



# Time to listen: a review of methods to solicit patient reports of adverse events

A King,<sup>1</sup> J Daniels,<sup>1</sup> J Lim,<sup>1</sup> D D Cochrane,<sup>2</sup> A Taylor,<sup>3</sup> J M Ansermino<sup>1</sup>

<sup>1</sup>Department of Anesthesiology, Pharmacology & Therapeutics, University of British Columbia, Vancouver, British Columbia, Canada

<sup>2</sup>Division of Neurosurgery, Department of Surgery, British Columbia Children's Hospital, Vancouver, Canada

<sup>3</sup>British Columbia Patient Safety and Learning System, Provincial Services Health Authority, Vancouver, British Columbia, Canada

## Correspondence to

J Mark Ansermino, Department of Anesthesia, British Columbia Children's Hospital, 4480 Oak Street, Vancouver, British Columbia, Canada V6H 3V4; anserminos@yahoo.ca

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## ABSTRACT

**Background** Patients have been shown to report accurate observations of medical errors and adverse events. Various methods of introducing patient reporting into patient safety systems have been published with little consensus among researchers on the most effective method. Terminology for use in patient safety reporting has yet to be standardised.

**Methods** Two databases, PubMed and MEDLINE, were searched for literature on patient reporting of medical errors and adverse events. Comparisons were performed to identify the optimal method for eliciting patient initiated events.

**Results** Seventeen journal publications were reviewed by patient population, type of healthcare setting, contact method, reporting method, duration, terminology and reported response rate.

**Conclusion** Few patient reporting studies have been published, and those identified in this review covered a wide range of methods in diverse settings. Definitive comparisons and conclusions are not possible. Patient reporting has been shown to be reliable. Higher incident rates were observed when open-ended questions were used and when respondents were asked about personal experiences in hospital and primary care. Future patient reporting systems will need a balance of closed-ended questions for cause analysis and classification, and open-ended narratives to allow for patient's limited understanding of terminology. Establishing the method of reporting that is most efficient in collecting reliable reports and standardising terminology for patient use should be the focus of future research.

ture review attempts to identify the state of the art in patient reporting systems used in research studies and reviews the healthcare setting populations, contact methods, verification, reporting methods, incentives, incident rates and terminology used for patient reports of adverse events. Successful approaches used in research studies may have wider application to general hospital or outpatient clinic operations, particularly in quality and safety improvement initiatives, providing they can be made acceptable to users.<sup>4 5</sup>

## METHODS

A search for relevant literature was carried out using the MEDLINE OvidSP (1950 to present) and PubMed (1949 to present) databases between January and April 2008. These searches were conducted with a combination of keywords relating to patient safety and patient reporting. We searched Pubmed for the terms Patient (MeSH term) survey ("data collection" (MeSH term)) AND medical events; Patient (MeSH term) perception (MeSH term) AND adverse events; patient (MeSH term) perception (MeSH term) AND "medical error" (MeSH term); Patient (MeSH term) survey ("data collection" (MeSH term)) and quality improvement; Patient (MeSH term) reported AND medical errors (MeSH term); "Patient survey" AND 'safety'. In addition, we searched MEDLINE for the terms Safety (MeSH term) AND adverse event reporting; patient (MeSH term) reported AND medical error (MeSH term) or undesirable events; Patient (MeSH term) reports AND safety (MeSH term) AND adverse events; Error reporting patients (MeSH term). The searches were limited to publications in English. Searches returning >200 papers were further filtered by additional keywords. Reference lists were used to locate additional papers.

After the search was conducted (see figure 1 for search strategy), the abstracts of the resulting publications were examined to determine their applicability. Relevant publications were defined to be those that collected reports from patients about medical errors or adverse events experienced in healthcare. Titles and abstracts were reviewed by one of the authors. Two other further authors independently confirmed the eligibility with full manuscript review. Reports of malpractice litigation and closed claims studies were excluded. All other discovered forms of safety or quality defect reporting from patients, such as spontaneous complaints, satisfaction surveys, research studies and systems designed for patient input were within the scope of the review. Papers meeting these inclusion criteria were further evaluated based on

Adverse events represent a significant challenge in effective healthcare provision worldwide. An adverse event is defined as an injury resulting from medical management rather than from an underlying illness.<sup>1</sup> Accurate identification and reporting of adverse events is needed to enable learning and prevent recurrence.

