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## **Palliative Care Bulletin October 2020 Vol (1) Issue (3)**

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### **Acceptability, Feasibility, and Efficacy Potential of a Multimodal Acceptance and Commitment Therapy Intervention to Address Psychosocial and Advance Care Planning Needs among Anxious and Depressed Adults with Metastatic Cancer**

Journal of Palliative Medicine; Oct 2020; vol. 23 (10); p. 1380-1385

Arch JJ, et al.

Background: Adults with metastatic cancer frequently report anxiety and depression symptoms, which may impact health behaviors such as advance care planning (ACP). Objective: The study leveraged acceptance and commitment therapy (ACT), an evidence-based approach for reducing distress and improving health behaviors, and adapted it into a multimodal intervention (M-ACT) designed to address the psychosocial and ACP needs of anxious and depressed adults with metastatic cancer. The study evaluated M-ACT's acceptability, feasibility, and efficacy potential. Design: The study was designed as a single-arm intervention development and pilot trial. Setting/Subjects: The trial enrolled 35 anxious or depressed adults with stage IV cancer in community oncology clinics, with a referred-to-enrolled rate of 69% and eligible-to-enrolled rate of 95%. Measurements: M-ACT alternated four in-person group sessions with three self-paced online sessions. Acceptability and feasibility were assessed through enrollment, attendance, and satisfaction ratings. Outcomes and theorized intervention mechanisms were evaluated at baseline, midintervention, post intervention, and two-month follow-up. Results: Participant feedback was used to refine the intervention. Of participants starting the intervention, 92% completed, reporting high satisfaction. One-quarter did not begin M-ACT due to health declines, moving, or death. Completer showed significant reductions in anxiety, depression, and fear of dying and increases in ACP and sense of life meaning. In this pilot, M-ACT showed no significant impact on pain interference. Increases in two of three mechanism measures predicted improvement on 80% of significant outcomes. Conclusions: The M-ACT intervention is feasible, acceptable, and shows potential for efficacy in community oncology settings; a randomized trial is warranted.

### **Advanced Stage of Disease and Systemic Inflammation as Factors Associated With Referral of Patients With Colorectal Cancer to a Palliative Care Unit.**

American Journal of Hospice & Palliative Medicine; Oct 2020; vol.37 (10); p.859-865

Silva TH, et al.

Objective: To identify factors associated with referral to an exclusive palliative care unit (PCU) in patients with colorectal cancer (CRC). Methods: Retrospective cohort study with patients having CRC of both sexes treated at a hospital unit, aged  $\geq 20$  years. Data were extracted from the medical records of pre-treatment patients between January 2008 and August 2014. The outcome was referral to the PCU within 5 years. Logistic regression analyses were performed to assess whether sociodemographic, clinical, nutritional, and biochemistry data were associated to referral, generating odds ratios (OR), and 95% confidence intervals (CI). Results: Four hundred fifteen patients were evaluated. The Patient-Generated Subjective Global Assessment demonstrated a prevalence of malnutrition of 57.3%. One hundred one (24.3%) patients were referred to the PCU after 16.3 months

(interquartile range: 7.2-33.5). These patients were more likely to be at an advanced stage of the disease and have malnutrition and exacerbated systemic inflammation. Tumor stage III and IV (OR: 2.05; 95% CI: 1.12-3.76) and neutrophil-to-lymphocyte ratio (NLR)  $\geq 3$  (OR: 1.89; 95% CI: 1.12-3.17) were predictors of an increased chance of referral to the PCU. Conclusion: Advanced disease stage and NLR were associated with referral of patients with CCR to a PCU.

### **Animal-assisted intervention to improve end-of-life care: The moderating effect of gender and pet ownership on anxiety and depression**

The Journal of Alternative and Complementary Medicine; Sep 2020; vol. 26 (no. 9); p. 843-844  
Scagnetto F, et al.

This study aims to examine moderating effect of gender and pet ownership on anxiety and depression in animal-assisted intervention (AAI) to improve end-of-life care. The study was conducted on a sample set of 44 patients, who were hospitalized in three palliative care Operative Units (O.U.) of the Aulss 3 Serenissima National Healthcare Centre, Venice, Italy. All the subjects enrolled were considered terminal patients, according to the definition of Lamont, although not necessarily affected by cancer but also by other deadly pathologies. Most of the patients were pet owners, or had been in the past. A set of generalized linear models was used to assess the patients' variations of anxiety and depression before and after the treatment, taking into account the interactions with the variables gender and pet ownership. Patients did not express significant variations in anxiety before and after the treatment, not even when anxiety was correlated to gender. The same results emerged when the linear model was applied to depression: no significant variation was found before and after the treatment also when depression was put in interaction with gender. The results changed when the variable pet ownership was correlated to anxiety or depression. The interaction between pet ownership and depression remained non-significant, whereas it became significant when pet ownership was correlated to anxiety. Interestingly, it is found that anxiety, after the interaction with a dog, slightly decreased in patients who were or had been pet owners, whereas it increased considerably in non-pet owners.

