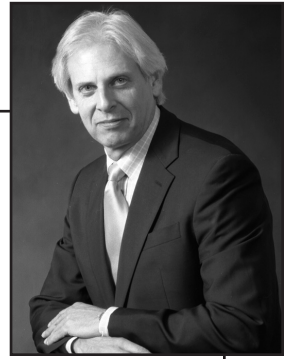


FOREWORD

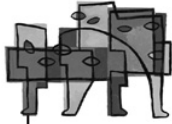


As *Patients as Partners: How to Involve Patients and Families in Their Own Care* was being developed, a provocative new piece of research by Vikki Entwistle et al. was published, finding that most patient safety advisory materials intended for patients were developed with very little patient input.¹ Generally, they were prepared by experts or committees who apparently believed they knew what patients wanted, needed to know, or could do. The study also found that there was virtually no evidence that these provider-developed materials were effective in educating patients or supporting behavior change that was advised, such as the suggestion that patients ask more questions.

Entwistle's study begs an important question underlying the entire field of patient-centered care: *Why* do we fail to include patients and their families in our safety and quality work, especially when it appears self-evident that their cooperation in following directions and participating in day-to-day care tasks is so crucial to producing good outcomes?

Most often the default answer to that question is fear of liability. But if we are honest with ourselves, that cannot be a complete response. If it were, we would be actively working with patients and families, after their liability claims were resolved, to determine what it was they experienced and what feedback they have for us. Study after study documents that patients and their families have a high desire to see their adverse experience used to prevent future harm,² yet we don't ask—even when it is legally safe to do so.

A deeper part of the answer is that talking with patients about safety and risk is hard and very uncomfortable work for which we lack training, skills, and tools. I will never forget my first real experience with feedback from patients and family members who had experienced medical error. I can still evoke a stomach-turning feeling as I recall it: the grief, the anger, the accusations, and—most troubling—the comparison between the victims of medical error and of the Holocaust, all surging out in a shabby conference room of a suburban Chicago hotel.



PATIENTS as PARTNERS

How to Involve Patients and Families in Their Own Care

It was 1999, I was the executive director of the National Patient Safety Foundation (NPSF) at the American Medical Association, and we were the target of a rally organized by Persons United Limiting Substandards and Errors (PULSE) on behalf of victims of medical error who had been left out of the NPSF's formation two years earlier. Well acquainted with organized medicine's defensive posture vis-à-vis criticism from victims' rights advocates, I was now at the sharp end of health care providers' worst nightmare. Being likened to Nazis is a hard pill for anyone to swallow and makes for a challenging conversation-starter.

I had been coached well for this meeting by Doni Haas, an NPSF board member and risk manager who had shepherded a powerfully healing disclosure process in her own hospital after the death of a young boy named Ben Kolb. "What will we say to these people?" I asked her. "You don't need to worry about that," she advised, "our job is to listen."

And so we did, Haas and I, sitting in the front row for two long days as more than 100 people stepped to the podium to tell story after story of injury and disrespect. And while I felt absolutely horrible most of that time, I also recognized that our presence was enormously appreciated. We were profusely thanked for coming; a few people even expressed sympathy *for us* for how hard it must be to hear what they said. But, most important, when I was able to listen through the pain and blame, these grief-stricken people communicated in some detail a few very valuable lessons. Haas was right; our job—at least one profoundly important dimension of it—really is to listen. When we do, we learn.

It's a simple truth that patients and their lay caregivers see things their health care providers do not. True also is the fact that it is usually painful to hear from consumers who have experienced a medical error, and some of the things they say are unfair. But when we reject their communication overtures—many of which might first manifest as complaints—or funnel them into the selective fact-finding of the litigation process, we lose the treasure of their lessons learned. We also lose an often short-lived chance to regain some trust and facilitate healing for everyone involved.

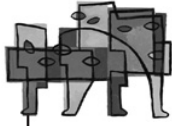
"It's a simple truth that patients and their lay caregivers see things their health care providers do not."



I recently had the opportunity to participate in a meeting that was scheduled—as part of the settlement of a malpractice claim—between the wife of a patient who had died as the result of medical error, the CEO and risk manager of the hospital where the injury occurred, and the patient’s surgeon, in whose care domain the error was made. This was a meeting that had been requested by the patient’s family shortly after the adverse event, before the patient died, because the family wanted to avoid litigation. That request had been denied, either because the request was not trusted to be sincere or because the hospital insurer and the surgeon’s insurer were at odds with each other about who was at fault.

