Patient perspectives of patient–provider communication after adverse events

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Abstract

Objective. To explore patient perceptions of patient–provider communication after an actual adverse medical event because prior patient error studies are rarely based on real situations.

Design. We conducted four patient focus groups using a semi-structured guide. We analyzed transcripts using an editing approach to identify themes.

Setting. Three sites in Colorado.

Study participants. Participants were recruited from statewide post-injury program. Purposeful sampling began with patients in a geographic location; we contacted every other patient (up to 50). Twenty-two patients initially agreed to participate; 16 adults participated, representing 13 cases.

Results. Complex issues and processes were involved in resolution attempts. Effective communication was an important factor in whether professional relationships continued after an adverse event. The communication nature and quality influenced whether patients defined event as ‘honest mistake’ or ‘error’. Two types of trauma (physical and emotional) were expected and found. A third (financial) uncovered and proved in some cases the most salient factor influencing patients’ subsequent actions. Caring, honest, quick, personal, and repeated provider responses were linked to patient satisfaction.

Conclusions. Provider communication timeliness and quality were important influences on patients’ responses to adverse events. Confronting an adverse medical event collaboratively helped both patients and providers with patients’ emotional, physical, and financial trauma and minimized the anger and frustration commonly experienced. Health organizations, providers, investigators, and policymakers should consider the patient experience when developing provider training or evaluating processes in patient resolution.

Keywords: medical errors, patient perspective, patient–provider communication, qualitative research

Adverse medical events are traumatic [1]. How health care providers and patients communicate during these trying times can significantly affect patient and provider outcomes [2,3]. We know little about the communication dynamics from the actual experience of patients who have suffered an adverse medical event. Patients surveyed from a general sample say that, when things go wrong with their health care, they need disclosure, an apology, and information about what happened and how it can be prevented from happening again [4]. An analysis of written complaints concerning care provided by practitioners in the United Kingdom showed many of the same characteristics [5]. However, providers do not always respond to these patient needs following medical errors or complications [5,6].

Few studies have focused specifically on patient perspectives after the injury [7]. Most of the studies are dated, are simply reviews of records, or include only the physician’s perspective [5,8–11]. Those studies that considered patient perspectives either pre- or post-injury included reviews of patient complaints [5,12], hospital records [13], plaintiffs’ depositions [14,15], criminal prosecutions [16], malpractice claims [17,18], and general patient surveys or interviews with or without the use of scenarios [4,6,19,20]. Only one recent study included in-depth interviews which described problematic incidents that resulted in perceived harm [21]. The findings suggest that for errors resulting in harm, breakdowns in access to and relationships with clinicians may be more prominent than technical errors in diagnosis and treatment. Other studies point to poor patient–provider communication, inadequate delivery of information, and negative interactions with the provider as leading causes of increased litigious intentions [1,2,6].

Greater insight into patients’ actual experiences following an adverse medical event might improve the medical community’s...
handling of these events. Thus, this study explored the patient ‘lived’ experience of an adverse medical event, learning patients’ insights of the factors leading to successes and failures in patient–provider communication post-injury.

**Methods**

**Subjects and setting**

Subjects were recruited in collaboration with a physician malpractice insurance company, COPIC, Inc. COPIC operates a post-incident risk management program called the 3Rs (Recognize, Respond, Resolve). This early intervention is aimed at supporting the doctor–patient relationship after an adverse medical event. Physicians who volunteer for the program are encouraged to apologize, explain the cause of the injury or complication and explain what can be done to expedite recovery. The program also provides funding for the reimbursement of reasonable out-of-pocket medical expenses whether or not the injury is caused by an error. Participant patients do not forgo their right to subsequent legal action.

All patients involved with the 3Rs, whether an open or closed case, were included in the sampling process. Three geographic areas within Colorado were chosen, as each contained adequate numbers of patients for focus groups. Within these geographic areas, every other case was selected for possible participation. The 3Rs staff telephoned all potential participants, described the study, and asked for participation (total called = 50 patients). If the patient agreed to participate, a follow-up letter was sent describing the study with location and time of the group. Initially, twenty-two patients agreed to participate. Sixteen patients actually participated with an average of 4 per group. Although additional groups were planned for data saturation, they were not required [12]. Participants were offered $50 gift certificates. All groups were completed in approximately 2 hours. Spouses of three patients also participated in the discussions.