Traditional adverse event reporting systems rely on the healthcare provider to report events. The World Health Organization has developed guidelines and terminology for use in healthcare provider reporting systems.<sup>2</sup> However, it is patients who are most affected by adverse events. Involving the patient in reporting provides a direct benefit to those affected and captures details of events not available through other reporting techniques.<sup>3</sup> As patient reporting is a relatively new addition to patient safety reporting systems, the techniques that are most successful and efficient are not yet known. Standardised guidelines on methods and terminology have yet to be developed. This litera-

healthcare setting population, contact method, incentives for report completion, reporting methods, reporting terminology, methods for corroborating patient reports and reporting types and rates.

## RESULTS

Ninety combination keyword database searches identified 11 relevant publications, two of which used the same data sets, and two papers were located from reference lists (see figure 1). Of the publications that were rejected after screening, three were found to be focused on the patient's perception of medical errors, two detailed quality of care issues and one pertained to error prevention involving patients. Four additional papers were suggested by colleagues, bringing the total to 17.

### Healthcare setting

The healthcare settings surveyed in these papers varied widely. Five papers asked patients about mistakes encountered involving any aspect of healthcare, including emergency and ambulatory care, and six papers asked about errors during hospitalisation. Four papers focused on errors in primary healthcare, and an additional paper's scope included both primary and specialty care. The remaining study surveyed oncology patients in a teaching hospital.

### Solicitation and study duration

Study participants were either involved via self-initiated interest or actively solicited. Eleven papers (65%) elicited patient reports, whereas the remaining five used self-initiated reporting surveys.<sup>3 6–21</sup> On average, more reports were collected from solicited patients than self-initiated participants. The shortest time period of study was 5 days, whereas the longest was 2 years.<sup>12 16</sup> Approximately a third (35%) of the studies collected reports over periods ranging from 2 to 4 months.<sup>3 6 7 10 11 14</sup>

### Incentives

Two studies used incentives to encourage reporting.<sup>8 16</sup> A recruitment technique involving random telephone number dialing and offering a \$50 payment for an in-person interview yielded one study participant per 10 to 20 calls. Thirty-eight usable interviews resulted from this recruitment method.<sup>8</sup> The study with the largest number of patient responses used an online survey with customised health and self-management resources as an incentive for participation.<sup>16</sup>

### Reporting methods and response rate

The methods used for collecting patient reports varied along with response rates (see table 1 for the terms used when asking patients about adverse events). Recruitment by random digit dialing was not used in any of the hospital patient studies; however, this method achieved the highest response rate of the five studies focused on broad healthcare experiences.<sup>6</sup> Primary care patient reporting studies used a combination of methods: one used telephone recruitment with a follow up in-person interview; another allowed patients to choose written, online or telephone reporting; and a third used telephone survey.<sup>8 12 21</sup> Interviewing patients in-person was effective in obtaining high response rates from hospital patients (average 87%) compared to telephone reports from non-hospital settings (average 44%). The highest response rate overall was 96%, achieved by in-person patient advocate interviews for a specific hospital unit.<sup>15</sup> The study with the highest number of responses, over a 2-year period, was a reporting system for various healthcare setting experiences with 44 860 responses.<sup>16</sup>

