

Putting a Face on Medical Errors: A Patient Perspective

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In 1999, the Institute of Medicine (IOM) defined medical error as “an adverse event that could be prevented given the current state of medical knowledge” and expanded this definition in 2000 to include “the failure of a planned action to be completed as intended or the use of a wrong plan to achieve an aim” (Kohn, Corrigan, & Donaldson, 2000). Errors may include problems in “practice, products, procedures and systems” (Leape & Berwick, 2005). A brief definition is “a preventable adverse event” (Kohn et al., 2000). Although not discounting human error, the IOM report emphasized the importance of focusing on problems in the system of care itself as well as the culture of that system rather than on any individual’s behavior (Kohn et al., 2000; Leape & Berwick, 2005).

Research on the patient’s understanding of what constitutes medical error is limited. Most studies focus on how patients prefer to have errors disclosed to them. Several studies found that patients wanted to have more emotional support following an error, including apologies (Gallagher & Levinson, 2005; Gallagher, Studdert, & Levinson, 2007; Gallagher, Waterman, Ebers, Fraser, & Levinson, 2003). In a study of patients recruited from a postinjury program, poor communication was identified as a source of trauma for patients resolving an adverse event (Duclos et al., 2005). Sixty-eight percent of patients surveyed in a study on physician and patient attitudes regarding error disclosure understood medical error not as an adverse event but as lack of access, poor quality of service, and rudeness or poor communication skills on the part of physicians, in contrast to physicians’ focus on technical medical error (Gallagher et al., 2003). In the aftermath of a medical error, a lack of shared understanding may make communication difficult (Blendon et al., 2002).

Patients apparently view medical error as a lower priority than access and patient-centered provider communication. A review of the literature on communicating with patients about medical error found little research on how patients and families view communication in error disclosure (Mazor, Simon, & Gurwitz,

Abstract: Knowledge of the patient’s perspective on medical error is limited. Research efforts have centered on how best to disclose error and how patients desire to have medical error disclosed. On the basis of a qualitative descriptive component of a mixed method study, a purposive sample of 30 community members told their stories of medical error. Their experiences focused on lack of communication, missed communication, or provider’s poor interpersonal style of communication, greatly contrasting with the formal definition of error as failure to follow a set standard of care. For these participants, being a patient was more important than error or how an error is disclosed. The patient’s understanding of error must be a key aspect of any quality improvement strategy.

2004), and patients are less likely to forgive a physician if they have experienced incompetence, inattention or lack of caring on the part of the physician (Mazor et al., 2005). One qualitative descriptive analysis of 38 patient narratives involving 221 problematic incidents postsurgery found that patients’ focused on access to healthcare, communication breakdown in the patient-provider relationship rather than technical medical error (Kuzel et al., 2004). This study calls attention to the need to explore patient perspectives on medical error because these perspectives are important as a tool for improving healthcare delivery as seen from the persons who receive the service.

Study Procedures

This article reports on the results of the qualitative phase of a larger randomized experimental design, a follow up telephone call with a purposive sample of 30 community members who agreed to “tell their stories” about medical error. The purpose of this study is to explore the community members perception of error. All aspects of this study were approved by the Health System’s Institutional Review Board. Written informed consent was obtained from all participants

The randomized experimental portion of the study is briefly describe here to provide context for the qualitative phase of the study. The participants were recruited from a larger sample of community members who

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participated in a randomized experiment viewing four different videotaped scenarios of medical error disclosure.

The final report *Putting a face on Hospital Errors: Communication* (Stewart, 2006) describes more fully the social experiment.

Telephone Interview Participants

Participants indicated their interest in telling their stories about medical error by checking a box on the questionnaire provided at the time of the social experiment and providing a phone number. These 30 participants were interviewed based on a valid phone number and participant's availability at the time of the phone call. Only one participant declined to be interviewed when reached by phone. The 19 female and 11 male participants ranged in age from 24 to 72.

Method

Qualitative narratives were collected during the phone calls. Open-ended questions were used such as, "Tell me about an event, a medical error that impacted you, a family member or someone close to you." Subsequent questions were asked about disclosure, how the participant felt about the experience, and how events or disclosure of medical error could have been handled differently. In general, the questioning was directed toward ways to improve communication and error disclosure between patients and healthcare providers.

Data Analysis

The phone interviews lasted between 3.5 and 25 min, with the average conversation about 10–11 min. Conversations were audiotaped and a digital file was created. In the initial step of analysis, these digital files were listened to repeatedly and emerging themes were noted.

Transcripts of the phone interviews were analyzed using qualitative content analysis to provide a thick rich description. Qualitative description offers a comprehensive summary of events that typically stay closer to the data than other interpretive qualitative methods and

does not require abstract and philosophically based analysis of data. Qualitative content analysis allows for unanticipated responses and expansive description of the participants' experiences (Morgan, 1993; Sandelowski, 2000).

