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# The missing evidence: a systematic review of patients' experiences of adverse events in health care

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## Abstract

**Purpose:** Preventable patient harm due to adverse events (AEs) is a significant health problem today facing contemporary health care. Knowledge of patients' experiences of AEs is critical to improving health care safety and quality. A systematic review of studies of patients' experiences of AEs was conducted to report their experiences, knowledge gaps and any challenges encountered when capturing patient experience data.
**Data sources:** Key words, synonyms and subject headings were used to search eight electronic databases from January 2000 to February 2015, in addition to hand-searching of reference lists and relevant journals.
**Study selection:** Titles and abstracts of publications were screened by two reviewers and checked by a third. Full-text articles were screened against the eligibility criteria.
**Data extraction:** Data on design, methods and key findings were extracted and collated.
**Results:** Thirty-three publications demonstrated patients identifying a range of problems in their care; most commonly identified were medication errors, communication and coordination of care problems. Patients' income, education, health burden and marital status influence likelihood of reporting. Patients report distress after an AE, often exacerbated by receiving inadequate information about the cause. Investigating patients' experiences is hampered by the lack of large representative patient samples, data over sufficient time periods and varying definitions of an AE.
**Conclusion:** Despite the emergence of policy initiatives to enhance patient engagement, few studies report patients' experiences of AEs. This information must be routinely captured and utilized to develop effective, patient-centred and system-wide policies to minimize and manage AEs.

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**Key words:** medical error, patient safety, health services research, quality of health care, patient participation, hospital incident reporting

## Introduction

Since the 1950s, patients have wanted their experiences taken into account, reflecting the consumer rights movement generally and health rights specifically [1, 2]. From the 1990s, retrospective medical record review studies of patient harm arising from health care focussed attention on the health system as a major factor contributing to adverse events (AE) [3–6]. An AE is 'an injury related to medical management, in contrast to complications of disease' [7].

Estimates vary but despite extensive investment by governments, AEs occur in ~10% of hospital admissions [8–10]. Quality and safety initiatives are routine for improving the efficiency and effectiveness of health care. Adverse event data are most commonly collected using retrospective medical record review and incident reporting by health professionals to incident management systems [5, 6, 11–14]. Neither method includes patients' experiences either for the validation of the AE or for an account of the impact of the AE on them [15–19].

Similarly, research on patients' experiences of AEs is little studied and data to inform the policy sphere for safe health care are scarce. Evidence to date suggests that patients might address information gaps in medical records, correct inaccurate data as well as identify inefficiencies in their health care [20–22]. Patients, being the only common link between points of care, care providers and treatments, are therefore in a unique position to identify transition issues and difficulties arising in their care [20–22]. These experiential data comprise the missing evidence necessary to fully understand AEs and their impact on patients [23]. Exploring patients' experiences of AEs adds a new perspective that may contribute to preventing AEs reoccurring [20, 24–26].

Acknowledging and utilizing patients' experiences of AEs reinforces patient-centred care, but capturing patients' experiences of AEs is challenging [15–18, 22, 27]. Patient satisfaction surveys have often been used to provide an indication of patients' experiences [28]. Yet patient satisfaction surveys often ask subjective questions that fail to capture the nature of the care experience. These surveys fail to ask patients about what actually happened to them during their care and to therefore identify the factors that contribute to a positive or negative care experience [29–33]. Patient satisfaction is a judgement of whether the patients' expectations were met, which is influenced by a range of factors and may vary widely between different patients in an identical set of circumstances. Patients can therefore report high levels of satisfaction even in instances of a negative care experience and vice versa depending on their expectations and perceptions of the care process [34, 35]. Unlike patient experience data, improvements in patient satisfaction data are not associated with improvements in care quality [36]. Service improvement activities are contingent upon specific data about the nature of events that occurred to identify areas for change; such data are not provided through satisfaction ratings and can only be captured via patient experience data [37]. Where patients' experiences of AEs have been captured, those who report having an event report a lower quality rating of the care received [38].

This is the first review to systematically identify and narratively synthesize literature reporting patients' 'experience' of AEs including their treatment, decision outcomes and the processes and events that occurred. Our review is pertinent because of the increased interest in patient engagement, particularly from 2000 onwards. The review explores the extent to which increased policy interest in patients' experiences has translated into greater understanding and utilization of patients' experiences of AEs.

## Study objectives

(i) To systematically identify literature since 2000 that has investigated patients' experiences of AEs in health care.
(ii) To describe the nature of AEs captured from the patient perspective.
(iii) To identify limitations in current knowledge regarding patients' experiences of AEs.
(iv) To ascertain challenges associated with capturing patients' experiences of AEs.

## Methods

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement is an evidence-based approach for reporting in systematic reviews and meta-analyses. The PRISMA statement was used to guide the reporting of this systematic review [39].

### Eligibility criteria

#### Inclusion criteria

(i) Types of publication: publications available in English that reported original primary data published from 2000 onwards were eligible.
(ii) Types of participants: Patients or the general public who have experienced an adverse patient safety event (self-defined) whilst in hospital, as an outpatient or post-discharge. Although an AE has been explicitly defined as 'an injury related to medical management, in contrast to complications of disease', for patients, an AE may be indistinguishable from other instances of unsafe care [7]. On this basis, we included literature that studied patients' experiences of any of the following: AEs, medical errors/mistakes, patient safety incidents, undesirable events and problematic and/or unsafe care.
(iii) Types of study design: Any study design that employed qualitative, quantitative or mixed-methods was eligible.
(iv) Outcomes: Patient-reported data of their AE experience using quantitative, qualitative or mixed-methods data collection tools.

#### Exclusion criteria

Articles were excluded if they did not meet the above criteria. Publications relying upon hypothetical vignettes, scenarios or that captured opinion rather than experience were also excluded. Papers reporting methods for collecting patients' experiences, including measurement tools, were excluded when there was no patient sampling. Studies that primarily focused on patients' complaints were excluded because of the many reasons for complaints (such as dissatisfaction with treatment options and complications). Disclosure literature was also excluded—this material often focused on open disclosure policy or on preferences for disclosure based on hypothetical scenarios rather than patients' reported experiences.

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### Study identification

A range of text words, synonyms and subject headings were developed for the three major concepts in this review of patient experience, AEs and health care settings and used to undertake a systematic search of eight electronic databases from January 2000 to February 2015. The databases searched were as follows: MEDLINE, EMBASE, PsycINFO, CINAHL, PUBMED, APIAS, Cochrane Database of Systematic Reviews and Cochrane Database of Controlled Trials. Hand-searching of relevant journals and reference lists was also undertaken to ensure that all relevant material was captured. Results were merged using reference-management software (Endnote) and duplicates were removed.

