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Patient Safety: A Patient Perspective

Linda K. Kenney
MITSS, Inc.

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Patient Safety: A Patient Perspective

By Linda K. Kenney

As the famed Institute of Medicine (IOM) report, *To Err Is Human*, was being released in November 1999, I underwent total ankle replacement surgery at a major medical facility in Boston, Massachusetts, expecting to wake up the same day with a new ankle. Instead, I awoke several days later to find that the nerve block had accidentally been delivered to my heart. I had gone into cardiac arrest. An emergency sternotomy with cardiopulmonary bypass for cardiac resuscitation had been performed to save my life.

This incident had a profound effect on me, my family, and my friends. However, it also offered me a glimpse of a side of health care that most patients and families never see - the emotional impact this adverse event had on my orthopedic surgeon, the anesthesiologist, the code team, and other health care providers who had witnessed it. It wasn't just "business as usual" for them. They hurt too, and felt as unsupported as I and my family did. I knew then that something needed to be done.

With the help of some extraordinary people, I founded Medically Induced Trauma Support Services (MITSS), Inc., in June 2002. Our mission is to support healing and restore hope to patients, families, and clinicians following adverse medical events. Recognizing that *everyone* involved in an adverse event needs support, MITSS strives to:

- Raise awareness.
- Educate consumers, health care professionals, and organizations about the emotional impact of adverse events and the need for support services.
- Provide direct support to patients and families as well as individual clinicians.
- Advocate for health care organizations to build infrastructures that support their staff.
- Serve as consultant and advisor to develop patient, family, and clinician support programs.

Scope of the Problem

National patient safety and quality movements in health care recognize the emotional impact that medical errors and unanticipated outcomes have on patients, families, and clinicians. The IOM report, *To Err Is Human,* estimated that 98,000 people die from medical errors each year. The Institute for Healthcare Improvement's 5 Million Lives Campaign calculated that there are approximately 15 million adverse medical events each year, 6 million of which cause harm to the patient resulting in a significant deviation in the patient care process.[1] In the hospital setting, this conservatively translates to 12 million affected family members and 12 million health care providers who are emotionally impacted by these events each year (Table 1).[2] Despite the multitude of patients, families, and health care providers affected, only a small number of systems have been set up to address the emotional impact.

Patients and Families

Almost all adverse medical outcomes have some psychological consequences for patients and their families. These range from worry and distress to depression and despair. The full impact of some incidents becomes apparent only in the longer term. Surprisingly, little attention has been paid to the long-term consequences for injured patients, and very few health care organizations have taken on the full responsibility of looking after the people who have been harmed.[3]

For patients and families, the impact of a medical injury differs from most other accidents in 2 very important respects:

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1. Because unintentional harm has been caused by health care providers in whom patients have placed significant trust, reactions may be especially powerful.

2. In general, patients continue to receive care in the same health care setting, and possibly from the same care providers, that harmed them. As a result, they may experience a range of conflicting feelings.[4]

Table 1. Patients affected by medical error each year

Deaths due to medical error	98,000/year
Affected family members	>196,000/year
Affected clinicians	>196,000/year
Patients surviving significant medical error	>6,000,000/year
Affected families and clinicians	>24,000,000/year*
Total affected	**>30,000,000/year**

*Assuming: the patient has at least 2 family members and 2 care providers closely involved with his or her care

Patients are at risk of being injured twice – once from the initial medical care they received and again if the health care provider's follow-up care is not transparent and compassionate. Following a serious adverse event, patients should receive timely, accurate, and empathetic communication, as well as assurance that a diligent investigation is under way. At minimum, the patients' emotional and social needs should be addressed by sympathetic caregivers. Care may also include psychological counseling.[3]

Patients and families want 4 things from health care providers following an adverse medical event:

1. Transparent communication in real time (ie, they want to know exactly what happened).

2. An apology for or acknowledgement of the adverse event.

3. An organizational response (ie, an explanation of how the provider organization will prevent a recurrence of the event).

4. Appropriate support that takes into account variations among individual patients.[5] This may include financial, emotional, and/or home health care services.

Health care organizations must begin to provide more training and education to their medical staff regarding the short- and long-term emotional impact of adverse medical events on patients and their families. Further, organizations should develop internal systems to better meet the emotional needs of patients and families following these events. The LEND System (Figure 1), was created by MITSS as a tool to help care providers consider how best to support patients and families.

