A number of other bulletins are also available – please contact the Academy Library for further details.

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Email: ruh-tr.library@nhs.net
Hello, my name is Helen Meehan and I’m lead nurse for palliative and end of life care at the RUH.

In recent End of Life Care bulletins we have seen more information on supporting palliative and end of life care during the COVID pandemic.

These are extraordinary times in which we work, but our principles of person and family centred care should remain central to all that we do in supporting patients with palliative and end of life care needs.

Now, more than ever, we need to work together, share knowledge, learn from each other and support each other. Please do take some time to reflect, share what you are learning and look out for each other. Take care this Christmas and look after yourself.

Best wishes
Helen

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**Journal Articles**

**Title:** End-of-life care for homeless people in shelter-based nursing care settings: A retrospective record study

**Citation:** Palliative Medicine; Dec 2020; vol. 34 (no. 10); p. 1374

**Author(s):** van Dongen Sophie I; Klop, Hanna T; Onwuteaka-Philipsen, Bregje D; de Veer Anke JE; Stockers, Marcel T; van Laere Igor R; van der Heide Agnes; Rietjens, Judith AC

**Objective:** Homeless people experience multiple health problems and early mortality. In the Netherlands, they can get shelter-based end-of-life care, but shelters are predominantly focused on temporary accommodation and recovery. This study aims to examine the characteristics of homeless people who reside at the end-of-life in shelter-based nursing care settings and the challenges in the end-of-life care provided to them.

**Design:** A retrospective record study using both quantitative and qualitative analysis methods.

**Setting/participants:** Two Dutch shelter-based nursing care settings. We included 61 homeless patients who died between 2009 and 2016.

**Results:** Most patients had somatic (98%), psychiatric (84%) and addiction problems (90%). For 75% of the patients, the end of life was recognised and documented; this occurred 0–1253 days before death. For 26%, a palliative care team was consulted in the year before death. In the three months before death, 45% had at least three transitions, mainly to hospitals. Sixty-five percent of the patients died in the shelter, 27% in a hospital and 3% in a hospice. A quarter of all patients were known to have died alone. Documented care difficulties concerned continuity of care, social and environmental safety, patient–professional communication and medical-pharmacological alleviation of suffering.
Conclusions: End-of-life care for homeless persons residing in shelter-based nursing care settings is characterised and challenged by comorbidities, uncertain prognoses, complicated social circumstances and many transitions to other settings. Multilevel end-of-life care improvements, including increased interdisciplinary collaboration, are needed to reduce transitions and suffering of this vulnerable population at the end of life.

Title: Examining the Relationship between Patient Fatigue-Related Symptom Clusters and Carer Depressive Symptoms in Advanced Cancer Dyads: A Secondary Analysis of a Large Hospice Data Set.

Citation: Cancer Nursing; Nov 2020; vol. 43 (no. 6); p. 498-505
Author(s): Buck; Benitez, Bryan; Fradley, Michael G.; Donovan, Kristine A.; McMillan, Susan C.; Reich, Richard R.; Wang, Hsiao-Lan

Objective: Most symptom management takes place in the community, conducted by patient and/or informal carer dyads with guidance from clinicians. Given the prevalence of cancer, there is a critical need for examination of the impact of managing multiple symptoms, particularly those that cluster with fatigue, on informal carers. This study aims to (1) examine clustering of patient fatigue-related symptom severity and distress in individuals with cancer and (2) test the hypothesis that patient fatigue-related symptom clusters (severity, distress) will be positively associated with carer depressive symptoms.

Methods: Secondary analysis of 689 hospice patient/informal carer dyads using exploratory factor analysis and structural equation modeling. Patient symptoms were measured by the Memorial Symptom Assessment Scale, and carer depressive symptoms were measured by the Center for Epidemiological Study–Depression Scale.

Results: Patients were 73 (SD, 12) years old, and 43% were female. Carers were 65 years (SD, 14) years old, and 74% were female. For symptom severity, dyspnea, dry mouth, lack of appetite, drowsiness, cough, dizziness, and difficulty swallowing clustered with fatigue. For symptom distress, dyspnea, cough, and dry mouth clustered with fatigue. Structural equation modeling results indicated that the patient fatigue severity cluster was positively related to carer depressive symptoms (b = 0.12, P <.05), but distress was not.

Conclusion: Managing multiple symptoms that cluster with fatigue negatively impacts informal carers. Implications for Practice: When patients complain of severe fatigue, clinicians need to explore all causes and ask about other symptoms while exploring whether the informal carer is feeling burdened or depressed.

Title: Measuring Communication Similarity between Hospice Nurses and Cancer Caregivers Using Latent Semantic Analysis.

Citation: Cancer Nursing; Nov 2020; vol. 43 (no. 6); p. 506-513
Author(s): Kane; Clayton, Margaret F.; Baucom, Brian R.; Ellington, Lee; Reblin, Maija

Objective: Optimal end-of-life care requires effective communication between hospice nurses, caregivers, and patients, yet defining and evaluating effective communication are challenging. Latent semantic analysis (LSA) measures the degree of communication similarity (talking about the
same topic) without relying on specific word choices or matching of communication behaviors (question-answer), thus more comprehensively evaluating communication interactions. Guided by the Communication Accommodation Theory, we evaluated communication similarity, indicating theoretical convergence, between hospice nurses and caregivers of cancer patients, identifying nurse attributes and communication skills that were associated with greater communication similarity.

**Methods:** A descriptive secondary analysis of self-reported nurse data and 31 audio-recorded cancer patient home hospice nursing visits across 2 states and 7 hospices. Results: The average LSA score was 0.83 (possible range, 0–1). A nurse preference for greater patient-oriented visits, use of more Nurse Partnering statements, and less Conversation Dominance (ratio of total nurse to total caregiver talk) were associated with higher LSA scores.

**Conclusions:** Effective communication is essential to optimal end-of-life care. Latent semantic analysis is a feasible and promising approach for assessing communication similarity during home hospice care. Implications for Practice: Hospice nurses are at the forefront of family caregiver communication, playing a vital role in empowering caregivers to assume required patient care tasks. Communication strategies such as the use of partnering statements that increase LSA scores can be taught to hospice nurses and other members of the hospice interdisciplinary team as a way to enrich communication skills and improve communication confidence and can be translated into other oncology nursing contexts.

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**Title: End-of-Life Dreams and Visions in Pediatric Patients: A Case Study.**

**Citation:** Journal of Palliative Medicine; Nov 2020; vol. 23 (no. 11); p. 1549-1552

**Author(s):** Levy ; Grant, Pei C.; Kerr, Christopher W.

**Background:** End-of-life dreams and visions (ELDVs) are a recognized phenomenon that can occur as part of the normal dying process. Data suggest that ELDVs can provide comfort, foster discussion of waking life concerns, and lessen the fear of death. Current literature on ELDVs focuses on the prevalence, content, and effects of ELDVs exclusively in adult populations.

**Methods:** We present the case of a 15-year-old girl with terminal glioblastoma who was enrolled in a pediatric palliative care program and later in hospice care. During her end-of-life trajectory, the patient experienced two distinct ELDV experiences, from which she recalled vivid details regarding the setting, characters, and content. These ELDV experiences afforded comfort and meaning to the patient and her family through her end-of-life trajectory as well as provided relief for her grieving family.

**Conclusion:** In the case presented, ELDVs appear to show similar characteristics and impact in the adolescent population as described in the previous literature examining adult ELDVs. In addition, this case demonstrates the potential benefits of ELDV awareness for the bereaved. Clinicians working with pediatric and adolescent end-of-life populations should take note of the potential for ELDVs and the impact they can have on both patients and families.

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**Title: The Cost of Visit-based Home Care for up to Two Weeks in the Last Three Months of Life: A Pilot Study of Community Care Based at a Hospice-at-home Service in South East of England.**

**Citation:** Journal of Community Health Nursing; Oct 2020; vol. 37 (no. 4); p. 203-213
Author(s): Spiro ; Ward, Alison; Sixsmith, Judith; Graham, Anne; Varvel, Sue

Abstract: The cost of visit-based community care based around a 24/7 hospice-at-home (HatH) service in the last 3 months of life was assessed. Thirty families completed a health and social carediary of at-home visits over two-weeks following contact with the HatH night service. Diaries captured 333 days of care provision, averaging 11 diary days per family, 708 health care professional and carer visits, lasting 604 hours at a cost of £20,192 ($24,946). Hat H care, integrated with community support, seems an economic proposition but highlights the complexities of assessing cost of end of life care.

Title: Open communication between caregivers' and terminally ill cancer patients about illness and death: The role of gender - A correlational study.

Citation: European Journal of Oncology Nursing; Dec 2020; vol. 49
Author(s): Carmel ; Singer, Yoram; Yosef-Sela, Nili; Bachner, Yaacov G.

