

End of Life Care

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Oxford palliative care 'virtual ward' launched

BBC News, 14 March 2024

A "virtual ward" enabling patients who want to die at home get the palliative care they need has launched. Hospice Outreach provides a "specialised pathway" for patients identified by existing services who would benefit from support. It is part of a project that supports people at the very end of their life.

Dr Victoria Bradley, of Oxford University Hospitals NHS Foundation Trust (OUH), said it was about giving people "control and agency". OUH claims Hospice Outreach's virtual ward will mean more people will receive personalised care, including in their own homes if that is their choice.

End of life: Ombudsman calls for better training on DNACPR conversations

BMJ 2024; 384

Doctors and nurses should have better training on end-of-life conversations, England's health ombudsman has said. The recommendation follows a higher number of complaints than normal about communication of "do not attempt cardiopulmonary resuscitation" (DNACPR) decisions made during the covid pandemic.

A DNACPR notice is made by a doctor and does not require patient consent, but legally a patient who has capacity must be informed, or otherwise their next of kin must be told.

However, the ombudsman, Rob Behrens, said that in some instances doctors had breached people's human rights by not even informing them or their family that a DNACPR decision had been made. In a report published on 14 March he called for urgent improvements to the way health professionals talk to patients and their loved ones about end-of-life care.

The Rhetoric and Reality of Choice and Autonomy When Older People Are Discharged from Community Hospital at the End-of-Life in England: A Constructivist Grounded Theory Study.

Mckean E. *Health and Social Care in the Community* 2024;:3808095.

A significant finding of this study was that of the carer, their burden, and their intrinsic role in facilitating discharge, filling in gaps in services, coordinating services, and enabling the patient to stay at home, with little consideration of their choices or autonomy. The "drive to discharge" impacts older people, their informal carers, and health professional. This study suggests how they may be supported, through an ethical lens.

1. Exploring unmet concerns in home hospice cancer care: Perspectives of patients, informal caregivers, palliative care providers, and family physicians

Authors: Ben-Arye, Eran;Samuels, Noah;Keshet, Yael;Golan, Miri;Baruch, Erez and Dagash, Jamal

Publication Date: 2024

Journal: Palliative & Supportive Care , pp. 1-9

Abstract: Objectives: The study examines perspectives of patients in home hospice care; their informal caregivers; palliative health-care providers (HCPs); and family physicians, all regarding patients' unmet needs and quality of life (QoL)-related concerns.; Methods: Participants from all 4 groups were approached within 2 months after the patient's admission to the home hospice care unit. Participants completed Edmonton Symptom Assessment Scale (ESAS) and Measure Yourself Concerns and Wellbeing (MYCAW) questionnaires, for patient's QoL-related concerns. Qualitative analysis of short narratives was conducted using ATLAS.ti software for systematic coding.; Results: In total, 78 participants completed the study questionnaires: 24 patients, 22 informal caregivers, 22 palliative HCPs, and 11 family physicians. Informal caregivers gave higher scores (i.e., greater severity) than patients for fatigue on ESAS ($p = 0.009$); and family physicians lower scores than patients for ESAS drowsiness ($p = 0.046$). Compared with patients, palliative HCPs gave higher scores for patient

emotional-spiritual concerns (77.2% vs. 41.7%, $p = 0.02$); lower scores for gastrointestinal concerns ($p = 0.048$); and higher scores for overall function ($p = 0.049$). Qualitative assessment identified a gap between how patients/informal caregivers vs. palliative HCPs/family physicians regard emotional-spiritual themes, including discussing issues related to death and dying.; Significance of Results: The findings of the present study suggest that exploring a multifaceted cohort of home hospice patients, informal caregivers, palliative HCPs, and family physicians may provide insight on how to reduce communication gaps and address unmet needs of patients, particularly regarding emotional and spiritual concerns.; Conclusions: While the 4 groups were similar in their scoring of patient QoL-related concerns, there were discrepancies for some concerns (e.g., patient fatigue) and expectations regarding the need to discuss emotional and spiritual concerns, including on death and dying. Educational initiatives with programs providing training to all 4 groups may help bridge this gap, creating a more open and collaborative hospice care environment.

