

End of Life Care

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New books available from the Academy Library

For you when I am gone : twelve essentials questions to tell a life story / Steve Leder.. 2022.

Beyond the Reach of Palliative Care': A Qualitative Study of Patient and Public Experiences and Anticipation of Death and Dying.

Pollock K. Qualitative Health Research 2024;

This paper presents findings from a qualitative study of how terminally ill patients, bereaved family members, and members of the public understand, anticipate, and experience death and dying. These findings contribute to a critique of the normative idealisation of death and dying in health policy and practice, and the need to attend closely to the real-world experiences of patients and the public as a prerequisite for identifying and remedying widespread shortcomings in end-of-life care.

https://journals.sagepub.com/doi/10.1177/10497323241246705

Time to care: findings from a nationally representative survey of experiences at the end of life in England and Wales

Marie Curie

This report sets out the findings from a national post-bereavement survey, the QUALYCARE survey, conducted in 2023 across England and Wales. The aim was to describe the outcomes, experiences, and use of care services by people affected by dying, death and bereavement in England and Wales. The report reveals that 1 in 3 people were severely or overwhelmingly affected by pain in the last week of life, with bereaved people reporting how difficult it was to get joined-up support from health and care professionals at home.

https://www.mariecurie.org.uk/globalassets/media/documents/policy/beol-reports-2024/beol-2024-time-to-care-report.pdf

Assisted dying legislation will have a big impact on end-of-life care: what is the state of play for services in England?

Nuffield Trust

With the subject of assisted dying much debated in recent months, this long read describes the main challenges facing palliative and end-of-life care in England, and discusses what legislation on assisted dying might mean for end-of-life care services.

https://www.nuffieldtrust.org.uk/news-item/assisted-dying-legislation-will-have-a-big-impact-onend-of-life-care-what-is-the-current-state-of-play-for-services-in-england

Medical assistance in dying for mental illness: a complex intervention requiring a correspondingly complex evaluation approach.

Bastidas-Bilbao H. British Journal of Psychiatry 2024;225(1):264-267.

Medical assistance in dying for mental illness as a sole underlying medical condition (MAiD MI-SUMC) is a controversial and complex policy in terms of psychosocial and ethical medical practice implications. The authors discuss the status of MAiD MI-SUMC in Canada and argue for the use of the UK Medical Research Council's framework on complex interventions in programme evaluations of MAiD MI-SUMC.

Using Palliative Care Needs Rounds in the UK for care home staff and residents: an implementation science study.

Forbat L. Health and Social Care Delivery Research 2024;12(19):KRWQ5829.

Our work suggests that Needs Rounds can improve the quality of life and death for care home residents, by enhancing staff skills and confidence, including symptom management, communications with general practitioners and relatives, and strengthen relationships between care home and specialist palliative care staff.

1. Racial disparities in end-of-life care among patients with neuroendocrine tumors

Authors: Baskar, Suriya and Grewal, Udhayvir Singh

Publication Date: 2024

Journal: Journal of Clinical Oncology 20, pp. 60

2. Urgent palliative care: An effective intervention to improve end-of-life experience and outcomes for patients with advanced cancer

Authors: Bowden, Kasey; Maurer, Grace and Treem, Jonathan

Publication Date: 2024

Journal: Journal of Clinical Oncology 20, pp. 203

3. Living for the Moment - How Important Is It in the End of Life?

Authors: Chintapalli, Renuka

Publication Date: 2024

Journal: The American Journal of Hospice & Palliative Care , pp. 10499091241292812

Abstract: This essay investigates the role of present-moment living in end-of-life care, drawing on reflections from a personal patient encounter in a palliative care setting, Mrs. B, a 63-yearold patient with terminal squamous cell lung cancer, whose experience underscores the impact of living with a sense of fulfillment and joy despite a life-limiting diagnosis. Mrs. B's approach to her illness-marked by an optimistic acceptance of mortality and a focus on daily joyschallenges traditional palliative care paradigms that emphasize somberness and futureoriented care. Through detailed narrative and reflective analysis, the essay highlights how Mrs. B's resilience and spiritual beliefs contributed to her ability to maintain a positive outlook in the face of terminal illness. This case study illustrates the potential for joy and present-moment living to coexist with palliative care practices, offering a nuanced perspective on patient care. The discussion extends to the implications for healthcare professionals, advocating for a more adaptable and empathetic approach that aligns with individual patient values and preferences. This reflection calls for a shift in palliative care practices towards recognizing and supporting the diverse ways patients navigate their end-of-life experiences.; 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.

