End of Life Care
Current Awareness Bulletin

November 2021

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Title: "If I die, they do not care": U.K. National Health Service staff experiences of betrayal-based moral injury during COVID-19.

Author(s): French, Lorna; Hanna, Paul; Huckle, Catherine

Objective: The COVID-19 pandemic brought unparalleled pressure, stress, and a dramatic change in practice to health care systems across the world. National Health Service (NHS) staff have reported higher levels of burnout, stress, and other mental health issues that they relate directly to the impact of the pandemic. Burnout is often used as a "catch-all" term for psychological distress in the workplace, and it has been suggested that, during the pandemic, experience of "burnout" may be influenced by "moral injury": the distress that can arise from actions, or lack of action, that are seen to violate one's ethical code. This study investigates NHS staff experiences of burnout and betrayal-based moral injury, in which a trusted authority betrays "what is right."

Method: Sixteen NHS staff members were interviewed in relation to their experiences during the COVID-19 pandemic, and data were thematically analyzed.

Results: Three themes were identified: abandonment as betrayal; dishonesty and lack of accountability; and fractured relationship to management or the NHS.

Conclusions: This analysis concludes that self-identified "burnout" in NHS staff may include a significant moral component, and that failure to engage in moral repair following betrayal-based moral injury may relate to a long-term loss of trust or fractured relationship with the organization. In addition to traditional trauma-informed psychological support, leadership at all levels should be trained to be aware of betrayal-based moral injury and to engage in moral repair to reduce staff intent to leave and encourage mutual trust. (PsycInfo Database Record (c) 2021 APA, all rights reserved).

Title: The role of hospice and palliative care in supporting and fostering trust among the LGBTQ+ population.

Author(s): Dhawan ; Ovalle, Anais A.; Yeh, Jonathan C.

Title: Delivering Hospice Care During the COVID-19 Pandemic.

Author(s): Medina ; Huey-Ming Tzeng

Abstract: This discussion article highlights the challenges of providing hospice care in nursing homes since the start of the COVID-19 (coronavirus disease 2019) pandemic and illuminates practice changes needed in nursing homes. The article provides an overview of the expectations of hospice care, explains the differences in delivering hospice care during the COVID-19 pandemic, examines social isolation and emotional loneliness and the role of familial caregivers, and describes policy changes related to the COVID-19 affecting hospice care delivery in nursing homes. This article answers the following questions: (1) How did residents receiving hospice care have their needs met during the COVID-19 pandemic? (2) What areas of nursing home care need to be improved through governmental policy and restructuring? This article also summarized the lessons learned as a result of the COVID-19

pandemic and provided practical implications for nursing, specific to changes in hospice care deliveries for nursing home residents.

Title: Social Model Hospice Home.

Author(s): Farrar ; Scott, Kelley Easterling; Clifton, Shari; Clark, Jennifer K.
Source: Journal of Hospice & Palliative Nursing; Sep 2021; vol. 23 (no. 5); p. 484-491

Abstract: The term social model hospice first appeared late in the 20th century as a label for a complementary model to medical hospice care. Two decades later, the term is inconsistently defined and used by scholars, health care providers, public consumers, and those within the movement. The purpose of this review is to trace the development of the concept and confirm an evolving definition based on Rodgers' evolutionary method. Database and hand searching was done for the years 1975 to 2020, resulting in 25 publications for analysis. Unique antecedents include presence of a resource crisis, unmet needs falling outside the scope of medical hospice care, and desire to experience death outside the medical system and/or personal home. Attributes include a dedicated home, round-the-clock, individualized end-of life care; care option when dying at home becomes unmanageable; collaboration with medical hospice services; nonprofit organization funded by community philanthropy; environment to support loved ones; and community volunteer involvement. Noted consequences are effective end-of-life care for dying patients and their families, innovative health care design, nationwide network of like-minded providers, and platform for end of- life community education. Clarity of the concept will facilitate access to end-of-life care, further the model's development, formalize research endeavors, and foster community education.

Title: Patient Portals to Support Palliative and End-of-Life Care: Scoping Review.

Citation: Journal of Medical Internet Research; Sep 2021; vol. 23 (no. 9)
Author(s): Ingle ; Valdovinos, Cristina; Ford, Kelsey L; Zhou, Shou; Bull, Sheana; Gornail, Starlynne; Zhang, Xuhong; Moore, Susan; Portz, Jennifer

Background: Although patient portals are widely used for health promotion, little is known about the use of palliative care and end-of-life (PCEOL) portal tools available for patients and caregivers.

Objective: This study aims to identify and assess the user perspectives of PCEOL portal tools available to patients and caregivers described and evaluated in the literature.

