Patients’ and family members’ experiences of open disclosure following adverse events

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Abstract

Objective. To explore patients’ and family members’ perceptions of Open Disclosure of adverse events that occurred during their health care.

Design. We interviewed 23 people involved in adverse events and incident disclosure using a semi-structured, open-ended guide. We analyzed transcripts using thematic discourse analysis.

Setting. Four States in Australia: New South Wales, Victoria, Queensland and South Australia.

Study participants. Twenty-three participants were recruited as part of an evaluation of the Australian Open Disclosure pilot commissioned by the Australian Commission on Safety and Quality in Health Care.

Results. All participants (except one) appreciated the opportunity to meet with staff and have the adverse event explained to them. Their accounts also reveal a number of concerns about how Open Disclosure is enacted: disclosure not occurring promptly or too informally; disclosure not being adequately followed up with tangible support or change in practice; staff not offering an apology, and disclosure not providing opportunities for consumers to meet with the staff originally involved in the adverse event. Analysis of participants’ accounts suggests that a combination of formal Open Disclosure, a full apology, and an offer of tangible support has a higher chance of gaining consumer satisfaction than if one or more of these components is absent.

Conclusions. Staff need to become more attuned in their disclosure communication to the victim’s perceptions and experience of adverse events, to offer an appropriate apology, to support victims long-term as well as short-term, and to consider using consumers’ insights into adverse events for the purpose of service improvement.

Keywords: patient satisfaction, measurement of quality, qualitative methods, discourse analysis, Open Disclosure

Introduction

Public awareness of adverse events is on the rise [1], and the pressure on health policy makers to address such events—particularly those that cause severe harm—is intensifying [2]. One policy response is ‘open disclosure’, mandating that clinicians apologize for adverse events and discuss what is known about them with those harmed. Disclosure of adverse events is now enshrined in several programs in the USA [3] and forms part of national policy in countries such as Canada [4], the UK [5] and Australia [6].

The fact that these developments are very recent may explain why the number of studies examining victims’ experiences of clinical harm and incident disclosure is low [7]. Studies of adverse event responses that have been published focus on organizational rather than patients’ personal consequences [e.g. 8–10], and studies that focus on the consumer experience do so mainly by eliciting hypothetical responses to adverse event scenarios [e.g. 11, 12]. Only a limited number of studies present accounts of consumers’ actual experiences of adverse events and their disclosure by health facility staff [7, 13–15].

The present article reports on 23 interviews conducted with patients and family members about the disclosure process following adverse events. Undertaken as part of an evaluation of an Open Disclosure pilot conducted in 40 hospital sites across Australia in 2006 and 2007 [16], this study provides insight into the principal concerns on the part of consumers when it comes to disclosing and resolving adverse events.

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Background

In Australia, the need to negotiate the consequences of adverse events was put on the public agenda by the Australian Council for Safety and Quality in Health Care in 2002. This led to the publication of the Australian Open Disclosure Standard in 2003 [17]. In 2006, a successor national body, the Australian Commission on Safety and Quality in Health Care, contracted 40 hospital sites in five Australian States to participate in the Open Disclosure Pilot. This arrangement enabled these sites to develop Open Disclosure policies, initiate training and appoint Open Disclosure project officers (frequently patient safety officers working in clinical governance units and primarily from a nursing background) to liaise with patients and staff.

The model generally deployed now in Australia for disclosure involves a liaison person (usually the patient safety officer) contacting the victim of an adverse event, gathering data about the incident, convening a meeting for clinical staff to plan the disclosure meeting (and determine its level of formality), facilitating the primary disclosure meeting and maintaining contact with the patient (and/or family) following the initial meeting(s). The present article reports on consumers’ experiences and views about these processes.

