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**HOSPICE &
PALLIATIVE CARE
TODAY**

April 27th, 2024

Saturday newsletters focus on headlines and research - enjoy!

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Research News

[Measuring decision aid effectiveness for end-of-life care: A systematic review](#)

PEC Innovation; M. Courtney Hughes, Erin Vernon, Chinenye Egwuonwu, Oluwatoyosi Afolabi; 4/24

A total of 715 articles were initially identified, with 43 meeting the inclusion criteria. Outcome measures identified included decisional conflict, less aggressive care desired, knowledge improvements, communication improvements, tool satisfaction, patient anxiety and well-being, and less aggressive care action completed. The majority of studies reported positive outcomes especially when the decision aid development included International Patient Decision Aid Standards.

*Publisher's note: Also by these co-authors, please see **[The effectiveness of community-based palliative care program components: A systematic review](#)** (*Age and Ageing*, 2023) and **[Measuring effectiveness in community-based palliative care programs: A systematic review](#)** (*Social Science & Medicine*, 2022).*

[End-of-life and palliative care for lesbian, gay, bisexual, transgender, queer or questioning, or another diverse gender identity older adults](#)

Clinics in Geriatric Medicine; by Evie Kalmar MD, MS, Jeffrey Mariano MD; 5/24

Lesbian, gay, bisexual, transgender, queer or questioning, or another diverse gender identity (LGBTQ+) people are more likely to have alternative family structures. It is important to engage in advance care planning to understand their values, clarify surrogate decision makers, and contribute to goal-concordant care at the end of life. Clinicians can follow recommendations in this article to ensure they are providing LGBTQ-inclusive palliative and hospice care.

[Making end-of-life health disparities in the U.S. visible through family bereavement narratives](#)

PEC Innovation; by Cassidy Taladay-Carter; 4/24

End-of-life experiences can have important implications for the meaning-making and communication of bereaved family members, particularly due to (in)access to formal healthcare services (i.e., palliative care and hospice). Grounded in Communicated Narrative Sense-Making theory, this study extends knowledge about how the stories told about end-of-life by bereaved family members affect and reflect their sense-making, well-being and importantly, potential disparities in end-of-life care. ... Four themes illustrated the continuum of communication that families engaged in when making sense of end-of-life experiences, including *reflections on silence, tempered frustrations, comfort with care, and support from beyond*.



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Eleology- A modest proposal

American Journal of Hospice and Palliative Medicine; by Caleb Knisley, MD, Steven J. Baumrucker, MD; 6/24

Words matter. This is a simple but profound truth. ... Since the titles we are known by carry so much weight, misunderstanding and misnomers can be incredibly frustrating. Practitioners of Hospice and Palliative Medicine (HPM) (more on that mouthful in a moment) are uniquely aware of this frustration. ... The name "Hospice and Palliative Medicine" is therefore not an entirely accurate representation of the specialty it represents. ... Eleos is the word for "mercy" in both classical Greek authors and the writings that make up the Greek New Testament of the Christian Bible. ... Eleology, therefore, is a fitting name for the medical specialty uniquely dedicated to relieving suffering through mercy and compassion.

Hospice satisfaction among patients, family, and caregivers: A systematic review of the literature

American Journal of Hospice and Palliative Medicine; Timothy Hoff, PhD, Kathryn Trovato, MPH, Aliya Kitsakos, BA; 6/24

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.

Textures of Black sound and affect: Life and death in New Orleans

American Anthropologist; by Matt Sakakeeny; 6/24

In a traditional New Orleans jazz funeral, the characteristic shift from mourning to joy is propelled by brass band musicians weaving melodies and rhythms together. This article is about how these thickly layered textures of sound elicit shared sentiments of lament and of joy.



Keeping life in our patients' years toward the end of our patients' lives

Annals of Surgery; by Courtney Collins, Ronnie A Rosenthal; 5/24

As surgeons we are trained, some may say indoctrinated, to care about traditional benchmarks like wound infections, the need for critical care, 30-day readmissions, and (of course) mortality. These factors are obsessively collected and analyzed looking for any and all possible opportunities to move the needle of surgical quality by even the tiniest amount (as long as it is statistically significant). To be sure, this approach has yielded vast improvements in how we care for our patients and correspondingly, surgical outcomes have continued to improve over time. This intriguing analysis by Keney et al asks us to consider that in our pursuit of perfection by standard definitions, we may be missing something even more critical: what "good" looks like from the patient's point of view.

Time to rethink assisted dying?

Bioethics; by Udo Schuklenk; 5/24

... But who should be tasked with the provision of such services [assisted suicide and / or voluntary euthanasia], given that it would no longer be the case that only people defined as patients would be eligible for an assisted death.

Healthcare professionals might object to providing such services to people who aren't patients. Different societies could decide to introduce permissive assisted dying regimes tasking different professionals with the provision of such services. If doctors are the profession tasked with the provision of such services in a particular jurisdiction, they ought to provide it to those eligible in that society. However, it is worth considering whether a newly created assisted dying profession, that is equally tightly regulated, may be a preferable way forward.

"It's a heavy thing to carry": Internal medicine and pediatric resident experiences caring for dying patients

American Journal of Hospice and Palliative Medicine; by Lindsay M Gibbon, Laura Buck, Lauren Schmidt, Jori F Bogetz, Amy Trowbridge; 5/24

Our data suggests a model for the process by which residents learn affective skills critical to EOL care: residents (1) notice strong emotion, (2) reflect on the meaning of the emotion, and (3) crystallize this reflection into a new perspective or skill. Educators can use this model to develop educational methods that emphasize normalization of physician emotions and space for processing and professional identity formation.



Environmental comfort in promoting sleep in critically ill patients: A scoping review

[Portugal] Dimensions of Critical Care Nursing; by Derek Braga Moura, Débora de Fátima Sousa Andrade, Carla Rodrigues Silva, Igor Emanuel Soares-Pinto; 5/24

It is important to understand the concept of comfort as a whole to build an assistance intervention plan that meets the person's needs. Therefore, it is necessary to monitor and assess the person's sleep by considering the surrounding environment, to provide a comfortable environment that is quiet

and provides privacy, especially in contexts of difficult management of environmental factors in the approach to the person in critical condition.

Publisher's note: Recall 2/16 /24 article "[Bristol Hospice's quest to help patients sleep](#)".

Today's Encouragement

A life spent making mistakes is not only more honorable, but more useful than a life spent doing nothing. ~George Bernard Shaw



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