

Patient safety: the patient's role

DAN FORD

REPRESENTING THE NATIONAL PATIENT SAFETY FOUNDATION, WORLD HEALTH PROFESSIONS ALLIANCE
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I work in the health care industry in the United States as an executive search consultant. I voluntarily serve on provider patient safety committees across the country because of a medical error in my family. I have become a passionate patient advocate and am told our story is compelling.

We need to rebuild trust in our industry and place the patient at the center of all that we do in a spirit of partnership between patients and providers. There are numerous ways that patients can play a role in their own safety. First, let me share our family story.

On 1 May, 1991, at the age of 47, Diane Ford, my wife, went into an Illinois hospital for a hysterectomy, at the recommendation of her physician, following much bleeding. During surgery, her colon was cut, leading to a colostomy. Twelve hours later, she over-dosed on morphine given to her through a PCA pump. The code team was called, and took over 20 minutes to intubate her. Narcan was not available. This time frame caused a respiratory arrest and permanent brain damage/short-term memory loss. We don't know how or what happened, if it was equipment malfunction, medication miscalculation, or what?

The colon was reversed in surgery two months later. Diane had little recollection of why she had the bag, how to clean, or how to change it. She then discovered bowel in her vagina. A fistula had been caused by stray staples from the colostomy reversal. It was repaired in a fourth surgery, three months later.

The colostomy nurse was the only person to give us substantive help when Diane was discharged from the hospital. I received no counsel regarding her short-term memory loss. Contact with area rehabilitation hospitals and therapists followed my research. I don't know that her physician ever picked up the phone to solicit counsel or referrals. Diane's short-term memory loss is permanent.

In late 1991, when I stopped feeling like a deer caught in the headlights, I started asking pointed questions. We received nice and polite responses. I persisted with more. Defenses went up. It became awkward. The attitude was one of superiority: "We know best. Sorry your wife has

brain damage. That happens." The approach of the senior risk manager was a mixture of gruffness, arrogance, condescension, insensitivity, antagonism, confrontation, lack of empathy, dismissive, and occasional obfuscation. He said his role was to save the hospital money.

Diane was a homemaker and mother of three children – Sarah 11, Jonathan 14, and Chris 17 – active in church. She was attending McCormick Theological Seminary in Chicago part time – studying theology for her second master's degree. She already had a master's degree in education. She was bright, alert, loving, and competent; a responsible parent and loving wife, and friend of many. She loved to learn and travel.

The quality of her life changed forever 2 May, 1991. She could no longer understand or communicate accurately, found it hard to sustain relationships. Her personality changed significantly. She became suspicious, frequently negative, sarcastic, argumentative and critical. Diane developed the emotions of a teenager. Her ability to analyze, reason and learn is gone. She cannot read a book. She cannot prepare a hot meal. She cannot remember a movie plot, or the cast, or her seat if she goes to the bathroom.

Our marriage dissolved in the mid '90s. I ran out of give after three years of taking care of her needs, having watched her personality change considerably and impact those around her. I talked with her for a year about my feelings – not easy when she could not remember conversations from the day before. My Christian vows are important, and I never thought this would happen. I simply could not be the Old Testament Job. I care a great deal about her, and much of what I am doing relates to that. Today Diane lives in an independent living facility.

In 1993, after 21 months of attempting constructive dialogue with risk management and the providers, we filed a medical malpractice lawsuit. In a final meeting with risk management, we had been offered a financial settlement that was the estimated cost of legal defence of a lawsuit. We turned the offer down. It was an insult. Diane's self esteem and ability to learn are destroyed. She has no ability to make a living. Our health care system failed her. We settled in the

fall of 2002 for a nominal financial settlement. She could no longer re-visit what happened, and quit the lawsuit. The defence strategy was clear; if the patient is brain-damaged, and the case is caused to go on long enough, we may wear down. They were right. They won. It was legal. It was not right or fair. It did not fit the spirit of medicine.

Recommendations on the role of the patient in their own safety

The following ideas are from my own thinking over the years and from others. We are all patients and family members as well as providers.

