EMBRACING OUR DECLINE MAY ENHANCE OUR LIVES

Daniel Hinshaw, MD, Notre Dame Institute for Advanced Study (NDIAS), is on a mission to highlight what the role of kenosis—a depletion or emptying—has to do with patient wellbeing, our healthcare system, and the world at large. Brandi Klingerman, in her Medical Xpress article “Can changing our views on death improve how we live our lives?”, describes how Hinshaw sees this idea of depletion of our vitality not as a “source of despair,” but rather something to embrace as a guiding principle.

Hinshaw describes a recent shift into an era in which non-communicable diseases of aging are the leading causes of death worldwide. “It is the first time in human history when, for the majority of people, death will come through the aging process,” Hinshaw says. This is “essentially a process of kenosis, first on a physical level but also extending to the psychological, social, and spiritual aspects of the person.”

This kenotic process includes a “progressive functional decline, diminished autonomy, and the increasing likelihood over time of developing one or more of the diseases of aging (e.g., cancer, heart disease, diabetes, or dementia), all of which are associated with enormous healthcare costs that are spiraling out of control.”

Acknowledging this, Hinshaw asks what would happen if instead of fighting our limitations, we embraced them. “How would this affect our decisions not only on a personal level but also on a societal political level?” The implications reverberate in both personal experiences and the broader culture, he says. A greater acceptance of kenosis could mean that patients take responsibility for their health and embrace preventative medicine. For the healthcare industry, it might disrupt patterns of “expensive rescue strategies in the advanced stages of disease.”

Hinshaw serves time as a fellow at Notre Dame, and he sees potential for the ripples of this concept to extend out even further. It has the potential to transform not just healthcare policy, but research, ethics, politics, the arts, and even our posture towards the earth. It’s a binding force, as he describes it, and one that can combat individualistic tendencies that hurt others for the benefit of a select few. (Medical Xpress, 9/3, https://medicalxpress.com/news/2018-09-views-death.html)
Paula Span, writing in the New York Times, asks, “Is suicide by older adults ever a rational choice?” Span asserts that many older adults are discussing the topic, and says that physicians are also encountering these inquiries as well. Span shares about Dr. Meera Balasubramaniam, a geriatric psychiatrist. While Balasubramaniam has not taken a position on the topic, her views, says Span, are “‘evolving.’” She co-authored an article on the issue in 2017, and has also written about the topic in the Journal of the American Geriatrics Society. “Every part of this idea, including the very phrase ‘rational suicide,’ remains intensely controversial.”

Over 8200 senior adults took their own lives in 2016, says the CDC. In spite of research that shows older adults are happier than younger ones, “a complex web of conditions contributes to late-life suicide, including physical illness and functional decline, personality traits and coping styles, and social disconnection. However, “The vast majority of older people who kill themselves also have a diagnosable mental illness, primarily depression,” according to Dr. Yeates Conwell, a geriatric psychiatrist and suicide researcher.

Conwell says, “‘The suicidal state is not fixed. It’s a teeter-totter. There’s a will to live and a will to die, and it goes back and forth.” Treatment of depression is critical to suicide prevention.

Baby boomers, much known for their autonomy, are looking at end of life differently, and those who consider “rational suicide” are not all “depressed or otherwise impaired in judgment.” Dena Davis is a bioethicist at Lehigh University and addresses “‘pre-emptive suicide.”’ Davis cared for her mother through the slow process of Alzheimer’s, and says she does not intend to have a similar death. “‘You’ve completed the things you wanted to do. You see life’s satisfactions getting smaller and the burdens getting larger — that’s true for a lot of us as our bodies start breaking down.’ At that point, ‘it might be rational to end your life,” Dr. Davis continued. ‘Unfortunately, in the world we currently live in, if you don’t take control of life’s end, it’s likely to go in ways that are inimical to your wishes.”

