

End of Life Care Current Awareness Bulletin

December 2019

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How technology can transform end-of-life care

12th November 2019, Digital Health News

Ian Bailey, a district nurse and clinical director at EMIS Health, explores how technology can help transform care for the increasing number of terminally ill patients being cared for at home. Every year, expert end-of-life teams care for more than 200,000 people with terminal or life-limiting illnesses in 220 hospices across the UK.

Title: Dilemmas Adult Children Face in Discussing End-of-Life Care Preferences with Their Parents.

Citation: Health Communication; Dec 2019; vol. 34 (no. 14); p. 1788-1794

Author(s): Roscoe, Lori A.; Barrison, Philip

Abstract: This study explored the perceived goals, barriers, and strategies that characterize family interactions about advance care planning (ACP), which is instrumental in guiding end-of-life care. Discussions within the family context can significantly improve end-of-life decision making but are complicated, partly because participants are attempting to achieve multiple, and often competing, goals. Participants (n = 75) responded to a hypothetical scenario about a conversation with a parent about ACP by completing an anonymous online survey. Respondents described their conversational goals, anticipated barriers, and strategies they thought would be helpful. Thematic data analysis identified four dilemmas participants faced while attempting to achieve multiple, conflicting goals: (1) the desire to make the parent feel wanted while discussing them not being around; (2) the need to be gentle but still direct; (3) the practical necessity of designating one decision-maker without provoking family conflict; and (4) the desire to lessen the burden on the designated decision-maker by providing necessary information while still placing them in a decision-making role. Participants reported using several strategies to manage these complex dilemmas. These findings provide support for the utility of Goldsmith's normative theory of social support in the context of discussions about ACP. The results also provide a foundation for developing conversational guides to facilitate high-quality family conversations about ACP between adult children and their parents.

Title: Faecal incontinence in palliative and end-of-life care.

Citation: British Journal of Community Nursing; Nov 2019; vol. 24 (no. 11); p. 528-532

Author(s): Palmer, Sarah Jane

Abstract: Faecal incontinence can be a distressing and undignified experience, and is particularly a care delivery need for those at the end of life. There are various publications by national bodies including NHS England, the Department of Health, NHS Scotland and others, discussed in this article, to inform readers of the best way to care for someone experiencing faecal incontinence who is being looked after through palliative care in the community. The article will also discuss the application of recommended faecal collection devices and some of the associated risks. The devices discussed are: anal pouches, rectal tubes and catheters, and rectal trumpets. The article aims to inform the practice of community and district nurses providing palliative care.

Title: Deprescribing in end-of-life care.

Citation: Journal of Prescribing Practice; Nov 2019; vol. 1 (no. 11); p. 540-543

Author(s): Gardner, Emma

Abstract: The aim of deprescribing in end-of-life care is to improve the patient's quality of life by reducing their drug burden. It is essential to engage the patients and enable them to make choices about medications by discussing their preferences and implement a pharmacy management plan. Withdrawing medications during the end stages of life is extremely complex because the period of care varies substantially. The aim of this article is to address polypharmacy within end-of-life care. It will review which medications should be stopped by examining the non-essential and essential drugs. The intention is to encourage an approach to care which provides an equal balance between treatment and patient expectation.

Title: Dying in acute hospitals: voices of bereaved relatives.

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

Author(s): Ó Coimín, Diarmuid; Prizeman, Geraldine; Korn, Bettina; Donnelly, Sarah; Hynes, GERALYN

Background: Internationally there is an increasing concern about the quality of end-of-life care (EoLC) provided in acute hospitals. More people are cared for at end of life and die in acute hospitals than in any other healthcare setting. This paper reports the views of bereaved relatives on the experience of care they and the person that died received during their last admission in two university adult acute tertiary hospitals.

Methods: Relatives of patients who died were invited to participate in a post-bereavement postal survey. An adapted version of VOICES (Views of Informal Carers - Evaluation of Services) questionnaire was used. VOICES MaJam has 36 closed questions and four open-ended questions. Data were gathered in three waves and analysed using SPSS and NVivo. 356 respondents completed the survey (46% response rate).

Results: The majority of respondents (87%; n = 303) rated the quality of care as outstanding, excellent or good during the last admission to hospital. The quality of care by nurses, doctors and other staff was highly rated. Overall, care needs were well met; however, findings identified areas of care which could be improved, including communication and the provision of emotional and spiritual support. In addition, relatives strongly endorsed the provision of EoLC in single occupancy rooms, the availability of family rooms on acute hospital wards and the provision of bereavement support.

