




2014

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Cindy Brach

Center for Delivery, Organization, and Markets, Agency for Healthcare Research and Quality, Cindy.Brach@ahrq.hhs.gov

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Recommended Citation

Brach, Cindy (2014) "A daughter's frustration with the dearth of patient- and family-centered care," *Patient Experience Journal*: Vol. 1: Iss. 1, Article 7.

Available at: <http://pxjournal.org/journal/vol1/iss1/7>

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A daughter's frustration with the dearth of patient- and family-centered care

Cindy Brach, *Center for Delivery, Organization, and Markets, Agency for Healthcare Research and Quality*

Abstract

Patient involvement in decision-making is an increasingly recognized ethical imperative, one that requires attention to health literacy. Health care that is truly patient- and family-centered, however, is the exception rather than the rule. This first person account of a hospitalization describes the lack of patient and family inclusion in decision-making, failure to use plain language and other health literacy strategies, and disregard for patient and family preferences. The author concludes that if the health care system is going to shift from paternalistic to patient- and family-centered, providers must be trained how to communicate and partner with patients and families. Even the most skilled health professionals, however, will not be able to deliver patient- and family-centered care if the system they work in is not designed to foster or support such care. Committed hospitals will integrate patient- and family-centered care throughout their organizations. This includes their mission statements, quality improvement activities, personnel policies, decision and self-management support, and patient portals. Payment policies can encourage, but are a blunt instrument to drive, health care toward patient and family-centered care. The author references resources to help hospitals make systematic changes to hard wire health literate and patient- and family-centered care.

Keywords

Health literacy, hospital quality, organization and delivery of care, patient- and family-centered care, patient engagement, patient preferences, plain language, quality improvement, shared decision-making

Note

I have worked for the Agency for Healthcare Research and Quality (AHRQ) for 17 years. There I am a member of a small team that focuses on the health care systems, quality improvement, and implementation. I have led the development of a hospital training module to promote teamwork and commissioned and co-authored a toolkit to re-engineer the discharge process. But I was totally unprepared for my first family health crisis.

It did not start out as a crisis. Shortly after my mother's hip replacement surgery, my sister emailed me from the hospital recovery room to say, "She looks fantastic, and was making lively, cogent conversation." By the next day my mother's status changed; she had become somewhat confused. The doctors assured us that this happens all the time, and perhaps it was due to the pain medicine. They took my mother off narcotics and expected her to rebound. She did not – she got worse. Two days after the surgery an MRI revealed that my mother had experienced small strokes throughout her brain.

I am the lead for health literacy at AHRQ. I develop tools to help health care organizations make it easier for people to navigate, understand, and use information and services to take care of their health. But, as demonstrated by my mother's experiences, I still have my work cut out for me. We're nowhere near the vision proffered by the *National Action Plan to Improve Health Literacy** of a society that provides everyone with access to accurate and actionable health information and delivers person-centered health information and services.

* U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. (2010). National Action Plan to Improve Health Literacy. Washington, DC.

Navigation Challenges

My mother needed to be transferred to a hospital with neurology inpatient beds, which her surgical hospital did not have. I started searching for a top neurologist at a high performing stroke center. Public reporting sites were not helpful – one erroneously indicated my mother's surgical

hospital had a neurology department, and went on to rate it highly! I switched gears and started networking on the phone with friends and zeroed in on a recommended neurologist. I gave the green light to have her transferred to his hospital.

Once in the new hospital, our preference for the neurologist who had been recommended was trumped by hospital protocol. I had not understood that the attending physician on duty that week would be my mother's doctor, even if we wanted her to get care from another physician with privileges there. How naïve I was!

Exclusion from Decision-making

It was after midnight when my mother was settled in the neurology department at the new hospital – after waiting over eight hours for “the bed to be cleaned.” I spent the rest of the night curled on my down coat on the floor next to my mother's bed. At 2:30 in the morning the nurse came in and announced that “the team” had decided to remove a urinary catheter that had been inserted while at the surgical hospital after the strokes. Clearly “the team” did not include my mother and me.