**Procedures**

An experienced moderator (the lead author) conducted the groups using semi-structured methods [22]. To accommodate participants’ work schedules, groups were scheduled at 6:00 P.M. A court reporter recorded the conversation so the moderator could focus on facilitation. Each participant was asked by the moderator about their comfort regarding allowing two 3Rs administrators to witness the group discussions. These administrators were integral to the program and wished to be present to gain insight for program refinement. No participant indicated any discomfort; in fact, they seemed pleased that the administrators would be there. The moderator explained the content of informed consent forms and participants signed them. Participants completed a short written survey that collected demographic information. The moderator explained the purpose of the group and the reason for recording the session. She proceeded with questions and prompts to explore issues raised by the group. Comfort was continually reassessed about the presence of the 3R administrators. If the moderator felt that the group was influenced by the presence of the administrators, she would have asked them to leave. At no time was this necessary.

A court reporter recorded all sessions, whereas the research associate took field notes. Additionally, the facilitator recorded notes immediately after each session. The field notes summarized major themes from the note taker’s perspective. They also provided the observer’s insights into the emotional context, personality, demeanor, and feelings of the group participants.

Each discussion began with some non-emotionally threatening questions concerning experiences with the 3Rs program (most liked, least liked, recommendations for program refinement, and so on). The facilitator then explored the communication with their provider before, during, and after their medical injury. For example, she asked the participants to describe the communication with their provider around their medical complication. Prompts such as the following were used: ‘How did it go?’ ‘What did you like?’ ‘What didn’t you like?’ ‘What were your expectations?’ ‘Were these expectations met?’ ‘What was important in talking about medical injury with your doctor? What could be done to make this discussion easier? To illicit additional themes, each session ended by asking if there was anything that had not been asked but that the participants felt was important to know in efforts to improve patient–provider communication following medical adverse events.

**Analysis**

Focus group transcripts and field notes were entered into ATLAS.ti version WIN 4.2 qualitative data analysis software. Data were analyzed using a combined template and editing organizing approach. First, general broad codes related to each semi-structured question were developed [23]. An editing approach to analysis, a technique derived from grounded theory, which allows for separation of preconceptions and identifies emerging themes and codes [24], was then used. A team approach (the principal investigator and research assistants) helped limit any personal biases, subjectivity, and preconceptions. A commitment to self-reflection resulted in ongoing assessment of subjectivity in all steps of the analyses. Analysis team members independently read the transcripts, highlighting particular issues, examples or quotations each felt was important. The team then met to discuss notations and interpretations. Transcripts were reviewed a second time to confirm or refute initial and ongoing themes and codes. The themes were then organized into an overall framework to describe the complexity of factors involved in patient–provider communication following adverse medical events. After summarizing the results, a return to the field notes assessed the comprehensiveness and accuracy of the data extraction. The full results were presented to COPIC staff for their validation of the experiences (debriefing). This analytic approach was consistent with criteria for enhancing the validity of qualitative findings [23,25].
Results

Each of the groups included three to four ‘adverse event’ cases. There were no differences as to general type of event or demographics between the groups. Three of the four groups included one spouse in the discussions; thus, five to six individuals participated in each group. The cases involved 12 white females and one African American male. One female was of Hispanic descent. The cases concerned the following specialties: four obstetrics–gynecology; two plastic surgery; and one each of orthopedic surgery, podiatry, infectious disease, emergency room treatment, oncology, and gastroenterology. Each adverse event required extensive medical follow-up. Events included perforations, suture infections, and surgical errors. Several themes emerged from the data: trauma, worries, frustrations, and communication factors.