Results

Thematic Analysis

The meaning of medical error

The formal definition of medical error is not following a set standard of care. However, for this group of patients or family members of patients, medical error was synonymous with poor communication.

Medical error was perceived overall by these 30 participants as a lack of communication, missed communication, or poor interpersonal styles of communication by physicians or other healthcare providers (Table 1). The participants also reported communication that involved negative attitudes directed toward themselves, family members, or other patients. Four participants viewed error as an unintended outcome or consequence rather than a deviation from a standard of care. Examples of these cases were immunization reactions, medication side effects such as the range of secondary effects of chemotherapy, and complications of medical devices such as an improperly placed stent leading to urinary system complications. Interestingly, the unintended outcome was not the main focus of the error story but, rather, the setting within which communication missteps occurred. A participant who experienced a drug reaction found that the physician reacted with disbelief. Two participants who voiced concerns about immunization and medication side effects were labeled as depressed, a security threat or mentally unstable. Such labels were a source of emotional pain for these individuals, further alienating them and making them angry and distrustful toward the healthcare system.

Only four of the 30 participants described a medical error as a technical medical error, as a deviation in care rather than a deviation in interpersonal communication: two participants

Table 1. Key Findings

- Medical error from the patient's viewpoint focused on lack of communication, missed communication, and poor interpersonal style of communication
- These communication missteps took the form of lack of respect, blame, and stigma
- Ways to improve patient/provider communication was stressed by these 30 participants

experienced a family member's delayed diagnosis of cancer; a participant's niece died of meningitis; and for the fourth participant, a medication was mislabeled by the pharmacist. In these four instances, there was no disclosure about the error but a defensive tone in communication from the healthcare professionals. There was never any admission of error by these professionals and the patient interpreted or pursued explanation for these events independently.

These stories focused, not on the deviation from a standard of care, but, on poor or missing communication. In one delayed cancer diagnosis, the hospital and staff reported the cancer diagnosis in a matter of fact manner; while in the other delayed cancer diagnosis, the physician avoided direct communication, mumbling under his breath, and looking down at his shoes rather than being forthright in his acknowledgement of the delayed events. In the death of a participant's niece, a small child, the mother was blamed by the physicians who did not seem to immediately diagnose the meningitis. The mother said she was made to feel negligent in not taking the child immediately to ER and not attending to her symptoms. The pharmacist felt the labeling error was no big deal and this participant had to go up the "chain of command" in the healthcare system to obtain a formal acknowledgement of error or inconvenience.

These communication missteps appeared to take several distinct forms.

Lack of respect

"A medical error is being dissed, treated badly as not being human." A middle aged woman described her son's treatment for his HIV disease as she struggled to advocate for him.

"I have a weight problem, okay! Not much I can do about it 'cause it is in my family but every time I see a nurse or doctor they have to talk about my weight. Like I'm obese-no respect and kind of judgmental."

A 42-year-old described her experience as a patient who struggled with weight issues.

Other interaction described as disrespectful was having a mental illness or a family member with mental illness, lack of understanding of ethnicity/culture—"not understanding our Native American ways"—and being treated

differently due to being a Medicaid patient. Providers freely communicated among themselves in front of a participant that she used or abused drugs, leading this 47-year-old woman to view herself as inferior. A history of drug addiction as noted in the chart was pointed out to a 39-year-old woman making her feel embarrassed and ashamed.

Blame

"Back then you know they thought mental illness was the mother's fault, she was blamed, I think the psychiatrist did not communicate with me about my son's problems. I wonder if I would have been able to change anything for him and how he was treated in the state mental hospital."

A female participant in her late 60s reflected on her family's treatment in the healthcare system. Participants also felt judged by their healthcare providers for their lifestyle choices and bad habits, implying that they were the cause of their conditions.

Stigma

"I had a complicated home delivery 28 years ago and was transported to the hospital via ambulance. The doctor looked at me with disdain even though I was bleeding heavily. After this difficult and painful delivery I wanted to rest but my baby was not allowed in the newborn nursery because he was contaminated. That word contaminated and the whole experience stuck with me all these years."

A 51-year-old woman reflects on her childbirth experience decades earlier. These participants felt labeled as mentally ill, emotionally unbalanced, a potential security threat, a somatizer. One woman felt like a freak due to a lack of a defined treatment, a course of action for her illness or a known cure.

Participants who experienced stigma and blame felt their providers did not believe them and so their concerns were easily dismissed. A woman experiencing significant side effects of a medication described being "discredited, pushed aside and swept away" by her healthcare provider.

