

# Improving Safety: Engaging With Patients and Families Makes a Difference!

Carol Kushner and Donna Davis

## Abstract

Following a brief review of the history and context for patient and family member involvement in healthcare safety improvements, a variety of tools and mechanisms for patient engagement will be offered along with specific examples from Patients for Patient Safety Canada (a patient-led program of the Canadian Patient Safety Institute) to illustrate the impact of involving patients and family members in safety work. Barriers and facilitators to patient engagement in safety will also be examined.

## History and Context

Patient safety became an issue of deep concern in Canada when the Baker–Norton Adverse Events Study (Baker et al. 2004) was released a few years after the Institute of Medicine's published *To Err Is Human*, which established that medical error was between the fourth and eighth leading cause of preventable death in the United States (Kohn et al. 1999). It has now been 10 years since the World Health Organization (WHO)<sup>1</sup> made patient safety a priority in October 2004 and called on the healthcare community to welcome patients and their family members as partners in creating a safer system. The WHO's Patients for Patient Safety (PFPS) program stream was created to support this initiative and the following year, invited a small group of 21 patients and family members who had experienced harm from healthcare to a meeting in London, England. This is where The London Declaration<sup>2</sup> was conceived, and it continues to be used to underpin the commitment and aspirations of PFPS Champions around the world as they work to make the system safer. To become a PFPS Champion, candidates must attend a WHO-approved patient safety workshop, must endorse The

London Declaration and must sign an agreement, signifying their willingness to work in collaboration with the health system and its providers. Today there are more than 300 WHO PFPS Champions<sup>3</sup> in more than 50 countries, including 43 in Canada, most of whom are also members of Patients for Patient Safety Canada (PFPSC), a patient-led program of the Canadian Patient Safety Institute (CPSI). The rationale for involving patients and family members in safety work is to recognize that the perspectives of patients and family members may often differ from those who work in the system and can be valuable in planning and implementing safety improvements that are truly patient- and family-centred.

## Strategies and Tools

Over the past decade, a great deal of work has been done to advance the involvement of patients and families in patient safety work both here in Canada and around the world. In the United States, for example, the Institute for Patient- and Family-Centered Care has developed a package of resources for health organizations wanting to advance patient engagement. This package includes a variety of specific strategies and tools tailored to specific healthcare settings including hospitals, primary care and other ambulatory settings.<sup>4</sup> These materials are available for free downloading and provide useful guidance for getting started and expanding and sustaining the work. Other helpful resources are available from the Institute for Healthcare Improvement (IHI), Planetree and the Joint Commission.<sup>5</sup>

In Canada, the CPSI has demonstrated a strong commitment to patient engagement since 2006 by providing staff support to help create and sustain PFPSC's volunteer network. CPSI also

involves PFPSC members in all of their safety initiatives. This includes the development of a national integrated patient safety strategy and the working groups established to develop action plans to advance four areas of clinical focus: medication safety, infection prevention and control, surgical safety and home care safety. Also, for the past three years, CPSI has begun each day of its virtual conference on quality and safety by featuring a patient safety story from a PFPSC member.<sup>6</sup>

PFPSC members sit on a variety of external bodies including, for example, the board of the International Society for Quality in Healthcare, and the advisory council of Accreditation Canada, and have worked as advisors to the Institute of Safe Medication Practices Canada and Canada Health Infoway. Provincial Ministries of Health have either created Patient Advisory Councils to provide input about provincial initiatives or asked PFPSC members to provide this feedback. PFPSC members have been consulted about the development of new PFPSC organizations in Malaysia, Ecuador, Ireland and Australia and are looking at ways to work together with the Canadian Family Advisory Network. PFPSC provided input to the revised Canadian Disclosure Guidelines<sup>7</sup> and to the Canadian Incident Analysis Framework<sup>8</sup> released by CPSI in 2011 and 2012, respectively, to reflect the perspectives of patients and family members. PFPSC has also developed or advised on other patient safety materials such as hand hygiene guides and patient-held medication lists, and has contributed to the development of instructional materials for students in the health professions, and helped to judge patient safety and quality competitions.

Since its inception, PFPSC members have also made hundreds of presentations to safety conferences and to provincial quality councils; addressed medical, nursing and pharmacy students; and participated in high-level roundtables, such as the recent patient safety summit hosted by the Royal College of Physicians and Surgeons, examining the implications of culture on safety and the curriculum changes needed to ensure safety competency for medical specialties.<sup>9</sup>

### **The Impact of Patient Engagement on Safety Improvements**

At the Royal College summit, mentioned above, one of the authors of this paper (CK) had the opportunity to ask Dr. Lucian Leape, arguably the grandfather of patient safety in the United States, what impact patient and family involvement has had on safety improvements. His response: “There is no evidence. [The impact] might be great, but we don’t really know.”