Methods: We performed a scoping review of the academic literature directed by the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) extension for Scoping Review and searched three databases. Sources were included if they reported the development or testing of a feature, resource, tool, or intervention; focused on at least one PCEOL domain defined by the National Coalition for Hospice and Palliative Care; targeted adults with serious illness or caregivers; and were offered via a patient portal tethered to an electronic medical record. We independently screened the titles and abstracts (n=796) for eligibility. Full-text (84/796, 10.6%) sources were reviewed. We abstracted descriptions of the portal tool name, content, targeted population, and reported user acceptability for each tool from included sources (n=19).

Results: In total, 19 articles describing 12 tools were included, addressing the following PCEOL domains: ethical or legal (n=5), physical (n=5), and psychological or psychiatric

(n=2). No tools for bereavement or hospice care were identified. Studies have reported high acceptability of tools among users; however, few sources commented on usability among older adults.

Conclusions: PCEOL patient portal tools are understudied. As medical care increasingly moves toward virtual platforms, future research should investigate the usability and acceptability of PCEOL patient portal resources and evaluate their impact on health outcomes.

Title: Patient awareness of palliative care: systematic review.

Author(s): Masoud, Bahrami; Imane, Bagheri; Naiire, Salmani

Background: One of the barriers to the integration of palliative care within the process of patient care and treatment is the lack of awareness of patients about palliative care. In order to develop efficient resources to improve patient awareness, comprehensive information is required to determine the specific aspects of palliative care where a paucity of evidence on patient awareness exists. This review aims to synthesise evidence from previous studies in order to provide a comprehensive information set about the current state of patient awareness of palliative care.

Methods: In this systematic literature review, PubMed, Scopus, Web of Science, ProQuest, Magiran, Scientific Information Database(SID) and Islamic Science Citation (ISC) were searched to identify articles published between 2000 and 2021 that considered patients' awareness of palliative care.

Results: Of the 5347 articles found, 22 studies were retained after quality evaluation; three full-text articles were excluded. Nineteen articles are included in this review. More than half of the patients did not have any information about palliative care or hospice care. Some patients accurately defined hospice care and palliative care; other patients had misunderstandings about palliative care. Patients had limited information about pastoral care, social care and bereavement care. Patients' awareness about individuals or centres providing palliative care or hospice care was limited. Video presentation and distribution of information at the community level indicated that this method would be beneficial in increasing the awareness.

Conclusion: The review points to the need for patient education programmes and interventional studies to increase patients' awareness.

Title: Decreasing Trends in Opioid Prescribing on Discharge to Hospice Care.

Author(s): Furuno, Jon P; Noble, Brie N; Fromme, Erik K; Hartung, Daniel M; Tjia, Jennifer; Lynn, Mary; Teno, Joan M

Context: There are concerns that policies aimed to prevent opioid misuse may unintentionally reduce access to opioids for patients at end-of-life.

Objective: We assessed trends in opioid prescribing among patients on discharge from the hospital to hospice care.

Methods: This was a retrospective cohort study among adult (age ≥18 years) patients discharged from a 544-576 bed, academic medical center to hospice care between January 1, 2010 to December 31, 2018. Study data were collected from a repository of patients' electronic health record data. Our primary outcome was the frequency of opioid prescribing on discharge to hospice care. Our primary exposure was the calendar year of discharge. We also investigated non-opioid analgesic prescribing and stratified opioid prescribing trends by patient characteristics (e.g., demographics, cancer diagnosis, and location of hospice care).

Results: Among 2,648 discharges to hospice care, mean (standard deviation) age was 65.8 (16.0) years, 46.3% were female, and 58.7% had a cancer diagnosis. Opioid prescribing on discharge to hospice care decreased significantly from 91.2% (95% confidence interval (CI) = 87.1%-94.1%) in 2010 to 79.3% (95% CI = 74.3%-83.5%) in 2018 adjusting for age, sex, cancer diagnosis, and location of hospice care. Prescribing of non-opioid analgesic medications increased over the same time period.

Conclusions: We observed a statistically significant decreasing trend in opioid prescribing on discharge to hospice care. Further research should aim to confirm these findings and to identify opportunities to ensure optimal pain management among patients transitioning to hospice care.

Title: Predicting Attrition Among Hospice Volunteers.

Author(s): Hayslip, Bert; Sethi, Andrew; Pinson, Melissa Ward; Carpenter, Casey

Abstract: To explore those factors predicting continued involvement among hospice volunteers, this study collected data from questionnaires distributed among 53 individuals who were hospice volunteers, to include personal demographics and measures of locus of control, burnout, hospice self-efficacy, spirituality, and death anxiety. Participants were then contacted between 6 and 8 months later to assess whether they were still actively volunteering for hospice. Those who remained in hospice reported less burnout when adjusting for previous volunteer experience, age, education, and duration of volunteering and a combination of burnout, spirituality, and hospice self-efficacy accurately predicted group membership (completers vs. dropouts) in 82% of the cases. The implications of these exploratory findings for the retention of hospice volunteers are discussed in the context to carefully screening persons before they enter the hospice volunteer role and providing hospice volunteer training for them.

