

## Patient Advocacy in Patient Safety: Have Things Changed?

### Perspective

by Helen Haskell, MA

In 1981, a cancer patient named Paula Carroll founded a nonprofit corporation called Consumers for Medical Quality, intended as an advocacy and support group for people who had experienced medical harm. Among the organization's goals were publicly available hospital ratings, transparency in state medical boards, maintenance of licensure requirements for doctors, and information on impaired physicians. In addition, Carroll provided a library of free medical reference works for the public, photocopying and mailing relevant pages to anyone who called for information.(1)

What is unusual about Carroll is not so much her activities, pioneering though they may have been, but the fact that we know about them. As the history of patient safety in the United States begins to be written, the patient role remains largely unremarked. But as the field of patient safety and quality developed over the past several decades, the patient movement has grown alongside it, stretching back at least into the 1970s, when the Boston Women's Health Book Collective kick-started health care advocacy with the publication of *Our Bodies, Ourselves*.(2)

For patient advocates, patient safety is necessarily broadly defined, depending on where problems are seen to lie and where it appears to be possible to influence change. For much of the history of what we would now call patient safety, advocacy by patients was set in the context of the consumer movement, and it focused primarily on public perceptions of unsafe medical practices, insufficient accountability, and lack of openness. In the 1970s and 1980s, events like the 1975 Congressional hearings on unnecessary surgery and ABC's 1982 "The Deep Sleep" special on anesthesia mortality formed the backdrop for activist groups like Public Citizen's Health Research Group, Charles Inlander's People's Medical Society, and the Center for Medical Consumers, all of which sought to influence regulation and provide medical information to the public.(3-7) While smaller local organizations like Paula Carroll's seem to have been uncommon, one of the most effective patient safety campaigns of the 1980s was the one-man crusade of New York reporter Sidney Zion, whose outrage over the death of his 18-year-old daughter Libby led to reforms in resident working conditions that continue to resonate today.(8)

The 1990s saw the rise of a grassroots patient safety movement comprised of groups of medical error victims like Illinois FAIR, the New England Patients' Rights Group, the Association for Responsible Medicine (ARM), and PULSE of Colorado and New York.(9-10) Like their predecessors, these organizations concentrated their efforts on medical transparency and accountability, particularly in the areas of resident care, informed consent, medical error disclosure, and medical board discipline. Though almost all operated on a shoestring, these loosely coordinated groups ran hotlines, funded billboards, and staged rallies. Their

primary aim was legislative. Physician profile laws passed in Texas, Massachusetts, and New York, but similar "Patients' Right to Know" bills languished in the legislatures of Florida, Illinois, and other states.

Medical error also hit the news in a significant way during the same period. The public and, even more, the medical establishment were mesmerized in 1995 by reports of the medication error that had led to the death of *Boston Globe* reporter Betsy Lehman, the wrong leg amputation of Florida patient Willie King, and the death of 7-year-old Ben Kolb from medication error. At a multidisciplinary meeting on error in health care convened at the Annenberg Center for Health Sciences in 1996, participants were asked to hold pictures of little Ben Kolb while listening to a description of his medical case. This meeting also saw the pledge by The Joint Commission to establish its sentinel events database and by the American Medical Association (AMA) to establish the National Patient Safety Foundation (NPSF), an attempt to duplicate for mainstream medicine the success the Anesthesia Patient Safety Foundation had had in its specialty.(11)

The worlds of provider and protester collided when representatives of medical error victims' groups gathered for a 1999 rally outside the AMA in Chicago. The AMA had police on standby for fear of violence, but the rally of about 100 people followed their accustomed routines and sang songs, gave speeches, and handed out literature. The following day the participants were invited to meet with Martin Hatlie, the head of the new NPSF, and Doni Haas, the risk manager who had handled the Ben Kolb case. Their stories of suffering and silence in the face of medical harm affected Hatlie and Haas profoundly, and ultimately led to the creation of the first patient and family advisory council at NPSF.(12)

Alongside the consumer movement, another patient-led movement was developing simultaneously—family-centered care. With its roots in the disability rights movement and pediatric hospital care, family-centered or patient-centered care aimed to change health care from within by facilitating partnerships among patients, families, and health care professionals.(13) The Institute for Patient- and Family-Centered Care, founded in 1992 by the indomitable [Bev Johnson](#), helped promote concepts (such as 24-hour family visiting hours and patient and family advisory councils) which began to appear in the mid- to late-1990s, primarily in children's hospitals.(14) The Center for Advancing Health, also founded in 1992, approached the problem by providing patients with information to help engage more closely in their own medical care.(15)

These streams began to converge in the early 2000s. The publication of the Institute of Medicine's (IOM) *To Err is Human* in December 1999 marked the beginning of a new way of looking at the health care system. The Bush administration's renewed attempts to limit medical liability engendered furious controversy and focused attention on the safety of medicine, while the rapid growth of the Internet provided an ease of communication and potential for national organizing that had not previously existed.

