Nine caregivers of patients with glioblastoma multiforme (GBM) enrolled in a pilot randomized controlled trial evaluating the feasibility, acceptability, and effects of MCP-C, and completed in-depth interviews about their experience in the therapy. One focus group with three MCP-C interventionists was also completed. RESULTS: Four key themes emerged from interviews: (1) MCP-C validated caregivers’ experience of caregiving; (2) MCP-C helped participants reframe their ‘caregiving identity’ as a facet of their larger self-identity, by placing caregiving in the context of their life’s journey; (3) MCP-C enabled caregivers to find ways to assert their agency through caregiving; and (4) the structure and sequence of sessions made MCP-C accessible and feasible. Feedback from interventionists highlighted several potential manual changes and overall ways in which MCP-C can help facilitate caregivers’ openness to discussing death and engaging in advanced care planning discussions with the patient. SIGNIFICANCE OF RESULTS: The overarching goal of MCP-C is to allow caregivers to concurrently experience meaning and suffering; the intervention does not seek to deny the reality of challenges endured by caregivers, but instead to foster a connection to meaning and purpose alongside their suffering. Through in-depth interviews with caregivers and a focus group with MCP interventionists, we have refined and improved our MCP-C manual so that it can most effectively assist caregivers in experiencing meaning and purpose, despite inevitable suffering.

A survey of hospice day services in the United Kingdom & Republic of Ireland: How did hospices offer social support to palliative care patients, pre-pandemic?

N. M. Bradley, C. F. Dowrick and M. Lloyd-Williams. (Bradley, Natasha. Centre for Health & Clinical Research, University of the West of England, Glenside Campus, BS16 1DD, Bristol, UK. Natasha Bradley@uwe.ac.uk)

BMC Palliat Care. 2022;21(1):170. doi: 10.1186/s12904-022-01061-9.

INTRODUCTION: Social support is described by patients and other stakeholders to be a valuable component of palliative day care. Less is known about the range of hospice services that have been used in practice that facilitate social support. An online survey aimed to gain an overview of all hospice day services that facilitated social support for adults outside of their own homes. METHODS: An online survey was distributed via email to people involved in managing hospice day services. Questions were asked on hospice characteristics, including staff and volunteer roles. Respondents were asked to identify services they felt offered social support to patients. Data collection took place between August 2017 and May 2018. RESULTS: Responses were received from 103 hospices in the UK and ROI (response rate 49.5%). Results provide an overview of hospice day and outpatient services that offer social support to patients. These are: multi-component interventions, activity groups, formal support groups, befriending, and informal social activities. Multi-component interventions, such as palliative day care, were the most commonly reported. Their stated aims tend to focus on clinical aspects, but many survey respondents considered these multicomponent interventions to be the ‘most social’ service at their hospice. The survey also identified a huge variety of activity groups, as well as formal therapeutic support groups. Informal ‘social-only’ activities were present, but less common. Over a third of all the services were described as ‘drop in’. Most responding hospices did not routinely use patient reported outcome measures in their ‘most social’ services. CONCLUSIONS: The survey documents hospice activity in facilitating social support to be diverse and evolving. At the time of data collection, many hospices offered multiple different services by which a patient might obtain social support outside of their own home and in the presence of other patients.

Post-traumatic stress disorder and end-of-life care: A well-being review.

A. Eleff and M. Shloush. (Eleff, Akiva. Department of Hospice/Palliative Care, Ohio University Heritage College of Osteopathic Medicine Cleveland Campus, Warrensville Heights, OH 44122, USA. akivaeleff770@gmail.com)

Am J Hosp Palliat Care. 2022:10499091221136287. doi: 10.1177/10499091221136287.

Post-Traumatic Stress Disorder can be a debilitating comorbidity for a patient on end-of-life care. Combat veterans make up a vast majority of patients diagnosed with Post-Traumatic Stress Disorder and are therefore a vulnerable group requiring a comprehensive approach to their health care management. This paper addresses certain challenges the hospice and palliative care providers may encounter and
offers solutions to ensure the patients maintain a high quality of life.

