End of Life Care
Current Awareness Bulletin
July 2020

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Title: ENVISION: A Tool to Improve Communication in Hospice Interdisciplinary Team Meetings

Citation: Journal of Gerontological Nursing; Jul 2020; vol. 46 (no. 7); p. 9

Author(s): Washington, Karla T; Demiris, George; Debra Parker Oliver; Uba Backonja; Norfleet, Meredith; Han, Claire J; Popescu, Mihail

Abstract: Hospice interdisciplinary teams (IDTs) are required to meet regularly to update care plans for terminally ill patients and their family caregivers. Although providers see value in these meetings, they also experience frustration over meeting inefficiencies and communication challenges. The current article presents ENVISION, a tool designed to improve communication in hospice IDT meetings by providing attendees with access to up-to-date patient and family data to inform clinical decision making. In the current qualitative descriptive study, researchers explored the perspectives of hospice providers (n = 21) and family caregivers (n = 10) regarding ENVISION's usefulness and ease of use. Numerous factors influenced participants' perceptions of the tool as useful, including its impact on task efficiency, effectiveness, and difficulty. Perceptions of ENVISION's ease of use focused on ease of learning, operating, and interpreting data the tool provided. Findings suggest ENVISION would benefit hospice nurses in care management and senior leadership positions. [Journal of Gerontological Nursing, 46(7), 9–14.]

Title: Employing newly qualified nurses to work in hospices: A qualitative interview study

Citation: Journal of Advanced Nursing; Jul 2020; vol. 76 (no. 7); p. 1717

Author(s): Rolt, Lucy; Gillett, Karen

Aim: To establish an understanding of the experiences of newly qualified nurses’ working in hospices from the perspective of both newly qualified and senior nurses.

Methods: Semi-structured interviews with six newly qualified nurses and five senior nurses from four UK hospices were conducted between March – July 2017.

Results: The hospices involved in this study were among the first to recruit newly qualified nurses. Participants believed that newly qualified nurses coped well with hospice working and received unique opportunities for professional development. Participants identified the value of formal and informal support, however, newly qualified nurses faced negative attitudes from some established staff. Newly qualified nurses expressed concerns about a perceived lack of technical clinical skills training, however, they highlighted gaining end-of-life care and communication skills that would be transferrable to other settings. Participants highlighted the need to allocate more time for education and formal support including preceptorship. Senior staff did not necessarily expect newly qualified nurses to remain in long-term hospice employment suggesting that they could disseminate their hospice learning to future workplaces.

Conclusion: This study supports recruitment strategies that increasingly target newly qualified nurses to work in hospices with findings suggesting that hospices can be a suitable environment for recent graduates to work in. The senior nurses in this study viewed the employment of newly qualified nurses in a positive light but shared the concerns of newly qualified nurses regarding skills training.

Impact: At a time when hospices need to expand if they are going to meet demand for their services, they along with most areas of healthcare face difficulties recruiting and retaining registered nurses. To increase the appeal of hospice employment, recruitment campaigns
aimed at newly qualified nurses should emphasize the transferability of skills gained in hospice settings.

Title: An Environmental Scan of Caregiver Support Resources Provided by Hospice Organizations

Citation: Journal of Palliative Care; Jul 2020; vol. 35 (no. 3); p. 135
Author(s): Gyapay Julia; Freeman, Shannon; Flood, Donna

Background: Informal caregiver support programs offered by hospice organizations support the health and wellbeing of clients and caregivers. However, an understanding of the best practices for informal caregiver support programs currently undertaken across Canada remains unknown, particularly across the province of British Columbia.

Aim: The aim of the present study was to describe what existing resources and supports are provided by hospice organizations for informal caregivers of persons who are nearing end of life or who are recently bereaved in British Columbia, Canada.

Methods: In this descriptive study, two thirds of hospice organizations (N = 42/66; 26 urban, 16 rural) participated in a semi-structured telephone interview focused on informal caregiver support programs. All interviews were recorded, transcribed and analyzed thematically and descriptive statistics were employed.

Findings: While no one-size-fit-all caregiver support program emerged as a gold standard across all hospice organizations, nearly two thirds (n = 26/42) offered one or more informal caregiver support programs. Four categories of caregiver support programs emerged from the data analysis, including companioning, bereavement and grief supports, education and service supports, and respite for caregivers.

Conclusion: Caregiver support programs are a valuable service provided by some but not all hospice organizations across British Columbia, Canada. Future studies are needed to determine best methods for hospice organizations to formally assess caregivers’ needs and to determine the success and effectiveness of such programs in support of program expansion and evaluation.

Title: Nursing competencies across different levels of palliative care provision: A systematic integrative review with thematic synthesis

Citation: Palliative Medicine; Jul 2020; vol. 34 (no. 7); p. 851
Author(s): Hökkä Minna; Martins Pereira Sandra; Pölkki Tarja; Kyngäs Helvi; Hernández-Marrero, Pablo

Background: Palliative care exists in diverse healthcare settings. Nurses play a crucial role in its provision. Different levels of palliative care provision and education have been recognized in the literature. Therefore, nurses need a set of various competencies to provide high-quality palliative care.

Aims: To systematically synthesize the empirical evidence of (1) nursing competencies needed in palliative care and (2) whether these competencies differ across the level of palliative care.

Design: Systematic integrative review with thematic synthesis.

Prospero: CRD42018114869.
Data sources: CINAHL, PubMed, Academic Search Premier, Scopus and Medic databases. Studies on nursing competencies linked to palliative care reported in English, Swedish, Finnish, Spanish, Portuguese or German were considered. Search terms: ‘palliative care or hospice care or end-of-life care’, ‘competency or professional competence or skills’ and ‘nursing’. Articles were independently screened and reviewed by two researchers. Quality appraisal was conducted following Hawker’s criteria.

Results: A total of 7454 articles were retrieved, 21 articles were included in the analysis. Six diverse nursing competencies dimensions, namely leadership, communication, collaboration, clinical, ethico-legal and psycho-social and spiritual were identified. The reports rarely defined the level of palliative care and covered a wide array of healthcare settings.

Conclusion: Nurses need a wide range of competencies to provide quality palliative care. Few studies focused on which competencies are relevant to a specific level of palliative care. Further research is needed to systematize the nursing competencies and define which nursing competencies are central for different levels of palliative care to enhance palliative care development, education and practice.

Title: Managing uncertainty and references to time in prognostic conversations with family members at the end of life: A conversation analytic study

Citation: Palliative Medicine; Jul 2020; vol. 34 (no. 7); p. 896

Author(s): Anderson, Rebecca J; Stone, Patrick C; Low, Joseph T, S; Bloch, Steven

Background: When patients are likely to die in the coming hours or days, families often want prognostic information. Prognostic uncertainty and a lack of end-of-life communication training make these conversations challenging.

Aim: The objective of this study is to understand how clinicians and the relatives/friends of patients at the very end of life manage uncertainty and reference time in prognostic conversations.

Design: Conversation analysis of audio-recorded conversations between clinicians and the relatives/friends of hospice inpatients.

Setting/participants: Experienced palliative care clinicians and relatives/friends of imminently dying hospice inpatients. Twenty-three recorded conversations involved prognostic talk and were included in the analysis.

Results: Requests for prognostic information were initiated by families in the majority of conversations. Clinicians responded using categorical time references such as ‘days’, allowing the provision of prognostic estimates without giving a precise time. Explicit terms such as ‘dying’ were rare during prognostic discussions. Instead, references to time were understood as relating to prognosis. Relatives displayed their awareness of prognostic uncertainty when requesting prognostic information, providing clinicians with ‘permission’ to be uncertain. In response, clinicians often stated their uncertainty explicitly, but presented evidence for their prognostic estimates, based on changes to the patient’s function previously discussed with the family.

Conclusion: Prognostic uncertainty was managed collaboratively by clinicians and families. Clinicians were able to provide prognostic estimates while being honest about the related uncertainty, in part because relatives displayed their awareness of uncertainty within their requests. The conversation analytic method identified contributions of both clinicians and families, and identified strategies based on real interactions, which could inform communication training.
Title: Advance care planning for patients with cancer in palliative care: A scoping review from a professional perspective

Citation: Journal of Clinical Nursing; Jul 2020; vol. 29 (no. 13-14); p. 2069
Author(s): Kuusisto, Anne; Santavirta, Jenni; Saranto, Kajja; Korhonen, Päivi; Haavisto, Elina

Aims and Objectives: To describe advance care planning (ACP) for patients with cancer in palliative care from professionals' perspective.

Background: The number of patients with cancer is increasing. Palliative care should be based on timely ACP so that patients receive the care they prefer.

Design: A scoping review.

Methods: A systematic literature search was conducted in January 2019. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist was used. The methodological quality of the studies was evaluated using the Joanna Briggs Institute (JBI) Critical Appraisal tools. Data were analysed with content analysis.

Results: Of 739 studies identified, 12 were eligible for inclusion. The settings were inpatient and outpatient facilities in special and primary care including oncology, palliative and hospice care. ACP consisted of patient-oriented issues, current and future treatment, and end-of-life matters. The participants were nursing, medical or social professionals. ACP conversations rarely occurred; if they did, they took place at the onset, throughout and late in the cancer.

