Trillium Health Centre's Journey to Disclosure

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Introduction

Disclosure has been defined in the Canadian Safety Patient Dictionary (Davies et al. 2003: 55) as "the imparting, by healthcare workers to patients or their significant others, of information pertaining to any health-care event affecting (or liable to affect) the patient's interests. The obligation to disclose is proportional to the degree of actual harm to the patient (or the realistic threat of such) arising from an untoward event." There has been increasing evidence to confirm that patients and their families (89–98%) and healthcare professionals (60–77%) believe that adverse events should be disclosed to patients (Blendon et al. 2002; Gallagher 2003; Hingorani et al. 1999; Witman et al. 1996). Organizations that have adopted disclosure policies have found that an honest apology, explanation of what happened and doing something to prevent future occurrences are important elements of an effective risk-management program (Hamm and Kraman 2001).

A study conducted in 2003 found that, in Canada, less than 50% of organizations have disclosure policies compared to 88% in the US and 74% in the UK (Blendon et al. 2004). It would appear that in those jurisdictions where disclosure policies are mandatory their existence is much greater. To date, the legal requirement for disclosure in Canada has been limited to a few provinces, including Quebec (National Assembly 2002). Some provincial Colleges of Physicians do have policy statements, including Saskatchewan, Manitoba and Ontario (College of Physicians and Surgeons of Ontario 2003; College of Physicians and Surgeons of Saskatchewan 2002; College of Physicians and Surgeons of Manitoba 2003). Beginning in 2006, organizations accredited by the Canadian Council on Health Services Accreditation will be required to have a disclosure policy (CCHSA 2004).

In 2003, as part of Trillium Health Centre's focus on developing an Enterprise-Wide Values-Based approach to risk management, including a strategic focus on patient safety, development and implementation of a disclosure protocol were identified as important. Further, it was noted that a comprehensive approach to incident reporting and management must include not only incident reporting and follow-up but also disclosure to patients and support for team members involved in incidents (second victims).

Background

Over the past 10 years, the issue of disclosure has become a significant topic of discussion in the literature. While this article will not provide a thorough review of the literature, it will draw linkages to relevant literature and resources, which were integral to the development and implementation of work at Trillium.

Prior to focussing on Trillium's journey, it is important, however, to focus on some of the well-documented advantages of an effective disclosure process and those beliefs and practices that may hinder an effective disclosure process, as these set the

context for some of the lessons learned identified later in this article.

Some of the advantages of an effective disclosure process include that disclosure allows the patient to obtain timely and appropriate treatment (Wu et al. 1997), may reduce litigation and liability costs (Boothman et al. 2001; Kraman and Hamm 1999; Vincent et al. 1994), maintains the physician's commitment to the fiduciary and trustful nature of the doctor-patient relationship (Hebert et al. 1997; Hebert et al. 2001; Wu et al. 1997), act as a driver for establishing investigation and follow-up processes (Australian Council for Safety and Quality in Health Care 2002) and may minimize the emotional distress of both patient, physician and the healthcare team (Wu et al. 1997).

Beliefs and practices that may hinder an effective disclosure process include fear of litigation, fear of reputation damage, a culture of infallibility among health professionals, confusion between providing an explanation of the facts and admitting liability (which may be the right and only thing to do in some situations), the limited support for health professions to discuss adverse events amongst colleagues and finally variation in communication skills amongst health professionals (Australian Council for Safety and Quality in Health Care 2002; Wu et al. 1997).

Increasingly, it is recognized that in the absence of disclosure, patients may turn to the legal process not only for financial compensation but to obtain an apology, explanation of what happened, and reassurance that others will not have the same experience (Australian Council for Safety and Quality in Health Care 2002; O'Connell and Keller 1999; Vincent et al. 1994)

Developing the Protocol: A Concurrent Process of Consultation, Awareness and Skill Building

The development of Trillium's disclosure protocol was a process deliberately undertaken over a lengthy period. This supported extensive consultation and ongoing dialogue with internal and external stakeholders regarding the protocol's content and the process for its implementation. At the outset, there was some interest in the direction coupled with hesitation primarily related to perceived barriers, which would prevent, in particular, physicians from participating in this process. Early recognition of these realities led to a thoughtful process of consultation and engagement, which continues today.

Early steps in developing the protocol included review of the literature related to disclosure and review of policies and position statements from other healthcare organizations and from professional colleges, insurers and malpractice carriers. It became clear that disclosure was a process that was well-supported.

