

End of Life Care Current Awareness Bulletin

March 2021

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

If you would like to receive these bulletins on a regular basis please contact the library.

If you would like any of the full references we will source them for you.

Contact us: **Academy Library 824897/98**

Email: ruh-tr.library@nhs.net

Title: Palliative care: Experts call for major reforms as pandemic accelerates demand by 20 years

Citation: BMJ : British Medical Journal (Online); Jan 2021; vol. 372

Author(s): Griffin, Shaun

Abstract: More than half a million people in England and Wales were predicted to need palliative or end-of-life care by 2040,¹ but this level of demand will have been achieved in 2020, said researchers from Cicely Saunders International.² They said that too many people who had life limiting illnesses or were approaching death were spending unnecessarily long periods in hospital without being offered alternatives, when most would prefer to die at home.³ Around 80% of people would prefer to die at home or in their place of residence, but in some parts of England and Wales less than 50% do so. Other recommendations in the report's seven point action plan include increased investment in social and community care services, a strategic approach to training, and a system of continuous learning and improvement. Gurch Randhawa, professor of diversity in public health at the University of Bedfordshire, said, "This report provides a welcome focus on the urgent need to improve access and quality in palliative care provision."

Title: Nursing home residents with cognitive impairment can participate in advance care planning: A qualitative study

Citation: Journal of Advanced Nursing; Feb 2021; vol. 77 (no. 2); p. 879

Author(s): Sævareid, Trygve J L; Pedersen, Reidar; Thoresen, Lisbeth

Aims: To describe advance care planning in nursing homes when residents with cognitive impairment and/or their next of kin participated and identify associated challenges.

Design: A qualitative study of nine advance care planning conversations in four Norwegian nursing home wards. During the implementation of advance care planning, we purposively sampled residents with cognitive impairment, their next of kin and healthcare personnel. The implementation followed a "whole-ward" approach aimed at involving the whole ward in fostering an inclusive, holistic advance care planning discussion. Involving as many residents as possible, preferably together with their next of kin, were central.

Methods: From observed and audio-recorded advance care planning conversations that took place from November 2015 to June 2016, we conducted a thematic analysis of the transcripts and field notes. Reporting adhered to the COREQ guidelines.

Results: Residents actively relayed their preferences regarding healthcare and end-of-life issues, despite the cognitive impairment. Next of kin provided constructive support and conversations were largely resident-focused. However, involving residents was also challenging, findings included: residents' preferences were often vague, relevant medical information from healthcare personnel lacked and the next of kin were sometimes unaware of the resident's previously held preferences. Moreover, residents tended to focus more on the past and present than the future end-of-life care.

Conclusions: Residents with cognitive impairment can participate actively and meaningfully in advance care planning, if the healthcare personnel actively listens. However, several challenges can arise. Supported decision-making can improve communication and resident involvement, reinforcing a relational understanding of autonomy.

Impact: Persons with cognitive impairment should be invited to participate in advance care planning. Their participation may make its benefits and more person-centred care attainable

to persons that are often not involved. Successful involvement of persons with cognitive impairment in advance care planning may rely on robust implementation.

Title: Experiences of new nurses dealing with death in a paediatric setting: A descriptive qualitative study

Citation: Journal of Advanced Nursing; Jan 2021; vol. 77 (no. 1); p. 343

Author(s): Yi Jie Meredith Chew; Su Ling Linda Ang; Shorey, Shefaly

Aims: To explore and describe the experiences, challenges and coping strategies of new nurses dealing with paediatric death in a clinical setting.

Design: A descriptive qualitative study design was used.

Methods: Semi-structured interviews were conducted to explore the experiences of 12 new paediatric nurses from a tertiary public hospital in Singapore. Data were collected from September 2019-December 2019. A thematic analysis was performed for data analysis.

Results: Four themes were generated: (a) a spectrum of emotions; (b) the 'blame' game; (c) getting through the grief; and (d) new nurses' wish list. The new nurses tended to be emotionally affected by their first death experience. They felt anxious and personally responsible for the death but eventually controlled their emotions. Colleagues, religion and self-actualization were key in overcoming grief.

Conclusion: The experiences nurses go through at the early stages of their profession shape future workplace attitudes. Additional training and support should be provided to new nurses to build their confidence in managing end-of-life care. Training should include cultural awareness and communication skills to equip nurses with the necessary skills.

Impact: This research will have an impact on institutions, which develop culturally congruent training and support platforms that prepare new nurses for nursing practice. This research will drive future investigations on the long-term effects of paediatric death on new nurses.

Title: The Development of A Scale to Assess "ICU Nurses' Difficulties toward Patient's Family Deciding on Do Not Attempt Resuscitation" (IND-FDNAR).

Citation: Journal of Japan Academy of Nursing Science; Feb 2021; vol. 40 ; p. 412-421

Author(s): The University of Shimane Faculty of Nursing and Nutrition Department of Nursing; Keiko Matsumoto; Misae Ito; Satoko Aika

Purpose: This study aimed to develop a scale to assess "ICU nurses' difficulties toward patient's family deciding on Do Not Attempt Resuscitation" (IND-FDNAR).

Methods: A scale was created based on literature review and previous research on DNAR, and a questionnaire survey was conducted with 2,544 ICU nurses.

Results: Seven hundred and sixty-eight responses (valid response rate: 30.1%) were analyzed. An exploratory factor analysis resulted in a 34 item list, and six factors were extracted: (1) Confusion dealing with families, (2) Difficulties coordinating among nurses, (3) Difficulties managing grief care, (4) Difficulties coordinating with physicians, (5) Uncertainty in determining the status of the patient, and (6) Ambiguity in the decision-making process. Cronbach's α internal consistency reliability coefficient was .93, indicating that the scale was reliable. Construct validity was assessed by confirmatory factor analysis. Criterion-related validity was confirmed by correlating the experimental scale with a scale for difficulties felt by ICU nurses providing end-of-life care.

Conclusion: The results indicated that a valid and reliable scale was developed to assess critical care nurses' difficulties toward patient's family deciding on Do Not Attempt Resuscitation.

Title: Valuing end-of-life care: translation and content validation of the ICECAP-SCM measure.

Citation: BMC Palliative Care; Feb 2021; vol. 20 (no. 1); p. 1-8

Author(s): Gühne ; Dorow, Marie; Grothe, Jessica; Stein, Janine; Löbner, Margrit; Dams, Judith; Coast, Joanna; Kinghorn, Philip; König, Hans-Helmut; Riedel-Heller, Steffi G.

Background: The evaluation of care strategies at the end of life is particularly important due to the globally increasing proportion of very old people in need of care. The ICECAP-Supportive Care Measure is a self-complete questionnaire developed in the UK to evaluate palliative and supportive care by measuring patient's wellbeing in terms of 'capability'. It is a new measure with high potential for broad and international use. The aims of this study were the translation of the ICECAP-Supportive Care Measure from English into German and the content validation of this version.

Methods: A multi-step and team-based translation process based on the TRAPD model was performed. An expert survey was carried out to assess content validity. The expert panel (n = 20) consisted of four expert groups: representative seniors aged 65+, patients aged 65+ living in residential care, patients aged 65+ receiving end-of-life care, and professionals in end-of-life care.

Results: The German version of the ICECAP-Supportive Care Measure showed an excellent content validity on both item- and scale-level. In addition, a high agreement regarding the length of the single items and the total length of the questionnaire as well as the number of answer categories was reached.

Conclusions: The German ICECAP-SCM is a valid tool to assess the quality of life at the end of life that is suitable for use in different settings. The questionnaire may be utilized in multinational clinical and economic evaluations of end-of-life care.

Title: Nurses' perceptions of dealing with death in the emergency department.

Citation: Collegian; Feb 2021; vol. 28 (no. 1); p. 71-80

Author(s): Gerace ; Giles, Tracey; Breaden, Katrina; Hammad, Karen; Drummond, Christine; Bradley, Sandra L.; Muir-Cochrane, Eimear

Abstract: Providing end-of-life care to patients and their families in the emergency department (ED) is challenging, with high workloads, the busy environment, and a focus on providing lifesaving treatments to patients at odds with providing end-of-life and palliative care. The purpose of this study was to investigate nurses' experiences of providing end-of-life care in EDs, including their perceptions of the most vital elements of care, ability to provide aspects of care, as well as perceptions of their role, communication processes, family presence/involvement, and the ED environment. Nurses (n = 211) working in Australian EDs for at least 12 months completed an anonymous online survey. Nurses identified vital elements of care for dying patients including adequate pain control and a move away from burdensome treatments, sensitive care of families and family access to loved ones, and a quiet environment. However, nurses were not always able to provide such care to their patients. Often, the ED was seen as an unsuitable place for end-of-life care or

care of families once the patient had died, and communication between staff and between staff and families was challenging. The ED physical environment, lack of staff training and debriefing, and lack of time to communicate with family, particularly after death, may compromise nurses' ability to provide end-of-life care that is satisfying to them, their patients, and families. There is a need for focus on the ED physical environment, staff training, and consideration of the emotional experiences of frontline nurses caring for patients at the end of life.

Title: Staff Training Interventions to Improve End-of-Life Care of Nursing Home Residents: A Systematic Review.

Citation: Journal of the American Medical Directors Association; Feb 2021; vol. 22 (no. 2); p. 268-278

Author(s): Lamppu ; Pitkala, Kaisu H.