Conclusions: Professionals could not separate day-to-day care planning and ACP. ACP documentation was scattered and difficult to find and use. Professionals were unfamiliar with ACP, and established practices were lacking. ACP conversations mostly occurred in late cancer. Further research clarifying concepts and exploring the significance of ACP for patients and relatives is recommended.

Relevance to clinical practice: Our results support the use of ACP by a multidisciplinary team from the early stages of cancer as a discussion forum around patients' wishes and choices. We showed the need to raise professionals' awareness of ACP. Education and appropriate data tools for ACP are important as they may reduce reluctance and promote ACP use. This paper contributes to the wider global clinical community by pointing out the importance of standardising ACP contents and practices.

Title: What factors predict the confidence of palliative care delivery in long-term care staff? A mixed-methods study

Citation: International Journal of Older People Nursing; Jun 2020; vol. 15 (no. 2)
Author(s): Frey, Rosemary; Balmer, Deborah; Robinson, Jackie; Boyd, Michal; Gott, Merryn

Background Research: has indicated that clinical staff in long-term care often lack self-confidence in palliative care delivery, particularly at the end of life.

Goals: (a) To examine the contribution of age, palliative care education, palliative care work-related experience and psychological empowerment to palliative care delivery confidence and (b) to explore the social reality shaping those factors for long-term care staff.

Design: Explanatory sequential design.

Setting: Twenty long-term care facilities in two district health boards in New Zealand.
**Participants:** Phase 1: 139 clinical staff. Phase 2: 46 clinical staff who provided care in the last month of a residents' life.

**Methods:** Phase 1: Cross-sectional survey. Phase 2: Individual semi-structured interviews.

**Results:** Phase 1: Previous experience ($\beta = .319$) and psychological empowerment ($\beta = .311$) contribute most to predicting an increase in palliative care delivery confidence. Phase 2: Four factors underlay palliative care delivery confidence, (a) mentorship by hospice nurses or colleagues (b) contextual factors (organisational culture, resources and experience), (c) maturity and (d) formal education.

**Conclusion:** Organisational leadership should use multiple strategies (e.g. power-sharing, increased opportunities for mentorship) to improve staff palliative care delivery confidence.

**Implications for Practice:** This study adds to the literature in understanding the predictors of palliative care delivery confidence specific to long-term care staff. The results indicate that educational interventions must be contextually appropriate to achieve sustainable improvements in palliative care confidence and ultimately in resident care at the end of life.

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**Title:** Managing delirium in terminally ill patients: perspective of palliative care nurse specialists.

**Citation:** British Journal of Community Nursing; Jul 2020; vol. 25 (no. 7); p. 346-351

**Author(s):** Harris; Spiller, Juliet; Finucane, Anne

**Abstract:** Delirium occurs frequently at end of life. Palliative care clinical nurse specialists (CNSs) are involved in community palliative care provision. Many patients prefer being cared for at home, yet managing delirium in this setting presents unique challenges, potentially resulting in emergency hospital or hospice admission. We examined the experiences and practice of palliative care CNSs managing delirium in the community; 10 interviews were undertaken. Data were analysed using the framework approach. Challenges to delirium management in the community included limited time with patients, reliance on families and access to medications. Assessment tools were not used routinely; time limited visits and inconsistent retesting were perceived barriers. Management approaches differed depending on CNSs' previous delirium education. Strategies to prevent delirium were not used. Community delirium management presents challenges; support surrounding these could be beneficial. Routine assessment tool use and delirium prevention strategies should be included in further education and research.

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**Title:** Health Care Worker Perceptions of Gaps and Opportunities to Improve Hospital-to-Hospice Transitions.

**Citation:** Journal of Palliative Medicine; Jul 2020; vol. 23 (no. 7); p. 900-906

**Author(s):** Izumi; Noble, Brie N.; Candrian, Carey B.; Tija, Jennifer; Bordley, Jessica; Mensik, Jennifer; Furuno, Jon P.

**Background:** Care transitions from the hospital to hospice are a difficult time, and gaps during this transitions could cause poor care experiences and outcomes. However, little is known about what gaps exist in the hospital-to-hospice transition.

**Objectives:** To understand the process of hospital-to-hospice transition and identify common gaps in the transition that result in unsafe or poor patient and family caregiver experiences.
Design: We conducted a qualitative descriptive study using semi-structured interviews with health care workers who are directly involved in hospital-to-hospice transitions. Participants were asked to describe the common practice of discharging patients to hospice or admitting patients from a hospital, and share their observations about hospital-to-hospice transition gaps.

Setting/Subjects: Fifteen health care workers from three hospitals and three hospice programs in Portland, Oregon.

Measurements: All interviews were audio recorded and analyzed using qualitative descriptive methods to describe current practices and identify gaps in hospital-to-hospice transitions.

Results: Three areas of gaps in hospital-to-hospice transitions were identified: (1) low literacy about hospice care; (2) changes in medications; and (3) hand-off information related to daily care. Specific concerns included hospital providers giving inaccurate descriptions of hospice; discharge orders not including comfort medications for the transition and inadequate prescriptions to manage medications at home; and lack of information about daily care hindering smooth transition and continuity of care.

Conclusion: Our findings identify gaps and suggest opportunities to improve hospital-to-hospice transitions that will serve as the basis for future interventions to design safe and high-quality hospital-to-hospice care transitions.

Title: "Difficult patients" in the advanced stages of cancer as experienced by nursing staff: A descriptive qualitative study.

Citation: European Journal of Oncology Nursing; Jun 2020; vol. 46
Author(s): Dobrina; Chialchia, Sara; Palese, Alvisa

Abstract: "Difficult patients", as labelled by staff members, have been studied for their peculiarities in primary care, family and internal medicine, physiotherapy, psychiatry, dermatology, and dentistry. However, no data has been documented on "difficult patients" in hospice care settings. The aim of the study was to address the following research questions: (a) When do nursing staff label a patient suffering from advanced cancer as "difficult" in a hospice care setting? (b) What are the problems that the nursing staff face in dealing with them, and (c) What are the specific strategies that nursing staff adopt in their daily practice to overcome issues and improve their relationship with "difficult patients"? A qualitative descriptive study design was performed in 2018 and reported according to the COnsolidated criteria for REporting Qualitative research. Three focus groups were conducted in three hospice settings in Northern Italy by involving 10 nurses and six nurses' aides. Three trained researchers performed interviews based on a set of open questions. Qualitative content analysis of the data collected was then performed by the same researchers. Participants were labelled "difficult patients" according to three main themes: (1) "Feeling rejected"; (2) "Feeling uncomfortable with the life story experienced by the patient" and (3) "Experiencing the limits of the profession". Participants reported feeling "Frustrated", "Exhausted", "Powerless", "Overwhelmed" or "Embarrassed" when dealing with "difficult patients". Strategies to overcome these issues emerged. As in other settings, hospice care nursing staff perceive some patients as "difficult". However, differently from other contexts, "difficult patients" are perceived as such also due to their relatives, who are perceived, in some cases, as being even more "difficult" than the patients themselves. Nursing staff should be aware of their personal attitudes and emotions in caring for patients perceived as "difficult" in order to identify and timely apply strategies to overcome issues that may compromise the therapeutic relationship and quality of care. • As in other settings, hospice care nurses perceive some patients and family members as "difficult". • Nurses experience frustration,
powerlessness and embarrassment when dealing with perceived "difficult" patients and families. • Identified strategies to overcome barriers in caring for perceived "difficult" families are education in communication skills on end-of-life decision-making, and on different end-of-life trajectories including a positive reframing of emotional challenges. • Education and support are needed for hospice nursing team to deal with moral distress when facing patients suffering with refractory symptoms, when patients are refusing treatments, when there are family conflicts and when the intimacy line is being crossed.

**Title:** Nurses' experiences of providing "sensitive nursing care" for terminally-ill individuals with cancer: A qualitative study.

**Citation:** European Journal of Oncology Nursing; Jun 2020; vol. 46

**Author(s):** Kwon ; Kim, Miyoung; Choi, Sujin

**Abstract:** To explore the sensitive nursing care provided by nurses who care for terminally-ill individuals with cancer. In-depth interviews were conducted using Colaizzi's phenomenological approach. Participants were 16 hospice specialists and four non-specialist nurses with experience in caring for terminal cancer patients in hospice specialized institutions in South Korea. Eight theme clusters were drawn from the data and these clusters had two dimensions consisting of sensitive attitudes and sensitive nursing behaviors. The sensitive attitudes included reflecting on past experiences, developing an accepting attitude toward death, using intuition to address critical situations, and having an open mind regarding collaborating with colleagues. The sensitive nursing behaviors contained listening to patients' needs, responding to patients in a manner suitable to their conditions, quickly responding to patients' problem, and providing a moment saying farewell. Teamwork and role models can help hospice specialists and non-specialist nurses caring for terminally-ill individuals with cancer to improve the sensitive nursing care. The sensitive attitudes and behaviors can be used as basic data for training programs designed to enhance nurses' sensitivity. • Sensitivity is a fundamental characteristic of the care nurses provide for terminally-ill individuals with cancer. • The sensitive attitudes and behaviours of the nurses are formed through accumulated experience of sensitive nursing care. • Teamwork and role models can help the nurses to enhance the level of sensitive nursing care.