4. Promising Impact of Telenovela Intervention for Caregivers of Hospice Patients: A Pilot Study

Authors: Cruz-Oliver, Dulce;Milner, Gabrielle E.;Mensh, Kelsea;Bugayong, Marielle;Blinka, Marcela D.;Durkin, Nowella;Abshire Saylor, Martha;Budhathoki, Chakra and Oliver, Debra Parker

Publication Date: 2024

Journal: The American Journal of Hospice & Palliative Care 41(12), pp. 1400–1407

Abstract: Background: Hospice family caregivers (HFCGs) support the needs of their loved ones but are at risk of developing distress and anxiety. NOVELA is a four-chapter telenovelastyle educational video to support topics related to hospice caregiving. Telehealth visits are scheduled in 4 weekly sessions consisting of a chapter and subsequent discussion with an interventionist. This feasibility pilot study tested NOVELA's effect to change HFCGs' outcomes, session and outcome measure completion (defined a priori as >70%).; Methods: This is a single-group pretest-posttest study of HFCGs of care recipients with PPS score >20% from 3 hospices in the U.S. Mid-Atlantic region. At baseline and at final posttest, participants completed a web-based survey assessing 3 outcomes: anxiety, self-efficacy, and satisfaction with intervention. Descriptive, t-test, and chi-square statistics were computed.; Results: Participants in our study (N = 59) were mainly collage educated, White, female, adult children of home-bound people with a non-cancer diagnosis. Outcomes changed in the expected direction (P > .05) with higher self-efficacy (Cohen's d = -.08 95% CI -.4 to .2) and lower anxiety (Cohen's d = .2 95% CI -.1 to .5]) scores from final to baseline, 86% of HFCGs were satisfied or very satisfied with NOVELA, session (33/59) and outcome measure (43/59) completion averaged 68%.; Conclusion: Encouraging trends in NOVELA's estimation of effect suggests that NOVELA may buffer stressful aspects of hospice caregiving. However, further refinement of NOVELA is needed. Supporting HFCGs through supportive educational interventions may reduce distress and anxiety with broad implications for quality improvement.

5. The Impact of Hospice Care Structures on Care Processes: A Retrospective Cohort Study

Authors: de Graaf, Everlien;Grant, Matthew;van der Baan, Frederieke;Ausems, Marieke;Leget, Carlo and Teunissen, Saskia

Publication Date: 2024

Journal: The American Journal of Hospice & Palliative Care 41(12), pp. 1423–1430

Abstract: Background: Palliative care is subject to substantial variations in care, which may be shaped through adapting the organisational structures through which care is provided. Whilst the goal of these structures is to improve patient care, there is a lack of evidence regarding their effect on care processes and patient outcomes. Aims: This study aims to describe the relationship between care structures and the quantity and domains of care processes in hospice care. Design: Retrospective cohort study. Settings/Participants: Data were collected from Dutch hospice patient's clinical records and hospice surveys, detailing hospice structures, patient clinical characteristics and care processes. Results: 662 patients were included from 42 hospices, mean age 76.1 years. Hospices were categorised according to their care structures - structured clinical documentation and multidisciplinary meetings. Patients receiving care in hospices with structured multidisciplinary meetings had an increased quantity of documented care processes per patient on admission through identification (median 4 vs 3, P < .001), medication (2 vs 1, P = .004) and non-medication (1 vs 0, P < .001) interventions, monitoring (2 vs 1, P < .001) and evaluation (0 vs 0, P = .014), and prior to death. Similar increases were identified for patients who received care in hospices with structured documentation upon admission, but these changes were not consistent prior to death. Conclusions: This study details that the care structures of documentation and multidisciplinary meetings are associated with increased quantity and breadth of documentation of care processes in hospice care. Employing these existing structures may result in improvements in the documentation of patient care processes, and thus better communication around patient care.; 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. The Effect on the Care Behaviors of Nurses Working in Intensive Care Clinics of Moral Distress Experienced During End of Life Patient Care