Abstract: The aim was to review evidence from all randomized controlled trials (RCTs) using palliative care education or staff training as an intervention to improve nursing home residents' quality of life (QOL) or quality of dying (QOD) or to reduce burdensome hospitalizations. A systematic review with a narrative summary. Residents in nursing homes and other long-term care facilities. We searched MEDLINE, CINAHL, PsycINFO, the Cochrane Library, Scopus, and Google Scholar, references of known articles, previous reviews, and recent volumes of key journals. RCTs were included in the review. Methodologic quality was assessed. The search yielded 932 articles after removing the duplicates. Of them, 16 cluster RCTs fulfilled inclusion criteria for analysis. There was a great variety in the interventions with respect to learning methods, intensity, complexity, and length of staff training. Most interventions featured other elements besides staff training. In the 6 high-quality trials, only 1 showed a reduction in hospitalizations, whereas among 6 moderate-quality trials 2 suggested a reduction in hospitalizations. None of the high-quality trials showed effects on residents' QOL or QOD. Staff reported an improved QOD in 1 moderate-quality trial. Irrespective of the means of staff training, there were surprisingly few effects of education on residents' QOL, QOD, or burdensome hospitalizations. Further studies are needed to explore the reasons behind these findings.

Title: Advance Care Planning and End-Of-Life Communications: Practical Tips for Oncology Advanced Practitioners.

Citation: Journal of the Advanced Practitioner in Oncology; Jan 2021; vol. 12 (no. 1); p. 89-95

Author(s): GOSWAMI

Abstract: Advance care planning discussions ensure patients' values and goals of care, including the freedom to choose their place of death, are respected. The benefits of advance care planning and early end-of-life care discussions are often delayed, as these discussions are not initiated early in patients' cancer trajectories. As a result, patients' wishes often remain unknown until the last phase of their life. Evidence suggests that many patients inappropriately receive aggressive treatment near the end of life, which leads to higher resource utilization, decreased quality of life, and increased cost. The purpose of this article is to provide practical tips to the oncology advanced practitioner on initiating advance care planning and end-of-life care discussions with patients and their families or caregivers.

Title: Developing a family-reported measure of experiences with home-based pediatric palliative and hospice care: a multi-method, multi-stakeholder approach.

Citation: BMC Palliative Care; Jan 2021; vol. 20 (no. 1); p. 1-18

Author(s): Boyden ; Feudtner, Chris; Deatrack, Janet A.; Widger, Kimberley; LaRagione, Gwenn; Lord, Blyth; Ersek, Mary

Background: Many children with serious illnesses are receiving palliative and end-of-life care from pediatric palliative and hospice care teams at home (PPHC@Home). Despite the growth in PPHC@Home, no standardized measures exist to evaluate whether PPHC@Home provided in the U.S. meets the needs and priorities of children and their families.

Methods: We developed and conducted a preliminary evaluation of a family-reported measure of PPHC@Home experiences using a multi-method, multi-stakeholder approach. Our instrument development process consisted of four phases. Item identification and development (Phase 1) involved a comprehensive literature search of existing instruments, guidelines, standards of practice, and PPHC@Home outcome studies, as well as guidance from a PPHC stakeholder panel. Phase 2 involved the initial item prioritization and reduction using a discrete choice experiment (DCE) with PPHC professionals and parent advocates. Phase 3 involved a second DCE with bereaved parents and parents currently receiving care for their child to further prioritize and winnow the items to a set of the most highly-valued items. Finally, we conducted cognitive interviews with parents to provide information about the content validity and clarity of the newly-developed instrument (Phase 4).

Results: Items were compiled predominantly from three existing instruments. Phase 2 participants included 34 PPHC providers, researchers, and parent advocates; Phase 3 participants included 47 parents; and Phase 4 participants included 11 parents. At the completion of Phase 4, the Experiences of Palliative and Hospice Care for Children and Caregivers at Home (EXPERIENCE@Home) Measure contains 22 of the most highly-valued items for evaluating PPHC@Home. These items include "The care team treats my child's physical symptoms so that my child has as good a quality of life as possible", "I have regular access to on-call services from our care team", and "The nurses have the knowledge, skills, and experience to support my child's palliative or hospice care at home."

Conclusions: The EXPERIENCE@Home Measure is the first known to specifically measure family-reported experiences with PPHC@Home in the U.S. Future work will include formal psychometric evaluation with a larger sample of parents, as well as evaluation of the clinical utility of the instrument with PPHC@Home teams.

Title: Palliative and Hospice Care in Correctional Facilities: Integrating a Family Nursing Approach to Address Relational Barriers.

Citation: Cancer Nursing; Jan 2021; vol. 44 (no. 1); p. 29-36

Author(s): Burles ; Holtslander, Lorraine; Peternelj-Taylor, Cindy

Background: The need for palliative and hospice care for persons with life-limiting conditions who are incarcerated is increasingly common in correctional facilities worldwide.

Objective: Through a family nursing lens, we critically analyze the unique challenges experienced by those requiring palliative care while incarcerated. Key concerns and implications for nursing are illustrated through the discussion of a representative case scenario.

Methods: The case scenario was developed based on the findings of a scoping review of academic and gray literature (such as policy documents and editorials) about palliative, hospice, and end-of-life care in corrections.

Results: The case scenario highlights multilevel barriers that were identified, including the individual, relational, institutional, and sociocultural contexts of palliative care in correctional facilities. Evidence is presented of how integration of a family nursing perspective can enhance specialized palliative and hospice care services in correctional settings.

Conclusions: By applying a family nursing approach, nurses practicing with correctional populations can ensure persons with life-limiting illnesses are not denied their right to appropriate end-of-life care by playing a key role in addressing barriers to palliative and hospice care access in corrections. Specific attention to relational issues and holistic care can contribute to enhanced palliative and hospice care, greater dignity in dying, and improved family and peer outcomes, which have benefits for individuals, families, communities, and society. Implications for Practice: Through the case scenario, we illustrate real issues emerging in correctional contexts and offer evidence of how family nursing relational principles can be applied to promote adequate palliative and hospice care.

Title: Are family carers part of the care team providing end-of-life care? A qualitative interview study on the collaboration between family and professional carers.

Citation: Palliative Medicine; Jan 2021; vol. 35 (no. 1); p. 109-119

Author(s): Vermorgen ; Vandenberghe, Isabel; Van Audenhove, Chantal; Hudson, Peter; Deliens, Luc; Cohen, Joachim; De Vleminck, Aline

Background: The attention of healthcare professionals is directed mainly towards the recipients of care and often insufficiently towards family carers. However, an effective collaboration between professionals and family carers is vital to provide quality palliative and end-of-life care. Such collaboration is under-studied in a palliative care context.

Aim: This study aimed to investigate how family carers of people who live at home with a life-limiting chronic illness experience and perceive collaboration with different healthcare professionals in the last phase of life.

Design: Face-to-face semi-structured interviews were conducted with the primary family carers of people with a life-limiting chronic illness. Interpretative phenomenological analysis was used to analyse the data.

Setting/participants: A heterogeneous sample of 30 family carers of people with cancer, heart failure or dementia was recruited through a variety of care providers and services, in order to reflect the heterogeneity of caregiving in serious illness.

Results: Five main themes emerged from interpretative phenomenological analysis that describe the quality of the collaboration between family carers and professionals: respecting family carers both as someone with care needs and as a member of the care team; the continuous availability and accessibility of healthcare professionals; the provision of information and communication including family carer issues; the coordination of care between all parties and contextual factors. The dominant experience by family carers was one of missed opportunities across these themes.

Conclusions: This qualitative study about the experiences and perceptions of family carers of people with a chronic life-limiting illness living at home regarding the collaboration with different healthcare providers in the last phase of life, showed that family carers experience a lot of possibilities, but perceive missed opportunities as well, for healthcare professionals to effectively collaborate with them for palliative care.

Title: Validation of the Distress Thermometer in patients with advanced cancer receiving specialist palliative care in a hospice setting.

Citation: Palliative Medicine; Jan 2021; vol. 35 (no. 1); p. 120-129

Author(s): Graham-Wisener ; Dempster, Martin; Sadler, Aaroon; McCann, Luke; McCorry, Noleen K

Background: Ongoing assessment of psychological reaction to illness in palliative and end of life care settings is recommended, yet validated tools are not routinely used in clinical practice. The Distress Thermometer is a short screening tool developed for use in oncology, to detect individuals who would benefit from further psychological assessment. However the optimal cut-off to detect indicative psychological morbidity in patients with advanced cancer receiving specialist palliative care is unclear.

Aim: To provide the first validation of the Distress Thermometer in an advanced cancer population receiving specialist palliative care in a UK hospice setting.

Design: Receiver Operating Characteristics analysis was used to compare the sensitivity and specificity of cut-offs indicative of psychological morbidity on the Distress Thermometer in comparison to the Hospital Anxiety and Depression Scale. Setting/Participants: Data were derived from 202 patients with advanced cancer who were approached on admission to inpatient or day hospice care, with 139 patients providing complete data on both measures.

Results: The area under the curve was optimal using a Distress Thermometer cut-off score of ≥ 6 for total distress and for anxiety, and a cut-off score of ≥ 4 optimal when screening for depression.

Conclusions: The Distress Thermometer is a valid, accurate screening tool to be used in advanced cancer but with caution in relation to the lack of specificity. With little variation between the area under the curve scores, arguably a Distress Thermometer cut-off score of ≥ 5 is most appropriate in screening for all types of psychological morbidity if sensitivity is to be prioritised.

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

Citation: Palliative Medicine; Jan 2021; vol. 35 (no. 1); p. 188-199

Author(s): Hudson ; Girgis, Afaf; Thomas, Kristina; Philip, Jennifer; Currow, David C; Mitchell, Geoffrey; Parker, Deborah; Liew, Danny; Brand, Caroline; Le, Brian; Moran, Juli

Background: Family meetings facilitate the exploration of issues and goals of care however, there has been minimal research to determine the benefits and cost implications.

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. Trial Registration: Australian and New Zealand Clinical Trials Registry ACTRN12615000200583

Title: Home or hospital as the place of end-of-life care and death: A grounded theory study of parents' decision-making.