### Study selection and data extraction

Two reviewers (R.H., L.R.) independently screened the titles and abstracts, and a copy of the full paper was obtained for potentially relevant articles. The inclusion criteria were then independently applied to the full text papers by each of the two reviewers. Disagreements were resolved by consensus or consultation with a third reviewer (M.W.). The following data were extracted from eligible publications: author (s), publication year, location, sample, setting, design, primary focus and main findings.

### Assessment of study quality

Study quality was assessed using the Quality Assessment Tool for Studies with Diverse Designs [40]. Studies were assessed against the 16 criteria (see Table 1). Publications were scored against each criterion on a four-point scale (0–3) to indicate the quality of each publication and the overall body of evidence. Two reviewers (R.H.; L.R.) individually assessed all publications; disagreements were resolved through discussion resulting in substantial agreement ($\kappa = 61.6\%$) between reviewers.

### Narrative data synthesis

Findings were analysed using a narrative empirical synthesis in stages, based on the study objectives [41]. A narrative approach facilitates synthesis of the qualitative and quantitative findings. A quantitative approach was not appropriate due to the substantial proportion of studies with no quantitative findings. In addition, a variety of outcome measures were used that were not directly comparable. Initial descriptions of the eligible studies and results were tabulated (Table 2). Patterns in the data were explored to identify consistent findings in relation to the study objectives. Interrogation of the findings explored relationships between study characteristics and their findings, the findings of different studies and the influence of the use of different outcome measures, methods and settings on the resulting data.

## Results

### Results of the search

After removing duplications, 7114 records were identified. Of the large number of records identified, studies were mainly excluded after title and/or abstract (5247) or full text review (15) because they were additional duplicates (7), they did not capture data on patients' lived experiences (5), they were the wrong publication type (2) or they reported work on patient complaints (1). Title and abstract screening resulted in obtaining full publications for 31 references. Reference list searching revealed an additional 17 publications for which the full text was obtained. Of the full texts, 33 publications fulfilled the eligibility criteria. Fig. 1 shows the selection process.

#### Characteristics of included studies

Thirty-three publications reported 30 unique datasets. Publications originated from: the USA (18), Canada (4), the UK (2), Switzerland (2), Australia (1), Iran (1), Oman (1), Germany (1), Finland (1) and Japan (1). The remaining publication reported comparative data from a multi-national nine-country study. Sample sizes ranged from 13 to 44 860 participants, with smaller sample sizes typically identified in qualitative publications and the largest samples drawn from national and multi-national database studies. Samples included hospital inpatients (7), hospital outpatients (2), both hospital in- and outpatients (1), recently discharged emergency department (2) or recently discharged inpatients (5), primary care patients (4) or the general public (12). Studies of the general public were those in which participants were not identified in relation to a particular health care context; these studies identified participants through random-digit dialling (5), consumer or research networks (5), a national telephone directory (1) or door-to-door recruitment (1). Most studies were cross-sectional

**Table 1** Quality assessment criteria

| Quality assessment criteria | Percentage of maximum score achieved |
|---|---|
| 1. Explicit theoretical framework | 7 |
| 2. Statement of aims/objectives in main body of report | 76 |
| 3. Clear description of research setting | 80 |
| 4. Evidence of sample size considered in terms of the analysis | 30 |
| 5. Representative sample of target group and of necessary size | 81 |
| 6. Description of data collection procedure | 82 |
| 7. Rationale for choice of data collection tool/s | 60 |
| 8. Detailed recruitment data | 68 |
| 9. Statistical assessment of reliability and validity of assessment tool/s (quantitative only) | 49 |
| 10. Fit between research question and method of data collection (i.e. use of survey/interview/focus group) | 89 |
| 11. Fit between research question and format and content of data collection tool (i.e. survey items and interview schedule) | 87 |
| 12. Fit between research question and method of analysis (i.e. use of framework analysis/statistics employed) | 85 |
| 13. Good justification for analytic method selected | 65 |
| 14. Assessment of reliability of analytic process (qualitative only) | 64 |
| 15. Evidence of user involvement in design (e.g. pilot work) | 25 |
| 16. Strengths and limitations critically discussed | 76 |

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**Table 2** Summary of included studies ($n = 33$)

| Author | Year of publication | Setting and location | Sample | Methods | Type of incident | Primary objective | Main findings |
|---|---|---|---|---|---|---|---|
| Adams [42] | 2004 | Any health care setting: general public<br>New York, USA | 1001 English- and Spanish-speaking adults<br>>18 years<br>Stratified by region of New York<br>Identified by random-digit dialling | Telephone interview survey<br>Average of 20 min per interview<br>Survey adapted from previous national survey | Medical error | To assess a community sample of health care consumers' experiences of medical errors | 21.1% community reported having a medical error.<br>Fewer errors reported by: divorced; widowed; separated; African American; higher income households.<br>More errors reported by: 30–65-year olds; those who visit doctor often; those who were more informed about health care |
| Adams [43] | 2009 | Any health care setting: general public<br>Adelaide, Australia | 3522 adults<br>Identified from North West Adelaide Health Study participants who attended clinic for examination as part of their participation in NWAHS | Interview survey<br>Survey tool replicated from a previous national study of health care experiences | AE | To identify the incidence of self-reported harmful AEs in a community sample and attitudes about safety in the health system | 4.2% annual incidence of error reported by patients.<br>Medication error most commonly reported (45.5%) then misdiagnosis or wrong treatment (25.6%).<br>More errors reported by those who: had been hospitalized in past 21 months; had low annual income; had higher education degree; were more risk averse; were dissatisfied with an aspect of their care |
| Agoritsas [44] | 2005 | All hospital departments<br>Geneva, Switzerland | 1518 adults who had been recently discharged from hospital<br>1433 of this sample completed items regarding undesirable events in hospital<br>>18 years<br>Identified because they had been recently discharged form hospital and were eligible to complete a routine patient opinion survey | Postal survey<br>Survey tool core component: Picker Survey (French version) | Undesirable event | To estimate the frequency of undesirable events reported by recently discharged patients and the characteristics of patients who experience these events | 50.6% patients reported at least one event.<br>Phlebitis most commonly reported (11%) and unavailable medical record (9.5%).<br>More reports made by those who had longer duration of stay; poor health; depressed mood.<br>Unfavourable ratings of care increased with the number of undesirable events that a patient reported |

