End of Life Care
Current Awareness Bulletin
April 2019

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Title: Understanding the factors associated with patients with dementia achieving their preferred place of death: a retrospective cohort study.

Citation: Age and ageing; Feb 2019
Author(s): Wiggins, Natasha; Droney, Joanne; Mohammed, Kabir; Riley, Julia; Sleeman, Katherine E

Objective: Dying in one’s preferred place is a quality marker for end-of-life care. Little is known about preferred place of death, or the factors associated with achieving this, for people with dementia. This study aims to understand preferences for place of death among people with dementia; to identify factors associated with achieving these preferences.

Population: Adults with a diagnosis of dementia who died between December 2015 and March 2017 and who were registered on Coordinate My Care, an Electronic Palliative Care Coordination System.

Design: Retrospective cohort study.
Analysis: Multivariable logistic regression investigated factors associated with achieving preferred place of death.
Results: We identified 1,047 people who died with dementia; information on preferred and actual place of death was available for 803. Preferred place of death was most commonly care home (58.8%, n = 472) or home (39.0%, n = 313). Overall 83.7% (n = 672) died in their preferred place. Dying in the preferred place was more likely for those most functionally impaired (OR 1.82 95% CI 1.06-3.13), and with a ceiling of treatment of ‘symptomatic relief only’ (OR 2.65, 95% CI 1.37-5.14). It was less likely for people with a primary diagnosis of cancer (OR 0.52, 95% CI 0.28-0.97), those who were ‘for’ cardio-pulmonary resuscitation (OR 0.32, 95% CI 0.16-0.62) and those whose record was created longer before death (51-250 days (ref <50 days) OR 0.60, 95% CI 0.38-0.94).

Conclusions: Most people with dementia want to die in a care home or at home. Achieving this is more likely where goals of treatment are symptomatic relief only, indicating the importance of advance care planning.

Title: The Effect of a Comprehensive Dementia Care Management Program on End-of-Life Care.

Citation: Journal of the American Geriatrics Society; Mar 2019; vol. 67 (no. 3); p. 443-448
Author(s): Jennings, Lee A; Turner, Maurice; Keebler, Chandra; Burton, Carl H; Romero, Tahmineh; Wenger, Neil S; Reuben, David B

Objective: Although Alzheimer disease and other dementias are life limiting, only a minority of these patients or their proxy decision makers participate in advance care planning. We describe end-of-life care preferences and acute care and hospice use in the last 6 months of life for persons enrolled in a comprehensive dementia care management program.

Design: Observational, retrospective cohort.
Setting: Urban, academic medical center.
Participants: A total of 322 persons enrolled in dementia care management after July 1, 2012, who died before July 1, 2016.
Intervention: Dementia care comanagement model using nurse practitioners partnered with primary care providers and community organizations to provide comprehensive dementia care, including advance care planning.
Measurements: Advance care preferences, use of Physician Orders for Life Sustaining Treatment (POLST), hospice enrollment, and hospitalizations and emergency department (ED) visits in the last 6 months of life obtained from electronic health record data.

Results: Nearly all decedents (99.7%, N = 321) had a goals-of-care conversation documented (median = 3 conversations; interquartile range = 2-4 conversations), and 64% had advance care preferences recorded. Among those with recorded preferences, 88% indicated do not resuscitate, 48% limited medical interventions, and 35% chose comfort-focused care. Most patients (89%) specified limited artificial nutrition, including withholding feeding tubes. Over half (54%) had no hospitalizations or ED visits in the last 6 months of life, and intensive care unit stays were rare (5% of decedents). Overall, 69% died on hospice. Decedents who had completed a POLST were more likely to die in hospice care (74% vs 62%; P = .03) and die at home (70% vs 59%; P = .04).

Conclusions: Enrollees in a comprehensive dementia care comanagement program had high engagement in advance care planning, high rates of hospice use, and low acute care utilization near the end of life. Wider implementation of such programs may improve end-of-life care for persons with dementia.
study found that a structured conversation about end-of-life care with a family member increased the likelihood of advance care orders being listed in residents' records.

**Conclusion:** There is little evidence about effective strategies to improve participation in advance care planning for persons with dementia. Methodologically rigorous intervention trials are needed to test interventions that encourage timely participation.

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**Title:** Perspectives of people with dementia and carers on advance care planning and end-of-life care: A systematic review and thematic synthesis of qualitative studies.

**Citation:** Palliative Medicine; Mar 2019; vol. 33 (no. 3); p. 274-290

**Author(s):** Sellars, Marcus; Chung, Olivia; Nolte, Linda; Tong, Allison; Pond, Dimity; Fetherstonhaugh, Deirdre; McInerney, Fran; Sinclair, Craig; Detering, Karen M.

**Objective:** Advance care planning aims to ensure that care received during serious and chronic illness is consistent with the person's values, preferences and goals. However, less than 40% of people with dementia undertake advance care planning internationally. This study aims to describe the perspectives of people with dementia and their carers on advance care planning and end-of-life care.

**Design:** Systematic review and thematic synthesis of qualitative studies. Data sources: Electronic databases were searched from inception to July 2018.

**Results:** From 84 studies involving 389 people with dementia and 1864 carers, five themes were identified: avoiding dehumanising treatment and care (remaining connected, delaying institutionalisation, rejecting the burdens of futile treatment); confronting emotionally difficult conversations (signifying death, unpreparedness to face impending cognitive decline, locked into a pathway); navigating existential tensions (accepting inevitable incapacity and death, fear of being responsible for cause of death, alleviating decisional responsibility); defining personal autonomy (struggling with unknown preferences, depending on carer advocacy, justifying treatments for health deteriorations); and lacking confidence in healthcare settings (distrusting clinicians' mastery and knowledge, making uninformed choices, deprived of hospice access and support at end of life).