Conclusions: This research provides a powerful snapshot in time into what works well and what could be improved in EoLC in acute hospitals. Findings are reported under several themes, including the overall quality of care, meeting care needs, communication, the hospital environment and support for relatives. Results indicate that improvements can be made that build on existing good practice that will enhance the experience of care for dying persons and their relatives. The study adds insights in relation to relative's priorities for EoLC in acute hospitals and can advance care providers', policy makers' and educationalists' priorities for service improvement.

Title: End-of-life and palliative care of patients on maintenance hemodialysis treatment: a focus group study.

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

Author(s): Axelsson, Lena; Benzein, Eva; Lindberg, Jenny; Persson, Carina

Background: Despite complex illness trajectories and a high symptom burden, palliative care has been sub-optimal for patients with end-stage kidney disease and hemodialysis treatment who have a high rate of hospitalization and intensive care towards end of life. There is a growing awareness that further development of palliative care is required to meet the needs of these patients and their family members. In this process, it is important to explore healthcare professionals' views on provision of care. The aim of this study was therefore to describe nurses' and physicians' perspectives on end-of-life and palliative care of patients treated with maintenance hemodialysis.

Methods: Four focus group interviews were conducted with renal nurses (17) and physicians (5) in Sweden. Qualitative content analysis was used to analyze data.

Results: Participants were committed to giving the best possible care to their patients, but there were challenges and barriers to providing quality palliative care in nephrology settings. Professionals described palliative care as end-of-life care associated with hemodialysis withdrawal or palliative dialysis, but also identified care needs and possibilities that are in line with an earlier integrated palliative approach. This was perceived as complex from an organizational point of view. Participants identified challenges related to coordination of care and different perspectives on care responsibilities that impacted symptom management and patients' quality of life. Communication issues relating to the provision of palliative care were revealed where the hemodialysis setting was regarded as an impediment, and personal and professional experiences, beliefs and knowledge were considered of major importance.

Conclusions: Nurses and physicians identified a need for the improvement of both late and earlier palliative care approaches. The results highlighted a requirement for and possibilities of training, counselling and support of health care professionals in the dialysis context. Further, multi-professional palliative care collaborations should be developed to improve the coordination and organization of end-of-life and palliative care of patients and their family members. A climate allowing conversations about advance care planning throughout the illness trajectory may facilitate the gradual integration of palliative care alongside life-prolonging treatment for improved support of patients and families.

Title: Context, mechanisms and outcomes in end-of-life care for people with advanced dementia: family carers perspective.

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

Author(s): Kupeli, Nuriye; Sampson, Elizabeth L.; Leavey, Gerard; Harrington, Jane; Davis, Sarah; Candy, Bridget; King, Michael; Nazareth, Irwin; Jones, Louise; Moore, Kirsten

Background: Keeping people living with advanced dementia in their usual place of residence is becoming a key governmental goal but to achieve this, family carers and health care professionals must negotiate how to provide optimal care. Previously, we reported a realist analysis of the health care professional perspective. Here, we report on family carer perspectives. We aimed to understand the similarities and differences between the two perspectives, gain insights into how the interdependent roles of family carers and HCPs can be optimised, and make recommendations for policy and practice.

Method: Qualitative study using a realist approach in which we used the criteria from guidance on optimal palliative care in advanced dementia to examine key contexts, mechanisms and outcomes highlighted by family carers.

Results: The themes and views of family caregivers resonate with those of health care professionals. Their overlapping anxieties related to business-driven care homes, uncertainty of families when making EOL decisions and the importance of symptom management referring to contexts, mechanisms and outcomes, respectively. Contexts specific to family carers were ad hoc information about services, dementia progression and access to funding. Not all family carers identified dementia as terminal, but many recognised the importance of continuity of care and knowing the wishes of the person with dementia. New mechanisms included specific resources for improving EOL care and barriers to discussing and planning for future care. Family carers identified the importance of comfort, being present, the meeting of basic care needs and feeling the right decisions have been made as good outcomes of care.

