Book Explores Alternatives to the ‘Medicalization’ of Death

An article in Social Justice Solutions shares an essay by Cassandra Yonder from an upcoming book by Victoria Brewster, M.S.W., and Julie Saeger Nierenberg, M.A. The book, Journey’s End: Death, Dying, and the End of Life, is expected to be published next spring.

Y ordereder asserts, “We have come to recognize ourselves as a death denying society.” “As the sick and dying members of our families and communities are institutionalized, death itself is ‘medicalized,’ and post-death care is undertaken by strangers outside our homes.” Yet there is hope for a more humane - and human - way of end-of-life care. “A new social movement has arisen in response to the cultural alienation we feel from death and dying,” one that could help bring us back in touch with the meaning and reality of the end-of-life process.

More and more Americans are wanting to better understand and prepare for the end-of-life. Just as midwives are able to help expectant mothers navigate the process of bringing new life into the world, “death midwifery” can be an invaluable help for us as we learn how to be present for the dying and how to care for the dead, the authors say. Yonder contends that death midwifery has an important role to play alongside more traditional end-of-life resources. “One might even say that death midwifery is to palliative care as the slow food movement is to large-scale agriculture and as birth midwifery is to obstetrics.”

Acknowledging that the term “death midwifery” conjures up a negative reaction in many who hear it for the first time, Yonder believes this results in part from the “unhealthy taboo around death and dying that results from our almost complete and utter disengagement from it.” The concept of death midwifery is a life-affirming response to the state of denial in which America lives -- death is something to be avoided at all costs.

Rather than medicalizing the process of death and dying, this alternative approach encourages a focus on the needs and experience of those who are going through the dying process. At the heart of death midwifery is “the ability to witness what is, recognizing the centrality of those who are living and dying their own authentic experience without directing or manipulating in order to forward one’s own agenda.”

Death midwifery represents a shifting perspective on the part of everyone in our society, whether we are dying or in perfect health, to fully embrace the reality of death in our lives. This involves a return to basic practices of care that don’t require a specialized medical establishment. “We are beginning to co-create a shift away from the post-industrial model of handing off our dirty business to private enterprise and instead reinvesting in doing it ourselves.” Many are discovering that it is “relevant and meaningful to participate in the most basic and essential acts of living within a community.” And that includes death.

It also goes beyond the immediate dying process. Yonder views the growing trend of home funerals as one expression of the death midwifery movement as a whole. More and more people in the developed world are interested in fully participating in the death and dying process, and that includes the final care and disposal of our loved one’s remains.

The philosophy and practice of death midwifery naturally lends itself to considering home funerals as an alternative to the industrialized funeral industry. From this perspective, do-it-yourself burials “make sense because we don’t hire professionals to do anything for us that we can do ourselves.” Being able to participate directly in the most basic and intimate activities of life and death produce a “visceral, physical participatory involvement with our surroundings.” (Social Justice Solutions, 12/1, www.socialjusticesolutions.org/2014/12/01/death-midwifery-home-funerals)
Are Feelings About Life After 75 a Gender-Related Issue?

Is life after 75 worth living? In a recently publicized article in *The Atlantic*, professor Ezekiel Emanuel expressed his view that the physical and mental diminishments of the golden years are more hassle than they are worth. Believing that most of his creativity, energy and productivity will be behind him by age 75, Emanuel makes it clear that he would prefer to die than to live in a diminished state. But is this just end-of-life machismo?

Cindia Cameron uses Emanuel’s article, along with observations on her own mother’s life experience, as a jumping off point to consider whether there might be gender-based differences in our understanding of the value of life after age 75. In contrast to Emanuel’s vision of life after 75 as being post-prime, Cameron suggests that for many women, the 80s and 90s can be prime time indeed.

Could it be that the life of vigorous activity that Emanuel idealizes sometimes overshadows the lives of those around us - particularly the lives of women? This seems to have been the case for Cameron’s parents. For her father, retirement was the end of the road. “My Dad did not think life worth living if he could not be a professor,” she writes, describing how her father actively began destroying himself through smoking and excessive drinking. He managed to kill himself off right on schedule, at age 75.

Cameron analyzes what happened to her father in terms of “Alpha male status.” She reflects that her father was unable to consider any other role in life besides that of the successful professor. Being primarily a loving presence for his grandchildren, or even focusing on “the classical music and gourmet cooking he always loved” was not possible. He would rather die than see his life relegated to such trivial pursuits. Ultimately, his fear of losing Alpha male status killed him.

While for Cameron’s father, the end of the prime productive years was the end of everything, for her mother it was just the beginning. In stark contrast to her dad, Cameron’s mom “began to bloom and be seen by any around her for the funny, engaging person she is.” All it took was her husband’s death to bring out this side of her. “‘Your Dad never thought my jokes were funny,’ she told me after his death, ‘so I stopped telling them years ago.’” With her father’s Alpha male life no longer overshadowing her, Cameron’s mother was finally able to come into her own.