Title: The experiences of palliative care professionals and their responses to work-related stress: A qualitative study.

Author(s): Fisher, Shaun; Gillanders, David; Ferreira, Nuno

Objectives: Previous qualitative research has demonstrated that palliative care professionals (PCPs) deal with a wide array of emotionally challenging issues associated with the care they provide. Although previous research has identified self-care strategies PCPs engage in, there is a lack of focus on what responses are helpful and/or unhelpful. The aim of the current study is to understand and describe the experiences of PCPs and to explore the helpful and unhelpful responses to work-related stress they employ.

Design: This was a qualitative study of the experiences of working PCPs in a hospice setting.

Methods: Nine semi-structured interviews were conducted and subsequently analysed using the framework method.

Results: The current study revealed five overarching themes: (1) Sources of Meaning and Purpose (making a difference, personal growth), (2) Sources of Stress (emotional challenges, patient family dynamics, work environment factors, public perception, uncontrollability of symptoms), (3) Personal Impact (life engagement, perceptions of death), (4) Unhelpful Responses (self-doubt, emotional suppression, rumination, overidentifying, lack of self-care), and (5) Helpful Responses (acceptance, being present, perspective taking, being able to switch off, social support, active self-care).

Conclusions: The experiences of PCPs can be interpreted from or directly mapped onto the psychological (in)flexibility model in Acceptance and Commitment Therapy (ACT). It is suggested that ACT training for professionals may encourage more reliable and explicit helpful responses and reduce the impact of unhelpful responses. Thus, an ACT training intervention may enhance wellbeing and effectiveness in PCPs.

Title: Hidden lives and deaths: the last months of life of people with intellectual disabilities living in long-term, generic care settings in the UK

Author(s): Todd, Stuart; Bernal, Jane; Worth, Rhian; Shearn, Julia; Brearley, Sarah; McCarron, Mary; Hunt, Katherine

Rationale: This paper concerns mortality and needs for end-of-life care in a population of adults with ID living in generic care homes.

Methods: Various sampling strategies were used to identify a difficult to find a population of people with ID in generic care homes. Demographic and health data were obtained for 132 people with ID. This included the Surprise Question. At T2, 12 months later, data were obtained on the survival of this sample.

Findings: The average age was 68.6 years, and the majority were women (55.3%). Their health was typically rated as good or better. Responses to the Surprise Question indicated that 23.3% respondents might need EoLC. At T2, 18.0% of this population had died. The average of death was 72.2 years. The majority died within the care setting (62.9%).

Implications: The implications for end-of-life care and mortality research are discussed.

Title: Evaluation of the Caring Ahead: Preparing for End-of-Life With Dementia Questionnaire.

Author(s): Durepos ; Akhtar-Danesh, Noori; Sussman, Tamara; Ploeg, Jenny; Boerner, Kathrin; Kaasalainen, Sharon

Abstract: Family caregivers of persons with dementia rarely feel prepared for end of life although preparedness predicts outcomes in bereavement. The Caring Ahead: Preparing for End-of-Life With Dementia questionnaire was developed to measure family caregiver death

preparedness. The aim of this study was to evaluate questionnaire psychometrics and refine the Caring Ahead questionnaire. A quantitative cross-sectional reliability study design was used to evaluate the questionnaire. Data were collected by mail from 134 English-speaking family caregivers of persons with dementia recruited from more than 50 congregate living facilities in Canada. Thirty-two participants completed a test-retest. Analysis of psychometrics included exploratory factor analysis, calculation of correlation with a single-global preparedness item, Cronbach alpha, intraclass correlation coefficient (ICC) over time. A 4-factor model with 20 items emerged through exploratory factor analysis with principal factors extraction and promax rotation. The revised questionnaire includes 4 factor subscales: Actions (7 items), Dementia Knowledge (5 items), Communication (4 items), and Emotions and Support Needs (4 items). Evidence was demonstrated for concurrent validity (0.44-0.55, P 0.7), and reliability (ICCs > 0.7). Lower levels of preparedness were reported for "knowing what the dying process with dementia may be like" and "discussing end-of-life care and preferences with health care providers." Preliminary evidence for validity and reliability of the refined 20-item Caring Ahead questionnaire suggests the questionnaire may be useful to clinicians and researchers seeking to assess caregivers' feelings of preparedness, identify specific areas for intervention, and evaluate the effectiveness of caregiver interventions. Additional testing is needed to evaluate predictive validity.