**Title:** Palliative Care and Interventional Radiology Interface to Improve Patient Outcomes.

**Citation:** Journal of Radiology Nursing; Jun 2020; vol. 39 (no. 2); p. 103-105

**Author(s):** Barner ; Hromadik, Lora K.

**Abstract:** Interventional procedures benefit palliative care team patients in a variety of different ways, providing a means to manage a wide array of debilitating symptoms. The interprofessional collaboration of palliative care and interventional radiology is imperative for the successful management of chronically ill patients in their homes. This article briefly defines the roles of the palliative care team and that of interventional radiology in patient symptom management, providing a better understanding of the differences and the interface of these disciplines in the complex symptom management of palliative patients. • A team approach to symptom management in chronically ill patients improves outcomes. • Interventional radiology procedures benefit patients choosing palliative care. • A wide variety
of interventional radiology procedures can be used to provide care for the palliative and hospice patients.

**Title:** Effectiveness of home hospice care: a nationwide prospective observational study.

**Citation:** Supportive Care in Cancer; Jun 2020; vol. 28 (no. 6); p. 2713-2719

**Author(s):** Ahn; Song, In Gyu; Choi, Jin Young; Jho, Hyun Jung; Park, Ilyeon; Sung, Suah; Shin, Seohyun; Park, So Jung; Nam, Eun Jung; Jeong, Sung Hoon; Chang, Yoon Jung

**Purpose:** Many assert the need for home hospice care. However, limited research has shown its effectiveness. The authors of this study thus evaluated the effectiveness of a home hospice care pilot project regarding (1) early enrollment in hospice care, (2) efficient use of inpatient hospice resources, and (3) enabling terminally ill patients to stay at their preferred place of care.

**Methods:** The authors conducted a nationwide prospective observational study. Patients were divided into home hospice care users (ever-users, n = 902) and inpatient-only hospice care users (never-users, n = 8210). Information about hospice service utilization was collected from a web-based registry system. Patients were registered if they started to receive the hospice service after providing written informed consent during the pilot project from March 2016-July 2017.

**Results:** Most ever-users preferred to stay at home (84.0%), while never-users preferred hospital admission (66.9%). Most ever-users were enrolled in hospice by home care (78.9%) and used both home and inpatient care (72.4%). The overall duration of hospice care was significantly longer among ever-users than never-users (median 39 vs. 15 days, respectively; mean ± SD 59.6 ± 62.8 vs. 24.8 ± 32.1, respectively; p < .001). Participation in the pilot program improved bed utilization (p = .025) and turnover rate (p < .001) of inpatient hospice service.

**Conclusions:** Home hospice care enabled early enrollment in hospice services and provided a valid option to patients who wished to stay at home. Policy efforts to facilitate home hospice care are needed.

**Title:** Evaluating the Outcomes of an Organizational Initiative to Expand End-of-Life Resources in Intensive Care Units With Palliative Support Tools and Floating Hospice.

**Citation:** Dimensions of Critical Care Nursing; Jul 2020; vol. 39 (no. 4); p. 219-235

**Author(s):** McAndrew

**Background:** There is evidence that palliative care and floating (inpatient) hospice can improve end-of-life experiences for patients and their families in the intensive care unit (ICU). However, both palliative care and hospice remain underutilized in the ICU setting.

**Objectives:** This study examined palliative consultations and floating hospice referrals for ICU patients during a phased launch of floating hospice, 2 palliative order sets, and general education to support implementation of palliative care guidelines.

**Methods:** This descriptive, retrospective study was conducted at a level I trauma and academic medical center. Electronic medical records of 400 ICU patients who died in the hospital were randomly selected. These electronic medical records were reviewed to determine if patients received a palliative consult and/or a floating hospice referral, as well
as whether the new palliative support tools were used during the course of care. The numbers of floating hospice referrals and palliative consults were measured over time.

**Results:** Although not significant, palliative consults increased over time (P = .055). After the initial introduction of floating hospice, 27% of the patients received referrals; however, referrals did not significantly increase over time (P = .807). Of the 68 patients who received a floating hospice referral (24%), only 38 were discharged to floating hospice. There was a trend toward earlier palliative care consults, although this was not statistically significant (P = .285).

**Conclusion:** This study provided the organization with vital information about their initiative to expand end-of-life resources. Utilization and timing of palliative consults and floating hospice referrals were lower and later than expected, highlighting the importance of developing purposeful strategies beyond education to address ICU cultural and structural barriers.

**Title:** Outcomes Associated With a Nurse-Driven Palliative Care Screening Tool in the Intensive Care Unit.

**Citation:** Critical Care Nurse; Jun 2020; vol. 40 (no. 3); p. 23-29

**Author(s):** Martz; Alderden, Jenny; Bassett, Rick; Swick, Dawn

**Background:** Access to specialty palliative care delivery in the intensive care unit is inconsistent across institutions. The intensive care unit at the study institution uses a screening tool to identify patients likely to benefit from specialty palliative care, yet little is known about outcomes associated with the use of screening tools.

**Objective:** To identify outcomes associated with specialty palliative care referral among patients with critical illness.

**Methods:** Records of 112 patients with positive results on palliative care screening were retrospectively reviewed to compare outcomes between patients who received a specialty palliative care consult and those who did not. Primary outcome measures were length of stay, discharge disposition, and escalation of care.

**Results:** Sixty-five patients (58%) did not receive a palliative care consult. No significant differences were found in length of hospital or intensive care unit stay. Most patients who experienced mechanical ventilation did not receive a palliative care consultation (χ² = 5.14, P = .02). Patients who were discharged to home were also less likely to receive a consult (χ² = 4.1, P = .04), whereas patients who were discharged to hospice were more likely to receive a consult (χ² = 19.39, P < .001).

**Conclusions:** Unmet needs exist for specialty palliative care. Understanding the methods of identifying patients for specialty palliative care and providing them with such care is critically important. Future research is needed to elucidate the factors providers use in their decisions to order or defer specialty palliative care consultation.

**Title:** Experiences of Lesbian, Gay, Bisexual, and Transgender Patients and Families in Hospice and Palliative Care: Perspectives of the Palliative Care Team.

**Citation:** Journal of Palliative Medicine; Jun 2020; vol. 23 (no. 6); p. 817-824

**Author(s):** Stein; Berkman, Cathy; O'Mahony, Sean; Godfrey, David; Javier, Noelle Marie; Maingi, Shail
**Background:** Lesbian, gay, bisexual, and transgender (LGBT) patients fear being open about their identities, not receiving equal or safe treatment, and having their family and surrogates disrespected or ignored by providers.

**Objective:** To examine inadequate, disrespectful, and abusive care to patients and family due to sexual orientation or gender identity.

**Design:** A cross-sectional study using an online survey. Setting/Subjects: Home and residential hospice, inpatient palliative care service, and other inpatient and outpatient settings. Subjects were 865 hospice and palliative care providers, including physicians, social workers, nurses, and chaplains.

**Measurements:** Inadequate, disrespectful, or abusive care to LGBT patients and discriminatory treatment of family and surrogates were measured.

**Results:** Among respondents, 53.6% thought that lesbian, gay, or bisexual (LGB) patients were more likely than non-LGB patients to experience discrimination at their institution; 23.7% observed discriminatory care; 64.3% reported that transgender patients were more likely than nontransgender patients to experience discrimination; 21.3% observed discrimination to transgender patients; 15% observed the spouse/partner of LGBT patients having their treatment decisions disregarded or minimized; and 14.3% observed the spouse/partner or surrogate being treated disrespectfully.

**Conclusions:** These findings provide strong evidence that LGBT patients and their families are more likely to receive discriminatory care as compared with those who are not LGBT. Disrespectful care can negatively impact the trust patients have in providers and institutions, and lead to delaying or avoiding care, or not disclosing relevant information. Partners/spouses and surrogates may be treated disrespectfully, have their treatment decisions ignored or minimized, be denied or have limited access to the patient, and be denied private time. Advocacy and staff training should address barriers to delivering respectful and nondiscriminatory care.

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**Title:** Top Ten Tips Palliative Care Clinicians Should Know About Amyotrophic Lateral Sclerosis.

**Citation:** Journal of Palliative Medicine; Jun 2020; vol. 23 (no. 6); p. 842-847

**Author(s):** Everett; Pedowitz, Elizabeth; Maiser, Samuel; Cohen, Joss; Besbris, Jessica; Mehta, Ambereen K.; Chi, Luqi; Jones, Christopher A.

**Abstract:** Amyotrophic lateral sclerosis (ALS) is a rapidly progressive and fatal neurodegenerative disorder with enormous palliative care (PC) needs that begin at the time of diagnosis. Although it is an uncommon disease, clinicians who work in PC or hospice are likely to encounter ALS somewhat frequently given the needs of patients with ALS with regard to psychosocial support, symptom management, advance care planning (ACP), caregiver support, and end-of-life care. As such, PC clinicians should be familiar with the basic principles of ALS symptoms, treatments, disease course, and issues around ACP. This article, written by a team of neurologists and PC physicians, seeks to provide PC clinicians with tips to improve their comfort and skills caring for patients with ALS and their families.