Authors: Elcelik, Ufuk Ercan; Ozcelik, Hanife and Muz, Gamze

Publication Date: 2024

Journal: Omega 90(1), pp. 388–403

Abstract: This research was conducted as a descriptive study in order to examine the effects of the moral problems experienced by nurses working in intensive care clinics on their end of life care behaviors. The data were collected using the Moral Distress Scale and Caring Behaviors Inventory. It was found that 74.5% of the nurses were women and their mean age was 32.60 ± 6.6 years. The frequency of moral distress in the nurses was 44.27 ± 16.25 and

total score was 111.02 ± 63.85. There were significant differences in the scores of the concept the use of futile treatment by nurses, the decision not to begin life-support treatment being made only by physicians, and moral distress and discomfort felt by pediatric intensive care nurses (p < .05). A statistically significant relationship was found between total scores of discomfort on moral distress and assurance, knowledge and skills, connectedness, and being respectful on the end of life care behaviors (p < .05).; Competing Interests: Declaration of Conflicting InterestsThe authors declare that they have no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

7. Enhancing End-of-Life Care With Home-Based Palliative Interventions: A Systematic Review

Authors: Feliciano, Diana Rodrigues and Reis-Pina, Paulo

Publication Date: 2024

Journal: Journal of Pain & Symptom Management 68(5), pp. e356–e372

8. Impact of a mortality prediction tool on end-of-life (EOL) quality measures

Authors: Garey, Jody S.;Gaston, Jake;Mills, Lydia;Gress, Jean A.;Broussard, Stephanie Broadnax;Lopez, Lorraine;Traul, Abigail;Payne-De Bock, Judi and Wilfong, Lalan S.

Publication Date: 2024

Journal: Journal of Clinical Oncology 20, pp. 404

9. End of Life in Neurodegenerative Diseases: An Unrecognized Opportunity for Better Care

Authors: Jiao, Jocelyn M. and Safarpour, Delaram

Publication Date: 2024

Journal: Neurology 103(9), pp. e210072

10. Immunotherapy at the end of life

Authors: Kaur, Gagandeep;Weir, Catherine;Sun, Terrence;Rosen, Havi;Puglisi, Leah;Xavier, Marin Feldman and Maslov, Diana Vesselinovitch

Publication Date: 2024

Journal: Journal of Clinical Oncology 20, pp. 188

11. Development and Feasibility Evaluation of a Family-Centred Neonatal End-of-Life Care Protocol

Authors: Kim, Eun Sook;Kim, Sue;Kim, Sanghee;Kim, Sujeong;Ahn, So Yoon and Lee, Hyejung

Publication Date: 2024

Journal: Journal of Clinical Nursing 33(11), pp. 4314-4326

Abstract: Aim: To develop a family-centred end-of-life care protocol and evaluate its feasibility.; Design: The draft protocol was created by integrating literature review results and existing protocols and interviewing bereaved parents. A Delphi study and an experts' review were conducted to refine the draft, followed by feasibility testing with neonatal intensive care unit nurses.; Results: A 71-item protocol based on an integrated end-of-life care model and the family-centred care concept was developed, comprising three sections: principal guidelines, communication during end-of-life care and five substeps (4, 17 and 71 items, respectively) according to changes in an infant's condition. The feasibility was confirmed by an increase in competency and a positive attitude towards infant end-of-life care participants who completed the protocol education.; Conclusion: The protocol was feasible and improved nurses' competency and attitude in providing end-of-life care for infants and parents requiring support due to the loss of their infants. It can positively impact the well-being of parents who have experienced the loss of their infants in neonatal intensive care units and enhance familycentred care within the units.; Implications for the Profession And/or Patient Care: Application of the family-cantered end-of-life care could support infants' dying process and improve bereaved parents' guality of life in neonatal intensive care units.; Impact: This study increased neonatal end-of-life nursing needs' awareness among nurses and parents during bereavement. It offered preliminary evidence regarding the feasibility of a neonatal end-of-life care protocol developed in this study.; Reporting Method: AGREE Reporting Checklist 2016.; Patient or Public Contribution: We interviewed bereaved parents to develop the draft protocol and involved neonatal care experts for the Delphi study and neonatal nurses (who would use the protocol) as feasibility test subjects.; Trial Registration: This was a doctoral dissertation and did not require protocol registration as the feasibility test involved a single neonatal intensive care unit. (© 2024 The Author(s). Journal of Clinical Nursing published by John Wiley & Sons Ltd.)