Trauma

Patients are often in vulnerable physical or psychological states, even with routine procedures. Therefore, when harm from an unexpected event occurs, especially from someone they trust, reactions can be severe and traumatic. Traumatic events are characterized as being ‘generally outside the range of usual human experience’. The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) defines ‘trauma’ as when subjective horror, fear, or helplessness is reported post-experience. Using this definition, the participants explained three types of trauma that occurred with adverse medical events: physical, emotional, and financial. This trauma seems to have a cumulative or compounded effect. Trauma developed in the two ways described previously by Vincent: from the incident itself or from the manner in which the event was subsequently handled [1].

I look at this just as traumatic as if a disaster came through as far as a flood or a hurricane; because it totally turns your life upside down. . . (study participant)

These things are catastrophic. Life shouldn’t have to be catastrophic because something that you didn’t plan on happening to you, especially in the medical arena.

All participants experienced physical trauma. ‘You know, it was a big deal to me to have scars going all over the place, a colostomy, and everything else. And I had scars going everywhere’. The emotional trauma seemed to vary by the communication process with the provider. Those who perceived what they felt as good communication (respect, active listening, caring, and so on) with their provider experienced less emotional trauma.

And he was very nice about the whole situation, polite, calm. He wasn’t excited about. . . oh you can’t be suing, and all that kind of stuff. And he just was you know very professional about it, very professional and gave me the information that I needed.

The reverse was also true.

I’m extremely hurt just because I’m still having complications. I’m going to get cut open again. . . Just the fact that he has no idea what I’m going through. And he’s just moved on with his life and never called me. That really hurts. It really bothers me.

The medical error literature has ignored financial trauma. However, the participants all mentioned the devastating impact of financial problems following an incident. This type of trauma in some cases was the salient issue that seemed to affect the impact of the other trauma.

You know if it comes to suing somebody or losing my house, you can about guarantee I’m going to be suing somebody.

I thought I was out for the count when all them [sic] bills were rolling in. There was a stack of bills like this from my insurance. And they just kept coming because I kept having surgery after surgery.

Participants reported that the financial impact became especially overwhelming when it threatened or negatively affected personal credit reports.

The credit thing was a big factor, too. Because even though I was staying in contact with the hospital, after a point they was [sic] still sending me to the credit bureau. . . They don’t care, they was [sic] just corrupting your credit.

Financial trauma seemed to also mediate the impact of the emotional trauma.

The emotional part is tied into the financial thing. . . how in the hell am I going to pay my bills because I can’t go to work because this happened.

Patient worries

A common human response to something going wrong is to ask: “What happened?” This experience was confirmed by our participants as the first worry in a progression of worries.

What is happening?

I was rushed to the hospital and they did all this stuff to me that I had no idea what they were doing.

What is next?

. . . not knowing what’s really going to happen, not knowing if I’m ever going to come home again.

I was on antibiotics for four weeks and they discontinued it because the antibiotics were affecting my kidneys. And it’s like, well, what else is going to happen to me now? It just seemed like one thing after another after another after another.

Will I return to my former self?

. . . most people only wanted just be made whole. To be back where I was when I started and we’ll call it even.

Financial worries began to set in, which, if not addressed, led to anger. Who is going to pay for my losses?
I had this $15,000 bill. I didn't know how I was going to pay for it. Was I going to pull the equity out of my home? Was I going to file for bankruptcy?

And it's almost to the point where... well, if the problem persists for two or three years, how long can it be before I sue the people who were involved to help pay for the problem. I mean, it's bad enough that I have to physically deal with it, but then to have to financially deal with it is a totally different situation.

**Patient frustrations**

Patients described many frustrations that influenced their coping ability. Adverse medical events were confusing and required resolution on several levels. Often patients worked through the process feeling very alone. Participants pointed out the importance of having information to help them cope, but having great trouble obtaining it. Frustration from poor information about their situation led to feelings of anger and a perceived need for battles or conflict. When information was made available, a sense of relief settled in that the battle was over.

I wanted as much... whether I understood it or not. I wanted to hear it. I wanted details because then I could sort through it in my head, and then come to my own conclusions.

It's refreshing not to be battling with insurance companies, hospitals, etc. We didn't have to get a lawyer.

Many patients mentioned their perceived need to 'threaten' to get action from the other parties involved.