Abstract: Caregivers face severe difficulties in communicating openly with their terminally ill relatives about illness and death. Some studies suggest that females are more likely than males to hold such conversations. We compared level of open communication between male and female spouse-caregivers, and the contribution of personal and situational characteristics to the explanation of open communication level within each gender group. The study design was correlational. We interviewed 77 spousal-primary caregivers of terminal cancer patients. Participants were recruited over a 10-month period from the home hospice unit of the central region of Israel's largest Health Maintenance Organization. The questionnaire included measures of open communication, along with caregiver's personal and situational characteristics. Female spouses reported higher levels of open communication about illness and death with their loved ones, compared to male spouses. Among males, duration of care and self-efficacy emerged as significant contributors to open communication level. Among females, self-efficacy and ethnic origin were found to be significant explanatory variables. This study demonstrates the important role gender plays in level of open communication between spousal caregivers and terminal cancer patients, concerning their illness and approaching death. Self-efficacy, ethnic origin and duration of care are also significant factors explaining open communication of both male and female caregivers. These factors should be considered by nurses and other healthcare professionals when developing intervention programs to increase the level of open communication between family caregivers and their terminally ill relatives.

Title: A Pilot Study of Nonpharmacological Interventions for Hospice Patients with Behavioral and Psychological Symptoms in Dementia.

Citation: Journal of Hospice & Palliative Nursing; Dec 2020; vol. 22 (no. 6); p. 489-494
Author(s): Krauss ; Schlievert, Matthew A.; Wagner, Bonnie K.; Deutsch, Diane D.; Powell, Rebecca J.

Abstract: Agitation is a common, treatable symptom that profoundly impacts quality of life and exacerbates caregiver fatigue in the hospice setting for patients with dementia. The objective of
this study was to analyze the efficacy of tailored nonpharmacological interventions for mitigation of unwanted behaviors in the population of patients with behavioral and psychological symptoms in dementia while receiving hospice care. The 4-domain Pittsburgh Agitation Scale (PAS; Motor, Verbal, Aggressive, Resistance to Care) was used for multiple baseline and posttest measurements of agitation. Effectiveness of nonpharmacological interventions was evaluated using analysis of variance for repeated measures for the total PAS score. Motor agitation was the presenting problem with highest-rated severity compared with Verbal, Aggression, and Resistance to Care domains. Analysis of variance demonstrated no difference between baseline referral and pretest total PAS measures (P =.8), but a significant drop in total PAS agitation after intervention (P <.001). The best outcomes, however, were with patients receiving both nonpharmacological and standard pharmacological interventions as opposed to nonpharmacological interventions alone (P =.034). For patients with dementia presenting with behavioral and psychological symptoms, selected nonpharmacological interventions provide significant mitigation of agitation.

**Title:** Professional oral care in end-of-life patients with advanced cancers in a hospice ward: improvement of oral conditions.

**Citation:** BMC Palliative Care; Nov 2020; vol. 19 (no. 1)

**Author(s):** Wu ; Liu, Hsiu-Yueh; Wu, Chien-Yi; Chen, Hung-Cheng; Huang, Shun-Te; Chen, Ping-Ho

**Objective:** In end-of-life patients with advanced cancers, oral examination, oral care, and oral re-examination are crucial. Although oral symptoms are among the major complaints of end-of-life patients, few studies have focused on oral care in these patients. In this study, the association between oral symptoms and oral dryness among end-of-life patients was examined, and improvement of oral conditions after oral care interventions by a professional dentist was quantified.

**Methods:** This prospective intervention study included 27 terminally ill patients with advanced cancers in a hospice ward. Professional oral care was administered every morning, and the improvement of oral conditions was assessed by comparing oral conditions before and after the intervention. Oral assessment was performed using the Oral Health Assessment Tool (OHAT) and Oral Assessment Guide. Oral dryness was evaluated through Clinical Diagnosis Classification of oral dryness and an oral moisture device. Oral cleanliness was evaluated using a bacterial counter, and tongue smears were collected for Candida examination; furthermore, oral function was recorded.

**Results:** The presence of oral mucositis was closely associated with severe oral dryness (odds ratio [OR] = 14.93; 95% confidence interval [CI]: 1.95–114.38). The level of oral debris retention was significantly related to the degree of oral dryness (OR = 15.97; 95% CI: 2.06–123.72). The group with higher scores (OHAT > 8), which represent poor oral conditions, showed severe oral dryness (OR = 17.97; 95% CI: 1.45–223.46). Total OHAT scores (median: 7 vs 2) and those of other subgroups (lip, tongue, gums and tissues, saliva, and oral cleanliness showed a significant decrease after the intervention. Furthermore, the occurrence of mucositis (47.1% vs 0%), candidiasis rate (68.8% vs 43.8%), oral dryness self-sensation (63.6% vs 9.1%), and severe oral debris (52.9% vs 11.8%) decreased significantly.

**Conclusions:** Proper oral care can improve oral health and hygiene, reduce the rate of mucositis, reduce the sensation of oral dryness, increase oral moisture, and reduce the chances of oral infections among end-of-life patients. Daily oral care is necessary and can alleviate oral discomfort,
increase food intake, and increase the chances of communication between end-of-life patients and their families.

Title: A qualitative evidence synthesis of healthcare professionals' experiences and views of palliative care for patients with a haematological malignancy.

Citation: European Journal of Cancer Care; Nov 2020; vol. 29 (no. 6); p. 1-25

Author(s): Dowling ; Fahy, Paul; Houghton, Catherine; Smalle, Mike

Objective: Patients with haematological malignancies may not be receiving appropriate referrals to palliative care and continuing to have treatments in the end stages of their disease. This systematic review of qualitative research aimed to synthesise healthcare professionals' (HCPs) views and experiences of palliative care for adult patients with a haematologic malignancy.

Methods: A systematic search strategy was undertaken across eight databases. Thomas and Harden's approach to thematic analysis guided synthesis on the seventeen included studies. GRADE-GRADAQual guided assessment of confidence in the synthesised findings.

Results: Three analytic themes were identified: (a) "Maybe we can pull another 'rabbit out of the hat,'" represents doctors' therapeutic optimism, (b) "To tell or not to tell?" explores doctors' decision-making around introducing palliative care, and (c) "Hospice, home or hospital?" describes HCPs concerns about challenges faced by haematology patients at end of life in terms of transfusion support and risk of catastrophic bleeds.

Conclusion: Haematologists value the importance of integrated palliative care but prefer the term "supportive care." Early integration of supportive care alongside active curative treatment should be the model of choice in haematology settings in order to achieve the best outcomes and improved quality of life.

Title: Prevalence, incidence and associated factors of pressure injuries in hospices: A multicentre prospective longitudinal study.

Citation: International Journal of Nursing Studies; Nov 2020; vol. 111

Author(s): Artico ; Piredda, Michela; D'Angelo, Daniela; Lusignani, Maura; Giannarelli, Diana; Marchetti, Anna; De Chirico, Cosimo; Mastroianni, Chiara; De Marinis, Maria Grazia

Abstract: Patients in palliative care are the population cohort that most frequently develop pressure injuries, severely impacting their quality of life. Data from prospective studies on the prevalence and incidence of pressure injuries in hospices are lacking. To describe the point prevalence and cumulative incidence of pressure injuries in patients admitted to residential hospices, and to analyze their predictive factors over time. Multicentre prospective longitudinal observational study. Adult patients (n = 992) enrolled in 13 Italian residential hospices, with a minimum sample of 280 for each macro-region (North, center, South/Islands). Assessments including the Karnofsky Performance Status, Braden, Edmonton Symptom Assessment System Revised scales and pressure injury staging according to National Pressure Ulcer Advisory Panel were conducted at least every four days, from admission to patients' death/discharge. The 7,967 observations recorded provided prevalence and incidence rates of 34.1% and 26.5%, respectively. The logistic regression model showed non-cancer disease (OR = 2.39, 95%CI = 1.65–3.47), age
>80 (OR = 2.01, 95%CI = 1.49–2.71), Braden score ‘at risk’ (OR = 1.92, 95%CI = 1.17–3.14), urinary catheter (OR = 1.96, 95%CI = 1.40–2.75), drowsiness (OR = 1.41, 95%CI = 1.02–1.95) and artificial nutrition (OR = 1.47, 95%CI = 1.01–2.14) as the variables associated with pressure injury at admission. The generalized estimating equations models, built on the timeframes for observation groups, revealed male gender (OR = 1.68, 95%CI = 1.01–2.79) and Braden score ‘at risk’ (OR = 4.45, 95%CI = 1.74–11.34) as predictive factors of a new pressure injury developed up to three weeks before a patient's death, while in the last ten days of life these predictors were replaced by diagnosis of cancer (OR = 1.80, 95%CI = 1.11–2.91), worsening pain (OR = 1.65, 95%CI = 1.10–2.49), drowsiness (OR = 1.79, 95%CI = 1.25–2.57) and dyspnea (OR = 1.48, 95%CI = 1.01–2.18). The high incidence and prevalence of pressure injuries confirm the importance of palliative care nurses continuously focusing on prevention and management strategies. In the last three weeks of a patient's life, the predictive power of the Braden scale for a new pressure injury is not confirmed, throwing doubt on the effectiveness of aimed interventions at modifying risk factors. Along the different disease trajectories, pressure injuries developed during the instability/worsening phases of illness, occurring before hospice admission for non-cancer patients and in the end-of-life phase for cancer patients. Despite continuous provision of appropriate interventions, most of the new pressure injuries were detected during the last ten days of a patient's life and assessed as ‘unavoidable’. These results are crucial to guiding palliative care nursing plans during the different phases of illness, and to predicting care needs, possible management strategies (‘wound management’ vs. ‘wound palliation’), and resource utilization.