Methods

Subjects and setting

Only 21 of the 40 pilot sites participated in the evaluation. Indicating the challenging nature of this kind of research and the trepidation experienced by both health facilities and ethics bodies when confronted with project applications targeting Open Disclosure, five Ethics Committees chose not to approve our evaluation; four sites (all in one State) considered legal (qualified privilege) provisions to prohibit discussion about disclosure-related information with the evaluation team, and a further ten sites failed to translate ethics approval that was granted into hospital-level support for the evaluation.

Between March and November 2007, consumers who had been offered Open Disclosure of adverse events were identified by these 21 sites’ Open Disclosure project officers. The evaluation team did not have access to Open Disclosure (or clinical) records, nor to the criteria applied for selection and rejection of patients and family members for the invitation to participate in the evaluation. Hospital staff contacted participants to obtain permission for the evaluation team to engage them in the study. In total, 24 participants’ contact details were provided to the evaluation team. All but one agreed to be interviewed: fifteen interviews were conducted with patients and eight with family members.

Procedures

Members of the evaluation team conducted the interviews either face-to-face or over the telephone. Lasting from 15 to 90 min, the interviews were semi-structured and in-depth, guided by an interview schedule (included in the Appendix), containing questions approved by all relevant ethics committees. They also allowed interviewees to expand on matters they considered important.

Analysis

Interviews were transcribed verbatim from sound files by project team members. Potentially identifying information was removed to ensure confidentiality. The accuracy of transcriptions was checked against the original audio-recordings. Data familiarization was achieved by up to four team members reading and checking the transcripts and independently tabulating issues into salient ‘themes’. These themes were collated and then verified in two ways: first, by team members comparing their theme choices against those of others at set intervals, and second, by reconnecting chosen themes to relevant interview data to maintain their representativeness. This process of iterative data anchoring and constant comparison [18] ensured that our analysis remained reliable and retrievable [19]. The five most prevalent themes that were identified in this way are covered here.

Results

Table 1 contains summaries of the 22 cases as revealed in interviews with consumers (among the 23 interviewees, interviewee #13 was the wife of interviewee #12 who was the person harmed, and both discussed the same case, giving 22 cases in total).

Overall, Open Disclosure was seen as positive and interviewees judged Open Disclosure to have been crucial to resolving their adverse event. Thus, interviewees reported that ‘It’s [sic] just sorry it ever happened, naturally, but . . . as far as I’m concerned, the outcome, everything come alright in the end’ (interviewee #6); ‘it was very good’ (#8) and ‘It was very useful’ (#12). One interviewee elaborated on the positive emotional impact of Open Disclosure: ‘I know there wasn’t a dry eye in the whole entire room when I was telling them about the guilt that I had felt and then [name doctor] said that it had nothing to do with me and it wasn’t my fault [so] I think since the Open Disclosure I’ve got some answers, I’ve been able to talk to the hospital, to the people involved’ (#1).

The remainder of this section addresses the five most prevalent themes identified in the interview analysis. These themes are recast as questions for the purpose of our discussion: was the adverse event promptly disclosed to the victim (or family) by staff at the facility where the adverse event occurred?; how formal was the disclosure meeting and did this match the victim’s expectations?; what kind of apology was offered?; was there an offer of tangible support?; was the consumer’s concern about practice improvement heard? and was there an opportunity to meet with the clinicians involved in the adverse event? We have included two tables that provide more comprehensive interview quotes.
## Table 1  Interviewee and adverse event summary