### **"The challenge of joining all the pieces together" - Nurses' experience of palliative care for older people with advanced dementia living in residential aged care units**

Journal of Clinical Nursing; Oct 2020; vol. 29 (19/20); p.3835-3846  
Pennbrant S, et al.

Aims and objectives: To describe nurses' experiences of palliative care for older people with advanced dementia living in residential aged care units. Background: Dementia is a global health problem and the number of older people with dementia who need palliative care is increasing. Previous research has revealed that care for older people with dementia in the final stage of life is usually complex. However, little is known about how nurses experience palliative care for older people with advanced dementia living in residential aged care units. Method: Nine individual, semi-structured face-to-face interviews with nurses working in residential aged care units for older people with advanced dementia in palliative care in Western Sweden were analysed using qualitative inductive content analysis. The COREQ checklist was followed. Results: The nurses considered that palliative care for older people with advanced dementia is a complex and challenging form of care. In particular, they identified three challenges that must be met: developing specialised knowledge and skills, developing teamwork as a working method and creating a caring relationship. Conclusions: The results of our analysis indicate that if nurses are aware of and understand that the challenges are essential for "joining all the pieces

together," the palliative care for older people with advanced dementia may become a positive experience for nurses and may increase their sense of satisfaction and security in their professional role. Relevance to clinical practice: For the palliative care to be successful, the nurses need to "join all the pieces together," that is succeed in developing specialised knowledge and skills, developing teamwork as a working method and creating a caring relationship to establish a person-centred care with the older person with advanced dementia and with his or her relatives.

### [Cost-effectiveness analysis of systematic fast-track transition from oncological treatment to specialised palliative care at home for patients and their caregivers: The DOMUS trial](#)

BMC Palliative Care; Sep 2020; vol. 19(1)

Halling CMB, et al.

Background: While hospitals remain the most common place of death in many western countries, specialised palliative care (SPC) at home is an alternative to improve the quality of life for patients with incurable cancer. We evaluated the cost-effectiveness of a systematic fast-track transition process from oncological treatment to SPC enriched with a psychological intervention at home for patients with incurable cancer and their caregivers. Method(s): A full economic evaluation with a time horizon of six months was performed from a societal perspective within a randomised controlled trial, the DOMUS trial (Clinicaltrials.gov: NCT01885637). The primary outcome of the health economic analysis was an incremental cost-effectiveness ratio (ICER), which is obtained by comparing costs required per gain in Quality-Adjusted Life Years (QALY). The costs included primary and secondary healthcare costs, cost of intervention and informal care from caregivers. Public transfers were analysed in separate analysis. QALYs were measured using EORTC QLQ-C30 for patients and SF-36 for caregivers. Bootstrap simulations were performed to obtain the ICER estimate. Result(s): In total, 321 patients (162 in intervention group, 159 in control group) and 235 caregivers (126 in intervention group, 109 in control group) completed the study. The intervention resulted in significantly higher QALYs for patients when compared to usual care (p-value = 0.026), while being more expensive as well. In the 6 months observation period, the average incremental cost of intervention compared to usual care was 2015 per patient (p value < 0.000). The mean incremental gain was 0.01678 QALY (p-value = 0.026). Thereby, the ICER was 118,292/QALY when adjusting for baseline costs and quality of life. For the caregivers, we found no significant differences in QALYs between the intervention and control group (p-value = 0.630). At a willingness to pay of 80,000 per QALY, the probability that the intervention is cost-effective lies at 15% in the base case scenario. Conclusion(s): This model of fast-track SPC enriched with a psychological intervention yields better QALYs than usual care with a large increase in costs. Trial registration: The trial was prospectively registered 25.6.2013. Clinicaltrials.gov Identifier: NCT01885637.

### [Creating person-centred support for people with intellectual disabilities at the end of life: An Australian qualitative study of unmet needs and strategies](#)

Journal of intellectual disabilities; Dec 2020; vol. 24 (4); p. 543-558

McNamara B, Same A, Rosenwax L.

Background: People with intellectual disabilities at the end of life are at risk of receiving inadequate and inequitable end-of-life care. This study explores their unmet needs, opportunities for person-centred care and experiences of health service use. Methods: Qualitative interviews with 26 experienced health professionals and carers were used to explore their patients' and residents' unmet needs and end-of-life

care options and to outline strategies to support them. Results: A range of challenges and unmet needs experienced by people with intellectual disabilities are presented in themes: (1) accommodation setting at the end of life: dying 'at home'; (2) personal factors and networks: a circle of support; (3) end-of-life medical care and decision-making. Strategies to facilitate good end-of-life care and a model of care are presented. Conclusions: Well-prepared and collaborative disability and health service workforces are needed, together with flexible and adequate end-of-life funding to ensure compassionate and person-centred care.

### **A dignified last phase of life for patients with a migration background: A qualitative study**

Palliative medicine; 2020; vol. 34 (10); p.1385-1392

De Voogd X, et al.