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**Title:** The family physician’s role in palliative care: Views and experiences of patients with cancer.

**Citation:** Progress in Palliative Care; Jun 2020; vol. 28 (no. 3); p. 192-200

**Author(s):** Couchman; Lempp, Heidi; Naismith, Jane; White, Patrick
**Background:** Family physicians (FPs) are a vital component of palliative care, yet little is known about how patients understand their FP's role in palliative care.

**Aims:** This study aimed to explore patients' views and experiences of: 1. The FP's role in providing palliative care to patients with cancer 2. The facilitators and barriers to the FP's ability to fulfil this perceived role.

**Methods:** Qualitative semi-structured interviews, with adults with a cancer diagnosis known to an inner-city hospice in England, were undertaken. Thematic and discourse analysis were applied.

**Results:** Fifteen participants reported their perceptions of the FP's role in palliative care: prescription management; home visits; care coordination; and emotional support. Observed facilitators and barriers to good FP palliative care were identified: accessibility to FP; continuity of care; FP's attitude and interpersonal skills; time and staffing levels; FP's involvement in diagnosis; and communication between primary and secondary care.

**Conclusion:** Accessibility and continuity were highlighted as key challenges within FP palliative care. The broadening responsibilities and competitive pressures facing FPs may undermine their capacity to effectively deliver palliative care. Further research is required to determine optimal models of FP palliative care provision.

**Title:** Systematic symptom and problem assessment at admission to the palliative care ward – perspectives and prognostic impacts.

**Citation:** BMC Palliative Care; May 2020; vol. 19 (no. 1); p. 1-11

**Author(s):** Coym; Ullrich, Anneke; Hackspiel, Lisa Kathrin; Ahrenholz, Mareike; Bokemeyer, Carsten; Oechsle, Karin

**Background:** Symptom assessment is essential in palliative care, but holds challenges concerning implementation and relevance. This study aims to evaluate patients' main symptoms and problems at admission to a specialist inpatient palliative care (SIPC) ward using physician proxy- and patient self-assessment, and aims to identify their prognostic impact as well as the agreement between both assessments.

**Methods:** Within 12 h after admission, palliative care specialists completed the Symptom and Problem Checklist of the German Hospice and Palliative Care Evaluation (HOPE-SP-CL). Patients either used the new version of the minimal documentation system for patients in palliative care (MIDOS) or the Integrated Palliative Care Outcome Scale (IPOS) plus the Distress Thermometer (DT).

**Results:** Between 01.01.2016–30.09.2018, 1206 patients were included (HOPE-SP-CL 98%; MIDOS 21%, IPOS 34%, DT 27%) whereof 59% died on the ward. Proxy-assessment showed a mean HOPE-SP-CL Total Score of 24.6 ± 5.9 of 45. Most frequent symptoms/problems of at least moderate intensity were weakness (95%), needs of assistance with activities of daily living (88%), overburdening of family caregivers (83%), and tiredness (75%). Factor analysis identified four symptom clusters (SCs): (1) Deteriorated Physical Condition/Decompensation of Home Care, (2) Emotional Problems, (3) Gastrointestinal Symptoms and (4) Other Symptoms. Self-assessment showed a mean MIDOS Total Score of 11.3 ± 5.3 of 30, a mean IPOS Total Score of 32.0 ± 9.0 of 68, and a mean distress of 6.6 ± 2.5 of 10. Agreement of self- and proxy-assessment was moderate for pain (k = 0.438) and dyspnea (k = 0.503), fair for other physical (k = 0.297 to 0.394) and poor for psychological symptoms (k = 0.101 to 0.202). Multivariate regression analyses for single symptoms and SCs revealed that predictors for dying on the SIPC ward included impaired ECOG performance status, moderate/severe dyspnea, appetite loss, tiredness,
disorientation/confusion, and the SC Deteriorated Physical Condition/Decompensation of Home Care.

**Conclusion:** Admissions to a SIPC ward are mainly caused by problems impairing mobility and autonomy. Results demonstrate that implementation of self- and reliability of proxy- and self-assessment is challenging, especially concerning non-physical symptoms/problems. We identified, specific symptoms and problems that might provide information needed for treatment discussions regarding the medical prognosis.

**Title:** Guidance for Safe and Appropriate Use of Antibiotics in Hospice Using a Collaborative Decision Support Tool.

**Citation:** Journal of hospice and palliative nursing : JHPN : the official journal of the Hospice and Palliative Nurses Association; Jun 2020

**Author(s):** Sinert, Molly; Stammet Schmidt, Michelle M; Lovell, Amanda G; Protus, Bridget McCrate

**Abstract:** Infections often impact care of hospice patients; however, limited guidance exists for end-of-life infection management. Regardless of patient prognosis, appropriate antibiotic use is necessary for maintaining quality of life. Antibiotics may be associated with serious adverse events, posing safety risks to patients that should be factored into the appropriateness determination. Fluoroquinolone antibiotics are prescribed frequently in hospice. There are 8 fluoroquinolone drug safety warnings regarding risk for serious adverse events communicated by the US Food and Drug Administration. A retrospective chart review at a hospice pharmacy services provider identified descendants who used a fluoroquinolone during a 1-month period. Charts were evaluated for the presence of risk factors for serious adverse events, including advanced age (86.0%), orders for multiple QTc prolongation risk medications (51.5%), hypertension (64.1%), and concomitant corticosteroids (22.9%). Findings demonstrate notable risk with the use of at least 1 class of antibiotics in a hospice population. STAMPS is a hospice decision support tool, developed to guide symptom-driven antibiotic use that incorporates safety assessment and individual goals of care into infection management planning. The tool can also serve as a framework for patient-centered communications about appropriate antibiotic use in hospice between providers, patients, and families.

**Title:** Improving Care Experiences for Patients and Caregivers at End of Life: A Systematic Review.

**Citation:** The American journal of hospice & palliative care; Jun 2020 ; p. 1049909120931468

**Author(s):** Quigley, Denise D; McCleskey, Sara G

**Background:** End-of-life care is increasing as the US population ages. Approaches to providing high-quality end-of-life care vary across setting, diseases, and populations. Several data collection tools measure patient and/or caregiver care experiences at end of life and can be used for quality improvement. Previous reviews examined palliative care improvements or available measures but none explicitly on improving care experiences. We reviewed literature on improving patient and/or caregiver end-of-life care experiences.

**Design:** We searched U.S. English-language peer-reviewed and grey literature after 2000 on adult end-of-life care experiences. We followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines for quantitative studies, Enhancing
Transparency in Reporting the Synthesis of Qualitative Research approach for qualitative studies, and Assessment of Multiple Systematic Reviews tool for the literature reviews.

Setting: Palliative and hospice care.

Population: Full-text abstraction of 84 articles, identifying 16 articles.

Measures: Patient and/or caregiver end-of-life care experiences (captured through administrative data or direct report).

Results: Articles examined palliative care experiences across settings; none studied hospice care experiences. Patients and/or caregivers assessed overall care experiences, clinician-staff interactions, provider communication, respect and trust, timeliness of care, spiritual support, caregiver knowledge of care plans, or bereavement support. Efforts aimed at improving end-of-life care experiences are limited and show mixed results.

Conclusions: Literature on improving patient and/or caregiver end-of-life care experiences is emerging and focused on palliative care experiences. Evidence on improving hospice care experiences is lacking. Research on strategies for improving end-of-life care experiences should go beyond overall care experiences to include specific aspects of palliative and hospice care experiences.

Title: Anticipatory prescribing in community end-of-life care in the UK and Ireland during the COVID-19 pandemic: online survey.

Citation: BMJ supportive & palliative care; Jun 2020

Author(s): Antunes, Bárbara; Bowers, Ben; Winterburn, Isaac; Kelly, Michael P; Brodrick, Robert; Pollock, Kristian; Majumder, Megha; Spathis, Anna; Lawrie, Iain; George, Rob; Ryan, Richella; Barclay, Stephen

Background: Anticipatory prescribing (AP) of injectable medications in advance of clinical need is established practice in community end-of-life care. Changes to prescribing guidelines and practice have been reported during the COVID-19 pandemic.

Aims and Objectives: To investigate UK and Ireland clinicians' experiences concerning changes in AP during the COVID-19 pandemic and their recommendations for change.

Methods: Online survey of participants at previous AP national workshops, members of the Association for Palliative Medicine of Great Britain and Ireland and other professional organisations, with snowball sampling.

Results: Two hundred and sixty-one replies were received between 9 and 19 April 2020 from clinicians in community, hospice and hospital settings across all areas of the UK and Ireland. Changes to AP local guidance and practice were reported: route of administration (47%), drugs prescribed (38%), total quantities prescribed (35%), doses and ranges (29%). Concerns over shortages of nurses and doctors to administer subcutaneous injections led 37% to consider drug administration by family or social caregivers, often by buccal, sublingual and transdermal routes. Clinical contact and patient assessment were more often remote via telephone or video (63%). Recommendations for regulatory changes to permit drug repurposing and easier community access were made.

Conclusions: The challenges of the COVID-19 pandemic for UK community palliative care has stimulated rapid innovation in AP. The extent to which these are implemented and their clinical efficacy need further examination.

Title: Live discharge from hospice care: psychosocial challenges and opportunities.