**Conclusion:** People with dementia and their carers felt uncertain in making treatment decisions in the context of advance care planning and end-of-life care. Advance care planning strategies that attend to people's uncertainty in decision-making may help to empower people with dementia and carers and strengthen person-centred care in this context.

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**Title:** The effectiveness of end-of-life care simulation in undergraduate nursing education: A randomized controlled trial.

**Citation:** Nurse Education Today; May 2019; vol. 76; p. 1-7

**Author(s):** Tamaki, Tomoko; Inumaru, Anri; Yokoi, Yumie; Fujii, Makoto; Tomita, Mayu; Inoue, Yuta; Kido, Michiko; Ohno, Yuko; Tsujikawa, Mayumi

**Objective:** Background Nursing students have limited opportunities to experience end-of-life care, so it is difficult for them to learn how to deliver it empirically. The use of simulations with standardized patients may be a way to provide realistic experience of end-of-life care for nursing students. The aim of this study was to evaluate the effectiveness of end-of-life care simulations with standardized patients in improving the knowledge, skill performance and self-confidence of undergraduate nursing students.
Design: Randomized controlled study.

Setting: Japanese university nursing school. Participants Thirty-eight students in the third year of the Bachelor's degree in nursing (simulation group = 20, control group = 18).

Methods: After randomization to a simulation or control group, participants in the simulation group participated in an end-of-life care simulation with standardized patients. The primary outcome of a change in the knowledge score was assessed using a knowledge questionnaire, skill performance by completing Objective Structured Clinical Evaluations, and self-confidence related to end-of-life care by self-reported questionnaires.

Results: The simulation group improved significantly in knowledge, skill performance in physical assessment and psychological care, and self-confidence related to end-of-life care. The results of the two-way analysis of variance showed a significant interaction between groups and time (p = 0.000). Analysis of the simple main effect showed a significant difference (p = 0.000) between groups after the end-of-life care simulation and a significant difference (p = 0.000) over time in the simulation group. There were large effects on knowledge improvement (η² = 0.372), physical assessment (η² = 0.619), psychological care skill performance (η² = 0.588), and self-confidence in both physical assessment (η² = 0.410) and psychological care (η² = 0.722).

Conclusions: End-of-life care simulation with standardized patients would be an effective strategy to train nursing students, who have limited opportunities to experience end-of-life care.

Title: Care staff’s self-efficacy regarding end-of-life communication in the long-term care setting: Results of the PACE cross-sectional study in six European countries.

Citation: International Journal of Nursing Studies; Apr 2019; vol. 92; p. 135-143


Background: An important part of palliative care is discussing preferences at end of life, however such conversations may not often occur. Care staff with greater self-efficacy towards end-of-life communication are probably more likely to have such discussions, however, there is a lack of research on self-efficacy towards end-of-life discussions among long-term care staff in Europe and related factors.

Objectives: Firstly, to describe and compare the self-efficacy level of long-term care staff regarding end-of-life communication across six countries; secondly, to analyse characteristics of staff and facilities which are associated to self-efficacy towards end-of-life communication. Design Cross-sectional survey.

Settings: Long-term care facilities in Belgium, England, Finland, Italy, the Netherlands and Poland (n = 290). Participants Nurses and care assistants (n = 1680) completed a self-efficacy scale and were included in the analyses. Methods Care staff rated their self-efficacy (confidence in their own ability) on a scale of 0 (cannot do at all) to 7 -(certain can do) of the 8-item communication subscale of the Self-efficacy in End-of-Life Care survey. Staff characteristics included age, gender, professional role, education level, training in palliative care and years working in direct care. Facility characteristics included facility type and availability of palliative care guidelines, palliative care team and palliative care advice. Analyses were conducted using Generalized Estimating Equations, to account for clustering of data at facility level.

Results: The proportion of staff with a mean self-efficacy score >5 was highest in the Netherlands (76.4%), ranged between 55.9% and 60.0% in Belgium, Poland, England and Finland and was lowest in Italy (29.6%). Higher levels of self-efficacy (>5) were associated with: staff over 50 years of age (OR 1.86 95% CI[1.30–2.65]); nurses (compared to care assistants) (1.75 [1.20–2.54]); completion of higher secondary or tertiary education (respectively 2.22 [1.53–3.21] and 3.11 [2.05–
Conclusion: Self-efficacy towards end-of-life communication was most often low in Italy and most often high in the Netherlands. In all countries, low self-efficacy was found relatively often for discussion of prognosis. Palliative care education and guidelines for palliative care could improve the self-efficacy of care staff.

Title: Planning Ahead: Using the Theory of Planned Behavior to Predict Older Adults’ Intentions to Use Hospice if Faced With Terminal Illness.

Citation: Journal of Applied Gerontology; Apr 2019; vol. 38 (no. 4); p. 572-591

Author(s): Nahapetyan, Lusine; Orpinas, Pamela; Glass, Anne; Song, Xiao

Abstract: Hospice is underutilized in the United States, and many patients enroll for short periods of times. The purpose of this cross-sectional study was to identify significant predictors of intentions to use hospice in community-dwelling older adults. The Theory of Planned Behavior informed the selection of predictors. Data were collected from 146 White older adults (M age = 69.5; 69% females). Multiple linear regression analyses showed that higher hospice knowledge, normative beliefs that support hospice utilization, higher perceived control to use hospice, and preferences for end-of-life care that favor comfort and quality of life over living as long as possible were significant predictors of intentions to use hospice. In spite of being a sample of mostly highly educated older adults, almost half did not know about funding for hospice. These results provide better understanding of where to focus interventions to educate older adults about hospice, ideally in advance of a crisis.

