Improving Communication and Resolution Following Adverse Events Using a Patient-Created Simulation Exercise

Thomas H. Gallagher, Jason M. Etchegaray, Brandelyn Bergstedt, Amelia M. Chappelle, Madelene J. Ottosen, Emily W. Sedlock, and Eric J. Thomas

Objective. The response to adverse events can lack patient-centeredness, perhaps because the involved institutions and other stakeholders misunderstand what patients and families go through after care breakdowns.

Study Setting. Washington and Texas.

Study Design. The HealthPact Patient and Family Advisory Council (PFAC) created and led a five-stage simulation exercise to help stakeholders understand what patients experience following an adverse event. The half-day exercise was presented twice.

Data Collection and Analysis. Lessons learned related to the development and conduct of the exercise were synthesized from planning notes, attendee evaluations, and exercise discussion notes.

Principal Findings. One hundred ninety-four individuals attended (86 Washington and 108 Texas). Take-homes from these exercises included the fact that the response to adverse events can be complex, siloed, and uncoordinated. Participating in this simulation exercise led stakeholders and patient advocates to express interest in continued collaboration.

Conclusions. A PFAC-designed simulation can help stakeholders understand patient and family experiences following adverse events and potentially improve their response to these events.

Key Words. Medical errors, truth disclosure, patient rights, professional-patient relations, professional liability

Patient and family centeredness is a health care mantra (Mazor et al. 2016). However, this focus has been slow to reach the area where it is needed most, namely the response to patients who have been injured by their care (Iedema

et al. 2011; Mazor et al. 2011; Iezzoni et al. 2012). Health care institutions and providers may not understand what patients and their families need following adverse events (Gallagher et al. 2003; Mazor et al. 2004, 2006; Hobgood et al. 2005) or experience barriers to meeting these needs (Gallagher et al. 2006a,b). Finally, multiple stakeholders are involved in the response to adverse events, ranging from health care providers and institutions to medical professional liability carriers, attorneys, and regulators. There may be insufficient coordination among these stakeholders, resulting in no one consistently advocating for the patient and family (Banja 2004; Gallagher et al. 2006a,b; Bell et al. 2011).

To explore these possibilities, the University of Washington (UW) HealthPact Patient and Family Advisory Council (PFAC) created a simulation exercise to help stakeholders understand patients' and families' needs following adverse events. The HealthPact PFAC was a group of 10 patient advisors, all of whom had experienced medical errors in either their own or a family member's health care. This work was a component of an AHRQ Patient Safety and Medical Liability Reform Demonstration Project based at the UW. The overall UW project was guided by an Oversight Committee, who decided to focus one of the project's large stakeholder meetings on exploring a truly patient-centered response to adverse events. They tasked the project's PFAC with designing a half-day simulation exercise as the meeting's centerpiece.

DESIGN PROCESS AND PRINCIPLES

Several core principles guided the simulation exercise, as articulated by the PFAC with input from the project Principal Investigator (PI) (Table 1). Critical was ensuring that the patient's voice be heard throughout the program: in the words of the UW PFAC Director (BB), "forcing participants to sit in the space of the patient." An iterative design process was used over several

Address correspondence to Thomas H. Gallagher, M.D., Professor and Associate Chair, Department of Medicine, UW Medicine Center for Scholarship in Patient Care Quality and Safety, University of Washington, 1959 NE Pacific Street, Suite BB1240 Seattle, WA; e-mail: thomasg@uw.edu. Jason M. Etchegaray, Ph.D., is with the RAND Corporation, Santa Monica, CA. Brandelyn Bergstedt is with the Seattle Cancer Care Alliance, Seattle, WA. Amelia M. Chapelle, M.A., M.S., is with the University of Washington School of Medicine, Seattle, WA. Madeleine J. Ottosen, Ph.D., R.N., Emily W. Sedlock, M.P.H., and Eric J. Thomas, M.D., M.P.H., are with the McGovern Medical School at The University of Texas Health Science Center at Houston, University of Texas – Memorial Hermann Center for Healthcare Quality and Safety, Houston, TX.

