

Patients and families as safety experts

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See related research article by Daniels and colleagues at www.cmaj.ca/lookup/doi/10.1503/cmaj.110393

Patient safety is addressed and discussed from many perspectives. Lessons are sought from all manner of industries and experts, from the disciplines of psychology, ergonomics, engineering and others. Yet the one source of experience and expertise that remains largely ignored is that of the patient.¹ In their study of reporting of adverse events, Daniels and colleagues² show that parents of children undergoing care in hospital can provide timely and important information about the safety of care that complements information recorded in staff reporting systems. Information from families revealed many harmful and potentially harmful events that would have otherwise remained undetected.

Patients can contribute to their own care at every stage of the care pathway (Box 1).³ Patients also carry out a great deal of “invisible work”⁴ to compensate for the failures and inefficiencies of the health care system. For instance, patients frequently provide repeat histories when notes are missing, relay information between clinicians, remind nurses of tests that should be done and chase down test results. Patients can also play an important role in reporting medical errors or adverse events that occur in their care.

Box 1: Opportunities for patients to contribute to their own safety*

- Choosing a treatment provider
- Helping to reach an accurate diagnosis
- Sharing decisions about treatments and procedures with physicians
- Contributing to medication safety
- Participating in infection control initiatives
- Checking the accuracy of medical records
- Observing and checking care processes
- Identifying and reporting treatment complications and adverse events
- Practising effective self-management strategies
- Shaping the design and improvement of services

*Based, in part, on Coulter and Ellins.³

Patients are privileged witnesses of health care in the sense that they are at the centre of the treatment process, and, unlike individual clinical staff, they observe almost the whole process of care. Patients may not understand all of the technical and clinical issues at stake, but they do observe inconsistencies in care, errors and harms that befall themselves and others.⁵ In the case of people with chronic illnesses, they become experts not only on their own disease but on the frailties and limitations of the health care system.

Previous studies of adult care have shown that patients can provide important safety information. In particular, two carefully conducted interview studies established that adult patients can report important details about errors and adverse events.^{6,7} In the first of these two studies, patients identified a host of process failures, such as problems with diagnosis, medication, procedures, clinical services and service quality, during simple five-minute interviews. In a later study,⁷ Weissman and coauthors interviewed 998 recently discharged patients, comparing their reports with standard reviews of medical records to detect adverse events. The record reviews showed that 11% of patients had suffered an adverse event. However, 23% of the patients reported an adverse event that was later validated by medical review, and there was little concordance between the events detected by the two methods. The inclusion of patient reports therefore tripled the rate of detecting adverse events. Weissman and coauthors suggested that neither record reviews nor patient reports represent a gold standard, but that both are necessary to obtain a reasonably complete picture of the harm from health care.

KEY POINTS

- Patients can provide timely and important information about the safety of care.
- When questioned, patients report safety incidents that would otherwise go undetected.
- Patients are highly motivated to report errors or problems in their care.
- Efforts need to focus on integrating patient reports into safety monitoring systems.

Competing interests:

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Daniels and colleagues have extended our understanding by showing that reports from families of pediatric patients can also play an important role in improving patient safety. As in previous studies, the family reports in this study frequently shed light on incidents not reported by staff and had no effect on the rate of staff reporting. Furthermore, the authors found that most families were highly motivated to report safety concerns and that the majority (62%) were willing to volunteer their time to help prevent the recurrence of the adverse events that had affected their children. The willingness of families to report contrasts with the well-known difficulty of getting health care staff, particularly doctors, to report safety issues.^{8,9} Used effectively, reports by patients and their families could be an extremely sensitive and productive form of safety information.

Establishing a proper and fruitful role for patients to play in their own safety is not straightforward, and many issues remain to be resolved. Asking patients to challenge staff, on hand-washing for instance, is contentious and arguably represents an abdication of responsibility by staff.¹⁰ The reporting of safety information, however, is willingly undertaken by many patients and is an appropriate role precisely because it draws on patients' unique perspective and expertise. Unlike other methods for estimating the rate of adverse events (such as record reviews), patients can provide real-time information about patient safety, capturing incidents that reflect actual or potential risks of adverse events and helping to mitigate the effects of these occurrences.⁴ Paying close attention to patients' and families' experience of care and their reports

of safety issues may be the best early warning system we have for detecting the point at which poor care deteriorates into care that is clearly dangerous. Future studies should examine the potential for integrating such information into safety monitoring systems and assessing the long-term effects of engaging patients and families in reporting.

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