Citation: Palliative Medicine; Jan 2021; vol. 35 (no. 1); p. 219-230

Author(s): Papadatou ; Kalliani, Vasiliki; Karakosta, Eleni; Liakopoulou, Panagiota; Bluebond-Langner, Myra

Background: While several studies have examined 'what' families want with regard to the place of a child's end-of-life care and death, few have explored 'how' parents reach a decision.

Aims: (1) to develop a model explaining how parents of a child with a life-threatening illness in Greece decide about the place of end-of-life care and death; (2) to identify the factors affecting decision-making; (3) to consider the implications for clinical practice.

Design: Grounded theory study of bereaved parents using semi-structured open-ended interviews following Strauss and Corbin's principles of data collection and analysis.

Setting/participants: Semi-structured interviews with 36 bereaved parents of 22 children who died at home (n = 9) or in a paediatric hospital (n = 13) in Athens, Greece.

Results: (1) Decisions regarding place of care and death were reached in one of four ways: consensus, accommodation, imposition of professional decisions on parents or imposition of parents' decisions without including professionals. (2) Six factors were identified as affecting decisions: awareness of dying, perceived parental caregiving competence, perceived professional competence, parents' view of symptom management, timing of decision-making, and being a 'good parent'. (3) Decisions were clear-cut or shifting. Few parents did not engage in decisions.

Conclusion: Parents' decisions about place of end-of-life care and death are affected by personal, interpersonal, timing and disease-related factors. Parents are best supported in decision-making when information is presented clearly and honestly with recognition of what acting as 'good parents' means to them, and opportunities to enhance their caregiving competence to care for their child at home, if they choose so.

Title: Education needed to improve antimicrobial use during end-of-life care of older adults with advanced cancer: A cross-sectional survey.

Citation: Palliative Medicine; Jan 2021; vol. 35 (no. 1); p. 236-241

Author(s): Datta ; Topal, Jeffrey; McManus, Dayna; Sanft, Tara; Dembry, Louise Marie; Morrison, Laura J; Quagliarello, Vincent; Juthani-Mehta, Manisha

Background: Antimicrobial use during end-of-life care of older adults with advanced cancer is prevalent. Factors influencing the decision to prescribe antimicrobials during end-of-life care are not well defined.

Aim: To evaluate factors influencing medicine subspecialists to prescribe intravenous and oral antimicrobials during end-of-life care of older adults with advanced cancer to guide an educational intervention.

Design: 18-item single-center cross-sectional survey. Setting/participants: Inpatient medicine subspecialists in 2018.

Results: Of 186 subspecialists surveyed, 67 (36%) responded. Most considered withholding antimicrobials at the time of clinical deterioration during hospitalization (n = 54/67, 81%), viewed the initiation of additional intravenous antimicrobials as escalation of care (n = 44/67, 66%), and believed decision-making should involve patients or surrogates and providers (n = 64/67, 96%). Fifty-one percent (n = 30/59) of respondents who conducted advance care planning did not discuss antimicrobials. Barriers to discussing end-of-life antimicrobials included the potential to overwhelm patients or families, challenges of withdrawing antimicrobials, and insufficient training.

Conclusions: Although the initiation of additional intravenous antimicrobials was viewed as escalation of care, antimicrobials were not routinely discussed during advance care planning. Educational interventions that promote recognition of antimicrobial-associated adverse events, incorporate antimicrobial use into advance care plans, and offer communication simulation training around the role of antimicrobials during end-of-life care are warranted.

Title: A survey of moral distress and end of life care in mechanical circulatory support nurses.

Citation: Heart & Lung; Jan 2021; vol. 50 (no. 1); p. 65-70

Author(s): Latimer ; Otis, Melanie D.; Flaherty, Christopher; Ross, Miriam A.

Abstract: Patients receiving left ventricular assisted device (LVAD) require the expertise of specialty trained nurses referred to as VAD coordinators. The long-term use of these devices has created morally distressing situations for VAD coordinators. This pilot study sought to explore the association between ventricular assistance device (VAD) coordinators' unique roles and responsibilities and moral distress. An online survey was distributed to VAD coordinators through a listserv. The non-probability sample consisted of 36 nurses across the United States. Bivariate analyses identified a number of areas of difference in respondent's levels of moral distress based on specific responsibilities associated with their role as a VAD coordinator. These findings indicate team communication, competence, and location of VAD discontinuation may be important factors related to VAD coordinators' distress. Future research is needed with larger sample sizes and continued exploration of the impact of specialized training and curricula content.

Title: Interprofessional End-of-Life Simulation in Nursing Education.

Citation: Clinical Simulation in Nursing; Feb 2021; vol. 51 ; p. 14-18

Author(s): Jenkinson ; Hartman, Nichole

Abstract: Many students report that they do not have the opportunity to provide end-of-life care before completing their undergraduate nursing degree. High fidelity simulation may

prepare both graduate and undergraduate students to collaborate when caring for patients in their last days of life and give them opportunities to explore their own beliefs, perceptions, and feelings related to death and dying. This article provides a brief overview of how one nursing program used simulation to bring prelicensure and graduate family nurse practitioner students together along with campus ministry to successfully deliver collaborative care. This innovative simulation exercise helped students and professionals develop shared goals and promoted communication when providing physical and spiritual care to end-of-life patients. • IPE EOL simulations can prepare nursing students to formulate a holistic plan of care. • Undergraduate and graduate nursing students were able to work collaboratively with campus ministry students and professionals to develop shared goals for physical and spiritual EOL care. • Students reported increased competence and comfort with delivering EOL care.

Title: Home hospitalization for palliative cancer care: factors associated with unplanned hospital admissions and death in hospital.

Citation: BMC Palliative Care; Jan 2021; vol. 20 (no. 1); p. 1-10

Author(s): Gamblin ; Prod'homme, Chloé; Lecoivre, Adrien; Bimbai, André -Michel; Luu, Joël; Hazard, Pierre-Alexandre; Da Silva, Arlette; Villet, Stéphanie; Le Deley, Marie-Cécile; Penel, Nicolas

Background: Home hospitalization at the end of life can sometimes be perturbed by unplanned hospital admissions (UHAs, defined as any admission that is not part of a preplanned care procedure), which increase the likelihood of death in hospital. The objectives were to describe the occurrence and causes of UHAs in cancer patients receiving end-of-life care at home, and to identify factors associated with UHAs and death in hospital.

Methods: A retrospective, single-center study (performed at a regional cancer center in the city of Lille, northern France) of advanced cancer patients discharged to home hospitalization between January 2014 and December 2017. We estimated the incidence of UHA over time using Kaplan-Meier method and Kalbfleish and Prentice method. We investigated factors associated with the risk UHA in cause-specific Cox models. We evaluated factors associated with death in hospital in logistic regressions.

Results: One hundred and forty-two patients were included in the study. Eighty-two patients (57.7 %) experienced one or more UHAs, a high proportion of which occurred within 1 month after discharge to home. Most UHAs were related to physical symptoms and were initiated by the patient's family physician. A post-discharge palliative care consultation was associated with a significantly lower incidence of UHAs. Sixty-five patients (47.8 % of the deaths) died in hospital. In a multivariate analysis, living alone and the presence of one or more children at home were associated with death in hospital.

Conclusions: More than 40 % of cancer patients receiving end of life home hospitalization were not readmitted to hospital, reflecting the effectiveness of this type of palliative care setting. However, over half of the UHAs were due to an acute intercurrent event. Our results suggest that more efforts should be focused on anticipating these events at home – primarily via better upstream coordination between hospital physicians and family physicians.

Title: Carer and staff perceptions of end-of-life care provision: case of a hospice-at-home service.

Citation: British Journal of Community Nursing; Jan 2021; vol. 26 (no. 1); p. 30-36

Author(s): Ward ; Sixsmith, Judith; Spiro, Stephen; Graham, Anne; Ballard, Heather; Varvel, Sue; Youell, Jane

Abstract: People requiring palliative care should have their needs met by services acting in accordance with their wishes. A hospice in the south of England provides such care via a 24/7 hospice at home service. This study aimed to establish how a nurse-led night service supported patients and family carers to remain at home and avoid hospital admissions. Semi-structured interviews were carried out with family carers (n=38) and hospice-at-home staff (n=9). Through night-time phone calls and visits, family carers felt supported by specialist hospice staff whereby only appropriate hospital admission was facilitated. Staff provided mediation between family carer and other services enabling more integrated care and support to remain at home. A hospice-at-home night service can prevent unnecessary hospital admissions and meet patient wishes through specialist care at home.

Title: End-of-life care during COVID-19: opportunities and challenges for community nursing.

Citation: British Journal of Community Nursing; Jan 2021; vol. 26 (no. 1); p. 44-46

Author(s): Bowers ; Pollock, Kristian; Oldman, Crystal; Barclay, Stephen

Abstract: The article discusses community nursing challenges and opportunities in end-of-life care during the coronavirus disease 2019 (COVID-19) pandemic in Great Britain. Topics covered include interpersonal communication barriers, the possible missing of important insights in remote consultations, and the flexible responses of nursing teams. Also noted is the need to support care provided at home and in care homes.

Title: After COVID-19: The Way We Die from Now On.

Citation: Cambridge Quarterly of Healthcare Ethics; Jan 2021; vol. 30 (no. 1); p. 69-72

Author(s): ELSNER, ANNA MAGDALENA

Abstract: Ethical issues raised by the outbreak of COVID-19 have predominantly been addressed through a public health ethics lens. This article proposes that the rising COVID-19 fatalities and the World Health Organization's failure to include palliative care as part of its guidance on how to maintain essential health services during the pandemic have exposed palliative care as an underlying global crisis. It therefore calls for a different ethical framework that includes a care ethics perspective and thereby addresses the ways in which the pandemic has triggered new difficulties in ensuring the delivery of appropriate end-of-life care for the dying. The article analyses the structural weaknesses of palliative care accentuated by the pandemic and proposes solutions that could set in motion lasting changes in the way it is delivered beyond COVID-19.