I told them that there was going to be a lawsuit to somebody, somehow, if this stuff doesn't get straightened out.

I had to write letters. [Threats] I've had to do all this when it wasn't even my fault, to try to get myself out.

The inability of admitting a mistake by the provider, hospital, and even providers who became involved after the event for consultation and resolution lead to frustration.

... as far as just the medical people involved. That was extremely frustrating for me because nobody was willing to say that they made a mistake.

The worst problem for me was that I had nobody that wanted to touch someone else's surgery.

Literature exists concerning the importance of an 'apology' [7]. Some participants mentioned that apologies did not routinely happen, but an apology remained important to their resolution process.

I just wanted him to take responsibility for it. 'Look, I'm sorry I did this and I'll do whatever it takes to make things right'. Just own up to what happened.

**Communication**

In the exploration of factors for good communication, the communication process appeared to predict whether the patient continued a relationship with the provider after an event. All patients who expressed that their communication did not go well also indicated that they no longer had an ongoing relationship with that provider. When the communication process was seen as satisfactory, the patient continued a relationship with the provider. In one case, the patient paid out-of-pocket to continue the relationship with the provider, even though he no longer belonged to her insurance provider group.

I still see him even though my insurance has changed and he's no longer on my insurance. I have total confidence in him... Well, he's honest. You know he laid it on the line and gave me the facts.

Those patients who experienced a good communication process with their provider also perceived a ‘no fault’ event. These patients were more likely to call these events ‘mistakes or complications’.

Everyone makes mistakes. My physician made a mistake but he was trying to do the best possible job he could and a mistake unfortunately happened.

Conversely, those patients who were dissatisfied with their communication with the provider had a tendency to see incompetence or malicious intent.

We don't feel that what happened to us was in any way near a honest mistake.

**What did not go well.** Patients described experiences related to poor communication (Table 1) and good communication (Table 2) with their providers during and after a medical event. The experiences identified as poor communication are not surprising, and some have been touched upon in the general literature on patient–provider communication processes [5,7,21,26]. Two experiences did emerge that have not been discussed previously. Patients need action taken quickly and confidently by providers. Quick action provides a sense of reassurance in the confusion. This action must be directed at answering the initial patient worries of 'what happened?', 'what is next?', 'is this fixable?'. Provider support of the patient must follow quickly and continue as the process unfolds.

I appreciated that somebody was prompt enough to take the initiative to do it. I didn't have to go banging on peoples' doors and threaten to get some kind of service and help.

Interestingly, patients commented about the provider setting the ‘tone’ of communication, especially around the perceived fear of a lawsuit. Once the patient perceived the provider as ‘fearing a lawsuit’ or ‘covering his butt’, the communication process appeared to take a turn for the worse. Patients began to react to this fear by then looking for justification.

Table 2 outlines experiences indicative of a good communication process; the provider comes across as a ‘human’.

Our relationship is tight, tighter than tight. There were quite a few complications. My wife, now, if it was left up to her, she'd have
Patient perspectives of errors

Table I  Emerging experiences of poor communication

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<th>Not communicating</th>
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<td>‘He has never called. And that probably is more hurtful, because I thought we had really good communication before.’</td>
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<td>Not ‘owning up’</td>
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<td>‘... and they called us up and they say, the investigation’s complete. Nobody at the hospital made any mistakes. None of their doctors, none of their nurses, none of their janitors, nobody made any mistakes.’</td>
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<td>Not giving respect (not listening, not hearing, dismissal of patient, and talking down)</td>
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<td>‘I don’t think he gave me the respect he should have given me, and I wouldn’t give him another chance. He didn’t listen to me.’</td>
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<tr>
<td>Not following through</td>
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<td>‘He did say that “I’ll call and I’ll give you all the information”. And he never did that. We had to call him repeatedly.’</td>
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<tr>
<td>Lack of caring</td>
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<td>‘But I felt like I needed help and I wasn’t getting it anywhere. They didn’t care.’</td>
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<tr>
<td>Action not soon enough</td>
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<td>‘I think [he/she needed] to be quick to admit when something happened. and take care of it right away instead of later.’</td>
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<tr>
<td>Perceived provider fear of lawsuit</td>
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<tr>
<td>‘He was worried, I’m certain, of what was going to happen, what the outcome. what he was going to say to us, what he could say to us. Everything he did say was very carefully worded.’</td>
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<tr>
<td>Being too busy or hurried</td>
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<td>‘I just think that she was too busy to try to explain it.’</td>
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<td>Patient needs</td>
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The groups gave suggestions for improving the medical event resolution process. They mentioned that after a significant poor outcome, a full assessment of aftercare needs should be done, including assessing the need for brief or long-term therapy or support for trauma (physical, emotional, and financial). The patients also suggested a role for an impartial ombuds-person who can help from initial confusion through subsequent interventions and aftercare. This person needs to be part of a perceived impartial system—thus, not hospital- or provider-based.

