Disclosure of patient safety incidents: a comprehensive review

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Abstract

Purpose. Adverse events are increasingly recognized as a source of harm to patients. When such harm occurs, problems arise in communicating the situation to patients and their families. We reviewed the literature on disclosure across individual and international boundaries, including patients’, healthcare professionals’ and other stakeholders’ perspectives in order to ascertain how the needs of all groups could be better reconciled.

Data sources. A systematic review of the literature was carried out using the search terms ‘patient safety’, ‘medical error’, ‘communication’, ‘clinicians’, ‘healthcare professionals’ and ‘disclosure’. All articles relating to either patients’ or healthcare professionals’ experiences or attitudes toward disclosure were included.

Results. Both patients and healthcare professionals support the disclosure of adverse events to patients and their families. Patients have specific requirements including frank and timely disclosure, an apology where appropriate and assurances about their future care. However, research suggests that there is a gap between ideal disclosure practice and reality. Although healthcare is delivered by multidisciplinary teams, much of the research that has been conducted has focused on physicians’ experiences. Research indicates that other healthcare professionals also have a role to play in the disclosure process and this should be reflected in disclosure policies.

Conclusions. This comprehensive review, which takes account of the perspectives of the patient and members of the care team across multiple jurisdictions, suggests that disclosure practice can be improved by strengthening policy and supporting healthcare professionals in disclosing adverse events. Increased openness and honesty following adverse events can improve provider–patient relationships.

Keywords: adverse event, communication, disclosure, patient safety

Purpose

Since the early-1990s there has been an increasing awareness that patients incur injuries and adverse outcomes as a direct consequence of healthcare. Studies from developed countries [1–8] have reported adverse events occurring in 0.4–16% of hospital admissions. The US Institute of Medicine’s (IOM) report ‘To Err is Human’ [9] estimated that between 44 000 and 98 000 Americans die each year from preventable errors in hospitals. Less work has been done on the nature and scale of errors in developing and transitional countries but it is evident that they also have safety problems [10, 11].

Iatrogenic injuries create significant tensions in the provider–patient relationship. Patients desire information on incidents that take place during their care, and are entitled to receive it [12]. However, healthcare professionals worry about the risks of disclosure for various reasons [13] (Table 1). We reviewed the literature on disclosure of patient safety incidents and adverse events to ascertain the outcomes desired by both patients and healthcare professionals, the gaps between ideal and actual practice, and to examine how the conflicting needs of the two groups may be better reconciled.

The World Health Organization

World Health Organization (WHO) defines a patient safety incident as an event that could have resulted, or did result, in
unnecessary harm to a patient. Incidents may arise from either intended or unintended acts. An adverse event is an incident that results in harm to a patient [14].

Data sources

We conducted a review of the literature using Embase, Medline and CINAHL databases and the search terms ‘patient safety’, ‘medical error’, ‘adverse event’, ‘communication’, ‘clinicians’, ‘healthcare professionals’ and ‘disclosure’. Additional relevant references were gleaned from articles identified. The Agency for Healthcare Research and Quality (AHRQ) Patient Safety Network database (www.psnet.ahrq.gov) was also searched.

Study selection and data extraction

All studies relating to the disclosure of patient safety incidents to patients or their families were included. These incorporated studies using real patient experiences, simulated patients or patient vignettes and those examining healthcare professionals’ attitudes to adverse event disclosure. The studies were largely descriptive and so quantitative analysis was not appropriate.

Results

Patients’ views of patient safety incidents

Patients are aware of patient safety as an issue. Up to 42% [15–22] have experienced a patient safety incident or adverse event in their own care or that of a family member. It is important to note that patients define patient safety incidents more broadly than healthcare professionals. Patients commonly include deficient interpersonal skills, poor service quality, and non-preventable adverse events [13, 18]. The incidents patients are most likely to be aware of are medication errors (17%), nursing mistakes (15%), problems with medical equipment (10%) and misdiagnoses (10%) [18]. The factors patients feel contribute most to these incidents are: lack of time with patients; overwork, stress or fatigue on the part of health professionals; failure to work or communicate as a healthcare team and understaffing [19].