Related to miscommunication is the healthcare provider's style of communication. Eight

participants cited a “bad” or “unprofessional” style of communication as error or a potential source of medical error. Three participants felt rushed by physicians. A 34-year-old woman reported that while she was still talking to her physician, his hand was on the door and looking at his watch. A physician not listening to her concerns is the reason one woman believed she almost suffered a life-threatening infection. Physicians were described as having a “cavalier-wing it” attitude such as, “let’s just see what happens.” One participant felt that his physician paid little attention to detail and that led to potential source of harm. Healthcare providers often expressed ominous or gloomy outcomes, such as saying a family member would be dead in a matter of weeks, giving family members no hope and a feeling they needed to give up care. A participant termed a physician’s communication style “egotistical,” as if the physician had the “power” to heal and cure immediately.

Unprofessional behavior included inappropriate provider–patient communication. A physician disclosed her personal problems and daily stresses to a patient in the emergency room. A psychiatrist who eventually became suicidal discussed personal anxieties with a mentally ill client and her family members. An oral surgeon asked a patient out on a date when she had multiple visits due to complications of oral surgery. These examples of unprofessional behavior were all viewed as error.

The focus of medical error and medical error research has been on healthcare systems and how disclosure should occur within these systems. However, for these 30 participants, the focus was not on the larger healthcare system but was individual/relationship based, that is, usually a one on one interaction between a physician or other healthcare providers.

Ways to improve patient–healthcare provider communication

If medical error is perceived as an error in communication, the phone conversations with these 30 participants naturally flowed in the direction of how to improve communication between patients and providers. Participants believed that by improving communication, all variations and variety of error could be decreased. Examples included developing better listening skills. Listening included ideas such as slowing down and listening to the patient’s

concerns and healthcare providers admitting lack of knowledge. Physician communication needs to be more patient-centered, less directed from provider and more focused on the patient and their concerns and issues. One participant discussed the need “to bring the physician back” from a focus on the business and administrative side of healthcare to a focus on the patient. Another participant suggested the development of collaborative communication skills among physicians to coordinate care between interns, residents, primary care providers, and specialists.

Limitations of the Study

These phone interviews occurred 2–3 weeks after the randomized experiment. The question arises whether the responses would have been different if the interviews occurred at the same time as the controlled experimental piece of the study. In addition, the participants were randomly assigned to 12 different groups with vastly different scenarios of medical error disclosure. It is possible group assignment potentially impacted how a participant responded in the phone interview. The interview responses may have been different if this was a stand alone qualitative study not related to a larger social experiment. However, because the experimental conditions were very controlled, it was felt each participant who wanted to do so should have an opportunity to share their personal experiences with medical error. Results caused us to be surprised by the gap between patient-safety advocacy definitions of medical error and patient-based definitions, being an area for further research.

Discussion

For this community-based study, being a “patient” was more important than the error itself or how an error was communicated. These community members relayed their stories of being a patient or a family member of a patient and viewed themselves not as experts but as outsiders. The role of an outsider in the healthcare system is apparently like that of a foreigner in a strange land experiencing a different culture and language. These moments of poor communication or interpersonal missteps highlight the inherent conflict between the personalized patient–provider relationship and the business or corporate model of healthcare. A number of other

studies have suggested that when miscommunication or a communication error occurs, it is perceived as a medical error by the patient (Duclos et al., 2005; Epstein, 2000; Gallagher et al., 2003; Epstein et al., 2005).

Often there is urgency by national organizations concerned with quality and patient safety to push for change and to confront error. However, for the participants in this qualitative study, actual error was less concerning than the relationship piece of their healthcare.

Implications for Practice

Providers can help patients feel understood and valued, by moving beyond the biomedical approach to care and exploring their needs, expectations and beliefs, attending to the psychosocial context, and increasing and empowering patients to be involved in their care and in decisions that affect their health (Epstein, 2000; Roberts, 2004). Providers' communication skills that allow patients to tell their troubles and stories and are given room to speak over a number of visits lead to the conditions that provide understanding and avoid misunderstandings (Roberts, 2004). Epstein was able to demonstrate a relationship between patient-centered communication and a reduction in diagnostic testing (Epstein, 2000). The question remains whether there is a relationship between patient-centered communication and associated decreases in medical error as technically defined. Patient perspectives of quality include access to care, responsiveness and empathy, good communication, clear information provision, appropriate treatment, relief of symptoms, improvement of health status and, above all, safety and freedom of injury (Donaldson, 2008; Stevens, 2008). Patients and their families often have a unique perspective about their experiences and can provide information and insight that healthcare providers and systems administrators might not have known (Donaldson, 2008). The patient perspective about medical error ought to be a key aspect of any quality improvement strategy.

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