Title: Priorities and opportunities for palliative and end of life care in United Kingdom health policies: a national documentary analysis.

Author(s): Sleeman ; Timms, Anna; Gillam, Juliet; Anderson, Janet E.; Harding, Richard; Sampson, Elizabeth L.; Evans, Catherine J.

Background: Access to high-quality palliative care is inadequate for most people living and dying with serious illness. Policies aimed at optimising delivery of palliative and end of life care are an important mechanism to improve quality of care for the dying. The extent to which palliative care is included in national health policies is unknown. We aimed to identify priorities and opportunities for palliative and end of life care in national health policies in the UK.

Methods: Documentary analysis consisting of 1) summative content analysis to describe the extent to which palliative and end of life care is referred to and/or prioritised in national health and social care policies, and 2) thematic analysis to explore health policy priorities that are opportunities to widen access to palliative and end of life care for people with serious illness. Relevant national policy documents were identified through web searches of key government and other organisations, and through expert consultation. Documents included were UK-wide or devolved (i.e. England, Scotland, Northern Ireland, Wales), health and social care government strategies published from 2010 onwards.

Results: Fifteen policy documents were included in the final analysis. Twelve referred to palliative or end of life care, but details about what should improve, or mechanisms to achieve this, were sparse. Policy priorities that are opportunities to widen palliative and end of life care access comprised three inter-related themes: (1) integrated care – conceptualised as reorganisation of services as a way to enable improvement; (2) personalised care – conceptualised as allowing people to shape and manage their own care; and (3) support for unpaid carers – conceptualised as enabling unpaid carers to live a more independent lifestyle and balance caring with their own needs.

Conclusions: Although information on palliative and end of life care in UK health and social care policies was sparse, improving palliative care may provide an evidence-based approach to achieve the stated policy priorities of integrated care, personalised care, and

support for unpaid carers. Aligning existing evidence of the benefits of palliative care with the three priorities identified may be an effective mechanism to both strengthen policy and improve care for people who are dying.

Title: Transitioning end-of-life care from hospital to the community: case report.

Author(s): Lino ; Williams, Mary

Abstract: Palliative/end-of-life care is an integral part of the district nursing service. There is increasing demand for palliative care to be delivered in the community setting. Therefore, there is a need for excellent collaboration between staff in primary and secondary care settings to achieve optimum care for patients. This article critically analyses the care delivered for a palliative patient in the hospital setting and his subsequent transition to the community setting. The importance of effective communication, holistic assessment in palliative care, advance care planning, organisational structures and the socio-cultural aspects of caring for patients at the end of life are discussed. Additionally, the article highlights the impact of substandard assessment and communication and the consequent effect on patients and families.

Title: How do hospice nurses prepare to give end-of-life care? A grounded theory study of nurses in one UK hospice.

Author(s): Griffith ; Gelling, Leslie

Background: Literature for preparing hospice nurses to deliver end-of-life care is sparse.

Aim: To investigate how nurses in one UK hospice prepared to deliver end-of-life care in their role.

Methods: A classic grounded theory approach was used to investigate the experiences of 22 registered nurses in one UK hospice, to discover how they prepared for their role. A total of 17 individual interviews and one focus group were conducted. Constant comparison of data and member checking were performed to establish validity.

Findings: Findings were synthesised into five categories: the 'shared ideal', feeling good at the job, making a difference, experience/exposure to hospice work and the importance of role models. The shared ideal formed the core category, which explained how hospice nurses feel a sense of 'fit' with their work.

Conclusion: The feeling of a nurse feeling well-suited to the work and that there the work was a good 'fit' for them was identified as a core element to nurses' feelings of preparedness to provide end-of-life care.

Title: What are the Emotional Experiences of Being a Volunteer in Palliative and End-of-Life Care Settings? A Systematic Review and Thematic Synthesis.

Author(s): Coleman ; Walshe, Catherine

Context: Previous research has focused on the risks of stress, burnout and the impact on general emotional well-being in paid palliative care staff, however volunteers in patient-facing roles are exposed to similar stressors. Volunteers increasingly provide emotional support to patients and families but receive little formal support for themselves. It is important to understand volunteers' emotional experiences of their role to identify strategies that could be implemented to support them effectively.

Objectives: To synthesize qualitative data on the emotional experiences of being a volunteer in palliative and end-of-life care settings, including how people cope with this role and how they can be best supported.

Methods: A systematic review with thematic synthesis design, with an iterative three-stage synthesis, including line-by-line coding, organizing this into descriptive themes and then developing analytical themes. Four databases (PsycInfo, CINAHL, MEDLINE, and EMBASE) were searched in November 2019. The Critical Appraisal Skills Programme was used to evaluate included papers.