The impact of a patient safety incident

Patients experience physical, emotional and financial trauma following a patient safety incident [13, 23–25] and describe a variety of negative emotions. Learning of an incident can make patients feel sad, anxious, depressed or traumatized. They fear additional errors, are angry at delays to their recovery, and are frustrated that the incident might have been preventable [13]. Feelings of guilt following a patient safety incident are common among family members of a harmed patient who may berate themselves for not protecting their family member [24, 26]. Patients and families that have been affected by such incidents fear further harm, including retribution from health care workers, if they express their feelings or even ask about such incidents [26].

Expectations following a patient safety incident

Patients and families consistently report wanting disclosure following a patient safety incident [12, 13, 15, 19, 24, 27–31]. There is less consensus about disclosure of near misses. Some patients think that hearing about a near miss could alert them to incidents they should watch for, others feel that hearing about a near miss would be upsetting [13, 15, 32].

The amount of emotional trauma experienced can be related to the communication process. In general, patients who report good communication with their healthcare provider undergo less emotional trauma. Patients need information to help them to cope with adverse medical events.
but highlight that they often have great trouble obtaining it [23, 33]. The information desired following a patient safety incident includes: an explanation of what happened, how and why it happened [13, 15, 27, 31, 33, 34]; the implications for their health [32, 35] and how future incidents and errors will be prevented [15, 27].

Apologies are important to patients and are a necessary part of the resolution process following an adverse event [13, 23, 24, 36]. Patients indicate that they want to know that a healthcare professional and their institution regret what happened to them. If a healthcare professional discloses an adverse event honestly and compassionately and apologizes, the patient’s distress is decreased. Explanations that are incomplete or evasive create additional distress [13]. Apologies also help patients and families maintain trust in their healthcare professional following a patient safety incident [26, 28].

A number of benefits of adverse event disclosure for the patient have been documented, including allowing a patient to obtain timely and appropriate treatment to correct problems and providing the necessary information to make informed decisions [37]. It enables better-informed consent for any further treatment that may be required and prevents needless worrying by patients about unexpected clinical outcomes. In some systems, disclosure may also permit a patient to obtain appropriate compensation for adverse outcomes [38].

The ideal timing of the disclosure of an adverse event having occurred is unclear. Most experts feel that disclosure conversations should be conducted as soon as possible after an adverse event has been discovered or detected [29, 32]. However, one study of patients and families revealed that a significant proportion would prefer to learn about an incident only when its full extent is known [32].

Actions desired following an adverse event

In the UK 34% of patients who had experienced an adverse event expressed a desire for an apology or explanation and a further 23% wanted an inquiry into the causes of the event [34]. The assurance that something is being done to prevent similar events occurring in the future is important to patients [15, 27].

Studies illustrate that patients support reporting of patient safety incidents to external agencies, such as government or regulatory agencies, in addition to informing the injured party [19, 29, 31, 32, 39]. Research indicates that an overwhelming majority of the general public think that it should be mandatory for healthcare organizations to report serious adverse events to an external agency [19, 39].

Some patients endorse punitive measures for healthcare professionals following an adverse event. Over 60% of surveyed New England health plan members in the USA indicated that they would want the professional involved in an adverse event to be reprimanded by an authority [15]. Thirty-nine percent of parents of paediatric patients thought that the party responsible for an adverse event should be reported to an agency that can punish them [29]. The forms of punishment proposed included fines, probation or licence suspension [15, 19]. The desire for punitive measures is mitigated by the healthcare providers’ approach to communicating an adverse event. An honest, empathic and accountable approach decreases the probability of participants’ support for strong sanctions against the individual involved [28, 38, 40].