**Title:** Transitional palliative care interventions for older adults with advanced non-malignant diseases and frailty: a systematic review.

**Citation:** Journal of Integrated Care; Oct 2020; vol. 28 (no. 4); p. 387-403

**Author(s):** Sezgin; Hendry, Anne; Liew, Aaron; O'Donovan, Mark; Salem, Mohamed; Carriazo, Ana María; López-Samaniego, Luz; Rodríguez-Acuña, Rafael; Kennelly, Siobhan; Illario, Maddalena; Arnal Carda, Cristina; Inzitari, Marco; Hammar, Teija; O'Caoimh, Rónán

**Objective:** To identify transitional palliative care (TPC) interventions for older adults with non-malignant chronic diseases and complex conditions.

**Design/methodology/approach:** A systematic review of the literature was conducted. CINAHL, Cochrane Library, Embase and Pubmed databases were searched for studies reporting TPC interventions for older adults, published between 2002 and 2019. The Crowe Critical Appraisal Tool was used for quality appraisal.

**Findings:** A total of six studies were included. Outcomes related to TPC interventions were grouped into three categories: healthcare system-related outcomes (rehospitalisation, length of stay [LOS] and emergency department [ED] visits), patient-related outcomes and family/carer important outcomes. Overall, TPC interventions were associated with lower readmission rates and LOS, improved quality of life and better decision-making concerning hospice care among families. Outcomes for ED visits were unclear. Research limitations/implications: Positive outcomes related to healthcare services (including readmissions and LOS), patients (quality of life) and families (decision-making) were reported. However, the number of studies supporting the evidence were limited.

**Originality/value:** Studies examining the effectiveness of existing care models to support transitions for those in need of palliative care are limited. This systematic literature review identified
and appraised interventions aimed at improving transitions to palliative care in older adults with advanced non-malignant diseases or frailty.

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**Title:** Hospice Use Among Patients with Cancer: Trends, Barriers, and Future Directions.

**Citation:** JCO oncology practice; Nov 2020; p. OP2000309

**Author(s):** Patel, Mihir N; Nicolla, Jonathan M; Friedman, Fred A P; Ritz, Michala R; Kamal, Arif H

**Abstract:** Patients with advanced cancer and their families frequently encounter clinical and logistical challenges related to end-of-life care. Hospice provides interdisciplinary and holistic care to meet patients' biomedical, psychosocial, and spiritual needs in the last phases of life. Despite increasing general acceptance and use among patients with cancer, hospice remains underused. Underuse stems from ongoing misconceptions regarding hospice and its purpose, coupled with the rapid development of novel anticancer treatments, such as immunotherapies and targeted therapies, that have changed the landscape of possibilities. Furthermore, rapid evolutions in how end-of-life care is structured and reimbursed for will affect how oncology patients will intersect with hospice care. In this review, we explore the current and future challenges to greater integration of hospice care in the care of patients with advanced cancer and propose five recommendations as part of the path forward.

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**Title:** Hospice inpatient services provision, utilization, and financial performance.

**Citation:** Health care management review; Nov 2020

**Author(s):** He, Mengying; O'Connor, Stephen J; Qu, Haiyan; Menachemi, Nir; Shewchuk, Richard M

**Objective:** Hospice performance is an overlooked area in the health care field due to the difficulty of measuring quality of care and the infrequent quality inspection. Based on the daily reimbursement mechanism for different levels of hospice care, inpatient services provision could influence both hospice-level length of stay (LOS) and financial performance. The objective of this study was to explore the relationship between hospice inpatient services provision and hospice utilization and financial performance.

**Methodology/approach:** A longitudinal secondary data set (2009-2013) was merged from three sources: (a) Hospice Cost Reports from the Centers for Medicare & Medicaid Services, (b) the Provider of Services files, and (c) the Area Health Resources Files. The dependent variable in this study was hospice average LOS and financial performance measured by total operating margin (TOM) and return on assets. The independent variable was hospice inpatient services' offering. Mixed-effects regression models were used in the multivariate regression analyses.

**Results:** When comparing to hospices not providing inpatient services, offering inpatient services by staff was negatively related to average LOS (b = -0.063, p < .05) and TOM (b = -0.022, p < .05). The combination method with providing inpatient services by staff and under arrangement was negatively associated with return on assets (b = -0.073, p < .05).

**Conclusion:** Hospice inpatient services provision was associated with average LOS and financial performance.
Practice implications: Offering the inpatient services to patients by staff decreased average LOS and TOM. Hospice agencies may seek strategies to maintain their financial sustainability through outsourcing.

Title: A Model Hospice Inpatient Unit Specializing in Patients Living with Advanced Dementia.

Citation: Journal of palliative medicine; Nov 2020
Author(s): Hamilton, Gillian; Volk-Craft, Barbara E

Objective: This report describes a pilot hospice inpatient unit dedicated to individuals experiencing distressing behaviors from dementia.

Background: Patients with dementia who experience distressing symptoms cannot be well managed on typical inpatient units. Hospice of the Valley selected one unit to dedicate to dementia care.

Methods: Data were analyzed from 237 patients admitted to the unit between May 2019 and April 2020. Behaviors were identified and rated for severity on admission, discharge, and postdischarge. Rates of inpatient death and associated behaviors were calculated.

Results: Fifty percent of patients had their behaviors sufficiently managed to allow discharge. The most common behavior exhibited was agitation; the most common symptom leading to death was pain.

Discussion: An inpatient hospice unit dedicated to patients with dementia can be successful. The hospice agency gains admissions that would otherwise be diverted to behavioral care settings. This successful pilot may be a model for other hospices.

Title: Parental Perceptions of Hospital-Based Bereavement Support Following a Child's Death from Cancer: Room for Improvement.

Citation: Journal of pain and symptom management; Nov 2020
Author(s): Helton, Gabrielle; Morris, Sue E; Dole, Olivia R; Wolfe, Joanne; Snaman, Jennifer M

Objective: The death of a child from cancer is a devastating event, placing bereaved parents at risk for both physical and psychosocial morbidities. Despite growing awareness of these outcomes and increased hospital-based support, bereaved parents continue to express a desire for additional assistance. We examined parental perceptions of bereavement support from the clinical teams and institution and suggested modifications to hospital support strategies.

Methods: We explored the answers to four questions on the bereavement support provided from the care team and institutional mailings from a larger survey, querying parents of children who died from cancer 6 to 24 months prior to participation. Answers were Likert-scale based with additional free text responses.

Results: Forty-nine parents completed the survey (response rate 36%). The respondents were predominantly white (N=43, 88%), female (N=32, 65%), and non-Hispanic/Latino (N=43, 88%). The mean length of time from child's death to completion was 13 months. Twenty-seven (55%) and 26 (53%) parents indicated that contact with care team and mailings, respectively, were at least a little helpful in their grief experience. In free text responses, parents identified support outside the
hospital (28 respondents), groups and events hosted by the hospital or hospice (8), contact with care team (3), and hospital mailings (1) as the most helpful. Findings support modifications to hospital support strategies.

**Conclusions:** Bereaved parents request additional supportive services. Using the parents' perspective and recommendations, we outline options to augment support and provide a variety of supportive resources for bereaved parents to access in their own time.

**Title:** Death and Grieving for Family Caregivers of Loved Ones With Life-Limiting Illnesses in the Era of COVID-19: Considerations for Case Managers.

**Citation:** Professional case management; Nov 2020

**Author(s):** Holland, Diane E; Vanderboom, Catherine E; Dose, Ann Marie; Moore, Derek; Robinson, Kelly V; Wild, Ellen; Stiles, Carole; Ingram, Cory; Mandrekar, Jay; Borah, Bijan; Taylor, Erin; Griffin, Joan M

**Objective:** Family caregivers of a loved one with a life-limiting or terminal illness are often overwhelmed by, and underprepared for, their responsibilities. They often need help from family members and friends to provide comprehensive care. When death occurs, funerals and other death-related rituals bring family and communities together to honor the life and mourn the death of a loved one and provide needed support to family and caregivers. These collective rituals are often deeply rooted in culturally-bound values and can facilitate grief and help make sense about loss. Rituals act as bridge-building activities that allow people to organize and appraise emotions, information, and actions after a loss. With the emergence of the coronavirus disease-2019 (COVID-19) pandemic and the recommended restrictions to reduce infection and transmission, family members and caregivers are often faced with weighing options for honored rituals to help them grieve. Grieving during the pandemic has become disorganized. The purpose of this article is to provide case managers and other clinical staff with recommendations on guiding caregivers/families through safety precautions when a loved one dies either because of a life-limiting illness or from COVID-19 during the pandemic using guidelines from the Centers for Disease Control and Prevention (CDC). The authors also present information about complicated grief and ways to support coping with death and suggest safe alternatives to traditional death-related rituals and funerals in a COVID-19 era.