Results: From the 22 included studies, four themes were developed: 1) intrinsic challenges (e.g., conflicting feelings); 2) extrinsic challenges (e.g., resources and expectations); 3) personal gain (e.g., learning and self-growth); and 4) developing relationships (e.g., appropriate boundaries). Challenges included personal feelings related to their role for example uncertainty, not being 'good enough' and feeling drained as well as frustrations within the palliative care system.

Conclusion: Volunteers face unique challenges but also positive impacts that can affect their emotional well-being. It is important to monitor how volunteers are coping and provide appropriate support.

Title: Experiences of surgical nurses in providing end-of-life care in an acute care setting: a qualitative study.

Author(s): Limbu ; Taylor, Paul M

Background: The number of deaths occurring in hospitals is rising, and many occur in settings other than specialist palliative care, oncology or critical care. Nurses working outside these specialist environments report end-of-life (EoL) care as a source of stress. This research aimed to explore these experiences.

Aims and methods: This qualitative study, using semi-structured interviews as a research technique, aimed to investigate the experiences of surgical nurses caring for dying patients.

Results: Five themes emerged: understanding of and preference for EoL care; perceived barriers while providing EoL care; robust support from the team as a facilitator while providing EoL care; symptom management; future training and support.

Conclusion: Participants considered providing EoL care as part of their professional role and reported that they were able to provide appropriate physical care. Participants identified challenges in providing emotional and psychological support to dying patients and their families in an acute surgical setting.

Title: Quality of dying in hospital general wards: a cross-sectional study about the end-of-life care.

Author(s): Binda ; Clari, Marco; Nicolò, Gabriella; Gambazza, Simone; Sappa, Barbara; Bosco, Paola; Laquintana, Dario

Background: In the last decade, access to national palliative care programs have improved, however a large proportion of patients continued to die in hospital, particularly within internal medicine wards.

Objectives: To describe treatments, symptoms and clinical management of adult patients at the end of their life and explore whether these differ according to expectation of death.

Methods: Single-centre cross-sectional study performed in the medical and surgical wards of a large tertiary-level university teaching hospital in the north of Italy. Data on nursing interventions and diagnostic procedure in proximity of death were collected after interviewing the nurse and the physician responsible for the patient. Relationship between nursing treatments delivered and patients' characteristics, quality of dying and nurses' expectation about death was summarized by means of multiple correspondence analysis (MCA).

Results: Few treatments were found statistically associated with expectation of death in the 187 patients included. In the last 48 h, routine (70.6%) and biomarkers (41.7%) blood tests were performed, at higher extent on patients whose death was not expected. Many symptoms classified as severe were reported when death was highly expected, except for agitation and respiratory fatigue which were reported when death was moderately expected. A high Norton score and absence of anti-bedsore mattress were associated with unexpected death and poor quality of dying, as summarized by MCA. Quality of dying was perceived as good by nurses when death was moderately and highly expected. Physicians rated more frequently than nurses the quality of dying as good or very good, respectively 78.6 and 57.8%, denoting a fair agreement between the two professionals (k = 0.24, P < 0.001). The palliative care consultant was requested for only two patients.

Conclusion: Staff in medical and surgical wards still deal inadequately with the needs of dying people. Presence of hospital-based specialist palliative care could lead to improvements in the patients' quality of life.

Title: Out-of-hours services and end-of-life hospital admissions: a complex intervention systematic review and narrative synthesis.

Author(s): Papavasiliou ; Hoare, Sarah; Bowers, Ben; Kelly, Michael P; Barclay, Stephen

Background: Out-of-hours (OOH) hospital admissions for patients receiving end-of-life care are a common cause of concern for patients, families, clinicians, and policymakers. It is unclear what issues, or combinations of issues, lead OOH clinicians to initiate hospital care for these patients.

Aim: To investigate the circumstances, processes, and mechanisms of UK OOH services-initiated end-of-life care hospital admissions.

Design and setting: Systematic literature review and narrative synthesis.

Method: Eight electronic databases were searched from inception to December 2019 supplemented by hand-searching of the British Journal of General Practice. Key search terms included: 'out-of-hours services', 'hospital admissions', and 'end-of-life care'. Two reviewers independently screened and selected articles, and undertook quality appraisal using Gough's Weight of Evidence framework. Data was analysed using narrative synthesis and reported following PRISMA Complex Intervention guidance.

Results: Searches identified 20 727 unique citations, 25 of which met the inclusion criteria. Few studies had a primary focus on the review questions. Admissions were instigated primarily to address clinical needs, caregiver and/or patient distress, and discontinuity or unavailability of care provision, and they were arranged by a range of OOH providers. Reported frequencies of patients receiving end-of-life care being admitted to hospital varied greatly; most evidence related to cancer patients.