2. Interventions for behavioral health comorbidities in the hospice setting: a scoping review

Authors: Brody, Lilla;Sadowska, Karolina;Ekwebelem, Maureen;Hollingsworth, Alexis;Ong, Michael;Subramanian, Tejas;Wright, Drew;Phongtankuel, Veerawat;Reid, M. C.;Silva, Milagros D. and Shalev, Daniel

Publication Date: 2024

Journal: Annals of Palliative Medicine

Abstract: Background: Behavioral health (BH) comorbidities in hospice patients are widespread and impact important outcomes, including symptom burden, quality of life, and caregiver wellbeing. However, evidencebased BH interventions tailored for the hospice setting remain understudied.; Methods: We conducted a scoping review with the objective of mapping studies of interventions for BH comorbidities in the hospice setting. We included empirical studies among hospice patients of interventions with BH outcomes. We abstracted data on study design, intervention type, and patient characteristics.; Results: Our search generated 7,672 unique results, of which 37 were ultimately included in our analysis. Studies represented 16 regions, with the United Kingdom ($n=13$) most represented. The most frequent intervention type was complementary and alternative interventions ($n=13$), followed by psychotherapeutic interventions ($n=12$). Most of the studies were either pilot or feasibility investigations. Fifteen studies employed a randomized controlled trial design. The most frequently utilized measurement tools for BH outcomes included the Hospital Anxiety and Depression Scale and the Edmonton Symptom Assessment Scale. Seventeen studies demonstrated statistically significant results in a BH outcome measure. BH conditions prevalent among hospice patients that were the focus of intervention efforts included depression symptoms, anxiety symptoms, and general psychological distress. No study focused on trauma-related disorders or substance use disorders.; Conclusions: This scoping review reveals a concerning gap in research regarding evidence-based BH interventions in hospice settings, especially in the U.S. Despite extensive utilization of hospice care services and the high prevalence of BH conditions among hospice patients, randomized controlled trials focused on improving BH outcomes remain scant. The current BH practices, like the widespread use of benzodiazepines and antipsychotics, may not be rooted in robust evidence, underscoring an urgent need for investment in hospice research infrastructure and tailored clinical trials to test behavioral approaches to mitigate mental health outcomes at the end of life.

3. Experiences of nursing students providing end of life care for children and young people: A focus group study

Authors: Camara, Claire;Rosengarten, Leah and Callum, Jane

Publication Date: 2024

Journal: Nurse Education Today 137, pp. 106147

Abstract: Background: End of life care for Children and Young People (CYP) is known to be an emotive area of practice. Previous studies involving qualified nurses have demonstrated that nurses feel they need more end-of-life care education, as well as a platform for sharing experiences and discussing them with others. Evidence relating to nursing students remains limited despite being widely acknowledged as a difficult aspect of nursing education.; Aims: This study aims to help improve understanding of the lived experiences of children's nursing students who have cared for a patient at, during, or immediately following end-of-life. The study describes the emotions experienced by children's nursing students and explores the student nurses' perceptions of education and support needs around caring for CYP during end-of-life care.; Methodology: A qualitative inquiry methodology allowed for a pragmatic approach to design this focus group study. Nine undergraduate student children's nurses participated in two focus groups. Ethical approval was granted by the host university. Thematic data analysis using Braun and Clarke's (2019) thematic analysis was conducted.; Findings: Six themes emerged from the data; Emotional practice (1), the heart of the care (2), a lasting impact (3), hierarchy of grief (4), experience, knowledge and understanding (5), and the value of support (6). End of life care for children and young people is recognised by students as a sad but important part of the job role, which can have a lasting impact and which students required improved education and support for.; Implications for Practice: Improved education on end-of-life care is required. This should be introduced early, encompassing practical approaches to the varied nature of end-of-life care, normalising a range of emotions and delayed responses. Furthermore, improved support is required for both student nurses and qualified staff, who are supporting students caring for CYP at the end of life.; Competing Interests: Declaration of competing interest The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper. (Copyright © 2024. Published by Elsevier Ltd.)