**Primary practice setting(s):** Primary practice settings include home health care, hospice, hospital discharge planning, case management, and primary care.

**Findings/conclusions:** Precautions necessary in a COVID-19 era may add anxiety and stress to an already difficult situation of caring for loved ones at end-of-life and grieving with their loss. Utilization of CDC guidelines lessens the risk of infection while honoring loved ones' wishes and cultural traditions surrounding death and burial. Recognition of social and spiritual connections that comfort mourners must also be considered.
Title: Perceived Benefits and Burdens of Participation for Caregivers of Cancer Patients in Hospice Clinical Trials: A Pilot Study.

Citation: Journal of pain and symptom management; Nov 2020
Author(s): Oliver, Debra Parker; Benson, Jacquelyn J; Ulrich, Connie; Washington, Karla T; Rolbiecki, Abigail J; White, Patrick; Smith, Jamie B; Lero, Christine; Landon, Olivia J; Demiris, George

Title: Polypharmacy, Medication Possession, and Deprescribing of Potentially Non-Beneficial Drugs in Hospice Patients.

Citation: The American journal of hospice & palliative care; Dec 2020; vol. 37 (no. 12); p. 1076-1085
Author(s): Duncan, Ian; Maxwell, Terri L; Huynh, Nhan; Todd, Marisa

Abstract: Patients frequently have comorbidities that when combined with their primary diagnosis qualifies the patient for hospice. Consequently, patients are at risk for polypharmacy due to the number of medications prescribed to treat both the underlying conditions and the related symptoms. Polypharmacy is associated with negative consequences, including increased risk for adverse drug events, drug-drug and drug-disease interactions, reduced functional status and falls, multiple geriatric syndromes, medication nonadherence, and increased mortality. Polypharmacy also increases the complexity of medication management for caregivers and contributes to the cost of prescription drugs for hospices and patients. Deprescribing or removing nonbeneficial or ineffective medications can reduce polypharmacy in hospice. We study medication possession ratios and rates of deprescribing of commonly prescribed but potentially nonbeneficial classes of medication using a large hospice pharmacy database. Prevalence of some classes of potentially inappropriate medications is high. We report possession ratios for 10 frequently prescribed classes, and, because death and prescription termination are competing events, we calculate prescription termination rates using Cumulative Incidence Functions. Median duration of antifungal and antiviral medications is brief (5 and 7 days, respectively), while statins and diabetes medications have slow discontinuance rates (median termination durations of 93 and 197 days). Almost all patients with a proton pump inhibitor prescription have the drug for their entire hospice stay. Data from this study identify those drug classes that are commonly deprescribed slowly, suggesting drug classes and diagnoses that hospices may wish to focus on more closely, as they act to limit polypharmacy and reduce prescription costs.

Title: Strengths and Struggles for Families Involved in Hospice Care During the COVID-19 Pandemic.

Citation: Journal of social work in end-of-life & palliative care; Nov 2020 ; p. 1-20
Author(s): Gergerich, Erika; Mallonee, Jason; Gherardi, Stacy; Kale-Cheever, Megan; Duga, Frankie

Abstract: The COVID-19 pandemic presented unique health and social challenges for hospice patients, their families, and care providers. This qualitative study explored the impact of the
pandemic on this population through the experiences and perceptions of social workers in hospice care. A survey was distributed through national and local listservs to social work practitioners throughout the United States between May 15 and June 15, 2020. The study was designed to learn the following: (1) Concerns patients experienced as a result of the pandemic, (2) strengths/resilience factors for patients during the COVID-19 pandemic, and (3) the personal and professional impact of the pandemic on social workers. Themes uncovered in hospice care included isolation, barriers to communication, disruption of systems, issues related to grieving, family and community support, adaptation, and perspective. The authors provide recommendations for social work practice related to virtual communication, emergency planning, and evidence-based intervention for Persistent Complex Bereavement Disorder. Recommendations for policy include uniform essential worker status for social workers, telehealth reimbursement and expanded caregiver respite benefits.

**Title:** Impact of Massage Therapy on the Quality of Life of Hospice Patients and Their Caregivers: A Pilot Study.

**Citation:** Journal of palliative care; Nov 2020; p. 825859720975991

**Author(s):** Havyer, Rachel D; Lapid, Maria I; Dockter, Travis J; McCue, Shaylene A; Stelpflug, Amy J; Bigelow, Maureen L; Robsahm, Mary Meg; Elwood, Theresa; Strand, Jacob J; Bauer, Brent A; Cutshall, Susanne M; Sloan, Jeff A; Walton, Monica P; Whitford, Kevin J

**Abstract:** Evidence for massage therapy (MT) in hospice patients remains limited. We conducted a prospective pilot study on MTs impact on quality of life of hospice patients and caregivers. Patient-caregiver dyads were enrolled if patients scored ≥5 on pain, depression, anxiety, or well-being using the revised Edmonton Symptom Assessment System Revised (ESAS-r). The patient received MT weekly for up to 3 massages with assessments completed at baseline, after each massage, and 1 week after the final massage for patients and at baseline and 1 week after final massage for caregivers. A satisfaction survey was completed at study completion. A pro-rated area under the curve (AUC) was utilized to assess the primary endpoints of change in ESAS-r for patient ratings of pain, depression and anxiety as well as the Linear Analogue Self-Assessment (LASA). Median difference scores (end of study value)-(baseline value) for each participant and caregiver were calculated. Of 27 patients and caregivers enrolled, 25 patients received MT. Fifteen patients completed all 3 MT sessions and were given the final symptom assessment and satisfaction survey and their caregivers completed final assessments. The proportion of patients considered success (AUC > baseline) in the primary endpoints were the following: pain 40.9%, depression 40.9%, anxiety 54.5%, LASA 54.5%. Median difference scores were largely zero indicating no significant temporal change in symptoms. Patients were highly satisfied with MT. This pilot study indicated that MT was a feasible and well-received intervention in our population of patients with inadequately controlled symptoms.

**Title:** Open communication between caregivers' and terminally ill cancer patients about illness and death: The role of gender - A correlational study.

**Citation:** European journal of oncology nursing : the official journal of European Oncology Nursing Society; Dec 2020; vol. 49; p. 101828

**Author(s):** Carmel, Sara; Singer, Yoram; Yosef-Sela, Nili; Bachner, Yaacov G
Objective: Caregivers face severe difficulties in communicating openly with their terminally ill relatives about illness and death. Some studies suggest that females are more likely than males to hold such conversations. We compared level of open communication between male and female spouse-caregivers, and the contribution of personal and situational characteristics to the explanation of open communication level within each gender group.

Methods: The study design was correlational. We interviewed 77 spousal-primary caregivers of terminal cancer patients. Participants were recruited over a 10-month period from the home hospice unit of the central region of Israel's largest Health Maintenance Organization. The questionnaire included measures of open communication, along with caregiver's personal and situational characteristics.

Results: Female spouses reported higher levels of open communication about illness and death with their loved ones, compared to male spouses. Among males, duration of care and self-efficacy emerged as significant contributors to open communication level. Among females, self-efficacy and ethnic origin were found to be significant explanatory variables.

Conclusions: This study demonstrates the important role gender plays in level of open communication between spousal caregivers and terminal cancer patients, concerning their illness and approaching death. Self-efficacy, ethnic origin and duration of care are also significant factors explaining open communication of both male and female caregivers. These factors should be considered by nurses and other healthcare professionals when developing intervention programs to increase the level of open communication between family caregivers and their terminally ill relatives.

Title: Rehabilitation for Cancer Patients in Inpatient Hospices/Palliative Care Units and Achievement of a Good Death: Analyses of Combined Data From Nationwide Surveys Among Bereaved Family Members.

Citation: Journal of pain and symptom management; Dec 2020; vol. 60 (no. 6); p. 1163-1169

Author(s): Hasegawa, Takaaki; Sekine, Ryuichi; Akechi, Tatsuo; Osaga, Satoshi; Tsuji, Tetsuya; Okuyama, Toru; Sakurai, Haruka; Masukawa, Kento; Aoyama, Maho; Morita, Tatsuya; Kizawa, Yoshiyuki; Tsuneto, Satoru; Shima, Yasuo; Miyashita, Mitsunori

Objective: In end-of-life care, rehabilitation for patients with cancer is considered to be an important means for improving patients' quality of death and dying. This study aims to determine whether the provision of rehabilitation for patients with cancer in palliative care units is associated with the achievement of a good death.