Table 1: Exercise Design Principles and Methodology

<i>Principle</i>	<i>Rationale and Methods to Accomplish</i>
The entire process, including the design of the exercise, should be PFAC driven	Only patients and families can help health care stakeholders understand their needs and preferences following adverse events. The UW PFAC met multiple times to develop and refine the case and all supporting material. A patient moderator led the exercise at UW to ensure the views of patients and families were expressed and supported
The exercise should promote learning and respectful interprofessional collaboration	Seating was assigned to ensure multiple stakeholders were present at each table to develop a shared mental model. Moderators were carefully selected to facilitate ground rules and lessen power differentials at each table that could inhibit interprofessional learning
The learning experience should be experiential and interactive	The exercise was designed to help participants experience the patient's perspective. For example, each person was given a copy of the risk management response letter to read as if they were the patient. Questions were designed to invite discussion of the patient's view
The experience should promote further discussion rather than seek solutions to specific problems	Questions were developed to discuss the challenges of a patient-centered response to adverse events rather than to seeking superficial solutions. We concluded the exercise with a group brainstorming of next steps and opportunities for collaboration
The exercise should be efficient and well organized	The activity was timed to keep role play to under 5 minutes and allow discussion time up to 10 minutes. Rehearsals were held for actors to practice their responses. A moderator kept the activity on schedule
The exercise should cover the entire range of relevant issues, but with a focus on those that have been less examined to date	Most prior work has focused on the initial disclosure conversation with the patient about the error. We created the exercise to cover the entire waterfront of what patients experience following significant breakdowns in their care, that is, patient conversations with the claims adjuster and the medical board
The exercise should use a rich, real-world case rather than a simple paradigm case	We used a realistic error case in which multiple providers, the delivery system, and the patient herself were potentially responsible. These complexities and nuances of the case helped stakeholders appreciate the gaps in their understanding of how patients experience adverse events and the systems meant to respond to them

months, in which the PFAC director (BB) solicited input from and reached consensus with the entire PFAC about the simulation exercise. She also met several times with the project PI (THG) to discuss the case and to refine the

exercise. The simulation material (case narrative, moderator guide, risk management response letter, actor training material) was then finalized through email.

Simulation Overview

The simulation exercise was implemented during a day-long meeting in Seattle that was attended by 86 stakeholders and patient advocates and titled, *Adverse Event Resolution: Creating a Truly Patient and Family Centered Approach*. Stakeholder groups that participated in the exercise included patient advocates, physicians, quality/patient safety leads, risk/claims management experts, plaintiff and defense attorneys, liability insurers, regulators (e.g., boards of medicine), and hospital administrators. Each participant was assigned a table group, with the goal of having a diversity of participants and at least one patient advisor per table. The exercise was then replicated at the University of Texas at Houston (UT Houston) during the meeting *Engaging Patients as Partners in Error Disclosure to Improve Patient Safety*, attended by 108 stakeholders and patient advocates.

The exercise was led by a patient advocate who served as the narrator. UW and UT Houston hired an actress to portray Mary McCarthy (the patient). The roles of Dr. Rogers and the claims representative were enacted by local volunteers from these professions who were identified and given a copy of the case in advance. Each table had a moderator chosen largely from the research teams and then trained to facilitate interprofessional dialog, along with note takers to capture the table and large group discussions. All material associated with this exercise including the session agenda, full case, moderator instructions, actor instructions, and evaluation forms are available on request.

THE CASE

The case was presented in five sections in which a part of the story was shared with participants, followed by discussion of that section at each table and then among the entire group. These sections, moderator prompts, and key take-home lessons from the discussions are summarized in Table 2. The case is presented in its entirety in Appendices SA2 and SA3.