The first draft of the protocol was generated in June 2003. As part of Trillium's National Healthcare Risk Management Week celebrations in June 2003, a series of focus groups with staff, physicians and volunteers who had been patients were conducted to elicit feedback about the protocol. Particular emphases of the focus groups were: What to call the process of open, frank conversation with patients? Which types of incidents should be disclosed to patients? Who should disclose to patients? A list of the focus group questions is provided in **Table 1**.

Table 1. Focus group questions related to disclosure process

Please provide some examples of incidents/adverse events.
Which incidents/adverse events should be disclosed to patients/families? • Incidents/adverse events that have resulted in injury or harm? • Incidents/adverse events that may result in injury or harm in the future, but extent may not be evident at the time of the event? • Incidents/adverse events that will not result in injury or harm?
When an incident/adverse event occurs, who should disclose this to the patient/family?
What supports do you need to effectively disclose?
How do we best learn from incidents/adverse events?
What terminology is most appropriate for use in our organization?

One of the most challenging elements of the protocol development was clearly defining what should be disclosed to patients. Dialogue with the Health Centre's ethicist resulted in some clarity regarding disclosure of near misses and assisted in generating some criteria to help determine when a near miss should be disclosed to the patient.

A year into the process, the Quality Healthcare Network launched two collaborative projects, one of which was called "Dialogue on Disclosure." The collaborative project was intended to bring member organizations together to learn from and share with each other along their disclosure journey. While the progress of the 22 healthcare organizations was varied, it proved to be a reflective opportunity for Trillium who had its policy well underway. The most substantial component of this project for Trillium Health Centre was the educational teleconferences, which brought opinion leaders and policy-makers together with industry leaders and experts on this topic to share their perspectives on disclosure. Members were encouraged to post their policies, as work in progress, in the spirit of learning together.

In March 2004, a draft policy was shared widely with key

internal stakeholders including the Medical Advisory Council, Leadership Executive Team, Patient Services Leadership Team and the Professional Advisory Council. While the Medical Advisory Council members were compelled by the ethical and fiduciary obligations for disclosure (Wu et al. 1997), despite transparent sharing of the College of Physicians and Surgeons of Ontario's Disclosure of Harm Policy (2003) and the Canadian Medical Protective Association's (CMPA) position statement on Disclosure of Adverse Events (Beilby 2001), many members continued to question the position of their malpractice carrier in particular. In recognition of this ongoing barrier, strategies to overcome this challenge were explored. With the assistance and support of the then Deputy Chief of Staff, a relationship was initiated with the CMPA. After some discussion, it was agreed that further educational sessions, as described in the next section, would be provided and that representatives of CMPA and their legal counsel would be invited to attend. In fact, in November 2004, the CMPA representatives were asked to play an active role by providing some introductory comments related to the CMPA's position prior to the trainer focussing on the workshop content. It was through this deliberate acknowledgement of the concerns and questions that the medical leadership began to embrace disclosure as not only the right thing to do, but also something that they were allowed and would be supported in doing.

Developing Knowledge and Skills

As part of the focus groups in 2003, it became clear that while healthcare providers wanted to engage in open and frank communication with patients and families regarding unanticipated clinical care or outcomes, many of them expressed a need for support in how to have these conversations. Others requested help with training materials and access to coaching support at the time of an incident.

As a result of these requests, it was decided that Trillium would benefit from the identification of a training program to support all those who may need to have disclosure conversations with patients and their families. A Patient Services Manager shared information about a training program, which she felt would be well-suited to Trillium. More details were obtained and references checked, resulting in a decision to develop internal expertise to deliver disclosure training through a train-the-trainer model (Bayer Institute for Health Care Communication 2004).

Recruitment of four trainers was undertaken with a particular emphasis on finding a physician trainer. Four trainers were identified, specifically an organizational development specialist, two social workers and the Director, Patient Safety. In partnership with another local healthcare organization, a two-day train-the-trainer workshop was launched in November 2003. In addition to training four workshop facilitators, 11 representatives were invited from the organization to experience the workshop. Careful consideration was given to identifying representatives from throughout the Health Centre in an effort to build interest and enthusiasm across clinical programs and disciplines. Two physicians attended this initial workshop and were enthusiastic about its content but expressed some hesitation about engaging physicians in a three-and-a-half-hour workshop on an ongoing basis.

Three of the trainers continued to develop their skill in delivering the workshop and hosted four three-and-a-half-hour workshops in April and May 2004 for the entire multidisciplinary team of the Birthing Suite. This team was already involved in the MOREOB™ Program (Managing Obstetrical Risk Efficiently), a risk-management program focussed on core clinical content, skill and emergency drills, and reporting and investigating adverse events. Coupling their commitment and enthusiasm for multidisciplinary learning with an opportunity to further broaden their risk-management skills created an ideal pilot environment.

