
HealthAffairs GrantWatch Blog

Foundation Convenes Statewide Conference on End-of-Life Care

by Nancy Zionts

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GrantWatch Blog asked the author, a staffer at the Jewish Healthcare Foundation, in Pittsburgh, to report on a conference that the funder and the Coalition for Quality at End of Life convened this spring.

Readmissions Reduction. Health Information Technology. Patient-Centered Medical Home. Cost Effectiveness. Best Practice. Provider Education. Workforce Training. Care Transitions. Public-Private Partnerships. Policy and Advocacy. Consumer and Family Engagement.

Does this sound like the 2012 List of Top Health Care Buzzwords?

You wouldn't expect that they would all be raised or could all be addressed in a single meeting. But all of those issues (and more) were part of the recent statewide meeting of Closure: Changing Expectations for Care at End of Life, a Jewish Healthcare Foundation initiative. The foundation and the Western Pennsylvania-based Coalition for Quality at End of Life convened the meeting, which was held in Harrisburg, Pennsylvania.

Over the course of a day and a half, nearly 100 physicians, nurses, clergy, policy makers, advocates, social service professionals, and consumers came together to engage on, define, discuss, and debate issues around care at end of life. Many of those who came together didn't know each other on Day One, but left on Day Two having reached consensus on issues and having expressed a shared desire to work together to advance a vision and implement practical solutions.

This event was a lesson on two levels: (1) on just how much consensus exists on the issues surrounding end-of-life care in the United States; and (2) the valuable—and dare I say, singular—leadership role that foundations play in convening otherwise disparate players and helping to drive action.

Why did the Jewish Healthcare Foundation and the coalition convene this gathering? For us, the reasons were simple. We took this on because we realized we were in a unique position with the ability to raise difficult issues, had the standing in the region, and funded a diverse portfolio of grants. We could reach across sectors, bring together a broad cast of characters, and challenge them to look beyond their personal, professional, or organizational agendas. As a health funder, we have a diverse portfolio that spans that list of health care topics mentioned above.

And, if you have that singular access and the wherewithal and independence, don't you have the responsibility to exercise it for an issue about which you are passionate, as the Jewish Healthcare Foundation is about end-of-life care?

So, we convened to listen, to share, to learn, and to develop strategy. We didn't have the answers—we didn't even know if others shared our view, or if there was consensus among attendees about the problems. But we had the framework, the questions, and a passion to fix a system that now fails patients, families, and providers.

Our major tasks were to make sure we gathered the right people and had a broad representation of perspectives; to create an environment where sharing was encouraged and supported; and to facilitate development of a network and plan to advance the resulting collective wisdom and vision.

This was not a traditional conference with “talking heads” and PowerPoints. We wanted to raise issues and spur discussion.

Karen Wolk Feinstein, the foundation's president and chief executive officer, pointed out in her opening remarks that a recent Modern Healthcare Big Impact Tournament (in which the magazine asked readers to vote online “for the person, event, organization, or innovation that they thought had the biggest impact on healthcare over the past three decades”) listed “hospice” as the single greatest advancement in health care in the past thirty-five years. Hospice. That low-tech, oft-feared service, was actually less feared and more revered than such advances as health information technology, robotic surgery, or telemedicine.

Linda Emanuel, the Beuhler Professor of Geriatric Medicine and director of the Beuhler Center on Aging, Health, and Society at Northwestern University's Feinberg School of Medicine, as well as the founder of the nationally and internationally renowned Education on Palliative and End of Life Care Program (EPEC), set the stage. She challenged all of us to consider our cultural roadblocks to talking about and improving the experience of death and dying in this country. She even had us question our existential maturity (think about that one!). Why can't we discuss and consider death in our lives and institutions? How can we balance health care with dignity?

For the next twenty-four hours, we followed a model of group engagement around end of life, originated by the Jewish Healthcare Foundation, called Closure Conversations, in which the responsibility for content and direction was up to all of us. Lead discussants framed issues, and then everyone—I mean everyone—participated in conversations about legal and policy issues; the roles of ethics, values, culture, and religion; health care practice issues; the role of family and caregivers; and much more. We uncovered issues that are, not surprisingly, based in culture, policy, and practice.

Usually, people sneak out of conferences before the last session or before the closing comments. Not so for this one! People stayed afterward to continue conversing with their new-found partners and have continued to keep in touch as we and they look for ways to advance a new vision for care at end of life.

We learned that we share common truths and experiences:

* The field has come a long way in a relatively short time. Hospice, palliative care, advanced directives—they are all relatively new. However, physician, nurse, and clergy education all include those issues now. That's a start.

* Laying out wishes and scenarios is critical—but not in and of itself sufficient. There is a great need to encourage, allow, facilitate, and then implement what comes out of end-of-life conversations—among providers, families, clergy, and policy makers who are in each of our communities.

* Our health care system's default option of "curing people till they die" isn't meeting their needs. Systems that reimburse procedures, that fail to ask about goals, that miss opportunities to plan before a crisis hits—are suboptimal. People don't just lose the battle with their disease; they often lose themselves in their battle within the system.

The conclusion reached during these two days of the conference is that the health care system is still broken in many ways, and this results in predictable failure for patients, families, and providers. While that might sound pessimistic, we left with a call to action: if the breaks in the system are predictable, shouldn't we be able to focus on the system fixes? And, shouldn't we be able to work on them together across organizational and professional lines and throughout our communities? The answers heard in Harrisburg on April 4 were yeses.