Canadian Patient Safety Champions: Collaborating on Improving Patient Safety

Katharina Kovacs Burns

Abstract

Patients for Patient Safety Canada champions have grown in numbers and purpose since their initiation into the World Health and Pan-American Health Organizations' Patients for Patient Safety initiative in May 2006. The 25 Canadian patients and family members not only share their adverse event experiences but are actively engaged in collaboration with health professionals, administrators and decision-makers to initiate proactive patient safety strategies. Their intention is to have their stories heard as tools for learning. They also wish to raise local, regional and national awareness of patient safety problems. The different patient and family stories and experiences share some common issues and suggested solutions that might make a difference in patient safety. One key solution is involving patients and families not only in discussions of treatment and follow-up when adverse events occur but also proactively on patient safety advisory committees. These actions would acknowledge a common interest in seeing that the right things are done. Patients and families share the common interest of all those advocating for patient safety, namely, *First do no harm* (attributed to Hippocrates, circa 470–360 B.C.). The patients and families of Patients for Patient Safety Canada are a group of committed, dedicated individuals who should be acknowledged for sharing their experiences and trying to make a difference in patient safety.

There are many different experiences of patients and families with patient safety in varying settings, with different health professionals and with a range of practices regarding the inclusion of patients and families in their care and treatment. Although each story is different, there is something familiar about them, regardless of whether the experiences are described by patients, parents, sons or daughters, spouses or other informal caregivers.

In addition to the data on adverse events in Canada (Baker et al. 2004; Canadian Institute for Health Information 2007), there are 25 Canadian patient safety champions who are sharing their detailed experiences of adverse events in hospitals and other healthcare settings across the country. Patients for Patient Safety (PFPS) Canada champions have grown in numbers and purpose since their initiation into the World Health and Pan-American Health Organizations' PFPS initiative in May 2006. The goals for PFPS Canada include their collaboration with consumers, healthcare providers and health system decision-makers to ensure the implementation of patient-centred care and patient safety strategies at all levels of health professional education, healthcare delivery and healthcare policies. This article provides an overview of their experiences with patient safety practices in different healthcare settings and their activities in helping to improve patient safety.

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Experiences of Patients and Families

The 25 Canadian patient safety champions come from every province across Canada, with diverse work and personal experiences. They include 19 women and six men, of whom 12 are health professionals or employees working within the healthcare system.

Eighty-six percent of the PFPS champions experienced their adverse events in hospitals; the remaining events occurred in clinics or continuing care facilities. Some events were unexpected, while others were viewed as complications from diseases or medical conditions. All were rated as urgent requiring emergency treatment and care. Their stories include surgical errors or complications, drug treatment errors, routine day surgery or procedural problems, birth complications, missed diagnoses and misdiagnoses, patient neglect, wrong emergency department triage classification and hospital-based infections. The majority describe a lack of disclosures and apologies and little compassion and empathy from healthcare providers and institutions. Patients and families were expecting empathy. Most of the family members and three patients described their interactions during and following the event as "condescending," "disrespectful" and "non-empathetic."

Six of the 25 champions are patients, five of whom have related their stories and their resulting physical challenges and psychological trauma. Only one patient viewed his experience as "positive" and "satisfying" before, during and following his surgery. He felt this was because he had been included in pre-treatment discussions of what to expect including potential challenges with the procedure or treatment involved. The other patients were not so fortunate. One experience was described by Beth, a nurse who had surgery in 2001 to correct a cardiac dysrhythmia:

> "An error occurred during the procedure and my right ventricle was perforated. This led to bleeding into the pericardium … and a subsequent pericarditis occurred. It is referred to as Dressler's syndrome, and it usually responds to anti-inflammatory medications and clears up quickly. However, I did not respond to traditional therapy … It seems that prednisone is the only drug that will alleviate my symptoms, but I am now reaping the curse of long-term steroid use."

Beth continues to experience additional medical complications as a result of the medications on which she is now dependent.

Another patient survivor is Alice L., who was treated for a bladder infection for six months following a multitude of procedures including an unnecessary radical hysterectomy and peritoneal wash in 2003 and 2004. During subsequent surgery to remove a cancerous kidney in 2004, she experienced a near miss that would have removed the wrong kidney.