12. "Death is Not a Dirty Word:" A Qualitative Study of Emergency Clinician End-of-Life Communication

Authors: Kotler, Hannah; Hinds, Pamela S. and Wolfe, Amy Hope Jones

Publication Date: 2024

Journal: Pediatrics

Abstract: Objectives: Pediatric patients with life-limiting diagnoses frequently seek care in the pediatric emergency department (PED) during times of acute illness, or at end-of-life (EOL). Although the population of patients with life-limiting diagnoses is heterogenous, clinician

expertise in EOL communication is essential to providing family-centered care. In this study, we explored PED physician and nurse experiences with communication when eliciting EOL values, including factors specified to the PED environment, clinician perceptions of family supports and preferences, and clinicians' self-reflection of their skills and challenges in this sphere.; Methods: We performed a prospective gualitative study using semistructured interviews of PED physicians and nurses recruited from a quaternary care center. Thematic content analysis was performed on the transcribed interviews to identify codes and, ultimately, themes.; Results: We interviewed 17 emergency department clinicians, including 10 physicians and 7 nurses. Thematic content analysis revealed 6 salient themes. The first theme related to contextual factors of the emergency department environment. Two additional themes related to patient and family characteristics, including unique patient and family factors and clinician interpretation of parental/family needs. Lastly, we found 3 clinician-focused themes including knowledge gaps in EOL communication, communication styles and priorities in EOL conversations with families, and coping with ethical challenges.; Conclusions: PED clinicians report communication-related challenges to providing optimal care for families and patients with life-limiting diagnoses. Participants self-identified gaps in communication skills in this area. Future studies should focus on clinician educational interventions on the basis of this needs assessment and include family perspectives to develop best practice.; Competing Interests: CONFLICT OF INTEREST DISCLOSURES: The authors have indicated they have no conflicts of interest to this article to disclose. (Copyright © 2024 by the American Academy of Pediatrics.)

13. Tensions between end-of-life care and organ donation in controlled donation after circulatory death: ICU healthcare professionals experiences

Authors: Le Dorze, Matthieu;Barthélémy, Romain;Lesieur, Olivier;Audibert, Gérard;Azais, Marie-Ange;Carpentier, Dorothée;Cerf, Charles;Cheisson, Gaëlle;Chouquer, Renaud;Degos, Vincent;Fresco, Marion;Lambiotte, Fabien;Mercier, Emmanuelle;Morel, Jérôme;Muller, Laurent;Parmentier-Decrucq, Erika;Prin, Sébastien;Rouhani, Armine;Roussin, France;Venhard, Jean-Christophe, et al

Publication Date: 2024

Journal: BMC Medical Ethics 25(1), pp. 110

Abstract: Background: The development of controlled donation after circulatory death (cDCD) is both important and challenging. The tension between end-of-life care and organ donation raises significant ethical issues for healthcare professionals in the intensive care unit (ICU). The aim of this prospective, multicenter, observational study is to better understand ICU physicians' and nurses' experiences with cDCD.; Methods: In 32 ICUs in France, ICU physicians and nurses were invited to complete a questionnaire after the death of end-of-life ICU patients identified as potential cDCD donors who had either experienced the withdrawal of life-sustaining therapies alone or with planned organ donation (OD(-) and OD(+) groups). The primary objective was to assess their anxiety (State Anxiety Inventory STAI Y-A) following the death of a potential cDCD donor. Secondary objectives were to explore potential tensions experienced between end-of-life care and organ donation.; Results: Two hundred six ICU healthcare professionals (79 physicians and 127 nurses) were included in the course of 79 potential cDCD donor situations. STAI Y-A did not differ between the OD(-) and OD(+) groups