Title: Learning From Experiences of Feeling Heard: A Qualitative Study of Hospice Volunteers.

Citation: *Illness, Crisis & Loss*; Jan 2021; vol. 29 (no. 1); p. 37-50

Author(s): Mundle

Abstract: What does it feel like when someone really listens to you? Data generated in qualitative interviews with ten individual hospice volunteers illuminate the quality of listening they received (and did not receive) from key role models in their lives. Analysis suggests that occasions of receiving listening are rare and pivotal events that can be used to learn more about how to listen to others, particularly in end-of-life care. The article closes with some recommendations for enhancing emotional support for hospice and palliative care volunteers, and for more training in reflective practice, including new approaches to teaching active empathic listening and communication skills.

Title: "It Made Me Feel Like I Didn't Know My Own Body": Patient-Provider Relationships, LGBTQ+ Identity, and End-of-Life Discussions.

Citation: *The American journal of hospice & palliative care*; Feb 2021 ; p. 1049909121996276

Author(s): Pecanac, Kristen E; Hill, Madison Vander; Borkowski, Elizabeth

Purpose: LGBTQ+ individuals experience multiple challenges receiving quality care at the end of life, such as lack of confidence in the healthcare system to address their needs and lack of knowledge about advance care planning. Important gaps remain about the needs of LGBTQ+ individuals in the provider-patient relationship and how critical discussions about the end of life occur or do not occur in that relationship. The purpose of this study is to explore patients' narratives of their relationship with their provider and their experiences discussing end-of-life care with their providers, among patients who do and do not identify as LGBTQ+.

Methods: Twenty-nine attendants of an event devoted to LGBTQ+ health, 15 of which identified as LGBTQ+, completed an altered version of the CAHPS® Patient Narrative Elicitation Protocol. We used inductive content analysis to qualitatively analyze the data.

Results: Respondents described wanting to be heard, finding safety and trust, and valuing competency in their relationship with their provider. Respondents who identified as LGBTQ+ additionally 1) valued providers who avoided making assumptions, 2) looked for cues of safety to indicate they would be accepted by the provider, and 3) sought providers competent in LGBTQ+ care needs. Few respondents had discussed end-of-life care with their provider, although some assumed that their provider may or may not be able to meet their needs based on aspects of their provider-patient relationship.

Conclusions: Strengthening patient-provider relationships may help improve the care of LGBTQ+ populations, particularly for the end of life.

Title: Multicenter Evaluation of 434 Hospital Deaths from COVID-19. How can we improve End-of-Life Care during a Pandemic?

Citation: Journal of pain and symptom management; Feb 2021

Author(s): Dewhurst, Felicity; Billett, Hannah; Simkiss, Lauri; Bryan, Charlotte; Barnsley, Julie; Charles, Max; Fleming, Elizabeth; Grieve, Jennifer; Hacking, Sade; Howorth, Kate; Huggin, Amy; Kavanagh, Emily; Kiltie, Rachel; Lowery, Lucy; Miller, Dene; Nicholson, Alex; Nicholson, Lucy; Paxton, Ann; Porteous, Anna; Rowley, Grace; Snell, Kaly; Woods, Elizabeth; Zabrocki, Elizabeth; Frew, Katherine; Srivastava, Leena

Context: The pandemic has substantially increased the workload of hospital palliative care providers, requiring them to be responsive and innovative despite limited information on the specific end of life care needs of patients with COVID-19. Multi-site data detailing clinical characteristics of patient deaths from large populations, managed by specialist and generalist palliative care providers is lacking.

Objectives: To conduct a large multicenter study examining characteristics of COVID-19 hospital deaths and implications for care.

Methods: A multi-center retrospective evaluation examined 434 COVID-19 deaths in 5 hospital trusts over the period 23/03/20-10/05/20.

Results: Eighty three percent of patients were over 70 and 32% were admitted from care homes. Diagnostic timing indicated over 90% of those who died contracted the virus in the community. Dying was recognized in over 90% of patients, with the possibility of dying being identified less than 48 hours from admission for a third. In over a quarter, death occurred less than 24 hours later. Patients who were recognized to be dying more than 72 hours prior to death are most likely to have access to medication for symptom control.

Conclusion: This large multicenter study comprehensively describes COVID-19 deaths throughout the hospital setting. Clinicians are alert to and diagnose dying appropriately in most patients. Outcomes could be improved by advance care planning to establish preferences, including whether hospital admission is desirable, and alongside this, support the prompt use of anticipatory subcutaneous medications and syringe drivers if needed. Finally, rapid discharges and direct hospice admissions could better utilize hospice beds and improve care.

Title: Treatment withdrawal of the patient on end of life: An analysis of values, ethics and guidelines in palliative care.

Citation: Nursing open; Feb 2021

Author(s): Nnate, Daniel A

Aim: Family surrogate decision-making during the later stage of a patient's life may sometimes result in conflict and emotional distress among the parties involved. The present article aims to promote ethical end-of-life decision-making among healthcare professionals in a view to eliminating any misunderstanding that may arise while meeting the care needs of the patient.

Design: A case study involving a request for treatment withdrawal by the family of a patient on end of life.

Methods: This paper draws upon a scenario encountered during practice to analyse the moral commitments in delivering high-quality end-of-life care with much emphasis on pre-existing palliative care guidelines for adults.

Results: Healthcare professionals are bound by the principle of beneficence, non-maleficence, autonomy and justice. Although the use of guidelines may be tenable, decisions often take into consideration the patient's choice and then weighed against the moral values of healthcare specialists and those required in the profession.

Title: Barriers to Optimal End-of-Life Care for Adolescents and Young Adults With Cancer: Bereaved Caregiver Perspectives.

Citation: Journal of the National Comprehensive Cancer Network : JNCCN; Feb 2021 ; p. 1-6

Author(s): Mack, Jennifer W; Currie, Erin R; Martello, Vincent; Gitzus, Jordan; Isack, Asisa; Fisher, Lauren; Lindley, Lisa C; Gilbertson-White, Stephanie; Roeland, Eric; Bakitas, Marie

Background: Adolescents and young adults (AYAs; aged 15-39 years) with cancer frequently receive intensive measures at the end of life (EoL), but the perspectives of AYAs and their family members on barriers to optimal EoL care are not well understood.

Methods: We conducted qualitative interviews with 28 bereaved caregivers of AYAs with cancer who died in 2013 through 2016 after receiving treatment at 1 of 3 sites (University of Alabama at Birmingham, University of Iowa, or University of California San Diego). Interviews focused on ways that EoL care could have better met the needs of the AYAs. Content analysis was performed to identify relevant themes.

Results: Most participating caregivers were White and female, and nearly half had graduated from college. A total of 46% of AYAs were insured by Medicaid or other public insurance; 61% used hospice, 46% used palliative care, and 43% died at home. Caregivers noted 3 main barriers to optimal EoL care: (1) delayed or absent communication about prognosis, which in turn delayed care focused on comfort and quality of life; (2) inadequate emotional support of AYAs and caregivers, many of whom experienced distress and difficulty accepting the poor prognosis; and (3) a lack of home care models that would allow concurrent life-prolonging and palliative therapies, and consequently suboptimal supported goals of AYAs to live as long and as well as possible. Delayed or absent prognosis communication created lingering regret among some family caregivers, who lost the opportunity to support, comfort, and hold meaningful conversations with their loved ones.

Conclusions: Bereaved family caregivers of AYAs with cancer noted a need for timely prognostic communication, emotional support to enhance acceptance of a poor prognosis, and care delivery models that would support both life-prolonging and palliative goals of care. Work to address these challenges offers the potential to improve the quality of EoL care for young people with cancer.

Title: Undergraduate nursing students' palliative care knowledge and attitudes towards end-of-life care: A cross-sectional descriptive study.

Citation: Contemporary nurse; Feb 2021 ; p. 1-27

Author(s): Gelegjamts, Delgersuren; Yoo, Jae Yong; Kim, Jinhee; Kim, Jin Sun

Background: It is crucial that future nurses be prepared with the knowledge and skills to provide palliative care (PC). However, despite an increased need for PC in Mongolia, little is known regarding Mongolian nursing students' PC preparedness.

Aims: This study aimed to investigate Mongolian nursing students' PC knowledge and attitudes towards end-of-life (EOL) care, as well as identify related predictors. Design: This study had a cross-sectional, descriptive design.

Methods: Participants were 141 students who enrolled in a nursing program at one of four universities from the capital city in Mongolia, selected using convenience sampling. PC knowledge was assessed using the Palliative Care Quiz for Nursing (PCQN), and attitudes towards EOL care were assessed using the Frommelt Attitudes Toward Care of the Dying Scale Form-B (FATCOD).

Results: Mean PCQN score was 7.15 out of 20 (35.8% correct answers). The mean FATCOD score was 64.2 out of 100, indicating that the participants had neutral attitudes towards EOL care. Age (older; $t= 2.060$, $p= .041$), gender (male; $t= -2.371$, $p= .019$), and higher satisfaction with nursing school ($t= 2.049$, $p= .042$) were significant predictors of higher levels of palliative care knowledge. Living in traditional Mongolian housing (Ger; $t= -2.928$, $p= .004$) and having clinical EOL experience ($t= 2.843$, $p= .005$) were significant predictors of positive attitudes towards EOL care.