**Table continued**

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**Table 2** Continued

| Author | Year of publication | Setting and location | Sample | Methods | Type of incident | Primary objective | Main findings |
|---|---|---|---|---|---|---|---|
| Al-Mandhari [41] | 2008 | Any health care setting: general public<br>Muscat, Oman | 212 fathers or eldest members of a family from 2 villages<br>Identified by going to each house. 212 of 250 households participated. 38 properties were unoccupied | Face-to-face interview survey<br>Survey tool developed for this study based on literature and piloted | Medical error | To assess community members' perceptions about medical errors and the factors influencing their perceptions | 78% ($N = 165$) of households indicated knowledge of the term 'medical error'.<br>49% of 165 households had experienced an error.<br>Most common perceived consequence of an error was severe pain (45%).<br>Most common perceived cause of error was an uncaring health professional (49%) |
| Blendon [45] | 2002 | Any health care setting: general public<br>Boston, USA | 831 physicians<br>1207 members of the general public<br>>18 years old<br>1332 physicians identified from a national list of physicians provided by the Medical Marketing Service invited.<br>1803 members of the general public invited by random-digit dialling | Postal and online survey<br>Survey developed for use in this study | Medical error | To understand the views of practicing physicians and the general public on medical errors | 45% of the public reported errors in their own care or a family members' care.<br>24% of the public reported the error had serious consequences including death (10%).<br>30% were disclosed to by a health professional.<br>33% of the public received an apology from the health professional |
| Carlesso [46] | 2011 | Primary care: manual therapy<br>Ontario, Canada | 13 patients receiving manual therapy | Semi-structured interview | AE | To describe how patients define and interpret AE associated with MT techniques | Two main themes emerged:<br>1. Post-treatment responses to manual treatment<br>Increased pain, a new pain, neurological symptoms or loss of function was considered by patients to indicate that an AE has occurred in treatment.<br>2. Beliefs and expectations of manual treatment<br>Informed consent/good understanding of potential problems that may occur following treatment reduced patients' perceptions that an AE had occurred. The degree of trust and rapport with practitioner influenced whether an AE was perceived |



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| Daniels [47] | 2011 | Children's Hospital<br>British Columbia, Canada | 544 families of children in hospital<br>>18 years old | Cross-sectional survey | AEs; near miss | To test whether the introduction of an A E-reporting system for use by families of paediatric patients changes the reporting behaviour of health professionals | AE rate: 37% of the 544 families that completed the study reported one or more AEs. 48% of these were deemed a legitimate safety concern by health professionals. Only 2.5% of the events reported by families were identified in health provider reports.<br>Events reported: 24% were medication problems, 22% miscommunication between staff, 15% complications of care, 13% miscommunication between staff and family, 10% other |
| Davis [48] | 2012 | Six medical and surgical wards<br>London, UK | 80 medical and surgical patients<br>>18 years old | Cross-sectional survey and medical record review | Medical errors; undesirable events | To investigate UK patients' willingness and ability to provide information about medical errors or undesirable events experienced in their care | Rate: 3.2 undesirable events reported per patient.<br>Patients reported 12% of events as medical complications, 35% as health care process problems and 53% as interpersonal problems from the list which was determined by health professionals |
| Fowler [49] | 2008 | Hospital; multiple departments<br>Boston, USA | 2582 medical or surgical patients discharged from 16 hospitals<br>Identified by hospital records | Telephone survey<br>Interviews between 10–30 min long<br>Survey tool developed for this study | AE | To estimate the frequency, type and correlates of AEs reported by patients | 29% of patients reported an unexpected event; 25% of these were considered an AE by physicians.<br>Most commonly reported AEs were adverse drug reaction to a newly prescribed drug (40%) and effects of surgery (34%).<br>Physician reviewers identified 31% as preventable |
| Friedman [50] | 2008 | Hospital; Emergency Department<br>Toronto, Canada | 201 patients who were discharged from the ED within the last 24 h<br>143 of these gave follow up interviews 3–7 days after their discharge<br>Identified through hospital records | Telephone structured survey<br>ED chart review<br>Survey items used from a previously validated tool | AE; medical error; near miss | To determine whether patients or their families can identify AEs that in ED; to characterize these and to compare patient and health care provider reports | 5% incidence of AEs, 4% incidence of near misses and no medical errors reported by patients.<br>Most commonly reported AEs were delayed or inadequate analgesia (60%).<br>50% of near misses were intercepted by staff.<br>None of the events were recorded in the hospital reporting system |

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**Table 2** Continued

| Author | Year of publication | Setting and location | Sample | Methods | Type of incident | Primary objective | Main findings |
|---|---|---|---|---|---|---|---|
| Hasegawa [37] | 2011 | Hospital; multiple departments<br>Tokyo, Japan | 1506 patients and 1738 inpatients from 3 teaching hospitals, 2 acute general hospitals and 1 care-mix hospital<br>All outpatients (1764) and inpatients (3198) invited (excluding psychiatric and emergency) | Postal survey distributed by hospital staff<br>Survey tool developed for this study and piloted | Unsafe event | To compare patient and health professional reports of unsafe events | 2.4% outpatients and 4% inpatients reported an unsafe event.<br>Medication events most common (47%).<br>Unsafe events more likely in longer hospital stay.<br>30.4% of outpatients and 33.5% of inpatients reported the event to hospital staff |
| Kaboli [51] | 2010 | Hospital; internal medicine<br>Iowa, USA | 103 patients from 1 inpatient general medical ward in 1 teaching hospital<br>All (126) patients directly admitted to the ward who spent the entire duration of their care there invited | Four methods of data collection: House officer reporting; nurse reporting; trigger tool medical record review; patient telephone interview<br>Interview tool was one used in a previous study | Medical misadventure | To analyse and compare four different methods of detecting medical misadventures to determine the optimal reporting system | 106 medical misadventures identified; only 20% were identified by more than one mechanism.<br>47% of patients had a medical misadventure.<br>85 events were identified by one mechanism only; 64% from medical record review; 11% from nurse reports; 12% from physician reports; 14% from patient reports.<br>Medication error most commonly reported (37%) |
| Kianmehr [40] | 2011 | Hospital; Emergency Department<br>Tehran, Iran | 638 patients discharged from the ED of 1 hospital; first survey at discharge and follow-up after 7 days<br>All 850 patients discharged from the ED during study period (unspecified) | Face-to-face survey and telephone survey at follow-up<br>Survey developed for this study and piloted | Medical error | To evaluate patients' worries about medical errors and their relationship with patient characteristics and satisfaction | 48.3% patients concerned about at least one error in their care.<br>61.6% patients were satisfied with their care.<br>Correlation between level of patient satisfaction and level of concern regarding error |
| Kistler [52] | 2010 | Primary care<br>North Carolina, USA | 1697 patients from 7 primary care medical practices surveyed<br>Subset of 59 patients interviewed (only 52 interviews used)<br>1754 patients identified in waiting rooms of primary care practices over a 15-day period. Random sample of these interviewed | Written survey and semi-structured interviews<br>Survey items derived from a range of existing tools | Medical error | To determine patient perceptions of mistakes in ambulatory care and whether patients change physicians after an error | 15.6% patients reported a mistake.<br>Wrong diagnosis most common (13.4%) then wrong treatment (12.5%)<br>14.1% reported changing physicians because of an error |