Numerous workshops have been held since late 2003 with over 250 physicians and staff attending in total. The author has noted in her role as a workshop trainer that the most significant contribution and outcome for participants is the recognition of their previous tendency to control conversations with patients and families by telling them what they thought they needed and wanted to know. The workshop provides participants with an opportunity to understand and practice a non-defensive, empathetic listening approach that provides the patient or family the opportunity to guide the pace and content of the conversation.

In addition to the workshops, throughout the past few years, a collection of training videos and materials has been compiled and used for lunch'n learn sessions to continue building interest in disclosure and generate dialogue amongst professionals (American Society for Healthcare Risk Management 2001; Buckman 2004; National Patient Safety Foundation 2002; Partnership for Patient Safety 2004).

Trillium's Protocol

After reviewing the literature and engaging in dialogue through focus groups, it was decided that Trillium's disclosure protocol would be called "Communication of Unanticipated Clinical Care or Outcome" to draw on the therapeutic relationship between healthcare providers and their patients (ASHRM 2001; ASHRM May 2003). The use of the term communication recognizes the opportunity to move to more open and shared dialogue and decision-making between providers and patients. This increased involvement of the patient in all aspects of her care is an important element of a culture of safety. This process further recognizes that disclosure is a component of the informed consent process (ASHRM Nov 2003), which is

more than consent to a single procedure rather, involvement of the patient in daily decisions affect the overall treatment plan by creating an open forum for raising questions and concerns. Trillium's protocol states: "Communication begins when the relationship is first established and may involve discussion of proposed assessments, diagnosis, proposed treatment plans, their benefits and potential risks. The sharing of information about the care process and/or outcome is a natural extension of this relationship (Trillium Health Centre 2005)." It was felt that the term disclosure sounded like an event, whereas communication recognized that the conversation was ongoing.

Table 2. Criteria for considering whether to communicate a near miss

Board and leadership strategic focus and commitment to risk management and patient safety are of key importance.
Physician leadership and champions can have a profound effect on physician interest and adoption.
CPSO policy and CMPA position statement are useful drivers. Misconceptions regarding CMPA position, in particular that physicians would not be supported in disclosure, need to be formally addressed.
CCHSA patient safety goals and required organizational practices create further supportive rationale for creating and implementing a disclosure policy.
Patience allows for thorough consultation, response to concerns and fears and identification of mitigation strategies.
Guidance through consultation enhances the organization's support of the policy adoption.
Concurrent protocol development, training and implementation can be very effective.
Training programs and materials are imperative to support the learner.
Careful selection of early workshop attendees can be helpful in generating interest for future workshop attendance.
Ongoing challenge exists in recruiting a physician trainer(s) in a community hospital setting.
Shared learning through a collaborative project can validate and question your assumptions regarding implementation of an effective disclosure policy.
Disclosure requires a different communication style, in particular moving from professionals telling patients what happened to non-defensive empathetic listening.
Variations amongst professionals in identifying that an event is an incident leads to variation in initiating the disclosure process.
Further formalization of processes to access coaching and support would be beneficial.

Using the same information sources, it was determined that in most circumstances the most responsible physician would be expected to communicate with the patient/family regarding unanticipated care or outcomes (ASHRM November 2003, February 2004). Again, this was built on the philosophy of the provider-patient relationship. In the event of an incident, which does not involve medical care, the Manager or Director would take the lead in communicating with the patient/family ensuring that the patient's most responsible physician is aware of the incident and provided with an opportunity to participate in the discussion. In all circumstances where there has been a high-risk incident (sentinel event), at least two people will meet with the patient/family. In addition to defining who should be involved in the communication process with a patient/family, the protocol does clearly identify that the Director, Patient Safety is available for consultation and support to assist individuals and teams prepare for conversations with patients and families.

The protocol focuses on communicating those incidents where unanticipated clinical care or outcomes did result in harm, injury or upset to the patient/family. Criteria are provided to assist with the determination of whether or not to talk with the patient/family regarding a near-miss, "a type of incident, which does not result in harm, loss or damage, but has the potential to do so" (Trillium Health Centre 2003) as summarized in **Table 2**.

The protocol also provides direction on when the communication should occur, how to prepare for a meeting with the patient/family and what should be documented following the meeting.

