

End of Life Care

Current Awareness Bulletin

November 2024

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Unlocking the learning in formal complaints: the development of an end-of-life care complaint analysis tool

Walker W. *British Journal of Healthcare Management* 2024;30(10):1-11.

A systematic approach to analysing and reporting complainants' experiences of end-of-life care has the potential to support organisational learning, quality monitoring and bespoke service improvements in response to collective complaints and concerns.

1. Expectations in the Communication About Death and Dying: Development and Initial Validation of the End-of-Life Conversations - Expectations Scale

Authors: Bendel, Yannik;Pinquart, Martin;Schulz-Quach, Christian and von Blanckenburg, Pia

Publication Date: 2024

Journal: *Omega* 90(2), pp. 710–725

Abstract: End-of-life (EOL) conversations with relatives or significant others are often avoided. One reason can be negative expectations regarding these conversations. The present study was conducted to develop and initially validate the End-of-Life Conversations - Expectations Scale (EOLC-E). An exploratory factor analysis ($N = 307$) resulted in a 20-item version with three distinct dimensions: expected own emotional burden ($\alpha = .92$), expected other person's emotional burden ($\alpha = .94$) and communication self-efficacy ($\alpha = .89$). The EOLC-E total score correlated significantly with communication apprehension about death ($r = .62$), fear of death ($r = .58$), death avoidance ($r = .52$) as well as readiness for end-of-life conversations ($r = -.38$) and occurrence of previous conversations ($r = -.29$). Results suggest that the EOLC-E is a reliable and valid instrument to assess death and dying communication expectations. This measure has utility in communication research focusing on optimizing expectations and increasing EOL communication.; 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.

2. Economic Value of Unpaid Family Caregiver Time Following Hospital Discharge and at End of Life

Authors: Kaufman, Brystana G.;Zhang, Wenhan;Shibeika, Sahar;Huang, Ro W.;Xu, Ting;Ingram, Cory;Gustavson, Allison M.;Holland, Diane E.;Vanderboom, Catherine;Van Houtven, Courtney,H. and Griffin, Joan M.

Publication Date: 2024

Journal: *Journal of Pain and Symptom Management* 68(6), pp. 632

Abstract: Context: Family caregivers (FCGs) play a crucial role in care for people with serious illness, yet unpaid care is often overlooked in estimates of care recipient (CR) care costs.; Objectives: This study quantifies the economic value of unpaid caregiving by FCGs between hospital discharge and end of life.; Methods: Trial participants were rural FCGs of CRs

receiving palliative care during hospitalization. Caregiving hours were self-reported by FCGs over six months following hospital discharge. Economic value was assigned to hours based on wage data from the United States Bureau of Labor Statistics. Time was valued using 1) home health aide wages (proxy cost), 2) median national wage by FCG sex and education level (opportunity cost), 3) opportunity cost if employed and proxy cost otherwise (combination cost).; Results: Of 282 FCGs, 94% were non-Hispanic White, 71% were female, 71% had a college degree, and 51% were in the workforce. FCGs of decedents (58%) compared to survivors reported significantly more caregiving hours per person-month (392 vs. 272), resulting in higher estimated economic value per person-month using opportunity (\$12,653 vs. \$8843), proxy (\$5689 vs. \$3955), and combined costing methods (\$9490 vs. \$6443)
CONCLUSION: This study informs more complete economic evaluations of palliative care by estimating the economic value of unpaid caregiving. The high intensity of unpaid caregiving for people with serious illness, especially toward the end of life, should be considered when designing policies and interventions to support FCGs. Better methods for approximating economic value are needed to address potential inequities in current valuation approaches. (Published by Elsevier Inc.)