Title: Palliative Care Nursing Communication: An Evaluation of the COMFORT Model.

Citation: Journal of Hospice & Palliative Nursing; Apr 2019; vol. 21 (no. 2); p. 124-130

Author(s): Fuoto, Abby; Turner, Kathleen M.

Abstract: Despite the frequency, complexity, and intensity of communication that occurs between nurses, patients, and families, palliative care nurses often struggle with end-of-life communication. The primary goal of this quality improvement project was to increase nurse confidence and satisfaction engaging in end-of-life communication following the implementation of the COMFORT model; the secondary goal was to improve patient-family satisfaction with care provided in the palliative care unit. Fourteen palliative care nurses attended a 4-hour course to learn the tenets of the COMFORT model and practice through role-play exercises. A repeated-measures design was used to measure nurse confidence and satisfaction precourse, postcourse, and 3 months postcourse. A between-subjects pre-post design was used to compare family satisfaction survey scores in the 3-month period before versus the 3 months after implementation. Analysis revealed a statistically significant increase in all measures of nurse confidence and satisfaction from precourse to postcourse and from precourse to 3 months postcourse. There was no statistical difference between the family satisfaction survey scores before versus after training, although survey results were generally high at baseline and most respondents rated palliative services with the best possible response. This project demonstrates that COMFORT model training increased confidence and satisfaction of palliative care nurses engaged in end-of-life communication and demonstrates potential for use in other clinical areas that do not specialize in end-of-life nursing.
(eg, critical care) but find themselves in need of the communications skills to address end-of-life care.

Title: Compassionate communities.

Citation: International Journal of Palliative Nursing; Mar 2019; vol. 25 (no. 3); p. 107-107
Author(s): Mills, Jason; Rosenberg, John P

Abstract: The author reflects on the advancement of the compassionate communities movement to support people with life-limiting conditions, as well as the possible role played by nurses through palliative nursing. Also cited are the four components of public health palliative care (PHPC) including specialist palliative care, generalist palliative care, and civic end-of-life care, as well as the potential contributions of palliative care nurses like conducting psychosocial assessments.

Title: Death and Dying: Tools to Help Respiratory Therapists Handle Frequent Exposure to End of Life Care.

Citation: Journal of Allied Health; Mar 2019; vol. 48 (no. 1); p. 72-75
Author(s): Mahan, Kyle

Abstract: Education and recognition of death anxiety are important for respiratory therapists. A vital component of respiratory therapy is managing mechanical ventilation and dealing with death and dying. For most institutions, respiratory therapy is a vital component of the rapid response team, code team, and trauma team. Removal of mechanical ventilation is a duty primarily bestowed upon the respiratory therapist. Exposure to death, on a frequent basis, can take an emotional toll and lead to burnout, stress, and increased turnover. Managers and leaders in the hospital must make efforts to provide counseling and education to support respiratory therapists and their ongoing exposure to death and dying. This paper examines coping mechanisms for physicians and paramedics, resulting in tools that can be used to provide support to the respiratory therapist.

Title: The ELCIDD Project: An Audit of End-of-Life Care in Persons with Intellectual Disabilities and Dementia.

Citation: Journal of Policy & Practice in Intellectual Disabilities; Mar 2019; vol. 16 (no. 1); p. 88-92
Author(s): Tromans, Samuel; Andrews, Hayley; Wani, Anu; Ganghadaran, Satheesh

Abstract: With a rise in the life expectancy of people with intellectual disabilities in recent decades, there has been a related increase in rates of dementia. As a chronic, progressive condition dementia presents opportunities for provision of pre-planned end-of-life care. This audit focussed on the level of compliance with pre-defined end-of-life care standards for a group of patients with intellectual disabilities and severe dementia. Compliance with pre-defined end-of-life care standards was found to be highly variable. Areas of high compliance included all 32 patients having access to their primary care physician, 84% (n = 27) having regular review by their psychiatrist and 94% (n = 30) having had a review of their medication regime. In contrast, there was only clear evidence of patient involvement in advance planning for 25% (n = 8) of patients, with similarly few patients having agreement on the use of cardiopulmonary resuscitation (22%; n = 7) a plan for supporting their carers and/or family (13%; n = 4) or a documented preferred place...
Title: Service Delivery Models to Maximize Quality of Life for Older People at the End of Life: A Rapid Review.

Citation: Milbank Quarterly; Mar 2019; vol. 97 (no. 1); p. 113-175

Author(s): Evans, Catherine J.; Ison, Lucy; Ellis-Smith, Clare; Nicholson, Caroline; Costa, Alessia; Oluyase, Adejoke O.; Namisango, Eve; Bone, Anna E.; Brighton, Lisa Jane; Yi, Deokhee; Combes, Sarah; Bajwah, Sabrina; Gao, Wei; Harding, Richard; Ong, Paul; Higginson, Irene J.; Maddocks, Matthew

Objective: In an era of unprecedented global aging, a key priority is to align health and social services for older populations in order to support the dual priorities of living well while adapting to a gradual decline in function. We aimed to provide a comprehensive synthesis of evidence regarding service delivery models that optimize the quality of life (QoL) for older people at the end of life across health, social, and welfare services worldwide.

Methods: We conducted a rapid scoping review of systematic reviews. We searched MEDLINE, CINAHL, EMBASE, and CDSR databases from 2000 to 2017 for reviews reporting the effectiveness of service models aimed at optimizing QoL for older people, more than 50% of whom were older than 60 and in the last one or two years of life. We assessed the quality of these included reviews using AMSTAR and synthesized the findings narratively.

