A conversation with Helen Haskell

Clinical Café is pleased to announce the latest in a series of conversations with newsmakers in the field of patient safety and quality. We spoke recently with patient safety advocate Helen Haskell, founder of *Mothers Against Medical Error* (MAME).

Nearly 10 years ago, after what was supposed to be routine surgery, Helen's healthy 15-year-old son *Lewis* died in a South Carolina hospital from medical errors. In 2005, MAME worked with South Carolina hospitals to pass the Lewis Blackman Hospital Patient Safety Act, a state law mandating, among other things, that hospital personnel wear badges indicating their jobs and status and that hospitals give patients a means of contacting their attending physicians.

Haskell's other areas of focus have included limiting work hours for physicians in training, expanding family directed rapid response teams, and establishing in-hospital patient support systems. Haskell, a Columbia, S.C. resident, was named in 2009 to Modern Healthcare magazine's 100 Most Powerful People in Healthcare. MAME has teamed with patient advocate Julia Hallisy and with *Consumers Union* on several initiatives. Hallisy and Haskell established the *Empowered Patient Coalition* last fall. The Coalition and Consumers Union partnered to create a patient-driven *adverse event database*.

Haskell with a picture of her son, Lewis.

Edited excerpts of our conversation:

Clinical Café: Talk about the new initiative you've launched with Consumers Union. What are your goals with the error reporting survey?

Haskell: I recently joined forces with Julia Hallisy--she has written a book called The Empowered Patient and we have co-authored a guide to hospital care for patients and families that we consider our organization's most important work. Julia and I have always had the idea that patient reporting of errors was a critical component of the patient safety movement. We don't pretend to be scientific in the data collection. The idea was simply to give patients a place where they could report and see that their report was counted, because most of the places you can report, like The Joint Commission and Medicare, you really don't see results. In this context, we can't address the individual incidents, but at least we can have them recorded and documented from the patient perspective. We will post the de-identified data online for anyone to use.

Clinical Café: It feels like you and others involved in this database project launched it out of a frustration that patient complaints aren't being heard and understood, let alone acted upon.

Haskell: That's certainly true. It is born out of frustration. The problem is that generally, when incidents are reported, even by providers, they tend to focus more on the system mechanics of the error, as opposed to what patients want to know, which is what was the error, what was the procedure, what was the response of the hospitals, what they need to know to keep it from happening to them.

Clinical Café: Talk about your involvement in promoting rapid response teams, or RRTs.

Haskell: One of the major components of the Lewis Blackman Act was patient-activated rapid response, and it's been legislated in Massachusetts recently as well. The fear that providers initially had was that patients would abuse this privilege, and I think that's a good example of how patients' and providers' perspectives can differ. The fact is that patients don't overcall rapid response systems—they under-call. The problem is getting them to use it. It takes a lot of effort to get patients and families comfortable with the idea of stepping outside the hierarchy to call a program like Condition H or Family Alert.

Clinical Café: Do you see a trend toward more adoption of patient-activated rapid response?

Haskell: I think there has to be, because in some situations it is really the only recourse that patients have. One of the interesting findings from existing patient-activated rapid response programs is that most of the calls don't seem to be for life-or-death situations. They're for things like pain management, medical management, premature discharge–serious problems that patients have, and they have no one else to call. The lesson I take from this is that you've got to have a hotline for patients to call, even if the calls aren't always going to be emergencies.

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>
> **-- Helen Haskell**

Clinical Café: It seems so many medical errors take place despite heroic efforts of loved ones to intercede, and afterward the families talk about the system overwhelming them. What's your advice to patients to safeguard themselves?

Haskell: The first line of defense is to have an advocate, and to be educated and aware. What we have tried to do in our patient education materials is to demystify the system, so that people know who does what, and what can go wrong, and whom to call. That really is what happened to my son. We were trapped in the hospital over the weekend, and we didn't know how to get past the bedside nurse to call for help. My son died because of that. So, we believe it's critical for people to understand not only the system but also some of the basic things that can go wrong, like shock and sepsis. Most patients are just intimidated. You don't know who is making the decisions, so you just let them do it.

Clinical Café: You must have talked to hundreds if not thousands of providers. What is lacking in terms of providers who aren't listening to concerns of patients and their loved ones?

Haskell: Fundamentally, at the root of most medical errors, there are two problems: one is arrogance and the other is time. You have people who really believe that they know more about the patient than the patient knows about himself, and at the same time, you have providers who are just so rushed, and they've got too many patients. I think providers need to learn not to be threatened by patients who ask questions, not to feel they need to be able to know everything, and maybe we need a revolution among healthcare providers who will say, "We need more time."

Clinical Café: It's well-documented in analyses of medical errors that a major contributing factor was a perceived lack of time or too great a workload.

Haskell: Paying personal attention to patients is no longer the priority of the healthcare system. And it needs to be, however you accomplish it.

Clinical Café: It's been 10 years since your son Lewis died as a result of a medical error, and five years since the Lewis Blackman Hospital Patient Safety Act became law in South Carolina. What have been the biggest accomplishments and frustrations for your organization?

Haskell: I think the biggest satisfaction we have had has been in the growth of the patient safety movement. When I began this work, secrecy prevailed. There was fear and denial among caregivers and a general lack of awareness among the public. Our philosophy has been that transparency is key to quality improvement, because both patients and providers have got to have the information they need to make informed decisions. We've worked with Consumers Union and many other advocates trying to promote openness and measurement and collaboration with healthcare providers. Over time we have seen the prevailing ethos of the much of the healthcare industry go from denial to pre-emptive action on patient safety and particularly on infection and in areas like disclosure of harm. We are certainly not there yet, but the walls are starting to come down.

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Clinical Café: What are your goals for MAME, the Empowered Patient Coalition and other initiatives?

Haskell: We're working hard on more educational materials. I have recently made a one-hour video and several short videos with Transparent Health and we are interested in exploring the use of those as educational tools. We've had several conferences and patient training sessions and we want to formalize that, and have provider training to go with it, because patient empowerment can't really achieve its potential unless everyone is on board. But on a broader level, we always try to keep our eye on the overarching goal, which is a safe, transparent, patient-centered healthcare system, from a national level right down to the individual provider.

Clinical Café: How can you do that?

Haskell: We try to work with others and encourage projects that will advance that goal on many fronts. There is more to be done than we could ever possibly do by ourselves.

(Endnote: Watch for the next installment in the series of Clinical Café conversations with patient safety and quality leaders. If you'd like to suggest someone we should interview, or a topic we should cover, email me at jnovack@quantros.com. If you're not a member yet of Clinical Café*, go online to www.clinicalcafe.com and click on the "Join Now" link.)*