The Hastings Center Report includes an article by Dina Davis, “Avoiding Deep Dementia.” She addresses the decision of legal scholar Norman Cantor. Cantor has explained “why he has an advance directive that calls for voluntary stopping of eating and drinking as a means of ending his life if he develops dementia and reaches a particular state of decline.” A response article says, “One sadly rational reason for suicide, a reason often given, is that people do not trust that their wishes will be followed as their lives come to a close.” (New York Times, 8/31, https://www.nytimes.com/2018/08/31/health/suicide-elderly.html; Hastings Center Report, 9/3, https://www.thehastingscenter.org/avoiding-dementia-causing-moral-distress/)

HOSPICE NOTES

* An NBC affiliate informs readers of the differences between hospice and palliative care. “Often patients are fearful when they hear the term palliative care because it’s often associated with hospice. We are trying to dispel some of that fear because quality at any stage of an illness is important,” says palliative care physician Dr. Jonathan Von Koenig. The article emphasizes
that palliative care ends and hospice care may come into play “when treatment of the disease is stopped, and it’s clear the person is not going to survive the illness.” In short, palliative care and hospice are “two different specialties that focus on keeping patients comfortable through a serious medical illness. (NBC, 8/6, www.nbc-2.com/story/38819041/health-matters-the-difference-between-hospice-and-palliative-care)

* A new study published in the *Journal of Palliative Medicine* is titled “Predicting Length of Hospice Stay: An Application of Quantile Regression.” Researchers, including Cordt Kassner and Don Taylor, found, “Methodological decisions can have a meaningful impact in the evaluation of factors influencing hospice length of use or cost.” Researchers report that they observed “significant (p < 0.001) heterogeneity in the marginal effects on hospice days and costs, with patient characteristics associated with generally larger shifts in the 75th percentile than the 25th percentile. Mean effects estimated by OLS regression overestimate the magnitude of the median marginal effects for all patient characteristics except for race.” (Journal of Palliative Medicine, 8/1, www.liebertpub.com/doi/10.1089/jpm.2018.0039)

* A new study titled “The Effect of Hospice on Hospital Admission and Readmission Rates: A Review” describes the challenges for terminally ill patients who are seeking to control symptoms as they near the end of life. Patients may seek hospital admission to treat pain, nausea, vomiting, and restlessness. The study praises palliative care’s focus on “control and mitigation of symptoms, while allowing patients to maintain their quality of life, whether in an outpatient or inpatient setting. Hospice care provides, in addition to inpatient care at a hospice facility or in a hospital, the option for patients to receive symptom management at home. This option for symptom control in the outpatient setting is essential to preventing repeated and expensive hospital readmissions.” (Home Healthcare Practical Management 2018;30(3):140-146)

* In a new study titled “Hospice Care for Patients With Dementia in the United States: A Longitudinal Cohort Study,” researchers conclude, “Patients with dementia are significantly more likely to be disenrolled from hospice following a long enrollment period compared with patients without dementia.” This finding is based on a longitudinal cohort study (2008-2011) of Medicare beneficiaries, and raises concerns for the growing number of individuals with dementia choosing hospice care. “It is critical to address potential barriers to the provision of quality palliative care for this population near the end of life.” (Journal of Post-Acute and Long-Term Care Medicine, 2018;19(7):633-638, www.jamda.com/article/S1525-8610(17)30577-7/fulltext)

**PALLIATIVE CARE AND END-OF-LIFE NOTES**

* David Mills writes about his experience with his sister Karen’s death in “Advice you absolutely need before someone close to you gets close to dying.” Mills laments that he “never got to say a proper goodbye” to his sister, who was asleep by the time she was transferred to hospice care and available for family to see her. “Say everything you want to say when the person you love can still hear it,” Mills says. (Aleteia, 9/7, https://aleteia.org/2018/09/07/advice-you-absolutely-need-before-someone-close-to-you-gets-close-to-dying)

* “When medical home models include palliative care, quality improves,” McKnight’s
The article outlines “a vastly better approach” than common alternatives that include a combination of a medical home and palliative care delivered in the home. “This specialized model encourages providers and care teams to meet patients where they are — from the simplest to the most complex conditions.” The article defines the “medical home” concept and traces its history back to the 1960s, when it was introduced by the American Academy of Pediatrics. It then details how the team works and the role of both palliative care and skilled nursing facilities. (McKnight’s, 9/7, www.mcknights.com/marketplace/when-medical-home-models-include-palliative-care-quality-improves/article/794406)