<table>
<thead>
<tr>
<th>Interviewee</th>
<th>Summary of adverse event</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. 29-year-old female (patient)</td>
<td>Pregnant woman induced, started vomiting, received (in her judgment) too little clinical attention for some hours, then suddenly taken to theatre for an emergency caesarean, but the baby dies. Conflicting explanations were offered</td>
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<tr>
<td>2. 58-year-old female (patient)</td>
<td>Woman was administered an anaesthetic overdose; she felt ‘strange’ following operation. She only received disclosure of the incident 2 months after the operation following a consult with her GP</td>
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<tr>
<td>3. 36-year-old female (mother of patient)</td>
<td>Baby was given twice the amount of antibiotics following a previous dose not being documented and loses hearing. Baby’s deafness is not immediately diagnosed. Patient receives conflicting accounts</td>
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<tr>
<td>4. 49-year-old male (patient)</td>
<td>Motorbike accident patient had a spinal injury that was not diagnosed due to incomplete x-ray of the spine, resulting in permanent spinal damage</td>
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<tr>
<td>5. 27-year-old male (fiancée of patient)</td>
<td>There is disagreement between doctors during a birth. This was explained as a result of understaffing. No real physical or permanent harm caused</td>
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<tr>
<td>6. 70-year-old male (patient)</td>
<td>Male patient advised nurse to change surgery site before operation; she did and the patient had wrong-site surgery. While patient felt ‘he caused it’, the hospital admitted it needed to investigate its procedures</td>
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<tr>
<td>7. 69-year-old female (patient)</td>
<td>When a stent sheath was withdrawn from patient’s groin, her blood pressure dropped rapidly, and she was administered a metaramine (vasopressor) overdose</td>
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<tr>
<td>8. 26-year-old female (patient)</td>
<td>Woman required an emergency caesarean due to prolapsed cord. The alarm went off in wrong area of the operating theatre and the operation was delayed. No permanent harm</td>
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<tr>
<td>9. 28-year-old female (patient)</td>
<td>Student midwife and junior doctor performed a delivery and doctor provided inappropriate rectal surgery that caused incontinence and required follow-up surgery</td>
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<tr>
<td>10. 59-year-old female (daughter of patient)</td>
<td>Patient had a mild stroke and went to a hospital for rehab physiotherapy; he fell out of his wheelchair and ended up with pneumonia in ICU where he died shortly after</td>
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<tr>
<td>11. mother (of 23-year-old suicidal male patient)</td>
<td>A 23-year-old man attempted suicide after being given a prescription of 400 pills despite being known to the mental health service. He is now in a nursing home in a vegetative state</td>
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<tr>
<td>12. 61-year-old male (patient)</td>
<td>Patient was given wrong plasma</td>
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<tr>
<td>13. wife (of 61-year-old male, patient 12)</td>
<td>Husband was given wrong plasma (same as patient 12)</td>
</tr>
<tr>
<td>14. 50-ish female (patient)</td>
<td>Patient had gallbladder surgery and suffered 8 months severe pain post-op. Because the suture was not tight enough she developed a hernia. Different surgeon needed to operate on the hernia</td>
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<tr>
<td>15. 38-year-old female (stepmother of patient)</td>
<td>Young man was ran over by car. During his 10 h operation a Hepatitis-C-infected piece of equipment was used</td>
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<tr>
<td>16. 64-year-old wife and 40-ish daughter (of 70-ish male patient)</td>
<td>Patient had cancer in the leg. He was supported by only one nurse (when the notes said he needed two at all times); he fell, and broke his leg. Family was on-site in the hospital when agency nurse failed to support the patient adequately and announced a doctor was needed; the doctor came to treat the patient but left ‘for a more serious case’. He had an operation 24 h later, but died 3 weeks later from a blood clot</td>
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<tr>
<td>17. 54-year-old female mother (of 29-year-old female suicide)</td>
<td>Following discharge from hospital a young woman made several suicide attempts. She eventually was successful. Information to her family about the case was denied</td>
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Table 1 Continued