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| Kooienga [38] | 2011 | Any health care setting: general public<br>Vancouver, USA | 29 community members<br>30 community purposively recruited from a larger study—1 declined | Semi-structured telephone interview<br>Interviews lasted 3.5–25 min<br>Interview items developed for this study | Medical error | To capture patients' stories of medical error and its disclosure | Lack of communication, missed or poor communication most commonly identified as, problems that caused error or in error disclosure.<br>Patients reported lack of respect, being apportioned blame and being stigmatized |
| Koch [39] | 2010 | Any health care setting: general public<br>Germany | 1201 German patients who reported this health as fair or poor in screening survey<br>3192 patients were screened out of 8402 eligible households. 1392 reported their health as fair or poor. 1201 of these completed the survey<br>This study was part of a larger study of 9633 patients from 9 participating countries | Structured telephone interview<br>Interviews lasted between 14–22 min (average 17 min)<br>Interview items were developed as part of a large multi-national study of experiences of sicker patients | Patient safety incident (including medical error and disclosure) | To establish the quality of care of sicker patients in Germany and compare this with patients from other commonwealth countries | 12% of patients reported errors compared with France (9%), the UK (10%) or Netherlands (8%).<br>34% rated their care quality as good or excellent |
| Kuzel [53] | 2004 | Primary care<br>Virginia and Ohio, USA | 38 adults who received care from general internists or family physicians or whose children did<br>>18 years old<br>Identified through random-digit dialling | Semi-structured telephone interview<br>Interview framework developed for this study | Preventable problem or harm | To develop patient-focused typologies of error and harm in primary care and which are considered to be most important | 23% of 221 harms reported were physician harms.<br>Other more commonly reported problems were breakdown of the relationship between clinician and patient (37%) and access to clinicians (29%).<br>Inadequate communications with patients regarding diagnosis, treatment or results of investigations were common errors accounting for 10.9% of the 221 harms |
| Lopez [54] | 2009 | Medical and surgical acute care<br>MA, USA (state-wide) | 603 medical and surgical acute care patients who had experienced an AE<br>4163 patients identified in a probability sample across state hospitals, 2582 of these interviewed, 603 had an AE and included | Telephone structured survey<br>Surveys lasted 20 min on average<br>Survey developed for this study and piloted | AE | To better understand how the characteristics of AEs affect the likelihood of disclosure and patients' perceptions of care quality | 845 AEs reported by patients.<br>Outcomes of AEs for patients were: increased discomfort (58.9%); increased length of hospital stay (24.4%); additional treatment (44.3%); continuing problems (21.7%).<br>40% of AEs disclosed to patients.<br>AEs requiring patients to have additional treatment significantly more likely to be disclosed.<br>Disclosure significantly less likely for preventable AEs |

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**Table 2** Continued

| Author | Year of publication | Setting and location | Sample | Methods | Type of incident | Primary objective | Main findings |
|---|---|---|---|---|---|---|---|
| Mazor [55] | 2012 | Hospital: cancer care<br>Seattle, USA | 78 breast cancer or gastro-intestinal cancer outpatients who experienced a problematic event in their care<br>708 patients identified through electronic records as recently screened positive. 416 agreed to participate but only included if they had a problematic event | Semi-structured telephone interviews<br>Interviews lasted ~60 min<br>Interview schedule developed for this study | Problematic event | To explore cancer patients' perceptions of preventable harmful events, the impact of these and interactions with clinicians after | 22.4% of patients reported something wrong in their care that could cause harm.<br>Communication problems common (47%) and problems with medical care, e.g. delayed diagnosis (28%).<br>Outcomes included physical harm (57.7%), psychological harm (96.2%), life disruption (38.5%), negative impact on family (57.7%), damaged relationship with health care provider (52.6%) and financial loss (uncompensated) (37.2%).<br>36% reported discussing the event with those they felt were responsible.<br>42% reported that no one took responsibility |
| Northcott [56] | 2008 | Any health care setting: general public<br>Alberta, Canada | 1500 members of general population<br>Identified by random-digit dialling (55% response rate) | Telephone structured survey<br>Alberta Patient Safety Survey—adapted from tool used by Blendon *et al.* (2002) | Medical error | To capture public perceptions of: those who have and have not experienced preventable errors; confidentiality and disclosure; the relationship between error reporting and perceptions of care quality | 37.3% reported a preventable medical error.<br>Those that had an error perceived errors to occur more frequently; that doctors would not tell them about an error; that the quality of the health care system was poorer |
| Ocloo [57] | 2010 | Any health care setting: general public<br>London, UK | Two data sources: (1) 14 group meetings of a self-help network of those affected by medical harm—data also included from members contributions to websites, legal material and inquiries; (2) 10 interviews and 18 surveys of those affected by medical harm who attended a 2-day residential programme.<br>Identified through hospital patient safety committees, Action Against Medical Accidents and Patient for Patient Safety Project | Semi-structured written survey, field notes, written material retrieved from websites, legal and inquiry literature<br>Survey developed for this study | AE; medical harm | To understand the experiences of harmed patients to gather knowledge of the medical and social processes involved in harm | Medical models of harm that focus on clinical markers and individual agency do not reflect patient perspectives of harm.<br>Patients are mostly concerned with social processes around the management of error; the power and dominance of the medical profession; activities of the wider state and the concealment of information |