Ultimately, Cameron’s gut-level response to Emanuel’s essay about life after 75 comes down to four words: “Welcome to my world.” While for some men, lower status and productivity may be a fate worse than death, it is the quotidian experience of many, if not most, of the world’s women. “I read his arguments as a fear of not just infirmity, financial insecurity or dependency, but of losing the social status that (primarily Caucasian) men with upper income, a top-flight education and high achievement are allowed to claim in our society.”

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Contrast this with the lives of so many in our society who are “low-wage workers, caregivers for the ill and elderly, those who live with disabilities of all kinds.” Are these people “not creative”? Are their lives worth living, at any age? Reflecting on his own father’s experience after a stroke, Emanuel states that a life of being able to merely “swim, read the newspaper, needle his kids on the phone and live in his own house” is not sufficiently meaningful to be worth living. Instead, Emanuel wants to be remembered “in his prime: active, vigorous, engaged, animated, astute, enthusiastic, funny, warm and loving.”


HOSPICE NOTES

• A hospice service in Georgia has agreed to pay $581,504 to settle claims with the U.S. Department of Justice. Claims stem from a whistleblower lawsuit, in which Serenity Hospice Care LLC of Dublin, about two hours southeast of Atlanta, was accused of “submitting claims for patients who were not eligible for hospice care under Medicare rules.” (Atlanta Journal-Constitution, 12/3, www.ajc.com/news/business/georgia-hospice-service-to-pay-581504-to-settle-cl/njKy6/)

• Hospice leaders watching the ICD-10 developments may follow breaking news at the ICD10Watch. (HealthcareITNews & HEALTHCAREFINANCENEWS, http://www.icd10watch.com/blog/icd-10-debate-doesnt-take-time-holidays)

• Tennessee Gov. Bill Haslam (R) is reviewing a TennCare budget proposal that would halt coverage of hospice care, as well as many other programs. Should the hospice care benefit be halted, the proposal suggests that the state would save $17.2 million per year. (The Tennessean, 12/5, http://www.tennessean.com/story/news/health/2014/12/05/million-cuts-proposed-tenncare/19965311/)

What’s New at NJHPCO

Marlina Schetting, MSW, LCSW, CT, Administrator of Karen Ann Quinlan Hospice and Chair of NJHPCO’s Committee on Reimbursement and Government Relations, offered NJHPCO’s testimony at an invitation-only discussion of New Jersey’s proposed assisted suicide bill this Monday at the Senate Committee on Health, Human Services and Senior Citizens. Speaking on favor of the bill were: Jessica Grennan from Compassion & Choices and Ed Barocas of the ACLU. Joining Schetting in speaking against the bill were Dr. Joseph Fennelly and Mishael Azam of the Medical Society of New Jersey and Sister Pat Codey of the Catholic Health Partnership. Janet Colbert, a terminally Ill patient, also spoke to the committee.

It was announced earlier that no vote would be taken at the hearing. The State Assembly passed the bill some weeks ago with the minimum number of votes needed. Schetting’s testimony read, in part:

“Hospice neither hastens nor postpones death. Hospice affirms living…and dying a natural death. Hospice respects patient choice, alleviates pain and suffering and supports patients and their families in their coping with the dying process. Finally, in hospice care, like virtually all aspects of medical care, quality of care is quantified and providers are required to use evidence based practice and show outcomes.

“When only three in 10 Americans have developed advance directives; New Jersey’s POLST is still newly implemented, and residents continue to die in arenas not of their own choosing, isn’t it time to consider hospice, death education and advance care planning, rather than relegate end-of-life to a health crisis that culminates with a single, autonomous act? People do not exist in vacuums...A short cut to this process is ill-advised, no matter how well-intentioned, and is neither “dignified” nor “humane” when a better option is present. That better option is hospice care.”
• Providing home support for chronically ill patients cuts costs by 44%, according to a recent study conducted by Wayne State University and Hospice of Michigan. “Researchers examined the effect of providing medical and daily-care help to patients who have a serious, chronic illness but who do not qualify for hospice care. The patients were enrolled in Hospice of Michigan’s At Home Support program.” (MLIVE, 11/25, www.mlive.com/news/grand-rapids/index.ssf/2014/11/home_support_for_critically_il.html)

• Dr. David Currow has been named Director of Palliative Medicine and Hospice Care at Dartmouth-Hitchcock. Dr. Currow will lead Dartmouth-Hitchcock’s new Center for Palliative and Hospice care, which is currently in the planning stages. (PR Newswire, 12/4, www.prnewswire.com/news-releases/dr-david-currow-named-director-of-palliative-medicine-and-hospice-care-at-dartmouth-hitchcock-300005049.html)

