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End of Life Care

Current Awareness Bulletin

May 2024

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1. **How to prepare children for the death of a parent from cancer: Honest conversations with children about end of life when a parent is dying of cancer can help them cope with the grieving process**

Authors: Anderson, Allie

Publication Date: 2024

Journal: Cancer Nursing Practice 23(3), pp. 15-16

Abstract: About in the 46,300 UK experience children the death of a parent each year, according to figures from the Childhood Bereavement Network – that is 127 children every day. And when a parent dies from a prolonged illness, such as cancer, evidence suggests their dependant children experience higher levels of maladaptive grief and symptoms of post-traumatic stress than children whose parent has died suddenly or naturally.

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2. **A Rapid Review on the Management of Constipation for Hospice and Palliative Care Patients**

Authors: Gill, Virpal;Badrzadeh, Houman;Williams, Sari;Crouch, Nadia Masroor;Buga, Sorin;Mooney, Stefanie and Fasolino, Tracy

Publication Date: 2024

Journal: Journal of Hospice and Palliative Nursing : JHPN : The Official Journal of the Hospice and Palliative Nurses Association 26(3), pp. 122-131

Abstract: Constipation is a distressing symptom that has a high prevalence in patients receiving hospice and palliative care services, particularly in cases of opioid use. A thorough assessment, root cause analysis, monitoring, and prophylactic approach are essential for symptom management and quality of life. This rapid review assessed studies published between 2018 and 2023 to identify strategies implemented by health care professionals to prevent and/or mitigate this distressing symptom. We identified 12 articles that addressed constipation in palliative and end-of-life settings and reported on the need for multifactorial management approaches with a focus on patient-centered care that includes the caregiver(s). Bedside nurses play a key role in assessing, identifying, and managing constipation. Proper documentation and communication with the interdisciplinary team help direct earlier intervention and ongoing awareness of constipation issues. Additional research is needed on specific tools and enhanced guidelines to ensure constipation is frequently addressed and preemptively managed.; Competing Interests: The authors have no conflicts of interest to disclose. (Copyright © 2024 by The Hospice and Palliative Nurses Association. All rights reserved.)

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3. **Hospice Satisfaction Among Patients, Family, and Caregivers: A Systematic Review of the Literature**

Authors: Hoff, Timothy;Trovato, Kathryn and Kitsakos, Aliya

Publication Date: 2024

Journal: The American Journal of Hospice & Palliative Care 41(6), pp. 691-705

Abstract: Background: Hospice care is an underused form of intervention at the end of life. The experiences of patients, families, and other caregivers are important to consider in thinking about how to encourage greater use of hospice care, through policies and advocacy that promote its benefits. Specifically, patient, family, and other caregiver satisfaction with hospice care is important to understand better. Methods: A PRISMA-guided review of the research on hospice care satisfaction and its correlates among patients, families, and other caregivers. Included in the review is research published over the time period 2000-2023 identifying a hospice care satisfaction finding. Results: Thirty-eight studies were included in the review. Key findings were: (a) higher levels of hospice care satisfaction among patients, families, and other caregivers; and (b) correlates of hospice care satisfaction falling into the categories of communication, comfort, and support. The published literature had fewer findings related to demographic correlates of satisfaction such as age or race/ethnicity and was lacking in comparative research examining satisfaction across different types of hospice care settings. Discussion: Extant research demonstrates a consistently higher level of hospice care satisfaction among patients, families, and other caregivers. This satisfaction appears related to specific aspects of care delivery that involve effective care coordination and communication; pain and symptom management; and emotional support. Strengthening future research involves testing additional interventions aimed at enhancing satisfaction; including more comparative research across hospice care settings; and more studies that include patients as the key respondents.; Competing Interests: Declaration of Conflicting InterestsThe author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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4. **Factors Contributing to Non-Concordance Between End-of-Life Care and Advance Care Planning**

Authors: Lee, Shih-Chieh;Shih, Chih-Yuan;Chen, Shan-Ting;Lee, Ching-Yi;Li, Shin-Rung;Tang, Chia-Chun;Tsai, Jaw-Shiun;Cheng, Shao-Yi and Huang, Hsien-Liang