Methods: This study involved a cross-sectional, anonymous, and self-report questionnaire survey of families of patients with cancer who died in palliative care units in Japan. We evaluated the short version of Good Death Inventory (GDI) on a seven-point scale. A logistic regression model was used to calculate the propensity score. Covariates included in this model were survey year, patients' characteristics, and families' characteristics. The associations between rehabilitation and GDI were tested using trend tests after propensity score matching adjustment.

Results: Of the 1965 family caregivers who received the questionnaires, available data were obtained from 1008 respondents (51.2%). Among them, 285 (28.2%) cases received rehabilitation in palliative care units. There was no difference in total GDI score between the groups with and without rehabilitation. In exploratory analyses, patients receiving rehabilitation were significantly more likely to feel maintaining hope and pleasure (mean 4.50 [SE 0.10] vs. 4.05 [0.11], respectively; effect size [ES] 0.31; P = 0.003), good relationships with medical staff (mean 5.67 [SE...
Conclusion: Rehabilitation in palliative care units may contribute to several domains of quality of death and dying, particularly maintaining hope and pleasure. Further research is needed to investigate whether palliative rehabilitation contributes to the achievement of a good death.

Title: Chaplaincy Care in the MICU: Describing the Spiritual Care Provided to MICU Patients and Families at the End of Life.

Citation: The American journal of hospice & palliative care; Dec 2020; vol. 37 (no. 12); p. 1037-1044

Author(s): Labuschagne, Dirk; Torke, Alexia; Grossoehme, Daniel; Rimer, Katie; Rucker, Martha; Schenk, Kristen; Slaven, James; Fitchett, George

Objective: Gravely ill patients admitted to the intensive care unit (ICU), and their families experience acute spiritual and existential needs and often require complex decisions about their care. Little is known about what constitutes chaplaincy care for patients or families in ICUs. Chaplains report that participation in medical decision-making is part of their role. This study aims to describe the spiritual care provided to patients and their families in the ICU.

Methods: This was a retrospective observational study of spiritual care for patients and families in the medical ICUs (MICUs) at 4 medical centers over a 3-month period. Inclusion criteria were death in the MICU or discharge to palliative care or hospice. Measures included medical, treatment, and spiritual care information (number of visits, length of visit, chaplain categories, and type of spiritual care provided).

Results: Of the 254 patients, 197 (78%) received a total of 485 spiritual care visits. Seventy-seven percent of visits included provision of emotional/spiritual support; only 15% included decision-making support such as family meetings or goals-of-care conversations. The proportion receiving spiritual care increased as patients neared death or discharge. Staff chaplains were involved in goals-of-care conversations to a greater extent than student or part-time chaplains (P < .05).

Conclusion: Spiritual care was provided to most patients and/or families at the end of life. Low chaplain involvement in decision-making in the MICU suggests opportunities to improve chaplains’ contributions to ICU care.

Title: Perceptions of optimal end-of-life care in hospitals: A cross-sectional study of nurses in three locations

Citation: Journal of Advanced Nursing; Nov 2020; vol. 76 (no. 11); p. 3014

Author(s): Waller, Amy; Chan, Sally; Chan, Carmen W H; Chow, Meyrick C M; Kim, Miyoung; Sook Jung Kang; Oldmeadow, Christopher; Robert Sanson-Fisher

Objective: To examine whether nurses' location of employment, demographics, or training influences their perceptions of what constitutes optimal care for dying patients in hospital.

Design: Questionnaire-based, cross-sectional study.

Methods: Between December 2016–June 2018, 582 registered or enrolled nurses from Australia (N = 153), South Korea (N = 241), and Hong Kong (N = 188) employed in a variety of hospital care
units rated the extent to which they agreed with 29 indicators of optimal end-of-life care across four domains: patient, family, healthcare team, and healthcare system. Latent class analysis identified classes of respondents with similar responses.

**Results:** Top five indicators rated by participants included: ‘physical symptoms managed well’; ‘private rooms and unlimited visiting hours’; ‘spend as much time with the patient as families wish’; ‘end-of-life care documents stored well and easily accessed’ and ‘families know and follow patient's wishes’. Four latent classes were generated: ‘Whole system/holistic’ (Class 1); ‘Patient/provider-dominated’ (Class 2); ‘Family-dominated’ (Class 3) and ‘System-dominated’ (Class 4). Class 1 had the highest proportion of nurses responding positively for all indicators. Location was an important correlate of perceptions, even after controlling for individual characteristics.

**Conclusion:** Nurses' perceptions of optimal end-of-life care are associated with location, but perhaps not in the direction that stereotypes would suggest. Findings highlight the importance of developing and implementing location-specific approaches to optimize end-of-life care in hospitals.

**Impact:** The findings may be useful to guide education and policy initiatives in Asian and Western countries that stress that end-of-life care is more than symptom management. Indicators can be used to collect data that help quantify differences between optimal care and the care actually being delivered, thereby determining where improvements might be made.

**Title:** Experiencing improved assessment and control of pain in end-of-life care when using the Abbey Pain Scale systematically

**Citation:** Nursing Open; Nov 2020; vol. 7 (no. 6); p. 1798

**Author(s):** Ludvigsson, Carola; Isaksson, Ulf; Hajdarevic, Senada

**Objective:** To describe staff's reflections on aspects influencing pain assessment at end-of-life (EoL) care in nursing homes before and after the implementation of the Abbey Pain Scale (APS).

**Background:** People with cognitive impairment in the EoL care often suffer from underdiagnosed and undertreated pain due to the lack of knowledge and guidelines for systematic pain assessment.

**Methods:** Semi-structured focus group interviews were conducted and analysed using qualitative content analysis.

**Results:** The staff described their experiences before the implementation of APS as striving to achieve control of pain by trusting in themselves and the team, while the experiences after the implementation of APS were described as improving symptom control with remaining weak confidence in the team.

**Conclusions/Implementation of APS was experienced as improving systematic pain assessment. Efforts to establish clear routines and improve confidence in the care team would be prioritized to optimize pain assessment and pain relief in EoL care.

**The Effect of Positive and Negative Poster Messages on Organ Donor Registration.**

**Citation:** Transplantation proceedings; Dec 2020; vol. 52 (no. 10); p. 2899-2900

**Author(s):** Green, Madeline; Byrne, Matthew H V; Legard, Chloe; Chen, Eileen; Critchley, Anna; Stainer, Benjamin; Chaggar, Harpreet; Symington, Matthew; Hu, Lisi; Brathwaite-Shirley, Charlotte; Mayes, Jonathan; Mogg, Jasper A W; Murphy, Juliette; Saeb-Parsy, Kourosh
**Objective:** There is a mismatch between the number of people who require transplants and the number of organ donors. Promotional materials have been shown to increase rates of organ donor registration. This study assessed the impact on the intention to join the organ donor registry of a gain-framed message about lives saved through organ donation compared to a loss-framed message about lives lost waiting for a transplant.

**Methods:** Two posters were designed that were identical other than the slogan. One slogan was gain-framed: "One organ donor can save 9 lives!" and the other loss-framed: "3 people die every day in the UK waiting for an organ transplant." Twenty copies of each were distributed between hospitals in Cambridge and Newcastle, UK, for 20 weeks. After 10 weeks, the gain-framed and loss-framed posters swapped locations. Each poster had a QR code that linked to the online organ donor register sign-up form, and the click-through rate was used to determine registration. Analysis was performed using a 2-tailed sign binomial test.

**Results:** Sixty-eight registrations occurred over a 20-week period. Overall, there was no significant difference in registrations between gain- and loss-framed posters (37 vs 31, \( P = .54 \)). However, poster location influenced registration, as prior to the location swap there was a significant difference in gain-framed vs loss-framed posters (28 vs 10, \( P = .005 \)). Additionally, registration was significantly higher in Cambridge vs Newcastle (47 vs 21, \( P = .01 \)).

**Conclusions:** Posters can increase organ donor register (ODR) registration independent of gain- or loss-framing. However, poster location, both intra- and inter-hospital, significantly influences effectiveness.

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**Title:** Renal transplantation during the SARS-CoV-2 pandemic in the UK: experience from a large volume centre.

**Citation:** Clinical transplantation; Nov 2020 ; p. e14150

**Author(s):** Georgiades, Fanourios; Summers, Dominic M; Butler, Andrew J; Russell, Neil K I; Clatworthy, Menna R; Torpey, Nicholas

**Abstract:** There is uncertainty about the safety of kidney transplantation during the SARS-CoV-2 pandemic due to the risk of donor transmission, nosocomial infection and immunosuppression use. We describe organ donation and transplant practice in the UK and assess whether kidney transplantation conferred a substantial risk of harm. Data from the UK transplant registry were used to describe kidney donation and transplant activity in the UK, and a detailed analysis of short-term, single-centre, patient results in two periods: during the pre-pandemic era from 30th December 2019 to 8th March 2020 ("Pre-COVID era") and the 9th March 2020 to 19th May 2020 ("COVID era"). Donor and recipient numbers fell by more than half in the COVID compared to the pre-COVID era in the UK, but there were more kidney transplants performed in our centre (42 vs 29 COVID vs pre-COVID respectively). Overall outcomes, including re-operation, delayed graft function, primary non function, acute rejection, length of stay and graft survival were similar between COVID and pre-COVID era. 6/71 patients became infected with SARS-CoV-2 but all were discharged without critical care requirement. Transplant outcomes have remained similar within the COVID period and no serious sequelae of SARS-CoV-2 infection were observed in the peri-transplant period.
Title: Antibiotic use during end-of-life care: A systematic literature review and meta-analysis.