We need an advocate. To have somebody available and know that they are there, that you can go to them at any time. But I think it’s a great idea to have them approach you as well.

You could attach a card or sheet of paper with some information on it, the number to call. You know. . . just by picking up the phone. . . being able to talk to somebody whose got some expertise in community relationships with hospitals and doctors.

Discussion and conclusion

This qualitative study is among the few to explore specific aspects of the ‘lived’ patient experience following a significant adverse medical event. Study participants described complex issues and processes involved in their attempts to reach resolution. Patient–provider communication was crucial to whether patients and providers continued their relationships and to the perceived definition of the event as a ‘mistake’ or ‘malpractice’. Though two types of trauma (physical and emotional) would be expected and have been addressed in the literature [7,21], we uncovered a third type (financial) that proved in some cases to be the salient influence on patient’s subsequent actions.

Helping to maintain a patient–provider relationship is an apology, and then personal, repeated attention to the needs of the patients and families. Study results support two principles outlined by Vincent in reducing trauma in this circumstance [1]. Providers should be honest and open about the incident and about what is being done to prevent a recurrence. Providers should offer to provide continuity of care to maintain the therapeutic relationship. This study adds that patients should be asked specific questions about emotional trauma as well as financial trauma. Additional support for the specific needs identified by these questions should follow quickly and repeatedly. During and after an event, patients and families need more support, not less.

A clear progression of anger existed in our patients’ experiences following an event. As Lamb points out, most patient anger is about how they were treated rather than the event itself [27]. It was clear that some patients tried to resolve issues through local and official channels, did this alone, and quickly felt a sense of futility. The anger progression identified in the study tracks closely to Flestiner’s et al. discussions
of the transformations by which injurious experiences develop into disputes [28]. Note that at the time of this writing, perhaps due to the rapid recognition of and payment for direct losses (a positive response to the transformations of blaming and claiming), none of the cases we studied progressed to a dispute (i.e. legal action.) As pointed out by others, legal action at least partly derives from desperation, born of the frustrated attempts to find out the truth, redress the wrong and get support for recovery [5,28].

Interestingly, the groups did not discuss threats to their personal identity as highlighted by Coyle [29]. Although many had suffered permanent physical losses and certainly discussed threats to their quality of life, the themes of feeling ‘dehumanized’ or considered ‘stupid’, ‘infantile’, or ‘incompetent’ were not prevalent. This may be due to communication processes built into the 3Rs program, particularly the case manager who is tasked to listen to the patient and family, inform them of what happened and how it will be dealt with and offer immediate redress for direct losses.

These qualitative findings should be interpreted in light of their limitations. Firstly, although a systematic process to sample patients who experienced adverse medical events was used, drawn from a population of patients that participated in a one-of-a-kind program that offers some financial relief, these groups may be influenced by their participation in this program and thus, may not reflect those of patients generally. Secondly, the sample had gender bias. Although both genders were approached to participate, the study was limited by those individuals who agreed and then attended the groups—primarily females. Thirdly, despite reaching thematic saturation on common factors affecting the patient experience in communication, the small sample prevented a more in-depth