Table 2: Exercise Sections, Moderator Prompts, and Take-Home Messages

<i>Section</i>	<i>Moderator Prompts</i>	<i>Table Discussion Take-Home Messages</i>
Initial disclosure	<ul style="list-style-type: none"> • What went well with this disclosure? • What could be improved? 	<ul style="list-style-type: none"> • Physician should avoid implying that the patient might be partly to blame for delay in diagnosis • When physicians try to get a patient focused on moving forward after an error, it can fail to acknowledge the patient's concern about the severity of the mistake
Written response to patient's concern	<ul style="list-style-type: none"> • Please open and read your letter as if you were the patient. • How do you feel reading this letter? 	<ul style="list-style-type: none"> • Typical response letters from risk management to patients following a complaints may strike patients as impersonal, scripted, patronizing, and preparing the institution to defend itself against a lawsuit • Important information is often either buried at the end of the letter (apology) or missing altogether (steps that would be taken to prevent recurrences)
Patient requests compensation	<ul style="list-style-type: none"> • Does this offer strike the appropriate balance between patient's concerns and the hospital's concerns? Why or why not? 	<ul style="list-style-type: none"> • When formulating an initial offer of compensation, it is important to consider the patient's perspective and needs • It can be awkward for patient and claims manager to have a discussion that attaches a dollar value to the patient's experience and suffering
Patient looks for plaintiff attorney	<ul style="list-style-type: none"> • How can we ensure patient/family representation is available for cases when the attorney's effort would cost more than the likely award? 	<ul style="list-style-type: none"> • Patients have few options for getting representation from a qualified plaintiff attorney for cases involving injuries that are less than catastrophic • Greater transparency about how attorney fees work, and nonattorney options for patient representation following adverse events, could be helpful

Continued

Table 2: Continued

Section	Moderator Prompts	Table Discussion Take-Home Messages
Patient complains to Board of Medicine	<ul style="list-style-type: none">• What does a regulatory body like a Board of Medicine need to consider when making a decision on what action to take?• How can a Board of Medicine assure the public that learning has occurred in cases like this?	<ul style="list-style-type: none">• Regulators such as Boards of Medicine are an important venue for patients to express concerns about the quality of care, especially when they feel they are not getting an adequate response from the organization where the adverse event occurred• Regulators have few tools at their disposal to deal with concerns about quality of care problems that strike the right balance between getting providers to change their behavior without being overly punitive

Section I: Case Introduction, Enactment of Initial Disclosure

Narrator: *Mary McCarthy, a 50-year-old woman with a history of hypertension, reported a breast lump to her primary care physician, Dr. Bloom. Dr. Bloom found a cystic area that did not feel significantly different from the rest of the breast tissue. Since the patient was 2 days before the start of her menstrual cycle, Dr. Bloom recommended that Ms. McCarthy be re-examined later. No imaging studies were ordered. Ms. McCarthy did not schedule a follow-up appointment for a repeat examination.*

Dr. Bloom then went on leave, and Dr. Rogers assumed care for Ms. McCarthy. Ms. McCarthy saw Dr. Rogers for hypertension on several occasions. Once her hypertension was controlled, Ms. McCarthy again brought up the breast lump. Dr. Rogers was not aware of the breast lump. He then reviewed the chart in detail, and saw Dr. Bloom's note documenting the cystic area in the left breast and his recommendation that she be re-examined.

A biopsy revealed cancer, with three positive axillary nodes. The patient wondered whether the cancer could have been diagnosed earlier and decided to talk with Dr. Rogers.

The disclosure conversation between Ms. McCarthy and Dr. Rogers was portrayed by an actor playing the role of the patient and the physician volunteer.

Section II: Patient Sends Letter Detailing Her Concerns to Hospital and Receives Written Response from Risk Management

Narrator: *Ms. McCarthy feels frustrated after her discussion with Dr. Rogers and contacts Risk Management. The Risk Manager calls Mary to get additional details, performs an investigation, and sends a response letter.*

Participants were asked to put themselves in the patient's situation, and then each opened a sealed envelope containing the risk management response letter (Appendix SA3).

Section III: Patient Appeals to Grievance Committee and Requests Compensation; Enactment of Patient Meeting with Claims Representative

Narrator: *As she reads the letter, Ms. McCarthy realizes the hospital doesn't believe what the doctors did was a big deal and are closing her complaint. Ms. McCarthy appeals to the grievance committee and requests compensation. She is invited to meet with a claims representative.*

The actor portraying Ms. McCarthy and a claims manager volunteer discussed her request in front of the audience. The hospital's review concluded that the delayed diagnosis caused Ms. McCarthy to require chemotherapy but did not affect her survival. Therefore, the claims representative decided that appropriate compensation would be \$15,625 to cover missed work during chemotherapy. Ms. McCarthy thought that \$100,000 would be appropriate.