Citation: Infection control and hospital epidemiology; Nov 2020 ; p. 1-7

Author(s): Marra, Alexandre R; Puig-Asensio, Mireia; Balkenende, Erin; Livorsi, Daniel J; Goto, Michihiko; Perencevich, Eli N

Objective: We performed a systematic literature review and meta-analysis measuring the burden of antibiotic use during end-of-life (EOL) care.

Methods: We searched PubMed, CINAHL (EBSCO platform), and Embase (Elsevier platform), through July 2019 for studies with the following inclusion criteria in the initial analysis: antibiotic use in the EOL care patients (advanced dementia, cancer, organ failure, frailty or multi-morbidity). If the number of patients in palliative care consultation (PCC) was available, antibiotic use data were pooled to compare the proportion of patients who received antibiotics under PCC compared to those not receiving PCC. Random-effect models were used to obtain pooled mean differences, and heterogeneity was assessed using the I2 value.

Results: Overall, 72 studies met the inclusion criteria and were included in the final review: 22 EOL studies included only patients with cancer; 17 studies included only patients with advanced dementia; and 33 studies included "mixed populations" of EOL patients. Although few studies reported antibiotic using standard metrics (eg, days of therapy), 48 of 72 studies (66.7%) reported antibiotic use in >50% of all patients. When the 3 studies that evaluated antibiotic use in PCC were pooled together, patients under PCC was more likely to receive antibiotics compared to patients not under PCC (pooled odds ratio, 1.73; 95% CI, 1.02-2.93).

Conclusions: Future studies are needed to evaluate the benefits and harms of using antibiotics for patients during EOL care in diverse patient populations.

Title: Timing of GP end-of-life recognition in people aged ≥75 years: retrospective cohort study using data from primary healthcare records in England.

Citation: The British journal of general practice : the journal of the Royal College of General Practitioners; Nov 2020

Author(s): Stow, Daniel; Matthews, Fiona E; Hanratty, Barbara

Objective: High-quality, personalised palliative care should be available to all, but timely recognition of end of life may be a barrier to end-of-life care for older people. This study aims to investigate the timing of end-of-life recognition, palliative registration, and the recording of end-of-life preferences in primary care for people aged ≥75 years.

Design and setting: Retrospective cohort study using national primary care record data, covering 34% of GP practices in England.

Method: ResearchOne data from electronic healthcare records (EHRs) of people aged ≥75 years who died in England between 1 January 2015 and 1 January 2016 were examined. Clinical codes relating to end-of-life recognition, palliative registration, and end-of-life preferences were extracted, and the number of months that elapsed between the code being entered and death taking place were calculated. The timing for each outcome and proportion of relevant EHRs were reported.
Results: Death was recorded for a total of 13,149 people in ResearchOne data during the 1-year study window. Of those, 6,303 (47.9%) records contained codes suggesting end of life had been recognised at a point in time prior to the month of death. Recognition occurred ≥12 months before death in 2,248 (17.1%) records. In total, 1,659 (12.6%) people were on the palliative care register and 457 (3.5%) were on the register for ≥12 months before death; 2,987 (22.7%) records had a code for the patient’s preferred place of care, and 1,713 (13.0%) had a code for the preferred place of death. Where preferences for place of death were recorded, a care, nursing, or residential home (n = 813, 47.5%) and the individual’s home (n = 752, 43.9%) were the most common.

CONCLUSION: End-of-life recognition in primary care appears to occur near to death and for only a minority of people aged ≥75 years. The findings suggest that older people’s deaths may not be anticipated by health professionals, compromising equitable access to palliative care.

Title: Sikh religion and palliative care.

Source: BMJ supportive & palliative care; Nov 2020

Author(s): Landa, Amarjodh Singh; Grewal, Bhajneek Kaur; Singh, Rajinder

Abstract: Over time, end of life care has been heavily influenced by the systems of religion, ethics and spirituality. The Sikh religion was started by Guru Nanak Dev Ji in 1469. It has a unique philosophical understanding of life, death and God which can be relevant to commonly encountered clinical scenarios. Concepts such as ‘Ik-Onkar’, Hukam (God’s will), ego and karma all influence how practising Sikhs respond to situations in everyday life. Understanding the spiritual underpinnings of the Sikh religion is therefore important for clinicians caring for this group of patients. This article will explore the fundamental concepts of the Sikh religion and how these apply to common scenarios encountered within palliative care.


Citation: The American journal of hospice & palliative care; Nov 2020; vol. 37 (no. 11); p. 992-997

Author(s): Ritchey, Katherine C; Foy, Alice; McArdel, Erin; Gruenewald, David A

Abstract: Telemedicine technology has become essential to healthcare delivery in the COVID-19 era, but concerns remain regarding whether the intimacy and communication that is central to high-quality palliative care will be compromised by the use of this technology. We employed a business model approach to identify the need for system innovation in palliative care, and a quality improvement approach to structure the project. Products from this project included a standard operating procedure for safe use of tablet computers for inpatient palliative care consultations and family visitations; tablet procurement with installation of video telehealth software; and training and education for clinical staff and other stakeholders. We describe a case illustrating the successful use of palliative care telehealth in the care of a COVID-19-positive patient at the end of life. Successful use of video telehealth for palliative care involved overcoming inertia to the development of telehealth infrastructure and learning clinical video telehealth skills; and engaging front-line care staff and family members who were open to a trial of telehealth for communication. Information gleaned from family about the patient as a person helped bedside staff to tailor care toward aspects meaningful to the patient and family and informed best practices to incorporate intimacy into future palliative video consultations and family visit.
Title: Experiences of Palliative and End-of-Life Care among Older LGBTQ Women: A Review of Current Literature.

Citation: Journal of palliative medicine; Nov 2020; vol. 23 (no. 11); p. 1532-1539
Author(s): Valenti, Korijna G; Jen, Sarah; Parajuli, Jyotsana; Arbo gast, Annabelle; Jacobsen, Anna Liss; Kunkel, Suzanne

Background: Understanding end-of-life (EOL) and palliative care continues to grow. However, little attention has been paid to the experiences, preferences, and needs of older lesbian, gay, bisexual, transgender, and queer (LGBTQ) women. While some universal expectations or preferences at EOL exist, this population may not receive adequate or appropriate attention or reporting of unique EOL issues and experiences.

Objective: Systematically search for and narratively review existing evidence concerning the expectations, preferences, and needs for palliative and EOL care of LGBTQ older women.

Design: A comprehensive literature review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. Articles reporting needs, experiences, and perspectives of palliative care and EOL care among LGBTQ older women were evaluated.

Measurements: Articles published between 1996 and 2019 were retrieved from PsycINFO, MEDLINE, Cochrane Library, Academic Search Complete, AgeLine, CINHAL, PubMed, LGBT Life, SocINDEX, Women's Studies International, Joanna Briggs Institute, and Open Grey. Results: A total of 16 articles were included. Articles described several concerns for the overall LGBTQ population; however, additional issues and experiences specific to older LGBTQ women were also identified, including vulnerability associated with isolation and poverty, women's social needs and support networks, and preferences for complementary care.

Conclusion: There remains a need for further research with older LGBTQ women concerning palliative and EOL care, particularly around preparation for EOL and preferences for support. Inclusion of diverse populations in terms of sexual and gender identification are needed to fully understand how to provide appropriate and preferred support.

Title: Do family meetings for hospitalised palliative care patients improve outcomes and reduce health care costs? A cluster randomised trial.

Citation: Palliative medicine; Oct 2020 ; p. 269216320967282
Author(s): Hudson, Peter; Girgis, Afaf; Thomas, Kristina; Philip, Jennifer; Currow, David C; Mitchell, Geoffrey; Parker, Deborah; Liew, Danny; Brand, Caroline; Le, Brian; Moran, Juli

Objective: Family meetings facilitate the exploration of issues and goals of care however, there has been minimal research to determine the benefits and cost implications. This study aims to determine: (1) if family caregivers of hospitalised patients referred to palliative care who receive a structured family meeting report lower psychological distress (primary outcome), fewer unmet needs, improved quality of life; feel more prepared for the caregiving role; and receive better quality of end-of-life care; (2) if outcomes vary dependant upon site of care and; (3) the cost-benefit of implementing meetings into routine practice.
**Design:** Pragmatic cluster randomised trial involving palliative care patients and their primary family caregivers at three Australian hospitals. Participants completed measures upon admission (Time 1); 10 days later (Time 2) and two months after the patient died (Time 3). Regression analyses, health utilisation and process evaluation were conducted. RESULTS 297 dyads recruited; control (n = 153) and intervention (n = 144). The intervention group demonstrated significantly lower psychological distress (Diff: -1.68, p < 0.01) and higher preparedness (Diff: 3.48, p = 0.001) at Time 2. No differences were identified based on quality of end of life care or health utilisation measures.

