REIMAGINING END OF LIFE CAN MAKE IT BETTER

“How might we reimagine the end-of-life experience for ourselves and our loved ones?” Paul Bennett, Chief Creative Officer of IDEO, explains that he and his company are working to make death less of “a downer,” and to focus on designing that will make death better. To further this end, they opened an industrial design challenge on OpenIDEO, encouraging designers to reimagine the end of life. They explain the challenge by saying, “Each year around 55 million people worldwide and over 2.5 million in the United States face the end-of-life. In the U.S., the end-of-life experience has shifted dramatically since the 1950s, as death has moved away from the home into institutions like hospitals and nursing homes. By the 1980s, less than 17% of people died at home. We believe the people and unmet needs behind these numbers inspire a huge opportunity for design.”

Dana Cho, who works for IDEO, explains that she was hesitant to talk about the subject at first. But a palliative care physician pointed out that we are all both experts and novices on death, because everyone has experiences with dying, but no one has done it themselves. The challenge has been divided into different areas of focus including: Connectedness, New Values, What Surrounds Us, Planning Now, Services & Care, the Cost of Dying, and After Death. To help manage the process IDEO has partnered with Sutter Health, the HELIX Centre, and the Ungerleider Palliative Care Fund.

Dr. BJ Miller, Senior Director and Advocate at Zen Hospice Project, helps IDEO as well. He sees that design can make a big impact on where people die. Since most Americans are dying in hospitals, design can help make those spaces more beautiful and more functional. Currently, Miller says, the focus in designing hospitals is on the people who work there, not the patients and their families. This kind of creative thinking about design can also be used in other places people tend to die, such as nursing homes, rehab centers, and similar places. Miller is also excited about the possibility of designing new kinds of places like residential care facilities and adult day centers.

Miller points out that design can also help with non-physical infrastructure issues, such as helping to create a functional medical records system, and a creating a way for first responders to access advance directives. Traditionally, medical equipment and products have also gotten little focus from designers, but they could be made more functional and aesthetically pleasing.
A significant part of the challenge is to engage people from around the world, and to have them submit ideas. Many have submitted ideas and these may be seen online. Cho explains that while IDEO would love to see some concrete changes come out of the process, just beginning the conversation about the end of life is a good outcome. (Core77) Read more... (Core77, 6/16) Read more... (Core77) Read more...

SURVEY FINDS SUPPORT FOR PHYSICIAN-ASSISTED DEATH IN ETHNICALLY DIVERSE CALIFORNIA AND HAWAII

“Physician-assisted death was supported by a majority of California and Hawaii residents, regardless of their ethnicity,” reveals an online survey that was done by researchers at Stanford University School of Medicine. The study is published in Journal of Palliative Medicine. As of June 9, the practice is legal in California, but is not legal in Hawaii. The survey asked people to identify their ethnicity, to indicate how important their faith is to them, and to “respond, true or false, to whether they believed it is acceptable to allow a physician to prescribe medication, at the request of a terminally-ill patient, in order to end that person’s life.”

The survey also found that older people were more supportive of physicians being allowed to prescribe medication for patients to end their own lives. Religious or spiritual people were less likely to be comfortable with the practice, though a majority of those asked still agreed that it should be an option. The authors of the study were surprised. “It is remarkable that in both states, even participants who were deeply spiritual (52 percent) were still in support of physician-assisted death. Both genders and all racial/ethnic groups in both states were equally in support of PAD.” VJ Periyakoil, the lead author of the study, concludes, “This study shows that in the ethnically diverse states of California and Hawaii, faith/religion/spirituality and age are major influencers of attitudes toward PAD and not ethnicity and gender.”

Periyakoil explains that doctors need to be both honest and culturally sensitive when they talk to patients about end-of-life care. “It takes a tremendous amount of courage on the patient’s part to ask these questions,” Periyakoil says. “How the doctor responds initially to the patient’s question is very important, and will set the tone for the rest of the interaction about this sensitive issue.”

The article also provides a link to Periyakoil’s teaching module that deals with physician-assisted death. (Stanford Medicine News Center, 6/09) Read more... (Journal of Palliative Medicine, 6/9) Learn more...
HOSPICE AND END-OF-LIFE NOTES

* US Department of Health and Human Services Office of Inspector General has released its "Mid-Year Update." It reports that there will be a continued focus on "additional oversight of hospice care, including oversight of certification surveys and hospice-worker licensure requirements." This includes reviewing election statements for hospice care, and making sure that the patients qualify for hospice care at the level they are receiving. (US Department of Health and Human Services Office of Inspector General, 04/2016) Read more...

* On June 22, The National Hospice and Palliative Care Organization will host a Congressional Screening of the PBS documentary, “Being Mortal.” Following the airing of the film, there will be a panel discussion about end-of-life issues and planning. On the panel will be best-selling author and physician Dr. Atul Gawande; Dr. Patrick Conway, MD, CMS Deputy Administrator for Innovation and Quality and CMS Chief Medical Officer; and, family caregiver Rory Feek, a country music artist whose wife Joey died recently. (PRNewswire, 6/08) Read more...