4. Racial Differences in Hospice Care Outcomes in Patients With Advanced Heart Failure: Systematic Review and Meta-analysis

Authors: Chambergo-Michilot, Diego;Becerra-Gonzales, Victor;Kittipibul, Veraprapas;Colombo, Rosario and Bravo-Jaimes, Katia

Publication Date: 2024

Journal: The American Journal of Cardiology 217, pp. 5-9

Abstract: There remains a paucity of investigational data about disparities in hospice services in people with non-cancer diagnoses, specifically in heart failure (HF). Black patients with advanced HF have been disproportionately affected by health care services inequities but their outcomes after hospice enrollment are not well studied. We aimed to describe race-specific outcomes in patients with advanced HF who were enrolled in hospice services. We obtained the data from PubMed, Scopus, and Embase for all investigations published until January 11, 2023. All studies that reported race-specific outcomes after hospice enrollment in patients with advanced HF were included. Of the 1,151 articles identified, 5 studies (n = 24,899) were considered for analysis involving a sample size ranging from 179 to 11,754 patients. Black patients had an increased risk of readmission (odds ratio 1.55, 95% confidence interval [CI] 1.34 to 1.79, I² 0%) and discharge (odds ratio 1.75, 95% CI 1.53 to 1.99, I² 0%) compared with White patients. Moreover, Black patients have a nonsignificant lower risk of mortality compared with White patients (relative risk 0.67, 95% CI 0.43 to 1.05, I² 90%). In conclusion, this study showed that Black patients with advanced HF receiving hospice care have a higher risk of readmission and discharge compared with White patients.; Competing Interests: Declaration of competing interest The authors have no competing interests to declare. (Copyright © 2024 Elsevier Inc. All rights reserved.)

5. Understanding how volunteer companionship impacts those during the end of life: A realist evaluation

Authors: Downey, John;Cooper, Susan;Bassett, Lynn;Dubeibe Fong, Alejandra;Doherty, Margaret and Cornwall, Jon

Publication Date: 2024

Journal: Death Studies , pp. 1-10

Abstract: Volunteers are a popular unpaid support role in end of life care yet how accompaniment influences the dying is underdeveloped. This study examined how companionship works, for whom, in what circumstances and why. Initial realist ideas were developed through participant observation (14 months), document analysis, and realist interviews with companionship trainers (n = 6). Theory testing involved volunteer interviews (n = 7), accounts from the dying, proxy accounts for the dying, and written reflections from companionship training. Companionship helps people live well until they die, prepare for death, and experience a good death. Four areas of volunteering explain these outcomes namely a loving friend, a holistic presence, a non-judgmental intermediary, and wrap around care. The four areas activate mechanisms related to reminiscing, preserving dignity/personhood, and easing suffering, contingent on specific contexts. The findings unpack how volunteering exerts its influence and what contextual factors facilitate outcomes, advancing the knowledge in this area.

6. Prognostic models and factors identifying end-of-life in non-cancer chronic diseases: a systematic review

Authors: Gebresillassie, Begashaw Melaku;Attia, John Richard;Mersha, Amanual Getnet and Harris, Melissa L.

Publication Date: 2024

Journal: BMJ Supportive & Palliative Care

Abstract: Background: Precise prognostic information, if available, is very helpful for guiding treatment decisions and resource allocation in patients with non-cancer non-communicable chronic diseases (NCDs). This study aimed to systematically review the existing evidence, examining prognostic models and factors for identifying end-of-life non-cancer NCD patients.; Methods: Electronic databases, including Medline, Embase, CINAHL, Cochrane Library, PsychINFO and other sources, were searched from the inception of these databases up until June 2023. Studies published in English with findings mentioning prognostic models or factors related to identifying end-of-life in non-cancer NCD patients were included. The quality of studies was assessed using the Quality in Prognosis Studies tool.; Results: The analysis included data from 41 studies, with 16 focusing on chronic obstructive pulmonary diseases (COPD), 10 on dementia, 6 on heart failure and 9 on mixed NCDs. Traditional statistical modelling was predominantly used for the identified prognostic models. Common predictors in COPD models included dyspnoea, forced expiratory volume in 1 s, functional status, exacerbation history and body mass index. Models for dementia and heart failure frequently included comorbidity, age, gender, blood tests and nutritional status. Similarly, mixed NCD models commonly included functional status, age, dyspnoea, the presence of skin pressure ulcers, oral intake and level of consciousness. The identified prognostic models exhibited varying predictive accuracy, with the majority demonstrating weak to moderate discriminatory performance (area under the curve: 0.5-0.8). Additionally, most of these models lacked independent external validation, and only a few underwent internal validation.; Conclusion: Our review summarised the most relevant predictors for identifying end-of-life in non-cancer NCDs. However, the predictive accuracy of identified models was generally inconsistent and low, and lacked external validation. Although efforts to improve these prognostic models should continue, clinicians should recognise the possibility that disease heterogeneity may limit the utility of these models for individual prognostication; they may be more useful for population level health planning.; Competing Interests: Competing interests: None declared. (© Author(s) (or their employer(s)) 2024. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.)