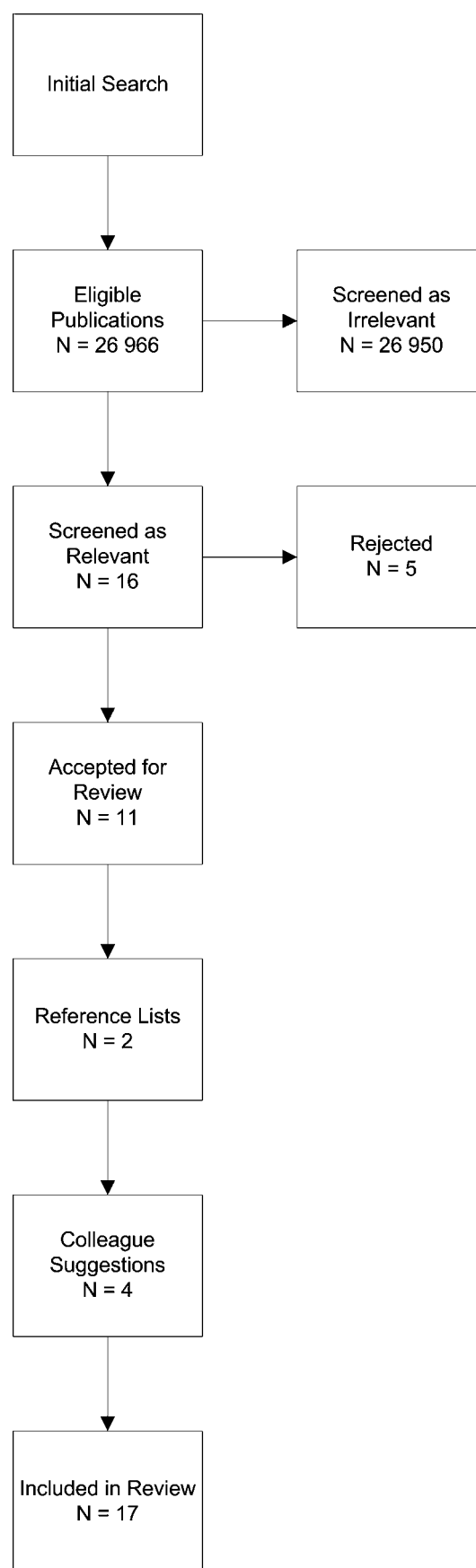


Figure 1 Schematic of literature search strategy.

**Table 1** Terminology for patient reporting of adverse events

Term used
Medical error, mistake <sup>3 6 10 14 16 18</sup>
Medical mistake <sup>13</sup>
Comments (stand-alone kiosk in hospital) <sup>7</sup>
Preventable incidents <sup>8</sup>
Unsafe <sup>15</sup>
Complications, problems, negative effects, or unexpected or unpleasant situations <sup>9 19</sup>
Safety related undesirable events <sup>17</sup>
Problem or injury <sup>3 20</sup>
Anything ever go wrong <sup>11</sup>
Should not have happened and that you don't want to see happen again <sup>12</sup>
Symptomatic inquiry <sup>21</sup>

**Corroboration**

Patient reports of adverse events were corroborated in three (18%) publications. One study reviewed medical records, whereas the other two compared patient reported incidents to hospital incident reports and/or incidence rates reported in the literature. All studies that performed corroboration targeted hospitalised patients.<sup>3 9 11</sup> Cross-referencing medical charts, physician notes and orders, and nurse notes proved to be an effective method for inpatients.<sup>3</sup> The incidence of nosocomial infections, pressure ulcers and drug-related events reported by patients was shown to be comparable to rates documented by healthcare providers in hospital and to rates reported in the patient safety literature.<sup>9</sup>

**Report characteristics**

The incidence rate for adverse events across settings and populations varied considerably, ranging from less than 0.1 to 5.8 per patient.<sup>8 16 20</sup> Incident rates in the target populations and healthcare settings varied widely and thus were not statistically comparable. More than half (55%) of studies targeting hospitals or primary care settings reported a rate of one incident or more per person, whereas surveys covering a broad range of healthcare environments reported a rate of 0.6 incidents or fewer per person. Disregarding any other differences in reporting method, five studies used only open-ended questions, averaging 1.9 reported incidents per person, whereas strictly closed-ended questions or a combination of both types achieved averages of 0.7 and 0.4 per person, respectively. Incident rates from reports of personal experiences averaged 1.3 per person, whereas rates from reporters including family or household members' experiences averaged 0.3 incidents per person.