This lack of evidence may begin to change soon. PFPSC is currently being formally evaluated to assess the impact of the work of the members of PFPSC on the system’s safety. The network is also the subject of a PhD thesis currently being completed. Other groups with an interest in quality and safety have entered the arena, notably Patients Canada<sup>10</sup> (formerly the Patients Association of Canada) with a large membership and an active and highly experienced board, and a number of provincial patient organizations such as BC’s Patient Voices Network.<sup>11</sup>

However, without the validation of research, the evidence of impact can only come from two sources: anecdotes and testimonials. And so, from the former category, the following examples about PFPSC members are offered to illustrate how patient engagement can help change policy and procedure and affect standards and norms in practice.

The following six examples demonstrate some of the ways in which patients and family members have worked and are working to transform personal tragedy into positive change. Note that these examples do not offer very much detail about individual patient safety stories; however, links to videos of these are offered for those who wish to know more.

Sabina Robin, an experienced nurse, has worked in partnership with other patient safety advocates and the healthcare system to champion open disclosure, after a sequence of adverse events led to the death of her baby daughter, Mataya, in 2004. She pushed for the creation of an order set for idiopathic thrombocytopenic purpura (an unknown cause for decreased platelets, which can cause bleeding) to standardize the management of patients with this condition in Calgary hospitals. She has advocated strongly for the adoption of improved communication techniques and the need for patients and family members to receive sincere apologies from the providers directly involved in the incident when things go wrong. Sabina has also been instrumental in promoting the adoption of “Condition H (Help),” which enables family members to summon a rapid response team when they are unable to get the current team to recognize a deterioration that they have noticed in the patient <<http://www.patientsafetyinstitute.ca/English/news/PatientSafetyNews/Pages/Patient-Safety-Stories---Mataya%27s-Story.aspx>>.

Following the death of her daughter, Annie, Barbara Farlow has become a well-known advocate for ethics and equity in healthcare, including respect for parental decision-making, the importance of informed consent and treating people with disabilities humanely. Barbara is a popular conference speaker and has worked to sensitize students in the health professions to some of the unjust labels that can affect treatment plans in ways that cause harm to patients. She has also published on these topics in notable medical journals. She just completed her term as the Honorary Patient Advisor on the board of the International Society of Quality in Health Care <<http://www.gowebcasting.com/events/cpsi-virtual-forum/2013/10/29/patients-for-patient-safety-canada-video/play/stream/9289>>.

Tania Maron turned her dreadful experiences of healthcare’s abandonment during the induced stillbirth at 18 weeks’ gestation of her daughter, Sophia, into potent messages for improving the care provided to others in similar circumstances at her local hospital. Asking the hospital to become a model for others, she was welcomed to participate in developing the new policies now in place to ensure that pregnant women and their partners receive compassionate service and appropriate support in what can be a very difficult and wrenching experience. She also sits on the hospital’s Perinatal Bereavement Committee and is working to see that the changes inspired by her advocacy locally

will spread across the province and the country <<http://www.patientsafetyinstitute.ca/English/news/PatientSafetyNews/Pages/Patient-Safety-Stories---Sophia%27s-Story.aspx>>.

Johanna Trimble's mother-in-law experienced severe side effects to new medications prescribed after an admission to the hospital for flu-like symptoms and dehydration. Subsequently, she and the family advocated successfully for a "drug holiday" and her mother-in-law, who had been further diagnosed with dementia and depression, fully recovered her mental capacities. Unfortunately, she lost independence due to functional decline after being bed-ridden for months while in the facility. Johanna has been using this experience to educate and inform others about the widespread overuse of medications and the poster she designed titled: "Is your mom on drugs?" was awarded the top prize at the international "Selling Sickness" conference in Amsterdam in 2010. Since then she has been invited to speak at many provincial, national and international conferences and also to participate on the British Columbia Polypharmacy Initiative Steering Committee. Johanna is also on the Patient Safety Advisory Council for Vancouver Coastal Health Authority <<http://www.patientsafetyinstitute.ca/English/news/PatientSafetyNews/Pages/Fervid%E2%80%99s-legacy-of-care-lives-on-through-loved-ones.aspx>>.