7. Primary care usage at the end of life: a retrospective cohort study of cancer patients using linked primary and hospital care data

Authors: Grant, M.;McCarthy, D.;Kearney, C.;Collins, A.;Sundararajan, V.;Rhee, J.;Philip, J. and Emery, J.

Publication Date: 2024

Journal: Supportive Care in Cancer : Official Journal of the Multinational Association of Supportive Care in Cancer 32(5), pp. 273

Abstract: Purpose: Health service use is most intensive in the final year of a person's life, with 80% of this expenditure occurring in hospital. Close involvement of primary care services has been promoted to enhance quality end-of-life care that is appropriate to the needs of patients. However, the relationship between primary care involvement and patients' use of hospital care is not well described. This study aims to examine primary care use in the last year of life for cancer patients and its relationship to hospital usage.; Methods: Retrospective cohort study in Victoria, Australia, using linked routine care data from primary care, hospital and death certificates. Patients were included who died related to cancer between 2008 and 2017.; Results: A total of 758 patients were included, of whom 88% (n = 667) visited primary care during the last 6 months (median 9.1 consultations). In the last month of life, 45% of patients were prescribed opioids, and 3% had imaging requested. Patients who received home visits (13%) or anticipatory medications (15%) had less than half the median bed days in the last 3 months (4 vs 9 days, $p < 0.001$, 5 vs 10 days, $p = 0.001$) and 1 month of life (0 vs 2 days, $p = 0.002$, 0 vs 3 days, $p < 0.001$), and reduced emergency department presentations (32% vs 46%, $p = 0.006$, 31% vs 47% $p < 0.001$) in the final month.; Conclusion: This study identifies two important primary care processes-home visits and anticipatory medication-associated with reduced hospital usage and intervention at the end of life. (© 2024. The Author(s).)

8. End-Of-Life and Palliative Care for Lesbian, Gay, Bisexual, Transgender, Queer or Questioning, or Another Diverse Gender Identity Older Adults

Authors: Kalmar, Evie and Mariano, Jeffrey

Publication Date: 2024

Journal: Clinics in Geriatric Medicine 40(2), pp. 333-345

Abstract: Palliative care focuses on improving the quality of life for people with serious illnesses and their loved ones. This article introduces considerations including barriers to care, intersectionality, minority stress, microaggressions, and social safety that may impact the experience and openness of people to receive this care. The authors outline tools to address these challenges including trauma-informed care and how to recognize bias and earn trust. The authors conclude by offering a model for incorporating these assessments and tools with sample scripts to provide patient-centered and holistic palliative care.; Competing Interests: Disclosure The authors have no disclosures. (Published by Elsevier Inc.)

9. Palliative and End-of-Life Family Caregiving in Rural Areas: A Scoping Review of Social Determinants of Health and Emotional Well-Being

Authors: Patano, Arienne;Wyatt, Gwen and Lehto, Rebecca

Publication Date: 2024

Journal: Journal of Palliative Medicine

Abstract: Introduction: Due to their remote location, rural-dwelling family caregivers (FCGs) experience

geographic and psychosocial challenges when providing home-based palliative and end-of-life (PEOL) care for their care recipient. Limited research has evaluated the social and environmental factors that may compound FCG burden and contribute to adverse emotional health outcomes among rural-dwelling PEOL FCGs. Objective: To characterize the social determinants of health (SDOH) that affect the provision of PEOL care among rural-dwelling FCGs, along with symptoms of anxiety and depression. Methods: A scoping review was conducted using Arksey and O'Malley's Framework. Searches were conducted in PubMed, CINAHL, PsycINFO, and Cochrane, and 511 articles published between 2010 and 2023 were screened. Keywords included "rural," "PEOL care," and "FCG." Inclusion criteria included FCGs, ages ≥ 18 years; findings reported on SDOH, anxiety, and/or depressive symptoms; within a rural context; and U.S. based. Findings: In this review, 18 studies met eligibility and were included. Apart from six studies that specifically investigated Black and Latinx FCGs, most FCGs were middle-aged White female spouses. SDOH impacting PEOL care provision included: limited access to PEOL services due to remote distance and travel needs for services; low health literacy in medical terminology and patient symptom management; limited English-language proficiency; perceived clinician racial and ethnic discrimination; financial vulnerabilities affecting health care coverage; and underdeveloped infrastructure. These barriers negatively impacted decision making, communication with clinicians, and patient symptom management. FCGs reported emotional distress related to patients' symptom management and limited opportunities for respite. There was a limited investigation of emotional well-being and minimal interventions aimed toward improving rural-dwelling FCG emotional health. The presence of community support promoted hospice use and facilitated the provision of care. Conclusions: FCGs are vulnerable to adverse emotional health when providing home-based PEOL care. Research is needed to develop supportive interventions (e.g., digital health) for rural-dwelling FCGs.