* Typically, says Eduardo Bruera, MD, “Academic medicine has had great difficulty incorporating palliative care, supportive care and—in a sense—whole-patient care into disease management.” But this is getting better. “There is no moment of greater distress than the moment in which we are going to end our lives,” says Bruera. “It is never easy to be ill. It is always going to be difficult to die. We can never expect to turn the end of our lives into a pleasant experience, but there’s a lot of unnecessary…physical, emotional, spiritual and family suffering. That is what we are very good at alleviating.” (TMC News, 9/4, www.tmc.edu/news/2018/09/palliative-care-and-spirituality-for-life)

* A new study in American Journal of Hospice Palliative Medicine, “Evaluating Palliative Care Resources Available to the Public Using the Internet and Social Media,” identifies and evaluates resources on the Internet and social media regarding palliative care. Top websites are identified, and researchers found that the most popular Google responses “were mostly from national organizations promoting palliative care, whose definitions of palliative care consistently mention ‘quality of life’ and ‘relief from symptoms and stress.’” Notably, “none of the websites mentioned children, and 77% cited palliative care as treatment for cancer with less focus on other diseases.” Other insights include a lack of personal stories on Google as opposed to personal stories being the majority (60%) of results on YouTube. Researchers concluded, “Palliative care resources are mostly positive and consistent with the current definition of palliative care. Major Internet search engines such as Google and YouTube provide valuable insight into information the public receives about palliative care.” (American Journal of Hospice Palliative Medicine 2018;35(9):1174-1180)

* A new study in the Journal of Holistic Nursing is titled “Finding Paradise Within: How Spirituality Protects Palliative Care Clients and Caregivers from Depression.” The article “explores depression among palliative care clients and caregivers, describes coping strategies, and clarifies the role of spirituality in “preventing and/or overcoming depression.” “The findings relate to participants succumbing to depression, but having spiritual beliefs and practices helped them cope. One of the most insightful understandings was the role spirituality played in protecting individuals from depression, encapsulated in the theme ‘finding paradise within.’” The author concludes, “Spirituality, understood from a religious or secular perspective, must be embedded in palliative care as it assisted in preventing and overcoming depression.” (Journal of Holistic Nursing 2018;36(3):243-254)

* “Death and its companion, grief, are often ignored at nursing homes and assisted living centers, yet ignoring the loss can lead to depression, staff burnout and other problems.” Worried that death of other residents might “upset residents,” these facilities often close the door to deceased patients’ rooms and act as if the resident “never existed.” “When feelings aren’t acknowledged, grief can go underground and lead to a host of physical and psychological
Dr. Toni Miles, a professor of epidemiology and biostatistics at the University of Georgia, is working in Georgia to help facilities create rituals to honor those who have died. (*Kaiser Health Network (KHN), 9/4, https://khn.org/news/creating-rituals-to-honor-the-dead-at-long-term-care-facilities/)

* A *STAT* article shares the poignant story of the journal of a young father as he lives with terminal brain cancer. It shares the ups and downs of his and his family’s experiences, and offers an inside view of the realities of living when knowing that death is near. (*STAT, 9/5, https://www.statnews.com/2018/09/05/a-young-dad-and-a-cancer-diagnosis/)

* The 4th edition of the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care (NCP) Guidelines will be released in October. The updated guidelines expand on the existing guidelines and specifically focus on two key topics. “First of all, the guidelines stress that palliative care is for all people who have serious illnesses, regardless of setting, diagnosis, prognosis, or age.” The second concept reinforces, “Palliative care is the responsibility of all clinicians and disciplines caring for the seriously ill, including primary care practices, specialist care practices (e.g., oncology or neurology), hospitalists, nursing home staff, as well as palliative care specialist teams such as hospice, hospital, and community-based palliative care teams.” Each of these foci is expanded with five key themes. (*JPM, 9/4, https://www.liebertpub.com/doi/10.1089/jpm.2018.0431*)