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| O'Hagan [58] | 2009 | Any health care setting: general public<br>Australia<br>Germany<br>France<br>New Zealand<br>Canada<br>Netherlands<br>USA<br>UK<br>Switzerland | 11 910 adults from the 9 participating countries<br>Identified through random-digit dialling | Telephone structured survey<br>Average of 17 min to complete survey<br>Interview items were developed as part of a large multi-national study | Medical error | To determine the rate of patient-reported medical errors in Canada with other commonwealth countries and to compare characteristics of individuals who do and do not report errors | 16.7% of patients reported an error in the previous 2 years (equivalent of 4.2-m adults).<br>Significant predictors or reporting an error were: high prescription use; chronic condition; lack of physician time spent with a patient; age under 65; lack of patient involvement in care; perceived inadequate nursing staff; absence of a regular doctor |
| Sahlstrom [59] | 2014 | Inpatients or day surgery hospital patients<br>Finland | 175 hospital patients<br>>18 years old | Cross-sectional survey | Patient safety events | To describe patients' experiences of patient safety during their most recent period of care | Rate: 22% experienced an error; 22% reported they being unsure whether they had an error; 32% of over 65s had experienced an error compared with 15% of younger patients.<br>Only 36% of patients who experienced an error were informed of it by staff |
| Schmidt [60] | 2004 | Academic medical centre; medical or surgical units<br>Florida and Texas, USA | 148 discharged patients<br>>18 years old<br>Identified patients who were discharged from the medical centre—all invited | Cross-sectional survey<br>Survey comprised of several validated measures | AE | To explore patients' perceptions of the nursing care they received and whether having an AE was a predictor for satisfaction | No figures on incidence but mean number of AEs reported by patients that had an AE was 2.24 (SD = 1.24).<br>The number of AEs experienced did not predict perceptions of the adequacy of nursing care |
| Schwappach [61] | 2011 | Any health care setting: general public<br>Switzerland | 1306 respondents from general public<br>Identified through random-digit dialling | Telephone structured survey<br>Average of 17 min to complete survey<br>Interview items were developed as part of a large multi-national study | Medical error | To assess the frequency of patient-reported errors in Switzerland and the risk factors for these | 11.4% of patients reported at least one error in the previous 2 years.<br>Errors were: medication errors (8%); medication errors (5.3%) and were due to: conflicting information from care providers (17.2%); lost test results (11.5%); unavailable test results (7.8%).<br>Predictors of reporting errors were: younger age; poor health; use of emergency care; inpatient stay; poor care coordination (measured as need to redo tests/unavailable health records) |

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**Table 2** Continued

| Author | Year of publication | Setting and location | Sample | Methods | Type of incident | Primary objective | Main findings |
|---|---|---|---|---|---|---|---|
| Solberg [62] | 2008 | Primary care<br>Minneapolis, USA | 1998 recently admitted patients at HealthPartners Medical Group<br>Identified through medical records | Postal survey, followed up once by phone after 2 weeks<br>Medical record two-stage review by doctor and nurse then head of department<br>Patient experience survey—2 items about error analysed | Medical error | To establish whether patients' reports of medical errors produce accurate data that can be used as a measure of patient safety | 11% of patients reported an incident (rate of 21.4 errors per 100 patients).<br>Most errors in primary (46.2%) or specialty care (27.9%).<br>19.4% of patient-reported errors identified as 'possible' clinician error by health professionals. 2% of these classified as 'real' errors.<br>Remainder classified as miscommunication (19.8%), misunderstanding (45.3%) or unable to code (15.4%).<br>Patients more likely to be dissatisfied if they had an error |
| Wasson [63] | 2007 | Any health care setting: general public<br>USA (national study) | 44 860 patient volunteers<br>Data retrieved from The Cooperative Practice-Based Research Network surveys over a 2-year period | Online survey<br>General patient health and experience survey used by the Cooperative Practice-Based Research Network | AE | To investigate how an automated patient-report health assessment system can be used to identify AEs | 1.4% of patients reported an AE over a 2-year period.<br>Most AEs reported in outpatients (88%).<br>Significant predictors of AE reports were: being female; low financial status; having a physical, emotional or social dysfunction; chronic disease; multiple prescriptions; more frequent hospital use; not exercising regularly; high alcohol consumption; low composite health behaviour score |



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|---|---|---|---|---|---|---|---|
| Weingart [64] | 2005 | Medicine Unit<br>Boston, USA | 228 adult inpatients in a medicine unit of one teaching hospital<br>>18 years old<br>264 eligible patients over a 3-month period in the unit invited | Two part medical record review and structured interviews 2/3 times per week with patients or support person—followed up 2 weeks after discharge<br>Interviews 5 min each long<br>Interview items used from a previous study | AE | To elicit incident reports from hospital inpatients to identify and characterize AEs and near misses | 8.8% of patients had an AE; 55% of these were documented in the medical record<br>4.8% of patients had a near miss; 31% were documented in medical record<br>12.7% of patients reported medical errors with minimal risk of harm.<br>None of the events were reported to the hospital incident reporting system<br>Patients who had three or more drug allergies were more likely to report errors.<br>Missed dose or time most common (43.5%).<br>Nursing was the profession most often involved in patient-reported events (51.6%) |
| Weingart [65] | 2006 | Inpatients: general medicine, geriatric and overflow patients<br>Boston, USA | 228 patients at 1 teaching hospital.<br>>18 years old | Structured interviews and medical record review | Service quality: mistakes or problems | To understand the incidence and types of patient-reported service quality deficiencies experienced | 38.6% experienced service quality issues. Main issues were delays, problems in communication with staff and problems with the hospital environment or with amenities.<br>Service quality issues were more common in: men, public patients, patients with medication allergies or those covered by hospitalists |
| Weingart [66] | 2007 | Outpatient Oncology<br>Boston, USA | 193 oncology patients in 1 cancer centre<br>202 patients identified over 29 weeks by unit nurses as eligible and invited | Semi-structured interview survey<br>Survey completed in 10–30 min<br>Interview items developed for this study<br>Unsafe care identified by two reviewers coding | Unsafe care (including AE, near miss and medical error) | To examine the feasibility of using patient safety liaisons to elicit patients' reports of errors, near misses and AEs | 43.4% of patients reported an incident they felt was an AE, near miss or error.<br>These were classified by investigators as: 1% AEs; 2% close calls; 7% errors without risk of harm; 52% service quality incidents.<br>22% of patients reported unsafe care; 64% of the events described were classified by reviewers as service quality issues not AE |

**Table continued**

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**Table 2** Continued

| Author | Year of publication | Setting and location | Sample | Methods | Type of incident | Primary objective | Main findings |
|---|---|---|---|---|---|---|---|
| Weissman [67] | 2008 | All hospital departments<br>MA, USA (state-wide) | 998 post-discharge patients from 16 hospitals<br>6003 post-discharge patients randomly selected and invited from 16 hospitals selected using a probability analysis | Telephone survey and physician medical record review<br>Survey completed in ~20 min<br>Survey tool developed for the study and piloted | AE | To compare AEs reported in post-discharge patient interviews with AEs detected by medical record | 23% of patients reported an AE via interview.<br>11% of patients had an AE according to record review.<br>Agreement was strongest between the two methods in relation to major incidents but low general ($\kappa = 0.2$).<br>More likely to report via interview if: female; younger; low Charlson score—these correlates were not found for record review.<br>AEs associated with longer length of stay using either method |
| Van Vorst [68] | 2007 | General public: rural community<br>Colorado, USA | 286 patients | Cross-sectional community survey | Medical mistakes | To develop and distribute a community survey to assess rural community members' experiences with medical mistakes | 30% of the 180 reported mistakes reflected the medical error taxonomy (ASIPS DMO) as identifiable medical mistakes, 29% were considered possible mistakes and 41% involved unanticipated outcomes but were not considered mistakes.<br>Mistakes were clinical events, medication or communication errors.<br>Patients most commonly experienced discomfort or no change to their health status as a result |