In the USA the majority of patients want additional medical fees as a result of an adverse event waived and financial compensation for any injury, pain or suffering caused [15]. In a British survey of people harmed as a result of medical care, however, only 11% of respondents expressed a desire for compensation [34]. Patients want assurances that they will not suffer financially due to an error [13], and financial burdens following an adverse event can exacerbate the effect of other forms of trauma [23].

Healthcare professionals’ experiences of patient safety incidents

Healthcare professionals’ experiences of adverse events have been examined over the years but there has been increased attention on the topic following the publication of ‘To Err is Human’ [9] in the USA and the report, ‘An Organisation with a Memory’ in the UK [41]. The following section examines healthcare professionals’ views and experiences of patient safety incidents.

Involvement in patient safety incidents

Despite the fact that healthcare is a complex enterprise delivered by multidisciplinary teams, much of the research on experiences of adverse events has focused on physicians [42–56]. For example, a number of studies document physicians’ experiences of adverse events, in particular the type of incidents experienced [42–47]. The majority of physicians have direct personal experience of patient safety incidents [44], the commonest being medication and diagnostic errors [42, 47]. Physicians’ beliefs as to which factors contribute to patient safety incidents are similar to those of patients with understaffing, overwork, stress and fatigue identified as the most important causes [19]. Additionally, they ascribe errors to complexity of the job, inadequate supervision, problems with handovers, lack of cooperation between teams, poor continuity of care, latent systems failures and insufficient knowledge or skill [42, 44, 48–50, 55].

A number of studies detail the effect of a patient safety incident on physicians [13, 42, 43, 47, 50, 53, 55, 56]. They experience powerful emotions following an adverse event including guilt about harming the patient, disappointment about failing to practise medicine to their own high standards, fear of legal action and anxiety about their reputation. For some, the emotional upheaval following an adverse event leads to sleeplessness, difficulty concentrating and anxiety [13]. Adverse events are associated with a decrease in physicians’ quality of life and increased likelihood of burnout [50]. Research suggests that junior physicians’ ability to cope with adverse events depends on reassurance and opportunities for learning [53, 55]. It highlights that interactions with
their colleagues and supervisors are critical to the coping process [53], and that learning is maximized when patient safety incidents or adverse events are formally discussed and constructive feedback offered [55]. The impact of adverse events can be so profound that physicians have been described as the ‘second victims’ of medical error [57].

**Actions following a patient safety incident**

Physicians surveyed consistently support disclosure to patients and their families following a patient safety incident [13, 45, 46, 51, 53, 54, 58, 59]. A survey of US and Canadian physicians revealed that disclosure attitudes were similar in both countries with 98% agreeing that serious adverse events should be disclosed and 78% supporting disclosure of minor adverse events to patients [45]. In another study, 99% of paediatricians endorsed reporting serious adverse events to patients’ families while 90% supported the disclosure of minor adverse events [47].

However, although physicians support adverse event disclosure in principle, this does not always happen in reality [39, 42, 47, 51, 55]. A survey of faculty and resident physicians in the USA revealed that the majority would disclose a hypothetical patient safety incident resulting in minor (97%) or major (93%) harm to a patient. However, only 41% had actually disclosed a minor patient safety incident, and only 5% a major incident to a patient. A further 19% of respondents revealed that they had not disclosed an actual minor patient safety incident and 4% indicated that they had not disclosed an actual major incident to patients [51]. A parallel national survey of both practising physicians and members of the public in the USA found that only a third of respondents in each group with experience of a patient safety incident reported disclosure of the incident by the healthcare professional involved [19].

There is limited research into other healthcare professionals’ and managers’ experiences of adverse events and involvement in the disclosure process [31, 58, 60–67]. A qualitative study with nurses suggests that they routinely tell patients about patient safety incidents that are within the control or accountability of the nurse. Examples include late or missed medications or treatments, failures in coordination of care or communication failures in nurse to nurse handovers [65]. However, the study noted that nurses were reticent to report independently incidents that involved serious harm or actions of other members of the healthcare team. In these situations, the nurses believed that the disclosure responsibility fell primarily to the patient’s physician [65]. Similarly, a US study of emergency medicine providers (physicians, nurses and out of hospital providers) found that although nurses were more likely to report a patient safety incident or adverse event than physicians (68 versus 54%), they were less likely to disclose it to the patient than physicians (59 versus 71%) [58].