10. Muslims and End-of-Life Healthcare in Non-Muslim Majority Nations: A Systematic Literature Review

Authors: Piracha, Natasha Z.;Nickel, Lauren B.;Quryshi, Afiya;Salah, Ramy and Padela, Aasim I.

Publication Date: 2024

Journal: Journal of Pain & Symptom Management 67(4), pp. e299-e312

11. Clinician and Family Caregiver Perspectives on Deprescribing Chronic Disease Medications in Older Nursing Home Residents Near the End of Life

Authors: Schleiden, Loren J.;Klima, Gloria;Rodriguez, Keri L.;Ersek, Mary;Robinson, Jacob E.;Hickson, Ryan P.;Smith, Dawn;Cashy, John;Sileanu, Florentina E. and Thorpe, Carolyn T.

Publication Date: 2024

Journal: Drugs & Aging

Abstract: Introduction: Nursing home (NH) residents with limited life expectancy (LLE) who are intensely treated for hyperlipidemia, hypertension, or diabetes may benefit from deprescribing.; Objective: This study sought to describe NH clinician and family caregiver perspectives on key influences on deprescribing decisions for chronic disease medications in NH residents near the end of life.; Methods: We recruited family caregivers of veterans who recently died in a Veterans Affairs (VA) NH, known as community living centers (CLCs), and CLC healthcare clinicians (physicians, nurse practitioners, physician assistants, pharmacists, registered nurses). Respondents completed semi-structured interviews about their experiences with deprescribing statin, antihypertensive, and antidiabetic medications for residents near end of life. We conducted thematic analysis of interview transcripts to identify key themes regarding influences on deprescribing decisions.; Results: Thirteen family caregivers and 13 clinicians completed interviews. Key themes included (1) clinicians and caregivers both prefer to minimize drug burden; (2) clinical factors strongly influence deprescribing of chronic disease medications, with differences in how clinicians and caregivers weigh specific factors;

(3) caregivers trust and rely on clinicians to make deprescribing decisions; (4) clinicians perceive caregiver involvement and buy-in as essential to deprescribing decisions, which requires time and effort to obtain; and (5) clinicians perceive conflicting care from other clinicians as a barrier to deprescribing.; Conclusions: Findings suggest a need for efforts to encourage communication with and education for family caregivers of residents with LLE about deprescribing, and to foster better collaboration among clinicians in CLC and non-CLC settings. (© 2024. This is a U.S. Government work and not under copyright protection in the US; foreign copyright protection may apply.)

12. End-of-life care at home: Dignity of family caregivers

Authors: Staats, Katrine;Jeppestøl, Kristin;Søvde, Bente Egge;Brenne, Bodil Aarmo and Tarberg, Anett Skorpen

Publication Date: 2024

Journal: Nursing Ethics , pp. 9697330241241773

Abstract: Background: Healthcare services are increasingly being shifted to home settings for patients nearing end-of-life. Consequently, the burden on family caregivers is significant. Their vulnerable situation remains poorly understood and there is little information available regarding their experiences of dignity.; Aim: This study seeks to understand the experiences of family caregivers related to dignity and loss of dignity, aiming to provide a deeper insight into their situation when caring for a home-dwelling family member nearing end-of-life.; Research Design and Participants: This exploratory study consists of a second analysis combining data from two primary studies, including 24 family caregivers of a family member nearing end-of-life, and is founded upon Gadamer's philosophical hermeneutics.; Ethical Considerations: Approval was obtained from the Norwegian Agency for Shared Services in Education and Research and was based on voluntary participation, informed consent, and confidentiality.; Results: The following three main themes were identified: Having a meaningful existence within the living environment, being seen and valued as a family caregiver in relation with others and suffering in a space of loneliness. These contextual, relational, and existential perspectives were found to be closely interrelated.; Conclusion and Final Considerations: The dignity of family caregivers was closely tied to being seen as unique individuals, not merely caregivers, thereby requiring healthcare professionals (HCPs) to understand their personal needs. This study highlights the emotional distress and loneliness family caregivers feel in their dual role within the healthcare system, thereby calling for HCPs to adopt an attitude of gentleness and recognition to impart dignity-preserving care in homecare practices.; Competing Interests: Declaration of conflicting interestsThe author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