Citation: Social work in health care; Jul 2020 ; p. 1-15
Abstract: Hospice social workers face many challenges in attempts to replicate or supplement the holistic support and unique services hospice provides for individuals discharged alive. This discontinuity in care can impact the types of supports needed by individuals and caregivers, which may or may not be accessible within their community. Patients and families who have access to community-based palliative care programs following a discharge generally tend to navigate the process with fewer challenges. This qualitative study (N = 24) explored both the challenges of the live discharge process and the opportunities within social work practice in the US. Results from this study emphasize the need for a framework to better approach a live discharge to ensure appropriate supports are accessible for all patients and caregivers. Specifically, results highlight both the concrete and psychosocial challenges in live discharges as a result of tension between current eligibility requirements and individual feelings and needs. Social workers also provided suggestions to improve the live discharge process, including attention to communication and preparation. This paper outlines specific challenges of live discharge from hospice, a framework for understanding presented challenges, and implications for policy and practice.

Title: Public Perceptions of Advance Care Planning, Palliative Care, and Hospice: A Scoping Review.

Citation: Journal of palliative medicine; Jul 2020

Author(s): Grant, Marian S; Back, Anthony L; Dettmar, Nicole S

Background: Although access to advance care planning (ACP), palliative care, and hospice has increased, public attitudes may still be barriers to their optimal use.

Purpose: To synthesize empirical research from disparate sources that describes public perceptions of ACP, palliative care, and hospice in ways that could inform public messaging.

Data Sources: Searches of PubMed and other databases were made from January 2011 to January 2020.

Study Selection: Studies reporting survey or interview data with the public that asked specifically about awareness and attitudes toward ACP, palliative care, or hospice were included.

Data Extraction and Synthesis: Two reviewers independently screened citations, read full texts, and performed data abstraction. Twelve studies met inclusion criteria and included >9800 participants. For ACP, 80% to 90% of participants reported awareness, and a similar proportion considered it important, but only 10% to 41% reported having named a proxy or completed a written document. For palliative care, 66% to 71% of participants reported no awareness of palliative care, and those who reported awareness often conflated it with end-of-life care. However, after being prompted with a tested definition, 95% rated palliative care favorably. For hospice, 86% of participants reported awareness and 70% to 91% rated it favorably, although 37% held significant misconceptions.

Limitations: A limited number of studies met inclusion criteria, and some were published in nonpeer reviewed sources. The studies reflect public perceptions pre-COVID-19.

Conclusion: Consumer perceptions of ACP, palliative care, and hospice each have a distinct profile of awareness, perceptions of importance, and reports of action taking, and these profiles represent three different challenges for public messaging.
Follow-Ups with callers of a palliative and hospice care hotline for severely affected multiple sclerosis patients: Evaluation of its impact.

Citation: Multiple sclerosis and related disorders; Jul 2020; vol. 42 ; p. 102079
Author(s): Strupp, Julia; Groebe, Bernadette; Voltz, Raymond; Golla, Heidrun

Background: Palliative and Hospice Care (PHC) focuses on improving quality of life for anyone who has a serious illness. Multiple Sclerosis (MS) patients have significant PHC needs, yet PHC still mostly attends to cancer patients. The implemented and evaluated nationwide PHC-MS hotline (Strupp et al., 2017) appeared to provide a useful service to patients.

Objectives: Prospective follow-up study to evaluate the impact of the hotline and analyse challenges and possible barriers to integrating PHC services.

Methods: Information on implementing PHC services was gathered through follow-up hotline consultations utilising a standardised documentary sheet. Data was analysed descriptively and several individual cases are presented.

Results: Of 303 calls to the hotline (54.5% female, mean age 51 years, 87.7% chronic progressive MS, mean duration of illness 17 years, median EDSS 8), for 84 (27.7%) PHC services were indicated. Of these 84 patients, 32 agreed to follow-up calls which were conducted at least once. For 6 (19%) patients, PHC service integration was successful. For 5 (16%) PHC was refused. For 5 (16%) PHC did not fit current patient needs, and for 7 (22%) PHC has not yet been contacted by patients (or caregivers). For a further 9 (28%) follow-ups revealed that no more consultation was possible (e.g., caller lost to follow-up).

Conclusion: The PHC approach and its services as well as legislation are still highly focused on cancer care, although patients with long-term neurological conditions would likely benefit greatly from them.

The Role and Response of Palliative Care and Hospice Services in Epidemics and Pandemics: A Rapid Review to Inform Practice During the COVID-19 Pandemic.

Citation: Journal of pain and symptom management; Jul 2020; vol. 60 (no. 1); p. e31
Author(s): Etkind, Simon N; Bone, Anna E; Lovell, Natasha; Cripps, Rachel L; Harding, Richard; Higginson, Irene J; Sleeman, Katherine E

Abstract: Cases of coronavirus disease 2019 (COVID-19) are escalating rapidly across the globe, with the mortality risk being especially high among those with existing illness and multimorbidity. This study aimed to synthesize evidence for the role and response of palliative care and hospice teams to viral epidemics/pandemics and inform the COVID-19 pandemic response. We conducted a rapid systematic review according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines in five databases. Of 3094 articles identified, 10 were included in this narrative synthesis. Included studies were from West Africa, Taiwan, Hong Kong, Singapore, the U.S., and Italy. All had an observational design. Findings were synthesized using a previously proposed framework according to systems (policies, training and protocols, communication and coordination, and data), staff (deployment, skill mix, and resilience), space (community provision and use of technology), and stuff (medicines and equipment as well as personal protective equipment). We conclude that hospice and palliative services have an essential role in the response to COVID-19 by responding rapidly and flexibly; ensuring protocols for symptom management are available, and training nonspecialists in their use; being involved in triage; considering shifting resources into the community; considering redeploying volunteers to provide
psychosocial and bereavement care; facilitating camaraderie among staff and adopting measures to deal with stress; using technology to communicate with patients and carers; and adopting standardized data collection systems to inform operational changes and improve care.

Title: A Pilot Study Evaluating the Effectiveness of a Training Module Designed to Improve Hospice Palliative Care Volunteers' Ability to Deal With Unusual End-of-Life Phenomena.

Citation: Omega; Jun 2020 ; p. 30222820935222
Author(s): Claxton-Oldfield, Stephen; Hicks, Robert; Claxton-Oldfield, Jane

Abstract: The need for training to help healthcare professionals and hospice palliative care volunteers deal with unusual experiences at or around the end of a person's life is an oft-repeated theme in the scientific literature. A pilot study was conducted to examine the effectiveness of a training module designed to improve volunteers' ability to recognize, understand, and respond to unusual end-of-life phenomena (EOLP) in their work with dying patients and their families. Twenty-four volunteers from two community-based hospice palliative care programs completed the 25-item Coping with Unusual End-of-Life Experiences Scale (CUEES) prior to and immediately after attending a lecture and PowerPoint training module. A series of paired samples t tests revealed significant pre- and post-training differences on 14 items, suggesting that volunteers felt more knowledgeable about EOLP, better prepared to deal with EOLP, and more comfortable talking about EOLP with others following the training. The need for additional data is discussed.

Title: Managing delirium in terminally ill patients: perspective of palliative care nurse specialists.

Citation: British journal of community nursing; Jul 2020; vol. 25 (no. 7); p. 346-352
Author(s): Harris, Clare; Spiller, Juliet; Finucane, Anne

Abstract: Delirium occurs frequently at end of life. Palliative care clinical nurse specialists (CNSs) are involved in community palliative care provision. Many patients prefer being cared for at home, yet managing delirium in this setting presents unique challenges, potentially resulting in emergency hospital or hospice admission. We examined the experiences and practice of palliative care CNSs managing delirium in the community; 10 interviews were undertaken. Data were analysed using the framework approach. Challenges to delirium management in the community included limited time with patients, reliance on families and access to medications. Assessment tools were not used routinely; time limited visits and inconsistent retesting were perceived barriers. Management approaches differed depending on CNSs' previous delirium education. Strategies to prevent delirium were not used. Community delirium management presents challenges; support surrounding these could be beneficial. Routine assessment tool use and delirium prevention strategies should be included in further education and research.

Title: Hypernatremia at admission predicts poor survival in patients with terminal cancer: a retrospective cohort study.

Citation: BMC palliative care; Jul 2020; vol. 19 (no. 1); p. 94
Background: Although palliative care providers, patients, and their families rely heavily on accurate prognostication, the prognostic value of electrolyte imbalance has received little attention.

Methods: As a retrospective review, we screened inpatients with terminal cancer admitted between January 2017 and May 2019 to a single hospice-palliative care unit. Clinical characteristics and laboratory results were obtained from medical records for multivariable Cox regression analysis of independent prognostic factors.

Results: Of the 487 patients who qualified, 15 (3%) were hypernatremic upon admission. The median survival time was 26 days. Parameters associated with shortened survival included male sex, advanced age (> 70 years), lung cancer, poor performance status, elevated inflammatory markers, azotemia, impaired liver function, and hypernatremia. In a multivariable Cox proportional hazards model, male sex (hazard ratio [HR] = 1.53, 95% confidence interval [CI]: 1.15-2.04), poor performance status (HR = 1.45, 95% CI: 1.09-1.94), leukocytosis (HR = 1.98, 95% CI: 1.47-2.66), hypoalbuminemia (HR = 2.06, 95% CI: 1.49-2.73), and hypernatremia (HR = 1.55, 95% CI: 1.18-2.03) emerged as significant predictors of poor prognosis.

