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Hearing on:

PATIENT SAFETY: INSTILLING HOSPITALS WITH A CULTURE OF CONTINUOUS IMPROVEMENT

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Good morning, Mr. Chairman and members of the Subcommittee. Thank your for the opportunity to speak to you today.

My brother Mike died of medical error in September of 1999, one and half months before the IOM report came out stating 98,000 people a year die of medical errors in hospitals alone. In my profession as an air traffic controller, that would equate to crashing an airliner with 250 people in it every day.

Mike's Story

I want to share with you the story of my brother, Mike.

Before September 22, 1999, I did not have a clue what the term "medical error" meant or that such a thing existed. Almost three years later I still do not have a clear definition of what it means. What I do know is that needless harm is coming to people who enter the healthcare system.

The only thing Mike wanted from life was to have a family, spend weekends with them, cook great meals and watch the Packers. Unfortunately Mike never found a person with whom to share his dreams. I last saw Mike in August, on his way through Minneapolis with friends going to the Sturgis Motorcycle Rally. We sat on the deck eating homemade pizza and drinking beer. Mike was gone on his motorcycle trip for two weeks. It was a tense two weeks for my parents, because my brother Craig had died 10 years earlier in a motorcycle accident. They did not know that one-month down the road Mike's life would be taken by something even more dangerous than riding a motorcycle.

Happiness filled the air when he stepped into my parents' living room in full riding gear and with a big grin on his face. "It was great Mom, so beautiful". He gave her a big hug. That memory now tears at her heart every day.

On September 21, 1999, my brother had gotten up, showered for work and as he was getting ready to leave he became light headed and then experienced severe pain in his stomach. He went over to my parents and asked if he could spend the day, because he thought he had the flu. By 4:00 PM he was in so much pain he could not speak and agreed to go to the Emergency Room. My dad took him and, after Mike was checked in, Dad went home. That was last he saw his son alive. He has never forgiven himself for leaving him there alone, but Dad was always taught and he believed that you are safe in the hospital.

Dad called around 6:00 PM to see how he was, but Mike was still in so much pain he could not talk. He was eventually admitted to the hospital and given a self-drip morphine infusion, even though they had not determinined where the pain he was having was coming from. My parents received a phone call from the hospital shortly after 3:00 AM on September 22, 1999, telling them Mike was not doing so well and would they come to the hospital. On the way there they decided they needed to take him somewhere else, not realizing he was already dead. When the elevator door opened on the second floor the whole staff was standing there whispering. My mom looked into the eyes of one of the nurses and knew. She turned to my father and said, “He is dead, Ray.” This is the part in my story I have the hardest time getting through. It is the picture my parents have of their son every morning they get up and every evening they go to bed.

Screaming, my parents ran down the hall to Mike’s room. They stood in the doorway and saw Mike lying in the bed, his arm hanging over the side with the IV still in it. My Mom and Dad traveled that space from the doorway to their son with a horrific feeling of failure, the failure every parent fears that they will not be able to protect their child from harm. They felt guilty for trusting someone else with this responsibility, and now they live with the ultimate consequences of their mistake – one that cannot be undone.

My dad tried to put Mike’s arm under the sheet but was unable to bend it. They leaned over their 6 foot 200 pound son and hugged and kissed him. He was so cold, Mike was never cold, and he certainly could not be dead.

Beginning a Journey as a Consumer Concerned about Safety

When people die in airplanes their families are brought to the site where parts of the plane are gathered so they can attempt to begin the process of closure. They have grief counselors and supporting family members with them. An investigative process is begun immediately to try and find answers as to why the tragedy occurred. The families are kept informed and told what is found.

My parents were allowed to go to the body of their dead son with no one there to support them. They were made to feel they deserved no answers as to

what happened to their son, as if dying under the care of the medical profession relieves the profession of any accountability. To this day, no one will talk to them about their son's last hours alive. My parents are treated with silence and compassionless statements. The death of my brother was a tragedy but the treatment of my family is what makes the tragedy truly horrific.