In recent years, there has been a remarkable shift toward greater transparency, disclosure, and apology. Increasing numbers of health care organizations are opting to "do the right thing" by providing patients and their families with an explanation of what happened, an apology, and a plan to prevent the event from recurring. However, patients and families often report that, even when things are handled with honesty and compassion, the emotional impact still may be devastating. Emotional issues (eg, feelings of anger, guilt, loss, fear of reengaging with the health care system) may not arise until 3 to 6 months after the event, and may linger for a prolonged period of time. Sometimes, these patients and their families require long-term emotional support services.

Figure 1. LEND SYSTEM

LISTENING - The goal of listening in this situation is not to placate, but to demonstrate a desire to understand how the patient feels.

EMPATHIC RESPONSE - While it is impossible to completely understand what a patient or family is going through, it is important to show a desire to understand and a willingness to be supportive. The focus here is not fixing the problem, but allowing the patient/family the space to express their pain.

NEEDS ASSESSMENT - Throughout the conversation, try to identify the person's needs.

DIRECTING TO SERVICES - It is important to follow through with commitments and to direct the patient and/or family member to any and all services that may benefit them. Pastoral Care, the Social Work Department, and MITSS are some of the resources available for follow-up support. It is important that patients/families do *NOT* leave without knowing about resources they can turn to when the going gets rough.

Clinicians and Staff

In 2000, Albert Wu coined the term "second victim" when referring to the physician, nurse, or other clinician on the "sharp end" of a medical error.[6] Physicians have reported experiencing powerful emotions following an adverse event (ie, guilt about harming the patient, disappointment about a failure to practice medicine to their own high standards, fear of a possible lawsuit, anxiety about the repercussions the error might have on their reputation).[6] Nurses have described experiencing symptoms similar to post-traumatic stress disorder in addition to sensing a loss of professional respect (for themselves and from colleagues), emotional distress, and feelings of anger, guilt, and inadequacy.[7]

The emotional impact of a medical error or unanticipated outcome on a care provider can affect his or her ability to function safely in a clinical environment. Emotional support services can minimize or ameliorate

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the psychological and physical stress on clinicians and help to facilitate a timely and healthy return to normal activity.[4]

In recent years, more attention has been directed at supporting the "second victim." A number of programs and models have sprung up across the country. In 2004, Kaiser Permanente rolled out a support model for clinicians through its Employee Assistance Program. Brigham and Women's Hospital in Boston, MA, has successfully piloted a "peer support program" in its operating room, a program that is being implemented throughout the hospital.[2] At Children's Hospital Boston an Office of Clinician Support has been established, led by its psychiatrist-in-chief and chairman of psychiatry.

Ideally, short- and long-term, formal and informal, internal and external support services should be made available in an all-inclusive clinician support program. Such services will be utilized as options become available and as providers become comfortable with a particular modality. Because there have been many barriers to making these positive changes (Figure 2), a strong preeducation program will be necessary to address and eventually overcome them.

Role of Health Organization Leadership

Given the profound impact of adverse medical events on clinicians, patients, and their families, it is incumbent on health care leadership to provide appropriate support to each. Leaders must establish and nurture a culture of quality and safety that is honest, empathetic, respectful, and forgiving.[8]

Figure 2. Barriers to Positive Culture Change with Respect to Adverse Medical Errors

- Perception of the clinician as "superhuman"
- Culture of clinical "perfection" instilled by Hippocratic Oath: "First do no harm"
- Feelings of shame, humiliation, and incompetence
- Culture of fear regarding medical-legal action
- Intense emotional discomfort caused by adverse medical events
- Lack of systems thinking

It is likely that every young person beginning medical education today will be involved in a serious adverse medical event at some time in his or her career.[9] Given this stunning statistic and its implications for the clinicians and patients involved, health care leaders must play an active role in reducing the emotional toll and fostering a climate of compassion and mutual respect.[8] Commitment from the top levels of leadership and allocation of necessary resources are key elements of the successful support models described.

Conclusion

Since MITSS's inception in 2002, we have witnessed significant progress toward a goal of supporting everyone involved in an adverse medical event. Although some successful clinician support programs have sprung up, support services available to patients and families beyond the hospital stay remain very limited. MITSS is committed to providing greater awareness, educating all involved (and potentially involved) parties, providing direct support services as needed, and advocating for systemic change in health care organizations' responses to these events.

Linda K. Kenney *is Executive Director and President of Medically Induced Trauma Support Services, Inc. She can be reached at: lkkenney@comcast.net.*

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