Results: Of the 2,238 reviews identified, we included 72, with 20 reporting meta-analysis. Although all the World Health Organization (WHO) regions were represented, most of the reviews reported data from the Americas (52 of 72), Europe (46 of 72), and/or the Western Pacific (28 of 72). We identified two overarching classifications of service models but with different target outcomes: Integrated Geriatric Care, emphasizing physical function, and Integrated Palliative Care, focusing mainly on symptoms and concerns. Areas of synergy across the overarching classifications included person-centered care, education, and a multiprofessional workforce. The reviews assessed 117 separate outcomes. A meta-analysis demonstrated effectiveness for both classifications on QoL, including symptoms such as pain, depression, and psychological well-being. Economic analysis and its implications were poorly considered.

Conclusions: Despite their different target outcomes, those service models classified as Integrated Geriatric Care or Integrated Palliative Care were effective in improving QoL for older people nearing the end of life. Both approaches highlight the imperative for integrating services across the care continuum, with service involvement triggered by the patient's needs and likelihood of benefits. To inform the sustainability of health system change we encourage economic analyses that span health and social care and examine all sources of finance to understand contextual inequalities.

Title: Health Professionals Perceived Concerns and Challenges in Providing Palliative and End-of-Life Care: A Qualitative Analysis.

Citation: American Journal of Hospice & Palliative Medicine; Apr 2019; vol. 36 (no. 4); p. 308-315

Author(s): Price, Deborah M.; Strodtman, Linda K.; Montagnini, Marcos; Smith, Heather M.; Ghosh, Bidisha
Objective: The Institute of Medicine identifies that quality palliative/end-of-life (EOL) care should be provided to patients with serious, life-limiting illnesses and their families by competently prepared health professionals. This study assessed perceived concerns of health professionals pertaining to the delivery of palliative/EOL care in the hospital setting. The specific aim was to determine thematic concerns in the delivery of palliative/EOL care which emerged from respondents’ impressions of a memorable palliative/EOL patient experience.

Methods: Interdisciplinary health professionals at a large academic health system in the Midwest were surveyed to reflect upon a memorable palliative/EOL life care patient situation (positive or negative). A Thematic Analysis approach was used to code qualitative responses to 4 open-ended questions and then extract themes and subthemes from the coded data.

Results: Concerns identified by participants (N = 425) emerged around 7 themes including communication (97%), decision-making/care planning (75%), education needs (60%), EOL care (48%), ethics (24%), satisfaction with care (9%), and spiritual/cultural sensitivity (6%). Conclusion: Challenges exist in the delivery of quality palliative/EOL care in the hospital setting which may be addressed through educational initiatives that focus on recognition of cultural influences on care preferences, improving communication between patients/families and providers, education about the differences between palliative and EOL care, and increased competency of health providers in having EOL/goals-of-care discussions. Health professionals must recognize the benefit of collaborative palliative care in order to meet patient and family needs holistically and comprehensively.

Title: Haematology nurses' perspectives of their patients' places of care and death: A UK qualitative interview study.

Citation: European Journal of Oncology Nursing; Apr 2019; vol. 39; p. 70-80
Author(s): McCaughan, Dorothy; Roman, Eve; Smith, Alexandra G.; Garry, Anne C.; Johnson, Miriam J.; Patmore, Russell D.; Howard, Martin R.; Howell, Debra A.

Objective: Patients with haematological malignancies are more likely to die in hospital, and less likely to access palliative care than people with other cancers, though the reasons for this are not well understood. The purpose of our study was to explore haematology nurses' perspectives of their patients' places of care and death.

Method: Qualitative description, based on thematic content analysis. Eight haematology nurses working in secondary and tertiary hospital settings were purposively selected and interviewed. Transcriptions were coded and analysed for themes using a mainly inductive, cross-comparative approach.

Results: Five inter-related factors were identified as contributing to the likelihood of patients' receiving end of life care/dying in hospital: the complex nature of haematological diseases and their treatment; close clinician-patient bonds; delays to end of life discussions; lack of integration between haematology and palliative care services; and barriers to death at home.

Conclusions: Hospital death is often determined by the characteristics of the cancer and type of treatment. Prognostication is complex across subtypes and hospital death perceived as unavoidable, and sometimes the preferred option. Earlier, frank conversations that focus on realistic outcomes, closer integration of palliative care and haematology services, better communication across the secondary/primary care interface, and an increase in out-of-hours nursing support could improve end of life care and facilitate death at home or in hospice, when preferred.

Highlights • Patients with haematological malignancies are more likely to die in hospital than people with other cancers. • No previous research has reported on UK haematology nurses' perspectives of their patients' place of care and place of death. • Hospital deaths were largely
attributed to disease characteristics, nature of treatment and difficulties with prognostication. However, other modifiable factors were also identified as barriers to death at home.

Title: Tools Measuring Quality of Death, Dying, and Care, Completed after Death: Systematic Review of Psychometric Properties.

Citation: Patient; Apr 2019; vol. 12 (no. 2); p. 183-197
Author(s): Kupeli, Nuriye; Candy, Bridget; Tamura-Rose, Gabrielle; Schofield, Guy; Webber, Natalie; Hicks, Stephanie E.; Floyd, Theodore; Vivat, Bella; Sampson, Elizabeth L.; Stone, Patrick; Aspden, Trefor

Objective: Measuring the quality of care at the end of life and/or the quality of dying and death can be challenging. Some measurement tools seek to assess the quality of care immediately prior to death; others retrospectively assess, following death, the quality of end-of-life care. The comparative evaluation of the properties and application of the various instruments has been limited. This systematic review identified and critically appraised the psychometric properties and applicability of tools used after death.