**PPC/PSY**

**Psycho-existential Symptom Assessment Scale (PeSAS)** screening in palliative care.

D. W. Kissane, J. Appleton, J. Lennon, et al. (Kissane, David. School of Medicine, University of Notre Dame, 160 Oxford St, Darlinghurst, NSW, Australia. david.kissane@monash.edu)

*J Pain Symptom Manage.* 2022;64(5):429–37. doi: 10.1016/j.jpainsymman.2022.08.002.

**CONTEXT:** Psycho-existential symptoms are common yet often missed or neglected in palliative care. Screening can be an effective way to recognize and respond to this need. **OBJECTIVES:** We aimed to implement routine use of the Psycho-existential Symptom Assessment Scale (PeSAS) as a screening tool in Australian palliative care services and discern the symptom prevalence identified. **METHODS:** In a multi-site rolling design, we established implementation site committees and embarked on experiential workshops to train clinicians in the tool’s efficient use. Patient symptom prevalence data were collected to compare uptake across sites. Descriptive statistics were applied. **RESULTS:** Over one year, we trained 216 clinicians across six palliative care services in the use of the PeSAS as a screening tool and collected data from 1405 patients. Clinicians reported significant growth in their sense of efficacy in assessing psycho-existential wellness. Services using electronic records implemented most easily. Psycho-existential symptoms with clinically significant prevalence (scores ≥ 4/10) included anxiety 41.1%, discouragement 37.6%, hopelessness 35.8%, pointlessness 26.9%, depression 30.3%, and the wish to die 17%. The precision of measurement within 3% was found for severe ratings (score ≥ 8/10) including anxiety 10.6%, depression 10.2%, the wish to die 7.6%, and confusion 3.6%. **CONCLUSION:** Clinicians can be trained to screen with the Psycho-existential Symptom Assessment Scale, which serves as a valuable measure to better recognize symptoms of psycho-existential distress among palliative care patients. Implementation barriers included the prior ethos of the service, confidence in talking about these themes, electronic data entry, and perceived time pressures.

**PPC/PSY**

**Palliative and hospice social workers’ moral distress during the COVID-19 pandemic.**

A. Latimer, S. Fantus, T. M. Pachner, et al. (Latimer, Abigail. University of Kentucky, College of Nursing, 751 Rose St #527, Lexington, KY 40536, USA. abbie.latimer@uky.edu)

BMJ Support Palliat Care. 2022;1(2):e91. doi: 10.1136/bmjpscare-2019-001774.

**OBJECTIVES:** Moral distress is associated with adverse outcomes contributing to health-care professionals’ worsened mental and physical well-being. Medical social workers have been frontline care providers throughout the COVID-19 pandemic, and those specializing in palliative and hospice care have been particularly affected by the overwhelming numbers of those seriously ill and dying. The main objectives of this study were (1) to assess palliative and hospice social workers’ experiences of moral distress during COVID-19 and (2) to identify and describe participants’ most morally distressing scenarios. **METHODS:** Using a mixed-methods approach, participants completed an online survey consisting of the Moral Distress Thermometer (MDT) and open-ended text responses. **RESULTS:** A total of 120 social work participants responded to the study, and the majority of participants (81.4%) had experienced moral distress with an average MDT score of 6.16. COVID-19 restrictions emerged as the main source of moral distress, and an overlap between the clinical and system levels was observed. Primary sources of moral distress were grounded in strict visitation policies and system-level standards that impacted best practices and personal obligations in navigating both work responsibilities and safety. **SIGNIFICANCE:** In the first year of the COVID-19 pandemic, palliative and hospice social work participants indicated high levels of moral distress. Qualitative findings from this study promote awareness of the kinds of distressing situations palliative and hospice social workers may experience. This knowledge can have education, practice, and policy implications and supports the need for research to explore this aspect of professional social work.

**PPC/PSY**

**Caregiver emotional distress: External open-behaviour signs.**

J. T. Limonero, J. Maté-Méndez, D. Mateo, et al. (Limonero, Joaquín T. School of Psychology. Stress and Health Research Group, Universitat Autonoma de Barcelona Facultat de Psicologia, Bellaterra, Spain. joaquin.limonero@uab.cat)

*BMJ Support Palliat Care.* 2022;1(2):e585–e91. doi: 10.1136/bmjpscare-2019-001774.