Background: Preserving personal dignity is an important part of palliative care. Generally, autonomy, independency and not being a burden to others are emphasised for preserving dignity. Dignity has not been studied yet from the perspective of the growing group of patients with a migration background living in Western countries. Aim: To gain insight into (1) what patients - and their relatives - with a Turkish, Moroccan or Surinamese background, living in the Netherlands, in their last phase of life find important aspects of dignity, and (2) how care professionals can preserve and strengthen the dignity of these patients. Design: Qualitative thematic analysis of semi-structured interviews. Participants: A total of 23 patients and 21 relatives with a Turkish, Moroccan or Surinamese background were interviewed. Results: For respondents' dignity encompassed surrender to God's or Allah's will and meaningful relationships with others, rather than preserving autonomy. Surrender to God or Allah meant accepting the illness, the situation and performing religious practice. A meaningful relationship meant being assisted or cared for by family members and maintaining a social role. Professionals could preserve dignity by showing respect and attention; guaranteeing physical integrity, hygiene and self-direction; and indirect communication about diagnoses and prognoses. Conclusions: Religion and appropriate involvement of family members are important aspects of dignity in the last phase of life, in addition to autonomy and independency. Care professionals need to take these factors into account in order to provide person-centred care.

### **Effect of an Early Palliative Care Telehealth Intervention vs Usual Care on Patients with Heart Failure: The ENABLE CHF-PC Randomized Clinical Trial**

JAMA Internal Medicine; Sep 2020; vol. 180 (9); p.1203-1213

Bakitas MA, et al.

Importance: National guidelines recommend early palliative care for patients with advanced heart failure, which disproportionately affects rural and minority populations. Objective(s): To determine the effect of an early palliative care telehealth intervention over 16 weeks on the quality of life, mood, global health, pain, and resource use of patients with advanced heart failure. Design, Setting, and Participant(s): A single-blind, intervention vs usual care randomized clinical trial was conducted from October 1, 2015, to May 31, 2019, among 415 patients 50 years or older with New York Heart Association class III or IV heart failure or American College of Cardiology stage C or D heart failure at a large South-eastern US academic tertiary medical center and a Veterans Affairs medical center serving high proportions of rural dwellers and African American individuals. Intervention(s): The ENABLE CHF-PC (Educate, Nurture, Advise, Before Life Ends Comprehensive



Heart care for Patients and Caregivers) intervention comprises an in-person palliative care consultation and 6 weekly nurse-coach telephonic sessions (20-40 minutes) and monthly follow-up for 48 weeks. Main Outcomes and Measures: Primary outcomes were quality of life (as measured by the Kansas City Cardiomyopathy Questionnaire [KCCQ]: score range, 0-100; higher scores indicate better perceived health status and clinical summary scores  $\geq 50$  are considered "fairly good" quality of life; and the Functional Assessment of Chronic Illness Therapy-Palliative-14 [FACIT-Pal-14]: score range, 0-56; higher scores indicate better quality of life) and mood (as measured by the Hospital Anxiety and Depression Scale [HADS]) over 16 weeks. Secondary outcomes were global health (Patient Reported Outcome Measurement System Global Health), pain (Patient Reported Outcome Measurement System Pain Intensity and Interference), and resource use (hospital days and emergency department visits). Result(s): Of 415 participants (221 men; baseline mean [SD] age, 63.8 [8.5] years) randomized to ENABLE CHF-PC (n = 208) or usual care (n = 207), 226 (54.5%) were African American, 108 (26.0%) lived in a rural area, and 190 (45.8%) had a high-school education or less, and a mean (SD) baseline KCCQ score of 52.6 (21.0). At week 16, the mean (SE) KCCQ score improved 3.9 (1.3) points in the intervention group vs 2.3 (1.2) in the usual care group (difference, 1.6; SE, 1.7; d = 0.07 [95% CI, -0.09 to 0.24]) and the mean (SE) FACIT-Pal-14 score improved 1.4 (0.6) points in the intervention group vs 0.2 (0.5) points in the usual care group (difference, 1.2; SE, 0.8; d = 0.12 [95% CI, -0.03 to 0.28]). There were no relevant between-group differences in mood (HADS-anxiety, d = -0.02 [95% CI, -0.20 to 0.16]; HADS-depression, d = -0.09 [95% CI, -0.24 to 0.06]). Conclusions and Relevance: This randomized clinical trial with a majority African American sample and baseline good quality of life did not demonstrate improved quality of life or mood with a 16-week early palliative care telehealth intervention. However, pain intensity and interference (secondary outcomes) demonstrated a clinically important improvement. Trial Registration: ClinicalTrials.gov Identifier: NCT02505425.

### [The evidence supporting educational videos for patients and caregivers receiving hospice and palliative care: A systematic review](#)

Patient Education and Counseling; Sep 2020; vol. 103 (9); p. 1677-1691  
Cruz-Oliver DM, et al.