END-OF-LIFE NOTES

• The Huffington Post blog features an article on how to find joy in the funeral planning process. Barbara Sedoric of LastingMatters.com suggests we put as much thought and care into our final memorial as we do into the next vacation. (The Huffington Post, 12/2, www.huffingtonpost.com/ellevate/how-to-find-joy-at-the-end-b_6115588.html)

• End-of-life groups are teaming up to discuss hospice and palliative care in Mandarin. The Palo Alto Medical Foundation and the Chinese American Coalition for Compassionate Care are joining forces to host discussions and share end-of-life tips for the Chinese-American community. (Mercury News, 12/1, www.mercurynews.com/ci_27046669/cupertino-groups-teaming-up-discuss-end-life-care)

• Even having end-of-life life conversations in advance of traumatic injuries or illness does not entirely prevent the anguish and ambiguity of making end-of-life choices for an incapacitated loved one, writes Elizabeth Reis for The New York Times Well blog. Reis suggests that physicians do families a service by “injecting a healthy pessimism - or realism [which] gives loved ones an opportunity to... stretch hope in a way that accommodates a better death.” (The New York Times, 12/1, well.blogs.nytimes.com/2014/12/01/hoping-for-a-good-death/)

• As end-of-life planning becomes increasingly common in the U.S., “concerns are emerging about how well patients and their doctors understand the forms they are signing and the care they want in their final days.” The Wall Street Journal reports on the Institute of Medicine’s “Dying in America” report, which calls for a “national effort to improve medical and social services for end-of-life care.” (The Wall Street Journal, 11/30, online.wsj.com/articles/how-to-make-your-wishes-for-end-of-life-care-clear-1417408059)

• Should employees have to choose between keeping their job and providing end-of-life care to a loved one? Duff McCutcheon writes that the aging and increased death rate of Boomers will mean greater employee demand for compassionate care leave. (Financial Post, 12/1, business.financialpost.com/2014/12/01/dont-make-employees-choose-between-their-job-and-providing-end-of-life-care-to-a-loved-one/)

• Legislation in California could create an electronic registry for end-of-life care directives. Sen. Lois Wolk (D-Solano) has introduced a bill that would ensure that electronic records of end-of-life care decisions would be immediately available to health care providers. (The Reporter, 12/2, www.thereporter.com/general-news/20141202/wolk-measure-would-create-electronic-registry-for-end-of-life-care-directives)

PALLIATIVE CARE NOTES

• Dementia is a terminal illness and the diagnosis is a time to start considering palliative care. An article in The Journal of Palliative Care finds that there are deficits in clinician dementia knowledge that need to be addressed so that individuals can get the care they need. (Medscape, 12/2, www.medscape.com/viewarticle/835470)

• Palliative care is playing an increasingly large role in the health care system, offering patients “dying with dignity.” Palliative care, says the article, provides “the most comprehensive physical, spiritual and psychosocial care for patients and families when there’s a life-limiting illness or a terminal illness.” (Time Warner Cable News, 11/29, rochester.twcnews.com/content/lifestyles/786666/dying-with-dignity--palliative-care-playing-larger-role-in-health-care/)
• The University of California - San Francisco is expanding the training that its nursing students receive, emphasizing palliative care techniques. The success of palliative treatments “are a big part of why the UCSF School of Nursing started a new palliative care minor for advanced practice nursing students.” (UCSF, 12/3, www.ucsf.edu/news/2014/12/121586/palliative-care%E2%80%99s-importance-grows-ucsf-nursing-expands-training)

• A physician in rural California has launched a start-up to provide palliative care services for dying patients in isolated areas. Dr. Michael Fratkin takes regular flights in a tiny Cessna airplane in order to reach patients in remote locations. (The California Report, 12/4, blogs.kqed.org/stateofhealth/2014/12/04/an-unlikely-start-up-end-of-life-doctor-breaks-out-on-his-own/)

ASSISTED SUICIDE NOTES

• If you want to see physician-assisted suicide legal, why not let commercial firms get involved? An article published in Bioethics examines the ethical coherence of supporting physician-assisted suicide, versus suicide assisted by professional, non-medical staff. The author makes a case that it is not logically coherent to support physician-assisted suicide while resisting commercial assistance for suicide. (Bioethics, 11/25, www.ncbi.nlm.nih.gov/pubmed/25425401)


• Lawrence M. Hinman, recently retired ethicist, writes about his change of mind on the issue of physician-assisted suicide. “The policy of physician-assisted dying poses real dangers, but the experience of Oregon’s law has been instructive,” says Hinman. He examines the role of suffering and concludes, “One of the important truths that has emerged from the Oregon experiment is simple: Ordinarily we don’t want to die. We want to keep living until it is intolerable to do so. But who should make the choice about what is intolerable — the individual or the government?” (U-T San Diego, 11/22, http://www.utsandiego.com/news/2014/nov/22/life-and-death-decision-should-be-individuals/2/?#article-copy)

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WEB TUESDAY, FEB. 24, 3:00-4:30 p.m. - “From Touchy to Touching: Talking About the Dying Process”

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