Other patient stories include misdiagnoses, medical and system errors and a lack of communication between health teams and the patients and family. The remaining 19 stories from family members describe what they observed and experienced; in more than half (63%), the patient involved died. Barb, a parent of a disabled child, describes the events they encountered at a children's hospital:

> "My three-month-old daughter died within 24 hours' arrival at the hospital. During that time, she was misdiagnosed for pneumonia, and policies regarding transfer to the ICU, 'Do Not Resuscitate' consent and multiple standards pertaining to nursing care including administration and documentation of medication were violated … We made suggestions of ways that physicians might be educated about the quality and value of the lives of disabled children by those who love them, but there was no interest. It was clear to us that the hospital did not regret our daughter's death as much as the fact that we discovered the truth of her care."

This parent is still in discussions with the hospital.

Sabina R. and Ryan S. have equally devastating experiences to relate about their two infant daughters. They describe two Canadian hospitals that failed to listen to and communicate with the families about what was happening prior to, during and following the adverse events. Sabina's daughter was diagnosed quite suddenly in April 2004 with idiopathic thrombocytopenia purpura and deteriorated in the hospital as Sabina tried to convey her concerns. Sabina stated:

> "The harsh reality is, [she] died. This April 5th [2007] marks three years … Let me tell you what it is like to be not heard … I have never felt so helpless in my entire life. I could feel my little girl slipping away, and I could not get anyone to listen to me. There is nothing worse than holding your child in your arms and watching her slowly and painfully

> die … It is heart-wrenching, it is unbearable and it sucks the life right out of you … Because no one would listen, they missed early signs of an intercerebral bleed … Because no one would listen, communication between attending resident and the nurses was non-existent."

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Ryan of Winnipeg, Manitoba, had a daughter, Paige, who died on October 30, 2003,

> "due to multi-organ failure brought about by a highly aggressive form of cancer, a type of cancer with less than a 30% survival rate at one year under 'ideal' conditions. These poor odds were further complicated by the fact that she was treated for a pathologically different type of cancer for over eight weeks due to misdiagnosis. Throughout the experience, communication was paternalistic, at times condescending, and always we were made to feel like a disease to be treated versus people to be cared for. There were no intentionally mean or bad people involved in my daughter's care. I saw enough tears in nurses' eyes to know that watching Paige slip away was very hard on them, both personally and professionally. However, the system in which these highly dedicated individuals work is so fundamentally flawed that it has become increasingly amazing to me how often they are able to actually get it right."

As a result of his experiences, Ryan has pursued a career with the Winnipeg Regional Health Authority and now works as leader in patient voice facilitation.

In January 2003, Theresa M. lost her 19-year-old son, Dan. He was misdiagnosed as having enteritis and dehydration when, in fact, he had viral myocarditis. Inappropriate treatment and care along with miscommunication led to a series of errors including laboratory work not done in a timely manner. In February 2007, after much persistence by Theresa and her family, they received

> "an open and honest disclosure conversation with hospital administrators, a verbal apology and a list of the changes that have been and are being made in the emergency department, the in-patient floor and the critical care unit. This came after a daunting and draining effort on our part to attain college reviews, appeals of the college reviews, a review by the Pediatric Death Review Committee of the Ontario Coroner's office, newspaper articles and a radio interview. All of the reviews found practice deficiencies, inappropriate care, failure in record keeping and breach of hospital guidelines."

Susan S. of Winnipeg, whose 19-year-old daughter has a congenital heart condition, had an experience transitioning from the pediatric to the adult system. On her first trip to the emergency department at an adult hospital, Susan was refused entry with her daughter to the treatment centre. The hospital had no records of her condition and refused her medical diary. Susan did try to enter to assist her daughter with the oxygen, which had been turned up too high, but she was threatened with security removing her. Things settled down when one of the residents recognized Susan from the Family Advisory Committee at the Winnipeg Children's Hospital, where she spoke on family-centred care to the residents. He spoke with the attending staff, and Susan was permitted to be with her daughter. Since then, Susan and her daughter have spoken to the managers of the Critical Care for Winnipeg Regional Health Authority and have assisted with the writing of a new protocol for families in the emergency room.

