

Consumers and the Patient Safety Movement: Past and Future, Here and There

November 30, 2004, marks the fifth anniversary of the Institute of Medicine's (IOM) landmark report, *To Err Is Human*, prompting policymakers, media, and other stakeholders to assess progress and revisit goals in what has become known colloquially as the patient safety movement. New benchmarks include a study estimating annual preventable medical deaths to be twice the IOM's original high-end estimate, confirming the enormity of the challenge we still face (Health Grades, 2004). Recent data that adverse events are being routinely disclosed to patients only 54% of the time underscore that resistance to change demanded by ethicists, accreditors, and consumers still is significant (Lamb et al., 2003).

But hope is alive. Encouraging developments include growing proactive consumer involvement as "full partners" in advancing safer, more highly reliable care as well as a number of international patient safety initiatives that have real traction. Each is driven by the same sense of urgency that prompted the IOM to declare medical error a public health epidemic five years ago.

Consumers as Motivators

As a baseline, consider that in June 1999—just months before the release of *To Err Is Human*—the National Patient Safety Foundation (NPSF) was picketed by self-styled "victims' rights" groups. Organized by Persons United Limiting Sub-standards and Errors in healthcare (PULSE), victims converged from around the country demanding to be heard and included. As NPSF executive director at the time, I agreed to sit with

Board member Doni Haas through two days of testimonials. "What do we say?" I asked Haas. "Just be respectful and listen" was her advice, and so we did.

The stories told of tragedy and profound grief. Blame was extreme, amplified by repeated analogies to the Holocaust. I came away dubious about how a forward-looking dialogue with such victims could ever be constructed. Yet these angry patient advocates were sincerely reaching out, contributing their stories to our work.

It's fair to say that the patient safety movement has taken consumers up on this offer. Stories of the human impact of systems failure have proven useful in creating a kind of patient-centeredness in our public discussion. They remind us of what the stakes are; why we became healthcare providers, administrators, or policymakers in the first place; and that we and our loved ones also are all consumers who face the same risks. Rosemary Gibson's and Janardan Singh's *Wall of Silence* (Gibson & Singh, 2003) is perhaps the most eloquent compilation of such stories, and it bridges beautifully to discussion of the need for reform. And to the great credit of both organizations, NPSF has integrated PULSE representatives and other patient advocates into its Board and established a Patient Family Advisory Council.

In short, consumers have succeeded as motivators by using their stories to become the patient safety movement's objects of sympathy or empathy. Important as this achievement is, it is just the start. Consumers have much more active roles to play, and they are working to define them with those ready to include them as partners.

Consumers as Full Partners

To date, almost all patient safety reform agendas have marginalized consumer input. Most often, they have been formulated by well-intentioned leaders or committees selected for their healthcare delivery expertise. If included at all, the voice of the consumer most often is used to accentuate the ideas of others or underscore core values. The initiatives produced typically make protective suppositions about what it is consumers want, fear, or can understand.

These approaches fail to appreciate that not all, but many consumers are intelligent, fully functioning adults who comprehend that we live in an increasingly complex and risky world. Indeed, at this moment in history some consumers have been trained and work in industries that are significantly *ahead* of healthcare in understanding organizational risk management, systems-based

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quality improvement, high-reliability performance, teamwork, and communication in complex, dynamic human enterprises. Even when they lack such professional training, as patients and lay caregivers they bring to the team an appreciation for gaps in the safety net that busy providers or researchers may not discern. It follows that safety will be improved if consumers' lessons learned are captured and factored into quality improvement.

Moreover, active consumer participation in the development and implementation of reform agendas serves important accountability functions. Consumer interaction with providers can lessen the fear, guilt, or shame still associated with medical error and malpractice. They counterbalance overly protective concerns about what the public should be told, and their very presence lends public confidence to the products produced.

Authentically Patient-Centered Goals

Motivated by the desire to make healthcare safer, two thoughtful consumer leaders—Roxanne Goeltz and Susan Sheridan—led the development of an Agency for Healthcare Research and Quality (AHRQ) funded workshop event in October 2003 that delivered invigorating results. Both women had experienced healthcare system failure with tragic outcomes; both had also seen healthcare work well. Interestingly, both were also trained in professional fields far more systems-based in their risk management than healthcare is today.* I had the good fortune to be involved in planning and facilitating the event along with a small team of communication and organizational design experts.**

Under the leadership of Goeltz and Sheridan, we turned the typical approach to a healthcare workshop on its head by *starting* with consumers—specifically experienced patients and lay caregivers who saw themselves as con-

structive partners and change agents. An equal-sized group of other stakeholders interested in consumer partnering were then engaged. Outcomes of the workshop included a mission, goals, and a new nonprofit organization—Consumers Advancing Patient Safety (CAPS; www.patientsafety.org)—activated to carry this work forward. Each workshop participant was invited to become a founding advisor of CAPS and assist in pursuing the following six goals, which, we submit, are authentically patient-centered:

Goal #1: Establish a national Patient Safety Authority. If we as a nation are serious about reducing medical harm, there must be a body or organization accountable for safety in healthcare. Like those organizations charged with advancing the safety of highways, air travel, or consumer products, the authority should be publicly led. It should serve as a place for gathering information from both patients and providers and a focal point for implementing change. State patient safety authorities like those now being implemented in Massachusetts, Pennsylvania, and Florida are steps in the right direction, but national coordination is needed.