Conclusions: Family carers and health care professionals share similar concerns about the challenges to good EOL dementia care. Better understanding of the effects of dementia at the advanced stages would improve confidence in EOL care and reduce uncertainty in decision making for family carers and health care professionals.

Title: Optimizing Advanced Care Planning in Hospitalized Patients With Advanced Cancers: A Quality Improvement Initiative.

Citation: Journal of Doctoral Nursing Practice; Oct 2019; vol. 12 (no. 2); p. 239-245

Author(s): Jackson, Gloria L.; Padilla, Blanca Iris; Schneider, Susan M.; Kyte, Jennifer Jo

Background: Advance care planning (ACP) that generates an advanced directive (AD) can ensure patient autonomy at end of life. ACP is challenging for healthcare providers. Delaying patient ACP may lead to poor quality end-of-life care. Facilitation of early ACP by bedside RNs and social workers (SWs) may improve end-of-life care.

Objective: To determine whether improved ACP by RNs and SWs impacts care transition times for patients with advanced cancers.

Methods: A pre-/post-educational intervention designed to reinforce the roles of RNs and SWs in facilitating early ACP and timely documentation of an AD on an inpatient oncology unit.

Results: AD documentation increased by 12% between pre- and post-intervention period. There was a nonsignificant trend toward longer lengths of stay for patients transitioning care without an AD compared to those patients with and AD. Discussion: Bedside RNs and SWs are in a key position to facilitate early ACP which can positively impact care quality at end of life. However, ACP is a collaborative team effort, best initiated early by the primary oncology providers.

Conclusion: Early ACP may improve quality end-of-life care. Implications for Nursing: Continuing education for RNs and SWs to enhance coordination with primary oncology teams to facilitate earlier ACP is recommended.

Title: Exploring End-of-Life Care Team Communication: An Interprofessional Simulation Study.

Citation: American Journal of Hospice & Palliative Medicine; Jan 2020; vol. 37 (no. 1); p. 65-71

Author(s): Lippe, Megan; Stanley, Alexandra; Ricamato, Allison; Halli-Tierney, Anne; McKinney, Robert

Abstract: Effective team communication is necessary for the provision of high-quality health care. Yet, recent graduates from diverse health-care disciplines report inadequate training in communication skills and end-of-life care. This study explored the impact of a withdrawal of life-sustaining measures interprofessional simulation on team communication skills of students representing medicine, nursing, and social work. The 3-phase simulation required teams to communicate with the patient, family, and one another in the care of a seriously ill patient at the end of life. Team communication in the filmed simulations was analyzed via the Gap-Kalamazoo Communication Checklist. Results revealed fair to good communication across the 9 communication domains. Overall team communication was strongest in "shares information" and lowest in "understands the patient's and family's perspective" domains. Field notes revealed 5 primary themes— Team Dynamics, Awkwardness, Empathy is Everything, Build a Relationship, and Communicating Knowledge When You Have It—in the course of the data analysis. Logistical challenges encountered in simulation development and implementation are presented, along with proposed solutions that were effective for this study. This simulation provided an opportunity for interprofessional health-care provider students to learn team communication skills within an end-of-life care context.

Title: Progress in advance care planning among nursing home residents dying with advanced dementia—Does it make any difference in end-of-life care?

Citation: Archives of Gerontology & Geriatrics; Jan 2020; vol. 86

Author(s): Konttila, Tarja; Finne-Soveri, Ulla Harriet; Leskinen, Riitta; Niemelä, Katriina; Antikainen, Riitta

Abstract:

- Physician treatment orders doubled between 2004–2009 and 2010–2013.
- Despite the increased number of treatment orders symptom burden remained high.
- The consistency with the physician treatment orders was high.

Increased awareness of the clinical course of nursing home residents with advanced dementia and advance care planning (ACP) has become the cornerstone of good palliative care. The aim of our study is to describe changes in ACP in the form of physician treatment orders (PTOs), symptom prevalence and possible burdensome interventions among nursing home (NH) residents who died between 2004–2009 and 2010–2013 Retrospective study The number of PTOs regarding forgoing antibiotics or parenteral antibiotics, forgoing artificial nutrition or hydration or forgoing hospitalisation doubled between 2004–2009 and 2010–2013 (38.1% vs. 64.9%, $p < 0.001$; 40.0% vs. 81.7%, $p < 0.001$; 28.1% vs. 69.5%, $p < 0.001$, respectively). PTOs were also done significantly earlier in 2010–2013 than in 2004–2009. The prevalence of distressing symptoms and possible burdensome interventions remained unchanged, although the prevalence of consistency with the PTOs was high. Despite the increased number of PTOs, this had little effect on symptom prevalence and possible burdensome interventions experienced by NH residents in the last days of life.