I informed the nurse that the catheter was not going to be removed then, and we could discuss it in the morning. My mother was in no position to ask for a bed pan, had been (according to my sister) very distressed in other hospital when she started peeing on herself, and did not want to wear a diaper. The nurse replied that it was against hospital policy to leave in a catheter that had been imported from another facility. There was no way I was going to have them take out one catheter out just to put another one in. So I told her I didn't care what the hospital policy was, that they could not do any procedure on my mother without our consent and we did not consent to her catheter being removed in the middle of the night.

I understand that there is a great deal of inappropriate catheter use. I also understand that infections as a result of catheters count against a hospital's quality metrics. Hospitals should have policies to guard against inappropriate catheter use, but the point is – it's my mother's or her health proxy's decision. In the morning we could have had a conversation with the clinicians about the risks of leaving the catheter in and what the options were and jointly come to a decision. What in fact happened was that although I asked about the risk of infection that next morning, “the team” was no longer interested in removing my mother's catheter. It remained for three additional days, and my mother wound up with a urinary tract infection.

Paucity of Plain Language

I have no head for medical terms, drug names, or diagnostic jargon. When my mom's orthopedic surgeon came to visit her, he explained how he was sure her strokes were from a fat emboli shower. As he described how the fat could pass from the venous side of her body where the surgery was done to the arterial side, I could not follow him. I asked him to use simple terms. When got I

confused again, I pleaded with him to use plain English. He misunderstood. “Oh, you don't understand English?” he asked, more sympathetic to my confusion. “No, I speak English; I don't speak medicalese.” But he could not convert medical terminology to language a layperson would understand.

When he started talking about an insult to the lung I could not contain my frustration. “What do you mean an insult to the lungs? Did someone say, ‘Hey lungs, you're ugly!’?” “Insult is a perfectly good English word,” he retorted. Although insult is a perfectly good English word, he was not using it as I do in everyday language. He meant injury. But between being stressed out and having been awake for 30 hours, I just could not work out what he meant. In presentations I often say, “Health literacy is a state, not a trait,” explaining that our capability to understand and use health information can deteriorate when we are sick, tired, or frightened. I certainly experienced this in spades.

A young cardiology fellow turned out to be the only doctor in the hospital who spoke to us in plain language. The cardiologists had been brought in to check heart monitoring data because my mother was experiencing sudden spikes in her heart rate. But they did not come into my mother's room to explain their findings. I had not known they had done their analysis until I tracked down a neurology resident to ask when the cardiologists were coming. The resident explained that the cardiologists had already visited, and there was no problem with my mother's heart. I said it was unacceptable to hear this secondhand and the cardiologist had to talk to my mother and me. “Well, I doubt if I can get the attending cardiologist to come down,” she said, “but maybe the cardiology fellow can come.”

At the end of the day the cardiology fellow came. He used the phrase “irregular heartbeat” instead of “a- fib.” In a way we could understand, he explained how he could tell that the 120 instances of spikes in my mother's heart rate were not the sign of an irregular heartbeat. He even asked, “What questions do you have?” and took the time to answer our questions. I learned later he had balked at coming to talk to us because he was so busy, but I forgave him since he did such a good job when he finally came. With the rest of the medical team I spent the week initiating “teach-backs,” telling clinicians what I thought they were saying and so they could correct me if I had it wrong.

Patient and Family Preferences Discounted

The hospital discharge orders and post-discharge treatment provide an example of how my family's preferences were not taken into account. A week after my mother's surgery, after a battery of tests and a cardiology consult, the attending neurologist concluded that a fat

emboli shower was the most likely cause of my mother's strokes and agreed with the cardiology team that no further cardiology follow-up was needed. The next morning, while we were waiting for a bed to free up at the rehabilitation facility, a new attending neurologist appeared on the scene. She did not agree with her predecessor or the cardiology team. Although an irregular heartbeat had not been detected in the five days my mother had been monitored in the hospital, the new doctor thought my mother could have an intermittent irregular heartbeat that just had not been detected. She wanted my mother to take a full therapeutic dose of warfarin (a blood thinner) until a 3-4 week heart monitoring study and an MRI of her heart could be done after discharge from the rehabilitation facility. The doctor wanted to treat my mother as if she had heart problems until further tests removed any shadow of a doubt.