**Conclusions:** Family meetings may be helpful in reducing family caregiver distress and enhancing their preparedness for the caregiving role and it appears they may be conducted without increased hospital health utilisation impacts; although opportunity costs need to be considered in order to routinely offer these as a standardised intervention. Additional health economic examination is also advocated to comprehensively understand the cost-benefit implications.

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**Title:** Innovative End-of-Life Simulation: Educating Nursing Students to Care for Patients During Transition.

**Citation:** Clinical Simulation in Nursing; Nov 2020; vol. 48; p. 68-74

**Author(s):** Jablonski; McGuigan, Jan; Miller, Carrie Westmoreland

**Abstract:** Historically, nursing students have not been adequately prepared to provide end-of-life (EOL) care. The faculty of a university in the northwest recognized the curriculum was deficient in EOL content. In response to this deficit, the simulation team developed an evidenced-based EOL simulation in accordance to INASCL Standards of Best Practice℠. The End-of-Life Nursing Education Consortium undergraduate curriculum includes six modules presenting content considered essential to prepare students for EOL care. Students complete the modules in preparation for the simulation. The simulation begins with prebriefing and orientation to the simulation space. Immediately after the simulation, students participate in a debriefing session to process their thoughts and feelings about the experience. Students submit a reflection after they have had time to further explore the impact of the simulation, both personally and professionally. Student reflections indicated an increase in knowledge of their role in EOL care and the importance of creating a calm environment for the patient and family. Participants reported the profound impact of the simulation and the opportunity to experience emotions evoked by the simulation in a safe setting. Students reported both the presence of a “family member” and performing postmortem care contributed to the reality of the simulation. Based on the reflections and feedback received from students after they experience the death of a patient for the first time as a nurse, the simulation played a significant part in preparing them for EOL care. • Simulation is a pedagogy used to educate nursing students about end-of-life care. • The ELNEC Undergraduate Curriculum effectively prepares students for simulation. • Presence of a family member and postmortem care add to reality of the simulation. • Debriefing and reflection help process emotions evoked by the simulation.

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**Title:** End of life care for long-term neurological conditions: A meta-ethnographic review of the experiences of informal carers.

**Citation:** Palliative medicine; Nov 2020; p. 269216320974262

**Author(s):** Toze, Michael; Ray, Mo; George, Thomas; Sisson, Kelly; Nelson, David
**Objective:** Family and friends are key providers of care for people living with a long-term neurological condition. Neurological conditions are a significant global contributor to disability and premature death. However, previous research suggests carers often struggle to access appropriate support at end of life. This review sought to synthesise qualitative studies discussing end-of-life and palliative issues for informal carers supporting people living with neurological conditions.

**Design:** This was a meta-ethnographic synthesis of 38 qualitative studies discussing end-of-life and palliative issues for informal carers supporting people living with long-term neurological conditions.

**Data sources:** Qualitative articles published after January 2010 in English, addressing carers of people with long-term neurological conditions with regard to palliative care, end of life and/or bereavement. Papers were excluded if it was not possible to separately assess the views of carers. Quality appraisal was not undertaken, but consideration was given to research context.

**Results:** Across the papers, five key themes were identified: the future (un)certainties in the progression of life-limiting neurological conditions; an information paradox of not receiving the right information at the right time; access to support; carers' roles in decision making around end of life; and maintaining continuity while facing change and disruption in day-to-day living.

**Conclusions:** Given the broad agreement on the challenges faced by carers of people living with long-term neurological conditions, future research should consider opportunities to improve information and support for this group, and the development and evaluation of practical models of service delivery.

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**Title:** End-of-life conversation from both sides of the bed: voices of family and staff.

**Citation:** Disability and rehabilitation; Nov 2020 ; p. 1-10

**Author(s):** Gilad, Dvorit; Goldblatt, Hadass; Zeilig, Gabi

**Objective:** Prolonged living with chronic illness and disability expands the discussion of end-of-life conversation because of the complex role of intercommunication among patient, family, and healthcare staff. Little is known about such interaction from participants' different perspectives. This qualitative case study examined end-of-life conversation among patient, family, and staff during long-term hospitalization in a neurological rehabilitation department.

**Methods:** After the patient's death, 18 participants responded to in-depth semi-structured interviews: 16 healthcare staff and two family members (the patient's wife and brother). In addition, we used the wife's autoethnographic documentation of her experiences during end-of-life conversation.

**Results:** Thematic analysis produced three themes: (1) The Rehabilitation Department's Mission - Toward Life or Death? (2) The Staff's Perception of the Patient; (3) Containing Death: End-of-life Conversation from Both Sides of the Bed. These themes represented participants' different perspectives in the intercommunication in overt and covert dialogues, which changed over time. Death's presence-absence was expressed by movement between clinging to life and anticipating death.

**Conclusion:** The study findings emphasize the importance of practitioners' training to accept and openly discuss death as an inseparable part of life-long disability, and the implementation of this stance during end-of-life care via sensitive conversations with patients and their families.
**Implications for rehabilitation:** It is vital for rehabilitation professionals to be trained to process and accept end-of-life issues as a natural and inseparable part of the life discourse among people with disabilities and their families. Rehabilitation professionals need to acquire tools to grasp the spoken and unspoken issues related to life and death, and to communicate their impressions and understandings with people with disabilities and their families. Rehabilitation professionals need to encourage an open dialogue when communicating with people with disabilities and their families on processes related to parting and death.

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**Title:** Effectiveness and sustainability of deprescribing for hospitalised older patients near end of life: a systematic review.

**Citation:** Expert opinion on drug safety; Nov 2020

**Author(s):** Cardona, Magnolia; Stehlik, Paulina; Fawzy, Peter; Byambasuren, Oyungerel; Anderson, Jarrah; Clark, Justin; Sun, Shelley; Scott, Ian

**Objective:** Polypharmacy is prevalent in hospitals and deprescribing strategies for older people are strongly promoted. However, evidence of their feasibility and sustainability among patients receiving end of life care is lacking. The objective of this review was to ascertain effectiveness and post-discharge sustainability of hospital-initiated deprescribing strategies in older people near the end of life.

**Areas covered:** The authors searched for controlled trials, with low risk of bias and measures of effectiveness post-discharge. Intervention description, duration and healthcare provider engagement were investigated for their impact on reduction of number of medications, proportions of patients prescribed inappropriate medications, returns to emergency, hospital admission and adverse events.

**Expert opinion:** Limited evidence suggests hospital-initiated deprescribing interventions may reduce prescribing inappropriateness among older terminal patients in the short term, but evidence beyond 3 months is lacking for significant prevention of adverse events or health service utilisation. Heterogeneity precluded meta-analysis, and short follow-up periods precluded quantitative assessment of sustainability. Trials of older people with terminal conditions with larger sample sizes and longer follow-up periods are needed to confirm the effectiveness and sustainability of deprescribing at the end of life. Objective tools to reliably identify near end-of-life status would be useful in selecting target groups for these interventions.

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**Title:** The experience of uncertainty for patients, families and healthcare providers in post-stroke palliative and end-of-life care: a qualitative meta-synthesis.

**Citation:** Age and ageing; Nov 2020

**Author(s):** Connolly, Teresa; Coats, Heather; DeSanto, Kristen; Jones, Jacqueline

**Objective:** Recent data show that there is limited evidence and guidance regarding the best practices for the integration of palliative care (PC) and end-of-life (EOL) post-stroke. The purpose of this meta-synthesis is to understand the PC/EOL experiences after a stroke.

**Methods:** A meta-synthesis was conducted to answer the following research question-What are post-stroke PC/EOL experiences from the perspectives of patients, families and healthcare professionals?
professionals (HCPs)? This approach was completed through two main phases—a systematic search and appraisal of the literature and reciprocal translation with interpretive triangulation of the extracted data. Databases searched were MEDLINE, EMBASE, PsycINFO, Joanna Briggs Institute and CINAHL databases (from their inception to April 2020). After data were extracted, a qualitative exploratory design was used to evaluate the PC/EOL in post-stroke experiences.

Results: the search identified 696 studies. A total of 14 studies were included in this meta-synthesis as they satisfied our eligibility criteria. Uncertainty post-stroke was the overarching main theme that emerged across post-stroke PC/EOL experiences. Within this theme of uncertainty, opportunities to decrease uncertainty emerged from two interdependent themes—presence of cohesive communication and shared dynamic decision process for both families and HCPs.

Conclusions: to mitigate the degree of uncertainty post-stroke, HCPs should be present, provide clear direct communication and incorporate the value-based goals of care within their medical treatment plan. These findings suggest that future research is needed to focus on how PC approaches can be integrated into stroke care programmes.