Theresa Malloy-Miller's son Dan died unexpectedly after being admitted to the local hospital for persistent vomiting after a series of diagnostic, communication, equipment and medication errors. The hospital has made many changes in the wake of this event: they now have a standard protocol for children with abnormal blood values, and for fluid resuscitation, new blood pressure equipment, new protocols for RN-MD communications and new guidelines for sedation. Following Dan's death, the Director of Nursing at the hospital set up a patient safety conference and invited Theresa to make a presentation. Theresa sat on the planning committee for this annual conference and now serves on the hospital's Corporate Quality Council <<http://www.gowebcasting.com/events/cpsi-virtual-forum/2013/10/28/patients-for-patient-safety-canada-video/play/stream/8261>>.

Donna Davis, a nurse with 26 years' experience, was powerless to help her 19-year-old son as she watched him deteriorate and die from a head injury that, if treated appropriately, could have been prevented from turning into a tragic outcome. Dismissing her concerns, health professionals insisted he had a minor injury. That mindset and multisystem breakdowns at all levels contributed to his death: a classic "Swiss cheese" example of harm. As a direct result of hearing (6 years later) the family perspective of what occurred during this critical incident, three healthcare providers from the same region designed a patient alert system for their department where a stop sign is placed on the patient tracking system so that the patient is not transferred or discharged until the concern has been addressed. Anyone can place "Vance's Stop Sign" on the chart. The CPSI Patient Safety Global Alert site was inspired by the work Donna has

done in partnering with the healthcare community to share the lessons of patient safety incidents. Knowing first-hand how important honest, transparent and compassionate disclosure is following a patient safety incident, Donna was successful in bringing a stronger patient voice to the 2012 revision of the Canadian Disclosure Guidelines and the 2013 revised Canadian Incident Analysis Framework. Working as a patient advisor to the Saskatchewan Ministry of Health, Donna has been able to shape policies and development of programs with patient and family needs as the priority (<<http://www.patientsafetyinstitute.ca/English/news/PatientSafetyNews/Pages/Patient-Safety-Stories---Vance%27s-Story.aspx>>).

These are only six of many examples where PFPSC members have been able to use their passion for patient safety to partner for changes in the way the system provides care and services. The true value of this input will only increase as patient- and family-centred policies – doing with, rather than doing to, or doing for – become the new normal.

### **Barriers and Facilitators for Patient Engagement in HealthCare Safety**

There are a variety of reasons why the healthcare community hesitates to embrace patient and family input in their safety work. The most obvious is fear.<sup>12</sup> Fear of showing vulnerability; fear of exposing that providers do not have all the answers; fear that it will take more time; fear of losing control; fear of the unknown; fear that patients and families will derail the planned course; fear that their expectations will be unrealistic; and perhaps most of all, fear that patients and families will be disruptive rather than constructive. Organizations may also worry about time and budget constraints, the potential negative reaction of providers and whether patients and family members are sufficiently versed in health literacy and health system literacy.

Culture also plays a critical role. A recent text analysis (Buchan et al. 2014) of 10 PFPSC patient safety stories revealed two dominant themes implicating the culture of the organizations where the harm occurred: an inability of healthcare workers to listen to patients or families when they asked questions or raised concerns, e.g., "whatever I said it wasn't sinking in with anyone," and the stereotyping of patients and families to dismiss concerns raised, e.g., "seen as a mother struggling unsuccessfully to blame someone for her daughter's death." The authors conclude, "Although the editing of these stories reduces their authenticity, they did provide a rich source of information about the cultural norms surrounding adverse events." (Buchan et al. 2014)

It is fortunate that there are also strong internal and external motivators to encourage organizations to embrace patient and family engagement. External motivators include, among others, the desire to mimic others' success, legislation or regulations making patient and family engagement mandatory (as in Saskatchewan) and leadership from outside organizations, like CPSI in Canada and IHI in the United States. Internal motiva-

tors include a sentinel event, the business case for doing it, the desire to improve safety and quality, patient safety stories and altruism (Agency for Healthcare Research and Quality. 2012).

There are also facilitating factors at the organizational level (Agency for Healthcare Research and Quality. 2012), which include prior experience with and knowledge about working with patients and families; the existing organizational culture, especially one that embraces continual learning and evaluation and emphasizes accountability and responsibility in a non-punitive way; viewing errors as opportunities to correct systemic failures; and leadership from the board of directors, senior administrators and clinical staff.

In a summary prepared for the IHI, the authors offered this ringing endorsement of patient and family engagement (Reinertsen et al. 2008):

”We have observed that in a growing number of instances where truly stunning levels of improvement have been achieved, organizations have asked patients and families to be directly involved in the process. And those organizations’ leaders often cite this change – putting patients in a position of real power and influence, using their wisdom and experience to redesign and improve care systems – as being the single most powerful transformational change in their history. Clearly, this is a leverage point where a small change can make a huge difference.”