Classification of reports was inconsistent among publications. Eight studies (47%) used reporter self-assessment, five had clinicians review reports, three authorised researchers to classify cate-

gories and one had lawyers evaluate possible compensation.<sup>3 6-20</sup> Severity of health consequences was used to classify events in five studies.<sup>3 6 11 15 16</sup> Table 2 shows the relationship between study setting and reporting method.

**DISCUSSION**

The publications reviewed in this paper varied considerably in terms of healthcare setting, method of reporting, time span, terminology, criteria for assessment and response rate. Open-ended questions, and solicitation techniques based exclusively on personal experiences tended to yield higher incident rates.<sup>3 7-9 12 13 15 17</sup> Patient reporting within a specific hospital unit using in-person patient advocate interviews had the highest response rate.<sup>15</sup> With only two studies using incentives, and with each using a different incentive, there is insufficient evidence to conclude whether incentives increase response rate.<sup>8 16</sup> There have been too few studies for definitive conclusions on which terminology could be most effectively used with patient reporting. Recall bias has been identified as a limitation in patient reporting.<sup>3 9 11</sup> At the present time, there is marginal evidence indicating that in-person and open-ended interview techniques are preferable to non-personally mediated closed-ended interview techniques. Future policy research is needed to determine the optimal use of language and setting for patient reporting.

**Reporting**

**Healthcare setting**

The 13 publications in this review ranged in setting, focusing on specific wards, hospitals, primary care facilities, or a combination thereof (table 3). The types and frequency of errors and adverse events in each are idiosyncratic, limiting generalisability. However, reporting within a hospital setting has been associated with higher response rates.<sup>3 8 9 11 17</sup>

**Accuracy of patient reports**

Whenever investigated, patients have been shown to be capable of reporting medical errors accurately.<sup>3 9 11</sup> Ensuring that adverse events are documented soon after occurrence would decrease recall bias for healthcare providers and patients, and would parallel a novel and promising new approach for detecting non-routine events during anaesthesia.<sup>22</sup>

**Reporting structure**

Recruiting and interviewing in-person within hospital and primary care settings tended to increase response rates. It has been demonstrated that patients can effectively use online surveys, which are both easily accessible and cost-effective.<sup>16 20</sup> Exclusively asking for personal experiences or using open-ended questions may yield higher incident rates but requires more time

**Table 2** Relationship between study setting and reporting method

Study Setting	Patient Reporting Method							
	Random Digit Dialling	Web-based survey	Written questionnaire	In-person interview	Newspaper Survey	Telephone survey	Internet Portal	Spontaneous Reports
Broad Population	Blendon 2002, Vanderheyden 2005, Northcott 2007	Wasson 2007			Van Vorst 2007			
Primary Care	Kuzel 2004		Schwappach 2008, Solberg 2008			Gandhi 2003		Phillips 2006
Specialty Care			Solberg 2008					
Hospital		Kivlahan 2002	Agoritsas 2005	Weingart 2005, Evans 2006, Weingart 2007		Weissman 2008	Weingart 2008	