Title: Taking care of dying patients through an 'interprofessional ecosystem': a grounded theory study on the experience of an interprofessional team in palliative care.

Citation: Scandinavian journal of caring sciences; Nov 2020

Author(s): Taffurelli, Chiara; Barello, Serena; Cervantes Camacho, Vittoria; Bertuol, Maria; Savarese, Mariarosaria; Artioli, Giovanna

Objective: The interprofessional approach is part of the philosophy in palliative care, and its benefits are already documented. However, there are no evidence regarding the process through which the interprofessional team faces the process of the patient's end-of-life and how this experience might be of value for the team's development itself. The aim of this study was to analyse and understand the psychosocial processes that occurs when an interprofessional team accompanies patients and their families to death in palliative care, with the ultimate aim to develop a substantive theory to describe this phenomenon.

Methods: A Grounded Theory method, as theorized by Strauss and Corbin, was adopted for this study. Data were collected through semi-structured interviews and then independently analysed using constant comparison analysis. Fourteen healthcare professionals—belonging to different disciplines (doctor, nurse coordinator, nurse, nurse assistant, psychologist)—were interviewed in a Northern Italy palliative care facility.

Findings: The core category of this study was identified to be the process of accompaniment of the dying patient as an interprofessional ecosystem. Moreover, the results showed four main factors determining the development of the core psychosocial process: from professionals’ 'Hidden Amazement' to 'Onerous Happiness' where 'Weaving of Professional Resources' and 'Work Meaning' are the underlying conditions to catalyse the process itself.

Conclusion: Interprofessional care appears an essential value, which becomes the source of the team's strength when facing end-of-life experiences. Health policies and organisations should take the importance of the characteristics of the work environment more carefully. The meaning that professionals attribute to their work and to the team itself, indeed, it may have impact on the overall quality of care and contribute to sustain work engagement, even in stressful situations like end-of-life care.
Title: The geriatrician's role in end-of-life care.

Citation: Age and ageing; Dec 2020
Author(s): Ahmed, Nisar; Ahmedzai, Sam H; Harwood, Rowan H

Abstract: Healthcare aims to help older people to live well, but ultimately must also support them to die well. Most people die in old age, but predicting death in both short- and long-term is impossible for many, although not all, older people. Frail older people live with hope and pride in coping, and often anticipate recovery when ill. Key objectives of healthcare for older people are to maintain independence, minimise suffering and preserve dignity, which requires active medical, mental health and rehabilitation management, even when extending life is not the main goal. Thorough medical diagnosis and appropriate treatment and rehabilitation minimise disability, physical and mental distress and problems resulting from acute illness and crises. In these terms, 'health gain' can be achieved from medical intervention, even when life expectancy is short. Assumptions derived from cancer care about lack of reversibility with medical interventions are sometimes unwarranted. This has to be balanced against investigation- and treatment-burden, including that associated with hospital admission and the adverse effects of drugs and therapy interventions, and the need to respect the identity and autonomy of individuals. The resolution of these tensions requires anticipation of care options, multi-professional assessment, judicious and targeted treatment, good communication with patients and stakeholders and rigorous shared decision-making. In this commentary, we compare geriatric and palliative medicine, and describe how the geriatric medical approach can deliver appropriate healthcare towards the end of life. This is well supported by the broad knowledge, skill-set, flexibility and professional values displayed by geriatricians working in multi-professional teams.

Title: Engaging persons with dementia in advance care planning: Challenges and opportunities.

Citation: Dementia (London, England); Dec 2020 ; p. 1471301220973059
Author(s): Sussman, Tamara; Pimienta, Rebecca; Hayward, April

Abstract: This study reports findings from a series of focus groups with persons with dementia and family caregivers intended to explore: (1) perceptions of and experiences with advance care planning (ACP); (2) concerns related to future care including, but not limited to, end-of-life care; and (3) practices that may support positive engagement with ACP. A total of 18 participants including 10 persons with dementia and eight family caregivers participated in five focus groups held in two urban cities in Canada. All focus group deliberations were audio recorded, transcribed verbatim, and analyzed in five stages using a semantic thematic approach. All participants expressed some form of engagement in ACP, but understandings were limited and divergence was expressed regarding the timing of more expansive conversations about future care. Although some persons with dementia were ready to engage in future care discussions, most preferred focusing on the present and suggested their families did not require direction. This placed families in the complex dilemma of protecting their loved ones while compromising their own needs for dialogue. Although individually focused models of ACP engagement hold promise for those persons with dementia ready to engage in future planning, our findings suggest that early engagement of families in the reflective process may go a long way in supporting ACP activation.
Our findings further suggest that persons with dementia who do not have close family/friends may require extensive ACP encouragement and support from service providers.

Title: The Impact of Obesity in End of Life Care in Patients with End Stage Liver Disease: An Observational Study.

Citation: The American journal of hospice & palliative care; Dec 2020 ; p. 1049909120978768
Author(s): Subramoney, Kavitha; Orman, Eric; Johnson, Amy W; Kara, Areeba

Background: Both obesity and end stage liver disease (ESLD) are increasing. Obesity's impact on hospice and palliative care in patients with ESLD is unknown.

Methods: We retrospectively evaluated patients admitted to an academic, Midwestern, tertiary center between January 2016 and May 2019 with a diagnosis of ESLD. Body Mass Index and MELD Na were calculated for each patient's first admission during the study period. Patients with MELD Na scores ≥ 21 or 18-20 with additional criteria were considered potentially eligible for hospice and palliative care referrals.

Results: Of 3863 patients admitted with ESLD, 1556 (40%) were potentially eligible for hospice and palliative care referrals. Of these, 703 (45%) were obese. Comorbidity burden was higher in obese patients (15.6% of obese patients had a Charlson Comorbidity Index ≥ 5, while 5% of non-obese patients had a comorbidity index of ≥ 5 (p < 0.001). Referral rates to hospice and palliative services in obese patients were 10.1% and 16.4% respectively. Hospice and palliative referral rates among non-obese patients were similar (10.1% and 15.5%). Among patients who died within 6 months of the first hospitalization, the mean time to referral to hospice or palliative care from index admission was longer in obese patients.

Conclusion: Obesity is common in patients hospitalized with ESLD who may be approaching the end of life. Referral rates to hospice and palliative care services are low and similar regardless of BMI and despite higher co-morbidity burdens in obese patients. Obesity may delay referrals to hospice and palliative care.

Title: Rehabilitation for Cancer Patients in Inpatient Hospices/Palliative Care Units and Achievement of a Good Death: Analyses of Combined Data from Nationwide Surveys Among Bereaved Family Members.

Citation: Journal of pain and symptom management; Dec 2020; vol. 60 (no. 6); p. 1163-1169
Author(s): Hasegawa, Takaaki; Sekine, Ryuichi; Akechi, Tatsu; Osaga, Satoshi; Tsuji, Tetsuya; Okuyama, Toru; Sakurai, Haruka; Masukawa, Kento; Aoyama, Maho; Morita, Tatsuya; Kizawa, Yoshiyuki; Tsuneto, Satoru; Shima, Yasuo; Miyashita, Mitsunori

Objective: In end-of-life care, rehabilitation for patients with cancer is considered to be an important means for improving patients' quality of death and dying. This study aims to determine whether the provision of rehabilitation for patients with cancer in palliative care units is associated with the achievement of a good death.

Methods: This study involved a cross-sectional, anonymous, and self-report questionnaire survey of families of patients with cancer who died in palliative care units in Japan. We evaluated the short version of Good Death Inventory (GDI) on a seven-point scale. A logistic regression model was
used to calculate the propensity score. Covariates included in this model were survey year, patients' characteristics, and families' characteristics. The associations between rehabilitation and GDI were tested using trend tests after propensity score matching adjustment.

**Results:** Of the 1965 family caregivers who received the questionnaires, available data were obtained from 1008 respondents (51.2%). Among them, 285 (28.2%) cases received rehabilitation in palliative care units. There was no difference in total GDI score between the groups with and without rehabilitation. In exploratory analyses, patients receiving rehabilitation were significantly more likely to feel maintaining hope and pleasure (mean 4.50 [SE 0.10] vs. 4.05 [0.11], respectively; effect size [ES] 0.31; P = 0.003), good relationships with medical staff (mean 5.67 [SE 0.07] vs. 5.43 [0.09], respectively; ES 0.22; P = 0.035), and being respected as an individual (mean 6.08 [SE 0.06] vs. 5.90 [0.07], respectively; ES 0.19; P = 0.049) compared with patients not receiving rehabilitation.

**Conclusion:** Rehabilitation in palliative care units may contribute to several domains of quality of death and dying, particularly maintaining hope and pleasure. Further research is needed to investigate whether palliative rehabilitation contributes to the achievement of a good death.

**Sources Used**

The following databases are searched on a regular basis in the development of this bulletin:

British Nursing Index, Cinahl, Medline along with a number of other sources

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