**OBJECTIVES:** To determine whether specific external signs of emotional distress (ESED) can be an indirect measure of emotional distress in caregivers. **METHODS:** A cross-sectional multicentre design was used. 148 primary caregivers of advanced cancer patients attended in four Spanish palliative care units participated in this study. The emotional distress of caregivers was measured using both the Emotional Distress of Caregivers Scale and a psychological interview. Health professionals col-
Progress in Palliative Care

Bibliography

lected data using a standard clinical interview process after a brief training period. RESULTS: More than half the caregivers (60%) presented with emotional distress. A positive correlation \((r = 0.566)\) was found between the intensity of ESED and emotional distress per se. Caregivers who presented emotional distress showed more ESED than those that did not \((p < 0.01)\). The study found significant differences for the categories ‘visible signs of sadness, fear, crying, feeling overwhelmed’ \((p < 0.001)\), ‘difficulty in separating from the patient: family refuses to let the patient make decisions and insists on care’ \((p < 0.001)\) and ‘visible signs of anger, irritability or frequent disagreement with therapeutic measures’ \((p < 0.001)\). No significant differences were found with respect to gender. The set of items to measure these external signs presented an adequate reliability assessed using Cronbach’s alpha \((\alpha = 0.773)\). CONCLUSIONS: The assessment of ESED in caregivers could serve as a useful method to assess their emotional distress. Incorporating the systematic assessment of these external signs as part of the assessment of the emotional distress of primary caregivers could improve the overall assessment and treatment provided to these caregivers.

**QUALITY OF LIFE**

**PPC/QOL1**

Trajectories of health-related quality of life in patients with advanced cancer during the last year of life: Findings from the compass study.

J. Lee, M. Shafiq, R. Malhotra, et al. (Malhotra, Chetna. Lien Centre for Palliative Care, Duke-NUS Medical School, Singapore, Singapore. chetna.malhotra@duke-nus.edu.sg)

*BMC Palliat Care. 2022;21(1):183. doi: 10.1186/s12904-022-01075-3.*

BACKGROUND: Patients with advanced cancer prioritise health-related quality of life (HrQoL) in end-of-life care, however an understanding of pre-death HrQoL trajectories is lacking. We aimed to delineate and describe the trajectories of physical, social, emotional and functional HrQoL during last year of life among advanced cancer patients. We assessed associations between these trajectories and patient socio-demographic characteristics, healthcare use and place of death. METHODS: We used data from 345 decedents from a prospective cohort study of 600 patients with a solid advanced cancer receiving secondary care at public hospitals in Singapore. Patients were surveyed every three months until death and HrQoL was assessed using the Functional Assessment of Cancer Therapy - General (FACT-G) questionnaire. Interviews were conducted between July 2016 and December 2019. Group-based multi-trajectory modelling was used to assess potential heterogeneity in the four HrQoL dimensions during patients’ last year of life. RESULTS: We identified four distinct trajectories of HrQoL - (1) overall high HrQoL (47% of sample), (2) progressively decreasing HrQoL (32%), (3) asymmetric decline in HrQoL (13%), (4) overall low HrQoL (8%). Compared to patients with secondary or above education, those with primary education or less \((\beta = 1.39, SE = 0.55, p\text{-value} = 0.012)\) were more likely to have ‘progressively decreasing HrQoL’ or ‘overall low HrQoL’ in contrast to ‘overall high HrQoL’. Compared to patients with ‘overall high HrQoL’, those with ‘overall low HrQoL’ had longer length of hospital stay during the last year of life \((\beta = 0.47, SE = 0.21, p\text{-value} = 0.026)\) and were more likely to die in a hospice/care home \((\beta = 1.86, SE = 0.66, p\text{-value} = 0.005)\). CONCLUSION: Our results showed heterogeneity in deterioration of HrQoL among patients with advanced cancer in the last year of life. Systematic monitoring of HrQoL, early identification and referral of high-risk patients to palliative care may provide timely relief and mitigate the steep decline in their HrQoL.