Conclusion: Hypernatremia may be a useful gauge of prognosis in patients with terminal cancer. Further large-scale prospective studies are needed to corroborate this finding.

Title: The Empathy Project: A Skills-Development Game: Innovations in Empathy Development.

Citation: Journal of pain and symptom management; Jul 2020; vol. 60 (no. 1); p. 164
Author(s): Hudnall, Jasmine A; Kopecky, Kimberly E

Context: Empathy is increasingly described as a learnable skill and is included in professionalism requirements for health care providers, yet there are few effective tools for developing and practicing empathy skills.

Innovation: An educational innovation intended to isolate and develop skills to respond to patients' emotions. The game-based tool was developed on the job during the authors' Hospice and Palliative Medicine fellowship year and was played with learners in various disciplines.

Outcomes: Feedback from learners was overwhelmingly positive, although a key factor in optimization of learning was the presence of a communication expert as facilitator. Learner responses were measured using a novel assessment tool, and findings suggest statistically significant expansion of language and intent to express empathy. Learners demonstrated immediate growth in naming emotions, reflecting understanding and respect of emotional expression, and supporting and exploring emotional content.

Comment: This innovative game-based learning tool is of low cost and feasible to deploy. It could be easily incorporated into medical education curricula aimed at developing communication skills, especially the skill of responding to emotion with empathy. Future research is needed to assess the effects the innovation has on behavior as well as its impact on patient-centered outcomes.
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; Jun 2020

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

Context: In end-of-life care, rehabilitation for cancer patients is considered to be an important means for improving patients' quality of death and dying (QODD).

Objectives: To determine whether the provision of rehabilitation for cancer patients in palliative care units is associated with the achievement of a good death.

Methods: This study involved a cross-sectional, anonymous, self-report questionnaire survey of families of cancer patients who died in palliative care units in Japan. We evaluated the Good Death Inventory (GDI) short version on a 7-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 1,965 family caregivers who received the questionnaires, available data was obtained from 1,008 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 [standard error = 0.10] vs. 4.05 [0.11], respectively; effect size (ES)= 0.31; p-value = 0.003), "good relationships with medical staff," (5.67 [0.07] vs. 5.43 [0.09], respectively; ES= 0.22; p-value = 0.035) and "being respected as an individual" (6.08 [0.06] vs. 5.90 [0.07], respectively; ES=0.19; p-value = 0.049) compared with patients not receiving rehabilitation.

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

Title: Randomized trial of a hospice video educational tool for patients with advanced cancer and their caregivers.

Citation: Cancer; Jun 2020

Author(s): El-Jawahri, Areej; Traeger, Lara; Greer, Joseph A; Vanbenschoten, Olivia; Markovitz, Netana; Cashavelly, Barbara; Tata, Lee Ann; Nipp, Ryan D; Reynolds, Kerry L; Goyal, Lipika; Bhatt, Sunil; Fishman, Sarah; Horick, Nora; Li, Zhigang; Volandes, Angelo; Temel, Jennifer S

Background: Patients with advanced cancer and their caregivers have substantial misperceptions regarding hospice, which contributes to its underuse.

Methods: The authors conducted a single-site randomized trial of a video educational tool versus a verbal description of hospice in 150 hospitalized patients with advanced cancer and their caregivers. Patients without a caregiver were eligible. Intervention participants (75 patients and 18 caregivers) viewed a 6-minute video depicting hospice. Control participants
(75 patients and 26 caregivers) received a verbal description identical to the video narrative. The primary outcome was patient preference for hospice. Secondary outcomes included patient and/or caregiver knowledge and perceptions of hospice, and hospice use.

**Results:** Between February 2017 and January 2019, approximately 55.7% of eligible patients (150 of 269 eligible patients) and 44 caregivers were enrolled. After the intervention, there was no difference noted with regard to patients’ preferences for hospice (86.7% vs 82.7%; P = .651). Patients in the video group reported greater knowledge regarding hospice (9.0 vs 8.4; P = .049) and were less likely to endorse that hospice is only about death (6.7% vs 21.6%; P = .010). Among deceased patients, those assigned to the intervention were more likely to have used hospice (85.2% vs 63.6%; P = .01) and to have had a longer hospice length of stay (median, 12 days vs 3 days; P < .001). After the intervention, caregivers assigned to view the video were more likely to prefer hospice for their loved ones (94.4% vs 65.4%; P = .031), reported greater knowledge concerning hospice (9.7% vs 8.0%; P = .001), and were less likely to endorse that hospice is only about death (0.0% vs 23.1%; P = .066).

**Conclusions:** A hospice video did not significantly impact patients’ preferences for hospice care. Patients with advanced cancer and their caregivers who were assigned to view the video were more informed regarding hospice and reported more favorable perceptions of hospice. Patients were more likely to use hospice and to have a longer hospice length of stay.

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**Title:** Mediation Effects of Compassion Satisfaction and Compassion Fatigue in the Relationships Between Resilience and Anxiety or Depression Among Hospice Volunteers.

**Citation:** Journal of hospice and palliative nursing : JHPN : the official journal of the Hospice and Palliative Nurses Association; Jun 2020; vol. 22 (no. 3); p. 246-253

**Author(s):** Jo, Minjeong; Na, Hyunjoo; Jung, Young-Eun

**Abstract:** Hospice volunteers are a high-risk group for anxiety and depression owing to their frequent exposure to patients at the end of life and their subsequent deaths. Resilience is known to be a powerful factor that affects the occurrence of anxiety and depression; however, research on this subject is scarce. We investigated the relationship of resilience with anxiety or depression in hospice volunteers. A total of 145 volunteers were included in the analysis. Participants completed self-reported scales, including the Korean version of the Connor-Davidson Resilience Scale, the State-Trait Anxiety Inventory, Patient Health Questionnaire-9, and the Professional Quality of Life Scale version 5. Pearson correlation coefficients were analyzed to identify the relationship of compassion satisfaction and compassion fatigue with anxiety or depression. A PROCESS macro mediation analysis was used to investigate the mediation effects of compassion satisfaction and compassion fatigue on the relationship between resilience and anxiety or depression. There were significant associations of compassion satisfaction and compassion fatigue with anxiety and depression. The relationship between resilience and anxiety/depression was mediated by compassion fatigue, which had indirect effects on anxiety and depression. Efforts to reduce compassion fatigue and increase resilience could help prevent anxiety and depression in hospice volunteers.

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**Title:** Incidence and prevalence of pressure ulcers in cancer patients admitted to hospice: A multicentre prospective cohort study.

**Citation:** International wound journal; Jun 2020; vol. 17 (no. 3); p. 641-649
Author(s): Jakobsen, Tina Bull Tafteberg; Pittureri, Cristina; Seganti, Patrizia; Borissova, Elena; Balzani, Isabella; Fabbri, Samanta; Amati, Piero; Donigaglia, Sara; Gallina, Silvia; Fabbri, Elisabetta

Abstract: Pressure ulcers lead to discomfort for patients and may have an important impact on a patient’s quality of life. Measure the incidence and prevalence of pressure ulcers in a Hospice environment; evaluate the risk factors associated with pressure ulcers; and calculate the incidence of Kennedy Terminal Pressure Ulcers. This multicentre prospective cohort study enrolled 440 cancer patients in advanced phase, consecutively admitted to five hospices of the AUSL della Romagna (Italy), during a period of 1 year. Five hundred more patients were excluded from the study because of inability to sign the consent form or refusal to participate. All patients were adults above 18 years of age. The National Pressure Advisory Panel Classification System was used to evaluate the pressure ulcers. Potential risk predictors were evaluated through the Braden Scale, the Numerical Scale, and the Pain Assessment in Advanced Dementia Scale. Starting in September 2016, 214 (48.6%) females and 226 (51.4%) males were analysed. The incidence of pressure ulcers in the total population was 17.3%. The risk factors that influence the development of pressure ulcers were age, proximity to death, and duration of stay in Hospice. The incidence of Kennedy Terminal Pressure Ulcers was 2.7%. This study demonstrates that 17.3% of all patients admitted to a hospice setting developed a pressure ulcer. The longer the patients stay in hospice and the clinical condition deteriorates, the higher the risk of developing a pressure ulcer.

Title: Effectiveness of home hospice care: a nationwide prospective observational study.

Citation: Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer; Jun 2020; vol. 28 (no. 6); p. 2713-2719

Author(s): Ahn, Eunmi; Song, In Gyu; Choi, Jin Young; Jho, Hyun Jung; Park, Ilyeon; Sung, Suah; Shin, Seohyun; Park, So Jung; Nam, Eun Jung; Jeong, Sung Hoon; Chang, Yoon Jung

Purpose: Many assert the need for home hospice care. However, limited research has shown its effectiveness. The authors of this study thus evaluated the effectiveness of a home hospice care pilot project regarding (1) early enrollment in hospice care, (2) efficient use of inpatient hospice resources, and (3) enabling terminally ill patients to stay at their preferred place of care.