**Table 3** Publications of patient-reported medical errors or adverse events

Study	Author(s)	Year of publication	Focus/Purpose	Population	Setting	Method of survey	Personal experience only or family included	Number of responses	Response rate	Types of errors reported	Number of reports	Number of incidents reported per person	Timeline of reporters recall	Where/how found
Views of Practicing Physicians and the Public on Medical Errors. <sup>6</sup>	Blendon RJ, DesRoches CM, Brodie M, et al.	2002	Physician & public views about the medical error statistics	General US	Broad	Random digit dialling. Open-ended & closed-ended questions.	Personal & family members'	1206	67%	Reporter classified: health consequences as serious (24%), minor (13%), none (5%).	507 reports of errors in own care or with family member.	0.4/person	Entire lifetime	Reference list "Perceptions of preventable medical errors in Alberta" Northcott H, et al 2007 <sup>14</sup>
Developing a comprehensive electronic adverse event reporting system in an academic health centre. <sup>7</sup>	Kivlahan C, Sangster W, Nelson K, et al.	2002	Web-based survey for staff, patients, family, & visitors	Specific University of Missouri Health Care discharged patients	Hospital	Web-based anonymous survey at stand-alone stations in hospital or online for access from home. Open-ended questions.	Personal	345	Could not be calculated	Reporter classified: 345 comments, or complaints, or suggestions.	345 comments.	Not reported	Recent experience	Database MEDLINE
Patient-reports of preventable problems and harms in primary health care. <sup>8</sup>	Kuzel AJ, Woolf SH, Gilchrist VJ, et al.	2004	Patients identifying harmful preventable incidents	General Virginia & Ohio Care rural, suburban, & urban public	Primary Care	Random digit dialling to recruit. In person interview. \$50 incentive to participate in interview. Open-ended, prompted narratives.	Personal	38	Could not be calculated	Clinician classified: 221 reported access breakdown (28.5%), communication breakdown (7.7%), relationship breakdown (37.1%), technical error (24.4%), inefficiency of care (2.3%), Harm (76.9%) classified into psychological & physical.	221 reported problematic incident.	5.8/person	Entire lifetime	Database MEDLINE
Patient reports of undesirable events during hospitalization. <sup>9</sup>	Agoritsas T, Bovier PA, Perneger TV.	2005	Events patients identify; comparing overall satisfaction rating with problems encountered	Specific Geneva University Hospital discharged patients	Hospital	Written questionnaire mailed out as 2001 routine patient opinion survey. Closed-ended questions.	Personal	1433	67%	Reporter classified: 1814 total medical complications (23.5%), interpersonal problems (29.9%), incidents related to the health care process (23.5%).	1814 total undesirable events: 725 (50.6%) reported at least 1 event.	1.3/person	Most recent hospitalisation	Database PubMed

Continued

**Table 3** Continued

Study	Author(s)	Year of publication	Focus/Purpose	Population	Setting	Method of survey	Personal experience only or family included	Number of responses	Response rate	Types of errors reported	Number of reports	Number of incidents reported per person	Timeline of reporters recall	Where/how found
What can hospitalized patients tell us about adverse events? Learning from patient-reported incident? <sup>3</sup>	Weingart SN, Pagovich O, Sands DZ, et al.	2005	Inpatients identify adverse events	Specific: Boston teaching hospital medical unit-inpatients	Hospital	In-person interviews (open-ended questions). Follow-up phone interviews 10 days after discharge (open-ended questions).	Personal	528	86%	Clinician classified: adverse events (7.5%), near misses (3.5%), & medical errors with minimal risk of harm (9.2%). Positive/favourable assessments of care (24.2%). Service quality problems (55.8%).	310 distinct incident reports received. 112 patients reported at least 1 incident.	1.4/person	Most recent hospitalisation	Database MEDLINE
Reports of Preventable Medical Errors from the Alberta Patient Safety Survey 2004, <sup>10</sup>	Vanderheyden LC, Northcott HC, Adair CE, et al.	2005	Survey to assess perceptions & personal experience with preventable medical errors	General Alberta	Broad	Random digit-dialling for households. Computerised-assisted phone interviewing system. Closed-ended & open-ended questions, narratives.	Personal & household members	1500	55%	Researcher classified: clinical performance (23.7%), medication member (22.8%), diagnosis (22.4%), communication (13.5%), other (17.6%), patient management, time, surgery, therapy, practitioner attitude or disposition, no improvement in condition, inefficiency with time or resources, & lack of procedures).	559 total reports of personal or family member experiencing a preventable medical error.	0.4/person	Entire life in Alberta	Database PubMed
Consumer perceptions of safety in hospitals, <sup>11</sup>	Evans SM, Berry JG, Smith BJ, et al.	2006	Safety of Australian hospitals	General Adelaide, South Australia & rural centres with population exceeding 1000	Hospital	In-person interview. Closed-ended questions.	Personal & household members	2884 representing 8068 persons	78%	Reporter classified: severity (really serious (59.7%), a little serious, not serious), prolonged hospitalisation (48.5%).	170 respondents reported 240 adverse events amongst household members.	0.1/person	In last 5 years	Database PubMed