Let's be responsible providers of information

- We should document and update our medical history, our active medications and our allergies. In Arizona we developed the “The Medication Form” (www.themedform.com). My patient safety colleague, Ming Ming, from the Chinese Cochran Centre, suggests the improper use, over-use and misuse of medicines is a huge threat to patient safety in China. Medication errors are a large problem all over the world.
- Literacy issues should be brought to the attention of providers. Over 90 million people have literacy challenges in the United States alone.
- We should register complaints. Marilyn Walton, a member of the Faculty of Medicine at the University of Sydney in Australia, suggests that patients provide a second set of eyes. Speak up quickly when we have side effects or adverse events, asking for appropriate action.
- Speak up. As JCAHO in the United States suggests in its “Speak Up” programme, patients should self-educate about diagnoses, medical tests and our treatment plan. In her book, *Partnering with Patients to Reduce Medical Errors*, Patricia Spath suggests: “It is likely that consumers have NOT been invited to be partners in health care safety because no one ever thought to ask.” She suggests that active participation with providers implies the sharing of information and opinions, joint problem solving and joint responsibility.

Let's ask questions and speak up

- “Doctor, did you wash your hands?” Let's ask about anesthesia, IV drips, special tests, etc.
- Insist on full disclosure, to know exactly what happened to our body: “Nothing about me without me.”
- Actively research for doctors and hospitals to meet our needs, asking for assistance from our primary providers. Ask for second opinions regarding a diagnosis and suggested treatment plan.
- Find out the primary physicians and nurses in charge of our treatment.
- Invite a family member, friend, patient advocate, navigator or vigilant partner to help when we visit the doctor or hospital. Help those who have no such advocate.
- Find out who we can talk with regarding anxieties and concerns about our care. Tell someone to stop if

something doesn't feel right; report questionable behaviour.

- Ask for medication sheets, help caregivers crosscheck medications, and receive safe medication practice tips. Ask about precautions, interventions, safe guards, checklists and surgery time-outs.
- Find out how infections occur, about early symptoms and avoiding infections, infection treatment, and prevention plans.
- Monitor for compliance with safe practices, including the administration of medications, after verifying our patient identification.
- Beg and be persistent, suggests Dale Ann Micalizzi, whose healthy 11-year-old son, Justin, died in 2001 in the United States from what started out as a swollen ankle. She learned this too late.

Let's be expectant and presumptuous

- The patient is the centre of the health care team.
- We are all public – all consumers – as patients or family members, at some point.
- The Picker Institute Europe suggests that patients desire a respect for their values, preferences and expressed needs, information and education, access to care, emotional support, involvement of family and friends, continuity and transition, physical comfort and coordination.
- Accountability by providers to patients. This may help to balance the unequal distribution of power between a physician and an injured patient. Nancy Berlinger discusses avoiding the abuse of this unequal distribution of power in her article in the Nov/Dec 2003 issue of the *Hastings Center Report*: “Avoiding Cheap Grace – Medical Harm, Patient Safety, and the Culture(s) of Forgiveness,”
- Expect providers to do the right thing when things go wrong, including taking responsibility for their own actions. Hurting patients are not interested in hearing about hospitals protecting their assets. There is a need for closure, and for an honest and candid understanding of what happened.
- Vasyl Kvariuk, Project Coordinator for the All-Ukrainian Council for Patients' Rights and Security, in Ukraine, suggests: “Civil Society is a great tool to unite patients who are willing to do something about medical harm which they experienced. Common patients need to get more aware about their rights and what they can do in case of medical services that are not of relevant quality.” Jolanta Ewa Bilinska, a health journalist in Poland, suggests: “Unfortunately the majority of patients are still passive because they are either not aware of their rights or do not believe in justice.” Meaning, they are not sure how to attain justice.
- Change the culture, if it does not encourage us to speak up, by questioning and challenging. Patrice Spath suggests: “When patients have a better understanding of their condition and their treatment, they can become the first line of defence against misadventures and unsafe situations.” Marilyn Walton from Australia

suggests that consumer involvement provides another layer of defense against adverse events.

- Our privacy and confidentiality should be honoured.
- Expect evidence-based medicine unless there are logical and convincing reasons for other approaches.
- Expect candor, honesty, open disclosure and transparency to be considered the norm. If a mistake happens without our knowledge, even without harm, we should be told.
- Expect that patients have the right to have their will and experience respected, as suggested by Silvana Simi of the Multiple Sclerosis Cochrane Group in Pisa, Italy.
- Be outraged by continuing medical errors.