for either physicians or nurses (STAI Y-A were 34 (27-38) in OD(-) vs. 32 (27-40) in OD(+), p = 0.911, for physicians and 32 (25-37) in OD(-) vs. 39 (26-37) in OD(+), p = 0.875, for nurses). The possibility of organ donation was a factor influencing the WLST decision for nurses only, and a factor influencing the WLST implementation for both nurses and physicians. cDCD experience is perceived positively by ICU healthcare professionals overall.; Conclusions: cDCD does not increase anxiety in ICU healthcare professionals compared to other situations of WLST. WLST and cDCD procedures could further be improved by supporting professionals in making their intentions clear between end-of-life support and the success of organ donation, and when needed, by enhancing communication between ICU physician and nurses.; Trial Registration: This research was registered in ClinicalTrials.gov (Identifier: NCT05041023, September 10, 2021). (© 2024. The Author(s).)

14. A Tale of 2 Experiences: Navigating End-of-Life Care With a History of Incarceration

Authors: Lutz, Gabriel; Yang, Yulin; Zhang, Yilin; Chen, Chixiang and Kheirbek, Raya Elfadel

Publication Date: 2024

Journal: The Journals of Gerontology.Series A, Biological Sciences and Medical Sciences 79(11)

Abstract: Background: The adverse health effects of incarceration are well-documented, affecting individuals throughout their life course. However, the influence of a history of incarceration on end-of-life (EOL) experiences remains unexplored. This study aims to examine how prior incarceration affects individuals' experiences and care needs as they approach the EOL.; Methods: Leveraging the Health and Retirement Study, we conducted secondary analyses on 1 710 individuals who participated between 2012 and 2018. Through retrospective cohort analysis, we explored the association between incarceration history and EOL care, focusing on pain and symptom burden.; Results: Analyses showed that individuals with a history of incarceration experienced significantly higher levels of pain (65% reported "moderate" or "severe" pain) compared to nonincarcerated individuals (50%; adjusted odds ratio = 1.45, 95% confidence interval CI]: 1.22-1.71, p < .001). Additionally, the symptom burden index revealed that formerly incarcerated individuals had a higher average symptom score (2.8 vs 2.1; β = 0.7, 95% CI: 0.5-0.9, p < .001), indicating a greater range of symptoms in their final year of life. These disparities persisted after adjusting for demographic, health, and socioeconomic variables.; Conclusions: This study reveals that a history of incarceration significantly affects EOL experiences, with formerly incarcerated individuals facing higher levels of pain and a greater symptom burden compared to nonincarcerated individuals. This underscores the need for tailored palliative care to address the unique needs of this vulnerable population. This research highlights a critical area for intervention and calls for healthcare systems to adapt their practices to better serve those with incarceration histories. (© The Author(s) 2024. Published by Oxford University Press on behalf of The Gerontological Society of America. All rights reserved. For commercial re-use, please contact reprints@oup.com for reprints and translation rights for reprints. All other permissions can be obtained through our RightsLink service via the Permissions link on the article page on our site-for further information please contact journals.permissions@oup.com.)

15. Oncologists' role in end-of-life chemotherapy and patient-centered care

Authors: Manz, Christopher and Wright, Alexi A.

Publication Date: 2024

Journal: Cancer 130(21), pp. 3628–3630

16. Application of Terror Management Theory to End-Of-Life Care Decision-Making: A Narrative Literature Review

Authors: Perry, Laura M.;Mossman, Brenna;Lewson, Ashley B.;Gerhart, James I.;Freestone, Lily and Hoerger, Michael

Publication Date: 2024

Journal: Omega 90(1), pp. 420–432

Abstract: Patients with serious illnesses often do not engage in discussions about end-of-life care decision-making, or do so reluctantly. These discussions can be useful in facilitating advance care planning and connecting patients to services such as palliative care that improve quality of life. Terror Management Theory, a social psychology theory stating that humans are motivated to resolve the discomfort surrounding their inevitable death, has been discussed in the psychology literature as an underlying basis of human decision-making and behavior. This paper explores how Terror Management Theory could be extended to seriously ill populations and applied to their healthcare decision-making processes and quality of care received.; 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.