Participants discussed the challenges of determining a fair offer of compensation following adverse events and discussing these offers with injured patients and their families.

Section IV: Patient Seeks an Attorney

Narrator: *Ms. McCarthy tries to contact an attorney to represent her, but can't find anyone to take her case. Reluctantly, Ms. McCarthy accepts the hospital's initial offer.*

Participants discussed the challenges of finding attorney representation for patients whose injuries are not catastrophic.

Section V: Patient Contacts Medical Board

Narrator: *Ms. McCarthy realizes that she has to do something to prevent doctors from missing important pieces of other people's medical care and reports Drs. Bloom and Rogers to the state Medical Board.*

Participants discussed the challenges that Boards of Medicine face in responding to these types of cases.

IDENTIFYING LESSONS LEARNED

The research team identified lessons learned from both the development and execution of the exercise by synthesizing notes and observations from the exercise planning, small and large group exercise discussions, and evaluations completed by exercise participants (Table 2). The evaluations differed at the two sites due to continuing education requirements, but both included quantitative ratings and qualitative comments. At the Seattle session, 42 open-ended responses were received for the question "What worked well?" with the most common responses emphasizing how much attendees valued the table discussions with a mixture of stakeholders and patient input. One participant noted that it was "surprising how hard it is for some to put themselves in the patients'

shoes—our profession(s) can blind us sometimes.” In Houston, 40 qualitative responses were received to the question “What part of the conference was most helpful to you?” and made repeated mention of the benefits of the extended case study, hearing the perspectives of multiple stakeholders, and the patient-centered focus.

DISCUSSION

This PFAC-designed and -led interprofessional simulation exercise helped a broad array of stakeholders understand how patients and families experience the aftermath of adverse events. The exercise not only helped stakeholders appreciate the patient and family perspective on responding to adverse events, but it also heightened both groups’ motivation to seek innovative solutions (Donaldson 2015; Southwick, Cranley, and Hallisy 2015).

Lessons Learned about the Response to Adverse Events

The Current Response to Adverse Events May Lack Patient-Centeredness because It Can Be Siloed and Uncoordinated. The PFAC believed that for stakeholders to understand what patients and families face after medical errors, they needed to experience all the different components of the response in sequence. As reflected in their comments during the exercise and in their evaluation responses, many stakeholders felt that the current response to adverse events fails to meet patients’ and families’ needs because the process can be complex, siloed, and uncoordinated. Participants suggested that creating a patient navigator-like role could help support the patient and family throughout the process.

Patients’ Interest May Not Be the Top Priority for Many Stakeholders Involved in Responding to Adverse Events. Having the patient advocates at each table quickly surfaced another challenge, namely that for many stakeholders the patients’ interest is not always their top priority (Mello et al. 2014; Sage et al. 2014). Risk and claims managers or defense attorneys may care about the affected patient and family, but their ultimate goal is protecting the institution or providers. The exercise also highlighted structural barriers that can hamper those stakeholders whose primary focus is indeed the patient, such as plaintiff attorneys or Boards of Medicine, from achieving these goals. Participants expressed the concern that the current system for compensating plaintiff

attorneys can limit the access of patients whose injury is less than catastrophic to a qualified attorney, and also acknowledged how the narrow range of tools available to Boards of Medicine can impair their ability to respond. Exercise participants recommended that an important goal for health care institutions and policy makers should be ensuring that the patient's and family's needs are the top priority in the aftermath of adverse events, and that sufficient tools and resources are available to achieve this goal.

Experiential, Patient-Directed Learning Can Help Stakeholders Appreciate What It Feels Like to Be a Patient Who Has Experienced an Adverse Event. The PFAC created an exercise in which the learning was intended to be both intellectual and visceral, reflecting the PFAC's belief that each stakeholder should experience what it feels like to be a patient or family member coping with an adverse event. The power of this approach was most evident when participants, having just witnessed the initial disclosure between the patient and her doctor, opened their envelopes containing the hospital's response to the patients' written complaint to the hospital about her delayed cancer diagnosis. By placing themselves in the patients' shoes, many participants observed that the language in the letter had significant opportunities for improvement.