On the morning the meeting was to occur, the surgeon’s wife called the hospital CEO and explained that her husband could not attend. He was in their bedroom sobbing and much too distraught to face his patient’s widow. Proceeding without the surgeon, the hospital CEO quoted extensively from the organization’s mission statement, which emphasized patient-centered care, as well as its disclosure policy, which was intended to embody compassion. However, no apology was offered and the CEO’s behavior was guarded throughout. The CEO did say the organization had taken steps to prevent a similar occurrence, but he was reluctant to discuss the details of those steps. After the meeting I debriefed with the hospital’s risk manager. Both of us agreed that this event had been a missed opportunity for both learning and healing, occasioned at least in part by advice from hospital legal counsel that no apology should be made by the hospital because the adverse event was the surgeon’s fault.

I share this story not to criticize either CEO or surgeon, but to underscore how daunting and irrationally fear-laden these communication episodes can be. Because the settlement papers had been signed months before, there really was no liability exposure remaining to chill the kind of person-to-person interaction that could benefit all concerned. It was fear and discomfort that prevented a conversation that was truly possible in this instance—one where compassion could naturally be expressed, accountability acknowledged, learning discussed, apologies offered, and forgiveness received.



PATIENTS as PARTNERS

How to Involve Patients and Families in Their Own Care

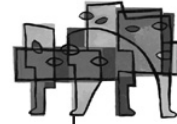
Just as systems-based thinking is now being applied to the work of delivering care, we need to grow a better understanding of its uses in encouraging and supporting difficult communication. Even the accomplished clinician and health organization executive in this case—the latter guided by a clear mission statement and thoughtful disclosure policy—lacked the skills they needed to do this kind of thing well. Organizational support and effective tools are needed to teach, assist, and encourage.

“This book reveals new avenues for consumer input and feedback, creating rich new potential for better prospective care as well.”

Patients as Partners: How to Involve Patients and Families in Their Own Care is such a tool. Building on the advice of experts and the experience of health care organizations that have paved new pathways for communicating with consumers about risk in health care, it can be very useful to leaders and teachers who are committed to actualizing their patient-centered care mission statements. This book goes well beyond provider–patient interaction after an error has happened. *Patients as Partners: How to Involve Patients and Families in Their Own Care* reveals new avenues for consumer input and feedback, creating rich new potential for better prospective care as well.

In so doing, it catches a wave. There is now emerging a new appreciation for varied roles consumers can play in improving the safety and quality of care. When patients and families are included in gatherings of patient safety stakeholders, their primary contribution so far has been to share stories of harm and its impact on their lives. In the patient safety movement we have found in such stories a powerful motivational force for health care providers to focus on preventing harm as a renewed priority. However, patients have much more to offer to safety work than emotional reminders to clinicians, health care administrators, and policymakers that they too often are victims of tragic medical errors. As the new World Health Organization (WHO) Patients for Patient Safety program recognizes:

Important as that perspective is, a victim orientation does not position us well as partners working with health care providers to prevent harm. Indeed, the perception that patients and their families are helpless or antagonistic victims has served to distance us from playing meaningful roles in the development and



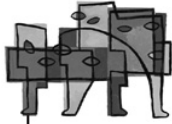
implementation of patient safety work in the past and generated fear among some clinicians who would have otherwise engaged with us.³

If we agree that patients and families see aspects of system failure or vulnerability that health care workers do not, it follows that we should develop the systems-based capacity to embrace them as full partners in our safety and quality improvement work, a point of view that *Patients as Partners: How to Involve Patients and Families in Their Own Care* champions. We should include them in the development of patient education materials, our clinical training, our policy-making and facilities design, and other frontiers now being explored by the innovators profiled in *Patients as Partners: How to Involve Patients and Families in Their Own Care*.

If the invitation to consumers is made, health care is sure to find willing respondents. Again quoting the WHO Patients for Patient Safety program:

Patients and consumers who choose to partner with health care policy makers and providers are highly knowledgeable, motivated, and eager to contribute. We approach our role with a profound sense of responsibility and desire to help create a health care system that is safe, honorable, and compassionate for patients and health care workers alike. We are here to challenge health care to be truly patient-centered—especially when it is resistant to change or slow to make safer care a priority—but most fundamentally, we are here to partner to help make care better.³

When caring, innovative leaders reading this book invite the participation of consumers into their safety and improvement work, I cannot promise that the process will always feel heart warming or drama free. But with confidence I will guarantee that your organization will learn things about your care delivery you cannot learn anywhere else, that you will feel proud for having the courage and commitment to do difficult, patient-centered work, and that you will earn well-deserved trust from your customers.



PATIENTS as PARTNERS

How to Involve Patients and Families in Their Own Care

Engaging patients with honesty about the challenges you face and the risks you manage is a profoundly important component of the care you deliver. Moreover, it is truly existential in effect. For, by doing it, you realize your mission and become what you aspire to be: an authentically patient-centered community.

—Martin J. Hatlie, J.D., president, Partnership for Patient Safety
and cofounder, Consumers Advancing Patient Safety

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