The doctors told my parents that Mike died from blood around the heart. When my parents asked how it got there, the answer was they did not know. And there were excuses. A car accident had happened that afternoon, and the emergency room was busy. That is the last thing a family wants to hear -- that someone else was more important than their own son, and therefore that they did not care for him. If the hospital was so busy, why not tell the family so they have a choice to take their loved one somewhere else?

The first thing we did was blame – the doctors, the nurses, anyone we felt should have cared for Mike better. They said Mike was misdiagnosed, and that the doctor made a mistake. A mistake! He never even tried to help Mike. Was any of the information my mother passed to the nurse even given a second thought? My parents left the hospital after this meeting, still in shock over the fact they actually trusted their son to these people. Oh, the guilt, anger, betrayal, disbelief they were experiencing. "Just give us one more chance God, we will do better."

A community in shock, Mike has so many friends, they want answers too, they are angry. Those that could give some answers hide behind the hospital doors. The hospital administrator, who attends church with my parents, offers no condolences. Is this the kind of person who is in charge of caring for their community's health? We are able to forgive mistakes but not indifference, not denial and hiding. So many people calling and stopping in to see my parents, trying to understand, offer condolences and support. Mike is gone and we cannot understand what happened, the hospital has no explanation, no apology, no condolences, and no help to try and deal with the loss. Why are the family members ignored, shunned and treated by the responsible facility as if they are at fault? Mike did not need to die? In an age of medical miracles he was not even given a chance. He was quieted with a drug and left alone.

Our initial reaction was to get a lawyer, so we could get some answers. I went with my parents to the first and only meeting with an out of town lawyer because no one in town would touch it. We were still in a great deal of pain during this visit. I decided it would not be the route I would go to try and deal with my pain. I did not trust this person who was not displaying any compassion towards my parents or I for what we were going through. Over the course of the next few weeks I tried to convince my parents to see someone else but they just did not have the stamina. The lawyer eventually sent them a letter saying with out a more thorough autopsy (he knew Mike had been cremated) he could do nothing and the money that could be gotten was not worth the work he would

have to put into it. That sealed it for me. Another profession that advertises they help people but forget to tell you only if they can make a profit.

I began spending much of my time trying to find answers or help to deal with the grief, injustice and murder of our trust. I searched the Internet for medical error and came up with one hit. It was to the National Patient Safety Foundation (NPSF) web site and there I found a regional forum that was going to take place in Milwaukee the end of October 1999. I wrote the contact via email and asked if I could attend. I told them I had recently lost my brother to a medical error and I wanted to see what was being done about the problem. They said yes.

It was a surreal experience. When the keynote speaker got up and began comparing the aviation profession to the medical field a light of understanding started to glow in my mind. I was in aviation, trained as an air traffic controller. I began to understand how what happened to Mike could have occurred, but unfortunately understanding and accepting were two different things. I ended up in front of the forum telling what little we knew of my brother's death and how we just wanted to be talked to honestly and for someone involved with Mike's death to validate our loss.

During the drive to my parent's house after attending the forum I started to realize how dangerous healthcare was and the struggle that was going on to bring out the errors to learn from them and do something about them. I started to think about what happened to Mike and wanting to work with the hospital to correct the flaws in the system that failed him and those entrusted to care for him. I slowly began to realize I was going to have to forgive so I could work with the healthcare system to make a change. This was a great struggle for me. I felt as if I was betraying my brother to want to work with people I felt had not cared for him. I had to come away from trying to blame an individual in Mike's death to looking at the system that failed all of us.

I tried to approach the subject of the system failing with my parents but they cannot remove the last image they have of Mike in that bed. An image that was preventable if those involved had been trained by the system to handle such a situation with compassion instead of fear. My parents have a great deal of anger in the loss of their son and I cannot deny them their feelings and pray every night their hearts can heal.

One lesson I took away from my brother's death is that you should never leave your loved one alone in the hospital. Patients are very vulnerable -- both emotionally and physically -- and need the support of family or friends. They may not always believe that themselves, and it is very easy to talk yourself out of the fact that you need it. But I was soon to learn first hand how important it was.