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<tr>
<td>18. 61-year-old daughter (of 88-year-old female patient)</td>
<td>An elderly patient was escorted to the toilet by two young nurses. Left unaided, the patient, using a walking-frame, attempted to leave the toilet and fell. She sustained an insoperable hip fracture to an already infected leg. The patient died 3 weeks later.</td>
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<tr>
<td>19. 40-ish daughter (71-year-old female patient)</td>
<td>A palliative care patient requiring IV fluids and pain relief was admitted Friday evening. <em>Ad hoc</em> and inadequate management ensued for both pain relief and hydration needs. This resulted in renal failure. The patient died Sunday evening.</td>
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<tr>
<td>20. daughter (of 93-year-old patient)</td>
<td>Against her daughter’s protests, the patient was discharged from hospital after surgery. The daughter claimed her mother was not well enough to be released. During the 300 km car trip home, the patient aspirated. She developed pneumonia, was re-admitted but subsequently died.</td>
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<tr>
<td>21. 52-year-old male (patient)</td>
<td>The patient was given a saline overdose following alcohol-related collapse</td>
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<tr>
<td>22. Mother (of 17-year-old male patient)</td>
<td>The patient had an unsuccessful spinal operation that staff had promised would relieve him of his symptoms.</td>
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<tr>
<td>23. 84-year-old male (patient)</td>
<td>The patient’s colonoscopy was conducted with unsterilized equipment</td>
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**Was the incident promptly disclosed to the patient and/or family?**

Interviewees felt that staff should have been more forthcoming about an adverse event having occurred. Indeed, seven interviewees had to explicitly request or insist on Open Disclosure. Wanting to find out why the birthing process had been so problematic, one interviewee (#1) approached different staff for explanations. Eventually, she was granted Open Disclosure: ‘I’ve talked and talked and talked and talked. I’ve talked to counsellors and I’ve talked to midwives, I’ve talked to doctors and I’ve talked to a lot of people. I’ve talked to the Health Rights Commission… and then finally, yeah, eighteen months later, no fifteen months later, we finally had the Open Disclosure.’

Another (#2) reported how their adverse event was noticed by their GP: ‘I went for a six-weekly, oh, sorry, two-weekly check up and in that check up I told the doctor then what had happened and he said, “Oh, my goodness me, I’ve not heard anything about this.” And from then that’s what started the ball rolling so that I had the [disclosure] interview with the other people [clinicians who originally treated this person].’ Yet another (#18) said, ‘it was probably more weeks, over a month I would say before they got round to … ask us to a meeting’

**How formal was the disclosure meeting and did it match victims’ expectations?**

Interviewees saw the level of formality of the disclosure meeting(s) as an indicator of respect. Formal disclosure is described in the Australian Open Disclosure Standard as ‘High-Level Open Disclosure’, which is to be provided in cases of serious harm and death [17: 37]. Formality should not necessarily be associated with the number of managerial staff present, however: ‘I probably didn’t like the fact that they were in suits and you know like it was “We’re going to fix this because we’re the hierarchy” that sort of thing.’ (#13).

Interviewees made it clear that for them formality referred to whether the situation was taken seriously by staff, and whether their communication was constant and supportive. As one of the one-third of interviewees who experienced their disclosure meetings as formal, interviewee #15, commented: ‘They both [the patient liaison person and the surgeon] sat with us. They were both there when they sat us down and told us about it. And they answered questions we wanted to know. It was really good’. Only one interviewee who had been offered such formal Open Disclosure remained dissatisfied: ‘They explained to us what had happened. They admitted that they made a mistake, that they didn’t get a chance to read the patient’s booklets, and folders on their conditions. They have something written up above their bed and that’s all they basically go by. Now the problem is that these nurses [involved with the incident] are, I feel, getting away with it… They did apologize but it wasn’t enough at the time’ (#16).

Nearly half of all interviewees regarded their disclosure as too informal, denying them the chance to formulate questions and probe clinicians about the adverse event: ‘she [clinician] just popped up to see me… it wasn’t planned so I didn’t have any questions planned or anything’ (#9). Another said, ‘I didn’t receive the opportunity to follow up and try to understand the whole’ (#17).

**Was an apology offered and of what kind?**

Almost half of all interviewees stated they had received a full apology, with staff acknowledging responsibility for the adverse event. The remainder included those who were not offered an apology when they felt they should have been: ‘All the doctor said was the [clinician involved in the incident]
Table 2 Selected interviewee responses: Was Open Disclosure offered? Was it sufficiently formalized? Was there a (full or partial) apology?