Continued

**Table 3** Continued

Study	Author(s)	Year of publication	Focus/Purpose	Population	Setting	Method of survey	Personal experience only or family included	Number of responses	Response rate	Types of errors reported	Number of reports	Number of incidents reported per person	Timeline of reporters recall	Where/how found
Learning from different lenses: reports of medical errors in primary care by clinicians, staff, and patients. <sup>12</sup>	Phillips RL, Dovey SM, Graham D, et al.	2006	To compare reports of medical errors made by family doctors, office staff, & patients	Specific 10 American Academy of Family Physicians National Research Network family clinics	Primary Care	Anonymous reports via web site, paper forms, & voice-activated phone system. Closed-ended & open-ended questions, narratives.	Personal	126	Could not be calculated	Reporter classified: Process errors, & knowledge & skill errors including extended waiting (33.3%), errors in past (16.7%), mistaken identity (11.1%), unnecessary blood draw (5.6%), prescription (5.6%), other (27.1%).	126 patients reported 18 errors (10 mail; 7 web; 1 phone)	0.1/person	Recent primary care visit	Reference list "Rural community members' perception of harm from medical mistakes: A High Plains Research Network study" Rebecca VanVorst 2007 <sup>13</sup>
Rural community members' perception of harm from medical mistakes: A High Plains Research Network study. <sup>13</sup>	Van Vorst RF, Araya-Guerra R, Felzien M, et al.	2007	To learn about rural community members' definitions & types of harm from medical mistakes	General 4 rural north-eastern Colorado communities	Broad	Surveys inserted in 4 local newspapers. Community advisory council members distributed 25 additional surveys. Open-ended questions.	Personal & family members	286	3%	Clinician classified: obvious medical mistakes (30%), possible mistakes (29%), problems or unanticipated outcomes (41%). Obvious mistakes classified further: communication errors (23%), medication errors (23%).	Total 180 incidents. 172 reports of at least one medical mistake involving respondent or family member.	0.6/person	Entire life-time	Database PubMed
Perceptions of preventable medical errors in Alberta, Canada. <sup>14</sup>	Northcott H, Vanderheyden L, Northcott J, et al.	2007	Comparing patients who report personal or family experience of preventable medical errors with the perceptions of patients who did not report first-hand experience	General Alberta	Broad	Random digit-dialling. Computerised-assisted phone interviewing system. Closed-ended & open-ended questions, narratives.	Personal & household members	1500	55%	Researcher classified: clinical performance (23.7%), medication diagnosis (22.8%), they or a family member had experienced a preventable error. patient management, time, medical error. surgery, therapy, 32% reported practitioner attitude error in or disposition, no improvement in care, 56% in a family member's inefficiency with time or resources, & lack of procedures).	559 total reports. 37.3% of medication patients reported that they or a family member had experienced a preventable error.	0.4/person	Entire life in Alberta	Database MEDLINE