Conclusion: Although OOH end-of-life care can often be readily resolved by hospital admissions, it comes with multiple challenges that seem to be widespread and systemic. Further research is therefore necessary to understand the complexities of OOH services-initiated end-of-life care hospital admissions and how the challenges underpinning such admissions might best be addressed.

Title: Lean in, don't step back: The views and experiences of patients and carers with severe mental illness and incurable physical conditions on palliative and end of life care.

Author(s): Jerwood ; Ward, G.; Phimister, D.; Holliday, N.; Coad, J.

Background and aim: People with severe mental illness (SMI) have a life expectancy of up to twenty years less than the general population and many live with incurable physical health conditions. Yet, they continue to experience barriers when trying to access palliative and end of life care (PEOLC). Little research has been carried out which includes the views and experiences of people with SMI, and this study presents first findings which include people with both SMI and an incurable condition and their carers. It aimed to seek their views, and those of their carers, on their experiences and expectations of accessing PEOLC and to understand how PEOLC for people with SMI could be improved.

Methods: Semi-structured interviews were carried out with 8 participants (5 patient participants and 3 carer participants). Thematic analysis of the interview transcripts was undertaken.

Findings: Four over-arching themes were developed. (1) Stigma and Prejudice – See Me, Not My Diagnosis (2) Hesitancy and Avoidance – Treading on Eggshells (3) Collaborators in Care – The Ignored Experts and (4) Connections – Leaning in, Not Stepping Back.

Significance of findings: This study presents the first accounts from the UK concerning experiences of PEOLC, barriers to access and how care can be improved, from the perspectives of patients with both a SMI and an incurable physical condition and their carers. The findings illuminate an under-researched area of clinical practice and contribute rich understandings to future service developments and innovations.

Title: 'Who would even want to talk about death?' A qualitative study on nursing students' experiences of talking about death with terminally ill patients with cancer.

Author(s): Üzar-Özçetin, Yeter Sinem; Hiçdurmaz, Duygu; Öcalan, Sinem

Objectives: This study aimed to describe nursing students' experiences of talking about death with terminally ill patients with cancer.

Methods: The study adopted a qualitative design, and participants (n = 28) were final-year undergraduate nursing students. Data were collected by conducting in-depth semi-structured face-to-face interviews using a pilot-tested interview guide. The researchers followed a systematic data analysis procedure which is an appropriate method of analysis when aiming to create knowledge based on experiences and meanings from cross-case analysis.

Results: The responses of the nursing students were subsumed under the following three themes: (1) 'balance on the rope', (2) 'who would even want to talk about death' and (3) 'need to talk but …'. The findings suggest that many nursing students do not believe that they are competent enough to talk about death with terminally ill patients with cancer, even though they believe it is essential to end-of-life care.

Conclusion: The findings underscore the importance of examining students' perspectives on death, which not only shapes their experiences of caring for terminally ill patients but also influences the quality of care. Further, students feel unprepared for talking to terminally ill patients with cancer and require support to avoid ignoring calls to speak about death.

Title: "Resuscitate and Push": End-of-Life Care Experiences of Healthcare Staff in the Emergency Department - A Hermeneutic Phenomenological Study.

Author(s): Bayuo, Jonathan; Anago, Emmanuel Kwadwo; Agyei, Frank Bediako; Salifu, Yakubu; Kyei Baffour, Prince; Atta Poku, Collins

Objective: Care in the emergency department focuses significantly on delivering lifesaving/ life-sustaining clinical actions, often with limited attention to health-related suffering even at the end-of-life. How healthcare staff experience and navigate through the end-of-life phase remains minimally explored. Thus, this study aimed to uncover the lived experiences of emergency department staff at the end-of-life.

Methods: van Manen's hermeneutic phenomenological approach was used. Nineteen healthcare staff were purposively recruited and interviewed. Interviews were audio-taped, transcribed verbatim, and thematic categories formulated. The existential lifeworld themes (corporeality, relationality, spatiality, and temporality) were used as heuristic guides for reflecting and organizing the lived experiences of participants.

Results: The overarching category, 'resuscitate and push', was captured as corporeality (resisting death and dying); relationality (connectedness to the body of the patient; and lacking support for family and self); spatiality (navigating through a liminal space and lack of privacy for patients); and temporality (having limited to no time for end-of-life care and grieving). The end-of-life space was unpleasant. Although participants experienced helplessness and feelings of failure, support systems to help them to navigate through these emotions were lacking. Grief was experienced covertly and concealed by the entry of a new patient.