<table>
<thead>
<tr>
<th>Interviewee (adverse event descriptor)</th>
<th>Did Open Disclosure take place? Was it sufficiently formalized?</th>
<th>Was there a (full or partial) apology?</th>
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<tr>
<td>2. 58-year-old female (anaesthetic overdose)</td>
<td>Yes, formalized 'a lovely lady there who organised this meeting with the head of the anaesthesia department, the head nurse and, I can’t remember her name just off the top of my head, but she was such a lovely lady and the three of us were there in the room. We had organised this meeting a month ahead of time, and it was then that I learnt what had actually happened.'</td>
<td>Yes, full ‘It was the nurse’s fault because of the way the dosage is given and they told me that they had put in place measures that will not allow this type of thing to happen again.’</td>
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<td>3. 36-year-old female (baby antibiotic overdose)</td>
<td>Yes, not formalized 'doctor popped in'</td>
<td>‘All I could get out of doctor was, um, ‘The nurses feel very bad. Some nurses even quit their jobs over this’, you know, ‘when they make a mistake’. And, well, I don’t really care. I don’t really care if they quit their jobs or whatever. You know, like this is my baby.’</td>
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<td>5. 27-year-old male (fiancée of pt)</td>
<td>Yes, formalized.</td>
<td>No apology. ‘That’s what the meeting was supposed to be about, but it was just a big defense mechanism for them. There wasn’t much admission of anything that went wrong . . . it was a lot like talking to a politician, it felt like, you know? He would answer questions in a long and roundabout sort of way?’</td>
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<td>9. 28-year-old female (failed rectal surgery)</td>
<td>Yes, not formalized 'she popped in'</td>
<td>Yes, partial apology. ‘Er, I mean . . . from what I can remember, I was quite sort of upset at the time. They were basically . . . the whole thing it seemed like they were covering their tails, basically. They haven’t. . . . The doctor at the time did apologise but no-one’s really taken responsibility for it. I would like to have an apology . . . a sincere apology, that, “yes, we shouldn’t have put you in that position.”’</td>
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<td>15. 38-year-old female (step mother of pt) (Hep C infected surgery equipment)</td>
<td>Yes, formalized ‘They both [the health and safety representative for patients and the surgeon] sat with us. They were both there when they sat us down and told us about it [improperly cleaned equipment]. And they answered any questions we wanted to know . . . And . . . they were quite approachable afterwards. You could go and talk to them about anything so . . . it was really good.’</td>
<td>Yes. Full ‘Oh look, they . . . they were very good to us. Um, we had social workers speaking to us all the time . . . Their doors were always open to us . . . if we had any questions, if we wanted to go and speak to anybody . . . I can honestly say to you, that they were fantastic to us, right from the nurses, doctors, social workers . . . they were fantastic.’</td>
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<tr>
<td>20. daughter of 93-year-old patient (early discharge causes complications and hastens death)</td>
<td>Yes, not formalized</td>
<td>Yes, full (by Quality Coordinator, not by clinicians).</td>
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<td>[Open Disclosure conducted by the Quality Coordinator, not by the clinical team].</td>
<td>‘All I had (was [Quality Coordinator]) giving me the answers, ah, what was said, ah, referred what she heard . . . was said to me . . . ’</td>
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<td>‘No doctor actually spoke to me . . . and the office person or floor person or whatever her title, when she seen me come that day she didn’t even have the decency to look at me and say I’m sorry for your loss, she turned and looked away from me.’</td>
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was very upset’ (#3). Other interviewees reported not being satisfied with staff giving partial apologies (expressions of regret eschewing responsibility): ‘ . . . but it would have been nice if someone had have just acknowledged and said “This is our fault”’. One interviewee reported receiving an apology which was subsequently undermined: ‘ . . . the first meeting she apologized . . . Then when I handed her the birth certificate that said staphylococcal chorioamnionitis she backtracked and said, “No, no, no . . . ”. And that to me seemed like she just completely and utterly was not sorry anymore’ (#1).