**PPC/QOL2**

A dual realist review: Compression for leg swelling at the end of life has potential quality of life benefit.

J. O’Brien and M. Dingle. (O’Brien, Joanna. St Christopher’s Hospice, 51– 59 Lawrie Park Road, London SE26 6DZ, UK. j.obrien@stchristophers.org.uk)

*J Adv Nurs. 2022;78(12):4003–18. doi: 10.1111/jan.15458.*

AIMS: To examine the evidence for the use of compression in the general population and determine how far it can be used to inform treatment at the end of life. DESIGN: In advanced illness, some patients suffer lower limb swelling and its resulting problems. In the general population, compression is used to treat lower limb swelling, but little is known about its use at the end of life. This review is designed to deeply explore the available evidence and identify what is known and areas for further research. DATA SOURCES: Five databases were searched; CINAHL, MEDLINE, Embase, AMED and Cochrane, in November 2021. Reference lists for included studies were hand-searched. A web search was carried out. REVIEW METHODS: Two parallel realist reviews were performed. The first reviewed the use of compression in the general population. The second explored lower limb swelling at the end of life. Findings were screened using inclusion and exclusion criteria, quality assessed and qualitative and quantitative data extracted. RESULTS: The initial searches returned 1179 articles in review one and 839 articles in review two. Following the screening, 10 articles remained in each review for analysis. A programme theory was drawn for each review. The theories had sufficient similarities to allow evidence from the general
population to be used to make recommendations for those at the end of life. IMPACT: People with advanced illness and leg swelling suffer physically and psychologically. Compression delivers a reduction in swelling and quality of life benefit in the general population. This study found people with advanced illness may experience the same benefits. A cautious approach should be taken and stockings or adjustable Velcro compression devices (AVCDs) are likely to be the best starter interventions. Existing guidelines should also be consulted. Further research to develop the right intervention in this group is needed.

SYMPTOM CONTROL

Impact of palliative care in end-of-life of fibrotic interstitial lung disease patients.

G. T. Chai, H. Y. Neo, J. Abisheganaden, et al. (Chai, Gin Tsen. Department of Respiratory and Critical Care Medicine, 11 Jalan Tan Tock Seng, 308433, Singapore. gin_tsen_chai@ttsh.com.sg)

Am J Hosp Palliat Care. 2022;39(12):1443–51. doi: 10.1177/10499091221083575.

Background: Interstitial lung disease (ILD) is associated with poor quality of life (QoL) and high symptom burden. Studies evaluating the benefits of palliative care examined mainly idiopathic pulmonary fibrosis (IPF) patients. We aim to examine the impact of palliative care on a broader group of fibrotic ILD patients. Methods: Single center retrospective cohort study comparing deceased ILD patients who received outpatient palliative care services (palliative-intervention group) against a usual care group. Results: Of 63 subjects, 26 (41%) were in the palliative-intervention group and 37 (59%) in the usual care group. Median time to palliative care referral was 8.6 (IQR .3–21.2) months. Dyspnea-related disability was greater in the palliative-intervention group [mMRC dyspnea score 3.5 (IQR 2–4) vs 2(IQR 2–4), P = .039], with more patients requiring long term oxygen therapy (70% vs 30%, P < .001). There was no difference in the median number of hospitalizations or length of stay in the last 6 months of life. Patients in the palliative-intervention group had a higher uptake of advance care planning (ACP) (39% vs 11%, P = .014), lower frequency of intensive care unit (ICU) admissions (5% vs 19%, P = .102) and were prescribed more opioids (96% vs 27%, P < .001) and benzodiazepines (39% vs 14%, P = .022). The palliative-intervention group experienced a longer median survival of 23.9 months (95% confidence interval [CI] 14.1–33.7) compared to the usual group (11.4 months [95% CI 5.4–17.3] (log-rank test: P = .023). Male gender was a strong predictor of 1-year mortality. Conclusions: The palliative-intervention group received earlier pharmacologic intervention for symptom relief. Healthcare utilization was not increased despite greater dyspnea-related disability.