Objective: The purpose of this study is to explore the evidence surrounding educational videos for patients and family caregivers in hospice and palliative care. We ask three research questions: 1. what is the evidence for video interventions? 2. What is the quality of the evidence behind video interventions? 3. What are the outcomes of video interventions? Methods: The study is a systematic review, following Preferred Reporting Items for Systematic reviews and Meta-Analysis (PRISMA) guidelines. Researchers systematically searched five databases for experimental and observational studies on the evidence supporting video education for hospice and palliative care patients and caregivers, published in 1969–2019. Results: The review identified 31 relevant articles with moderate-high quality of evidence. Most studies were experimental (74 %), came from the United States (84 %) and had a mean sample size of 139 participants. Studies showed that video interventions positively affect preferences of care and advance care planning, provide emotional support, and serve as decision and information aids. Conclusion: A strong body of evidence has emerged for video education interventions in hospice and palliative care. Additional research assessing video interventions' impact on clinical outcomes is needed. Practice implications: Videos are a promising tool for patient and family education in hospice and palliative care.

### Exploring Community-Dwelling Older Adults' Considerations about Values and Preferences for Future End-of-Life Care: A Study from Sweden

Gerontologist; Oct 2020; vol. 60 (7); p. 1332-1342

Eneslatt M, Helgesson G, Tishelman C.

**Background and Objectives** There is a substantial body of research on advance care planning (ACP), often originating from English-speaking countries and focused on health care settings. However, studies of content of ACP conversations in community settings remain scarce. We therefore explore community-dwelling, older adults' reasoning about end-of-life (EoL) values and preferences in ACP conversations. **Research Design and Methods** In this participatory action research project, planned and conducted in collaboration with national community-based organizations, we interviewed 65 older adults without known EoL care needs, about their values and preferences for future EoL care. Conversations were stimulated by sorting and ranking statements in a Swedish version of GoWish cards, called the DöBra cards, and verbatim transcripts were analyzed inductively. **Results** While participants shared some common preferences about EoL care, there was great variation among individuals in how they reasoned. Although EoL preferences and prioritizations could be identical, different individuals explained these choices very differently. We exemplify this variation using data from four participants who discussed their respective EoL preferences by focusing on either physical, social, existential, or practical implications. **Discussion and Implications** a previously undocumented benefit of the GoWish/DöBra cards is how the flexibility of the card statements support substantial discussion of an individual's EoL preferences and underlying values. Such in-depth descriptions of participants' reasoning and considerations are important for understanding the very individual nature of prioritizing EoL preferences. We suggest future users of the DöBra/GoWish cards consider the underlying reasoning of individuals' prioritizations to strengthen person-centeredness in EoL conversations and care provision.

### Good palliative nursing care: Design and validation of the palliative nursing care quality scale (PNCQS)

Journal of Advanced Nursing, Oct 2020; vol. 76 (10); p. 2757-2767

Egea MZ, Prieto-Ursua M, Toro LB.

**Aims:** Develop and psychometrically assess the Palliative Nursing Care Quality Scale (PNCQS, escala de Calidad del Cuidado Enfermero Paliativo, CCEP, in Spanish). An interview-based qualitative study (1) was conducted to verify construct validity evidence, with psychometric properties of reliability and validity verified by two quantitative studies (2 & 3). **Design:** Quantitative instrumental, correlational, and cross-sectional study. **Methods:** Study 1 was carried out with 10 key informants. For Study 2, a sample of 103 nursing professionals was obtained and 176 nurses from palliative care resources in Spain participated in Study 3. Data was collected between May 2017 – May 2018. **Results:** Evidence of adequate reliability (internal consistency) and validity was found. The confirmatory factor model yielded a single latent factor for the 20 items, with adequate goodness-of-fit indices. The convergent validity data showed that the highest correlations were with the Dedication subscale of the Utrecht Work Engagement Scale and the Personal Growth subscale of Psychological Well-being, with values of 0.35 and 0.34, respectively ( $p < 0.01$  in both cases). **Conclusion:** The scale shows good psychometric properties, with high internal consistency and evidence of internal and convergent validity. **Impact:** Proposing a valuable instrument which identifies good nursing in different areas of palliative care while also establishing quality indicators to guide nursing practice entails the recognition of autonomy in care. The resulting work tool can be used to

systematize the assessment of nursing care in a process of open and continuous improvement.

### **Humour and laughing in patients with prolonged incurable cancer: An ethnographic study in a comprehensive cancer centre**

Quality of Life Research: Sep 2020; vol. 29 (no. 9); p. 2425-2434

Buiting, HM, et al.

**Purpose:** Most people are familiar with the expression 'laughter is the best medicine'. By enhancing cognitive flexibility and strengthening relationships, laughter can be considered a holistic care-approach. Yet, in medical oncology, especially the palliative phase, using humour can be considered inappropriate or taboo. We aimed to explore the acceptability and functions of humour and laughter in patients with prolonged incurable cancer. **Methods:** This study was performed in a Dutch Comprehensive Cancer Centre. We included four short conversations with patients, eighteen in-depth patient-interviews and eleven observational fieldnotes in which humour was a major topic of the conversation. We further administered an online questionnaire to thirty-three oncology clinicians about their experiences with humour. Qualitative data were thematically analysed. We specifically distinguished between humour and laughter. **Results:** Nearly all specialists reported using humour (97%), and all reported sometimes laughing during consultations; 83% experienced a positive effect of laughter. These results were in line with patients' experiences: Patients noted that humour always stayed alive despite medical difficulties. Apart from this human aspect, patients also used humour to broach difficult topics and downplay challenges. Patients and specialists acknowledged that using humour is sometimes inappropriate, partly because they did not always share the same humour. Laughter, in contrast, was regarded as 'lighter' than humour, and could, accordingly, more easily be implemented. Specialists cautioned against patients using laughter to avoid broaching difficult topics. **Conclusion:** Many conversations were full of laughter. Hierarchy as usually experienced between healthcare professionals and patients/relatives seemed to disappear when using laughter. If applied appropriately, adding shared laughter may help optimize shared decision-making.