Continued

Table 3 Continued

Study	Author(s)	Year of publication	Focus/Purpose	Population	Setting	Method of survey	Personal experience only or family included	Number of responses	Response rate	Types of errors reported	Number of reports	Number of incidents reported per person	Timeline of recall	Where/how found
Patient-reported safety and quality of care in outpatient oncology. <sup>15</sup>	Weingart SN, Price J, Duncombe D, et al.	2007	Oncology patients observe & report unsafe experiences	Specific Boston cancer centre inpatients	Oncology	Interviewed in-person by patient-advocates. Open-ended questions.	Personal	193	96%	Reporter classified: adverse events (1.6%), close calls (3.3%), errors without risk or harm (11.6%), service quality incidents (83.5%).	138 comments about safety or general care. Only coded 121 reports affecting 83 patients.	1.4/person	Recent treatment at cancer centre	Database PubMed
Patients use an internet technology to report when things go wrong. <sup>16</sup>	Wasson JH, MacKenzie TA, Hall M.	2007	Evaluating accuracy of patient reported medical errors & an electronic reporting survey	General US	Broad	Health survey online. Customised health & self-management resources as incentive. Open-ended & closed-ended questions.	Personal & family members	44,860	Not reported	Lawyer classified: nuisance (91%) & potential compensable injury (9%).	610 reports of health-related adverse event (2979 reports of harm, hurt, or injury to themselves or a family member over lifetime).	Less than 0.1/person	Previous year	Database PubMed
"Against the silence": Development and first results of a patient survey to assess experiences of safety-related events in hospital. <sup>17</sup>	Schwappach DLB.	2008	Develop & pilot test patient safety survey for inpatients	Specific 2 Swiss hospital general surgical & internal medicine discharged patients	Hospital	In-patient or discharged written questionnaire (closed-ended questions). Follow-up phone interview (open-ended questions).	Personal	125- with 18 follow up interviews	31%	Researcher classified: process of care (39.8%), medication communication (30.5%), fall (4.6%). Definitive (73.4%) or uncertain (26.6%)	128 reports.	1.0/person	Recent hospital stay	Database PubMed
Can Patient Safety Be Measured by Surveys of Patient Experiences? <sup>18</sup>	Solberg LJ, Asche SE, Averbach BM, et al.	2008	To determine whether patient medical errors can be used to measure safety	Large multi-specialty medical group located in Minneapolis-St. Paul	Specialty and Primary Care	Mailed questionnaire. Open ended.	Personal & family	1,998	65%	Reporter classified: wrong diagnosis, wrong treatment, wrong prescription, wrong procedure, or other. Clinician classified: medical error (10%), non-medical error (9%), behaviour / communication (20%), misunderstanding (45%), inadequate information (13%), unable to determine (3%)	247 reports	12.4/family	Previous year	Colleague recommendation

Continued

Table 3 Continued

Study	Author(s)	Year of publication	Focus/Purpose	Population	Setting	Method of survey	Personal experience only or family included	Number of responses	Response rate	Types of errors reported	Number of reports	Number of incidents reported per person	Timeline of reporters recall	Where/how found
Comparing Patient-Reported Hospital Adverse Events with Medical Record Review: Do Patients Know Something That Hospitals Do Not? <sup>19</sup>	Weissman JS, Schneider EC, Weingart SN, et al.	2008	To compare adverse events reported in patient interviews with adverse events detected by medical record review.	Massachusetts Hospitals	Hospital	Telephone interview. Combination open and closed ended questions.	Personal	2582	62%	Clinician classified: severity (life-threatening (1%), serious (13%), clinically significant (63%), or trivial or insignificant (23%)) and preventability (definitely (1%), probably (29%), probably not (68%), or definitely not (3%))	253 reports	0.3 events / person	April 1 – October 1, 2008	Colleague recommendation
Medication safety messages for patients via the web portal: The MedCheck intervention. <sup>20</sup>	Weingart SN, Hamrick HE, Tutkus S.	2008	To determine whether electronic medication safety messages can improve communication about medications and identify ADEs.	Specific: Three adult sites	Primary care	Electronic messages delivered via web portal. Open ended.	Personal	1821	12%	Reporter classified: problems filling prescriptions (48%), problems with drug effectiveness (12%), and medication symptoms (10%).	17	0.06 events / person	April 1, 2001 - June 10, 2002	Colleague recommendation
Adverse Drug Events in Ambulatory Care. <sup>21</sup>	Gandhi TK, Weingart SN, Borus J, et al.	2003	To determine the rates, types, severity, and preventability of adverse drug events among outpatients and to identify preventive strategies.	Specific: Four adult practices	Primary care	Telephone interview. Combination open and closed ended questions.	Personal	661	55%	Clinician classified: Serious (13%), amenable (28%), preventable (11%), Of amenable events, 63% due to physician's failure to respond to medication-related symptoms, and 37% due to patient's failure to inform physician.	181	0.27 events / person	September 1999 – March 2000	Colleague recommendation



for analysis. The trends observed in response rate are not statistically significant and could be due to numerous factors, such as population sample size or terminology and assessment schemes used for classifying a patient-reported adverse event. Therefore, these comparisons are limited in providing recommendations for future reporting systems.