The research suggests that nurses envision a shared approach to disclosure, even though they expect physicians to lead the process [65]. Nurses’ desire to participate represents a desire to communicate directly with the patient about nursing’s role in an incident or event but also reflects concern that they might be blamed for an incident or event if they are not present during the disclosure. Nonetheless, nurses acknowledge that they might not be present for a disclosure due to work schedules and that nurse managers or supervisors are appropriate substitutes in such an event [65].

The study also highlighted that interprofessional issues may arise following an adverse event such as a breakdown in team communication. Nurses revealed that in some circumstances medical teams can avoid patients until they have made a decision about whether they will disclose a patient safety incident or adverse event. However, the nurse is still interacting with the patient during this time and can often be asked difficult questions by the patient or their family. Nurses can be placed in ethically compromising situations when they are not aware of what has been or will be disclosed to a patient and they often have to resort to stalling strategies in such circumstances such as encouraging the patient to write down their questions or offering to set up a meeting with the medical team [65]. Adverse events can also lead to interprofessional conflict when other members of the healthcare team are reluctant to disclose an adverse event. Nurses revealed that in such situations they used multiple strategies to encourage disclosure, including direct confrontation in the form of questioning the physician, or indirect approaches, such as coaching patients or families to confront team members about an adverse event [65].

A 2006 survey of US risk managers provides an insight into the role of risk managers in the disclosure process. It highlighted that risk managers have varying levels of involvement in the process [66]. Sixty-nine percent reported that they provide general education about disclosure, 58% indicated that they can provide just-in-time coaching for staff members who will disclose an adverse event and 51% revealed that they personally follow up with the patient and family after disclosure. Twenty-four percent of risk managers reported being personally responsible for disclosure, whereas 43% indicated that they are present when a disclosure takes place. Sixty-two percent revealed that they had personally disclosed a serious event to a patient [66]. Research also suggests that risk managers are more likely than physicians to recommend disclosure (76 versus 50%) and to provide full details about how a similar event would be prevented in the future (62 versus 51%). However, physicians were more likely than risk managers to provide a full apology to the patient recognizing the harm caused by the event (39 versus 21%) [67].

Multiple barriers to disclosure have been identified [13, 45, 46, 59, 68]. Physicians describe situations in which they might not disclose an adverse event that harmed a patient. Some feel that there was no need to disclose an adverse event if the harm was trivial or if the patient was unaware that an adverse event had taken place. Others believe that certain patients would not want to know about an error and informing these patients diminishes their trust in the physicians [13]. A survey of US and Canadian physicians revealed that 60% of respondents would be less likely to disclose a serious adverse event to a patient if they thought that the
patient would not understand what they were telling them. Thirty percent would be less likely to disclose if they thought that the patient would not want to know about the adverse event, and 21% would be less likely if the patient was unaware that the event had occurred [45].

Finkelstein [59] suggests that there may be psychological reasons for non-disclosure as acknowledging an error may damage a physician's confidence and self-esteem, and render them less effective. He highlights that physicians may have different reasons for non-disclosure according to their grade. Junior physicians may be concerned about professional advancement, whereas seniors want to preserve their authority.

Fear of litigation has been identified as an important barrier to disclosure. For example, a survey of US and Canadian physicians revealed that an individual's beliefs about malpractice affected their support for disclosing serious adverse events. In both countries, physicians who believed that disclosure decreased malpractice risk were considerably more supportive of disclosure [45]. Not surprisingly, fear of medical malpractice litigation is the most common institutional barrier to disclosure [61].