Publication Date: 2024

Journal: Journal of Pain and Symptom Management 67(6), pp. 544-553

Abstract: Context: Despite making do-not-resuscitate or comfort care decisions during advance care planning, terminally ill patients sometimes receive life-sustaining treatments as they approach end of life.; Objectives: To examine factors contributing to nonconcordance between end-of-life care and advance care planning.; Methods: In this longitudinal retrospective cohort study, terminally ill patients with a life expectancy shorter than six months, who had previously expressed a preference for do-not-resuscitate or comfort care, were followed up after palliative shared care intervention. An instrument with eight items contributing to non-concordant care, developed through literature review and experts' consensus, was employed. An expert panel reviewed electronic medical records to determine factors associated with non-concordant care for each patient. Statistical analysis, including descriptive statistics and the chi-square test, examines demographic characteristics, and associations.;

Results: Among the enrolled 7871 patients, 97 (1.2%) received non-concordant care. The most prevalent factor was "families being too distressed about the patient's deteriorating condition and therefore being unable to let go" (84.5%) followed by "limited understanding of medical interventions among patients and surrogates" (38.1%), and "lack of patient participation in the decision-making process" (25.8%).; Conclusions: This study reveals that factors related to relational autonomy, emotional support, and health literacy may contribute to non-concordance between advance care planning and end-of-life care. In the future, developing an advance care planning model emphasizes respecting relational autonomy, providing emotional support, and enhancing health literacy could help patients receiving a goal concordant and holistic end-of-life care.; Competing Interests: Conflict of interest The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article. (Copyright © 2024 The Authors. Published by Elsevier Inc. All rights reserved.)

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5. **Fearing Pain at the End of Life: A Review of Advance Directives**

Authors: Luck, George;Eggenberger, Terry Lynn;Bautista, Adriana;Peters, Darian;Mellman, Ross T.;Keller, Kathryn B. and Jacomino, Mario

Publication Date: 2024

Journal: The American Journal of Hospice & Palliative Care 41(7), pp. 824-830

Abstract: Background: Patients, caregivers, and healthcare professionals often describe a "good death" as a pain-free process. However, many patients experience pain during their last weeks of life. Advance directives (ADs) are legally binding documents that allow individuals to express their wishes for end-of-life care which should include management of their pain.; Methods: An interprofessional team conducted a comprehensive analysis of ADs from all 50 states and the District of Columbia to assess the inclusion of language that reflects patients' wishes for pain relief at the end of life.; Results: Thirty-seven (73%) of the 51 entities examined reflected the prototypical directive, containing explicit instructions for withholding or withdrawing interventions that may prolong suffering rather than options for treating pain. Of these, 12 (24%) did not include the word "pain". Only 14 states (27%) provided clear guidance for managing pain. Unexpectantly, researchers found that 13 (25%) addressed the common fears of patients, caregivers, and healthcare teams when using opioids to relieve suffering, such as addiction, sedation, appetite, or respiratory suppression, and hastening death.; Conclusion: The majority of ADs reviewed lacked clear and comprehensive measures for addressing pain relief. This deficiency may contribute to the undertreatment of pain and amplify the anxiety felt by patients, families, and healthcare providers when making end-of-life decisions. The results highlight the need for improvements in ADs to help ensure that patients' wishes regarding pain management are adequately addressed, documented and respected.; Competing Interests: Declaration of Conflicting InterestsThe author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

6. **Informal caregivers' experiences of transitioning during end-of-life care—A scoping review**

Authors: McCarthy, Brid;Timmins, Fiona;Eustace-Cook, Jessica and Connolly, Michael

Publication Date: 2024

Journal: Journal of Advanced Nursing (John Wiley & Sons, Inc.) 80(5), pp. 1719-1731

Abstract: Background: Dying well at home usually requires the help and assistance of an informal caregiver. This role is usually unpaid, wide-ranging and oftentimes demanding. From diagnosis to death of a loved one, informal caregivers can experience one and frequently numerous transitions, however, little is known about this process. The purpose of this scoping review is to chart, explore and understand caregivers' experiences of transitioning when providing end-of-life care. A preliminary search of the literature indicated a paucity of research highlighting a notable absence of caregiver's perspectives and acknowledgements of the support they need to ensure successful transitions during this time. Consequently, this review has the potential to make a valuable contribution to the literature. Methods: Arksey and O'Malley's (2005) framework, further enhanced by Levac et al. (2010) and Peters et al. (2020) was used to conduct this scoping review. The Extension for Scoping Reviews (PRISMA-ScR) guided reporting. A systematic search of the databases PUBMED, PsychINFO, CINAHL, EMBASE, and Web of Science and a selection of grey literature was undertaken from the year 1990 to date by two researchers. Titles and abstracts of the literature identified were screened and finally, a narrative synthesis of 11 articles was undertaken to answer the following research question: What is known from the literature about informal caregivers' transitions when caring for a dying person in the home? Conclusions: Current knowledge on this topic is limited; however, from this review, two main themes were identified: 'Challenges arising during transitioning' with subthemes of burden of care and fading away. The second theme 'Coping strategies' comprised subthemes of meaning-making, seeking normality and hope. This evidence may support the development of transitional care interventions in the future and improve patient and caregiver outcome measures and experiences to inform a larger research study exploring this phenomenon. Patient or Public Contribution: N/A as this is a Scoping Review. What this paper contributes to the wider global community: An understanding of the experiences of transitioning when caring for a loved one dying at home could help mitigate challenges informal caregivers face when providing end-of-life care in the home.While informal caregivers are crucial to support people who want to die at home, the role is often invisible and family carers need support and recognition to reduce the burden of care and challenges they experience as they transition in their role.