17. Should we Continue Cardiac Medications during End-Of-Life Care?

Authors: SAUNDERS, STEVEN;CHIN, JESSICA;KHANIJO, SAMEER;PELAEZ BENJUMEA, MONICA,M.;MAGALEE, CHRISTOPHER and LOPEZ, SANTIAGO

Publication Date: 2024

Journal: Chest 166(4), pp. A5058

18. Patients' understanding of treatment decisions: Impact on major quality metrics and patient informed decision-making at end of life

Authors: Sweeney, Ann;Crocker, Eric;Candelario, Elise;Tarpley, Trish;Skelton, Matthew Rama and Elia, Giovanni

Publication Date: 2024

Journal: Journal of Clinical Oncology 20, pp. 170

19. Pediatric Oncology Hospice: A Comprehensive Review

Authors: Tafazoli, Ali and Cronin-Wood, Katharine

Publication Date: 2024

Journal: The American Journal of Hospice & Palliative Care 41(12), pp. 1467–1481

Abstract: Pediatric hospice is a new terminology in current medical literature. Implementation of pediatric hospice care in oncology setting is a vast but subspecialized field of research and practice. However, it is accompanied by substantial uncertainties, shortages and unexplored sections. The lack of globally established definitions, principles, and guidelines in this field has adversely impacted the quality of end-of-life experiences for children with hospice needs worldwide. To address this gap, we conducted a comprehensive review of scientific literature, extracting and compiling the available but sparse data on pediatric oncology hospice from the PubMed database. Our systematic approach led to development of a well-organized structure introducing the foundational elements, highlighting complications, and uncovering hidden gaps in this critical area. This structured framework comprises nine major categories including general ideology, population specifications, role of parents and family, psychosocial issues, financial complications, service locations, involved specialties, regulations, and quality improvement. This platform can serve as a valuable resource in establishing a scientifically reliable foundation for future experiments and practices in pediatric oncology hospice.; Competing Interests: Declaration of conflicting interestsThe authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

20. Organisation and management of multi-professional care for cancer patients at endof-life: state-of-the-art from a survey to community and hospital-based professionals

Authors: Zuccarino, Sara;Gioia, Angela;Quattrone, Filippo;Nuti, Sabina;Emdin, Michele and Ferrè, Francesca

Publication Date: 2024

Journal: Research in Health Services & Regions 3(1), pp. 15

Abstract: Providing timely and satisficing End-of-Life care (EOLC) is a priority for healthcare systems since aging population and chronic diseases are boosting the global demand for care at end-of-life (EOL). In OECD countries the access to EOLC is insufficient. In Italy, the average rate of cancer patients assisted by the palliative care (PC) network at EOL was 28% in 2021, with high variability in the country. Among the Italian regions offering the best coverages, Tuscany has a rate of about 40%, but intraregional variation is marked as well. The study aims to explore the delivery of EOLC to adult cancer patients in public facilities in the Tuscany region through survey data collection among professionals. Two online surveys were delivered to Directors of community-based PC Functional-Units (FUs) and Directors of hospital-based medical-oncology units. All FU Directors responded to the survey (n = 14), and a response rate of 96% was achieved from hospital-unit Directors (n = 27). The results highlight the availability of numerous dedicated services, but reveal heterogeneity among and within organisations, including variations in the professionals involved, pathways, and tools adopted. Care continuity

is supported by institutionalized collaboration between hospital and community settings, but hindered by fragmented care processes and heterogeneous transition pathways. Late referral to PC is perceived as a major constraint to EOLC. Developing structured pathways for patient transition to end-stage PC is crucial, and practices/processes should be uniformly implemented to ensure equity. Multi-professional care should be facilitated through tailored supporting tools. Both hospital-unit and FU Directors suggest developing shared pathways between organisations/professionals (82% and 80% respectively) and digital information sharing (61% and 80% respectively). Hospital and community-based professionals have similar perceptions about the concerns and challenges to EOLC provision in the region, but communication on PC to the public and early discussing EOLC with caregivers. This finding suggests the need of enhancing hospital personnel's awareness about these issues. Professional training and the capacity to assess patients' needs and preferences should be improved. The identified needs can inform future research and interventions to improve the quality and outcomes of EOLC for cancer patients. (© 2024. The Author(s).)

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