The years immediately after the IOM report saw a flurry of new patient organizations, among them the Josie King Foundation, Medically Induced Trauma Support Services (MITSS), Mothers Against Medical Error, and Consumers Advancing Patient Safety.(16-19) Stories of patients were featured in Rosemary Gibson and Janardan Prasad Singh's 2003 book, *Wall of Silence*.(20) The patient voice began to be invited directly into the larger patient safety movement, with Sorrel King's keynote address to the Institute for Healthcare Improvement's forum in 2002, a notable early example.(21) More patient-sponsored state laws began to pass: Taylor's Law in Massachusetts and the Michael Skolnik Medical Transparency Act in Colorado addressed medical board transparency, while the Lewis Blackman Hospital Patient Safety Act in South Carolina and patient-sponsored provisions of the 2008 Massachusetts Omnibus Health Care Reform Act were concerned with rapid response and patient-friendly policies in hospitals.(22-25) By 2010, driven by the support of patient advocates and Consumers Union, requirements for reporting of hospital-acquired infections were the law in more than half the states.(26)

Online research and connectivity became the norm as the power of the Internet began to be felt. In 2003, the Pew Research Center's Internet and American Life Project found, to the dismay of many physicians, that

80% of Internet users had sought medical information online.(27) A new type of patient advocate, the e-Patient, started to emerge, self-defined as a "breed of informed health consumers, using the Internet to gather information about a medical condition of particular interest to them."(28) In fact the vision laid out by the e-Patient prime mover, Tom Ferguson, went much deeper than that. Ferguson died in 2006 before his initial whitepaper could be completed, but via his team of posthumous editors, he proposed electronic media as a disruptive technology that would upend medicine by creating a community of self-reliant patients whose group wisdom contained more expertise than that of the physician.(28) Health 2.0 expanded upon this concept by promoting the use of social media, open source content, and innovative technology to drive personalized, user-generated medicine.(29)

The passage of the Affordable Care Act (ACA) in 2009 marked another discernible leap forward. While the idea of consumer involvement in implementation of legislation was not a new one, two of the ACA's new platforms, the Patient-Centered Outcomes Research Institute (PCORI) and the Partnership for Patients, led to a sea change in the interaction of patients with hospitals, researchers, and other health care groups. (30,31) As PCORI sought to include patients in all aspects of research and the Partnership for Patients promoted patient involvement in driving down harm in hospitals, patients and patient groups found themselves being actively courted by organizations whose ear they had had trouble getting not long before. The principles of family-centered care have now gained wide acceptance, and in some hospitals patients have been placed on key committees throughout the institution—a move with transformative potential if purposefully done. Concurrently, the move toward accountable care organizations and community-based care has led to greater emphasis on provider collaboration with ethnically diverse and vulnerable populations on an outpatient basis.

This amounts to a great deal of change. Yet in many ways it is much less change than we would wish. In spite of much forward motion over the years, it is clear that many major patient safety problems have remained depressingly constant, and that gains in some areas have been offset by setbacks in others. One area that has seen significant advances is public reporting of quality data, at a federal level (Hospital Compare), in some states (hospital-acquired infection and sentinel events), and by private entities like Consumer Reports and The Leapfrog Group. Even so, raters have been constrained by the compartmentalized nature of publicly available data. This situation has the potential to change considerably with the availability of more granular "big data" like the recently released Medicare Part B Supplier Billing and Payment Data, but we are still far from meeting the goals of the earliest consumer advocates of providing information that will drive truly informed consumer choices.(32)

Another vexing question is the changing view of what constitutes high-quality health care and how patient safety fits into the picture. Patient safety was born and came of age in hospitals, where issues are relatively easily defined and measured. Patient safety advocates, too, have generally concentrated their efforts on hospitals, where the most devastating patient injuries are seen as occurring. But as health care reform moves out into the community, some programs have visibly shifted their emphasis from enhancing health care delivery to improving a more obvious target, the patient himself or herself, sometimes by blaming them for their illness. This approach risks oppressing the patient, sidelining serious issues of system performance, and undermining the potential benefits of community-based health care. At the same time, the rapid expansion of patient-driven issues has widened and blurred what was previously a precise, if not always productive, focus on patient safety and quality. Important topics like health care disparities, personal technology, and much of what falls under the rubric of patient engagement have yet to be integrated into the framework of safety and quality, and it is far from clear exactly how that will be done.

It should be axiomatic that without safe and effective health care, other reforms have little meaning. Yet despite decades of work by patient safety advocates, both inside and outside the health care system, our systems are still far from safe. The topic preoccupying this patient safety advocate is that in the rush

toward inclusiveness, population health, and integrated care, the vital unfinished business of safety may be pushed to the margins.

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