13. Patient altruism at the end of life: A scoping review

Authors: Sterie, Anca-Cristina;Borasio, Gian Domenico;Deml, Michael J.;Gamondi, Claudia;Jox, Ralf J.;Larkin, Philip;Trombert, Alexia;Rubli Truchard, Eve and Bernard, Mathieu

Publication Date: 2024

Journal: Palliative & Supportive Care , pp. 1-13

Abstract: Objectives: The concept of altruism is evidenced in various disciplines but remains understudied in end-of-life (EOL) contexts. Patients at the EOL are often seen as passive recipients of care, whereas the altruism of professionals and families receives more research and clinical attention. Our aim was to summarize the state of the scientific literature concerning the concept of patient altruism in EOL contexts.; Methods: In May 2023, we searched 11 databases for scientific literature on patient altruism in EOL contexts in consultation with a health information specialist. The scoping review is reported using the PRISMA checklist for scoping reviews. We used a data charting form to deductively extract data from the selected articles and then mapped data into 4 themes related to our

research questions: how authors describe and employ the concept of patient altruism; expressions of patient altruism; consequences of patients' altruistic acts; and possible interventions fostering patient altruism.; Results: Excluding duplicates, 2893 articles were retrieved; 33 were included in the final review. Altruism was generally considered as an act or intention oriented toward the benefit of a specific (known) or non-specific (generic) recipient. Patients expressed altruism through care and support, decisions to withhold treatment or actively hasten death, and engagement in advance care planning. Consequences of altruism were categorized in patient-centered (contribution to meaning in life and quality of life), non-patient-centered (leaving a positive impact and saving money), and negative consequences (generating feelings of guilt, exposing individuals with low self-esteem). Interventions to encourage altruism comprised specific interventions, providing opportunities to plan for future care, and recognizing and respecting the patients' altruistic motivations.; Significance of Results: We identified heterogeneous and limited research conceptualization of patient altruism and its operationalization in palliative care settings. A deeper conceptual, empirical, and theoretical exploration of patient altruism in EOL is necessary.

14. Older Adults' Unmet Needs at the End of Life: A Cross-Country Comparison of the United States and England

Authors: Swearinger, Hazel;Lapham, Jessica L.;Martinson, Melissa L. and Berridge, Clara

Publication Date: 2024

Journal: Journal of Aging and Health , pp. 8982643241245249

Abstract: Objectives: This study aimed to compare the end-of-life (EOL) experiences in concentration with place of death, for older adults in the U.S. and England. Methods: Weighted comparative analysis was conducted using harmonized Health and Retirement Study and English Longitudinal Study of Ageing datasets covering the period of 2006-2012. Results: At the EOL, more older adults in the U.S. (64.14%) than in England (54.09%) had unmet needs (I/ADLs). Home was the main place of death in the U.S. (47.34%), while it was the hospital in England (58.01%). Gender, marital status, income, place of death, previous hospitalization, memory-related diseases, self-rated health, and chronic diseases were linked to unmet needs in both countries. Discussion: These findings challenge the existing assumptions about EOL experiences and place of death outcomes, emphasizing the significance of developing integrated care models to bolster support for essential daily activities of older adults at the EOL.; Competing Interests: Declaration of Conflicting InterestsThe author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

15. Evaluation of a Novel Hospice-Specific Patient Decision Aid

Authors: Tate, Channing E.;Mami, Gwendolyn;McNulty, Monica;Rinehart, Deborah J.;Yasui, Robin;Rondinelli, Nicole;Treem, Jonathan;Fairclough, Diane and Matlock, Daniel D.