My mother was fine taking the small dose of warfarin that the orthopedic surgeon had ordered to prevent blood clots, but she, my sister, and I were all wary of the risks of increasing it. We had received two conflicting recommendations regarding the course of treatment following discharge, with no attempt to reconcile them. Both doctors should have clearly explained the options and their benefits and risks, elicited our preferences, and worked with us to reach a decision. Instead, we were left with making sense of these contradictory opinions on our own. We decided to hold off on the warfarin pending consultation with professionals we trusted. The second neurologist, however, included instructions for a therapeutic dose of warfarin in my mother's discharge plan despite our wishes to the contrary.

Upon arrival at the rehabilitation facility we flagged that we did not want the additional warfarin administered. That message did not get into the medication orders. Two days later we discovered that my mother was receiving a therapeutic dose of warfarin and was fully anti-coagulated.

Once my mother was on a therapeutic dose of warfarin, it was difficult to get her off. The doctor at the rehabilitation facility was resistant to taking her off medicine that another physician had prescribed. The doctor pressured my mother to stay on the warfarin. My mother could have refused to take the medicine. But she worried about angering the doctor, of getting kicked out of the facility, and thought there was no point in fighting against the inevitable. She did not want to be on warfarin, but felt overwhelmed with information and not strong enough to go up against the doctor despite having the support of both her daughters.

Similarly, the cardiologist whom my mother saw after leaving the rehab facility was reluctant to take my mother off the warfarin. My mother told him that her father had almost died of poorly managed warfarin and she had

concerns. The doctor, however, had a narrow interpretation of "do no harm." He only considered potential harm from his actions, not his inaction. Since my mother was already on the medicine, he wanted to leave her on it since taking her off could result in a stroke. This doctor was a good communicator. He spent lots of time with us going over all her test results and describing additional tests he wanted her to do. But he did not take into account her preferences about being on warfarin.

At the next visit I pressed the cardiologist on risks and benefits. He told us there was a 3 to 4 percent reduction in the risk of a stroke when on warfarin, compared to an under 1 percent chance of a cerebral hemorrhage from taking warfarin. But I pointed out that the risk reduction is *only if you have an irregular heartbeat*. If you don't have an irregular heartbeat (and at that point in time he put the likelihood that her stroke was due to a fat emboli shower at 80 percent or higher) then the benefit of warfarin was zero. Furthermore, he discounted risks of other adverse reactions to the medicine because he did not consider them irreparable. Those potential adverse reactions, however, were not inconsequential to my mother. He conceded that if my mother had come to him as a patient with her history, he would not have put her on warfarin. But now that she was on it, he was disinclined to take her off. When my mother heard that, and that he would not be upset with her if she decided to go off it, she made the decision to discontinue the warfarin. It took three physicians and four weeks for my mother's preferences to be honored.

Prognosis and Prescription for Patient- and Family-Centered Care

I am happy to say that my mother recovered fully from her strokes. I, on the other hand, am still recuperating. I am disheartened at how little progress we have made in making patient- and family-centered health care a reality.

On one hand, patient involvement in decision-making is an increasingly recognized ethical imperative, one that requires attention to health literacy. For example, a 2010 AMA publication¹, based on the American Medical Association's (AMA) *Code of Medical Ethics*, recognizes the following as physician responsibilities:

- Educating patients about their health situation and *treatment options*.
- Answering patients' health questions and *check that the answers have been understood*.
- Answering patients' questions about their health care choices and document *their decisions*. (Emphasis added.)

On the other hand, health care that is truly patient- and family- centered is the exception rather than the rule. If we

are to make any progress, education and training programs have to teach health professionals how to communicate effectively and partner with patients. Schools do not choose students because they are good communicators. Those who happen to have talent may lose it by virtue of learning and being expected to use thousands of specialized medical terms. They often train in settings that do not serve as models of patient- and family-centered care. While national medical licensing exams now include evaluations of interactions with simulated patients, the commitment to clear communication, honoring patient preferences, and equipping patients to make decisions has not become central in medical education. For example, medical schools spend an average of three hours on health literacy training² and no medical boards require health literacy training to maintain board certification.

In-service training is needed to re-orient clinicians already in practice. The paternalistic practice of medicine has been the predominant model. With the best of intentions, many physicians believe that they know what is best for their patients, and that patients are not able to understand the complexities of medical care. Application of health literacy strategies³ to clearly communicate and confirm understanding can help rectify the imbalance of power stemming from a knowledge differential. Equally important is for physicians to accept that **all** treatment decisions are preference sensitive and that decisions should not be made by physicians on their own.

