

HealthAffairs

A Foundation in Pittsburgh Encourages Frank Talk about End-of-Life Care

December 1st, 2010



by **Nancy Zions**

■

End-of-life care presents emotional, physical, and financial burdens for patients and their loved ones. At the [Jewish Healthcare Foundation \(JHF\)](#), in Pittsburgh, we have become somewhat fixated on the fact that the health care system too often fails families and patients at end of life. Unfortunately, failure is what most people expect. But JHF end-of-life initiatives in the Pittsburgh area are showing that better realities are possible.

Recently, the [Dartmouth Atlas Project](#) released its first-ever report on cancer care at end of life, which showed that one in three Medicare cancer patients spends his or her final days in hospitals and intensive care units (ICUs), an indication that many clinical teams aggressively and often futilely treat patients with curative care close to the times of their deaths. The report suggests that we are underutilizing hospice and palliative care, which receive high marks from families and patients at end of life.

We know from research that there is no correlation between intensity of medical services delivered during end stages and patient and family satisfaction. Almost always, the inverse is true. When patients spend more time in an ICU during their final stages of life, families report more inadequacies in (1) emotional support, (2) shared decision making with their medical team, and (3) information on what to expect, and a greater lack of respect and lower overall satisfaction.

The Pittsburgh community did not fare well in this report. In general, patients are overtreated and undersupported. This was not a surprise. Through a JHF-supported initiative, [Closure](#), we had already heard stories directly from patients and families that brought the Dartmouth numbers to life.

Through Closure, we brought—and continue to bring—together groups of thirty or so community members, including health professionals of all stripes (clergy, professional care providers, insurers, and the group often left out of the conversation—family caregivers). Through a six-part series of facilitated discussions, we address topics such as values, the health care system, legal considerations, grief, and the caregiver journey.

What exactly do we hear from our Closure participants? Many said that death was seen by health care providers as a failure, not an acceptable or expected outcome. Families reported being pressed for decisions in moments of “acute terror.” While providers and policy makers

focus on the interventions and their costs, families experience end-of-life differently—over time and in multiple sites, often beginning before a real diagnosis is made and stretching far beyond the final medical intervention into the grieving process. During this stressful experience, the tendency is that few health care professionals talk to patients and families about their wishes for their end of life and what care they want. Plans are made around the patient and family, not with them; the interventions just keep coming. Options are not presented early or clearly enough to be helpful or meaningful. Even within families, conversations about what path a patient would want to take occur too late, or not at all.

The Closure initiative has been and continues to be an effort that is both very meaningful and worthy of investments of time and money by the JHF and others within the Pittsburgh community. We have identified gaps—in health care providers' practice, training, and understanding, and in state and federal policy on payment and other issues—that impede informed decision making, good care, and appropriate uses of resources. We are focused now on developing resources to support patients, families, and health care providers: online education, advance-planning aids, and strategic partnerships.

But there is still a major hurdle to overcome: silence. No one thinks that anyone is really eager to talk about "it"—that is, about the end of life. In fact, many do want to talk about it, but conversations require at least two willing parties. Whether and how well we are able to address this issue (for example, through establishment of community systems and supports) will determine outcomes for families and will impact our health care systems. It is not an easy conversation to start or to have—personally, professionally, or politically. But avoidance of the issue—the easy but unfortunate status quo—doesn't seem to be working very well for anyone.

To help further conversations about end-of-life issues, the JHF in partnership with our local Public Broadcasting Service (PBS) station, [WQED-TV](#), is producing an original one-hour documentary, "Promoting Community Conversations at End of Life," and, in partnership with [Creative Non-Fiction](#), a literary journal with a national outreach, the JHF is publishing a special edition of short stories. We expect both projects will be completed next year. The goal is to demystify many of the concepts and issues at end of life and allow community members the chance to think about their own preferences and learn about opportunities to have their care and healing needs heard and respected. If we can get the general public talking, will we be ready to help facilitate those conversations and to listen? In Pittsburgh, we are getting ready.