Conclusion: End-of-life in the emergency department is poorly defined. In addition to shifting from the traditional emergency care model to support the streamlining of palliative care in the department, staff will require support with navigating through the liminal space, managing their grief, and developing a better working relationship with patients/ families.

Title: How does English national end-of-life care policy impact on the experience of older people at the end of life? Findings from a realist evaluation.

Author(s): Barker, Rhiannon; Wilson, Patricia; Butler, Claire

Aim: To explore the extent to which national policy in end-of-life care (EOLC) in England influences and guides local practice, helping to ensure that care for older people at the EOL is of a consistently good quality.

Background: Whilst policy is recognised as an important component in determining the effectiveness of EOLC, there is scant literature which attempts to interrogate how this happens or to hypothesise the mechanisms linking policy to better outcomes.

Method: This article reports on the second phase of a realist evaluation comprising three case studies of clinical commissioning groups, including 98 in-depth interviews with stakeholders, meeting observation and documentary analysis.

Findings: This study reveals the key contextual factors which need to be in place at micro, meso and macro levels if good quality EOLC for older people is to be achieved. The findings provide insight into rising local inequalities and reveal areas of dissonance between stakeholder priorities. Whilst patients privilege the importance of receiving care and compassion in familiar surroundings at EOL, there remains a clear tension between this and the medical drive to cure disease and extend life. The apparent devaluing of social care and subsequent lack of resource has impacted significantly on the way in which dying is experienced. Patient experience at EOL, shaped by the care received both formally and informally, is driven by a fragmented health and social care system. Whilst the importance of system integration appears to have been recognised, significant challenges remain in terms of shaping policy to adequately reflect this. This study highlights the priority attached by patients and their families to the social and relational aspect of death and dying and shines a light on the stark disparities between the health and social care systems which became even more evident at the height of the Covid-19 pandemic.

Title: Patient card games in palliative care: integrative review.

Author(s): Fernandes, Carla Silvia; Lourenço, Marisa; Vale, Belem

Background: In the context of palliative care, a new approach has been documented that allows for sensitive end-of-life conversations to be established through a game of cards.

Objective: This study aimed to identify the use of card games with patients in palliative care, assess self-reported satisfaction and synthesise findings on the effectiveness of its application.

Design: We performed an integrative review study. The studies were collected from five databases, with no time limit until February 2021: Medical Literature Analysis and Retrieval System Online, Cumulative Index to Nursing and Allied Health Literature, Psychology and Behavioral Sciences Collection, SCOPUS and Scientific Electronic Library Online. The inclusion criteria were studies describing the use of card games in adult patients undergoing palliative care, in which the authors performed some type of evaluation. The methodological evaluation of the studies was carried out using the different standardised assessment tools from the Joanna Brigg's Institute.

Results: Of the 685 articles identified, 9 met the inclusion criteria. Regarding methodological aspects, 4 studies were quantitative, 4 mixed-method methodologies, and 1 was qualitative. Card games have been in use for the last decade. The use of card games not only allows for participation in the game without any inhibitions and with a high degree of satisfaction, but also allows for the discussion of sensitive topics related to the end of life, motivating participants to engage in advanced care planning behaviours.

Conclusion: Our findings suggest that using a card game to facilitate conversations with patients in palliative care is a useful and effective approach to discussing uncomfortable topics of death, dying and end-of-life care.

Title: Role and support needs of nurses in delivering palliative and end of life care.

Author(s): Gardiner, Clare; Bolton, Louise

Abstract: The coronavirus disease 2019 (COVID-19) pandemic has led to a significant increase in the demand for palliative and end of life care, particularly in the community. Furthermore, palliative and end of life care services face growing pressures due to the increasing number of older people and increasing prevalence of chronic illness. Palliative and end of life care cannot be provided solely by specialists but needs to be integrated into mainstream healthcare. All nurses have a role in supporting patients with life-limiting conditions, and their families, by providing what is termed 'generalist palliative care'. However, some nurses may feel unprepared, unsupported or lacking the confidence and skills for that role. This article explores the definitions of palliative and end of life care, as well as the changes and challenges in service provision brought about by the COVID-19 pandemic. It also considers how nurses who have not specialised in this area of practice can be supported to care effectively for patients with life-limiting conditions, and their families, notably through workforce development initiatives such as training programmes and clinical supervision. This could not only increase the skills of the nursing workforce but also improve patient care.

Title: ILIVE Project Volunteer study. Developing international consensus for a European Core Curriculum for hospital end-of-life-care volunteer services, to train volunteers to support patients in the last weeks of life: A Delphi study.