Method: We conducted a systematic review according to PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines by systematically searching MEDLINE, Embase, CINAHL, and PsycINFO for relevant studies. We then appraised the psychometric properties and the quality of reporting of the psychometric properties of the identified tools using the COSMIN (Consensus-based Standards for the selection of health Measurement Instruments) checklist. The protocol of this systematic review has been registered on PROSPERO (CRD42016047296).

Results: The search identified 4751 studies. Of these, 33 met the inclusion criteria, reporting on the psychometric properties of 67 tools. These tools measured quality of care at the end of life (n = 35), quality of dying and death (n = 22), or both quality of care at the end of life and dying and death (n = 10). Most tools were completed by family carers (n = 57), with some also completed by healthcare professionals (HCPs) (n = 2) or just HCPs (n = 8). No single tool was found to be adequate across all the psychometric properties assessed. Two quality of care at the end of life tools—Care of the Dying Evaluation and Satisfaction with Care at the End of Life in Dementia—had strong psychometric properties in most respects. Two tools assessing quality of dying and death—the Quality of Dying and Death and the newly developed Staff Perception of End of Life Experience—had limited to moderate evidence of good psychometric properties. Two tools assessing both quality of care and quality of dying and death—the Quality Of Dying in Long-Term Care for cognitively intact populations and Good Death Inventory (Korean version)—had the best psychometric properties.

Conclusion: Four tools demonstrated some promise, but no single tool was consistent across all psychometric properties assessed. All tools identified would benefit from further psychometric testing.

Title: Discussing end of life wishes – the impact of community interventions?

Citation: BMC Palliative Care; Mar 2019; vol. 18 (no. 1)
Author(s): Abba, Katharine; Lloyd-Williams, Mari; Horton, Siobhan

Objective: Many people do not discuss end of life preferences with those closest to them, although this can be beneficial to the individual and wider population. This study evaluated a
community intervention to promote end of life preparation and discussion among people who are currently well.

**Methods:** A series of presentations and workshops (the intervention) were delivered to community groups and people working within health and social care. Participants were invited to complete a three-stage follow-up survey at Baseline, Post intervention and at three months’ follow-up.

**Results:** Baseline questionnaires were completed by 498 individuals. Overall, 51% reported talking with close family or friends about their end of life care and 58% reported talking about what they would like to happen after their death. There was a significant positive relationship between increasing age group and having talked about end of life wishes. The majority of participants were already comfortable in talking about end of life (overall mean score 8.28/10). Post intervention, 73% stated that they planned to take action including 61% who planned a specific conversation and 55% who planned another action. At follow-up 64% reported that they had taken some action due to the intervention, including 43% who had talked about their own end of life preferences and 39% who had taken some other action.

**Conclusions:** Well-designed community-based interventions can be successful in prompting people to consider and discuss their end of life preferences.

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**Title:** Factor structure of the Quality of Children’s Palliative Care Instrument (QCPCI) when complete by parents of children with cancer.

**Citation:** BMC Palliative Care; Mar 2019; vol. 18 (no. 1)

**Author(s):** Widger, Kimberley; Brennenstuhl, Sarah; Duc, Jacqueline; Tourangeau, Ann; Rapoport, Adam

**Objective:** Currently available indicators of quality pediatric palliative care tend to focus on care provided during the end-of-life period rather than care provided throughout the disease trajectory. We adapted a previously developed instrument focused on mothers' perspectives on the quality of end-of-life care and assessed its psychometric properties with mothers and fathers of children with cancer at any stage of the illness.

**Methods:** Four subscales were included in the analysis: Connect with Families, Involve Parents, Share Information Among Health Professionals, Support Siblings. The number of items across the four subscales was reduced from 31 to 15. We conducted confirmatory factor analysis, composite reliability, internal consistency, and tests of correlation between the overall scale and subscale totals and a separate question inquiring about overall quality of care. Measurement invariance between mothers and fathers was assessed.

**Results:** A total of 533 mothers and fathers completed the survey. The four-factor model was confirmed and there were significant correlations between each subscale score and responses to the overall item on care quality. Cronbach's alpha was adequate for the scale as a whole and for each subscale ranging from 0.78 to 0.90. We also found the factor structure, means, and intercepts were similar across mothers and fathers, suggesting the tool can be used by both groups.

**Conclusions:** There is evidence for a four-factor structure within a new Quality of Children’s Palliative Care Instrument (QCPCI) with demonstrated reliability when used with mothers and fathers of children with cancer. Ongoing assessment of the psychometric properties is needed, including testing in additional populations. However, our initial findings suggest that the QCPCI may be a helpful tool for assessing the quality of palliative care for pediatric patients anywhere along the disease trajectory from the perspective of parents.
Title: Establishing a structured plan to provide high-quality end-of-life care in community settings.

Citation: British Journal of Community Nursing; Mar 2019; vol. 24 (no. 3); p. 120-127

Author(s): Ramplin, Charlotte

Abstract: The purpose of this project was to explore how registered community nurses experienced providing holistic end-of-life care and how having a structured end-of-life care pathway plan would help develop their knowledge and skills, particularly in respect of communication and their ability and confidence in providing evidence-based compassionate care. For some practitioners there exists a lack of confidence surrounding end of life care, which can result in nurses' reluctance to become involved and avoid engaging in those 'difficult conversations'. Following implementation, early reviews from practice suggest that incorporating the 19 steps of the plan into the delivery of community-based care at end of life has enhanced practice and patient experience.