Methods: The authors conducted a nationwide prospective observational study. Patients were divided into home hospice care users (ever-users, n = 902) and inpatient-only hospice care users (never-users, n = 8210). Information about hospice service utilization was collected from a web-based registry system. Patients were registered if they started to receive the hospice service after providing written informed consent during the pilot project from March 2016-July 2017.

Results: Most ever-users preferred to stay at home (84.0%), while never-users preferred hospital admission (66.9%). Most ever-users were enrolled in hospice by home care (78.9%) and used both home and inpatient care (72.4%). The overall duration of hospice care was significantly longer among ever-users than never-users (median 39 vs. 15 days, respectively; mean ± SD 59.6 ± 62.8 vs. 24.8 ± 32.1, respectively; p < .001). Participation in the pilot program improved bed utilization (p = .025) and turnover rate (p < .001) of inpatient hospice service.
Conclusions: Home hospice care enabled early enrollment in hospice services and provided a valid option to patients who wished to stay at home. Policy efforts to facilitate home hospice care are needed.

Title: Role of clinical psychology in UK hospices.

Citation: BMJ supportive & palliative care; Jun 2020; vol. 10 (no. 2); p. 196-200

Author(s): Russell, Charlotte; Fountain, Averil

Objective: The National Institute of Clinical Excellence (NICE) (2004) guidance recommends a tiered approach to psychological care within cancer care. This includes the provision of Clinical Psychologists to support other professionals to deliver high-quality psychological care at levels 1 and 2 and to provide direct input to patients experiencing high levels of distress at level 4. However, little is known about the role of Clinical Psychology within UK Hospices currently. A survey of Clinical Psychologists working in this area was undertaken to address this gap in knowledge.

Methods: We conducted an anonymous online survey of Clinical Psychologists working in Hospice organisations across the UK. Recruitment was completed via professional networking groups, social media and by contacting UK Hospice organisations. The survey included quantitative and qualitative items about professionals' experience, how their input is organised, their roles and activities and their views on the valuable and challenging aspects of working in this setting.

Results: Eighteen Clinical Psychologists responded and there was considerable variance in how their roles were organised. The tasks undertaken by most respondents were direct work with and consultation for hospice patients, and teaching and training staff. However, the findings demonstrated that Clinical Psychologists can undertake a wide range of tasks and draw on a range of therapeutic approaches including Cognitive Behavioural Therapy, Acceptance and Commitment Therapy and Compassion Focused Therapy, in their hospice work.

Conclusion: Our results provide an overview of the role of Clinical Psychology in UK Hospices and demonstrate the contribution that Psychologists can make to this field.

Title: Suitable support for anxious hospice patients: what do nurses 'know', 'do' and 'need'? An explanatory mixed method study.

Citation: BMJ supportive & palliative care; Jun 2020; vol. 10 (no. 2); p. e15

Author(s): Zweers, Danielle; de Graaf, Everlien; Teunissen, Saskia

Objective: To provide insight into what nurses know, do and need to provide support to anxious patients in hospice care (HC).

Methods: A mixed method study consisted of an online survey and focus groups (FGs) about what nurses know, do, and need was conducted. 336 HC nurses were invited to participate. Descriptive statistics were computed using SPSS. The χ2 and t-tests were conducted to compare. The FGs were transcribed verbatim and thematically analysed.

Results: The survey was completed by 265 nurses (79%), and five FGs (n=25) were conducted. Most nurses had >10 years working experience; mean age was 52. The majority (59%) felt that they were equipped with sufficient knowledge; however, lack of knowledge (31%) as well as lack of time (50%) were hampering factors. Identification of anxiety was difficult due to the variety of its expression. Tools for identifying were used by 37%.
Interventions were generally chosen intuitively. A major responsibility was experienced in caring for patients with panic attacks during late night shifts, making immediate decisions necessary.

**Conclusion:** This study highlights the struggles of nurses caring for anxious patients in HC. Anxiety management is dependent on the competencies and preferences of the individual nurse. One-third of the nurses require additional training. According to HC nurses, the intervention set should include guidelines for applying assessment tools, effective communication strategies and decision models as well as prediction models in order to select tailored interventions. Future research should focus on patients' perspectives in order to understand crucial measures for anxiety management.

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**Title:** Conversations on Cancer Chemotherapy Cessation in Patients With Advanced Cancer: Qualitative Findings From a Multi-Institutional Study.

**Citation:** The American journal of hospice & palliative care; Jun 2020; p. 1049909120930710

**Author(s):** Stout, Jeremiah; Kumbamu, Ashok; Tilburt, Jon; Fernandez, Cara; Geller, Gail; Koenig, Barbara; Lenz, Heinz-Josep; Jatoi, Aminah

**Purpose:** As many as 20% of oncology patients receive chemotherapy in the last 14 days of their lives. This study characterized conversations between patients and cancer clinicians on chemotherapy cessation in the setting of advanced cancer.

**Methods:** This 3-site study captured real-time, audio-recorded interviews between oncology clinicians and patients with cancer during actual clinic visits. Audio-recordings were reviewed for discussion of chemotherapy cessation and were analyzed qualitatively.

**Results:** Among 525 recordings, 14 focused on stopping chemotherapy; 14 patients participated with 11 different clinicians. Two types of nonmutually exclusive conversation elements emerged: direct and specific elements that described an absence of effective therapeutic options and indirect elements. An example of a direct element is as follows: "...You know this is...always really tough...But I-I think that you may need more help...I think we're close to stopping chemotherapy...And hospice is really helpful to have in place..." In contrast, the second conversation element was more convoluted: "...transplant is not an option and surgery is not an option...The options...are taking a pill...It doesn't shrink the tumor...It may help you live a little longer. But I'm worried if [you] had the pill, it's still a therapy and it still has side effects. I [am] worried if I give it to you now, that you're so weak, it will make you worse." No relationship seemed apparent between conversation elements and chemotherapy cessation.

**Conclusions:** Conversations on chemotherapy cessation are complex; multiple factors appear to drive the decision to stop.

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**Title:** The COMFORT Communication Model: A Nursing Resource to Advance Health Literacy in Organizations.

**Citation:** Journal of hospice and palliative nursing : JHPN : the official journal of the Hospice and Palliative Nurses Association; Jun 2020; vol. 22 (no. 3); p. 229-237

**Author(s):** Goldsmith, Joy V; Wittenberg, Elaine; Parnell, Terri Ann

**Abstract:** The COMFORT Model has recently been revised based on feedback from bedside nurses working in palliative care and oncology and includes the following
components: Connect, Options, Making Meaning, Family Caregiver, Openings, Relating, and Team. Based on clinical and nonclinical research in hospital, hospice, palliative care, and interdisciplinary education settings, the authors present the updated COMFORT Model. Originally introduced in 2012 to support the work of the nurse, the model is not a linear guide, an algorithm, a protocol, or a rubric for sequential implementation by nurses, but rather a set of communication principles that are practiced concurrently and reflectively during patient/family care. In its restructuring, we focus on the role of health literacy throughout the COMFORT components in relationship to the health literacy attributes of a health care organization. A brief summary of COMFORT components is provided and includes strategies and competencies contributing to a health-literate care organization. Both health literacy and COMFORT are explored using specific communication challenges that underscore the role of the nurse in accomplishing person-centered and culturally responsive care, especially in chronic and terminal illness. The integration of the COMFORT Model into nursing education is proposed.

Title: Specialist palliative medicine physicians and nurses accuracy at predicting imminent death (within 72 hours): a short report.

Citation: BMJ supportive & palliative care; Jun 2020; vol. 10 (no. 2); p. 209-212

Author(s): White, Nicola; Reid, Fiona; Vickerstaff, Victoria; Harries, Priscilla; Stone, Patrick

Objectives: Research suggests that clinicians are not very accurate at prognosticating in palliative care. The 'horizon effect' suggests that accuracy ought to be better when the survival of patients is shorter. The aim of this study was to determine the accuracy of specialist palliative care clinicians at identifying which patients are likely to die within 72 hours.

Design: In a secondary data analysis of a prospective observational study, specialist palliative care doctors and nurses (in a hospice and a hospital palliative care team) provided survival predictions (yes/no/uncertain) about which patients would die within 72 hours.

Results: Survival predictions were obtained for 49 patients. A prediction from a nurse was obtained for 37/49 patients. A prediction from a doctor was obtained for 46/49 patients. In total, 23 (47%)/49 patients actually died within 72 hours of assessment. Nurses accurately predicted the outcome in 27 (73%)/37 cases. Doctors accurately predicted the outcome in 30 (65%)/46 cases. When comparing predictions given on the same patients (27 [55%]/49), nurses were slightly better at recognising imminent death than doctors (positive predictive value (the proportion of patients who died when the clinician predicted death)=79% vs 60%, respectively). The difference in c-statistics (nurses 0.82 vs doctors 0.63) was not significant (p=0.13).

Conclusion: Even when patients are in the terminal phase and close to death, clinicians are not very good at predicting how much longer they will survive. Further research is warranted to improve prognostication in this population.

Title: Systematic Literature Review of Interventions for Promoting Postmortem Organ Donation From Social Marketing Perspective.