* Physician Niran S. Al-Agba writes about her experience of being shocked by the death of a young patient. She and the rest of the medical team were not ready to allow death to happen, but the father chose to discontinue care. Al-Agba writes dramatically and emotionally about the shock of realizing that stopping intervention was the right decision. (KevinMD, 6/02) Read more...

* A law student writing in The National Law Review believes minors should have the right to refuse life-sustaining medical treatment (LSMT). The article “examines the statutory and constitutional landscape surrounding a minor’s right to refuse LSMT, and promulgates that the best method to address this issue is by creating specialized health care courts.” The article examines current legal questions around physician-assisted suicide, and explores who has the right to end life-sustaining treatment. (The National Law Review, 6/06) Read more...

* Researchers at the Hospice of Cincinnati have developed “Conversations of a Lifetime,” an advanced care model designed to improve advance care planning by allowing the elderly to make decisions about care they would want to receive if they become unable to speak. According to a presentation at the American Geriatrics Society Annual Meeting, the hospice has “combined training from two well-known evidence-based strategies, Vital Talk and Respecting Choices, made some custom improvements to [their] Epic system and provided substantial technical support in the PCP practices to enable and support change.” The physicians who have been trained as part of the program so far have ranked the experience highly. (Healio, 6/07) Learn more...
* At the recent American Society of Clinical Oncology (ASCO) meeting in Chicago, researchers presented preliminary findings showing, “Three-quarters of patients with metastatic cancers (lung, colorectal, breast, pancreatic or prostate) received aggressive or invasive procedures or were admitted to tertiary care facilities within the last 30 days of life.” The study examined six kinds of aggressive care offered at the end of life: “chemotherapy, radiation, invasive procedures (eg, biopsy, surgery), emergency department visits/hospitalization, intensive care and in-hospital death.” “Overuse of aggressive care at the very end of life for a cancer patient can translate to increased burden on patients and their families. In essence what we’re doing is we’re giving patients side effects without giving them the benefits of the treatment, and that’s really the fundamental problem with aggressive care at the very end of life.” according to Aaron Falchook, a co-author of the study. Ronald C. Chen, an oncologist at UNC Lineberger Comprehensive Cancer Center, explained, “Aggressive medical care for patients with incurable cancers at the end of life is widely recognized to be harmful to patients and their families. Additional efforts are critically needed to improve end-of-life care for patients with terminal disease to ensure that the care provided meets the goals and preferences of patients and their families.” Earlier entry into palliative care might significant lower these numbers and raise the patient’s quality of life. (American Council on Science and Health, 6/08) Read more... (AJMC, 6/07) Read more... (Cure, 6/01) Read more...

* Skilled rehabilitation facilities have shifted from a short-term recovery space after surgery to “a crossroad for patients to transition to long-term, palliative, or hospice care.” Charity Maniates argues in NEJM Journal Watch that this is because of “poor communication between providers and patients and their families during the early stages of illness, when a dialogue should occur about goals of care, especially when a serious or advancing illness is experienced.” This means that care is often reactive, rather than anticipating future symptoms and needs. Having each provider take responsibility for having advance care planning conversations will help alleviate this problem. (NEJM Journal Watch, 6/03) Read more...

**PALLIATIVE CARE NOTES**

* Because the field of palliative care has grown substantially in the last decade, and because patient’s needs are increasingly complex and time-consuming, there is a need to make good decisions about where to direct limited resources. A new article in Journal of Palliative Medicine shares about the work that one hospital “considered in rationing palliative care resources, evaluating the advantages and disadvantages of each for health systems.” The strategies they considered included prioritizing care based on potential clinic impact, offering care based on the most favorable financial impact on the hospital, and a “random strategy” based on “a predetermined formula.” In the end, they chose “a strategy that caps the service when consult volume or census becomes unmanageable.” The authors note that their strategy has weaknesses too. “Widespread palliative care education will take decades to implement. In the meantime, palliative care teams wrestle with the unanswerable question of ‘which patient’ needs palliative care most.” (Journal of Palliative Medicine, 5/31) Read more...
* The new restrictions on prescription opioid pain medications are more likely to affect older adults, since they are prescribed the drugs in higher numbers. Patients and doctors are looking for other options for those suffering with chronic pain. Older patients tend to be more concerned about, and prone to, negative side effects of the drugs. (*The New York Times*, 6/06) [Read more...]

* Zaldy S. Tan writes that physicians should consider how caregivers of dementia patients are faring. “Stress and burnout can lead to detrimental outcomes not only for the caregiver but also for their patient.” Currently, caregivers of dementia patients are more likely to experience depression, early institutionalization, and even death. Doctors, Tan argues, should know how to screen for caregiver stress and suggest appropriate interventions. (*Medscape Multispecialty*, 6/01) [Read more...]