Stakeholders' Interest in the Patient Perspective and Desire to Improve the Response to Adverse Events Was Inspiring to Patient Advocates. Many of the patient advocates also experienced visceral learning. Several patient advocates reported being impressed by interacting with well-intentioned providers and other stakeholders who were committed to responding to adverse events in more patient- and family-centered ways. Patients also appreciated the opportunity to "see behind the curtain" and learn what the different components of the response to adverse events are and how they should function together (Langer et al. 2016). These patient advocates reported that the experience strengthened their commitment to their PFAC work and their confidence that significant change is possible.

Lessons Learned about Using a Patient-Designed Simulation Exercise to Improve the Response to Adverse Events

The central learning for the research team occurred as they witnessed the benefits of a PFAC-led process of designing and implementing of the simulation

exercise (Bell et al. 2014). While this approach was more time consuming than if the research team had planned the session with input from the PFAC, the result was superior. The case, moderator questions, and table discussions had an authenticity that engaged the stakeholders and patient advocates alike. The PFAC members were justifiably proud of what they had created, and as a result participated in the session as equal partners with the other stakeholders and with confidence that their perspective would be heard and valued.

The selection and training of moderators was also key to ensuring that the patient voice was heard and understood at the table discussions. While the stakeholders came to the simulation exercise eager to hear from patients, their excitement about the challenging issues under discussion could easily have led to conversations that were mostly between stakeholder peers or were dominated by assertive individuals. The moderators led off each section of the table discussion by asking the patient advocates to speak and then encouraged brief responses by each of the stakeholders in their small group. If the structure and moderation of the small groups had not emphasized the primacy of the patient perspective, the patient advocates would likely have quickly stopped participating and the entire premise of the exercise would have been undermined.

Using This Simulation Exercise at Other Organizations

Organizations could use this simulation exercise with only minimal modification to engage its stakeholder community and patient advocates in understanding how to make the response to adverse events more patient centered. Key steps in this process would include the following: (i) partnering with their PFAC to adapt the simulation to the local culture and regulatory environment; (ii) identifying a diverse group of relevant stakeholders to invite to this meeting; (iii) identifying and training the actor and volunteers for the two enactments (physician for initial disclosure, claims manager); (iv) identifying and training table moderators and note takers; (v) arranging the room with round tables and a range of stakeholders and at least one patient advocate at each table; and (vi) considering next steps to build on the momentum and eagerness for change among the stakeholders and patients advocates.

Developing a response to adverse events that is truly patient and family centered requires that all the involved stakeholders come to terms with the gap between current practice and what injured patients expect and deserve.

Health care institutions can use this PFAC-designed simulation exercise to move closer to this goal.

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REFERENCES

- Banja, J. D. 2004. *Medical Errors and Medical Narcissism*. Sudbury, MA: Jones and Bartlett Publishers.
- Bell, S. K., T. Delbanco, L. Anderson-Shaw, T. B. McDonald, and T. H. Gallagher. 2011. "Accountability for Medical Error: Moving beyond Blame to Advocacy." *Chest* 140 (2): 519–26.
- Bell, S. K., R. Pascucci, K. Fancy, K. Coleman, D. Zurakowski, and E. C. Meyer. 2014. "The Educational Value of Improvisational Actors to Teach Communication and Relational Skills: Perspectives of Interprofessional Learners, Faculty, and Actors." *Patient education and counseling* 96 (3): 381–8.
- Donaldson, L. J. 2015. "The Wisdom of Patients and Families: Ignore It at Our Peril." *British Medical Journal Quality & Safety* 24 (10): 603–4.
- Gallagher, T. H., A. D. Waterman, A. G. Ebers, V. J. Fraser, and W. Levinson. 2003. "Patients' and Physicians' Attitudes Regarding the Disclosure of Medical Errors." *Journal of the American Medical Association* 289 (8): 1001–7.
- Gallagher, T., G. Brundage, K. M. Bommarito, E. A. Summy, A. G. Ebers, A. D. Waterman, V. J. Fraser, and W. B. Dunagan. 2006a. "Risk Managers' Attitudes and Experiences Regarding Patient Safety and Error Disclosure: A National Survey." *Journal of Healthcare Risk Management* 26: 11–6.
- Gallagher, T. H., J. M. Garbutt, A. D. Waterman, D. R. Flum, E. B. Larson, B. M. Waterman, W. C. Dunagan, V. J. Fraser, and W. Levinson. 2006b. "Choosing Your Words Carefully: How Physicians Would Disclose Harmful Medical Errors to Patients." *Archives of Internal Medicine* 166 (15): 1585–93.
- Hobgood, C., J. H. Tamayo-Sarver, A. Elms, and B. Weiner. 2005. "Parental Preferences for Error Disclosure, Reporting, and Legal Action after Medical Error in the Care of Their Children." *Pediatrics* 116 (6): 1276–86.
- Iedema, R., S. Allen, K. Britton, D. Piper, A. Baker, C. Grbich, A. Allan, L. Jones, A. Tuckett, A. Williams, E. Manias, and T. H. Gallagher. 2011. "Patients' and