3. Addressing Statistical Power and Increasing Diversity in Hospice Research: Electronic Medical Record Participant Identification Compared to Nurse Referral Approaches to Recruitment

Authors: Oliver, Debra Parker; Ersek, Mary; White, Patrick; Jorgenson, Lucas; Pitzer, Kyle; Rolbiecki, Abigail; Mayahara, Masako; Washington, Karla and Demiris, George

Publication Date: 2024

Journal: Journal of Pain and Symptom Management 68(6), pp. 594–602

Abstract: Context: Recruitment of targeted samples into hospice clinical trials is often challenging. While electronic medical records (EMR) are commonly used in hospital-based research, it is uncommon in hospice research. The community setting and the variability in hospices and their medical record creates unique challenges.; Objectives: This paper compares recruitment in two hospice randomized controlled trials, each of which had a group recruited by using the EMR identification and a group recruited by nurse referral. We sought to answer three questions: 1) What is the impact of using the EMR to identify hospice participants for clinical research? 2) How do the referral count and consent rate (referrals that ultimately result in verbal informed consent to participate in research) differ between hospice agencies using an EMR participant identification approach compared to those using a nurse referral approach? and 3) What are the challenges associated with using the EMR to identify potential research participants?; Method: Recruitment data from two hospice clinical trials was combined into a new database. Data from hospice nurse referral agencies was compared with data from those agencies who participated in EMR-identified referrals.; Results: The EMR identification process was feasible and efficient, resulting in more referrals and more consented participants than the nurse referral method. Of particular interest is that 8% more black caregivers were recruited using the EMR identification process than the nurse referral.; Conclusions: The EMR-identified recruitment process is the recommended method in hospice research. (Copyright © 2024 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.)

4. Towards a Crisis Management Playbook: Hospice and Palliative Team Members' Views Amid COVID-19

Authors: Schulman-Green, Dena;David, Daniel;Moreines, Laura T.;Boafo, Jonelle;Franzosa, Emily;Kim, Patricia;McDonald, Margaret V.;Brody, Abraham A. and Aldridge, Melissa D.

Publication Date: 2024

Journal: Journal of Pain and Symptom Management 68(6), pp. 573

Abstract: Context: The critical role of hospice and palliative care in response to the COVID-19 pandemic is well recognized, but there is limited evidence to guide healthcare leadership through future crises.; Objectives: Our goal was to support future organizational resilience by exploring hospice and palliative team members' perspectives on crisis leadership during the COVID-19 pandemic in New York City (NYC).; Methods: This qualitative descriptive study used individual, semi-structured interviews of purposively sampled interdisciplinary team members. Enrollment sites were two large NYC metro hospice care organizations and one outpatient palliative care practice. We asked participants to complete a demographic form and a 45-60 minute interview. We used descriptive statistics and thematic analysis, respectively, for data analysis. We triangulated the data by presenting preliminary study findings to a group of clinicians (n=21) from one of the referring organizations.; Results: Participants (n=30) were professionally diverse (e.g., nurses, physicians, social workers, chaplains, administrators), experienced (mean=17 years; 10 years in hospice), and highly educated (83% ≥ master's degree). About half (n=15) self-identified as white, non-Hispanic, and nearly half (n=13) self-identified as being from a racial/ethnic minoritized group. Two (n=2) did not wish to self-identify. We identified four themes that reflected challenges and adaptive responses to providing care during a crisis: Stay Open and Stay Safe; Act Flexibly; Lead Adaptively; and Create a Culture of Solidarity.; Conclusion: While additional work is indicated, findings offer direction for a crisis management playbook to guide leadership in hospice, palliative care, and other healthcare settings in future crises. (Copyright © 2024 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.)

5. End-Of-Life Care From the Perspectives of Patients With Cancer and Their Nurses: A Qualitative Study

Authors: Terzi, Kübra and Kapucu, Sevgisun

Publication Date: 2024

Journal: Omega 90(2), pp. 503–520

Abstract: This study aimed to determine the needs of end-of-life cancer patients' and their nurses' perspectives and experiences regarding end of life period. A qualitative descriptive phenomenological study design was adopted comprising face-to-face, semi-structured interviews with patients and their nurses. Content analysis was conducted using the 'Induction' approach. 15 patients and 15 nurses participated in study. This study emerged three categories, nine themes for patients, and seven themes for nurses. Categories were determined according to the Donabedian model. The interviews revealed that although the

nurses wanted to provide the necessary care, they could not accomplish it because of excessive workload, inadequately informed patients, and less than desired knowledge and education levels of the nurses and healthcare team. Improved care coordination and partnership working are essential for supporting both patient and their nurses at the end of life.; 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.

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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