In cases where staff resisted acknowledging responsibility, interviewees expressed disappointment: ‘I definitely didn’t like the defensive nature of the people involved’ (#5), and ‘They were blaming the cancer’ (#16). Important to note here is that the Australian Open Disclosure requires staff to ‘express regret’; that is, offer partial apologies. In practice, as our interview data show, staff may assume responsibility in the interest of strengthening their apology [20]: ‘That person that did own up was very upset that it happened, which . . . would have taken a lot of guts’ (#23) (Table 2).

Was the consumer’s concern about system improvement heard?

Besides offers of support for the patients harmed, staff responses to adverse events also included taking seriously the service implications of patients’ concerns: What I liked about the meeting was that they said they would make sure that they would review the procedures [. . .] and the hospital to identify how this could have happened’ (#13). Interviewee #6 commented that: ‘the outcome was that they just have to tighten up on procedure . . . a couple of months after . . . oh yes [laughs] it was a changed situation.’ Similarly, interviewee #1 reported that ‘he said to me that they’d actually had some more cases of infection in the Department but thanks to case studies and observation logs and things like that, and he said, “[name], you put that in place.” “It happened because of you so that’s a pat on your back”’.

Were consumers able to meet with the clinicians involved in the adverse event?

Interviewees saw the opportunity to meet with staff closely involved in the incident as important, and regarded being denied this opportunity as a negative. One interviewee (#3) felt that she was denied crucial information by not being told who had been involved: ‘And they wouldn’t even tell me who the nurse was.’ Others expressed their disappointment as follows: ‘The nurses didn’t come and see me . . . it was just the two doctors that kept coming to the bedside’ (interviewee #7); ‘no, no doctor actually spoke to me’ (#20) and ‘All the doctor said was the [clinician involved in the incident] was very upset’ (#3). Out of the 13 instances where contact with one or more staff who were close to the incident was possible, seven reported a positive experience: ‘I think since the Open Disclosure I’ve got some answers’ (#1); ‘They were very good at explaining exactly what was happening and they were very honest’ (#8) and ‘It was very useful’ (#12) (Table 3).
<table>
<thead>
<tr>
<th>Consumer interviewee (adverse event descriptor)</th>
<th>Was contact possible with clinician(s) most closely involved in incident?</th>
<th>Was there an offer of tangible support or evidence of practice improvement?</th>
<th>Outcome of OD process judged to be successful?</th>
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<tr>
<td>2. 58-year-old female (anaesthetic overdose)</td>
<td>No (nurse absent from OD meeting). Measures were put in place to make sure it never happened again, but consumer was not given details.</td>
<td>‘Well, there was a lady [Patient Support Officer], her actual name has just escaped me. She was just wonderful. She phoned me and she said she was setting up this meeting and any questions I had, try ask everything that I wanted to know.’</td>
<td>‘Do you feel the health professionals were open and honest with you?’</td>
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<td>‘It would have been nice to have actually seen what they had done and what happened previously, and then the measures that they’d taken to, so this would never happen again.’</td>
<td>At the meeting they were. But generally overall. No, not really overall.’</td>
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<td>3. 36-year-old female (baby antibiotic overdose)</td>
<td>No (nurses absent from OD meeting). Some financial support was offered, but not enough to cover disability costs and challenges later in life.</td>
<td>‘And they wouldn’t even tell me who the nurse was. Like I was there for three weeks. I was there for most shift changes. I just about knew every nurse in NICU. You know, I sat there from daylight till dark, and they wouldn’t even tell me who the nurse was.’</td>
<td>Formal meeting was seen to be too delayed; conflicting advice was given by different paediatricians.</td>
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<tr>
<td>7. 69-year-old female</td>
<td>No.</td>
<td>Limited support.</td>
<td>No.</td>
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<td>‘The nurses didn’t come and see me. They just came, it was just the two doctors that kept coming to the bedside ... they were both, both cardiologists.’</td>
<td>‘They paid us expenses, except his [husband’s] meals when they, they flew him back, oh, no, they didn’t ’cause he drove back. They paid his seventy dollars for petrol, ... and they paid his, ar, accommodation expense ... You have to pay your own meals and everything. They don’t, they don’t provide for that.’</td>
<td>‘They seemed to talk above your head somehow. Even though they’re trying to say it simply...”I feel as though I’m, er, just, er, a subject rather than a person, if you know what I mean...” ell, I had to press for it, to get the information I wanted. See, my question was, if I was given this, er, injection, why wasn’t it checked and double checked before it was administered...’</td>
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<td>‘You know, I’ve had to wait all that extra time to get the analysis report before I could find out. Nobody would tell me why this drug wasn’t, I asked repeatedly, ‘Why wasn’t it checked? Why wasn’t it checked?’ Nobody could tell me.’</td>
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<td>‘The support of ‘Hospital in the home’ was marvellous because they were monitoring him as well as me. And they were a very good service support for me as well. Because if anything goes wrong they are there. I just have to ring them.’</td>
<td>‘What I liked about the meeting was that they said they would make sure that they would review the procedures [...] and the hospital to identify how this could have happened, that was probably it. I didn’t like the fact that they were in suits and you know like it was ‘we’re going to fix this because we’re the hierarchy’ that sort of thing.’</td>
<td>‘The meeting was somewhat useful. They couldn’t let us know what was going to happen to his body and what the consequences would be.’</td>
</tr>
</tbody>
</table>
15. 38-year-old female (step mother of pt) (Hep C infected surgery equipment)  

