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June 1st, 2024

Saturday newsletters focus on headlines and research - enjoy!

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Research News

Deaths of despair surged among Black people over past decade

JAMA Network; by Emily Harris; 5/24

Guided by findings reported in 2015, researchers have thought that the uptick in midlife deaths of despair—those resulting from suicide, drug overdose, and alcoholic liver disease—disproportionately affected White people. Now, new data published in JAMA Psychiatry illustrate that the decrease in life expectancy from deaths of despair among people aged 45 to 54 years is not unique to White individuals.

Publisher's Note: Some hospices exclude suicide, drug overdose, alcoholic liver disease, etc., from hospice use calculations or consideration - should we?

Challenges and solutions of conducting dementia clinical trials: A palliative care at home pilot for persons with dementia

Journal of the American Geriatrics Society; by Leah V. Estrada, PhD, Laura Gelfman, MD, Meng Zhang, MD, Christian Espino, BA, Nathan Goldstein, MD; 4/24

We enrolled 30 patients and their 30 caregivers in our pilot trial of home-based palliative care. We found two significant barriers to enrollment: (1) the electronic health record was insufficient to determine the severity of patients' dementia; and (2) rates of follow-up survey completion were low, with completion rates at 6 months between 14 and 44%. We created an iterative training process to determine dementia severity from electronic health records and applied person-centered approaches to improve survey completion. ... Electronic health records are not set up to include discrete fields for dementia severity, which makes enrollment of older adults with dementia in a clinical trial challenging. The strain of caring for a loved one with advanced dementia may also make participation in health-services research difficult for patients and their families. Novel approaches have the potential to counteract these challenges, improve recruitment and retention, and ultimately improve care for people with dementia and their caregivers.

Procedural interventions for terminally ill children – Are we aiding palliation?

Journal of Palliative Care; by Hannah Phillips, MD, Sarah Perry, MS, Laura A Shinkunas, MS, Erica M Carlisle, MD; 5/24

Many children undergo surgery or an invasive procedure during their terminal hospital admission. The types of procedures, patients, and the intent of the

procedures has not been well defined. Understanding these details may help pediatric surgeons better determine the clinical settings in which certain procedures will not enhance palliation or survival. ... 132 children met inclusion criteria. Most children were White and less than one year old. The most common type of diagnosis was cardiac in nature. Children underwent an average of three procedures. 75% were intubated and 77.5% had palliative care involved. Patients who were less than one year old at death were more likely to have been intubated, had longer terminal hospital stays, and had more procedures. Those who were intubated underwent more procedures and had longer hospital stays. Those with longer palliative care involvement had fewer procedures. ... Ongoing study may help refine which procedures may have limited impact on survival in the chronically ill pediatric population.

Beyond the diagnosis: A deep dive into the end stage liver disease experience from the patient perspective

American Journal of Hospice and Palliative Medicine; Sheza Malik, MD, Venkat Arutla, MD, Tariq Alamin, MD, Fatima Warraich, MD, Tausif A. Syed, MD, Mahesh Nepal, MD, Muhammad Farhan Ashraf, MD, and Karin J. Dunnigan, MD; 5/24

The study identified six primary themes: the significance of communication style in diagnosis delivery, the crucial role of family and social support, varied understanding and preferences for palliative care, diverse attitudes towards advanced care planning, preferences for coordinated healthcare experiences, and the emotional and psychological impact of ESLD. ... Our study underscores the complexity of ESLD patient care beyond medical treatment, highlighting the importance of clear communication, empathetic care, and the integration of family and palliative care services.

“When I do have some time, rather than spend it polishing silver, I want to spend it with my grandkids”: a qualitative exploration of patient values following left ventricular assist device implantation

BMC Palliative Care; by Avery C. Bechthold, Colleen K. McIlvennan, Daniel D. Matlock, Deborah B. Ejem, Rachel D. Wells, Jesse LeJeune, Marie A. Bakitas, J. Nicholas Odom; 5/24

Values are broadly understood to have implications for how individuals make decisions and cope with serious illness stressors, yet it remains uncertain how patients and their family and friend caregivers discuss, reflect upon, and act on

their values in the post-left ventricular assist device (LVAD) implantation context. This study aimed to explore the values elicitation experiences of patients with an LVAD in the post-implantation period. ... Clinicians should consider assessing the values of patients post-implantation to facilitate shared understanding of their goals/priorities and identify potential changes in their coping.

The balance between honesty and hope

JAMA Cardiology; by Sarah Godfrey; 5/24

I am training to be a palliative cardiologist, often delivering heartbreaking news, but I was not prepared to receive it as a mother. Before [her new baby boy] N's diagnosis, I would have said that our responsibility as physicians is to prepare families for the worst possible outcome. But how can we balance honesty and hope? Could that neurologist have prepared us for the potentially devastating outcome while also allowing us to believe more was possible? When I enter critical illness conversations now, I remember my desperate need for hope when I faced a parent's worst nightmare. N has made me a better mother and physician, and he has taught me that we must allow hope to flourish even in the darkest of situations.

The other side of the curtain

JAMA; by Paige Stevens; 5/23/24

Each day, clinicians have a sacred opportunity to foster the patient-physician bond and provide holistic care to patients. Too many times, the stress and hectic nature of my daily life as a physician has caused me to lose sight of this special connection and sometimes shortchanged the care that I provided. This journey has taught me more about being a physician than any of my years of formal education ever could. Now, having experienced medicine from the other side of the curtain, I am forever thankful that the physicians and nurses who cared for me took the time to learn my story and attend to all my needs—medical, emotional, and spiritual. These are the moments that I am most thankful for and the moments that will stay with me forever.

A joint frailty model for recurrent and competing terminal events: Application to delirium in the ICU

Statistics in Medicine; by Lacey H. Etzkorn, Quentin Le Coënt, Mark van den Boogaard, Virginie Rondeau, Elizabeth Colantuoni; 5/24

Motivated by studies of recurrent delirium events in patients receiving care in an

intensive care unit (ICU), we devise a joint model for a recurrent event process and multiple terminal events. ... We propose a competing joint model that uses a latent frailty to link a patient's recurrent and competing terminal event processes. ... Lastly, we discuss limitations and possible extensions for the competing joint model.

Publisher's Note: While complicated, some readers might find this methodological model of interest.

Be Well Lead Well Pulse

A scientifically-backed assessment empowering leaders to make wellbeing a game-changer for teams, workplaces, and communities, starting with themselves. It is a holistic tool for human development, cultivating the innate capacity of people to thrive and setting a new standard for thriving in leadership globally.

Publisher's Note: More to follow on this leadership assessment tool...

Today's Encouragement

Keep your face always toward the sunshine - and shadows will fall behind you. ~Walt Whitman

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