Title: Does post-registration palliative care education for nurses improve practice? A systematic review.

Citation: International Journal of Palliative Nursing; Nov 2019; vol. 25 (no. 11); p. 552-564

Author(s): Thavaraj, Angela; Gillett, Karen

Aims: We aimed to answer the question: what is the evidence that post-registration palliative care education for nurses improves practice?

Background: The 2008 End of Life Care Strategy emphasised the need for a workforce equipped to provide high-quality end-of-life care for patients and their families. As registered nurses are the healthcare professionals spending most time with patients and families at the end of life, associated policy documents stress the importance of educating nurses to equip them with the necessary knowledge and skills to provide effective care. Despite education being a consistent recommendation, the ability of education to influence nursing practice is uncertain.

Methods: We undertook a systematic review of literature using Joanna Briggs Institute Methodology for Mixed Methods by searching the Medline, Embase and CINAHL databases between January 2006 and December 2018.

Findings: Ten studies met the inclusion criteria, seven contained quantitative data. Six demonstrated improvements in outcome measures, but not all results were statistically significant. Most quantitative data related to self-reported measures of confidence. Six studies contained qualitative findings that were categorised into themes: confidence, practice change, skills and proactivity.

Conclusion: Little research exists exploring the impact of post-registration palliative care education for nurses. Existing outcome measures do not clearly demonstrate changes to end-of-life practice. Research is suggested to establish links between self-reported confidence and improvements to practice. Evaluation of the impact on practice should be an integral component of end-of-life education initiatives.

Title: Healthcare utilization at the end of life in people dying from amyotrophic lateral sclerosis: A retrospective cohort study using linked administrative data.

Citation: Journal of the neurological sciences; Nov 2019; vol. 406 ; p. 116444

Author(s): Maetens, Arno; Deliens, Luc; De Bleecker, Jan; Caraceni, Augusto; De Ridder, Mark; Beernaert, Kim; Cohen, Joachim

Background: ALS is an incurable neurodegenerative disorder, with the recommendation that symptom management and palliative care start immediately or soon after diagnosis. However, little is known about healthcare utilization at the end of life in this patient group.

Aim: To describe healthcare utilization at the end of life in patients who died from ALS.

Design: We performed a retrospective cohort study using population-level administrative databases. The description of healthcare utilization was based on (1) validated quality indicators for end-of-life care, and (2) the European Federation of Neurological Societies guidelines on the clinical management of ALS.

Setting: We included all people who died from ALS in Belgium between 2010 and 2015 (using ICD-10 code G12.2). RESULTS 1636 people died from ALS in Belgium between 2010 and 2015. The mean age at death was 71 years (SD 11.3), and 56% were men. Specialized palliative care was used by 44% at some point in the last two years of life. In the last month of life, 13% received tube feeding, 48% received diagnostic testing, 41% were admitted to a hospital, and 25% were admitted to an emergency department. Medications were used mainly to treat pain (43%), insomnia and fatigue (33%) and thrombosis (32%); 39% used riluzole. Non-invasive ventilation was used by 18%. 39% died at home.

Conclusion: Administrative data provide a valuable source to describe healthcare utilization in small populations such as ALS, but more clinical evidence is needed on the advantages and disadvantages initiating or terminating treatments at the end of life.

Title: End-of-life care among adolescent and young adult patients with cancer living in poverty.

Citation: Cancer; Nov 2019

Author(s): Roeland, Eric J; Lindley, Lisa C; Gilbertson-White, Stephanie; Saeidzadeh, Seyedehnaz; Currie, Erin R; Friedman, Sarah; Bakitas, Marie; Mack, Jennifer W

Background: To the authors' knowledge, end-of-life (EOL) care outcomes among adolescents and young adults (AYAs) with cancer who are living in poverty remain poorly understood. The primary aim of the current study was to examine the effect of poverty on EOL care for AYA patients with cancer.