Conclusions: Mongolian senior nursing students were inadequately prepared to provide PC. PC nursing curricula and textbooks need to be improved to meet an appropriate global standard while remaining sensitive to Mongolian culture. Considering the geographical characteristics and limited resources of Mongolia, online PC courses, and train-the-trainer programs to enable PC experts to prepare nursing educators who can support undergraduate nursing students' theoretical and clinical learning are recommended.

Title: Enabling first and second year doctors to negotiate ethical challenges in end-of-life care: a qualitative study.

Citation: BMJ supportive & palliative care; Feb 2021

Author(s): Donnelly, Sinead; Walker, Simon

Objective: To understand the unique ethical and professional challenges confronting first and second year doctors in caring for people who are dying, and to learn what factors help or hinder them in managing these.

Method: 6 first year and 7 second year doctors were interviewed one-to-one by a senior palliative medicine physician (SD), quarterly over 12 months, using a semistructured approach. Thematic analysis was conducted with the findings, following the general inductive approach.

Results: 21 hours of recorded interviews were analysed by SD, and ethical and professional issues were identified. These were discussed with SW, and sorted into seven broad categories. The participants' accounts of the issues convey a strong ethical sensitivity, developed through their undergraduate training. A recurring challenge for them through their first 12-24 months of work as doctors is being responsible for the decisions, knowing that what they do can have life and death consequences. The participants frequently describe senior doctors as an important source of support, and the lack of such support as leading to moral distress and demoralisation. Another important factor is having opportunity to discuss and reflect on the decisions after they are made. Where such reflection had been facilitated properly, participants displayed considerable growth in their ability to manage ethical challenges.

Conclusion: Senior support and opportunities for reflection need to be recognised as key factors in enabling first and second year to respond appropriately to ethical challenges in end-of-life care, and in sustaining their well-being through this critical stage of their professional life.

Title: What mediates end-of-life care choices?

Citation: The Lancet. Public health; Feb 2021

Author(s): Bloomer, Melissa J; Walshe, Catherine

Title: Dementia and Early Do-Not-Resuscitate Orders Associated With Less Intensive of End-of-Life Care: A Retrospective Cohort Study.

Citation: The American journal of hospice & palliative care; Jan 2021 ; p. 1049909121989020

Author(s): Luth, Elizabeth A; Pan, Cynthia X; Viola, Martin; Prigerson, Holly G

Background: Dementia is a leading cause of death among US older adults. Little is known about end-of-life care intensity and do-not-resuscitate orders (DNRs) among patients with dementia who die in hospital.

Aim: Examine the relationship between dementia, DNR timing, and end-of-life care intensity.

Design: Observational cohort study.

Setting/participants: Inpatient electronic health record extraction for 2,566 persons age 65 and older who died in 2 New York City hospitals in the United States from 2015 to 2017.

Results: Multivariable logistic regression analyses modeled associations between dementia diagnosis, DNR timing, and 6 end-of-life care outcomes. 31% of subjects had a dementia diagnosis; 23% had a DNR on day of hospital admission. Patients with dementia were 18%-40% less likely to have received 4 of 6 types of intensive care (mechanical ventilation AOR: 0.82, 95%CI: 0.67 -1.00; intensive care unit admission AOR: 0.60, 95%CI: 0.49-0.83). Having a DNR on file was inversely associated with staying in the intensive care unit (AOR: 0.57, 95%CI: 0.47-0.70) and avoiding other intensive care measures. DNR placement later during the hospitalization and not having a DNR were associated with more intensive care compared to having a DNR upon admission.

Conclusions: Having dementia and a do-not resuscitate order upon hospital admission are associated with less intensive end-of-life care. Additional research is needed to understand why persons with dementia receive less intensive care. In clinical practice, encouraging advance care planning prior to and at hospital admission may be particularly important for patients wishing to avoid intensive end-of-life care, including patients with dementia.

Title: Developing a family-reported measure of experiences with home-based pediatric palliative and hospice care: a multi-method, multi-stakeholder approach.

Citation: BMC palliative care; Jan 2021; vol. 20 (no. 1); p. 17

Author(s): Boyden, Jackelyn Y; Feudtner, Chris; Deatrck, Janet A; Widger, Kimberley; LaRagione, Gwenn; Lord, Blyth; Ersek, Mary

Background: Many children with serious illnesses are receiving palliative and end-of-life care from pediatric palliative and hospice care teams at home (PPHC@Home). Despite the growth in PPHC@Home, no standardized measures exist to evaluate whether PPHC@Home provided in the U.S. meets the needs and priorities of children and their families.

Methods: We developed and conducted a preliminary evaluation of a family-reported measure of PPHC@Home experiences using a multi-method, multi-stakeholder approach. Our instrument development process consisted of four phases. Item identification and

development (Phase 1) involved a comprehensive literature search of existing instruments, guidelines, standards of practice, and PPHC@Home outcome studies, as well as guidance from a PPHC stakeholder panel. Phase 2 involved the initial item prioritization and reduction using a discrete choice experiment (DCE) with PPHC professionals and parent advocates. Phase 3 involved a second DCE with bereaved parents and parents currently receiving care for their child to further prioritize and winnow the items to a set of the most highly-valued items. Finally, we conducted cognitive interviews with parents to provide information about the content validity and clarity of the newly-developed instrument (Phase 4).

Results: Items were compiled predominantly from three existing instruments. Phase 2 participants included 34 PPHC providers, researchers, and parent advocates; Phase 3 participants included 47 parents; and Phase 4 participants included 11 parents. At the completion of Phase 4, the Experiences of Palliative and Hospice Care for Children and Caregivers at Home (EXPERIENCE@Home) Measure contains 22 of the most highly-valued items for evaluating PPHC@Home. These items include "The care team treats my child's physical symptoms so that my child has as good a quality of life as possible", "I have regular access to on-call services from our care team", and "The nurses have the knowledge, skills, and experience to support my child's palliative or hospice care at home."

Conclusions: The EXPERIENCE@Home Measure is the first known to specifically measure family-reported experiences with PPHC@Home in the U.S. Future work will include formal psychometric evaluation with a larger sample of parents, as well as evaluation of the clinical utility of the instrument with PPHC@Home teams.

Title: Development of a Decision Aid for Patients and Families Considering Hospice.

Citation: Journal of palliative medicine; Jan 2021

Author(s): Tate, Channing E; Venechuk, Gracie; Pierce, Kenneth; Khazanie, Prateeti; Ingle, M Pilar; Morris, Megan A; Allen, Larry A; Matlock, Daniel D

Background: Hospice is underutilized. Miscommunication, decisional complexity, and misunderstanding around engaging hospice may contribute. Shared decision making (SDM), aided by patient decision aids (PtDAs), can improve knowledge and decision quality. Currently, there are no freely available hospice-specific PtDA to facilitate conversations between patients and providers about hospice care. Objective: To develop a theory-based and unbiased hospice specific PtDA.

Design: Guided by the Ottawa Decision Support Framework and International Patient Decision Aid Standards, we used a theory-driven, eight-step, iterative, user-centered approach with multistakeholder input to develop a hospice-specific PtDA for anyone facing end-of-life decisions. Subjects: Feedback was obtained from a 10-member Patient Advisory Panel composed of lay patient advisors; focus groups of hospice providers, family caregivers, and patients; and the Palliative Care Research Group at University of Colorado Hospital consisting of palliative care physicians, midlevel providers, nurses, social workers, chaplains, and researchers.

Results: There are many challenges in developing an unbiased hospice decision aid, including (1) balancing the provision of education (eligibility, payment) with decisional support, (2) clarifying values and incorporating emotion, (3) ideally representing the potential downsides of hospice, and (4) adequately capturing and describing care alternatives to hospice. Within this context, we developed a 12-page article and 17-minute video PtDAs. The PtDA openly acknowledges the emotional complexity of the decision and incorporates values clarification techniques to help decision makers reflect and evaluate their goals and preferences for end-of-life care.

Conclusions: Hospice decision making is complex and emotional, demanding high-quality SDM aided by a formal PtDA. This work resulted in a freely available article and video PtDA for patients considering hospice. The effectiveness and implementation of these tools will be studied in future research. Clinical Trials Registration (NCT03794700 & NCT04458090).

Title: Advance Care Planning for Adolescents and Young Adults with Cancer: A Retrospective Case Note Audit from a Regional Specialist Center in the United Kingdom.

Citation: Journal of adolescent and young adult oncology; Dec 2020

Author(s): Murray, Hazel; Pettitt, Nicola; Tomas, Jon

Abstract: The extent of Advance Care Planning (ACP) among Adolescent and Young Adult (AYA) cancer patients is not well characterized. This retrospective case note audit scrutinized the records of all AYA patients (aged 16-25 years) known to a regional specialist center in the United Kingdom, and who died between 2013 and 2019, for evidence of ACP. Eighty-four patients were included. ACP was identified for 67% of patients. Sixty-four percent expressed a preferred place of death; actual place of death reflected this in 65% of cases. Creation of a bespoke document may help to standardize ACP and improve end-of-life care.

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

Citation: Expert opinion on drug safety; Dec 2020 ; p. 1-11

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

Introduction: 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 utilization. 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.

Title: Delivery of Palliative Care in Acute Care Hospitals: A Population-Based Retrospective Cohort Study Describing the Level of Involvement and Timing of Inpatient Palliative Care in the Last Year of Life.

Citation: Journal of palliative medicine; Dec 2020

Author(s): Webber, Colleen; Chan, Raphael; Scott, Mary; Brown, Catherine; Spruin, Sarah; Hsu, Amy T; Bush, Shirley H; Isenberg, Sarina R; Quinn, Kieran; Scott, John; Tanuseputro, Peter

Background: Much end-of-life care is provided in hospital, yet little is known about the delivery of palliative care during end-of-life hospitalizations.