### **Hypodermoclysis as a Strategy for Patients with End-of-Life Cancer in Home Care Settings.**

American Journal of Hospice & Palliative Medicine; Sep 2020; vol. 37 (9); p. 675-682

Coelho TA, Wainstein AJA, Drummond-Lage AP.

**Background:** The increase in the elderly population associated with a higher incidence of cancer strongly endorses palliative care (PC). Hypodermoclysis (HDC) is a feasible technique for drugs and fluids delivery at the home care setting. **Objectives:** To assess the use and benefits of HDC in patients with end-of-life cancer assisted by a single home-based palliative care program (HPCP) in Belo Horizonte, Brazil. **Methods:** This was a retrospective study that analyzed medical charts from patients with end-of-life cancer who were assisted by an HPCP in a 1-year period of time. **Results:** A total of 333 patients, 81.7% with advanced cancer, were included. The most frequent symptoms were fatigue (44.4%) and pain (43.2%). Hypodermoclysis was used in 77.5% of the patients for the administration of fluids or medicines. Continuous palliative sedation was applied to 70.5% of patients. The place of death was home for 90.2% of the patients. **Conclusion:** Receiving home care assistance with palliative intention may decrease the need for dying patients with cancer to visit emergency units, as their symptoms were well controlled. Hypodermoclysis was a safe and effective alternative for hydration and drug

delivery when provided and supervised by an experienced team. The place of death is a reliable indicator of the quality of death, and, in this study, the HPCP allowed patients to die at home with their families. It is essential for PC professionals to understand the impact of HDC use at home care setting for patients with end-of-life cancer allowing the increase of quality of death indicators.

### **The Impact of Varying Levels of Advance Care Planning Engagement on Perceptions of the End-of-Life Experience Among Caregivers of Deceased Patients With Cancer.**

American Journal of Hospice & Palliative Medicine; Dec 2020; vol. 37(12); p.1045-1052

Levoy K, et al.

Context: Advance care planning (ACP) is used to prepare patients and caregivers for future "in the moment" decisions at the end-of-life. Patients with cancer generally do not engage in all 3 components of ACP (documented living will, health-care surrogate, end-of-life discussions); however, little is known about the impact of these varying levels of ACP engagement on caregivers post death. Objective: To examine the relationship between varying levels of ACP engagement and caregivers' perceptions of cancer decedents' end-of-life experiences. Methods: A secondary analysis of the 2002 to 2014 waves of the Health and Retirement Study data using structural equation modelling was conducted. Five levels of ACP engagement were defined: full (discussions/ documents), augmented discussions, documents only, discussions only, and no engagement. Results: Among the 2172 cancer death cases, the analyzed sample included 983 cases where end-of-life decisions occurred. Compared to no ACP, all levels of ACP were significantly associated with caregivers' positive perceptions of cancer decedents' end-of-life experiences ( $P \leq .001$ ), controlling for sex, race, and Hispanic ethnicity ( $R^2 = .21$ ). However, the relative impact of each level of ACP engagement was not equal; full engagement ( $\beta = .61$ ) was associated with a greater impact compared to each of the partial levels of engagement (augmented discussions [ $\beta = .33$ ], documents only [ $\beta = .17$ ], discussions only [ $\beta = .17$ ]). Conclusion: Partial ACP engagement, not just non-engagement, serves as an important clinically modifiable target to improve the end-of-life care experience among patients with cancer and the perceptions of those experiences among bereaved caregivers.

### **Methadone for Cancer Pain in Pediatric End-of-Life Care**

American Journal of Hospice and Palliative Medicine; 2020

Hall EA, et al.

Background: The goal of adequate pain control becomes increasingly salient for children with cancer and their families as the patients approach the end of life. Methadone is one option that is particularly desirable in end-of-life care given its long duration of action and NMDA antagonism that may help in controlling pain refractory to conventional opioids. The purpose of this study was to describe a single institution's experience with methadone for the treatment of cancer pain in pediatric end-of-life care. Method(s): This retrospective, observational, single-center study included all patients during a 9-year period who died in the inpatient setting and were receiving methadone in their last 30 days of life. Result(s): Twenty patients were identified, 18 (90%) of whom received methadone for nociceptive pain. The median duration of methadone use was 32 days (range 2-323 days). Methadone doses ranged from 0.09 to 7.76 mg/kg per day. There were no instances of discontinuing methadone due to an increased QTc interval. No episodes of torsades de pointes were observed. Conclusion(s): In patients with pediatric cancer who are nearing the end of life, methadone is a valuable adjunctive therapy to treat nociceptive and neuropathic pain and to prevent opioid-induced hyperalgesia and opioid tolerance. An individualized approach to dosage and route should be considered based on specific clinical circumstances.