Methods: The authors conducted a multisite, retrospective study of AYA patients with cancer aged 15 to 39 years who died between January 2013 and December 2016 at 3 academic sites. Medical record-based EOL care outcomes included hospice referral, palliative care (PC) consultation, cancer treatment within the last month of life, and location of death. Two measures of poverty were applied: 1) zip code with a median income $\leq 200\%$ of the federal poverty level; and 2) public insurance or lack of insurance. Logistic regression analyses were conducted.

Results: A total of 252 AYA cancer decedents were identified. Approximately 41% lived in a high-poverty zip code and 48% had public insurance or lacked insurance; approximately 70% had at least 1 poverty indicator. Nearly 40% had a hospice referral, 60% had a PC consultation (76% on an inpatient basis), 38% received EOL cancer treatment, and 39% died in the hospital. In bivariable analyses, AYA patients living in low-income zip codes were found to be less likely to enroll in hospice ($P \leq .01$), have an early PC referral ($P \leq .01$), or receive EOL cancer treatment ($P = .03$), although only EOL cancer treatment met statistical significance in multivariable models. No differences with regard to location of death ($P = .99$) were observed.

Conclusions: AYA patients with cancer experience low rates of hospice referral and high rates of in-hospital death regardless of socioeconomic status. Future studies should evaluate early inpatient PC referrals as a possible method for improving EOL care.

Title: Palliative and end-of-life care and junior doctors': a systematic review and narrative synthesis.

Citation: BMJ supportive & palliative care; Nov 2019

Author(s): Bharmal, Aamena; Morgan, Tessa; Kuhn, Isla; Wee, Bee; Barclay, Stephen

Background: Palliative and end-of-life care is a core competency for doctors and is increasingly recognised as a key clinical skill for junior doctors. There is a growing international movement to embed palliative care education in medical student and junior doctor education. To date there has been no review of the literature concerning the views and experiences of junior doctors delivering this care.

Aim: To review the published literature between 2000 and 2019 concerning junior doctors' experience of palliative and end-of-life care.

Methods: Systematic literature review and narrative synthesis.

Results: A search of six databases identified 7191 titles; 34 papers met the inclusion criteria, with a further 5 identified from reference searching. Data were extracted into a review-specific extraction sheet and a narrative synthesis undertaken. Three key themes were identified: (1) 'Significance of death and dying': all papers found that junior doctors care for many patients approaching the end of life, and this often causes emotional distress and can leave persisting memories for many years afterwards; (2) 'Thrown in at the deep end': junior doctors feel unprepared and unsupported in providing palliative and end-of-life care; and (3) 'Addressing the gaps': junior doctors often experience a medical culture of disengagement towards dying patients and varying attitudes of senior doctors. Subsequently they have to learn the skills needed through seeking their own opportunities.

Conclusion: Medical education needs to change in order to better prepare and support junior doctors for their role in caring for dying patients. This education needs to focus on their knowledge, skills and attitudes.

Title: End-of-Life Care of Persons With Alzheimer Disease: An Update for Clinicians.

Citation: The American journal of hospice & palliative care; Nov 2019 ; p. 1049909119885881

Author(s): Trinh, Eric; Lee, Andrew; Kim, Kye Y

Abstract: While end-of-life (EOL) care has been a relatively common option for patients with terminal cancer, the utilization of EOL care in Alzheimer disease and other dementias has become available more recently. By the time end-stage dementia is present, the clinicians and caregivers become faced with multiple clinical issues-their inability to provide subjective complaints of pain and discomfort, behavioral symptoms, delirium, food refusal, and so on. In addition to providing quality EOL care to the patients, clinicians need to work with their families in an open and empathic manner, assuring that their loved ones will receive supportive measures to keep them comfortable.

Title: Piloting Me and My Wishes-Videos of Nursing Home Residents' Preferences.

Citation: Journal of pain and symptom management; Nov 2019

Author(s): Towsley, Gail L; Wong, Bob; Mokhtari, Tahereh; Hull, William; Miller, Susan C

Context: A key challenge in nursing homes is how to attain and clarify resident preferences for care and then communicate these preferences to family members and staff.

Objectives: We evaluated the feasibility and acceptability of Me & My Wishes- person-centered videos of residents discussing their preferences for daily and end-of-life (EOL) care.