Palliative care symptoms, concerns and well-being of older people with frailty and complex care needs upon hospital discharge: A cross-sectional study.

K. de Nooijer, N. Van Den Noortgate, P. Pype, et al. (de Nooijer, Kim. End-of-life Care Research Group, Vrije Universiteit Brussel (VUB) & Ghent University, Laarbeeklaan 103, 1090, Brussels, Belgium. Kim.De.Nooijer@vub.be)

BMC Palliat Care. 2022;21(1):173. doi: 10.1186/s12904-022-01065-5.

BACKGROUND: Little is known about the nature and intensity of palliative care needs of hospitalised older people. We aimed to describe the palliative care symptoms, concerns, and well-being of older people with frailty and complex care needs upon discharge from hospital to home, and to examine the relationship between palliative care symptoms and concerns, and well-being. METHODS: Cross-sectional study using baseline survey data of a pilot randomised controlled trial. Hospital staff identified patients (≥ 70 years) about to be discharged home, with a clinical frailty score of 5 to 7 and complex needs based on physician-assessment. Patients completed structured interviews, using the Integrated Palliative Care Outcome Scale (IPoS), ICEpop CApability measure for supportive care (ICECAP-SCM) and IPOS Views on Care quality of life item. We calculated descriptive statistics. RESULTS: We assessed 37 older people with complex needs (49% women, mean age 84, standard deviation 6.1). Symptoms rated as causing severe problems were weakness (46%) and poor mobility (40%); 75% reported that their family felt anxious at least occasionally. Of the 17 IPOS items, 41% of patients rated five or more symptoms as causing severe problems, while 14% reported that they were not severely affected by any symptom. 87% expressed feeling supported. There was a negative correlation between symptoms (IPoS) and well-being (ICECAP); r = -0.41. CONCLUSION: We identified a large variety of symptoms experienced by older people identified as having frailty and complex needs upon hospital discharge. Many were severely affected by multiple needs. This population should be considered for palliative care follow-up at home.

Determine the symptom intensities, performance and hopelessness levels of advanced lung cancer patients for the palliative care approach.

E. Dogan and H. Ozcelik. (Ozcelik, Hanife. Nigde Omer Halisdemir University Zubeyde Hanim School of Health,
This research was conducted descriptively to determine the symptom intensities, performance and hopelessness levels of advanced lung cancer patients for the palliative care approach. The research sample consisted of 130 patients with advanced lung cancer, who were selected from 600 lung cancer populations in thoracic surgery and intensive care, outpatient chemotherapy, oncology in a university hospital in Turkey. Ethics Committee permission and the patients’ written consent was obtained. Study data were collected face to face between January 2020 and July 2020 using the Edmonton Symptom Assessment System, Karnofsky Performance and Beck Hopelessness Scale. The mean age of the patients was 62.68 ± 8.867, 72.3% were males, and 89.2% were not currently working. The most common symptom in the patients was found to be fatigue 5.46 ± 2.12, worsening in general health and well-being 5.69 ± 1.87, loss of appetite 5.40 ± 2.59, and total symptom score 47.17 ± 19.03. Feelings and expectations about the future 1.40 ± 1.66, loss of motivation 3.43 ± 2.41, hope 2.05 ± 1.75, and total score of hopelessness 7.41 ± 6.01. There was a positive correlation between the patients’ hopelessness level and their symptom burden, and a negative correlation was found with Karnofsky performance ($P < .05$). A significant difference was found between the patients’ age, months since diagnosis, gender, education and employment status, stage of the disease, presence of metastases and analgesic use, and hopelessness scores ($P < .05$). It was determined that the symptom burden of patients with advanced lung cancer increased and as their Karnofsky performance decreased, their hopelessness level further increased. Hopelessness scores are affected by the socio-demographic and disease variables of the patients.

