Health Literacy and Palliative Care: What Really Happens to Patients

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The authors gave a presentation at an Institute of Medicine Roundtable on Health Literacy workshop titled “Health Literacy and Palliative Care” in July 2015. The presentations highlighted the experience of the health care system for those who need palliative care and the difficulty in accessing it. The authors believe the take-home message from the day was that the health literacy problem in our health system resides within the health care system. The system’s inability to find out, understand, and respond to what matters most to patients and their families is exemplified in Bev’s moving and infuriating story of her husband’s experience after a diagnosis of pancreatic cancer in upstate New York. Joe Alves’s diagnosis of inoperable metastatic cancer brought the couple into a world with which they were not familiar and had little time or energy to learn to navigate. The saddest thing about Bev and Joe’s story, as told the shaded boxes below, is how typical it is. This commentary is offered to point to the system changes that are necessary.

“We were left on our own…”

When the gastroenterologist called to give us the results of the biopsy, he said, “The results of the biopsy are not good: you need an oncologist.” Then he hung up! He never referred us to an oncologist or gave Joe meds for his intense pain. He just hung up! We were left on our own to get Joe the care he needed.

Palliative care offers a comprehensive approach to medical care for people with serious illnesses. It can include end-of-life care but can also be delivered along with curative treatments at any age, diagnosis, or stage in a serious illness. An interdisciplinary care team works with patients, families, and other health care professionals to provide support to the patient and his or her family. Palliative care is not something provided only when no other alternative exists. This approach to care guides treatment throughout a serious illness. Health systems and providers should screen patients for entry into palliative care on the basis of functional limitations, frailty, dementia, and family and caregiver needs. Prognosis is not the only gateway into palliative care.

“His pain was monumental…”

Joe was in pain. Before he was admitted to the hospital, because we didn't have an oncologist, our family doctor was writing emergency prescriptions, which had to be refilled every 48 hours. I watched my husband counting out pills to see if he would have enough to last for 48 hours, knowing he needed a higher dose. It was a true nightmare!

Joe was stoic, but his pain was monumental, frequently hovering around 8 or 9, even being “off the charts.” He also had a lot of anxiety. While in the hospital, a nurse told us she had made repeated requests to the pharmacy for his meds, through e-mail and voice mail. She
said, “There is no one to speak with directly in the pharmacy, even if it’s an emergency.”

It may be difficult to believe, but doctors receive essentially no training in pain and symptom management in medical school and residency training. Many physicians are taught to see someone in pain as a manipulative drug seeker. This causes so much completely unnecessary suffering. Appropriate symptom and pain management are essential to providing high-quality care for patients with serious illnesses.

“All wanted to do was go home.”

As Joe’s illness progressed, he was admitted to the hospital with complications. The hospital lost his written Do Not Resuscitate (DNR) order and did not write down his oral DNR either. As Joe’s illness progressed, all he wanted to do was go home. I told Joe’s oncologist this, but no one from the hospital helped me make any plans. No one! Instead, this doctor told me to “put him in a nursing home.” I felt like he was just tossing Joe away.

Again, the public may find this unbelievable, but doctors and nurses also get no training in finding out what’s most important to patients and their families and talking with them realistically and compassionately about prognosis, what to expect in the future, treatment options and their benefits and drawbacks, and how we—the medical profession—will stand by them no matter what. Doctors practice as we are trained. If the training isn’t changed, Bev and Joe’s experience will continue to happen.

“Family members are in crisis too…”

Watching your loved one die is a terrifying and agonizing experience. When a patient is dying, family members are in crisis too and also need support. I was alone.

A colleague used to boast that he rounded on his patients most efficiently at 5 a.m. because there were no family members at the bedside. It is the author’s strong belief that this attitude, that somehow families are an unavoidable hassle, is detrimental to providing high-quality care. Without families or other caregivers, negotiating a serious illness
is next to impossible. Providers need to see the patient and the family as the unit of care and teach, measure, and provide incentives for doing so. For example, electronic health records could include a routine assessment of family caregiver burden and support needs, information that is prerequisite to addressing them.

“Be a partner with your patients…”

Be a partner with your patients in their care, because even if you cannot cure your patients, it will make all the difference in the time they have left. Then you will truly be healers.

As the authors of this commentary, we believe that effective palliative care can lead to better outcomes and quality of life for patients and a better value for the money spent on medical care and that the obligation to be literate in what matters most to patients and their families belongs to the health care system. The Institute of Medicine has recommended that palliative care become the standard of care for people with serious complex illnesses (IOM, 2015). To accomplish this goal, the health care system needs to expand palliative care practices to include home and community settings, as well as hospitals, and health care providers would need to be trained in the core practices and principles of palliative care. Routinely offering high-quality palliative care to patients with serious illnesses would represent a major shift in the way the system delivers medical care, but we believe it is the single greatest opportunity to improve value in health care in the United States.

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References


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