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7. **"Do you Really Believe that There is Something More?" - The Offer of Transcendental Communication by Pastoral Care Workers in German Hospices and Palliative Care Units: A Qualitative Study**

Authors: Nassehi, Armin;Saake, Irmhild;Breitsameter, Christof;Bauer, Anna;Barth, Niklas;Berger, Katharina and Gigou, Sophie

Publication Date: 2024

Journal: The American Journal of Hospice & Palliative Care 41(7), pp. 730-738

Abstract: Background: Palliative Care also encompasses the dimension of spiritual pain. Pastoral care workers and chaplains are specialists in the provision of spiritual care. Decreasing religious affiliation and increasing spiritual diversification in modern societies raise the question of the function of pastoral care.; Aim: The goal of this study is to answer the question of what pastoral care workers can offer to dying residents in hospices and palliative care units.; Design: A qualitative interview study was designed to explore the specific perspective of pastoral care workers in a multidisciplinary environment. The study is based on differentiation theory which is particularly well adjusted to reveal differences in perspectives in so called 'holistic' care settings. The reporting follows the COREQ guidelines.; Setting: Problem centered interviews were conducted at five hospices and two palliative care units.; Results: Eight pastoral care workers were interviewed (5 Catholic, 3 Protestant, mean age of 58 years). The analysis of the interviews revealed three major themes: (A) Self-positioning in relation to the organization, (B) Offering conversations to patients and relatives, (C) Performing religious rituals. Minor themes were: mediating conflicts between patients, relatives and staff, sensing moods in silence with patients and organizing workshops for staff.; Conclusion: In modern hospice care, pastoral care workers routinely address the problem of making death more tangible and of answering the unanswerable question of what comes afterwards. Through this, they support dying residents in hospices and palliative care units in dealing with the inexplicability of death.; Competing Interests: Declaration of Conflicting InterestsThe author(s) declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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8. **Depressive Symptoms in Caregivers of Hospice Cancer Patients**

Authors: Oliver, Debra Parker;Washington, Karla T.;Benson, Jacquelyn;Mayhara, Masako;Pitzer, Kyle;White, Patrick and Demiris, George

Publication Date: 2024

Journal: The American Journal of Hospice & Palliative Care 41(7), pp. 786-791

Abstract: Objectives: Family members and close friends provide countless hours of care for patients enrolled in hospice care. They do so without pay, often sacrificing their own financial well-being and health in the process. This study asks 4 research questions: (1) What is the prevalence and severity of depressive symptoms among caregivers of hospice cancer patients? (2) What demographic and contextual factors (such as relationship with patient) are related to the severity of depressive symptoms among caregivers of hospice cancer patients? (3) Are caregiver quality of life and caregiver burden associated with depressive symptoms? and (4) Is baseline depression associated with change in depression over time? Methods: This was a secondary analysis of data collected in a cluster randomized controlled trial. Results: Thirty-five percent of caregivers reported depressive symptoms of moderate or greater severity. These depressive symptoms were found to increase depending on the relationship of the caregiver to the patient. Caregivers with higher reported burden and lower reported quality of life were also found to have higher depressive symptoms. Significance of Results: Hospice agencies are encouraged to assess caregiver depressive symptoms and have protocols in place to assist caregivers with high depressive symptoms.; Competing Interests: Declaration of

Conflicting InterestsThe author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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9. **End-of-Life Symptoms in Adult Patients With Stroke in the Last Two Years of Life: An Integrative Review**