Methods: For this descriptive study, Me & My Wishes videos were created with residents in three nursing homes in the Pacific Northwest. Feasibility was evaluated by tracking resident enrollment, completing and sharing their video, and conducting debriefing interviews to ascertain residents' impressions of the recording process and personalized conversation. After viewing the video, staff and family assessed communication quality via survey--the extent to which they perceived messages from the video (e.g., preferences for EOL) to be timely, accurate, adequate, complete, and credible, and items on resident preferences for daily and EOL care.

Results: Twenty of 33 residents approached created videos; 18 of these residents shared their videos with family or staff. Residents reported that they liked the opportunity to express

their wishes. On a scale of 1-7 (lower is better), mean ratings were: 2.0 (family) and 1.3 (staff) for communicating preferences for daily care; 1.9 (family) and 1.2 (staff) for communicating preferences for EOL. Both family and staff reported increased knowledge about resident preferences for daily and EOL care.

Conclusion: This research supports the feasibility and acceptability of a videotaping approach (Me & My Wishes) for viewing, listening and discussing residents' preferences for daily and end-of-life care.

Title: Silent Illumination: A Case Study Exploring the Spiritual Needs of a Transgender-Identified Elder Receiving Hospice Care.

Citation: Journal of Hospice & Palliative Nursing; Dec 2019; vol. 21 (no. 6); p. 467-474

Author(s): Campbell, Cathy L.; Catlett, Lauren

Abstract: With a growing population of transgender-identified elders in the United States, their unique spiritual end-of-life needs are coming to light. This article presents a case study of a hospice volunteer who used skillful means as an artist to help a transgender-identified woman express her spirituality in the last 6 months of her life. After data analysis, 4 themes emerged related to the expression of spirituality by lesbian, gay, bisexual, transgender, and queer (LGBTQ) elders at end of life. The themes that emerged included (1) the human element in advocacy for spiritual care, (2) the importance of safe spaces for reflection and meditation, (3) the importance of skillful means to work with LGBTQ people, and (4) acknowledgement of gender identity as a spiritual need. This case study serves as a springboard to advance research into the end-of-life needs of LGBTQ elders and the ways in which members of the hospice team can support spiritual care and alleviate suffering for this population.

Title: Live Discharge From Hospice: A Systematic Review.

Citation: Journal of Hospice & Palliative Nursing; Dec 2019; vol. 21 (no. 6); p. 482-488

Author(s): Wu, Serena; Volker, Deborah L.

Abstract: Live discharges from hospice may occur because of patient choice or provider choice. However, when discharges occur before death, patients and families may feel abandoned and left to manage care needs previously provided by hospice. The purpose of this systematic review was to better understand the nature of live discharges, including frequency, patient characteristics, and hospice characteristics. Of 44 studies identified for review, 13 met inclusion criteria and were published between 2008 and 2018. Live discharge rates varied from 5% to 23%. Patients' pre-hospice characteristics varied widely based on diagnosis, comorbidities, gender, race, and ethnicity. Hospice characteristics indicated that the likelihood of a live discharge was increased for patients enrolled in for-profit hospices and in rural areas. Only 2 studies captured the patient/family perspective of the live discharge experience, finding that the loss of hospice support was fraught with difficulties. A need for further study of the live discharge experience and the practices of hospices with high live discharge rates was identified.

Title: Palliative care nurse specialists' reflections on a palliative care educational intervention in long-term care: an inductive content analysis.

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

Author(s): Frey, Rosemary; Balmer, Deborah; Boyd, Michal; Robinson, Jackie; Gott, Merryyn

Background: Older people in long-term care facilities are at a greater risk of receiving care at the end of life that does not adequately meet their needs, yet staff in long-term care are often unprepared to provide palliative care. The objective of the study was to explore palliative care nurse specialists' experiences regarding the benefits of and barriers to the implementation of a palliative care educational intervention, Supportive Hospice Aged Residential Exchange (SHARE) in 20 long-term care facilities.

Methods: Reflective logs (465), recorded over the course of the yearlong SHARE intervention by the three palliative care nurse specialists from two local hospices, who were the on-site mentors, were qualitatively analyzed by two researchers utilizing inductive content analysis.

Results: Categories emerging from the logs include the importance of relationships, knowledge exchange, communication, and the challenges of providing palliative care in a long-term care setting.

Conclusion: Evidence from the logs indicated that sustained relationships between the palliative care nurse specialists and staff (registered nurses, healthcare assistants) as well as reciprocal learning were key factors supporting the implementation of this palliative care educational intervention. Challenges remain however in relation to staffing levels, which further emphasizes the importance of palliative care nurse specialist presence as a point of stability.