There is currently no consensus on the relationship between disclosure and litigation costs. Studies suggest that, at best, open disclosure will bring financial benefit by reducing litigation, and at worst it will have a neutral effect by increasing the number of cases but reducing the value of each case [38, 69, 70]. It should be noted that few studies have focused on the real-world impact on the volume and costs of litigation following implementation of a full disclosure policy. Many studies have been in the context of capped settlements and the outcome in an unconstrained environment may be different [71].

A lack of confidence in addressing sensitive issues is a further barrier to disclosure [72]. Eighty-eight percent of paediatricians felt that disclosing a serious adverse event would be very difficult and junior staff were more likely to believe this than senior staff [46]. Twenty-three percent of physicians in training reported that they are uncomfortable disclosing adverse events to patients and families, although they become more comfortable with such conversations over time [49]. Physicians desire further training in how to handle adverse events [39, 46, 54].

The reality of disclosure

It is clear that patients have specific information needs following an adverse event. They want an acknowledgement that an incident has occurred, information about why the event happened, how recurrences will be prevented and an apology [13, 15, 23, 27, 31–33, 35, 36]. It is also clear that there is a gap between the information that patients desire and what is actually provided [13, 31, 33, 51, 55, 73].

Physicians admit that although they are committed to being truthful with patients they want to put the most positive ‘spin’ on events possible. Fear of litigation limits what they tell patients about patient safety incidents [13, 54, 68]. Full and frank disclosures of the type that patients desire are the exception rather than the rule. It is more common for physicians to give partial disclosure of adverse events. They may describe an incident but not make it clear that this was the cause of harm or they may imply that the harm was a result of their underlying condition rather than the incident [74]. Similarly, they may mention the adverse event but not explicitly state that an incident took place [13, 31, 73]. The likelihood of mentioning an adverse event varies with specialty with medical specialists being more likely to explicitly mention adverse events than their surgical counterparts [73]. Even when an adverse event is acknowledged it is not universal to accept responsibility for the adverse event, offer an apology or explain how it may be prevented in the future [74, 75].

Physicians’ disclosure practices are influenced by their culture [76]. Members of the European Society of Intensive Care Medicine were surveyed about their views and practices relating to disclosure of adverse events. There was great variation between countries. Physicians from the Netherlands and Scandinavia are most likely to give the exact details and those from Greece and Portugal most likely to say nothing about the incident. In all countries, physicians felt they should be giving more complete information regarding iatrogenic incidents than they are, the largest difference being in Italy where 11% of physicians claim to give complete details while 73% felt they should [76].

When hospitals’ institutional approaches to disclosure are examined in the USA, the research suggests that officially approved, established disclosure policies are becoming more common [61, 66]. The most common elements of these policies include an explanation (80%), description of an undertaking to investigate an event (80%) and an apology (71%). Only 50% of policies included a promise to share the results of the investigation with the patient or their family, whereas 48% reported that they included an acknowledgement of harm and 20% included a declaration of responsibility for the harm [66].

The effect of policies on disclosure is unclear. Many nurses are unaware of their organization’s policies on disclosure despite such policies being in place. Nurses tend to be sceptical about the influence of formal policies on disclosure practices, in part because they see the issue of disclosure as dependent on contextual factors and therefore not amenable to clarification through a detailed procedure. However, they agree that policies could promote more transparent practices if they provide a framework and guidelines for disclosure as opposed to a detailed step by step procedure. They also considered that policies that articulate a role for nurses would provide the authority to proactively initiate a team process for planning and conducting the disclosure [65].

Discussion

Patients and families advocate disclosure following a patient safety incident and they have specific information requirements. However, they often do not receive the information that they require. Physicians are also in favour of disclosing patient safety incidents but there are numerous barriers preventing them from doing so. These include fear of litigation, lack of knowledge of how best to deal with the incident and
their own personal emotional response. The findings from the published literature on disclosure have implications for practice, policy and future research.