Ed M. of Orleans, Ontario, lost his wife, Madeleine, in March 2003 as a result of adverse events related to post-surgical care, including misdiagnosis, inappropriate clinical treatment and neglectful care. When Madeleine died, the surgeon offered his sympathies to Ed, who reminded the surgeon of the gastroenterologist report that pointed out that there were ulcers in Madeleine's colon next to the surgical site. The surgeon denied seeing these ulcers. The autopsy report confirmed that Madeleine had died from "gastrointestinal ulcer, perforated." Later when he talked with the surgeon by phone, Ed was told, "I know how you feel, Mr. M., but as you can see from the autopsy report, your wife had many serious bowel problems and probably wouldn't have lived very much longer."

Patients and families want to know that people are truly sorry for what happened and that the necessary steps are being implemented to prevent similar events from happening again.

Katarina S., a registered nurse living in Toronto, Ontario, saw her father receive devastating news about metastatic colon cancer. He experienced a series of system failures and died in 2004. There were problems in the tests to locate the primary site, surgery for a tumour in his colon and complications from the anesthetic related to his liver dysfunction. After an anesthetic-induced delirium and being physically restrained, a chemical restraint was given at double the maximum recommended dose, leading to coma and intubation. He could not receive any food or fluids because he was intubated. "He died three weeks later

– the same way he was born … unable to speak, with nothing to eat or drink."

There are many other stories of adverse events resulting from errors and a lack of communication at all levels of the healthcare system, including with patients and family members. Patients and families who have experienced adverse events have many questions for the hospital healthcare team and administrators: What happened? What went wrong? How did this happen? Why did this happen? Why were treatments and interventions done in error or not done, or not followed up? Why were we not listened to when we said, "Things are not right – something is very wrong!"? Why won't someone talk with me and tell me what is going on? Doesn't anyone in this place care? These patients and family members, in their commitment, have continued to ask questions in their current efforts to seek the truth for their own peace of mind and to ensure that appropriate education and changes to patient safety practices are implemented. All the PFPS Canada champions are active within their own regions and in the institutions where their adverse events occurred. Their stories and experiences have become valuable educational tools, and the lessons learned can be a tribute to patients and families who have experienced adverse events, and benefit patient safety education within and across healthcare institutions in Canada.

Most of the stories of Canadians who have experienced adverse events have not been told or made public. There are also many adverse events and patient care errors that are never reported by health professionals and remain silent experiences (Sinnema 2006, November 24).

Analysis and Discussion: Patient and Family Involvement in Improving Patient Safety in Canada

There are many common themes arising from patients and families who have experienced adverse events. These have become key elements in many institutional and regional guidelines that are currently being developed for "what should happen when an adverse event occurs" and for how-to guides for measuring and improving patient safety in organizations (Fleming 2005). Yet, each adverse event experience is unique, and some are frightening and fraught with intense emotions for all concerned. Most patients and families describe their experiences as painful, both in terms of their suffering and anxiety as well as the lack of support, compassion and answers from those providing care and treatment. For some, it is a deafening, uncomfortable silence with no answers or consolation, and for others, there is screaming, crying and yelling, with finger pointing. In the early post-event stage, any of these can happen.

What everyone involved in the event really wants are facts and explanations. Patients and families want answers – they need to know what actually happened soon after the event and be told that an investigation or root-cause analysis will be done. They want to know that people are truly sorry for what happened and that the necessary steps to assist patients and families will be taken and that measures are being implemented to prevent similar events from happening again (Duclos et al. 2005; Gallagher et al. 2003). No single patient, family member, health professional or administrator can tackle all aspects related to what needs to happen following an adverse event. Adverse events require collaborative efforts from all involved. These lessons learned need to be conveyed to others within and across healthcare settings.

Health professionals and administrators have important roles to play in all aspects of patient safety, including knowledge transfer and transformation of organizational culture. It is not quite as clear what role patients have or will be allowed to have in patient safety improvement efforts (Coulter and Magee 2003). "Plans for improving safety in medical care often ignore the patient's perspective" (Vincent and Coulter 2002: 76). So, how can patients and families be involved in working collaboratively with healthcare professionals, administrators, policy decision-makers and others to ensure patient safety knowledge transfer and transformation of practices occur?