Publication Date: 2024

Journal: American Journal of Hospice & Palliative Medicine 41(4), pp. 414-423

Abstract: Background: We tested a novel hospice-specific patient decision aid to determine whether the decision aid could improve hospice knowledge, opinions of hospice, and decision self-efficacy in making decisions about hospice. Methods: Two patient-level randomized studies were conducted using two different cohorts. Recruitment was completed from March 2019 through May 2020. Cohort #1 was recruited from an academic hospital and a safety-net hospital and Cohort #2 was recruited from community members. Participants were randomized to review a hospice-specific patient decision aid. The primary outcomes were change in hospice knowledge, hospice beliefs and attitudes, and decision self-efficacy Wilcoxon signed rank tests were used to evaluate differences on the primary outcomes between baseline and 1-month. Participants: Participants were at least 65 years of age. A total of 266 participants enrolled (131 in Cohort #1 and 135 in Cohort #2). Participants were randomized to the

intervention group (n = 156) or control group (n = 109). The sample was 74% (n = 197) female, 58% (n = 156) African American and mean age was 74.9. Results: Improvements in hospice knowledge between baseline and 1-month were observed in both the intervention and the control groups with no differences between groups (.43 vs. .275 points, P = .823). There were no observed differences between groups on Hospice Beliefs and Attitudes scale (3.29 vs 3.08, P = .076). In contrast, Decision Self-Efficacy improved in both groups and the effect of the intervention was significant (8.04 vs 2.90, P = -.027). Conclusions: The intervention demonstrated significant improvements in decision self-efficacy but not in hospice knowledge or hospice beliefs and attitudes.

16. Anticipatory prescribing of injectable controlled drugs (ICDs) in care homes: a qualitative observational study of staff role, uncertain dying and hospital transfer at the end-of-life

Authors: Teggi, Diana and Woodthorpe, Kate

Publication Date: 2024

Journal: BMC Geriatrics 24(1), pp. 310

Abstract: Background: The anticipatory prescribing of injectable controlled drugs (ICDs) by general practitioners (GPs) to care home residents is common practice and is believed to reduce emergency hospital transfers at the end-of-life. However, evidence about the process of ICD prescribing and how it affects residents' hospital transfer is limited. The study examined how care home nurses and senior carers (senior staff) describe their role in ICDs prescribing and identify that role to affect residents' hospital transfers at the end-of-life.; Methods: 1,440 h of participant observation in five care homes in England between May 2019 and March 2020. Semi-structured interviews with a range of staff. Interviews (n = 25) and fieldnotes (2,761 handwritten A5 pages) were analysed thematically.; Results: Senior staff request GPs to prescribe ICDs ahead of residents' expected death and review prescribed ICDs for as long as residents survive. Senior staff use this mechanism to ascertain the clinical appropriateness of withholding potentially life-extending emergency care (which usually led to hospital transfer) and demonstrate safe care provision to GPs certifying the medical cause of death. This enables senior staff to facilitate a care home death for residents experiencing uncertain dying trajectories.; Conclusion: Senior staff use GPs' prescriptions and reviews of ICDs to pre-empt hospital transfers at the end-of-life. Policy should indicate a clear timeframe for ICD review to make hospital transfer avoidance less reliant on trust between senior staff and GPs. The timeframe should match the period before death allowing GPs to certify death without triggering a Coroner's referral. (© 2024. The Author(s).)

17. Social media for palliative and end-of-life care research: a systematic review

Authors: Wang, Yijun;Koffman, Jonathan;Gao, Wei;Zhou, Yuxin;Chukwusa, Emeka and Curcin, Vasa

Publication Date: 2024

Journal: BMJ Supportive & Palliative Care

Abstract: Background: Social media with real-time content and a wide-reaching user network opens up more possibilities for palliative and end-of-life care (PEoLC) researchers who have begun to embrace it as a complementary research tool. This review aims to identify the uses of social media in PEoLC studies and to examine the ethical considerations and data collection approaches raised by this research approach.; Methods: Nine online databases were searched for PEoLC research using social media published before December 2022. Thematic analysis and narrative synthesis approach were used to categorise social media applications.; Results: 21 studies were included. 16 studies used social media to conduct secondary analysis and five studies used social media as a platform for information sharing. Ethical considerations relevant to social media studies varied while 15 studies discussed ethical considerations, only 6 studies obtained ethical approval and 5 studies confirmed participant consent. Among studies that used social media data, most of them manually collected social media

data, and other studies relied on Twitter application programming interface or third-party analytical tools. A total of 1 520 329 posts, 325 videos and 33 articles related to PEO LC from 2008 to 2022 were collected and analysed.; Conclusions: Social media has emerged as a promising complementary research tool with demonstrated feasibility in various applications. However, we identified the absence of standardised ethical handling and data collection approaches which pose an ongoing challenge. We provided practical recommendations to bridge these pressing gaps for researchers wishing to use social media in future PEO LC-related studies.; Competing Interests: Competing interests: None declared. (© Author(s) (or their employer(s)) 2024. Re-use permitted under CC BY. Published by BMJ.)