A combination of closed-ended questions and open-ended narratives may be the most effective for soliciting reports and data for analysis. Direct questions and limited response options allow for accurate analysis and provide a structure for classifying adverse events and near misses but do not allow patients to explain details of events.<sup>3 9 16 17</sup> Patients' fear of providing inaccurate observations was alleviated by refining survey options to allow for reporting a "possible" event.<sup>17</sup> An alternative method initially provides a definition of adverse event, then allows respondents to narrate experiences; analysis is based on a standardised patient safety definition.<sup>3 8 10 12 14 15</sup>

### Terminology

The language used to solicit responses from patients and families about adverse events or near misses can have a significant impact on what is reported. Reports solicited from patients are likely to increase when lay language is used. Patients may prefer the term "mistake" to "medical error".<sup>6</sup> Numerous alternative terms have been used for soliciting reports from patients, as seen in table 3, with little consensus on which term is the most reliable for patient reports.

Common terms used by patient safety professionals, such as adverse event or medical error, are often misunderstood by the general public.<sup>10 13 23</sup> Patient reporting literature suggests that the use of lay language is more effective in soliciting reports. To facilitate patient reporting, different terminology is required and will need to be developed.

### Limitations

The search strategy, including the search terms used, is a limitation of this research. Relevant publications that were not found because of the use of only the two databases could bias our findings. This review is based on a small sample size in very diverse settings. Consensus among so few studies that vary in focus and methods is unattainable and does not permit statistical analysis.

### Recommendations

Further research is required to identify the optimal language, method of report solicitation, reporting tool and incentive in each specific clinical setting. By using the patient as a source of input to a health system, an obligation is established that requires the system to respond to concerns and address issues raised. How to close the loop with the reporter, especially if the reporting is anonymous, requires further definition. A sustained cycle of event identification and quality improvement should be the goal of future efforts to translate this research into clinical practice. Unlike many of the studies identified, future studies should be conducted as a sustainable process within the clinical environment. A patient reporting system should support a learning and action system and be an integral part of every clinical environment.

Potential issues affecting confidentiality remain to be elucidated and resolved. Improving the reporting of adverse events especially when patient advocates are actively involved in soliciting these reports may compromise confidentiality for patients or staff members. Research will be required to identify and mitigate these concerns and harness the advantages of patient advocates.

Based on the studies reviewed, a number of recommendations can be made for the design and implementation of future reporting systems. When designing a reporting tool, it should be evaluated in the local setting to ensure appropriate terminology is used. International terminology standards should be adopted, or translation tables developed, to ensure general applicability of results. Reports from patients should be actively solicited. This work should ideally be undertaken in person as soon after the event as possible; however, telephone interviews do produce acceptable response rates. Incentives increase response rates and should be considered. Efforts should be made to corroborate patient reports.

From the policy perspective, the engagement of patients in reporting for the purposes of learning from their experiences changes the obligations a health system or institution has to the patient. Although engaging patients strengthens the patient-centred focus of an organisation, it also requires that actions are taken and improvements made on issues identified in the reports. Patients have a personal interest in seeing improvements made and risks mitigated. In the future, patients will become a key component of implementing quality improvement initiatives.

### CONCLUSIONS

Families and patients, rather than healthcare providers exclusively, can be involved with improving safety in healthcare. As the patient is the one true constant in care, actively and consistently collecting observations about the healthcare experience provides a valuable perspective for improving patient safety. The reliability of patient reporting of adverse events has been established as trustworthy, and using these reports as part of patient safety learning systems could identify problems that currently go unreported in healthcare provider reporting systems.<sup>3 9 11</sup> The most efficient method for each healthcare setting and the best terminology to use with patients for collecting adverse events reports are still unknown. Taking a lead from anaesthesia safety research, reporting immediately after an incident could address recall bias among reporters, both healthcare providers and patients.<sup>22</sup> There have been too few studies for definitive conclusions and the studies that have been conducted are too diverse to compare statistically. On a positive note, the World Health Organization's work on an International Classification for Patient Safety is helping to standardise the definitions used for adverse event reporting, which will aid in attempts to compare different reporting systems.

The overall objective for reporting systems must stay in focus. Patient reporting systems could enhance patient safety by increasing follow-up by healthcare providers, analysis of trends, identification of causes and, most importantly, implementation of solutions. Reporting on its own is insufficient to increase patient safety.

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