Authors: Ramsburg, Hanna;Moriarty, Helene J. and MacKenzie Greenle, Meredith

Publication Date: 2024

Journal: The American Journal of Hospice & Palliative Care 41(7), pp. 831-839

Abstract: Background: Stroke is a leading cause of death globally, yet End-of-Life (EOL) symptoms and their management in these patients are not well understood.; Purpose: This integrative review aims to critique and synthesize research on EOL symptoms and symptom management in adult patients with stroke in the last 2 years of life in all settings.; Methods: The Whittemore and Knafl integrative review methodology guided this review. PubMed, CINAHL, Scopus, Web of Science, and Google Scholar were used for the literature search. Included studies were published in English and quantitatively examined symptoms and symptom management. Quality appraisal was guided by the Effective Public Health Practice Project (EPHPP) assessment tool.; Results: Seven studies, all rated weak, were included in this review. A total of 2175 adult patients from six countries were represented. Results are classified into three main themes: EOL symptom experience, symptom assessment, and symptom management. Commonly reported EOL symptoms among adults with stroke include both stroke-specific (dysphagia, dysarthria) and non-specific symptoms (pain, dyspnea, constipation, and psychological distress). However, communication difficulties and the infrequent use of standardized tools for symptom assessment limit what is known about the EOL symptom experience. Although the relief of pain is generally well-documented, dyspnea and anxiety are much more poorly controlled.; Conclusions: There is a need for better assessment and management of EOL symptoms in patients with stroke. Established palliative and EOL care guidelines need to be incorporated into clinical practice to ensure access to high-quality care.; Competing Interests: Declaration of Conflicting InterestsThe author declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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10. **Radiotherapy at the End of Life: From Retrospective Analysis to Strategies to Improve Outcomes**

Authors: Rossi, Romina;Cravero, Paola;Pallotti, Maria Caterina;Valenti, Vanessa;Massa, Ilaria;Foca, Flavia;Nanni, Oriana;Pieri, Martina;Romeo, Antonino;Tontini, Luca;Donati, Costanza Maria;Morganti, Alessio Giuseppe and Maltoni, Marco

Publication Date: 2024

Journal: Journal of Pain and Symptom Management 67(6), pp. e927-e929

11. **Survivors' perspectives on saying goodbye: Implications for end-of-life engagement across the lifespan and grieving process**

Authors: Scheinfeld, Emily;Tenzek, Kelly E. and Cherry, Jessica

Publication Date: 2024

Journal: Death Studies 48(6), pp. 571-583

Abstract: Family members are often unaware of their loved ones' final wishes and underestimate the need to talk about them before parents reach end-of-life (EOL). The benefits of engaging in EOL conversations alleviate needless suffering and can allow an opportunity to say goodbye in a meaningful way. We examined final conversations 13 adults recalled having with their aging parents through the lens of the opportunity model for presence (OMP) during the EOL process, a communication process model based on engagement in the dying process from diagnosis through bereavement, to understand the process from the survivor's perspective, looking at content of conversations and where they occurred in the dying process. Findings illustrate final conversations that align with the socio-cultural space of the OMP before the knowledge that a parent was dying, and when entering imminent death engaging in the critical moments, have implications for the grief and bereavement.

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12. **Advocating for Training in End-Of-Life Conversations With Seriously Ill Patients During Residency**

Authors: Schukow, Casey and Alawy, Bilal

Publication Date: 2024

Journal: American Journal of Hospice & Palliative Medicine 41(7), pp. 726-729

Abstract: According to section IV.B.1.e of common residency program requirements from the Accreditation Council for Graduate Medical Education (ACGME), "r]esidents must learn to communicate with patients and families to partner with them to assess their care goals, including, when appropriate, end-of-care EOL] goals". EOL conversations are frequently appropriate for patients suffering from serious, life-threatening diseases (ie, terminal illness) or otherwise chronic health conditions with poor disease trajectories. These conversations are often followed with services and care from palliative medicine or hospice specialists depending on patients' projected prognoses (ie, 6 months or less). The focus of this patient-centered care, then, is on relieving patient and caregiver suffering, establishing clear treatment goals, and managing the physical, psychosocial, and spiritual burdens of disease. Although palliative medicine and hospice care have been shown to reduce health care costs and improve the overall care of patients who require these services, recent literature still suggests a gap in training programs being able to provide effective, educational strategies to their trainees regarding the appropriate and competent delivery of EOL conversations. Herein, this commentary will provide a discussion on what EOL is, palliative vs hospice care indications, and address current literature regarding EOL exposure within training programs while offering our personal insight and advocacy on the manner.