Implementing the Protocol

Trillium's protocol for Communication of Unanticipated Clinical Care or Outcome was formally approved in March 2005. It is evident from the previous discussion that implementation of the protocol began in June 2003 and that there has been a concurrent process of development and implementation over the past two years. On reflection, there have been a number of lessons learned along this journey as captured in **Table 3**.

Table 3. Lessons learned

The patient is or may become aware of the near miss.
There is something documented in the health record.
A treatment or follow-up plan needs to be initiated as a result of the near miss.
There is potential future health risk associated with the near miss.
The potential benefit of open communication outweighs the potential harm for the patient/family/substitute decision-maker.

Early Evidence of Success

Some stories suggest that opportunities to communicate with patients about unanticipated clinical care and outcomes are increasingly being embraced at Trillium, including:

- telephone calls from healthcare professionals to the Director, Patient Safety the day after attending a workshop to discuss specific patients and incidents;
- an invitation to a family to return to the hospital so that the healthcare team could discuss an incident that may have hastened the death of their loved ones;
- timely meetings with patients and families to apologize in person, discuss what happened and share strategies to prevent the same incident from occurring in the future.

Efforts have been made by Trillium's team of trainers to design an evaluation process for this work. To date, a system for capturing evidence of effective disclosure has been challenging to develop. It is hoped that a more formal system of evaluation will evolve over the next year.

Next Steps

The journey to disclosure at Trillium has progressed and matured over the past two years. A substantial focus for 2005/06 will be the continued implementation of the protocol by providing interactive workshops and rounds to further develop healthcare providers' communication skills. Continued efforts to recruit at least one physician to join the team of trainers will be a priority recognizing the credibility and support that participants have experienced in the presence of a physician trainer. While the protocol clearly identifies that consultation and support are available from the Director, Patient Safety, to date, that assistance has been engaged to a limited extent. As open and frank communication with Trillium's patients and families becomes the norm, additional supportive processes for those participating in these conversations may need to be developed. Finally, but most importantly, there remains some hesitation and misconception regarding disclosure and admission of liability. It will be imperative that we begin to tell stories of the comprehensive approach to reporting and following-up incidents, including the communication with patients/families, support provided to members of the Trillium team and the learning and improvement arising from Trillium's reflective learning approach based on root cause analysis. This will enable Trillium to demonstrate the positive relationships arising from open communication and its impact on both patients and healthcare professionals.

References

American Society for Healthcare Risk Management. 2001, April. Perspective on Disclosure of Unanticipated Outcome Information. Chicago, IL: Author. Retrieved July 11, 2005. <http://www.hospitalconnect.com/ashrm/resources/files/Disclosure.2001.pdf>.

American Society for Healthcare Risk Management. 2001. Disclosure of Medical Errors: Demonstrated Strategy to Enhance Communication (video). Chicago, IL: Author. Available from <http://www.ahaonlinestore.com>.

American Society for Healthcare Risk Management. 2003, May. Disclosure of Unanticipated Events: The Next Step in Better Communication with Patients. Chicago, IL: Author. Retrieved July 11, 2005. <http://www.ashrm.org/ashrm/resources/files/Disclosure.Pt1.pdf>.

American Society for Healthcare Risk Management. 2003, November. Disclosure of Unanticipated Events: Creating an Effective Patient Communication policy. Chicago, IL: Author. Retrieved July 11, 2005. <http://www.hospitalconnect.com/ashrm/resources/files/DisclosurePart2.Policy.pdf>.

American Society for Healthcare Risk Management. 2004, February. Disclosure: What Works now & What Can Work Even Better. Chicago, IL: Author. Retrieved July 11, 2005. <http://www.hospitalconnect.com/ashrm/resources/files/Disclosure.Part3.0204.pdf>.

Australian Council for Safety and Quality in Health Care. 2002. When Things Go Wrong: An Open Approach to Adverse Events. Retrieved July 10, 2005. <http://www.nsh.nsw.gov.au/teachresearch/cpiu/CPIUwebdocs/Issues_paper.pdf>.

Bayer Institute for Health Care Communication. 2004. Disclosing Unanticipated Outcomes and Medical Error. West Haven, CT: Author. Workshop information and materials available from <http://www.bayerinstitute.org>.

Beilby, W. 2001, October. Disclosing Adverse Clinical Outcomes. Canadian Medical Protective Association.

Blendon, R.J., C. Schoen, C.M. DesRoches, R. Osborn, K. Zapert and E. Raleigh. 2004. "Confronting Competing Demands to Improve Quality: A Five-Country Hospital Survey." *Health Affairs* 23(3): 119–35.