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|---|---|---|---|---|---|---|---|
| Zhu [69] | 2011 | All hospital departments MA, USA (state-wide) | 2582 discharged patients 4163 eligible patients identified from discharge lists of 16 hospitals selected using a probability analysis invited | Telephone survey and physician medical record review<br>Survey developed for this study in a multi-step process | AE | To examine the degree to which physician reviewers agree that patient reports of 'negative effects' constituted AEs | 29% of patients reported 'negative effects'; reviewers determined 71.2% as AEs; 52.9% serious AEs.<br>Newly prescribed medication (93.9%) and changes to medication (85.1%) most commonly reported.<br>Negative effects most commonly reported by patients who: were not admitted through the ED; perceived they were less able to protect themselves from errors; were not treated in church-operated hospitals.<br>Negative effects more often corroborated by reviewers as AEs for patients who: were female; reported good or excellent health status; not admitted through ED; were younger |

(30). Three studies included follow-ups [40, 50, 62]. Data were gathered using structured or semi-structured interviews or surveys, conducted either by telephone, post or face-to-face. Retrospective medical record review was used in seven publications; record review was compared with patient reports and used in conjunction with survey methods in three of these. Papers focused on AEs (12) and/or medical error (11), unsafe care/events (2), patient safety events (2), problematic event (2), medical misadventure/mistake (2), undesirable care (1), service quality problem (1) and preventable problem (1). See Table 2 for a summary of the included publications.

### Study quality

Studies scoring more highly in the quality assessment framework shared the following common features: clarity in the topic of study, clear study design and analytic strategy. A notable weakness across the reviewed papers was a lack of theoretically informed work; only one study explicitly made reference to a theoretical or conceptual standpoint, drawing upon Longtin's conceptual model of patient participation [64]. Only 25% of the maximum quality score was awarded to the body of evidence for engaging the target group in designing the research, which was mostly in cases where pilot work was undertaken. Studies scored weakly in relation to their justification for decisions regarding sample size (30% of maximum possible score obtained) and for the data collection method (60% of the maximum possible score obtained). Studies that scored 50% or less of the maximum possible quality score (5) possessed the lowest scores on several common quality criteria [41–45, 70]. Weaknesses included a lack of detail regarding justification for analytic method, justification for sample size and rationale for choice of data collection tools. 'Medical errors' or 'adverse events' were rarely or poorly defined in these articles. However, definitions varied across the reviewed papers and an accepted taxonomy not utilized [46]. Events were often conceptualized as patients' dissatisfaction with care processes (particularly with communication), rather than events resulting in, or with potential for, patient harm.

## Review findings

Patients reported a large number and types of AEs. Authors used various different definitions of an AE from the patient perspective; some used the health service definition of events that cause harm but others allowed the patient to define the events of relevance. Despite the lack of consistency in definitions of AEs, the studies demonstrate that patients are able to recognize things that go wrong in their care.

### Patients' definitions of AEs

The evidence suggests that patients have a different view of AEs to health professionals. Patients in the included studies defined AEs broadly, including a range of quality and safety concerns. Health care providers operated a more stringent definition and unsurprisingly disagreed with patient reports of their own AEs [53, 55, 67, 71]. When comparing patient-identified AEs against medical records, Solberg *et al.* found that health professionals described many patient-identified AEs as misunderstandings (45.8%) or miscommunication (19.8%) rather than mistakes [67]. Similarly, of 321 AEs reported by families in paediatric care, only 48% of these were deemed a legitimate safety concern by health professionals [52]. Discordance between the health professional and patient understanding of an AE meant that patients' report of having suffered an event was often not included in their medical records [55, 67, 71]. Only 2.5% of the events reported by families in paediatric care were identified in health provider reports [52].

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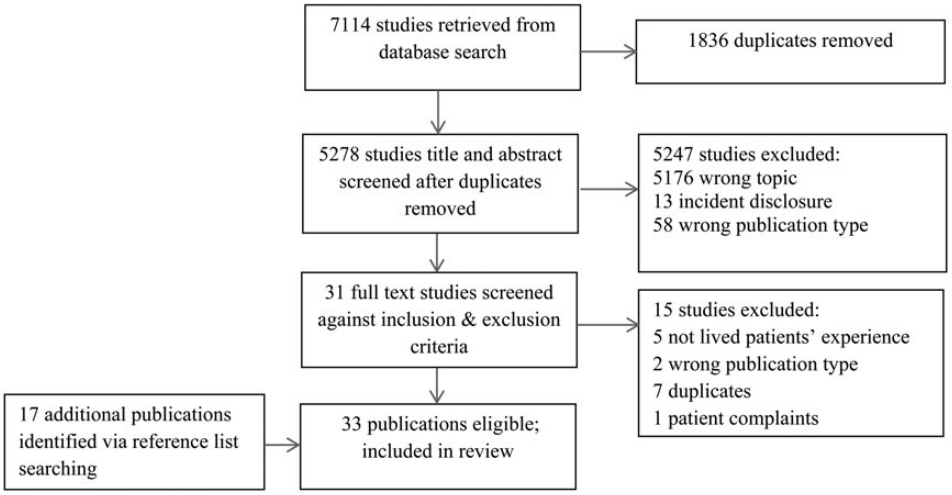


**Figure 1** Flow chart of study selection process.

In some cases, patient reports focused on their experience of the event rather than whether the harm was preventable. This focus is exemplified in relation to adverse drug reactions. Fowler *et al.* reported patients' described adverse drug reactions to newly prescribed drugs as AEs [54]. An adverse drug reaction is not conventionally categorized as preventable harm by the health system because the drug was usually correctly prescribed and administered [54]. Similarly, in manual therapy (e.g. physiotherapy, massage and osteopathy), increased pain, a new pain, neurological symptoms or loss of function after treatment can indicate that an AE may have occurred but patients were less able to pinpoint the mistake in this context [51].

Patients' beliefs and expectations about their care were critical in influencing their perception of an event as being adverse in manual therapy. Informed consent or a good understanding of potential problems that may occur following treatment reduced patients' perceptions that an AE had occurred. The degree of trust, rapport and satisfaction with a practitioner also influenced perceptions of care and whether an AE was perceived [43, 51]. Loss of trust and confidence in the treating health professional following an event was also reported [72].