Objectives: To characterize the level of palliative care involvement across hospitalizations in the last year of life. **Methods:** A population-based retrospective cohort study of adults in Ontario, Canada, who died between April 1, 2012, and March 31, 2017, and had at least one acute care hospitalization in their last year of life. Using linked administrative health data, we developed a hierarchy of inpatient palliative care involvement reflecting the degree to which care was delivered with palliative intent. This hierarchy was based on palliative care diagnosis and service provider codes on hospitalization records and physician claims. We examined variations in the level of palliative care involvement across key patient characteristics.

Results: In the last year of life, 65.1% of hospitalizations had no indication of palliative care involvement, 16.7% had a low level of involvement, 13.5% had a medium level of involvement, and 4.7% had a high level of involvement. Most hospitalizations with palliative care involvement (85.6%) occurred in the two months before death. Compared to patients who received no inpatient palliative care, patients who received a high level of palliative care involvement tended to be younger, died of cancer, resided in urban or lower income neighborhoods, and had fewer chronic conditions.

Discussion: While many hospitalizations occurred in the last year of life, the majority did not involve palliative care, and very few had a high level of palliative care involvement.

Title: "Why Couldn't I Go in To See Him?" Bereaved Families' Perceptions of End-of-Life Communication During COVID-19.

Citation: Journal of the American Geriatrics Society; Dec 2020

Author(s): Feder, Shelli; Smith, Dawn; Griffin, Hilary; Shreve, Scott T; Kinder, Daniel; Kutney-Lee, Ann; Ersek, Mary

Background/objective: The COVID-19 pandemic has resulted in rapid changes to end-of-life care for hospitalized older adults and their families, including visitation restrictions. We examined bereaved families' perceptions of the quality of end-of-life communication among Veterans, families and staff in Veterans Affairs (VA) medical centers during the COVID-19 pandemic.

Design: Qualitative descriptive study using data from a survey of bereaved family members of Veterans administered from March-June 2020. Data were analyzed using qualitative content analysis.

Setting: VA medical centers with the highest numbers of COVID-19 cases during the study period.

Participants: Next-of-kin of 328 Veterans who died in one of 37 VA medical centers' acute care, intensive care, nursing home, or hospice units.

Measurements: Open-ended survey questions (response rate = 37%) about family member's perceptions of: 1) communication with the healthcare team about the patient, 2) communication with the patient, and 3) use of remote communication technologies.

Results: Bereaved family members identified contextual factors perceived to impact communication quality including: allowing family at the bedside when death is imminent, fears that the patient died alone, and overall perceptions of VA care. Characteristics of perceived high-quality communication included staff availability for remote communication and being kept informed of the patient's condition and plan of care. Low-quality communication with staff was perceived to result from limited access to staff, insufficient updates regarding the patient's condition, and when the family member was not consulted about care decision-making. Communication quality with the patient was facilitated or impeded by the availability and use of video-enabled remote technologies.

Conclusion: Communication between patients, families, and healthcare teams at the end of life remains critically important during times of limited in-person visitation. Families report that low-quality communication causes profound distress that can affect the quality of dying and bereavement. Innovative strategies are needed to ensure that high-quality communication occurs despite pandemic-related visitation restrictions.

Title: A Tale of Two Surveys: Life-Affirming Strategy of Mortuary Improves the Quality of Bereavement Care After Hospital Death.

Citation: Omega; Feb 2021 ; p. 30222821992188

Author(s): Lau, Tiffany W S; Chan, Gavin S W; Yip, H Y; Poon, Jackie C K; Tsang, Gary K F; Yip, Winnie P W; Chow, Amy Y M; Beh, Philip S L

Background: The mortuary plays an important, under-recognized role in end-of-life care. A 'Life-affirming strategy' was introduced in the mortuary of a university hospital to enhance respect for the deceased and next-of-kin (NOK).

Design: NOK who collected bodies in the mortuary of a university hospital participated in a survey. The satisfaction scores, needs and expectations were compared with a similar survey from 2015.

Results: The overall experience for NOK improved significantly compared with 2015. The greatest improvement was achieved in 'mortuary environment', 'attitude of mortuary staff' and 'body viewing arrangement in the mortuary'. The perceived need for additional psychosocial support was significantly reduced.

Conclusions: Results demonstrate success of the life-affirming strategy in enhancing end-of-life care for bereaved families. The person-centered approach modernizes and professionalizes mortuary services, with a positive impact on the deceased, NOK, mortuary staff, hospital administration and wider community.

Title: Cultivating Cultural Competence: How Are Hospice Staff Being Educated to Engage Racially and Ethnically Diverse Patients?

Citation: The American journal of hospice & palliative care; Feb 2021; vol. 38 (no. 2); p. 169-174

Author(s): Boucher, Nathan A; Johnson, Kimberly S

Background: Compared to Whites, racial/ethnic minorities are less likely to enroll in hospice and if they enroll, more likely to experience poor quality care. Building cultural competence (CC) among hospice staff is a strategy that may reduce disparities.

Objective: To describe the state of CC training across hospices.

Design: National survey of hospices' practices to promote CC.

Results: A total of 197 hospices participated; most were not-for-profit (80%) with an average daily census less than 100 (47%); 73% offered staff cultural competence training (CCT). There were no differences in characteristics of hospices who offered CCT and those that did not. Of hospices offering CCT, 61% held it annually. Most trainings were 1 hour (60%); content was delivered via web (58%) and/or lecture (58%). While over 90% of staff (i.e., nurses, social workers, chaplains) completed CCT, a smaller proportion of medical directors (64%), senior leaders (71%) and board members (26%) did so. Most common topics were: cross-cultural communication, death/illness beliefs, spirituality's role, and healthcare disparities. The majority focused on African-Americans (83%), Hispanics (76%), and Asians (62%)-the most common U.S. minority groups. Almost 30% reported no effectiveness assessment of CCT, while 51% reported a quiz at the end of training. Most hospices offered some CCT.

Conclusions: CCT has been shown to improve healthcare providers' knowledge and skills in caring for diverse patients and it is associated with increased patient satisfaction. Future research should evaluate effectiveness of CCT in improving the ability of hospices to deliver high quality end-of-life care to diverse groups of older adults.

Title: Time to Deprescribe: A Time-Centric Model for Deprescribing at End of Life.

Citation: Journal of palliative medicine; Feb 2021; vol. 24 (no. 2); p. 273-284

Author(s): Meyer-Junco, Laura

Abstract: In end-of-life care, deprescribing practices may vary considerably from one practitioner to the next, although most published frameworks for evaluating medication appropriateness in advanced illness consider three key principles (1) patient and caregiver goals, (2) remaining life expectancy (LE), and (3) medication time to benefit (TTB). The objective of this article is to provide clinicians with a structured, consistent approach for deprescribing that does not replace clinical judgment or the preferences of patients and their families but enhances it through clinical data. The emphasis will be on the time component of published models, including how to estimate remaining LE and medication TTB. Through case examples of two new hospice admissions, LE and TTB will be estimated and applied to deprescribing decisions. This time-centric approach may satisfy the palliative and hospice clinicians' desire for clear clinical justification for medication discontinuation while at the same time providing a strategy for communicating deprescribing rationale to patients and families.

Title: NeuroEthics and End of Life Care.

Citation: Emergency medicine clinics of North America; Feb 2021; vol. 39 (no. 1); p. 217-225

Author(s): Cacic, Kelsey; Bonomo, Jordan

Abstract: The emergency department is where the patient and potential ethical challenges are first encountered. Patients with acute neurologic illness introduce a unique set of

dilemmas related to the pressure for ultra-early prognosis in the wake of rapidly advancing treatments. Many with neurologic injury are unable to provide autonomous consent, further complicating the picture, potentially asking uncertain surrogates to make quick decisions that may result in significant disability. The emergency department physician must take these ethical quandaries into account to provide standard of care treatment.

Title: Palliative and end of life care for a child: Understanding parents' coping strategies.

Citation: Acta paediatrica (Oslo, Norway : 1992); Feb 2021; vol. 110 (no. 2); p. 673-681

Author(s): Darlington, Anne-Sophie; Randall, Duncan; Leppard, Lisa; Koh, Michelle

Aim: Understanding of coping strategies that parents use before the death of their child is crucial and will enable us to best provide support. The current study aimed to explore parents' coping strategies, and map these onto an existing theoretical framework.

Methods: Bereaved parents and parents of a child with a life-limiting/threatening condition were interviewed to investigate coping strategies, recruited through Intensive Care Units (2 Neonatal, 2 Paediatric, 1 Paediatric Cardiac) and a children's hospice. Analysis focused on coping strategies and mapping these onto the framework.

Results: 24 parents of 20 children were interviewed and identified. Parents use a variety of coping strategies (n = 25) such as humour, staying positive, advocating and staying strong for others, expressing emotions and preparing, while also living life to the full, supported by others. The themes were successfully mapped onto the theoretical framework, which focuses on the constructs of approach and avoidance, as well as coping for self and others.

Conclusion: The findings have provided a detailed account of the breadth and depth of coping strategies parents use, including those classed as avoidance. The strategies were successfully mapped onto the theoretical framework. Future research should investigate changes over times, and associations to negative long-term outcomes.

Title: Expanding HIV-positive organ donation

Citation: The Lancet; Jan 2021; vol. 397 (no. 10270); p. 184

Author(s):

Abstract: Jacqui Thornton reports. Since the first organ transplants were carried out, the mismatch between demand and supply of donated tissues has presented a huge challenge. After they were pioneered in South Africa in 2008, surgeons have reported follow-up on 51 transplants. Since 2013, 25 have been reported in the USA. The alternative was certain death within a few months at best", she says. Since transplants began, the aim was to use the best possible organs for the most suitable recipients, matched by tissue type, race, and age, with strict criteria in place. 30 years ago, transplants were not widely done on HIV-positive patients because of their poorer survival compared with HIV-negative people. In the USA, such transplants were actually outlawed—in 1988, the use of organs from donors "infected with the etiologic agent for AIDS" was banned through the National Organ Transplant Act. Since the introduction of triple combination ART in 1996, people living with HIV have been more accepted as transplant recipients.