### **The need for early referral to palliative care especially for Black, Asian and minority ethnic groups in a COVID-19 pandemic: Findings from a service evaluation**

Palliative Medicine; Oct 2020; vol. 34 (9); p.1241-1248

Chidiac C, et al.

Background: Palliative care services face challenges in adapting and responding to the COVID-19 pandemic. Understanding how palliative care needs and outcomes have changed during the pandemic compared to before the pandemic is crucial to inform service planning and research initiatives. Aim(s): To evaluate the impact of COVID-19 on symptoms, clinical characteristics, and outcomes for patients referred to a hospital-based palliative care service in a district general hospital in London, UK. Design(s): A retrospective service evaluation. Data were extracted from the electronic patient records. Setting/participants: The first 60 inpatients with confirmed COVID-19 infection, referred to the hospital palliative care service between 1 March 2020 and 23 April 2020, and another 60 inpatients, referred to the hospital palliative care service between 11 March 2019 and 23 April 2019, were included from a district general hospital in East London, UK. Result(s): Patients with COVID-19 have lower comorbidity scores, poorer performance status, and a shorter time from referral to death compared to patients without COVID-19. Breathlessness, drowsiness, agitation, and fever are the most prevalent symptoms during COVID-19 compared to pain and drowsiness pre-COVID-19. Time from admission to referral to palliative care is longer for Black, Asian and minority ethnic patients, especially during COVID-19. Conclusion(s): Early referral to palliative care is essential in COVID-19, especially for Black, Asian and minority ethnic groups. There is urgent need to research why Black, Asian and minority ethnic patients are referred late; how palliative care services have changed; and possible solutions to setting up responsive, flexible, and integrated services.

### **Nurses' experiences and perspectives on collaborative discharge planning when patients receiving palliative care for cancer are discharged home from hospitals**

Journal of Clinical Nursing; Sep 2020; vol. 29 (no. 17-18); p. 3382-3391

Lundereng ED, Dihle A, Steindal SA.

Aims and objectives: To explore nurses' experiences and perspectives on discharge collaboration when patients receiving palliative care for cancer are discharged home from hospitals. Background: Patients receiving palliative care for cancer experience multiple transitions between the hospital and their home. Poor discharge collaboration is a major cause of preventable hospital readmissions. Collaborative discharge planning could improve the care for these patients outside the hospital setting. Previous research has mostly been conducted in noncancer populations. Further research regarding both home care nurses' and hospital nurses' perspectives on care transitions is required. Design: A qualitative study with descriptive and explorative design. Methods: Data were collected through 10 individual, semi-structured interviews of nurses working at two oncology wards at a university hospital and home care services in four municipalities within the hospital's catchment area. Data were analysed using systematic text condensation. COREQ guidelines were adhered to in the reporting of this study. Results: Three categories emerged from the data analysis: lack of familiarity and different perceptions lead to distrust; inefficient communication creates a need for informal collaboration; and delayed discharge planning challenges collaboration. Conclusions: The nurses lacked an understanding of each other's work situation, which created distrust, misunderstandings and misconceptions regarding each other's abilities to care for the patient. This led to inefficient communication, relying on individual knowledge,

informal communication and personal networking. Delays in the discharge planning resulted in poorly prepared discharges often lacking necessary equipment and documentation. Relevance to clinical practice: To improve the care of patients receiving palliative care for cancer outside the hospital setting, better communication is a key factor to promote confidence and understanding between nurses working in different settings of health care.

### **Opioid Prescribing Patterns Before and After an Inpatient Palliative Care Consultation.**

American Journal of Hospice & Palliative Medicine; Sep 2020; vol. 37 (no. 9); p. 738-742  
Al-shahri MZ, et al.

Background: To the best of our knowledge, the change in opioid prescription patterns upon referral to a palliative care team (PCT) was not previously investigated in the Middle East. Objective: This study aimed to explore the change in the pattern of opioid prescription and the pain scores before and after referring inpatients to a PCT. Methods: We conducted a retrospective review of patients' records including all inpatients  $\geq 15$  years newly referred to the PCT over a period of 21 months at King Faisal Specialist Hospital and Research Center, Riyadh. Results: Of 631 patients, 52.3% were females, the median age was 54 years, and 96.7% had cancer. The proportion of patients on opioids before referral (83.4%) increased to 93.3% in the postreferral period,  $P < .0001$ . Patients receiving opioids on a regular basis increased from 31.9% before referral to 49.9% after referral to the PCT,  $P < .0001$ . Morphine was the most commonly prescribed opioid on a regular basis pre- and postreferral. Upon referral, the administration of opioids through the subcutaneous route increased from 3.7% to 10.9%,  $P < .0001$ . On average, pain scores were reduced by 1 point on a 0 to 10 numeric scale within 48 hours of seeing a patient by the PCT,  $P < .0001$ . Conclusion: Patients referred to a PCT are likely to get their opioid prescription optimized and pain scores improved shortly after the PCT involvement. Patients with cancer-related pain requiring opioids should be referred to a PCT as early as possible.