Blendon, R.J., C.M. DesRoches, P.H.M. Brodie, J.M. Benson, A.B. Rosen, E. Schneider, D.E. Altman, K. Zapert, M.J. Herrmann and A.E. Steffenson. 2002. "Views of Practicing Physicians and the Public on Medical Errors." *N Engl J Med* 347(24): 1933–40.

Boothman, Hamm and Kraman 2001, Kraman and Hamm 1999, Vincent et al. 1994. Excited Actuaries at University of Michigan Hospital System. Retrieved July 18, 2005. <http://www.sorryworks.net/media22.phtml>.

Buckman, R. 2004. How to Deal with Anger and Other Emotions in Adverse Event and Error Disclosure. Available from <http://www.cinemedic.com/products/>.

Canadian Council on Health Services Accreditation (CCHSA). 2004, December. "CCHSA Patient Safety Goals and Required Organizational Practices." Communiqué #2. Retrieved July 10, 2005. <http://www.cchsa.ca/pdf/PSCommunique2.pdf>.

College of Physicians and Surgeons of Manitoba. 2003. Physician Disclosure of Harm that Occurs in the Course of Patient Care. Retrieved July 11, 2005. <http://www.cpsm.mb.ca/about/bylaws_guidelines/statements/Ethics/Statement169>.

College of Physicians and Surgeons of Ontario. Disclosure of Harm Policy. 2003. Retrieved July 10, 2005. <http://www.cpso.on.ca/Policies/disclosure.htm>.

College of Physicians and Surgeons of Saskatchewan. 2002. D*isclosure of Adverse Events and Treatments.*

Davies, J.M., P. Hebert and C. Hoffman. 2003. *The Canadian Patient* Safety Dictionary. Retrieved July 11, 2005.<http://www.crha-health.ab.ca/qihi/patient_safety_dictionary.pdf>.

Gallagher, T.H., A.D. Waterman, A.G. Ebers, V.J. Fraser and W. Levinson. 2003. "Patients' and Physicians' Attitudes Regarding the Disclosure of Medical Errors." *JAMA* 289(8): 1001–07.

Hamm, G.M. and S.S. Kraman. 2001. "New Standards, New Dilemmas – Reflections on Managing Medical Mistakes." *Bioethics Forum* 17(2): 19–25.

Hebert, P.C., B. Hoffmaster, K.C. Glass and P.A. Singer. 1997. "Bioethics for Clinicians: 7. Truth Telling." *Canadian Medical Association Journal* 156(2): 225–28.

Hebert, P.C., V.L. Levin and G. Robertson. 2001. "Bioethics for Clinicians: 23. Disclosure of Medical Error." *Canadian Medical Association Journal* 164(4): 509–13.

Hingorani, H., T. Wong and G. Validis. 1999. "Patients' and Doctors' Attitudes to Amount of Information Given After Unintended Injury During Treatment: Cross Sectional, Questionnaire Survey." *BMJ* 318(7184): 640–41.

Kraman, S.S. and G. Hamm. 1999. "Risk Management: Extreme Honesty May Be the Best Policy." *Annals of Internal Medicine* 131(12): 963–67.

National Assembly. 2002. Bill 113: An Act to amend the Act respecting health services and social services as regards to the safe provision of health services and social services, *L.Q.* c.71

National Patient Safety Foundation. 2002. *Let's Talk: Disclosure After an Adverse Medical Event.* Available from www.npsf.org.

O'Connell, D. and V.F. Keller. 1999. "Communication: A Risk Management Tool." *JCOM* 6(1): 35–38.

Partnership for Patient Safety. 2004. First, Do No Harm Part 3: Healing Lives, Changing Cultures. Available from <http://www.p4ps.org>.

Trillium Health Centre. 2003, November. *Incident Reporting and Handling Protocol.*

Trillium Health Centre. 2005, March. *Communication of Unanticipated Clinical Care or Outcome Protocol.*

Vincent, C., M. Young and A. Phillips. 1994. "Why Do People Sue Doctors? A Study of Patients and Relatives Taking Legal Action." *Lancet* 343(8913): 1609–13.

Witman, A.B., D.M. Park and S.B. Hardin. 1996. "How Do Patients Want Physicians to Handle Mistakes? A Survey of Internal Medicine Patients in an Academic Setting." *Archives of Internal Medicine* 156(22): 2565–69.

Wu, A.W., T. Cavanaugh, S. McPhee, B. Lo and G. Micco. 1997. "To Tell the Truth: Ethical and Practical Issues in Disclosing Medical Mistakes to Patients." *Journal of General Internal Medicine* 12(12): 770–75.

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