Patients and families have had to first overcome challenges in being acknowledged and recognized as contributors to changing the current patient safety culture. There is a perception that patients and their families who have experienced adverse events are inclined to file legal claims against healthcare professionals and their institutions. But there are very few such cases. The more serious interests for the majority of patients and families concern two major areas that remain largely unaddressed – the impact of patient safety (or its absence) on patients and families, and the contributions that patients and families can make toward ensuring patient safety measures are in place (Vincent and Coulter 2002). Patients and families share the common interest of all those advocating for patient safety, namely, *First do no harm* (attributed to Hippocrates, circa 470–360 B.C.). Patients and families deserve nothing less than having access to safe healthcare services and environments.

With the recent emphasis on patient safety, patients and families are becoming more vocal, not only about open disclosure but also about improving awareness, education and safety practices. Patients and families are the best teachers for what happens when patient safety measures are not constantly monitored or checked (Anderson et al. 2006; Weingart et al. 2005). They also see a larger issue for the Canadian public: the number of adverse events is still very high. This has created a growing desire for patients and families to become more actively engaged in discussions, decisions and actions

- regarding their care and treatment to possibly identify and prevent unforeseen adverse events (Coulter and Magee 2003; Weingart et al. 2005);
- contributing to safe medication use and reporting side effects

or adverse events (Koutantji et al. 2005; Lowe et al. 1995);
- participating in infection control initiatives, such as ensuring that healthcare staff wash their hands (National Patient Safety Agency 2004);
- supporting and encouraging disclosure of treatment complications and adverse events (Duclos et al. 2005; Ford 2006); and
- advocating for changes in patient safety initiatives and policies in every institution and facility throughout the Canadian healthcare system (Mireles 2005).

More patients and families are being invited to participate as members of patient safety advisory committees at hospitals, such as the Toronto's Hospital for Sick Children's Families as Partners in Patient Safety. This group aims to raise awareness among health professionals about the role of parents in patient safety, empower family members to speak up and provide education to families about patient safety (Fleming-Carroll et al. 2006; Stevens et al. 2005). Regional health authorities also have patients and family members on patient safety advisory committees, including Calgary Health Region's Patient/Family Safety Council (Cuthbertson et al. 2007) and Winnipeg Regional Health Authority's Patient Advisory Council (Berry et al. 2005). Other similar committees or councils are in place across the country.

There are also public members, including patients and families, involved in various national organizations such as the Canadian Patient Safety Institute. Also, at a national level, patients and consumers are involved in Health Canada's consultations and advisory committees to discuss safety issues related to the Health Products and Food Branch, Office of Consumer and Public Involvement and National Pharmaceuticals Strategy.

Unless the current record of adverse events and the treatment of patients and families change, Canadians will not trust the healthcare system.

Conclusion

Important efforts are being made by Canadian patients and families through the PFPS initiative, but much work is still needed. Patients and families face challenges, the most critical being the need to convince more healthcare organizations and service providers to engage patients and families in every aspect of patient safety initiatives. These include health professional education, meetings, consultations, advisory committees, patient safety councils, research and knowledge transfer initiatives, disclosure guidelines and policies and patient safety policies. What is currently in place in these areas is not working, and transformation requires everyone's commitment. Unless the current record of adverse events and the treatment of patients and families change, Canadians will not trust the healthcare system and will choose to enter it only with a second medical opinion (Elder et al. 2005) and legal advice. This latter is not the best solution for anyone. Patients and families need and deserve to be part of the process, and not be perceived as liabilities!

In early 2005, the World Health Organization supported the role of patients, families and lay caregivers in identifying the gaps in the healthcare safety net that busy healthcare providers, administrators and decision-makers might unknowingly overlook. "Patients have much more to offer than visceral reminders to healthcare workers, administrators and policy makers that we are victims of tragic medical errors. Important as that perspective is, a victim orientation does not position us well as partners working with healthcare providers to prevent harm" (Sheridan et al. 2006: 6). As the rates of adverse events and patient harm continue to grow in Canadian healthcare settings, so will the patient safety movement. Patient safety is everyone's business! HQ

About the Author

Katharina Kovacs Burns, MSc, MHSA, PhD, is with the University of Alberta, Edmonton, Alberta. She is Associate Director, Health Sciences Council.

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