Goal #2: Create local Patient Safety Advisory Boards in every community. Community-based organizations would be a valuable asset to hospitals, clinics, long-term care facilities, and other healthcare organizations looking for consumer input on patient education materials, policies and protocols, ethics, complaint management, and facility design, among many other activities. Patient safety coalitions, now existing in several states, are well-positioned to organize such advisory groups.

Goal #3: Institute a non-punitive national patient safety learning/reporting system. Public confidence in the accountabilities of reporting programs will be increased if consumers are involved in their development and governance. Consumer participation in error reporting schemes also should be considered, although it will require reporting, feedback, and querying

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pathways distinct from those used by providers.

Goal #4: Establish a national education effort on patient safety for providers and consumers. There are significant gaps between consumers and providers in understanding safety science, the needs of consumers when bad outcomes occur, and the roles of consumers in prevention. Community education is needed to close the gaps.

Goal #5: Develop a national patient safety awareness campaign that emphasizes partnership, trust, and open communication. Before education can really happen, denial about the extent of the public health challenge we face must be overcome. Like commercial aviation or driving on the freeways, healthcare is inherently risky. Accordingly, consumers and providers alike must be mindful of risk, willing to discuss it, and collaborative in minimizing it.

Goal #6: Provide just compensation for patients who are harmed and alternatives to litigation for obtaining it. Patients who are injured deserve to be fairly compensated. “Fair” does not mean a lottery ticket. Nor does it mean the haphazard pattern we have today, often dependent on whether a claimant has the wherewithal to stick out brutal litigation. Many physicians fail to realize that blame flows both ways in the litigation game. Plaintiffs are dissatisfied with that, just as defendants are. Our general view is that legal systems must become more patient- (or client-) cen-

* Goeltz is an air traffic controller. Sheridan previously was an international banker.

** Other facilitators included futurists Jonathan Peck and Bill Rowley of Institute for Alternative Futures; risk manager and communications educator Geri Amori of Communicating Healthcare, Inc.; and Roger Fritz, an organizational design leader from Leadership by Design, Inc. Sherry Martin and Debora Simmons of The University of Texas M.D. Anderson Cancer Center also played crucial roles as hosts for the event.

tered, just as the healthcare system aspires to be.

On behalf of the CAPS Board and its founding advisors, we offer these goals to the patient safety movement for further deliberation. We are eager to discuss them and work with others with whom they strike a chord to achieve them.

Global Progress on Patient Safety

While much of the thought leadership on patient safety is American-grown, other developed countries appear to be moving forward significantly faster on implementation. The United Kingdom, Australia, and Canada already have patient safety authorities in place and are either building or in an advanced stage of planning research and education efforts, reporting systems, and

patient outreach activities, among other programs. In addition, the World Health Organization (WHO) launched a World Alliance for Patient Safety in October of this year, dedicated to “bringing significant benefits to patients in countries rich and poor, developed and developing, in all corners of the globe (WHO, 2004).” Under the leadership of Sir Liam Donaldson, MSc, MD, chief medical officer of England, the WHO Alliance includes six action areas, including a global challenge to reduce healthcare-associated infection in 2005-2006 and, notably, a Patients for Patient Safety initiative that actually *relies on consumers* to develop and lead implementation of its objectives.

Progress elsewhere may be partially explained by structural differences between the U.S. and other nations. It is probably easier to establish a national patient safety authority when a nationally coordinated health system already is in place. There may be fewer obstacles to working with consumers in venues where injured patients are less dependent on litigation as a means of obtaining compensation when they need it. But leadership has also been a factor. Each of the international efforts mentioned above has been driven by dedicated policymakers like Sir Liam, motivated by a sense of urgency to address what they hold to be a true public health crisis. Consumers who share this sense of urgency are their natural allies, and new partnerships are now being formed that promise to fuel action.

Domestically, both Dennis O’Leary, MD, of the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and Ken Kizer, MD, of the National Quality Forum also have proven to be tireless leaders in implementing change. Each should be commended for expanding their organizations’ use of consumers as key advisors and active participants in technical patient safety work. JCAHO also is poised to play a key role in coordinating WHO patient safety work in the U.S., which fits nicely. As standard setters push systems-based, patient-centered care forward in coordination with increasingly active consumer partners,

there is every reason to expect escalating progress in the next five years. 

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