18. Providing holistic end-of-life care for people with a history of problem substance use: a mixed methods cohort study of interdisciplinary service provision and integrated care

Authors: Webb, Lucy;Yarwood, Gemma;Witham, Gary;Wright, Sam and Galvani, Sarah

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Journal: BMC Palliative Care 23(1), pp. 1-12

Abstract: Harmful use of illicit drugs and/or alcohol is linked to life-limiting illness and complex health and social care needs, but people who use substances and have complex needs do not receive timely palliative care and fail to achieve quality standards for a good death. They and their families often require support from multiple health and social care services which are shown to be poorly integrated and fail to deliver interdisciplinary care. This study aimed to identify the existing barriers and facilitators within and between services in providing this population with a good death. Using a mixed methods approach of survey, focus groups and semi-structured interviews, we explored the perspectives of practitioner and management staff across a range of health and social disciplines and organisations in one combined authority in a large city in the north west of England. Our findings indicate that practitioners want to provide better care for this client group, but face structural, organisational and professional boundary barriers to delivering integrated and shared care. Differences in philosophy of care, piecemeal commissioning and funding of services, and regulatory frameworks for different services, lead to poor and inequitable access to health and social care services. Ways forward for improving care are suggested as bespoke hostel-based accommodation for palliative care for this client group, and specialist link workers who can transcend professional and organisational boundaries to support co-ordination of services and support. We conclude that it is no longer adequate to call for more training, better communication and improved joint working. Complex care at the end of life requires creative and cohesive systemic responses that enable multi-disciplinary practitioners to provide the care they wish to give and enables individuals using substances to get the respect and quality service they deserve.

19. Facilitators and barriers of implementing end-of-life care volunteering in a hospital in five European countries: the iLIVE study

Authors: Yildiz, Berivan;van der Heide, Agnes;Bakan, Misa;Iversen, Grethe Skorpen;Haugen, Dagny Faksvåg;McGlinchey, Tamsin;Smeding, Ruthmarijke;Ellershaw, John;Fischer, Claudia;Simon, Judit;Vibora-Martin, Eva;Ruiz-Torreras, Inmaculada and Goossensen, Anne

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Abstract: Background: End-of-life (EoL) care volunteers in hospitals are a novel approach to support patients and their close ones. The iLIVE Volunteer Study supported hospital volunteer coordinators from five European countries to design and implement an EoL care volunteer service on general wards in their hospitals. This study aimed to identify and explore barriers and facilitators to the implementation of EoL care volunteer services in the five hospitals.; Methods: Volunteer coordinators (VCs) from the Netherlands (NL), Norway (NO), Slovenia (SI), Spain (ES) and United Kingdom (UK) participated in a

focus group interview and subsequent in-depth one-to-one interviews. A theory-inspired framework based on the five domains of the Consolidated Framework for Implementation Research (CFIR) was used for data collection and analysis. Results from the focus group were depicted in radar charts per hospital.; Results: Barriers across all hospitals were the COVID-19 pandemic delaying the implementation process, and the lack of recognition of the added value of EoL care volunteers by hospital staff. Site-specific barriers were struggles with promoting the service in a highly structured setting with many stakeholders (NL), negative views among nurses on hospital volunteering (NL, NO), a lack of support from healthcare professionals and the management (SI, ES), and uncertainty about their role in implementation among VCs (ES). Site-specific facilitators were training of volunteers (NO, SI, NL), involving volunteers in promoting the service (NO), and education and awareness for healthcare professionals about the role and boundaries of volunteers (UK).; Conclusion: Establishing a comprehensive EoL care volunteer service for patients in non-specialist palliative care wards involves multiple considerations including training, creating awareness and ensuring management support. Implementation requires involvement of stakeholders in a way that enables medical EoL care and volunteering to co-exist. Further research is needed to explore how trust and equal partnerships between volunteers and professional staff can be built and sustained.; Trial Registration: NCT04678310. Registered 21/12/2020. (© 2024. The Author(s).)

Sources Used:

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