Table 2  Emerging experiences of good communication

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<th>Experience</th>
<th>Example</th>
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<tr>
<td>Perceived caring</td>
<td>‘I thought he was caring and showed concern. His whole staff I think is very caring.’</td>
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<td>Perceived honesty</td>
<td>‘Well, he’s honest. You know he laid it on the line and gave me the facts. Just owned up to what happened.’</td>
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<td>Took responsibility</td>
<td>‘He said, “I’m going to do whatever it takes to make sure you are good again”.’</td>
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<td>Quick personal response</td>
<td>‘He gave me the information and he set up the appointment and everything. He did just about everything but take me to the appointment.’</td>
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<td>Repeated response</td>
<td>‘He called me at home, sometimes several days in a row when this came up again. He was just as devastated as (spouse) was. I don’t know how else to describe it. He’s caring. He’s incredible.’</td>
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<tr>
<td>Dependable</td>
<td>‘I just assumed that things like this only happened in movies and storybooks and didn’t happen to real people. And it did. And he was right there every step of the way.’</td>
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<tr>
<td>Perceived trust</td>
<td>‘But I went right back to my doctor because he is the only one I trust. He did nothing wrong. He did what he had to do in order to either keep my leg on its body or keep me alive.’</td>
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<tr>
<td>Reassurance</td>
<td>‘What did I need? I needed to know that we could fix this... things were going to be alright.’</td>
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<tr>
<td>Provider’s recognition of limitations</td>
<td>‘Instead of just fumbling around and trying to fix things that he thought he could fix... he sent me to somebody who he knew would take care of the problem.’</td>
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<td>Received information immediately</td>
<td>‘And I think that the most important thing is to give them all the pieces to the puzzle so that they can figure out how that puzzle fits... and what the picture is so that they can make an intelligent decision about what has to happen.’</td>
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<tr>
<td>Spent time, repeated time</td>
<td>‘She must have spent almost an hour with us just talking, answering questions.’</td>
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<tr>
<td>Being heard</td>
<td>‘She listened. She listened very carefully.’</td>
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<tr>
<td>Physical touch</td>
<td>‘What I did like was he did come and hold my hand. He never said sorry, but he held my hand and he’d squeeze it.’</td>
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<tr>
<td>Perceived long-term personal support</td>
<td>‘Mine asked... Was there anything else he could do. So he wrote letters to all my credit card companies so that they would waive my payments. He sat down personally and wrote letters to them. I can’t tell you how wonderful he is. This is a remarkable man.’</td>
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</table>
analysis of patients with different socioeconomic status, health literacy, and job types (e.g. those working within the health care system versus those who do not). Fourthly, we need to recognize that retrospective accounts of past events can vary with ‘what actually happened’. Dingman points out that respondents in their reconstruction of ‘what happened’ may affirm their identity as ‘good’ patients being the subject of an adverse event by ‘bad’ health care professionals [30]. Thus, reconstruction may provide some problematic access to the ‘lived’ patient experience. These findings should not be treated as offering patients’ experiences without offering some recall bias. A field study approach which follows patients and families from the time of an adverse event until resolution, though technically difficult, could possibly uncover different information [30]. Finally, because we limited our semi-structured focus group interviews on patient–provider communication using a common set of questions, we may not have heard about other important factors besides communication that may mediate trauma and other outcomes.

Despite these limitations, this study supports the importance of communication as an essential component of adverse event resolution. Our findings also suggest that studies of adverse event resolution must consider multiple dimensions of trauma in the provider and system response. Additional studies are warranted to confirm and extend this qualitative research, including quantitative measurement studies of trauma symptomology among adverse medical event survivors. We identified important themes shared by the patients. A trusting relationship between provider and patient is the bedrock of medical care [2,14,19,26,29]. Following an adverse medical event, patient and provider relationships face their greatest test. The key to success is open patient–provider communication and a true sense of caring.

Acknowledgements

This project was sponsored by AHRQ grant U18 HS11878, Wilson D. Pace, PI. We are very grateful to the patients who honored us with their stories. Additionally, we also thank Linda Niebauer for her help with facilitation of the groups and editing of the manuscript.

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Accepted for publication 18 June 2005