Title: Advanced care planning during the COVID-19 pandemic: ceiling of care decisions and their implications for observational data.

Citation: BMC Palliative Care; Jan 2021; vol. 20 (no. 1); p. 1-11

Author(s): Straw ; McGinlay, Melanie; Drozd, Michael; Slater, Thomas A.; Cowley, Alice; Kamalathasan, Stephe; Maxwell, Nicholas; Bird, Rory A.; Koshy, Aaron O.; Prica, Milos; Patel, Peysh A.; Relton, Samuel D.; Gierula, John; Cubbon, Richard M.; Kearney, Mark T.; Witte, Klaus K.

Background: Observational studies investigating risk factors in coronavirus disease 2019 (COVID-19) have not considered the confounding effects of advanced care planning, such that a valid picture of risk for elderly, frail and multi-morbid patients is unknown. We aimed to report ceiling of care and cardiopulmonary resuscitation (CPR) decisions and their association with demographic and clinical characteristics as well as outcomes during the COVID-19 pandemic.

Methods: Retrospective, observational study conducted between 5th March and 7th May 2020 of all hospitalised patients with COVID-19. Ceiling of care and CPR decisions were documented using the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process. Unadjusted and multivariable regression analyses were used to determine factors associated with ceiling of care decisions and death during hospitalisation.

Results: A total of 485 patients were included, of whom 409 (84.3%) had a documented ceiling of care; level one for 208 (50.9%), level two for 75 (18.3%) and level three for 126 (30.8%). CPR decisions were documented for 451 (93.0%) of whom 336 (74.5%) were 'not for resuscitation'. Advanced age, frailty, White-European ethnicity, a diagnosis of any co-morbidity and receipt of cardiovascular medications were associated with ceiling of care decisions. In a multivariable model only advanced age (odds 0.89, 0.86–0.93 $p < 0.001$), frailty (odds 0.48, 0.38–0.60, $p < 0.001$) and the cumulative number of co-morbidities (odds 0.72, 0.52–1.0, $p = 0.048$) were independently associated. Death during hospitalisation was independently associated with age, frailty and requirement for level two or three care.

Conclusion: Ceiling of care decisions were made for the majority of patients during the COVID-19 pandemic, broadly in line with known predictors of poor outcomes in COVID-19, but with a focus on co-morbidities suggesting ICU admission might not be a reliable end-point for observational studies where advanced care planning is routine.

Title: The new 'opt-out' organ donation English law: Is the NHS ready for this?

Citation: Clinical Medicine; Jan 2021; vol. 21 (no. 1)

Author(s): Mahenthiran

Abstract: In May 2020, the new 'opt-out' organ donation law was passed in England. This law is a crucial step to help battle the long waiting lists of patients awaiting a transplant. This article aims to explore some of the challenges that the transplant teams may face with the new law, as well as raising awareness among the junior doctors, especially with the new COVID-19 transplant guidelines. Successful transplantations require immense training of healthcare professionals, fast retrieval services, pre- and postoperative care of patients, intensive care management, life-long follow-up and management of patients. Organ transplant surgery is a life-changing moment for a patient. Ultimately, commissioning groups, clinicians and managers need to work together, evaluate the changes required and enact thorough business plans to ensure the NHS is not overwhelmed. Together with increasing the awareness of organ donation within the public, the government needs to support the

NHS to fund, train and manage transplant centres to welcome this much-awaited 'opt-out' organ donation law in England successfully.

Title: Shared electronic care coordination systems following referral to hospice.

Citation: British Journal of Community Nursing; Feb 2021; vol. 26 (no. 2); p. 58-61

Author(s): Sampey ; Finucane, Anne M.; Spiller, Juliet

Abstract: In Scotland, the Key Information Summary (KIS) enables health providers to access key patient information to guide decision-making out-of-hours. KISs are generated in primary care and rely on information from other teams, such as community specialist palliative care teams (CSPCTs), to keep them up-to-date. This study involved a service evaluation consisting of case note reviews of new referrals to a CSPCT and semi-structured interviews with palliative care community nurse specialists (CNSs) regarding their perspectives on KISs. Some 44 case notes were examined, and 77% of patients had a KIS on CSPCT referral. One-month post-referral, all those re-examined (n=17) had a KIS, and 59% KISs had been updated following CNS assessments. CNSs cited anticipatory care planning (ACP) as the most useful aspect of KIS, and the majority of CNSs said they would appreciate KIS editing access. A system allowing CNSs to update KISs would be acceptable to CNSs, as it could facilitate care co-ordination and potentially improve comprehensiveness of ACP information held in KISs.

Title: Burnout and compassion fatigue among organ and tissue donation coordinators: a scoping review.

Citation: BMJ open; Dec 2020; vol. 10 (no. 12); p. e040783

Author(s): Silva E Silva, Vanessa; Hornby, Laura; Almost, Joan; Lotherington, Ken; Appleby, Amber; Silva, Amina Regina; Rochon, Andrea; Dhanani, Sonny

Objectives: To collate and synthesise available literature on burnout and compassion fatigue (CF) among organ and tissue donation coordinators (OTDCs) and to respond to the research question: what is known about burnout and CF among OTDCs worldwide?

Design: Scoping review using Joanna Briggs Institute methodology for scoping reviews.

Data sources: Medline, EMBASE, PsycINFO, CINAHL, LILACS, PTSpubs and grey literature (ResearchGate, OpenGrey, Organ Donation Organization (ODO) websites, open access theses and dissertations) up to April 2020.

Study selection: Studies reporting aspects of burnout and CF among OTDCs, including risk and protective factors.

Data extraction: Two reviewers independently screened the studies for eligibility and extracted data from chosen sources using a data extraction tool developed for this study; NVIVO was used to perform a qualitative directed content analysis.

Results: The searches yielded 741 potentially relevant records, of which 29 met the inclusion criteria. The majority of articles were from the USA (n=7, 24%), Canada (n=6, 21%) and Brazil (n=6, 21%), published between 2013 and 2020 (n=13, 45%) in transplant journals (n=11, 38%) and used a qualitative design approach (n=12, 41%). In the thematic analysis, we classified the articles into five categories: (1) burnout characteristics, (2) CF characteristics, (3) coping strategies, (4) protective factors and (5) ambivalence.

Conclusion: We identified aspects of burnout and CF among OTDCs, including defining characteristics, demographic predispositions, protective factors, coping strategies, precursors, consequences and personal ambivalences. Researchers described burnout and CF characteristics but did not use consistent terms when referring to CF and burnout, which may have hindered the identification of all relevant sources. This gap should be addressed by the application of consistent terminology, systematic approaches and appropriate research methods that combine quantitative and qualitative investigation to examine the underlying reasons for the development of burnout and CF among OTDCs.

Title: 'We needed to talk about it': The experience of sharing the emotional impact of health care work as a panellist in Schwartz Center Rounds® in the UK.

Citation: Journal of Health Services Research & Policy; Jan 2021; vol. 26 (no. 1); p. 20-27

Author(s): McCarthy ; Taylor, Cath; Leamy, Mary; Reynolds, Ellie; Maben, Jill

Objectives: Schwartz Center Rounds® ('Rounds') are multidisciplinary forums where health care staff come together to reflect upon the emotional impact of their work. In each Round, a small number of staff (panellists) share experiences through stories to trigger reflection in audience members. Previous research has identified impacts associated with Rounds' attendance, but little is known about the experience and impact of Rounds from panellists' perspectives. This study is the first to explore the role of disclosure and reflection through storytelling in Rounds, specifically exploring panellists' motivations, experiences and reported impacts associated with panel participation.

Methods: Interviews with 50 panellists, from nine case-study sites in the United Kingdom, representing acute, community and mental health National Health Service trusts and hospices. Data were analysed using thematic analysis.

Results: Most panellists spoke positively about their experience of sharing their stories in Rounds. Reported impacts included: increased emotional resilience and acceptance of experiences; reduced negative assumptions about colleagues and increased approachability and trust increasing tolerance and compassion; the creation of a space to stop and think and to reframe negative patient experiences facilitating greater empathy and emotional disclosure becoming more visible and normative, thereby helping change culture. Impacts on staff were similar regardless of contextual variability, including their professional group or role, with the exception of impact on patient care, which was not mentioned by non-clinical staff. The extent of panel preparation and audience characteristics (e.g. size, composition and response to their stories) influenced panellists' experiences and outcomes.

Conclusions: Rounds highlight the important role of disclosure and reflection through storytelling to support panellists with the emotional aspects of their work, providing a space for support with the emotional demands of health care, reducing the need for employees to be stoic. Panel participation also offers an important source of validation in organizations marked by scrutiny.

Title: Happiness at the End of Life: A Qualitative Study.

Citation: American Journal of Hospice & Palliative Medicine; Mar 2021; vol. 38 (no. 3); p. 223-229

Author(s): O'Callaghan ; Bickford, Ben; Rea, Conor; Fernando, Antonio; Malpas, Phillipa

Background: Happiness is a core ingredient of health and well-being, yet relatively little is known about what happiness means for individuals near the end of life, and whether perceptions of happiness change as individuals approach the end of their lives.

Aim: The aim of this study was to explore, through interviews, how individuals experiencing hospice care understood and conceptualized happiness.

Design: Qualitative interviews with hospice patients were analyzed thematically.

Setting/Participants: Adult patients (n = 20) in a New Zealand hospice who were receiving palliative care and who could give their informed consent were invited by hospice nurse coordinators to an interview.