**OTHER NOTES**

* A study published in the *Journal of Pain and Symptom Management*, that investigates anxiety and sadness at the end of life, found that advanced care planning and appointing a healthcare proxy can be disproportionately detrimental to the mental health of African American patients. “Although advance care planning can help reduce unnecessary treatments,” *Medical Bag* says, “Black patients do not necessarily benefit as much as white patients do from this planning.” Researchers at Weill Cornell Medicine examined the 2011-2016 National Health and Aging Trends Study as well as data from over 300 Medicare beneficiaries. They say more research is needed to understand why a tool intended to improve patient experiences “is associated with increased and unaddressed distress among older black adults.” Finally, they say the findings “highlight a need for clinicians to pay increased attention to and work with caregivers to address these patients’ mental health as life draws to a close.” (*Medical Bag, 9/4, www.medicalbag.com/medicine/advance-care-planning-end-of-life/article/792979*)

* As The Virginia Joint Commission on Health Care considers releasing its study on Medical Aid in Dying, its commissioner Virginia Turner calls on “pro-life Virginians to contact their local lawmakers and commission member” to have their voices heard. Turner says the study was postponed until later in September in order to hear a “separate report from a group” that includes Turner herself. “And it is hoped at that time,” Turner says, “that the members of the Joint Commission on Health Care will take a vote to take no action.” She calls medical aid in dying a “direct violation” of current state law and warns, “Vulnerable patients are always the ones who suffer when these laws are expanded.” (*NE News Now, 9/6, www.onenewsnow.com/pro-life/2018/09/06/va-pro-lifers-urged-to-be-vocal-be-heard*)

* The work of Compassion and Choices is detailed in “End of Life Options and Medical
Aid in Dying,” published in Edhat. The article shares information from Compassion and Choice’s Public Outreach Manager Erika Ruiz. Ruiz presented at the Humanist Society of Santa Barbara regarding end-of-life options under the current California law. The article also looks at the state’s history with the issue. The California law was passed. But that is not always the same as having actual access.” The summary of those efforts is combined with links to tools that help patients find care and understand their medical options. (Edhat, 9/3, www.edhat.com/news/end-of-life-options-and-medical-aid-in-dying)

* Medpage reports that a “Death Certificate Project” threatens hundreds of California physicians with disciplinary action over opioid prescriptions given to patients who overdosed. The project was established to attempt to stop the epidemic of accidental deaths from such drugs. The state’s prescription drug database known as CURES identified doctors like Dr. Brian J. Lenzkes as having “prescribed long-term excessive amounts” of opioids and benzos.” Lenzkes says he was shocked at this accusation, saying he’d tried various pain management strategies for a patient who was very ill and who he’d come to know well. “I don't prescribe inappropriately,” he says. And Medpage points out that no complaint had been filed against him by a patient or family member. While Lenzkes and others interviewed say the board is right to be concerned about overprescribing, they now understand why some doctors are saying to patients, “Sorry, if you have a lot of medical conditions, we’re not going to take care of you.” Personally, Lenzkes says the experience left him shaken and changed the way he will practice pain treatment. From now on, he expects to refer patients to pain specialists instead. (Medpage, 8/30, www.medpagetoday.com/painmanagement/painmanagement/74856)

* The Pancreatic Cancer Action Network speaks out about four common hospice and palliative care myths. Allison Rosenzweig, PhD, acknowledges the overwhelming nature of pancreatic cancer diagnoses and dives into the facts behind these myths: “Myth #1: Patients should choose the most aggressive cancer treatment available. Myth #2: Patients must choose between cancer-fighting medicine and palliative care. Myth #3: Palliative care is the same as end-of-life care. Myth #4: A patient who enrolls in hospice care is quitting or giving up hope.” (Pancreatic Cancer Action Network, 9/1, www.pancan.org/news/4-common-hospice-care-palliative-care-myths)

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