

James L. Holly, M.D.

The Conversation Project

By James L. Holly, MD

Your Life Your Health

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For patients, traditionally, healthcare has been a spectator sport. Almost like a passive bystander, patients were told what, when, where and how to receive “healthcare.” That system worked fairly well when there was little which could be done for illness; but, in the 21st century when many things can be done, new questions arise such as:

1. Even when something can be done, should it be done?
2. When there are several different things which can be done, which one does the patient want done?

Maureen Bisognano, CEO of the Institute for Healthcare Improvement (IHI) and a recognized international expert on improving healthcare systems, has taught us to ask a much more profound question and that is, “What do you want?” The elimination of the word “done,” changes the healthcare conversation from one of procedures, tests, services, etc., to one of outcomes, goals and desires. It changes the conversation from science to humanity

One of Maureen’s most significant contributions to healthcare improvement – The Conversation Project -- resulted from her personal experience. The Project; is IHI’s program to make certain that healthcare providers, healthcare recipients and the healthcare system know how to talk about end-of-life issues. The key is to ask the question, “What do you want?”

Maureen’s personal and poignant story was about her brother who died when he was 21 and Maureen was 23. She shared their story:

“When my brother Johnny was 17 years old, he was diagnosed with Hodgkin’s disease. It progressed quickly, and he was in and out of hospitals regularly over the next several years. When Johnny was 20, he came to my apartment////and told me, ‘I’m not gonna make it.’ He was ready to face death, but I wasn’t. I didn’t know what to say or do. All I could think of was to offer encouragement and try to give him hope. But Johnny stopped me and asked me, ‘Can I tell you what I want?’ ‘What do you want? I asked him. ‘I want to turn 21,’ he said.

“Johnny did turn 21 and died just a few days after that birthday. Throughout that last year of his life, I still didn’t grasp the power of that simple question that Johnny was asking me to ask: “‘What do you want?’” Looking back, I wonder what might have come from asking that question. I wonder about the people Johnny would’ve wanted to meet and see. I wonder about the conversations they might have had. And I wonder about the functionality he could have had, to the extent he could, out of the hospital. But instead of Johnny realizing his wishes for his last year, he spent it mostly in the hospital. I finally learned the power of the question from a radiation oncologist. While Johnny was in the hospital during that last year of his life, doctors would come and go from his room. They’d speak over him, and about him, but almost never to him. Finally, this radiation oncologist went into my brother’s room and asked him, ‘Johnny — what do you want?’ ‘I want to go home,’ Johnny answered.

“The doctor then took off my jacket, put it on Johnny, picked him up from his hospital bed, and carried him to my car. Johnny came home, and spent his final days surrounded by the friends and family that loved him. That one interaction between Johnny and the radiation oncologist taught me not to rely on just providing encouragement and hope. These things are important, but more important, almost always, is having the conversation with a loved one about what they want. Find out what they want, then act on it, and carry it through. Trust me, you’ll be forever grateful you asked, ‘What do you want?’” I wept as I read this story for the first time.

Patient-Centered Medical Home (PC-MH)

As Southeast Texas Medical Associates has spent the last five years becoming a PC-MH, we have developed technologies to do “things” and to perform “actions” and to fulfill “metrics,” but we have only recently begun to understand the power of “patient centric conversations,” “patient activation,” patient engagement,” and “shared decision making.” We have begun to understand that each of these categories is more than a once-and-for-all act. They are a dynamic which are more accurately addressed in the continuing tense of the verb. We have begun to understand that patient-centric requires continuous re-engagement more than just engagement, continuous re-activation more than just activation, and patient-centric conversions are not a single conversation but is an on-going dialogue which takes place at many venues, at many times and with many different contents. We have begun to understand that patient-centric is more completely defined by the profound question, “What do you want?” than it is by the powerful electronic capabilities we have created.

IHI’s ‘the Conversation Project’

SETMA’s end-of-life conversation, which we perform with every patient and which we document as part of the structure of our medical home, is always begun by “What do you want us to do?” What we should be asking is, “What do you want?” My life stories reinforce what Maureen has taught us.

As a sophomore in high school, I learned a lesson which has enabled me to carry out the most difficult personal and professional tasks. One day, my friend’s father died suddenly. That evening, I went his home. I remember feeling very awkward. I knew that I should be there, but at fifteen, I didn’t have the foggiest idea what to do, or what to say.

Only one other friend came. We made small talk and tried to forget the great loss. At one point, we were talking about our families. I said, “If my father ever did that, I’d kill him.” If spoken words have a life beyond the hearing and memory of those present, these words seemed to have; eternal life. They hung in the air like a Damocles sword waiting to fall on my head. If I did not know what to say, I surely knew what not to say and I had just said it. Kindly, my friend glossed over my blunder. The evening ended with goodbyes and expressions of sorrow.

The next day, after his father’s memorial service, my friend was sitting in the family car. I walked over and said, “Louis, I don’t know what to say.” Wiser than I at fifteen, he said, “You don’t have to say anything, you were there.” To that point in my life, I had never heard kinder words. They echoed in my mind louder than what I had blurted out the night before. I turned them over and over in my mind, again and again. My friend and I never spoke about this, but fifty-five years later, I have never forgotten those words.

Twenty years ago, I had a 24-year-old patient who declared that she had a dread disease but no diagnosis could be made. A year later, during a pregnancy, we found the malignancy which was incurable. She was from the Pacific Northwest and returned there. Three months later, she called me and said, “Can I come home?” As she was with her parents, I thought she was. She added, “No one will talk to me; they pretend that everything is OK,” They had the same problem I had when I was fifteen. She concluded, “I want to come home so that I can talk about what is happening to me.”

She returned to Southeast Texas and for the next six months, we visited and talked often. We prayed and planned for her son’s life. My wife and family were involved with her. Never once did we talk about medicine, surgery, pills or treatment. She did not want that; she wanted to come home. She wanted to talk about the future and her life, not her death. We never talked about healthcare; we talked about what she wanted.

Provider Training

Tuesday, October 15th, SETMA’s office will be closed for our monthly, half-day, provider training. We will talk about technology and evidenced-based medicine. We will continue to pursue our goal of fulfilling the Triple Aim, another creation of IHI. But, we will mainly learn about “the conversation project.” We will go through IHI’s “Your Conversation Starter Kit,” and “How to Talk to Your Doctor.” We will learn how to ask the profound and simple question, ‘What do you want?’

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The following is Ms. Bisognano’s response to SETMA’s work (this is posted with her permission):

Larry,

Can I tell you that you are my hero? You are such an amazing visionary, an articulate spokesperson for change, and an advocate for patients and families. I am honored that you would share my brother’s story. It’s in my heart (one of many) and I so appreciate you sharing it. But everything you write moves me. Thanks for being you, the whole country benefits from your leadership. Hope to have coffee with you some day! Warm thanks for all, Maureen

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