Yes.

‘The ... surgeon involved ... and the patient and safety officer were involved ... And I’m sure that if we’d asked to speak with somebody else they would not have hesitated to get somebody.’

‘They told us all of the things that [the improperly cleaned equipment] could ... have given him this infection and he could’ve got hepatitis, but the fact that he’s been immunised against hepatitis, and the fact that they were ... giving him high dosages of antibiotics to combat any infection that he might or might not have got.

They were covering everything. They weren’t just letting it run its course. They weren’t just leaving him to it.’

‘It felt like we weren’t just fobbed off after it all, and forgotten about ... they did follow through ... I think they have changed the way they do things ... I did [find it useful]. And it was useful for them too I think. It sort of opened their eyes to the fact that these things can happen, human error happens and that’s just the way it is. We’re all human. But, they found other ways [to] ... minimise that [the error and] ... the impact on their patients, which is really good.’

Yes.

‘I liked the fact that it was never a rigid thing. You could, you felt comfortable with these people, they spoke to you ... not like you were an idiot, they spoke to you like you were a person.’
Discussion

This study confirms earlier reports regarding the importance of recognizing the consumer’s perspective on the incident [12], of the need for constant and supportive communication [7], of offering tangible support [13] and of improvements to clinical practice to rule out re-occurrence of the adverse event [21]. The present article contributes two additional findings.

First, disclosures are complex social events: some aspects can be experienced as positive and others as negative. Particularly in the cases of interviewees #1, #2 and #17, disclosure was judged to be satisfactory in some ways but not in others. Interviewee #17 comments, for example, that ‘I think you know we were treated quite well [but] we did not get the opportunity to follow up’ (#17). Positive comments were made about support staff (the Open Disclosure project officers) who were generally perceived as caring and attentive, but not always about clinical staff who were seen to distance themselves at times (‘The nurses didn’t come and see me’; #7). The positive impact of the disclosure in these cases was counter-balanced by staff not making themselves freely available or by providing what appeared to be defensive or irreconcilable explanations. This finding points to the importance of not just constant communication, but also of consistent disclosure communication.

