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How Texas Hospitals Help Patients Craft An End-Of-Life Plan

By Mary Ann Roser

Before former First Lady Barbara Bush died April 17, she planned her last goodbye. She told her doctors and her family she no longer wanted treatment, only comfort care. She died peacefully at home.

"I'm comfortable with her passing because she was comfortable with her passing," Bush's son, former President George W. Bush, said two days later. As providers know, this kind of deliberate and clear planning often is not the experience for patients and families at the end of life.

Increasingly, U.S. hospitals are turning their attention to end-of-life care and collaborating with primary care doctors, nursing homes and home health providers. The goal is to start planning earlier, long before seriously ill patients are dying.

But in American society, patients like Barbara Bush are still an exception. Seven in 10 families don't have open and clear discussions about final wishes, said Kim Callanan, coordinator of the statewide organization Texas MOST/POLST Coalition (Medical Orders for Scope of Treatment and Physician Orders for Life-Sustaining Treatment), which promotes better end-of-life care.

Consequently, people with life-threatening illnesses come to the hospital, leaving staff in the unenviable spot of initiating new discussions on a particularly challenging topic or struggling to ascertain the patient's wishes. If the person has never voiced a preference or if the family disagrees with the patient — or with each other — "that's a nightmare we've all faced," said Robert Greenberg, M.D., chief medical officer of emergency services at Baylor Scott & White Health Central Texas Division. Greenberg, a board member representing the Texas College of Emergency Physicians with Texas MOST/ POLST Coalition works in a place rife with end-of-life challenges: the emergency room. "It's much better to have these discussions when you have the luxury of time," he said, such as when drafting a will or doing financial planning.

Erin Perez, APRN, a board certified adult and geriatric nurse practitioner who specializes in palliative and hospice care at University Health System in San Antonio, has experienced end-of-life difficulties — professionally and personally. When her grandmother went to a Del Rio-area hospital near death in 2010, neither the staff nor her family coped well, she said.

"She suffered tremendously," said Perez who today practices palliative care to ease suffering in patients who are seriously ill or dying. Perez said the experience with her grandmother fueled her transition to palliative care, which focuses on comfort to relieve physical, emotional and spiritual pain. It emphasizes the quality of life the patient wants. It should begin at the onset of a serious illness, long before a patient might die. Hospice includes palliative care but is reserved for dying patients.

A study in The Journal of the American Medical Association reported in 2015 that clinicians said major barriers to end-of-life planning included difficulties patients and families have accepting a poor prognosis and understanding the limits and complications of life-sustaining treatment. Further, a 2016 physician poll spearheaded by The John A. Hartford Foundation found that nearly half of doctors said they felt unsure about what to say to patients and families and less than a third reported having any formal training in such end-of-life discussions

Texas Hospitals' Path to Improving Palliative Care

Perez serves on the Palliative Care Interdisciplinary Advisory Council, authorized by House Bill 1874, 84th Legislature to assess the availability of patient-centered and family-focused palliative care in Texas. The council submitted a report to state lawmakers in November 2016 on improving end-of-life care in Texas, recommending the state create incentives to expand palliative care statewide.

"One of the challenges Texas has is geography," said Elizabeth Kvale, M.D., section chief of palliative care at Dell Medical School in Austin. "We're a fairly large state and a fairly rural state," which impedes access to palliative and hospice care.

Hospitals also face workforce shortages in palliative care, insufficient time for end-of-life discussions and reimbursement models that don't value such talks

Although Texas hospitals must ask patients being admitted whether they have an advance directive, or living will, as well as whether they have someone designated to represent their wishes if incapacitated (a medical power of attorney), the discussion may end with a yes or no. It can be a missed opportunity, Kvale said, if hospitals don't use it to provide more patient education and more staff training

Yet, she said, "We don't prioritize it."