### Patients who reported AEs

Many factors were associated with patients who were more likely to report AEs or those more likely to report a higher number of AEs, including treatment-related and demographic characteristics. Patients were more likely to report an event who were on multiple medications, had greater health burden, had medication allergies or who had access to higher quality medical information [48, 49, 73]. One or more AEs were more often reported by patients who had longer hospital stays (of 6 or more days), were public patients, were not admitted through the emergency department (ED), were in an intensive care unit, were receiving new medications or were having surgery [46, 49, 54, 73, 74]. Hospital location and bed size were not identified as significant correlates [74]. Patients' demographic factors that were associated with an increased likelihood of reporting were as follows: having a lower income, having a higher level of education or being married, cohabiting or never married (rather than divorced or widowed) [49, 54, 55, 57, 59, 63, 66, 75]. Several studies identified that patients younger than 60 or 65 years reported more incidents than other patient groups [48, 55, 63, 65, 71, 74]. In three studies, women were also identified as reporting more incidents [67, 71, 74]. Yet significant differences by age and/or sex were not identified in a further study [57].

### Frequency of AEs

Few studies used patient-provided data to determine incidence, and definitions of an AE varied widely between these studies [42, 44, 46, 54, 55, 60, 64]. Higher incidence was reported where the type of event studied was more broadly defined, e.g. 'unsafe' event or 'patient safety event'.

Reported incidence varied widely. Data collected from patients in hospital identified perceived AEs in 4% of cases in one study and 5% in another [44, 55]. Yet in two studies of inpatients post-discharge, incidence of 29 and 51% was reported, respectively [46, 54]. Two outpatient studies reported AE rates of 2.4% in a general patient population and 22.4% in a cancer patient sample [44, 60]. Only one study combined inpatients and outpatients; 22% of patients in this study reported an error and a further 22% reported being unsure whether they had experienced an error [64]. One study included a general public sample in which 8% of patients in the Netherlands reported an error, 9% in France, 10% in the UK and 12% in Germany [42].

### Types of AEs

In 20 studies, patients identified particular types of AEs. The remaining studies (13) did not sufficiently describe the types of patient-reported events or did not describe them from the patient perspective because physician corroboration was used [42, 45, 48–52, 56, 61, 62, 64, 65, 68, 74]. The most common patient-identified AEs were medication errors and communication breakdown before, during or after treatment [44, 53, 69, 73]. Communication problems included a lack of, or conflicting information from, health professionals about the care process, what to expect from the treatment whilst in hospital and following discharge, and lack of information about possible side effects [53, 66, 73].

Types of events varied depending on the patient group. Inpatients often reported medication problems [44, 69]. For example, one study reported that 71% of patient-reported events were medication errors and/or problems [69]. Two other studies reported medication related problems in 33 and 39% of cases, respectively [44, 55]. Adverse drug events were also reported in three studies: by 53% of patients in two

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studies and 40% of patients in the third study [54, 59, 72]. Surgical infections or injuries were also cited by 13% of inpatients in one study and by 34 and 42% of patients in two others [54, 59, 71]. Communication and interpersonal problems were reported by 41 and 53% of patients in two studies [53, 73]. Service quality issues, primarily waits and delays, were identified by <20% of patients in four studies [43, 55, 69, 73]. Health care-acquired infections were reported by 6 and 8% of patients, respectively, in two studies [46, 71].

Outpatients most often identified poor communication when reporting AEs, evidenced by two studies of cancer care in which poor communication was reported by 47 and 21% of patients, respectively [60, 75]. Delays in diagnosis, treatment and poor information sharing between staff were also prevalent in ~30% of reports in both studies. Additional service quality problems including, problems in coordination of care (13%), lack of amenities (12%), lack of respect (5%) and poor interpersonal skills (5%) were identified in one of the studies [75]. A further general hospital outpatient study identified unsafe medication events (14%) and dissatisfaction with physician's examination (18%) as problematic in smaller proportions of their samples [44].

Communication problems were consistently identified in three studies of primary care patients. Misunderstanding between patients and clinicians, communication challenges or the provision of inadequate information accounted for 84% of issues in one study [67]. Breakdown in the clinician–patient relationship accounted for 37% of problems in another compared with 24% of concerns relating to treatment issues [58]. Communication issues also featured highly in patient interviews in the third primary care study [57].

Many studies with the general public did not ask patients to describe their AEs or had no details. Of the four that did, communication problems were identified by 40% of patients in one study and were frequently cited in qualitative patient interviews in another [70, 72]. Medication errors were also frequently identified in three studies, but the proportion of medication errors varied from 5 to 40% between these studies [63, 66, 72].

### Harm resulting from AEs

Nine studies explored the nature of harm experienced by the patient as a result of their AE; seven of these were with primary care patients or the general public. Patient-defined 'harm' was physical, financial and/or psychological. Physical effects were often reported as short term in comparison with psychological harms. Inpatient harm was reported in one study; harms included increased discomfort (59%), additional treatment (44%), increased length of hospital stay (24%) and continuing health problems (22%) [59]. In the only outpatient study to report harms, 96% reported psychological harm, 58% of outpatients reported physical harm, 58% described a negative impact on family, 53% a damaged relationship with health care provider, 39% life disruption and 37% reported uncompensated financial loss [60]. Of the outpatients reporting AEs, 42% felt that no one took responsibility [60].

Perceived harm resulting from an AE was reported in three primary care studies. Around half of the included patients reported 'a lot of' or 'severe' harm in one primary care study (46%) which often related to diagnostic or treatment errors, but a lack of detail regarding the nature of the perceived harm from the patient perspective was provided [57]. A further primary care study identified a high proportion of psychological harm [58]. Seventy per cent of harms were psychological in this study, including feelings of anger (26%), frustration (14%), belittlement (13%) and loss of relationship with and trust in their clinician (15%). Physical and financial harms were also cited including pain and avoidable personal expense [58]. A third primary care study of manual therapy patients identified AEs as physical harm, which included loss of or reduced function, or the need for an extended treatment duration [51]. Harms were rarely. No details regarding the nature of harm was only reported in one study of the general public. In this study, the harm reported was financial loss, which included the need to utilize savings and retirement monies because of the expense involved in additional treatment or loss of earnings [72].