### **Palliative care transitions from acute care to community-based care: A qualitative systematic review of the experiences and perspectives of health care providers**

Palliative medicine; 2020; vol. 34 (10); p.1316-1331  
Killackey T, et al.

Background: Transitioning from the hospital to community is a vulnerable point in patients' care trajectory, yet little is known about this experience within the context of palliative care. While some studies have examined the patient and caregiver experience, no study to date has synthesized the literature on the healthcare provider's perspective on their role and experience facilitating these transitions. Aim: The purpose of this systematic review was to understand the experience and perspective of healthcare providers who support the transition of patients receiving palliative care as they move from acute care to community settings. Design: A qualitative systematic review of studies using thematic analysis as outlined by Thomas and Harden. PROSPERO: ID # CRD42018109662. Data Sources: We searched four databases: MEDLINE, Embase, ProQuest and CINAHL for studies published in English from 1995 until May 22, 2020. Four reviewers screened records using the following selection criteria: (1) peer-reviewed empirical study, (2) adult sample, (3) qualitative study design, (4) perspective of healthcare providers, and (5) included a component of transitions between acute to community-based palliative care. Study findings were analyzed using thematic analysis which entailed: (1) grouping the

findings into recurring themes; (2) iteratively referring back to the articles to obtain nuances of the theme and quotations; and (3) defining and solidifying the themes. Results: Overall 1,791 studies were identified and 15 met inclusion criteria. Studies were published recently (>2015, n = 12, 80%) and used a range of qualitative methods including semi-structured interviews, focus groups, and field interviews. Three core themes related to the role and experience of healthcare providers were identified: (1) assessing and preparing for transition; (2) organizing and facilitating the logistics of transition; and (3) coordinating and collaborating transitional care across sectors. The majority of studies focused on the discharge process from acute care; there was a lack of studies exploring the experiences of healthcare providers in the community who receive patients from acute care and provide them with palliative care at home. Conclusion: This review identified studies from a range of relatively high-income countries that included a diverse sample of healthcare providers. The results indicate that healthcare providers experience multiple complex roles during the transition facilitation process, and future research should examine how to better assist clinicians in supporting these transitions within the context of palliative care provision.

### **Patients and Caregivers Rate the PAIN Report It Wireless Internet-Enabled Tablet as a Method for Reporting Pain During End-of-Life Cancer Care**

Cancer Nursing; Sep 2020; vol. 43 (no. 5); p. 419-424

Schoppee T, et al.

Background: In several studies, investigators have successfully used an internet-enabled PAIN Report It tablet to allow patients to report their pain to clinicians in real-time, but it is unknown how acceptable this technology is to patients and caregivers when used in their homes. Objective: The aims of this study were to examine computer use acceptability scores of patients with end-stage cancer in hospice and their caregivers and to compare the scores for differences by age, gender, race, and computer use experience. Intervention/Methods: Immediately after using the tablet, 234 hospice patients and 231 caregivers independently completed the Computer Acceptability Scale (maximum scores of 14 for patients and 9 for caregivers). Results: The mean (SD) Computer Acceptability score was 12.2 (1.9) for patients and 8.5 (0.9) for caregivers. Computer Acceptability scores were significantly associated with age and with previous computer use for both patients and caregivers. Conclusions: This technology was highly acceptable to patients and caregivers for reporting pain in real time to their hospice nurses. Implications for Practice: Findings provide encouraging results that are worthy of serious consideration for patients who are in end stages of illness, including older persons and those with minimal computer experience. Increasing availability of technology can provide innovative methods for improving care provided to patients facing significant cancer-related pain even at the end of life.

### **Sociocultural factors associated with awareness of palliative care and advanced care planning among asian populations**

Ethnicity and Disease; Sep 2020; vol. 30 (3); p. 459-468

Shen JJ, et al.

**Objective:** Underutilization of palliative care (PC) among racial/ethnic minorities remains consistent despite projected demand. The purpose of this study was to examine knowledge of palliative care and advanced care planning (ACP) and potential variations among subgroups of Asian Americans. **Design(s):** A survey was conducted to collect information about awareness, knowledge, and perspective of PC and ACP in the southwestern region of the United States, from October 2018 to February 2019. A total of 212 surveys were collected from the general public at such places as health fairs, New Year celebration events, church, and community centers; 154 surveys were included in the descriptive and multivariate data analysis. **Result(s):** About 46.1% and 40.3% participants reported having heard of palliative care and advanced care planning, respectively. The average score of the Knowledge of Care Options Instrument (KOCO) was 6.03 out of 11 and the average score of the Palliative Care Knowledge Scale (PaCKS) was 4.38 out of 13. Among those who have heard of PC, both Chinese (odds ratio (OR) .19 [CI, .05, .73]) and Vietnamese (.22 [.06, .84]) were less likely to have heard of palliative care compared with Filipinos (1.00). Among those who have ever heard of advanced care planning, age (.60 [.43, .84]) was negatively and education level (1.91 [1.18, 3.08]) was positively associated with awareness about advanced care planning. The majority of survey participants preferred family members to serve as their power attorneys. **Conclusion(s):** The low levels of palliative care and advanced care planning awareness and knowledge in the diverse Asian groups living in the United States raise concerns and shed light on the critical need for culturally appropriate education programs.