Title: The Effect of a Comprehensive Dementia Care Management Program on End-of-Life Care.

Citation: Journal of the American Geriatrics Society; Mar 2019; vol. 67 (no. 3); p. 443-448

Author(s): Jennings, Lee A.; Turner, Maurice; Keebler, Chandra; Burton, Carl H.; Romero, Tahmineh; Wenger, Neil S.; Reuben, David B.

Objectives: Although Alzheimer disease and other dementias are life limiting, only a minority of these patients or their proxy decision makers participate in advance care planning. We describe end-of-life care preferences and acute care and hospice use in the last 6 months of life for persons enrolled in a comprehensive dementia care management program.

Design: Observational, retrospective cohort.

Setting: Urban, academic medical center.

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Measurements: Advance care preferences, use of Physician Orders for Life Sustaining Treatment (POLST), hospice enrollment, and hospitalizations and emergency department (ED) visits in the last 6 months of life obtained from electronic health record data.

Results: Nearly all decedents (99.7%, N = 321) had a goals-of-care conversation documented (median = 3 conversations; interquartile range = 2-4 conversations), and 64% had advance care preferences recorded. Among those with recorded preferences, 88% indicated do not resuscitate, 48% limited medical interventions, and 35% chose comfort-focused care. Most patients (89%) specified limited artificial nutrition, including withholding feeding tubes. Over half (54%) had no hospitalizations or ED visits in the last 6 months of life, and intensive care unit stays were rare (5% of decedents). Overall, 69% died on hospice. Decedents who had completed a POLST were more likely to die in hospice care (74% vs 62%; P =.03) and die at home (70% vs 59%; P =.04).

Conclusions: Enrollees in a comprehensive dementia care comanagement program had high engagement in advance care planning, high rates of hospice use, and low acute care utilization near the end of life. Wider implementation of such programs may improve end-of-life care for

Title: Unpacking Communication About End-of-Life Care: Resulting Recommendations.

Citation: Journal of the American Medical Directors Association; Mar 2019; vol. 20 (no. 3); p. 225-226
Author(s): Zimmerman, Sheryl; Hanson, Laura C.

Title: Association Between End-of-Life Conversations in Nursing Homes and End-of-Life Care Outcomes: A Systematic Review and Meta-analysis.

Citation: Journal of the American Medical Directors Association; Mar 2019; vol. 20 (no. 3); p. 249-261
Author(s): Gonella, Silvia; Basso, Ines; Dimonte, Valerio; Martin, Barbara; Berchialla, Paola; Campagna, Sara; Di Giulio, Paola

Objective: Less aggressive end-of-life (EOL) care has been observed when health care professionals discuss approaching EOL and preferences about life-sustaining treatments with nursing home (NH) residents or their families. We performed a comprehensive systematic review to evaluate the association between health care professionals–residents and health care professionals–family EOL conversations and EOL care outcomes. Design Systematic review with meta-analysis.

Setting and Participants: Seven databases were searched in December 2017 to find studies that focused on health care professionals–residents (without oncologic disease) and health care professionals–family EOL conversations and aimed to explore the impact of EOL conversations on resident's or family's EOL care outcomes. Measures Random effects meta-analyses with subsequent quality sensitivity analysis and meta-regression were performed to assess the effects of EOL conversations on the decision to limit or withdraw life-sustaining treatments. A funnel plot and Egger test were used to assess publication bias.

Results: 16 studies were included in the qualitative and 7 in the quantitative synthesis. Health care professionals–family EOL conversations were positively associated with the family's decision to limit or withdraw life-sustaining treatments (odds ratio = 2.23, 95% confidence interval: 1.58-3.14). The overall effect of health care professionals–family EOL conversations on the family's decision to limit or withdraw life-sustaining treatments remained stable in the quality sensitivity analysis. In the meta-regression, family members with a higher level of education were less influenced by EOL conversations with health care professionals when making decisions about limiting or withdrawing life-sustaining treatments. No publication bias was detected (P = .4483).

Conclusions/Implications: This systematic review shows that EOL conversations promote palliative care. Structured conversations aimed at exploring NH resident preferences about EOL treatment should become routine. NH administrators should offer health care professionals regular training on EOL conversations, and resident-centered care that involves residents and their families in a shared decision-making process at EOL needs to be promoted.

Title: Condition-Specific Pamphlets to Improve End-of-life Communication in Long-term Care: Staff Perceptions on Usability and Use.

Citation: Journal of the American Medical Directors Association; Mar 2019; vol. 20 (no. 3); p. 262-267
Author(s): Sussman, Tamara; Kaasalainen, Sharon; Lee, Eunyoung; Akhtar-Danesh, Noori; Strachan, Patricia H.; Brazil, Kevin; Bonifas, Robin; Bourgeois-Guérin, Valérie; Durivage, Patrick; Papaioannou, Alexandra; Young, Laurel

Objectives: This article reports findings on the usability and staff use of 5 condition-specific pamphlets of high prevalence in long-term care (LTC): dementia, heart failure, chronic obstructive pulmonary disease, renal failure, and frailty. The pamphlets were created in response to residents', families', and staff's recommendations for activating early reflections and communication about end-of-life care.

Design: A mixed-method (qualitative and quantitative) survey design was used. Step 1 collected survey data on the usability of the pamphlets. Step 2 collected survey data on pamphlet use.

Settings and Participants: Two nurses with specialized palliative care training, 2 resident/family representatives, 10 condition-specific specialists, and 33 LTC palliative leads reviewed the pamphlets for usability prior to distribution. A total of 178 LTC home staff in 4 participating LTC homes reported on pamphlet use.