**PPC/SYM$_4$**

**Experiences of symptoms and impact on daily life and health in hepatocellular carcinoma patients: A meta-synthesis of qualitative research.**

J. Drott, B. Björnsson, P. Sandström, et al. (Drott, Jenny. Division of Nursing Science, Department of Health, Medicine and Caring Sciences, Linköping University, House 001, Entrance 5/76/78, Floor 13, Campus US, 581 83 Linköping, Sweden. Jenny.Drott@liu.se)

*Cancer Nurs.* 2022;45(6):430–7. doi: 10.1097/ncc.0000000000001044.

**BACKGROUND:** The incidence of hepatocellular cancer (HCC) has continually increased. To achieve optimal supportive cancer care for HCC patients, it is important to consider patients’ experiences and preferences. **OBJECTIVE:** This meta-synthesis aims to critically interpret how patients with HCC experience symptoms and the impact of the disease on daily life and health. **METHODS:** Searches were performed in the following databases: PubMed, Embase, The Cochrane Library and clinicaltrials.gov were searched for eligible articles, published between 1960 and September 9, 2021. Quality of the evidence was assessed in accordance with Grading of Recommendations, Assessment, Development and Evaluations. Risk of bias was assessed using the RoB 2 tool for randomised controlled trials and the Risk of Bias in Non-randomized Studies-of Interventions (ROBINS-I) tool for non-randomized trials. **RESULTS:** Fifty-two studies (20 randomised; 32 non-randomised) with 4786 participants diagnosed with cancer ($n = 4491$), dementia ($n = 43$), AIDS ($n = 235$), spasticity ($n = 16$), NORSE syndrome ($n = 1$) were included. The quality of evidence was 'very low' or 'low' for all studies, and low for only two randomised controlled trials. Positive treatment effects (statistical significance with $P < 0.05$) were seen for some MC products in pain, nausea and vomiting, appetite, sleep, fatigue, chemosensory perception and paraneoplastic night sweats in patients with cancer, appetite and agitation in patients with dementia and appetite, nausea and vomiting in patients with AIDS. Meta-analysis was unable to be performed due to the wide range of cannabis products used and the heterogeneity of the study outcomes. **CONCLUSION:** While positive treatment effects have been reported for some MC products in the palliative care setting, further high quality evidence is needed to support recommendations for its use in clinical practice.

**PPC/SYM$_5$**

**Cannabis in palliative care: A systematic review of current evidence.**

M. Doppen, S. Kung, I. Majiels, et al. (Braithwaite, Irene. Medical Research Institute of New Zealand, Private Bag 7902, Wellington 6242, New Zealand. Irene.Braithwaite@mrinz.ac.nz)

*J Pain Symptom Manage.* 2022;64(5):e260–e84. doi: 10.1016/j.jpainsymman.2022.06.002.

**CONTEXT:** Palliative care aims to improve the quality of life in patients with incurable illness. Medicinal cannabis (MC) has been used in the palliative care setting to address multiple symptoms in patients. **OBJECTIVES:** To evaluate the full scope of available literature investigating the effects and potential harms of MC on symptom management and quality of life in palliative care. **METHODS:** PubMed, Embase, The Cochrane Library and clinicaltrials.gov were searched for eligible articles, published between 1960 and September 9, 2021. Quality of the evidence was assessed in accordance with Grading of Recommendations, Assessment, Development and Evaluations. Risk of bias was assessed using the RoB 2 tool for randomised controlled trials and the Risk of Bias in Non-randomized Studies-of Interventions (ROBINS-I) tool for non-randomized trials. **RESULTS:** Fifty-two studies (20 randomised; 32 non-randomised) with 4786 participants diagnosed with cancer ($n = 4491$), dementia ($n = 43$), AIDS ($n = 235$), spasticity ($n = 16$), NORSE syndrome ($n = 1$) were included. The quality of evidence was 'very low' or 'low' for all studies, and low for only two randomised controlled trials. Positive treatment effects (statistical significance with $P < 0.05$) were seen for some MC products in pain, nausea and vomiting, appetite, sleep, fatigue, chemosensory perception and paraneoplastic night sweats in patients with cancer, appetite and agitation in patients with dementia and appetite, nausea and vomiting in patients with AIDS. Meta-analysis was unable to be performed due to the wide range of cannabis products used and the heterogeneity of the study outcomes. **CONCLUSION:** While positive treatment effects have been reported for some MC products in the palliative care setting, further high quality evidence is needed to support recommendations for its use in clinical practice.
Hematologic malignancies patients face high symptom burden and are latey referred to palliative consultation: Analysis of a single center experience.