13. **Effects of Prognostic Communication Strategies on Prognostic Perceptions, Treatment Decisions and End-Of-Life Anticipation in Advanced Cancer: An Experimental Study among Analogue Patients**

Authors: van der Velden, Naomi,C.A.;Smets, Ellen M. A.;van Vliet, Liesbeth,M.;Brom, Linda;van Laarhoven, Hanneke,W.M. and Henselmans, Inge

Publication Date: 2024

Journal: Journal of Pain and Symptom Management 67(6), pp. 478

Abstract: Context: Evidence-based guidance for oncologists on how to communicate prognosis is scarce.; Objectives: To investigate the effects of prognostic communication strategies (prognostic disclosure vs. communication of unpredictability vs. non-disclosure; standard vs. standard and best-case vs. standard, best- and worst-case survival scenarios; numerical vs. word-based estimates) on prognostic perceptions, treatment decision-making and end-of-life anticipation in advanced cancer.; Methods: This experimental study used eight videos of a scripted oncological consultation, varying only in prognostic communication strategies. Cancer-naive individuals, who imagined being the depicted patient, completed surveys before and after watching one video (n = 1036).; Results: Individuals generally perceived dying within 1 year as more likely after prognostic disclosure, compared to communication of unpredictability or non-disclosure (P < 0.001), and after numerical versus word-based estimates (P < 0.001). Individuals felt better informed about prognosis to decide about treatment after prognostic disclosure, compared to communication of unpredictability or non-disclosure (P < 0.001); after communication of unpredictability versus non-disclosure (P < 0.001); and after numerical versus word-based estimates (P = 0.017). Chemotherapy was more often favored after prognostic disclosure versus non-disclosure (P = 0.010), but less often after numerical versus word-based estimates (P < 0.001). Individuals felt more certain about the treatment decision after prognostic disclosure, compared to communication of unpredictability or non-disclosure (P < 0.001). Effects of different survival scenarios were absent. No effects on end-of-life anticipation were observed. Evidence for moderating individual characteristics was limited.; Conclusion: If and how oncologists discuss prognosis can influence how individuals perceive prognosis, which treatment they prefer, and how they feel about treatment decisions. Communicating numerical estimates may stimulate prognostic understanding and informed treatment decision-making. (Copyright © 2024 The Authors. Published by Elsevier Inc. All rights reserved.)

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14. **End of life decision making when home mechanical ventilation is used to sustain breathing in Motor Neurone Disease: patient and family perspectives**

Authors: Wilson, Eleanor;Palmer, Jonathan;Armstrong, Alison;Messer, Ben;Presswood, Edward and Faull, Christina

Publication Date: 2024

Journal: BMC Palliative Care 23(1), pp. 1-13

Abstract: Background: Motor Neurone Disease (MND) leads to muscle weakening, affecting movement, speech, and breathing. Home mechanical ventilation, particularly non-invasive ventilation (NIV), is used to alleviate symptoms and support breathing in people living with MND. While home mechanical ventilation can alleviate symptoms and improve survival, it does not slow the progression of MND. This study addresses gaps in understanding end-of-life decision-making in those dependent on home mechanical ventilation, considering the perspectives of patients, family members, and bereaved families. Methods: A UK-wide qualitative study using flexible interviews to explore the experiences of people living with MND (n = 16), their family members (n = 10), and bereaved family members (n = 36) about the use of home mechanical ventilation at the end of life. Results: Some participants expressed a reluctance to discuss end-of-life decisions, often framed as a desire to "live for the day" due to the considerable uncertainty faced by those with MND. Participants who avoided end-of-life discussions often engaged in 'selective decision-making' related to personal planning, involving practical and emotional preparations. Many faced challenges in hypothesising about future decisions given the unpredictability of the disease, opting to make 'timely decisions' as and when needed. For those who became dependent on ventilation and did not want to discuss end of life, decisions were often 'defaulted' to others, especially once capacity was lost. 'Proactive decisions', including advance care planning and withdrawal of treatment, were found to empower some patients, providing a sense of control over the timing of their death. A significant proportion lacked a clear understanding of the dying process and available options. Conclusions: The study highlights the complexity and evolution of decision-making, often influenced by the dynamic and uncertain nature of MND. The study emphasises the need for a nuanced understanding of decision-making in the context of MND.

Sources Used:

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