Citation: Progress in transplantation (Aliso Viejo, Calif.); Jun 2020; vol. 30 (no. 2); p. 155-168

Author(s): Čož, Sinja; Kamin, Tanja
Introduction: This systematic review examines the factors that make some interventions promoting postmortem organ donation more successful and more likely to change behaviors than others. We analyzed the effectiveness of different types of interventions for promoting postmortem organ donation against the criteria identified by previous research in other health-related areas as the most important for designing effective behavior change programs. We observed a correlation between the use of social marketing benchmarks and the reported success of intervention goals.

Methods: We conducted a systematic review of all articles describing interventions promoting postmortem organ donation published in scientific journals between January 2008 and November 2018. We analyzed these articles against the 7 social marketing benchmark criteria using a coding questioner.

Findings: The analysis revealed a correlation between the use of social marketing benchmark criteria in an intervention's design and the success of the intervention. Interventions that employed 6 or 7 criteria reported successful achievement of all intervention objectives. We observed a decrease in success rates when fewer than 6 social marketing benchmark criteria were included in the intervention design.

Discussion: The findings suggest that a social marketing approach may prove useful to efforts to promote postmortem organ donation. More social marketing benchmark criteria should be included in the design and implementation of interventions promoting postmortem organ donation.

Title: Organ donation during the coronavirus pandemic: an evolving saga in uncharted waters.

Citation: Transplant international : official journal of the European Society for Organ Transplantation; Jul 2020; vol. 33 (no. 7); p. 826-827

Author(s): Moris, Dimitrios; Shaw, Brian I; Dimitrokallis, Nikolaos; Barbas, Andrew S

Title: Improving access to organ donor registration in general practice: a feasibility study.

Citation: The British journal of general practice : the journal of the Royal College of General Practitioners; Jul 2020; vol. 70 (no. 696); p. e497

Author(s): Penn-Jones, Catrin P; Papadopoulos, Chris; Randhawa, Gurch; Asghar, Zeeshan

Background: Organ donor registration helps guide decision making for families. UK general practice provides the facility to register on the NHS Organ Donor Register, but only to new patients. An intervention was developed to present a registration opportunity to existing patients in this setting.

Aim: To assess the feasibility and acceptability of an organ donation intervention implemented in UK general practice.

Design and Setting: The intervention ran in a large practice in Luton in the UK, for 3 months in 2018. A single practice feasibility study was conducted using an embedded experimental mixed methods design.

Method: Staff were trained to ask patients in consultations if they wished to join the register, and leaflets and posters were displayed in the waiting room. Data on feasibility and acceptability were captured using SystmONE questionnaires, surveys, and focus groups.
Results: Over 3 months, in 12.4% of face-to-face consultations, patients were asked if they would like to join the register (812 of 6569), and 244 (30.0%) of these patients joined the register. Common reasons staff did not ask patients were due to telephone consultations, lack of time, and it not being appropriate. Nurses and healthcare assistants performed prompted choice more than doctors (23.4%, 17.1%, and 1.6% respectively). Certain clinic types, such as phlebotomy or routine clinics, facilitated asking compared to those where patients presented with unknown or more serious issues.

Conclusion: The intervention was found to be feasible and acceptable by some staff and patients. Feasibility criteria were met; therefore, the intervention can progress to further testing.


Citation: Palliative medicine; Jun 2020 ; p. 269216320935361
Author(s): Jackson, Timothy; Hobson, Katie; Clare, Hannah; Weegmann, Daniel; Moloughney, Catherine; McManus, Sally

Background: Hospital clinicians have had to rapidly develop expertise in managing the clinical manifestations of COVID-19 including symptoms common at the end of life, such as breathlessness and agitation. There is limited evidence exploring whether end-of-life symptom control in this group requires new or adapted guidance.

Aim: To review whether prescribing for symptom control in patients dying with COVID-19 adhered to existing local guidance or whether there was deviation which may represent a need for revised guidance or specialist support in particular patient groups.

Design/Setting: A retrospective review of the electronic patient record of 61 hospital inpatients referred to the specialist palliative care team with swab-confirmed COVID-19 who subsequently died over a 1-month period. Intubated patients were excluded.

Results: In all, 83% (40/48) of patients were prescribed opioids at a starting dose consistent with existing local guidelines. In seven of eight patients where higher doses were prescribed, this was on specialist palliative care team advice. Mean total opioid dose required in the last 24 h of life was 14 mg morphine subcutaneous equivalent, and mean total midazolam dose was 9.5 mg. For three patients in whom non-invasive ventilation was in place higher doses were used.

Conclusion: Prescription of end-of-life symptom control drugs for COVID-19 fell within the existing guidance when supported by specialist palliative care advice. While some patients may require increased doses, routine prescription of higher starting opioid and benzodiazepine doses beyond existing local guidance was not observed.

Title: Living in the moment for people approaching the end of life: A concept analysis.

Citation: International Journal of Nursing Studies; Aug 2020; vol. 108
Author(s): Dönmez ; Johnston, Bridget

Abstract: 'Living in the moment' is an essential part of dignity-conserving practice in end-of-life care settings. Although living in the moment is important for care at the end of life, from the perspective of both the person and their family, there is no clear conceptual understanding of what it represents. To explore the concept of 'living in the moment' in the context of dignity-conserving care at the end of life. A concept analysis. The databases of
Medline, CinAHL, PubMed, Web of Science, PsycINFO, SocINDEX and Cochrane were searched for studies published between 1941 and 2019, and searches of dictionaries and grey literature, as well as hand-searching were conducted, to yield qualitative, mixed methods and systematic reviews published in English, related to the term 'living in the moment'. The methods of Walker and Avant were used to identify antecedents, attributes and consequences of the concept of 'living in the moment'. The literature review generated a total of 37 papers for this concept analysis. The attributes identified were (1) simple pleasure, (2) prioritising relationships, (3) living each day to the fullest, (4) maintaining normality, and (5) not worrying about the future. The antecedents were (1) awareness of dying, (2) living with life-threatening illness, (3) positive individual growth, and (4) living with an uncertain future. The consequences were (1) a good quality of life, (2) preserving dignity, and (3) coping with the uncertainty of life. A universal definition and conceptual model of the main concept, including theoretical relationships between its antecedents, attributes and consequences, was developed. The definition and proposed conceptual model can allow instruments to be developed that measure the effects, existence or attributes of the concept, and identify a theoretical model, and can also lead to new perspectives and strategies for implementation by nurses to improve dignified person-centred care at the end of life.

Title: Advance care planning for people living with dementia: An umbrella review of effectiveness and experiences.

Citation: International Journal of Nursing Studies; Jul 2020; vol. 107
Author(s): Wendorich-van Dael ; Bunn, Frances; Lynch, Jennifer; Pivodic, Lara; Van den Block, Lieve; Goodman, Claire

Abstract: End of life care is often inadequate for people with dementia. Advanced care planning (ACP) has the potential to improve outcomes for people with dementia. The aim of this review is to establish the strength of the evidence and provide decision makers with a clear understanding of what is known about ACP for people living with dementia. Evidence synthesis including systematic reviews and primary studies. PROSPERO registration: CRD42018107718. PubMed, CINAHL Plus, SCOPUS, Social Care Online and Cochrane Library were searched (July 2018). No year limit applied. To be included, reviews had to evaluate effectiveness of ACP for people with dementia or report on views and experiences of ACP from the perspective of people with dementia, carers, or health and care professionals. Additional searches (September 2018) were conducted to identify recent primary studies not included in the reviews. Data extraction was undertaken by one reviewer and checked by a second. Methodological quality was assessed using AMSTAR-2 and Joanna Briggs Institute instruments by two authors independently. Outcomes were categorized and tabulated to assess effectiveness. Qualitative data was analysed using thematic synthesis. Nineteen reviews (163 unique studies) and 11 primary articles with a range of advance care planning definitions and of variable quality were included. Advance care planning was associated with decreased hospitalizations, increased concordance between care received and prior wishes and increased completion of advance care planning documents but quality of primary research was variable. Views of ACP for people with dementia can be clustered around six themes; 1) timing and tailoring, 2) willingness to engage, 3) roles and responsibilities of healthcare professionals, 4) relationships, 5) training and 6) resources needed. Diminishing decision-making capacity over time is a key overarching feature. Advance care planning is acceptable for people with dementia and their carers and is associated with improved outcomes. Guidelines on which outcomes and which definition to use are necessary, as is research to test different approaches to ACP. Education on topics related to diminishing decision-making capacity is key to optimize advance care planning for people with dementia and their carers.
Title: The effects of nonconventional palliative and end-of-life care during COVID-19 pandemic on mental health-Junior doctors' perspective.

Citation: Psychological trauma : theory, research, practice and policy; Jun 2020
Author(s): Cheng, Joyce Oi Suet; Li Ping Wah-Pun Sin, Edwin

Abstract: The COVID-19 pandemic has changed the way doctors approach palliative and end-of-life care, which has undoubtedly affected the mental health of patients, families, and health care professionals. Given these circumstances, doctors working on the front line are vulnerable to moral injury and compassion fatigue. This is a reflection of 2 junior doctors experiencing firsthand demands of caring for patients during the outbreak. (PsycInfo Database Record (c) 2020 APA, all rights reserved).

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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