* In 2013, forty million family caregivers in the US provided care worth $470 billion in uncompensated care. Shifting demographics suggest there will be fewer caregivers available to support increasing numbers of older Americans. US Rep. Michelle Lujan Grisham, D-NM, has introduced a measure that would create a national “Care Corps” to create a pool of volunteer caregivers. (*American Academy of Hospice and Palliative Medicine SmartBrief*, 6/8)

* The number of cancer survivors in the United States is hitting record highs and is expected to continue to climb. “Because of the toll cancer takes on patients and their families, it is important to offer emotional, financial and physical support,” said Dr. Stephanie Bernik, chief of surgical oncology at Lenox Hill Hospital in New York City. According to a new report in *CA: A Cancer Journal for Clinicians*, cancer survivor groups can be helpful, but primary care physicians need to support survivors, continue cancer screenings, and encourage healthy habits. (*Health Day*, 6/02) [Read more...]

* A letter to the editor of *Journal of Palliative Medicine* argues that the work of Erik Erikson, a social psychologist, can help guide contemporary palliative care and counter the prevailing “deficit” model of contemporary medicine. Erikson argued for eight life stages, including “old age” in which death is a natural end. The authors of the letter argue that this viewpoint “frees dying from any guilt-ridden link to failure.” Hospice and palliative care can help people continue through this stage and create a feeling of meaning. (*Journal of Palliative Medicine*, 6/01) [Learn more...]
PHYSICIAN-ASSISTED SUICIDE NOTES

* California’s aid-in-dying law has meant that California physicians must grapple with whether they will write a prescription for a patient to use to end their own life. Physicians who support the law, as well as those who oppose it, expect that the option will be used rarely. Despite this, medical associations and hospitals have been holding months of training on the new law and its implications for physicians. Many of those who are choosing not to participate are looking for ways that they can increase social and emotional support for the dying and their families. (Los Angeles Times, 6/06) Read more...

* An article in Los Angeles Times, shares about Dr. Katrina Hedberg, the Oregon state health officer and epidemiologist at the public health division, explaining how physician-assisted suicide has worked in Oregon. She explains some of the requirements of the Oregon law, how many people have taken their lives there, and why people choose that option. She also explains her concerns about proper pain management and support, and highlights the need for efforts to determine if people are trying to “not be a burden.” (Los Angeles Times, 6/08) Read more...

* As California’s PAS law goes into effect, California healthcare professionals must decide if they will participate. Catholic and Adventist hospitals have announced they will not, while Kaiser and Sutter have said that they will give their doctors the option. Timothy Gieseke, a Northern California physician and palliative care specialist, calls the law an “overreaction” to the “bad deaths” that people have seen, which are often the result of lack of access to the best kind of care. Even so, Gieseke acknowledged, “If I were convinced in my own mind that I and my team had exhausted optimal palliative care, I would likely refer someone” to a prescribing doctor. (The Christian Century, 6/07) Read more...

* Ellen Goodman writes in The Salt Lake Tribune of her concerns about the new physician-assisted suicide law in California. She explains that she agrees with the concerns that the end-of-life choices law tries to address, but is afraid that these kinds of options are not addressing the real issues. She explains, “Americans face the health care system with two conflicting fears — the fear that they won’t get enough care and the fear they will get unwanted care.” And her hope is that our society will not “set up a false choice between suffering miserably or hastening death.” (The Salt Lake Tribune, 6/06) Read more...

* On June 9, the day that California’s End of Life Bill went into effect, Berkeley physician Lonny Shavelson opened a health practice that specializes in aid in dying care for terminally ill patients. He hopes that the clinic will help normalize the process and open a conversation with his patients about the best kind of end-of-life care they might receive. Shavelson also plans on encouraging patients to speak with their primary care physician as well, since that is the person most familiar with their medical history. (The Daily Californian, 6/09) Read more...
OTHER NOTES

* In tracking the effect that critical health events have on caregivers, researchers found that caregivers reported high levels of depressive symptoms in the year following an ICU stay for the patient. Published in *The New England Journal of Medicine*, researchers found, “Variables that were significantly associated with worse mental health outcomes in caregivers were younger age, greater effect of patient care on other activities, less social support, less sense of control over life, and less personal growth.” (*The New England Journal of Medicine*, 5/31)

* Many who are chronically ill live on “a thin ledge of independence” which can easily become untenable if the slightest thing changes. David Casarett points out that these often develop into a crisis, and may result in patients being hospitalized. This is expensive and is not currently addressed by end-of-life planning like advance directives. Casarett wants the money that is saved on end-of-life care to be shifted to better at-home care for those who are mostly independent but needs extra supports sometimes. “For someone around my patient’s age,” says Casarett, “the average cost of a hospitalization is about $13,000. So Medicare should have been willing to spend $13,000 to keep her safe and comfortable at home.” (*The New York Times*, 6/09)

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