

Massachusetts Coalition for the Prevention of Medical Errors
Accountability Project Patient/Family Focus Group Meeting

June 29, 2006
10:00 – 11:30 am

Report

As one important step in obtaining feedback and guidance from key stakeholders, a focus group of former patients and families met on Thursday, June 29 from 10:00 am – 11:30 am. Invitations were extended to individuals identified in three ways: because of their participation in the Medically Induced Trauma Support Services (MITSS), because they were suggested by the Board of Registration in Medicine, or because they had contacted the Department of Public Health Division of Health Care Quality (DPH/HCQ) around an incident of unsatisfactory care. The final group consisted of eight members. Stephanie Buia, a facilitator not involved in the ongoing work of the Accountability Project (Project) managed the group process. Paula Griswold and Eloise Cathcart welcomed the group and briefly explained the work of the Project and of the Massachusetts Coalition for the Prevention of Medical Errors (Coalition).

The participants were asked to respond to the following four questions to the degree that they were comfortable in doing so:

Question # 1: Can you describe your unsatisfactory healthcare experience or the experience you came to talk about?

Question # 2: Did you bring this situation to the attention of anyone at the hospital? If yes, to whom did you bring it and what happened as a result of that? If no, why not?

Question # 3: Did you report this situation to the Department of Public Health or to any other regulatory board? If yes, what happened as a result of that? If no, why not?

Question # 4: If you could repeat the experience and it went well, what would be different? What areas can you identify for improvement? What advice do you have for the Project?

There were several common themes which emerged from the rich discussion among the participants. One major issue was the communication or lack thereof between the group members and their caregivers. Terms that were used to describe those interactions were “insufficient” “confusing” and “crass”. In some situations, there was simply no communication – no explanation of what had happened or about the plan of care. One group member said that for the five and a-half months following her father’s adverse event, there was no explanation to the family

about the plan for his care. In fact, there didn't even seem to be a plan as the various groups of medical specialists contradicted each other about what to do. When her father died, no one came in to his room to explain what would happen next. One participant said "it was easy to get lost" in the hospital processes. Another explained "all I wanted to do was understand what happened" in the case of an adverse event surrounding her care.

Most group members described a wish for a simple acknowledgement that something had gone wrong in their own or a family member's care. They were in agreement that such an acknowledgement or an apology was not an admission of wrongdoing by the physician. One member said "after two years, I finally got an apology from the doctor, which I had to work hard for." Another spoke of her continuing strong desire to have an apology even though it has been two years since the adverse event occurred.

The issue of fear of retribution was discussed. One group member said her family felt intimidated to ask the surgeon for a full explanation (and apology?) even though several family members were health professionals. Members expressed fear that they wouldn't be allowed to visit, or that the care team would " take it out" on the patient. Another member said that when her physician learned she had contacted a hospital official, he asked "what was that about?"

There was discussion about the ways in which the hospital protects itself from a patient's dissatisfaction with care. Hospital attorneys and hospital policies were felt by the group members to be responsible for withholding information and cutting off dialogue between providers and patients. The group in general felt that patient advocates were unhelpful to them in addressing concerns about their care. Persons in these roles felt "more like PR (public relations) people" for the hospital, intent on protecting the hospital rather than advocating for the patient and family. Several members expressed their beliefs that patient advocates would never address issues with powerful physicians for the sake of dissatisfied patients, and that patient advocates are "on the hospital payroll, and who will jeopardize their job?" One member who "just wanted someone to talk with me about what happened" described that communication between her and the hospital's risk manager and patient representative abruptly ceased when they learned she had filed a complaint with DPH/HCQ and the Board of Registration in Medicine. Another participant said she wrote a letter to the president of the hospital describing her unsatisfactory experience,

while acknowledging one member of the care team who had been supportive and helpful, and received a letter back saying “he was happy to hear that she was satisfied with her care”.

Although the majority of participants had very negative experiences with the hospitals in which they received care and said their “faith in the system was non-existent,” one member had an entirely different experience. She spoke of feeling very genuine concern by the physicians involved in her care who were very understanding, very accessible (to the point that one physician had given her a home phone number), and very present (“the doctor never looked at her watch while she was with me”).

Most group members described the heavy burden of needing to deal in the moment with the untoward events which happened to them or to their family member. They described the sense of being unheard or dismissed by those in whom they entrusted their care and the blatant fear or anger they felt as a result of how they were treated. They felt that, if a process existed by which they could seek remedy, it was invisible. It was not clear to whom they should or could go in their frightened and vulnerable states.

Some group members had contacted DPH/HCQ in an effort to satisfy their concerns about what happened to them. While there was general agreement that staff at DPH/HCQ were compassionate and attentive and provided guidance to them about how to begin a process of complaint and how to put things in writing, the final report was disappointing because it was a succinct “clinical report of what happened.” The report was perceived as not very helpful to the participants when they had hoped for a full explanation of what had happened, and steps the hospital would take to prevent it from happening in the future. One member was told simply that “treatment and care were within established guidelines.” Another member (describing an event that occurred in another state) wrote to the Insurance Commissioner out of frustration when she was unable to get her physician to speak with her about options for her complicated clinical condition following a medical error. She told of receiving a letter in return which “made me sound like a lunatic” and which suggested that she convene a meeting with her physician to discuss her concerns.

The group offered the following recommendations to be included in the Project’s final report:

1. All hospitals should ensure continuity of the patient-clinician relationship. It should be clear to the patient and family at all times which physician and nurse are accountable for the patient's care and to whom the patient and family can turn with any question they have regarding care.
2. The process for expressing concern and dissatisfaction with care should be clearly described and accessible. Information about this process could be provided to the patient and family during the signing of consent forms.
3. Hospital governing boards and executive leadership should ensure that patient and family advisory councils are embedded in the infrastructure of hospitals so that the voice of the patient and family are heard in all hospital policies and decisions.
4. The best practices of patient-centered care should be widely publicized for all hospitals to embrace.
5. Hospitals should have programs available to address the emotional concerns of patients and families involved in medical errors, which include billing for care in question.
6. Patients and families have the right to be educated about all aspects of their care in language and terminology which they understand.
7. Medical care, including errors, should be documented in the patient's record; this information may be essential for future care.
8. The response of DPH/HCQ to patient complaints and inquiries should include more dialogue and exchange of information.
9. Ensure that the reporting system includes near-misses to increase learning about those situations which could harm a patient.
10. Create a clearinghouse which tracks numbers and types of medical errors and alerts hospitals and clinicians about high-risk situations.
11. Standardize the terms and process for clinicians reporting adverse events and near misses.