- Family Members' Views on How Clinicians Enact and How They Should Enact Incident Disclosure: The "100 Patient Stories" Qualitative Study." *British Medical Journal* 343: d4423.
- Iezzoni, L. I., S. R. Rao, C. M. DesRoches, C. Vogeli, and E. G. Campbell. 2012. "Survey Shows That at Least Some Physicians Are Not Always Open or Honest with Patients." *Health Affairs (Millwood)* 31 (2): 383–91.
- Langer, T., W. Martinez, D. M. Browning, P. Varrin, L. B. Sarnoff, and S. Bell. 2016. "Patients and Families as Teachers: A Mixed Methods Assessment of a Collaborative Learning Model for Medical Error Disclosure and Prevention." *British Medical Journal Quality and Safety* 25 (8): 615–25.
- Mazor, K. M., S. R. Simon, R. A. Yood, B. C. Martinson, M. J. Gunter, G. W. Reed, and J. H. Gurwitz. 2004. "Health Plan Members' Views about Disclosure of Medical Errors." *Annals of Internal Medicine* 140 (6): 409–18.
- Mazor, K. M., G. W. Reed, R. A. Yood, M. A. Fischer, J. Baril, and J. H. Gurwitz. 2006. "Disclosure of Medical Errors: What Factors Influence How Patients Respond?" *Journal of General Internal Medicine* 21 (7): 704–10.
- Mazor, K. M., S. M. Greene, D. Roblin, C. A. Lemay, C. L. Firreno, J. Calvi, C. D. Pro-uty, K. Horner, and T. H. Gallagher. 2011. "More than Words: Patients' Views on Apology and Disclosure When Things Go Wrong in Cancer Care." *Patient Education and Counseling* 90 (3): 341–6.
- Mazor, K. M., K. M. Smith, K. A. Fisher, and T. H. Gallagher. 2016. "Speak Up! Addressing the Paradox Plaguing Patient-Centered Care." *Annals of Internal Medicine* 164 (9): 618–9.
- Mello, M. M., R. C. Boothman, T. McDonald, J. Driver, A. Lembitz, D. Bouwmeester, B. Dunlap, and T. Gallagher. 2014. "Communication-and-Resolution Programs: The Challenges and Lessons Learned from Six Early Adopters." *Health Affairs (Millwood)* 33 (1): 20–9.
- Sage, W. M., T. H. Gallagher, S. Armstrong, J. S. Cohn, T. McDonald, J. Gale, A. C. Woodward, and M. M. Mello. 2014. "How Policy Makers Can Smooth the Way for Communication-and- Resolution Programs." *Health Affairs (Millwood)* 33 (1): 11–9.
- Southwick, F. S., N. M. Cranley, and J. A. Hallisy. 2015. "A Patient-Initiated Voluntary Online Survey of Adverse Medical Events: The Perspective of 696 Injured Patients and Families." *British Medical Journal Quality & Safety* 24 (10): 620–9.

SUPPORTING INFORMATION

Additional supporting information may be found in the online version of this article:

- Appendix SA1: Author Matrix.
- Appendix SA2: Case Description.
- Appendix SA3: Letter from Risk Management.