Measures: Specialists and resident/family representatives were asked to provide open comments and LTC home palliative leads were asked to complete a survey on the accuracy, readability, and relevance of the pamphlets. After 6 months of distribution, all staff in participating LTC homes were asked to complete a survey on pamphlet use, usefulness, and comfort with distribution.

Results: The pamphlets were reportedly accurate, relevant, and easy to understand. Following 6 months of availability, most staff in LTC had read the pamphlets, found the information useful, and planned to share them. However, half of the staff questioned their role in pamphlet distribution and most had not distributed them. Regulated staff (ie, staff affiliated with a regulated profession) expressed more comfort sharing the pamphlets than care aides and support staff.

Conclusions/Implications: Condition-specific pamphlets appear to hold promise in providing residents and families with relevant information that may activate early reflections and conversations about end-of-life care. However, structured implementation strategies, training, and discussions are required to improve staff comfort with distribution and explore roles in distribution and follow-up.

Title: Families' Experiences with End-of-Life Care in Nursing Homes and Associations with Dying Peacefully With Dementia.

Citation: Journal of the American Medical Directors Association; Mar 2019; vol. 20 (no. 3); p. 268-272

Author(s): Bolt, Sascha R.; Verbeek, Laura; Meijers, Judith M.M.; van der Steen, Jenny T.

Objectives: To examine family caregivers' experiences with end-of-life care for nursing home residents with dementia and associations with the residents dying peacefully. Design A secondary data analysis of family caregiver data collected in the observational Dutch End of Life in Dementia (DEOLD) study between 2007 and 2010.

Setting and participants: Data were collected at 34 Dutch nursing homes (2799 beds) representing the nation. We included 252 reports from bereaved family members of nursing home residents with dementia.

Measures: The primary outcome was dying peacefully, assessed by family members using an item from the Quality of Dying in Long-term Care instrument. Unpleasant experiences with end-of-life care were investigated using open-ended questions. Overall satisfaction with end-of-life care was assessed with the End-of-Life Satisfaction With Care (EOLD-SWC) scale, and families' appraisal of decision making was measured with the Decision Satisfaction Inventory. Associations
were investigated with multilevel linear regression analyses using generalized estimating equations.

**Results:** Families' reports of unpleasant experiences translated into 2 themes: neglect and lack of respect. Neglect involved facing inaccessibility, disinterest, or discontinuity of relations, and negligence in tailored care and information. Lack of respect involved perceptions of being purposefully disregarded, an insensitive approach towards resident and family, noncompliance with agreements, and violations of privacy. Unpleasant experiences with end-of-life care were negatively associated with families' perceptions of the resident dying peacefully. Families' assessment of their relative dying peacefully was positively associated with satisfaction with end-of-life care and decision making.

**Conclusions/Implications:** Families' reports of unpleasant experiences with end-of-life care may inform practice to improve perceived quality of dying of their loved ones. Humane and compassionate care and attention from physicians and other staff for resident and family may facilitate recollections of a peaceful death.

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**Title:** Effectiveness of interventions to increase participation in advance care planning for people with a diagnosis of dementia: A systematic review.

**Citation:** Palliative Medicine; Mar 2019; vol. 33 (no. 3); p. 262-273

**Author(s):** Bryant, Jamie; Turon, Heidi; Waller, Amy; Freund, Megan; Mansfield, Elise; Sanson-Fisher, Rob

**Objective:** Advance care planning involves considering, discussing and documenting future wishes in case a person is unable to make or communicate decisions. Given people with dementia are at high risk of future decisional incapacity, it is critical that advance care planning occurs early in the illness trajectory. This study aims to determine (1) the number of intervention studies published between 1997 and July 2017 that aimed to increase advance care planning for persons with dementia, (2) the methodological quality of studies and (3) the effectiveness of interventions in increasing advance care planning for persons with dementia.

**Design:** Systematic review.

**Data sources:** Medline, Cochrane, EMBASE, PsycINFO and CINAHL were searched for articles published from 1997 to July 2017. Studies were included if they utilised a methodologically robust study design and reported on an intervention designed to increase participation in advance care planning for persons with dementia that was targeted at the person with dementia and/or a carer/family member. Methodological quality was assessed independently by two authors.

**Results:** Four studies met the criteria for inclusion. Methodological quality was variable. Two studies did not report analyses comparing advance care planning outcomes for intervention and control participants. A third study found no effect for a nurse-facilitator intervention. The fourth study found that a structured conversation about end-of-life care with a family member increased the likelihood of advance care orders being listed in residents' records.

**Conclusion:** There is little evidence about effective strategies to improve participation in advance care planning for persons with dementia. Methodologically rigorous intervention trials are needed to test interventions that encourage timely participation.

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**Title:** Perspectives of people with dementia and carers on advance care planning and end-of-life care: A systematic review and thematic synthesis of qualitative studies.

**Citation:** Palliative Medicine; Mar 2019; vol. 33 (no. 3); p. 274-290
Author(s): Sellars, Marcus; Chung, Olivia; Nolte, Linda; Tong, Allison; Pond, Dimity; Fetherstonhaugh, Deirdre; McLnerney, Fran; Sinclair, Craig; Detering, Karen M.

Objective: Advance care planning aims to ensure that care received during serious and chronic illness is consistent with the person's values, preferences and goals. However, less than 40% of people with dementia undertake advance care planning internationally. This study aims to describe the perspectives of people with dementia and their carers on advance care planning and end-of-life care.

Design: Systematic review and thematic synthesis of qualitative studies. Data sources: Electronic databases were searched from inception to July 2018.