Let's be encouraging and supporting

- Encourage providers to put the patient and family at the centre of the health care system. Providers can better plan and deliver care through involvement by patients, by gaining our help and insights.
- Encourage providers to tell the truth when unexpected outcomes happen, and to apologize.
- The front line nurse can still be the patient's best advocate. Patient loads, stress and human frailties get in the way. Lucian Leape from Harvard suggests: "Let's help the clinician do the right thing, rather than chastising them for not."
- Encourage providers to understand the deer in the headlights syndrome experienced by patients and families and by providers when unexpected outcomes happen. Patients and families are suffering terribly. Physicians, nurses and others do not wake up in the morning with the intent or anticipation of hurting someone that day.
- Encourage providers to remember the dignity of patients and staff. Medical errors require compassion and personal empathy. We have much arrogance. We find the human side of medical errors to be awkward. Cold and unfeeling attitudes will build barriers. This is about trust, mutual respect, communications and teamwork.
- Empathize with providers that engaging patients and families is a new and learning experience.

Let's participate with providers in many venues

- Volunteer for provider patient safety, quality and family advisory committees and self help groups. The Dana Farber Cancer Institute in Boston involves patients and family members on most committees and boards.
- Patients and family members around the world are becoming involved in consumer and patient advocate organizations. I participated in a "Patients for Patient Safety Workshop" in San Francisco in May, a profound experience, sponsored by the World Health Organization World Alliance for Patient Safety and Pan American Health Organization region – following the inaugural workshop in London in December. A "London Declaration" of patients for patient safety was developed by the 24 participants from around the world.
- Storytelling is important. Providers are inviting stories

as a catalyst for change. This can also help the healing process of those who have lost loved ones or are injured.

- Patients and family members are taking part in multi-disciplinary rounds in hospitals.

Let's encourage an openness to other new ideas

- Patients and families should have access to the entire medical record, and be invited to provide input into electronic medical/health records – not to change what is written by providers, but as supplemental information.
- Creating partnerships for the healing process is essential. The patient and those closest alongside need an advocacy framework that allows for normative expectations to be understood.
- Increased research on patient and family involvement. Dr Saul Weingart and his colleagues at Dana Farber Cancer Institute and Harvard University, as well as others, are conducting substantive studies on patient and family involvement.
- Establish patient advocate training programmes. Sarah Lawrence College in New York offers a master's degree in patient advocacy.
- Invite the patient and family members to participate in the Root Cause Analysis. It is the right thing to do, will enhance learning and decrease the malpractice risk, even with reticence, legal considerations, tradition, change, role behaviours, ego's and other human behaviours.
- Be PEACEMAKERS, not divisive. I respect that the *Bible* is not the source of everyone's faith, but the universal spirit of James 3: 17 & 18 can be understood: "But the wisdom that comes from heaven is first of all pure; then peace-loving, considerate, submissive, full of mercy and good fruit, impartial and sincere. Peacemakers who sow in peace raise a harvest of righteousness."

Concluding remarks

Everyone in the hospital should share responsibility for making the patient experience a good one, for doing what is right and for nurturing a safe environment... through attitude, behaviour and performance. Role modeling starts at the top.

There were two common themes in the feedback I received for this presentation – the focus on the patient, and teamwork. From Ryan Sidorchuk in Canada, whose daughter Paige died at too young an age in a hospital: "The one constant in all the interactions a patient will have, in all the different care settings that a patient will encounter, is the patient." Paige's cancer was misdiagnosed... the wrong treatment given. Ryan now works for the regional authority that oversees the operations of the hospital as a patient safety advocate. From Kathryn Townsend: "Everyone involved in the patient's care, including the patient, needs to be willing to take responsibility for the care. The patient can no longer simply hand over her/his care to the physician, nurse, or other providers, and providers can no longer treat the patient as some sort of uninformed interloper. It's all about building respect and trust in each team member, through communications and teamwork

development.” Katherine was a Fellow in the 2001 Salzburg Seminar on “Patient Safety and Medical Error,” and is an attorney, consultant and risk management and patient safety executive in the United States.

Let’s involve patients and families in our work – to convert anger to passion, becoming true partners in medical care. Patient safety is a human right, along with access.

The way we treat each other as human beings is at the heart of how we perform as professionals. Every provider should live and breathe making the patient experience compassionate, safe and accessible. We can move away from cultures of shame and blame to cultures of compassion and learning. Let’s do it together! □