Title: Myths about hospices need to be shaken.

Citation: Nursing Times; Nov 2019; vol. 115 (no. 11); p. 14-15

Author(s): Hanna, Lindsay

Title: Work Satisfaction Among Hospice and Palliative Nurses.

Citation: Journal of Hospice & Palliative Nursing; Oct 2019; vol. 21 (no. 5)

Author(s): Head, Barbara PhD, CHPN, ACSW, FPCN; Middleton, Alyssa MSSW; Zeigler, Craig PhD

Abstract: Job satisfaction among hospice and palliative nurses is important as turnover and a dissatisfied workforce impact the work environment and the care provided to seriously ill patients and their families. This article reports the results of a nationwide survey of 633 hospice and palliative nurses evaluating job satisfaction, intent to leave, job stressors, suggested work improvements, and self-care strategies. Statistically significant correlations were found between the Home Healthcare Job Satisfaction Scale and subscales and the individual's self-rating of overall job satisfaction, likelihood of leaving the job, and thoughts of quitting. Multiple regression revealed a significant positive association between salary and overall job satisfaction, relationship with the organization, professional pride, autonomy, and control. A grounded theory approach was utilized to analyze qualitative data. Top job stressors identified were workload and problems with administration. Physical activities were cited as the most popular for self-care. Results indicate that most participants were highly satisfied with their work, but almost half think of quitting some or all of the time, indicating

dissatisfaction with the work environment. Respondents suggested that employers increase recognition and salary, create a more positive work environment, decrease workload, and focus on patient needs rather than profits.

Title: Mind the gap: Patients' experiences and perceptions of goal setting in palliative care.

Citation: Progress in Palliative Care; Dec 2019; vol. 27 (no. 6); p. 291-300

Author(s): Boa, Sally; Duncan, Edward; Haraldsdottir, Erna; Wyke, Sally

Background: Palliative care aims to support people to live actively until death. A rehabilitative approach which includes goal setting could be an important way of achieving this. Goal setting is well established in best practice guidelines for palliative care. However little is known about how the process of goal setting actually happens in practice, especially from patients' points of view. We aimed to investigate patients' expectations, experience and perceptions of goal setting in one hospice.

Methods: We conducted 15 semi-structured interviews with a sample of patients who had been admitted to a Scottish hospice for symptom control. Interviews were digitally recorded, transcribed verbatim and analysed using Framework Analysis.

Results: Participants understood and valued goal setting but did not always share their goals with hospice staff. These were often participants' own personal activity-based goals that they worked on in parallel, but not always in partnership with hospice professionals. Participants were able to adapt their goals as their situation changed.

Conclusions: Our findings revealed a gap between the goals that participants identified and worked towards compared with those that participants perceived the professionals focussed on. As a result, opportunities were missed for patients and professionals to work together to achieve goals.

Title: Hospice at Home services in England: a national survey.

Citation: BMJ supportive & palliative care; Nov 2019

Author(s): Rees-Roberts, Melanie; Williams, Peter; Hashem, Ferhana; Brigden, Charlotte; Greene, Kay; Gage, Heather; Goodwin, Mary; Silsbury, Graham; Wee, Bee; Barclay, Stephen; Wilson, Patricia M; Butler, Claire

Objective: Hospice at Home (HAH) services aim to enable patients to be cared for and die at home, if that is their choice and achieve a 'good death'. A national survey, in 2017, aimed to describe and compare the features of HAH services and understand key enablers to service provision.

Methods: Service managers of adult HAH services in the 'Hospice UK' and National Association for Hospice at Home directories within England were invited to participate. Information on service configuration, referral, staffing, finance, care provision and enablers to service provision were collected by telephone interview.

Results: Of 128 services invited, 70 (54.7%) provided data. Great diversity was found. Most services operated in mixed urban/rural (74.3%) and mixed deprivation (77.1%) areas and provided hands-on care (97.1%), symptom assessment and management (91.4%), psychosocial support (94.3%) and respite care (74.3%). Rapid response (within 4 hours) was available in 65.7%; hands-on care 24 hours a day in 52.2%. Charity donations were the main source of funding for 71.2%. Key enablers for service provision included working with

local services (eg, district nursing, general practitioner services), integrated health records, funding and anticipatory care planning. Access to timely medication and equipment was critical.