Results: From 84 studies involving 389 people with dementia and 1864 carers, five themes were identified: avoiding dehumanising treatment and care (remaining connected, delaying institutionalisation, rejecting the burdens of futile treatment); confronting emotionally difficult conversations (signifying death, unpreparedness to face impending cognitive decline, locked into a pathway); navigating existential tensions (accepting inevitable incapacity and death, fear of being responsible for cause of death, alleviating decisional responsibility); defining personal autonomy (struggling with unknown preferences, depending on carer advocacy, justifying treatments for health deteriorations); and lacking confidence in healthcare settings (distrusting clinicians' mastery and knowledge, making uninformed choices, deprived of hospice access and support at end of life).

Conclusion: People with dementia and their carers felt uncertain in making treatment decisions in the context of advance care planning and end-of-life care. Advance care planning strategies that attend to people's uncertainty in decision-making may help to empower people with dementia and carers and strengthen person-centred care in this context.

Title: End-of-life care in an Australian acute hospital: A retrospective observational study.

Citation: Internal medicine journal; Mar 2019

Author(s): Maubach, Ninya; Batten, Monique; Jones, Scott; Chen, Judy; Scholz, Brett; Davis, Alison; Bromley, Jonathan; Burke, Brandon; Tan, Ren; Hurwitz, Mark; Rodgers, Helen; Mitchell, Imogen

Objective: There is a gap in knowledge about the kind and quality of care experienced by hospital patients at the end of their lives. This study aims to document and compare the patterns in end-of-life care for patients dying across a range of different medical units in an acute care hospital.

Methods: A retrospective observational study of consecutive adult inpatient deaths between 1 July 2010 and 30 June 2014 in four different medical units of an Australian tertiary referral hospital was performed. Units were selected on the basis of highest inpatient death rates and included Medical Oncology, Respiratory Medicine, Cardiology and Gastroenterology/hepatology.

Results: Overall, 41% of patients died with active medical treatment plans, but significantly more Respiratory and Cardiology patients died with ongoing treatment (46% and 75% respectively) than Medical Oncology and Gastroenterology patients (each 27%, p<0.05). More Medical Oncology and Gastroenterology patients were recognised as dying (92% and 88%) compared to 72% of Respiratory and only 38% of Cardiology patients (p<0.001). Significantly more Medical Oncology patients were referred to palliative care and received comfort care plans than all other patient groups. However, the rate of non-palliative interventions given in the final 48 hours was not significantly different between all four groups.

Conclusions: There were differences in managing the dying process between all disciplines. A possible solution to these discrepancies would be to create an integrated palliative care approach across the hospital. Improving and reducing inter-disciplinary practice variations will allow more
patients to have a high-quality and safe death in acute hospitals. This article is protected by copyright. All rights reserved.

Title: Transport Home and Terminal Extubation by Emergency Medical Services: An Example of Innovation in End of Life Care.

Citation: Journal of pain and symptom management; Mar 2019
Author(s): Clemency, Brian M; Grimm, Kathleen T; Lauer, Sandra L; Lynch, Jenna C; Pastwik, Benjamin L; Lindstrom, Heather A; Dailey, Michael W; Waldrop, Deborah P

Abstract: For the majority of terminally ill patients, the preferred place of death is at home. Previous literature has demonstrated the feasibility of at-home terminal extubation performed by critical care and hospice physicians. This case report describes a terminal extubation performed by a paramedic under the direct supervision of an Emergency Medical Services (EMS) physician in the patient's home. Guided by a comprehensive plan and logistical support from a team of hospice providers, a successful out-of-hospital terminal extubation is possible. To truly achieve patient-centered care at end-of-life, the choice for an out-of-hospital death is necessary.

Title: Sitting with silence: hospital social work interventions for dying patients and their Families.

Citation: Social work in health care; Mar 2019; p. 1-15
Author(s): Moon, Felicity; Fraser, Lucinda; McDermott, Fiona

Abstract: The recent controversy around the hospital end of life care has highlighted the vulnerability of dying patients and their families. However, little is known about how social workers provide support and intervention around the end of life in the hospital. Eight hospital social workers provided qualitative descriptions of their clinical practice for adult patients and their families. Highlighting a theoretical orientation towards a person-in-environment approach, social workers develop unique interventions to contribute to multidisciplinary care. Findings emphasize the need to prepare social work students and clinicians for the reality of working with end of life issues.

Title: How effective are organ donation committees, and how can they be improved?

Citation: British Journal of Healthcare Management; Mar 2019; vol. 25 (no. 3); p. 113-121
Author(s): Silva, Geeth; Gor, Ratan; Patel, Nishil; Gupta, Shubham; Manivannan, Thulashie; Manu, Susan; Sharma, Ashwini; Gardiner, Dale; Cox, Benita

Objective: Organ donation committees were established in 2008 by NHS Blood and Transplant to improve the rates of organ donation in the UK. The aims of this study were three-fold: to review the role and structure of organ donation committees in England; to assess how effective organ donation committees are at driving improvements; and to make recommendations regarding the future role, responsibilities and structure of organ donation committees.

Methods: This study adopted a cross-sectional mixed-methods research approach using questionnaires and semi-structured interviews.

Results: There was a divergence between how each committee functioned and how effective they were in achieving their aims. Discussion: There were seven key findings which related to the
effectiveness of organ donation committees. These included, but were not limited to, a lack of consistency in how the role of an organ donation committee was viewed by members of NHS Blood and Transplant; and that the influence a chair has within their respective NHS Trust is key to an organ donation committee being effective in achieving its aims.

**Conclusion:** A framework and several recommendations were produced and aimed to help improve the effectiveness of organ donation committees.

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**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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