Creating Palliative Care Teams

Fine Robert Fine, M.D., a nationally known end-of-life expert and director of clinical ethics and palliative care for Baylor Scott and White Health, said most people don't understand the importance of end-of-life planning and don't fully understand the potential physical impact of CPR. Fine shared a letter from a woman who described the agony she and her brother endured when their 81-year-old mother was resuscitated from a cardiac arrest. They didn't know a CPR order remained in her chart. Their mother had to "die twice," rather than being let go peacefully, the woman said.

Fine became interested in end-of-life care in medical school in the 1970s. He founded the palliative care program at Baylor University Medical Center in Dallas in the early 2000s and now co-leads it for Baylor Scott & White Health.

"I thought even more about end-of-life care during my first months of practice when I was making routine rounds in a nursing home and came across an elderly patient whose life I had saved as a resident and who told me I should have let him die in the hospital," Fine said. "I also saw a tremendous amount of additional suffering that I had not been exposed to as a resident in the hospital since, as a resident, we never followed patients to the nursing home."

Under Fine's leadership, Baylor Scott & White, which spans 48 hospitals and more than 800 patient-care sites, has trained physicians, nurses, social workers, pharmacists and chaplains on palliative care teams. They pursue conversations with patients and families about what the patients understand about their condition and how much or how little treatment they want. They also train hospital staff beyond the palliative teams to have these talks. The patient's wishes are documented in the chart

"We explore their hopes, their fears and the trade-offs they are willing to make," Fine said. "The goal is to have the conversation well before the patient is actually dying."

The American Hospital Association gave the program its 2014 Circle of Life Award for innovation in palliative and end-of-life care.

Help on the Final Journey

Baylor Scott & White believes providing family support, before and after the patient's death, is crucial.

Jennifer Homsey said that support was invaluable to her and her 4-year-old son, Sammy, when his father was dying. Before they arrived for a visit at Baylor Scott & White Hospital — Fort Worth last November, child-life specialist Magellan Taylor had already talked to Homsey about how to make it less scary for Sammy.

Taylor met them at the hospital that day and has stayed in touch since her exhusband died in February, Homsey said

“We can’t change the situation, but this is one area of their medical journey we can help with,” Taylor said.

“We can make it a little less stressful and a little more peaceful.

At Baylor Scott & White Medical Center – Carrollton, advanced practice nurse Pam Green was the only palliative care professional when the program started, about five years ago. Now, there’s a team.

Three years ago, she visited a patient with congestive heart failure while his wife was there.

“When I went in … she crossed her arms and had such a stern look on her face,” Green recalled.

Green talked about the man’s options, and as the conversations ensued that week, the wife followed Green out of the room. “With tears in her eyes, she hugged me and said, ‘When I met you, I did not want to have anything to say to you,’” Green recalled. “‘Now, because of you, we can face my husband’s end-of-life just like we have faced everything — together.’ “

At The University of Texas M.D. Anderson Cancer Center, oncologists engage cancer patients in such discussions early on, said Larry Driver, M.D., professor of pain medicine and chairman of the Palliative Care Interdisciplinary Advisory Council on which Fine also serves. The palliative care team provides ongoing support to the patient and the family, including bereavement care up to a year after a loved one dies, Driver said.

“I would like for every hospital, whether it’s a major medical center or a small, community hospital, to have someone on the staff, whether it’s an administrator or a social worker, trained to have those discussions,” he said.

Ascension Seton has palliative care teams at most hospitals and believes the work is crucial to its mission, said Dawn Seery, director of ethics integration at Ascension Texas.

In addition, Seton offers a program, No One Dies Alone, in which volunteers “provide a compassionate presence at the bedside, sometimes reading aloud, playing music, or sitting quietly,” said Elizabeth Powell, palliative care chaplain for the Seton Healthcare Family.

Callanan, coordinator of Texas MOST/ POLST Coalition, said the coalition offers forms and other materials to guide hospitals in conversations with patients who may die within a year.

“It’s very clear Barbara Bush had these conversations and talked with her family and was prepared,” Callanan said.

“That’s the important thing: having the conversation.”