Conclusion: There is considerable variation in HAH services in England. Due to this variation it was not possible to categorise services into delivery types. Services work to supplement local care using a flexible approach benefitting from integration and funding. Further work defining service features related to patient and/or carer outcomes would support future service development.

Title: Advertising hospice care services.

Citation: Death studies; Nov 2019 ; p. 1-9

Author(s): Hakola, Outi J

Abstract: Many hospices advertise their services, yet the audience may frown upon the commercialization of death. Because research has ignored the content of hospice advertising, I analyzed quantitatively and qualitatively the content of 105 American television commercials. The hospices used four major solutions to invite positive readings. They narrated hospices as salvation, provided empowerment, represented hospices as quality service, and appealed to positive values, including comfort and support. Consequently, the commercials used affective advertising to create an emotional appeal where hospices appeared as solutions to difficult life situations. Consequently, the commercials represented both dying and hospices as potentially positive, and marketable experiences.

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

Citation: Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer; Nov 2019

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

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

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

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

the pilot program improved bed utilization ($p = .025$) and turnover rate ($p < .001$) of inpatient hospice service.

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

Title: Study title: Barriers to palliative and hospice care utilization in older adults with cancer: A systematic review.

Citation: Journal of geriatric oncology; Nov 2019

Author(s): Parajuli, Jyotsana; Tark, Aluem; Jao, Ying-Ling; Hupcey, Judith

Abstract: The number of older adults with cancer and the need for palliative care among this population is increasing in the United States. The objective of this systematic review was to synthesize the evidence on the barriers to palliative and hospice care utilization in older adults with cancer. A systematic literature search was conducted using PubMed, CINAHL, PsycINFO, Embase, and Cochrane Library databases (from inception to 2018) in accordance to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. Research articles that examined palliative or hospice care utilization in older adults with cancer were included in this review. Fineout-Overholt's Level of Evidence was used for quality appraisal. A total of 19 studies were synthesized in this review. Barriers to palliative and hospice care utilization were categorized into socio-demographic barriers, provider-related barriers, and health insurance-related barriers. Findings revealed that male, racial minority, unmarried individuals, individuals with low socio-economic status or residing in rural areas, and fee-for-service enrollees were less likely to use palliative or hospice care. Lack of communication with care providers is also a barrier of using palliative or hospice care. The factors identified in this review provide guidance on identification of high-risk population and intervention development to facilitate the use of palliative and hospice care in older adults with cancer. Larger prospective studies on this topic are needed to address this critical issue.

Title: The Impact of Advance Care Planning on End-of-Life Care: Do the Type and Timing Make a Difference for Patients With Advanced Cancer Referred to Hospice?

Citation: The American journal of hospice & palliative care; Dec 2019; vol. 36 (no. 12); p. 1089-1095

Author(s): Prater, Laura C; Wickizer, Thomas; Bower, Julie K; Bose-Brill, Seuli

Purpose: This study aimed to determine the impact of advanced care planning (ACP) on potentially avoidable hospital admissions at the end of life (EOL) among a sample of hospice-referred patients with cancer, in order to present actionable considerations for the practicing clinician.

Methods: This study was designed as a retrospective cohort using electronic health record data that assessed likelihood of hospital admissions in the last 30 days of life for 1185 patients with a primary diagnosis of cancer, referred to hospice between January 1, 2014, and December 31, 2015, at a large academic medical center. Inverse probability treatment weighting based on calculated propensity scores balanced measured covariates between those with and without ACP at baseline. Odds ratios (ORs) were calculated from estimated potential outcome means for the impact of ACP on admissions in the last 30 days of life.

Results: A verified do-not-resuscitate (DNR) order prior to the last 30 days of life was associated with reduced odds of admission compared to those without a DNR (OR = 0.30; P < .001). An ACP note in the problem list prior to the last 30 days of life was associated with reduced odds of admission compared to those without an ACP note (OR = 0.71, P = .042), and further reduced odds if done 6 months prior to death (OR = 0.35, P < .001).

Conclusions: This study shows that dedicated ACP documentation is associated with fewer admissions in the last 30 days of life for patients with advanced cancer referred to hospice. Improving ACP processes prior to hospice referral holds promise for reducing EOL admissions.

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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