### **Structural relationship between mindful self-care, meaning made, and palliative worker's quality of life**

International Journal of Stress Management; Sep 2020

Depner RM, Cook-Cottone CP, Kim S.

Research is clear that palliative care workers (PCW) are at risk for burnout and secondary traumatic stress, it is unclear how to address these risks and support PCWs. A recent meta-analysis of interventions supporting PCWs reported that despite ample programs implemented for PCWs, most have failed to demonstrate desired outcomes or are based on non-rigorously tested research. This study seeks to evaluate factors that may contribute to professional quality of life (ProQoL) for PCWs. Specifically; it uses structural equation modelling to examine the relationship between ProQoL, mindful self-care (MSC), and meaning made in PCWs. A total of 141 multidisciplinary palliative and hospice care clinicians from a county-wide agency completed The Mindful Self-Care Scale-33, The Integration of Stressful Life Experiences Scale, and The Professional Quality of Life Scale. MSC behaviors exhibited a direct effect on ProQoL for PCWs so that more engagement in MSC predicted higher ProQoL ( $\beta = .81, p < .001$ ). MSC behaviors also demonstrated a direct relationship with meaning made for PCWs so that higher engagement in MSC predicted higher meaning made ( $\beta = .33, p < .01$ ). Similarly, meaning made indicated a direct effect on ProQoL so that higher meaning made resulted in higher ProQoL ( $\beta = .25, p < .01$ ). The current study suggests that ProQoL for PCWs may be directly affected by meaning made as well as the degree of engagement in MSC behaviors. Based on these findings, future programs aimed at supporting PCWs should consider adding MSC behaviors and meaning-making interventions as components.

### **Use of palliative chemotherapy near the end of life: A retrospective cohort study**

Annals of Palliative Medicine; Sep 2020; vol. 9 (5); p. 2809-2816

Zhang Z, et al.



**Background:** For patients with metastatic cancer, treatment with palliative chemotherapy can lead to more aggressive end-of-life (EOL) care. This retrospective study aimed to assess the time from the last chemotherapy treatment to death and investigate the variables associated with the delivery of palliative chemotherapy near the end of life. **Method(s):** Data from patients who died from metastatic cancer after receiving palliative chemotherapy from April 2007 to June 2019 at the Department of Integrated Therapy of Fudan University, Shanghai Cancer Center were analyzed. Statistical analysis was performed to evaluate variables including the patient's age, Charlson comorbidities, caregivers, and the type of cancer. **Result(s):** A total of 605 patients were included in the analysis, of whom 335 (58.7%) were treated with palliative chemotherapy during their last year of life and 16.2% were treated in their last month of life. Treatment with palliative chemotherapy in the last month was independently associated with age ( $P<0.001$ ). In the last year of life, treatment with palliative chemotherapy differed significantly according to caregivers and age ( $P<0.001$ ). The interval between the last chemotherapy treatment and death was the shortest for patients whose caregivers were adult children or those aged  $\leq 50$  years. **Conclusion(s):** In this study, palliative chemotherapy was used to treat 58.7% of patients in their last year, and 16.2% of patients in their last month, which is in line with international recommendations. In the last month, palliative chemotherapy was independently associated with age ( $P<0.001$ ), whereas patients were more likely to receive palliative chemotherapy in their last year if their caregivers were adult children or if they were aged  $\leq 50$  years. Significant variations in EOL treatment strategies were observed according to caregivers and patient age during the last year of life.

### **Virtual Reality Use for Symptom Management in Palliative Care: A Pilot Study to Assess User Perceptions**

Journal of Palliative Medicine; Sep 2020; vol. 23 (9); p. 1233-1238

Johnson T, et al.

In the past two decades, virtual reality (VR) technology has found use in a variety of clinical settings including pain management, physical medicine and rehabilitation, psychiatry, and neurology. However, little is known about the utility of VR in the palliative care setting. Moreover, previous investigations have not explored user perceptions of the VR experience in this population. Understanding user perceptions of the VR intervention will be critical for the development and delivery of effective VR therapies. To examine the utility of VR for palliative care patients, a pilot study of VR use was conducted with 12 adult patients diagnosed with life-limiting illness who were residents at a free-standing hospice facility. The intervention consisted of a one-time 30-minute VR experience. User perceptions were assessed through both quantitative and qualitative means, including participant responses to open-ended questions after the VR intervention. Acute changes in symptom burden were assessed using the revised Edmonton Symptom Assessment Scale. Participants found the VR experience to be both enjoyable and useful, and the intervention was well-tolerated overall. This study provides support for VR as a promising new therapeutic modality for patients undergoing palliative care.

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