### Prevention of AEs

Six studies explored patients' perceptions of the causes of AEs and their ideas around prevention [45, 49, 61, 63, 65, 72]. Patients identified causes from both a systems and a person perspective. Inadequate clinical knowledge and/or skill, errors in judgement and inadequate attention to the task were identified [61, 65, 72]. The need for professional accountability amongst those responsible for their care was noted by respondents [61, 65, 72]. Strategies to reduce AEs focused on additional resources and training—citing the need for more staff, better training of health professionals and improved training in patient-provider communication [49, 63]. A small number of patients were identified taking greater responsibility for their own health and safety as a way to prevent AEs [49]. Patients sometimes found it difficult to determine the cause of errors and therefore ways to prevent them; one study reported that for 60% of errors patients could not identify the cause [72].

## Discussion

Despite the emergence of policy initiatives to enhance patient engagement, few studies comprehensively report patient AE experience data. Furthermore, there is no evidence to show this information is routinely captured and utilized to develop effective, patient-centred and system-wide policies to minimize and manage AEs. Discordance between the health care profession and patients regarding what constitutes an AE is evident. For patients, an AE might include a much broader range of quality and safety issues that arise in their care. The studies highlight that an AE from a patient' s perspective is a chain of problems in care, connecting problematic care before an event, the event itself (clinically defined) and 'care' (or lack of satisfactory care) in response to the event. Health professionals' definition of an AE is embedded in the protocol and policy that relate to specific types of occurrences [76–78]. From this perspective, any event that falls outside this category is not governed by the same criteria. Without organizational policy and protocol that gives weight to patient-defined events, experiences that do not fit the health profession's definition of an AE will continue to be inconsistently and often inadequately addressed.

The review provides evidence that medication errors and communication problems occur frequently in a range of health care settings. Patients are able to recognize when things go wrong in their care, with particular patient groups more likely to experience or to report an event [48, 49, 73]. Patients can also contribute to the data using health professionals' reports or medical record reviews. Specifically, patients can provide valuable information regarding problems with continuity of care, medication errors and communication between staff and with patients [23, 52, 56, 57]. The information from patients is critical to identifying incidents and ultimately to reducing patient harm, but they are not routinely asked to provide these data. The type of information that patients provide may be dependent on the methods used to elicit information. In-depth interviews, focus group discussions and surveys with free-text components offer patients the opportunity to report events pre- and post-discharge events that are not included in medical records, particularly those related to communication during care [60,

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62, 71]. Patient involvement is becoming a core component of health service policy internationally [79–82]. The review findings suggest that extending patient involvement to the reporting of adverse safety events may add value to quality of data captured.

In contrast to the expansive literature regarding clinician distress associated with AEs, the physical, financial and psychological harms to patients that result from AEs are understudied [25, 26]. This review suggests that patients experience a range of harms that have a substantial and detrimental impact [69, 71–75]. Data around the psychological impact of AEs on patients are particularly sparse. Work is required to establish the duration that patients experience psychological harm, the factors associated with a full recovery and the needs of patients who have been affected by an AE.

### Challenges of obtaining patients' experiences

Obtaining patient experience data in relation to AEs is challenging. Current evidence is limited by difficulties in defining an AE, identifying patients who have experienced an AE, recruiting a representative patient sample and capturing data of sufficient scale to make conclusive statements. These limitations reflect earlier patient experience studies [83]. No single validated tool currently captures the patient experience of an AE. Inconsistent methods and measures to capture patients' experiences of AEs between studies collectively create challenges for data synthesis to compare reports between individual patients, patient groups, health care settings and geographical locations. Inconsistent terminology and inadequate definition of AEs not only confuses patients regarding what constitutes an event but also unintentionally limits the validity of the data captured. Exploring AEs from a patient's perspective may require the event to be studied in the context of the patient's care experience before, during and after the AE.

### Limitations

The limitations of the included studies and the review methods used must be considered. The quality appraisal demonstrated several areas of weakness in the included studies. The lack of theoretically informed work contributed to the poorly defined concepts of 'medical error' and 'adverse event' and lack of detail regarding rationale for the research and analytic methods selected. Lack of clarity around these concepts and the frequent use of broadly defined 'dissatisfaction' created challenges in the synthesis of the reviewed articles and creates further challenges for generalizing the findings to health systems or particular services. Although the exploration of patients' experiences has close links to patient-centred care, the patient groups of interest were rarely consulted in the development of the study or even in pilot work. Patients can provide input into the study aims, design and methods used for data collection, in addition to taking part in pilot work. Involving the target groups may have enhanced the value of the resulting research.

The reviewed papers were limited to published material; important perspectives from non-published work may have been overlooked. There is evidence that the level of sensitivity and precision of bibliographic databases is dependent on the topic searched, and this may affect the number of articles returned [84]. The efficacy of database searches to capture articles in the area of patient safety is yet to be evaluated, but the implication from other health-related research is that some articles will be missing [85]. This issue was addressed through the use of several databases to broaden coverage and additional handsearching, but there may have been some omissions. Nonetheless, even in the event of a faultless search strategy, the problem of publication bias means that important negative findings from unpublished research may have been omitted [85].

### Implications and application

The findings have implications for research and practice. Policy interest in patients' experiences remains a novel idea yet to manifest in more rigorous research that provides reliable data. The body of evidence reviewed clearly identifies medication errors and communication problems as key areas of concern for patients—patient-provided data relating to these issues could be used to design strategies to reduce harm and improve health care. Further work is required to explore the psychological impact of AEs and to explore how detrimental psychological consequences of an event affect patients' personal and professional lives. In addition, further work assessing patients' experiences must include large population samples and provide greater clarity in defining the concept in order to provide a coherent evidence base [86]. The review highlights that inconsistent terminology and measurement tools create challenges for synthesizing evidence in this area.

Improving practice requires the routine collection of data about patients' experiences of AEs and how they are managed; this is critical to developing safer health care services with decreased opportunities for harm. This review demonstrates that patients' experiences are not routinely captured in practice and opportunities to use these data to improve quality and safety are being missed. Evidence suggests that the extent to which patients' experiences are utilized may be associated with health professionals' attitudes, including their willingness to consider and act upon the patient perspective [87]. Effective and sustainable utilization of the patient experience to detect and prevent mistakes is therefore likely to require a working partnership between patients and health care providers, which is embedded in models of health care delivery. Health care providers may also seek to assess the provision of psychological support for patients in the immediate aftermath of an AE.

## Conclusion

Knowledge of patients' experiences is critical to making the health system safer, yet we lack understanding of AEs from their perspective. Research to date suggests that patients, often distressed by their experience of an AE, have much to offer in detecting and preventing AEs. Data on patient experiences must therefore be routinely collected through existing reporting frameworks and synthesized to add context and relevance to organizational policies and protocols for avoiding and resolving AEs.

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