## Conclusion

No one has a greater interest in seeing improvements than those who have been harmed by the system. No one is in a better position to know when things just do not seem right. And when things go wrong, no one is more concerned than patients and families about making sure that what happened to them or their loved ones does not happen to others. As one of us (DD) said recently, “We cannot get back what has been lost, we cannot undo what has been done, but we can work together to make things better for others.”

Patients and family members are increasingly being seen as an important resource to caregivers, armed with unique knowledge about themselves and their loved ones. That knowledge needs to be tapped to make the best decisions about an individual’s care, but patients and families are also showing they can play a role in the broader arenas of helping to create safety tools and resources, planning and implementing safety improvements and in motivating and inspiring health workers to make “Every Patient Safe.” **HQ**

## Notes

1. [http://www.who.int/patientsafety/patients\\_for\\_patient/state-ment/en/](http://www.who.int/patientsafety/patients_for_patient/state-ment/en/) (accessed 9 March 2014).
2. Retrieved March 9, 2014. <[http://www.who.int/patient-safety/patients\\_for\\_patient/pfps\\_london\\_declaration\\_2010\\_en.pdf?ua=1](http://www.who.int/patient-safety/patients_for_patient/pfps_london_declaration_2010_en.pdf?ua=1)>

3. Retrieved March 9, 2014. <[http://www.patientsorganizations.org/attach.pl/576/1998/PFPS-Newsletter-Winter2013%20\(3\).pdf](http://www.patientsorganizations.org/attach.pl/576/1998/PFPS-Newsletter-Winter2013%20(3).pdf)>
4. Retrieved March 9, 2014. <<http://www.ipfcc.org/tools/downloads.html>>.
5. Available at: <[www.ihl.org](http://www.ihl.org) [www.jointcommission.org](http://www.jointcommission.org) and [www.planetree.com](http://www.planetree.com)>
6. Retrieved March 9, 2014. <<http://www.patientsafetyinstitute.ca/english/news/pages/ask-listen-talk.aspx>>. For a complete set of videos of PFPSC’ members’ patient safety stories click here: retrieved March 9, 2014. <<http://www.patientsforpatientsafety.ca/English/Resources/Pages/Member-Videos-and-Stories.aspx>>
7. Available at: <http://www.patientsafetyinstitute.ca/English/toolsResources/disclosure/Pages/default.aspx>
8. Available at: <http://www.patientsafetyinstitute.ca/English/toolsResources/IncidentAnalysis/Pages/default.aspx>
9. Royal College of Physicians and Surgeons of Canada, Transitioning to safe care: Culture meets Competence, March 3-4, 2014
10. Retrieved March 9, 2014. <<http://www.patientscanada.ca/>>
11. Retrieved March 9, 2014. <<https://www.patientvoices.ca/>>
12. Retrieved <http://www.psqh.com/marchapril-2010/454-patient-engagement-in-patient-safety-barriers-and-facilitators.html> (accessed 9 March 2014).

## Reference

- Agency for Healthcare Research and Quality. 2012. *Methods (continued, 2): Guide to Patient and Family Engagement: Environmental Scan Report*. Agency for Healthcare Research and Quality, Rockville, MD. Retrieved March 10, 2014. <<http://www.ahrq.gov/research/findings/final-reports/ptfamilyscan/ptfamily3a.html>>
- Baker, G.R., P.G. Norton, V. Flintoft, R. Blais, A. Brown, J. Cox et al. (2004). “The Canadian Adverse Events Study: The Incidence of Adverse Events Among Hospital Patients in Canada” *Canadian Medical Association Journal*, 170(11): 1678–86.
- Buchan, V., M. Fleming and A. Bishop. 2014. “Unheard Voices: Patient and Family Stories of Adverse Events Provide Insight into Patient Safety Culture”, from Dr. Fleming’s oral presentation at the Royal Society of Physicians and Surgeons, Ottawa, March 4, 2014.
- Kohn, L.T., J.M. Corrigan and M. Donaldson, eds. 1999. *To Err Is Human: Building a Safer Health System*. Washington, DC: National Academy of Sciences.
- Reinertsen, J., M. Bisgnano and M. Pugh. 2008. *Seven Leadership Leverage Points for Organization-Level Improvement in Health Care* (2nd ed.). Cambridge, MA: Institute for Healthcare Improvement.

## About the Authors;

**Carol Kushner** and **Donna Davis** are co-chairs of Patients For Patient Safety Canada, a patient-lead program of the Canadian Patient Safety Institute.