R. P. C. Ebert, M. M. Magnus, P. Toro, et al. (de Melo Campos, Paula. Hematology and Transfusion Medicine Center - University of Campinas/Hemocentro- UNICAMP, Campinas, Carlos Chagas St, 480, Campinas 13083-878, Brazil. pmcampos@unicamp.br)

Am J Hosp Palliat Care. 2022;1049901221132285. doi: 10.1177/1049901221132285.

Although hematologic neoplasms have been on the vanguard of cancer therapies that led to notable advances in therapeutic efficacy, many patients face significant symptom burden, which make them eligible for early palliative care (PC) integration. However, previous reports demonstrated that hematological malignancies receive more aggressive care at the end-of-life and are less likely to receive care from specialist palliative services compared to solid tumors. Our aim was to characterize symptom burden, performance status and clinical characteristics of a cohort of hematologic malignancies patients referred to PC outpatient consultation, according to their diagnosis. Fifty-nine hematologic malignancies patients referred to PC consultation between January 2018 and September 2021 were included. Clinical and laboratory data were evaluated retrospectively by medical charts analysis. Patients exhibited high ESAS and reduced PPS scores at the time of PC referral. Acute leukemia and multiple myeloma patients had the highest symptom burden scores; in spite of this, median time from the first PC consultation until death was only 3 and 4 months, respectively. In conclusion, we identified that hematologic neoplasms patients are highly symptomatic and are frequently referred to PC in end stages of their disease.
Determining massage dose-response to improve cancer-related symptom cluster of pain, fatigue, and sleep disturbance: A 7-arm randomized trial in palliative cancer care.

M. Miladinia, M. Jahangiri, A. B. Kennedy, et al. (Miladinia, Mojtaba. Pain Research Center, Ahvaz Jundishapur University of Medical Sciences, Golestan St., Ahvaz, 61357-15794, Iran. Miladinia.m@ajums.ac.ir)

Palliat Med. 2022:2692163221129158. doi: 10.1177/02692163221129158.

BACKGROUND: The efficacy of various massage doses in palliative cancer care settings is still debated, and no specific protocol is available. AIM: Evaluating response to various massage doses for symptom cluster of pain-fatigue-sleep. DESIGN: A 7-arm randomized-controlled trial with weekly massage for 4 weeks depending on the prescribed dose (15-, 30-, or 60-min; 2× or 3×/week) and a 4-week follow-up. The intensities of pain, fatigue, and sleep disturbance were measured using a 0–10 scale at nine-timepoint: baseline, weekly during the intervention, and the follow-up period. Then, the mean scores of the three symptoms were calculated as the symptom cluster intensity at each timepoint.

RESULTS: The odds of clinical improvement (at least 30% reduction in symptom cluster intensity from baseline) increased with dose-escalation significantly [(OR = 17.37; 95% CI = 3.87–77.90 for 60-min doses); (OR = 11.71; 95% CI = 2.60–52.69, for 30-min doses); (OR = 4.36; 95% CI = 0.94–20.32, for 15-min doses)]. The effect durability was significantly shorter at 15-min doses compared to 30- and 60-min doses. The odds of improvement for doses 3×/week was not significant compared to doses 2×/week (OR = 12.27 vs OR = 8.34); however, the effect durability for doses 3×/week was significantly higher. CONCLUSIONS: The findings indicated that dose-escalation increases the efficacy of massage for the pain-fatigue-sleep symptom cluster. Although the 60-min doses were found to be more effective, the 30-min doses can be considered more practical because they are less costly and time-consuming. Our findings can be helpful to develop massage guidelines in palliative care settings. TRIAL REGISTRATION: Iranian Registry of Clinical Trials, IRCT20150302021307N5.