Author(s): McGlinchey, Tamsin; Mason, Stephen R; Smeding, Ruthmarijke; Goosensen, Anne; Ruiz-Torreras, Inmaculada; Haugen, Dagny Faksvåg; Bakan, Miša; Ellershaw, John E

Background: Volunteers make a huge contribution to the health and wellbeing of the population and can improve satisfaction with care especially in the hospice setting. However, palliative and end-of-life-care volunteer services in the hospital setting are relatively uncommon. The iLIVE Volunteer Study, one of eight work-packages within the iLIVE Project, was tasked with developing a European Core Curriculum for End-of-Life-Care Volunteers in hospital.

Aim: Establish an international consensus on the content of a European Core Curriculum for hospital end-of-life-care volunteer services which support patients in the last weeks of life.

Design: Delphi Process comprising the following three stages:1. Scoping review of literature into palliative care volunteers.2. Two rounds of Delphi Questionnaire.3. Nominal Group Meeting.

Setting/participants: Sixty-six participants completed the Round 1 Delphi questionnaire; 75% (50/66) took part in Round 2. Seventeen participants attended the Nominal Group Meeting representing an international and multi-professional group including, clinicians, researchers and volunteer coordinators from the participating countries.

Results: The scoping review identified 88 items for the Delphi questionnaire. Items encompassed organisational issues for implementation and topics for volunteer training. Three items were combined and one item added in Round 2. Following the Nominal Group Meeting 53/87 items reached consensus.

Conclusion: Key items for volunteer training were agreed alongside items for implementation to embed the end-of-life-care volunteer service within the hospital. Recommendations for further research included in-depth assessment of the implementation and experiences of end-of-life-care volunteer services. The developed European Core Curriculum can be adapted to fit local cultural and organisational contexts.

Title: Moral Injury and Burnout in Health Care Professionals During the COVID-19 Pandemic.

Author(s): Mantri, Sneha; Song, Ye Kyung; Lawson, Jennifer M; Berger, Elizabeth J; Koenig, Harold G

Abstract: The coronavirus pandemic (COVID-19) is predicted to increase burnout in health professionals (HPs), but little is known about moral injury (MI) in this context. We administered the Moral Injury Symptoms Scale for Health Professionals (MISS-HP) and the abbreviated Maslach Burnout Inventory via online survey to a global sample of 1831 HPs in April and October 2020. Mean MISS-HP increased from 27.4 (SD, 11.6) in April to 36.4 (SD, 13.8) in October ($p < 0.001$), with an accompanying increase in personal accomplishment (April: 4.7; SD, 3.1; October: 9.3; SD, 3.1; $p < 0.001$) and no change in other burnout subscales. In April, 26.7% of respondents reported at least moderate functional impairment from MI, increasing to 45.7% in October ($p < 0.001$). Predictors of MISS-HP included younger age and being a nurse. Odds of functional impairment were higher in respondents who were widowed, divorced, never married, or had direct experience caring for patients with COVID-19. COVID-19 has increased MI but not burnout in HPs; younger or unmarried individuals, nurses, and frontline workers may benefit from targeted outreach to reduce downstream effects of MI, depression, and/or posttraumatic stress disorder

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Title: Understanding Moral Injury Morbidity: A Qualitative Study Examining Chaplain's Perspectives.

Author(s): Boska, Rachel L; Dunlap, Shawn; Kopacz, Marek; Bishop, Todd M; Harris, J Irene

Abstract: Moral injury tends to be conceptualized through an interplay of psychological and religious concerns. Recent qualitative research has begun utilizing chaplains to bolster the understanding of moral injury within veterans. The current study examined qualitative data regarding how moral injury is viewed through the lens of Chaplain Services within the Veterans Health Administration (VA). Specifically, chaplains were asked to describe how moral injury presents, what kinds of complaints veterans voice with regard to moral injury, and how moral injury impacts social functioning. Chaplains highlighted how moral injury is a pervasive issue affecting veterans across multiple domains. Clinical implications discussed further.

Title: Moral Injury: An Increasingly Recognized and Widespread Syndrome.

Author(s): Koenig, Harold G; Al Zaben, Faten

Abstract: Moral injury (MI), originally discussed in relationship to transgressing moral beliefs and values during wartime among military personnel, has expanded beyond this context to include similar emotions experienced by healthcare professionals, first responders, and others experiencing moral emotions resulting from actions taken or observations made during traumatic events or circumstances. In this article, we review the history, definition, measurement, prevalence, distinctiveness, psychological consequences, manifestations (in and outside of military settings), and correlates of MI in different settings. We also review secular psychological treatments, spiritually integrated therapies, and pastoral care approaches (specific for clergy and chaplains) used to treat MI and the evidence documenting their efficacy. Finally, we examine directions for future research needed to fill the many gaps in our knowledge about MI, how it develops, and how to help those suffering from it.

Sources Used:

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

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

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