Limitations
It must be acknowledged that the vast majority of research on this topic has been conducted in the USA. Hence, it could be argued that the literature represents the views and cultural expectations of a Westernized culture. Berlinger and Wu [77] make the point that, while not universal, the Judeo-Christian traditions of confession, repentance, and forgiveness inform the cultural expectations of many individuals within secular Western societies. Therefore, it is possible that disclosure and apology may be less appropriate or acceptable to non-Western societies.

Much of the research also derives from use of hypothetical scenarios, focus groups, simulations or surveys rather than genuine adverse events. What people say they desire or claim to do in the event of an adverse event may be different in a real situation.

Despite the fact that patients want to be informed about patient safety incidents or adverse events the research suggests that many healthcare professionals feel ill-equipped to conduct such conversations with patients and their families [39, 46, 54] and that they are uncomfortable doing so [49]. Healthcare staff surveyed as part of the evaluation of the National Open Disclosure pilot in Australia thought that disclosure was best performed by staff who have been trained and who have gained experience in carrying out open disclosure [64]. There are now increasing efforts to teach the communication skills necessary to conduct an effective disclosure to healthcare professionals [78]. For example, in the USA and Canada standardized patients and role playing techniques are being used to teach practising surgeons and medical residents the requisite skills for such conversations [75, 79]. A lack of team communication following an adverse event can prove stressful for healthcare team members and can also lead to conflict within the team [65]. This suggests that it may be appropriate to have disclosure training and education delivered on a team-based model to more accurately reflect the environment in which healthcare professionals work.

Implications for policy
The research suggests that even when hospitals have open disclosure policies in place, it does not always take place [65, 66]. However, healthcare professionals think that disclosure policies can promote more transparent practices particularly if they provide a framework and guidelines for disclosure [65]. Ideally hospital disclosure policies should take into account the needs of the patient, not only for information but also for other support as well, including a plan for their immediate care and how the adverse event will be investigated and acted upon. Informing patients about the existence of a disclosure policy, as well as explaining in advance the potential for adverse events to occur, could help them understand the role systems play in the causes of adverse events, and might reduce the desire for punishment of individuals. This might help to engage patients in taking measures to improve their own safety.

Healthcare professionals should be assured within hospital disclosure policies that they will be supported by their institution in disclosing adverse events [62, 64]. In addition, such policies would benefit from a learning component in order to facilitate organizational and individual learning following adverse events. This would be especially beneficial for younger healthcare professionals [53, 55].

In general, national policy on disclosure would be useful in most countries to help guide local policies. The various stakeholders involved in the handling of adverse events should harmonize their policies and advice to prevent healthcare professionals from receiving mixed messages about disclosing. These include professional and licensing bodies, malpractice insurers and defence organizations and reporting system managers.

Implications for research
Much work remains to be done around disclosure. It has been difficult to evaluate the impact of disclosure on patients and clinicians following real patient safety events. This is partly due to the rarity of the events themselves and the ethics of such studies. In the meantime, despite theoretical concerns [80] there is no empirical evidence that disclosure is harmful to healthcare organizations, and there is some evidence of its benefit [36–38, 62, 64, 81, 82].

The questions remain about how best to go about disclosing adverse events to patients and how clinicians’ behaviour can be changed, in terms of both frequency and quality of disclosure. Additional questions remain about how organizations can support patients and clinicians in handling adverse events and disclosure. The role of patients themselves has not been examined. Future research could usefully focus on the effectiveness of training programme and policies intended to increase disclosure.

Conclusions
Both healthcare professionals and patients support the concept of disclosing adverse events when they occur. Despite this agreement disclosure is far from universal. Closing the gap between aspirations and the reality of disclosure will be challenging as it entails a change in attitude among healthcare professionals and a greater understanding from institutions about the effect on litigation. The evidence is limited but what there is suggests that full and frank disclosure offers potential benefits for improved patient experience and provider–patient relationships.

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