Learning to be a Partner in My Own Care

On July 20, 2000 I underwent open chest surgery to remove a tumor next to my heart and lungs. It had been diagnosed as a malignant thymoma. I put into practice what I had been preaching to family, friends and co-workers -- and that was to have someone with you at all times while in the hospital. I called this my “24/7 Team.” My team was great; they worked with the healthcare staff, making themselves knowledgeable about my medications and when I was to get them. They also supported me emotionally. Anytime I opened my eyes someone I recognized was sitting there.

I suffered a pulmonary embolism my second day in the hospital. Many nurses have tried to convince me it was the fault of the RN on duty that day. I do not believe that for one minute. She was covering twice the number of patients she should have, and I was not educated to the fact of how important it was to get up as soon after surgery as possible. Later, a doctor specializing in this area indicated to me that this clot was waiting to happen and the surgery just hurried it along. I was fortunate to be in the hospital when it happened. The nurse should not be blamed for this outcome. I believe the system failed her.

The journey I am having in the healthcare system is very different than the one I would have been on if Mike had not have died the way he did. My little brother's death opened my eyes to the fact that consumers need to be partners in our healthcare. I also realized that our healthcare workers are not infallible gods, and that we should not rely on them to be miracle workers. They are human just like me, they work in complex system just like I do, and they need our help to do their job well and make our journeys as safe as possible.

In my attempt to understand medical error, I began looking at the parallels between healthcare and air traffic control. I looked at the decisions that are made by controllers in the normal course of a day and how they could mean the life or death of someone. We do not work in a vacuum where our decisions and actions are completely our own. Instead we work in a complex system where every decision made or action taken becomes part of a history that results in a particular outcome. There are times we must distance ourselves from the image of our customer to accomplish the job and at the same time communicate with them in a professional, humane manner to instill confidence and trust in our abilities. As humans in both aviation and healthcare we make mistakes and must learn from them to improve.

Having made the comparison, I could also see the contrasts between the professions. We split in the way we address error. I asked someone at my facility who was recently involved in the evaluation of an error what he thought punishment accomplished in dealing with errors. He said, "punishment does not prevent error it prevents the reporting of it."

The system healthcare workers function in is failing them and their patients. We have been blaming and punishing the individual and it has not made healthcare safe. It has actually built a wall of distrust and misunderstanding between healthcare workers and their customers, it is this wall that prevents the communication and honesty that is needed to identify and correct the flaws in the system that are contributing to errors.

Now, well along in my journey, I firmly believe that the key to improving the system and making it safe is that we all must do our part to make it work. Responsibility for safety needs to be shared from the top down to the bottom, and that includes the consumer. I know there is concern that if we take the responsibility for an error away from the healthcare workers in the system, there will be no responsibility taken at all. I dispute that. If we work as a team, the concept of teamwork actually increases the responsibility for each individual to do their part.

It takes a lot when you are in a profession where mistakes take peoples lives to admit and deal with the fact that you are capable of making mistakes. That's true in air traffic control as well as medicine. In healthcare, you are told you have to be perfect and cannot make mistakes. Therefore, when they do happen the culture of perfection and blame prompts you to hide them, deny them and even ostracize those who have made them as if you would never have made the same mistake. In air traffic control, our approach is very different. Our culture acknowledges that we are human and constantly reminds us that we can make deadly mistakes at any time, prompting us to be vigilant at all times.

As a family, we take part of the responsibility for Mike's death. We left him alone and should have been there to speak for him when he could not. Maybe he would have died anyway, but at least he would not have died alone. I envision in the new world of healthcare that Mike would have taken a more active part in, as well. He would have known more about the medical risks in our family, and how his own history of high blood pressure could contribute to his risk of injury. He would have been more aware, and alert for the symptoms of a medical problem.

The Important Work of Educating Consumer Partners

When I began to understand the enormous amount of work need to improve patient safety, I was initially overwhelmed. I had to decide what contribution I could make. I now believe in the crucial importance of involving consumers in healthcare improvement, whatever direction it takes. Consumers are key players on the team and all the efforts attempted in healthcare will be for naught if the consumer is not educated about their role. We need to help the public understand it is the system that is failing, not the healthcare workers in it.