Second, analysis of the data reveals that interviewees regarded staff as comfortable with disclosing non-serious adverse events, and as less comfortable with having to disclose serious adverse events. Echoing findings that the response to the adverse event needs to be proportional to its severity [5], interviewees who expressed satisfaction about the disclosure process were typically those whose expectations of a full apology, formal disclosure and an offer of tangible support were met. Consumers commented that clinicians drew back from showing the kind of openness and honesty that consumers regard as naturally complementary to the trust invested in the clinical service provided, and that they therefore expect to have contact with their clinicians following serious adverse events. This finding points to the need to educate (junior) clinical staff not just in the technicalities of their profession, but also about the full set of responsibilities that professional expertise incurs, such as communicating with their patients when things go wrong. The finding also suggests that health facilities should deploy Open Disclosure officers for adverse event communication coaching, instead of relying on them to relieve clinical staff of adverse events disclosure. To lay claim to professional expertise but instead of relying on them to relieve clinical staff of adverse events disclosure. To lay claim to professional expertise but

Conclusion

Hospital-initiated harm brings with it an onus on clinicians and health services to redeem themselves through Open Disclosure. Our limited data suggests however that the Open Disclosure process is not yet reliably meeting consumer needs. Casually informing consumers about an adverse event was not sufficient for the interviewees who participated in our study. Full apology and adequate recognition of what the adverse event means to them is needed, as well as a clear plan of how the patient will be supported after the adverse event, physically, emotionally, clinically and financially.

In Australia, the positive findings of the present study notwithstanding, the policy of Open Disclosure may still remain somewhat aspirational. Lest Open Disclosure policy fail its health reform objectives, more insight into what works for consumers involved in adverse events is essential, requiring institutional support for practice-based research into consumers’ experiences of existing approaches to adverse event management.
Action has been proposed on a number of fronts to bolster the Open Disclosure initiative. Legal reform may promote collaborative principles to govern lawyers' roles in negotiating adverse events [24], make tangible support a standard component [3, 25] and strengthen clinicians' accountability for (appropriate) disclosure [26]. Education of clinicians and managers should encompass response procedures to adverse events, emphasize disclosure communication that includes apologizing and listening to consumers and give prominence to the need to take account of the consumer experience to improve the disclosure process. Most important is that health facilities accord consumers a voice in how adverse event responses are to be structured. For this to occur, scenario-based surveys confirming consumers' in-principle preference for disclosure [27] need to be complemented with practice-based research such as that described here, in order to determine best practice in error response processes and to make sure this is delivered to every patient.

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**References**


**Appendix: Interview guide for patients and family members**

**OPEN DISCLOSURE—INTERVIEW GUIDE FOR PATIENTS AND THEIR FAMILY MEMBERS**

1. What is your age?
2. What is your gender?
3. Are you the patient, a family member or close friend?
4. What was the main reason why you were admitted to hospital?
5. What were the unexpected harms that occurred to you that led to the OD meetings?
6. When were you first made aware the unexpected harm was done to you?
7. How did you feel when you were told that unexpected harm was done to you?
8. Did you feel that health professionals had been open and honest with you?
9. Did you feel listened to and all your questions answered. Were the answers explained to you in simple English?
10. What supports were you offered and received? What did you need?
11. What notification did you get about the meeting? When, where, duration, attendees, how much notice?
12. Were you involved in an RCA and notified of the findings?
13. How serious was the unexpected harm that occurred to you or your relative or friend (very serious, serious, somewhat serious, not serious, not very serious)?
14. How many Open Disclosure meetings have you attended where a doctor or another health worker spoke to you about the unexpected harm that occurred in hospital?
15. What type of health professionals were present at these meetings? (doctor, nurse, pharmacist, other)?
16. How useful did you find the meetings in dealing with harms that occurred to you or your relative or friend?
17. How involved have you felt in relation to health professionals’ interactions with you since your unexpected harms were found?
18. Do you see Open Disclosure as a useful approach to acknowledging errors in care to patients and their families? In what ways?
19. Have you found the outcomes of these sessions satisfactory? In what ways?
20. What did you like about these meetings?
21. What did you not like about these meetings?
22. Is there anything you would like to change about the way the meetings were carried out in the hospital for you or for your relative or for your friend?
23. Are there any other comments you would like to make about Open Disclosure?

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