Even the most skilled health professionals will not be able to deliver patient- and family-centered care if the system they work in is not designed to foster or support such care. Almost all of the health professionals we encountered were well-intentioned, competent people. But they worked in an environment where they were not given the time to engage patients and families as care partners. Systems have to be structured to make patient- and family-centered care hard-wired.

Most hospitals that strive to deliver patient- and family-centered care do so because they are mission-driven or have inspired leaders. They have moved beyond lip service by incorporating a patient and family orientation into job descriptions, performance evaluation, and rewards. These hospitals supply proof of concept that patient- and family-centered care can become a reality.

For organizations that have not yet seen the benefit of partnering with patients, there are now several policies encouraging hospitals to become more patient- and family-centered. One is the policy of the Centers of Medicare and Medicaid Services (CMS) that makes some of hospitals' reimbursement contingent on scores on surveys of patient experiences of care.⁴ Another is CMS' Hospital Readmission Reduction Program, whose penalties for excess readmissions are driving some hospitals to pay

more attention to patient education and discharge preparation.

Basing health care payment on quality metrics, however, is a blunt instrument to drive health care toward patient- and family-centered care. And hospitals can only respond to inducements if they have the know-how to achieve the incentivized results. Hospitals need to engage patients and families in the quality improvement process, to identify both the opportunities for improvement and form a vision of what constitutes patient- and family-centered care. They need to recognize that being health literate is a prerequisite to being patient-centered. Health literate organizations make it easier for people to navigate, understand, and use information and services to take care of their health. This requires top to bottom changes, such as integrating health literacy in their mission, quality improvement activities, decision and self-management support, and patient portals.^{5,6} Training curricula, guides, and toolkits that have been produced to help them with such integration.^{3,7-9}

Hospitals serious about pursuing patient- and family-centeredness will team up with patients and families to chart a course together. They will use tools developed to help hospitals partner with patients and families.¹⁰⁻¹³ And they will evaluate their progress on a regular basis to inform their continued quality improvement efforts.

On a more personal level, my thoughts about what patient- and family-centered care means have crystallized. I want care from a facility that welcomes patients and their families to be partners in the health care venture, that makes time to educate and engage us, and that respects our preferences. Isn't that what most people want from the health care system?

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Table 1. Supporting Resources & Toolkits

The [Guide to Patient and Family Engagement in Hospital Quality and Safety](#) focuses on four strategies for promoting patient/family engagement in hospital safety and quality of care.

The [HCAHPS \(Hospital Consumer Assessment of Healthcare Providers and Systems\) Survey](#) measures patients' perspectives of hospital care. The [HCAHPS Items Set for Addressing Health Literacy](#) focuses on how well hospitals communicate information to patients and prepares them for discharge.

The [Health Literacy Universal Precautions Toolkit](#) describes 20 discrete tools to implement health literacy strategies.

The [Health Literacy Program Improvement Module](#), which involves implementing a health literacy quality improvement project, satisfies Part 4 of the American Board of Pediatrics maintenance of certification requirements.

The [National Action Plan to Improve Health Literacy](#) consists of seven health literacy improvement goals and suggests strategies for achieving them.

The [Re-Engineered Discharge \(RED\) Toolkit](#) provides implementation guidance to hospitals interested in using health literacy strategies to prepare patients better for discharge and reduce avoidable re-hospitalizations.

[Strategies for Leadership: Patient-and Family-Centered Care](#) includes a Hospital Self Assessment Tool and other resources to help hospitals become more patient- and family-focused in their care practices.

[Strategies to improve communication between pharmacy staff and patients: training program for pharmacy staff](#) is a training program designed to introduce pharmacists to strategies for communicating with patients who may have limited health literacy.

[Training Modules in Decision Support as a Clinical Skill](#) contain background reading and slide sets for self-teaching or training workshops on implementing patient decision support.

["What Did the Doctor Say?:"Improving Health Literacy to Protect Patient Safety](#) details solutions for making effective communications a priority in protecting the safety of patients; addressing patient communications needs across the spectrum of care; and pursuing public policy changes that promote better communications between health care practitioners and patients.