The individuals here today represent the movement that is taking place that will make our healthcare not only the best I the world but the safest as well.

AHRQ already has made important contributions to patient safety in general, and the role of consumers in particular. Among other projects, AHRQ is supporting a workshop in October that will bring consumers who are “frequent fliers” in the system together to mine our experience for lessons learned in being constructive, proactive partners in our own care. Facilitated by the Institute for Alternative Futures and the Partnership for Patient Safety, I am involved in the development of this grant and want to commend Carolyn Clancy for her agency’s commitment to the notion of a patient- and consumer-centered system. The AHRQ’s work in this area has just begun, and as a consumer I urge the committee to support it with appropriate resources, so this kind of work can continue.

The National Patient Safety Foundation is also to be commended. I am grateful for the opportunities they afford consumers to be “at the table,” by establishing the Patient and Family Advisory Council, on which I have the privilege to serve. The NPSF’s efforts in creating a national database of patient safety information are crucial to the education needed about this issue.

I believe the Leapfrog Group, through its call for patient safety reforms and advocacy on behalf of employees, is one of the most important patient-centered forces in healthcare today. Among other resources, the Leapfrog Group’s ability to use its member companies human resources departments to educate consumers about their roles and responsibilities is enormous.

I have personal knowledge of the Fairview Health System's dedication to patient safety under Dr. Page's leadership, because I had the opportunity to bring to his attention a family who had experienced a system failure and were very angry about it. While I cannot discuss the details here today, for confidentiality reasons, I witnessed how his staff agreed to meet with this family, listened to them, and responded by telling them what Fairview had learned from them and was going to investigate. It was not an easy meeting for Fairview, but the difference between this approach and the way in which my family was handled after Mike's death is like day and night. Consumers are ready to work with leaders like Dr. Page who respect us and show it in the way their organizations operate. I think we can accomplish great things by working together in partnership.

There are several things I believe could be done to further the culture changes needed in healthcare and society. The first would be to require disclosure in a reasonable timeframe of any bad outcomes. Since facilities are required to sign contracts for care to receive Medicare and Medicaid funds, I urge you to consider whether this could be a condition of participation.

Another important step would be to prohibit the confidentiality agreements that seal the records when a medical liability claim is settled. One of the great disparities between aviation safety and patient safety is that we widely publicize our lessons learned and use them as safety tools. Allowing the facts that produce accidents to be hidden, as healthcare routinely does, means healthcare repeats the same mistakes over and over again as each hospital and clinic climbs its own, carefully hidden learning curve.

Finally let us start educating the public about the true cause of errors. We need to stop scapegoating individuals and look at the system that is failing them and us. We should inform healthcare consumers not only of their rights, but just as importantly their responsibilities as partners in their care. A friend said to me just before coming out here that if it were not for conversations we have had she would not be the consumer she is. When her daughter was being given medication in grams and being weighed in kilos, she asked them to double check the dosage amount and explain to her how they arrived at the answer. This is not a mother being difficult, as family members are so often labeled. This is a mother trying to be a partner in her daughter's care. We should encourage and celebrate that. If there were more mothers like her, we'd have a stronger safety net and fewer bad outcomes.

So, let me leave you with this invitation to healthcare and those who fund healthcare research: First, work with us to educate consumers about the real risks of healthcare and our responsibility to work in partnership with you to keep our loved ones safe. Second, listen to consumers when we try to talk to you. We see things that you often don't, and we want you to use what we learn to help keep future patients safe. Third, always tell us the truth, and the sooner the better. Otherwise, we cannot trust you. Finally, be transparent. Talk publicly about system failures, so we can all learn from your analysis of accidents. The airline industry doesn't bury accidents, and neither should healthcare. Going public may feel frightening to you, but educated consumers will praise you for your honesty and trust you more when you do openly share what you've learned. Thank you very much.