Results: Four themes emerged from analysis of the transcribed interviews. Participants defined happiness most frequently and in most depth in relation to connection with others. They identified being in the present moment, particularly in relation to nature, and that happiness had become less associated with money, status, or possessions. They had an attitude of determination to focus on what mattered now.

Conclusion: Patients receiving palliative care were generally happy with their lives, appreciated the simpler aspects of life away from the material. There was a common exhortation to young people to avoid focusing too much on acquisition and the internet and to prioritize instead social connection and engagement with the natural world.

Title: Survival in hospice patients with dementia: the effect of home hospice and nurse visits.

Citation: Journal of the American Geriatrics Society; Feb 2021

Author(s): Luth, Elizabeth A; Russell, David J; Xu, Jiehui Cici; Lauder, Bonnie; Ryvicker, Miriam B; Dignam, Ritchell R; Baughn, Rosemary; Bowles, Kathryn H; Prigerson, Holly G

Background: Hospice patients with dementia are at increased risk for live discharge and long lengths of stay (>180 days), causing patient and family caregiver stress and burden. The location and timing of clinician visits are important factors influencing whether someone dies as expected, in hospice, or experiences a live discharge or long length of stay.

Objective: Examine how home hospice and nurse visit frequency relate to dying in hospice within the Medicare-intended 6-month period.

Design: Retrospective cohort study.

Setting: Non-profit hospice agency.

Participants: Three thousand eight hundred and thirty seven patients with dementia who received hospice services from 2013 to 2017. **METHODS** Multivariable survival analyses examined the effects of receiving home hospice (vs. nursing home) and timing of nurse visits on death within 6 months of hospice enrollment, compared to live discharge or long length of stay. Models adjust for relevant demographic and clinical factors.

Results: Thirty-nine percent (39%) of patients experienced live discharge or long length of stay. Home hospice patients were more likely to experience live discharge or long length of stays (HR for death: 0.77, 95%CI: 0.69-0.86, p < 0.001). Frequency of nurse visits was inversely associated with live discharge and long lengths of stay (HR for death: 2.87, 95%CI: 2.47-3.33, p < 0.001).

Conclusion: Nearly 40% of patients with dementia in our study experienced live discharge or a long length of stay. Additional research is needed to understand why home hospice may result in live discharge or a long length of stay for patients with dementia. Nurse visits were associated with death, suggesting their responsiveness to deteriorating patient health. Hospice guidelines may need to permit longer stays so community-dwelling patients with

dementia, a growing segment of hospice patients, can remain continuously enrolled in hospice and avoid burden and costs associated with live discharge.

Title: Hospice care access inequalities: a systematic review and narrative synthesis.

Citation: BMJ supportive & palliative care; Feb 2021

Author(s): Tobin, Jake; Rogers, Alice; Winterburn, Isaac; Tullie, Sebastian; Kalyanasundaram, Asanish; Kuhn, Isla; Barclay, Stephen

Background: Inequalities in access to hospice care is a source of considerable concern; white, middle-class, middle-aged patients with cancer have traditionally been over-represented in hospice populations.

Objective: To identify from the literature the demographic characteristics of those who access hospice care more often, focusing on: diagnosis, age, gender, marital status, ethnicity, geography and socioeconomic status.

Design: Systematic literature review and narrative synthesis.

Method: Searches of Medline, PsycINFO, CINAHL, Web of Science, Assia and Embase databases from January 1987 to end September 2019 were conducted. Inclusion criteria were peer-reviewed studies of adult patients in the UK, Australia, New Zealand and Canada, receiving inpatient, day, outpatient and community hospice care. Of the 45 937 titles retrieved, 130 met the inclusion criteria. Narrative synthesis of extracted data was conducted.

Results: An extensive literature search demonstrates persistent inequalities in hospice care provision: patients without cancer, the oldest old, ethnic minorities and those living in rural or deprived areas are under-represented in hospice populations. The effect of gender and marital status is inconsistent. There is a limited literature concerning hospice service access for the LGBTQ+ community, homeless people and those living with HIV/AIDS, diabetes and cystic fibrosis.

Conclusion: Barriers of prognostic uncertainty, institutional cultures, particular needs of certain groups and lack of public awareness of hospice services remain substantial challenges to the hospice movement in ensuring equitable access for all.

Title: Constructing a new role for family carers and volunteers providing care towards the end of life: an action research approach exploring a new model of hospice care.

Citation: Health & social care in the community; Feb 2021

Author(s): Walshe, Catherine; Barnes, Helen; Turner, Mary; Hughes, Sean

Abstract: The objective of this study was to understand the conceptualisation and development of a novel way of providing end-of-life care in a Cottage Hospice setting, with a focus on the role of family carers and volunteers within this care model. A participatory action research design enabled a situational analysis, together with change processes. The study setting was a hospice in the South of England, and its network of wider associates in the local health economy. Participants were purposively sampled to provide relevant information. Data collection (2017-2018) included documents (e.g., meeting minutes) and interviews (individual and group) with external (e.g., GPs) and internal (e.g., staff, managers, volunteers, patients, family carers) stakeholders. These were followed by action cycles conducted by a core action group which explored issues related to family and young carers,

the relationship between the main and Cottage Hospices and workforce engagement with the change process. Iterative, inductive, thematic analysis was followed by axial coding facilitated within NVivo. Twenty-six individual and eight follow-up interviews, two group interviews and five discrete action cycles were completed. At the core was a focus on disruption of the norm of professionally provided and mediated care, with three main themes: imagining the future of Cottage Hospice (growing demand, a home-like space, innovative roles for families and volunteers); developing the role of family caregivers (making agreements, meeting needs, social inclusion and the 'unknown' expectations) and quality and safety issues (negative perceptions, personalised care and volunteer roles). Change was viewed as both a threat and an opportunity. Cottage Hospice represents the possibility of a truly new way of meeting the needs of dying people and their families, and could act as a template for progressive service developments elsewhere.

Title: Gypsy, Traveller and Roma experiences, views and needs in palliative and end of life care: a systematic literature review and narrative synthesis.

Citation: BMJ supportive & palliative care; Feb 2021

Author(s): Dixon, Kathryn Charlotte; Ferris, Rebecca; Kuhn, Isla; Spathis, Anna; Barclay, Stephen

Background: Gypsy, Traveller and Roma communities are known to experience health inequalities. There has been little focus on palliative care in these communities despite the well-recognised inequalities of access to palliative care in other minority ethnic groups.

Methods: Systematic review and thematic analysis of the current evidence concerning palliative care experiences, views and needs of Gypsy, Traveller and Roma communities. Medline, Embase, Emcare, CINAHL, PsycINFO, Web of Science, Scopus, AMED, Global Health, Psychological and Behavioural Sciences Collection and BNI were searched up to November 2020, alongside author and citation searching. NHS England, Hospice UK, National Audit Office and OpenGrey were searched as grey literature sources. Gough's 'Weight of Evidence' framework was used for quality appraisal.

Results: Thirteen papers from eight studies were included in the synthesis. Although there was variation between communities, three overarching and inter-related themes were identified. (1) Strong family and community values include a preference for healthcare to be provided from within the community, duty to demonstrate respect by attending the bedside and illness as a community problem with decision-making extending beyond the patient. (2) Distinct health beliefs regarding superstitions around illness, personal care, death rituals and bereavement. (3) Practical barriers to non-community healthcare provision include communication difficulties, limited awareness of and access to services, tensions between patients and healthcare professionals and lack of training in delivering culturally appropriate care.

Conclusion: A wide range of factors influence Gypsy, Traveller and Roma community access to palliative care. Community diversity requires sensitive and highly individualised approaches to patient care. PROSPERO REGISTRATION NUMBER 42019147905.

Title: Virtual reality in specialist palliative care: a feasibility study to enable clinical practice adoption.

Citation: BMJ supportive & palliative care; Feb 2021

Author(s): Nwosu, Amara Callistus; Mills, Mark; Roughneen, Simon; Stanley, Sarah; Chapman, Laura; Mason, Stephen R

Background: The use of virtual reality (VR) is increasing in palliative care. However, despite increasing interest in VR, there is little evidence of how this technology can be implemented into practice.

Aims: This paper aims to: (1) explore the feasibility of implementing VR therapy, for patients and caregivers, in a hospital specialist inpatient palliative care unit and a hospice, and (2) to identify questions for organisations, to support VR adoption in palliative care.

Methods: The Samsung Gear VR system was used in a hospital specialist palliative inpatient unit and a hospice. Patients and caregivers received VR distraction therapy and provided feedback of their experience. Staff completed a feedback questionnaire to explore their opinion of the usefulness of VR in palliative care. A public engagement event was conducted, to identify questions to support implementation of VR in palliative care settings.

Results: Fifteen individuals (12 (80%) patients and 3 (20%) caregivers) participated. All had a positive experience. No adverse effects were reported. Ten items were identified for organisations to consider ahead of adoption of VR in palliative care. These were questions about: the purpose of VR; intended population; supporting evidence; session duration; equipment choice; infection control issues; content choice; setting of VR; person(s) responsible for delivery and the maintenance plan.

Conclusions: It is feasible to use VR therapy in palliative care; however, further evidence about its efficacy and effectiveness is needed. Palliative care practitioners considering VR use should carefully consider several factors, to ensure that this technology can be used safely and effectively in clinical practice.

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

Disclaimer:

The results of your literature search are based on the request that you made, and consist of a list of references, some with abstracts. Royal United Hospital Bath Healthcare Library will endeavour to use the best, most appropriate and most recent sources available to it, but accepts no liability for the information retrieved, which is subject to the content and accuracy of databases, and the limitations of the search process. The library assumes no liability for the interpretation or application of these results, which are not intended to provide advice or recommendations on patient care.