

The courage to find peace - a mother's story

Mary Ellen Mannix is one of our international correspondents writing from Pennsylvania, USA. Her first contribution for us starts with a quote on peace:

Peace is not something you wish for ; it's something you make, something you do, something you are, and something you give away. Robert Fulghum

Although this is my first 'encounter' with Mary Ellen I realised that for her, a mother who lost a newborn child James through a series of preventable medical errors, finding peace has been a way of coming to terms with this great loss. In her journey towards peace Mary Ellen has laid down milestones which include being the founder of PULSE of PA, Pennsylvania's chapter of the nationally recognized grassroots patient safety organization, PULSE America. PULSE stands for Persons United Limiting Substandards and Errors in Health care.

PULSE ([HYPERLINK "http://www.pulseofpa.org/whoweare.html"](http://www.pulseofpa.org/whoweare.html)) is a nonprofit support group and organization dedicated to raising awareness about patient safety and reducing medical errors through advocacy, education, and support. They "work to empower the public to make informed decisions, increase effective communication and respect between healthcare providers and the public, and create community partnerships that will foster and ultimately lead to safer healthcare environments".

Mary Ellen began her work in patient safety following the death of James. Having gone through the crucible of fire emotionally and the legal proceedings after that she resurfaced with the knowledge that working constructively and compassionately holds the key to healing. Through PULSE of PA she provides support to survivors of medical errors, patient safety education to healthcare institutions and communities, and advocacy for the safest delivery of healthcare. The aim is to save patients' lives and providers' livelihoods. Below Mary Ellen writes of her work and experiences in furthering her journey to peace and giving meaning to James' death:

Whose point of view?

"Though only able to attend part of the 'The Quality Colloquium at Harvard', I spent the few bucks I had to get there because its topic (patient safety) is just so very important. Ever since my son lost his given name and became "adverse event/medical error #459783", well meaning family, friends, and colleagues who have listened to

just a portion of his sad story have innocently and ignorantly offered, "I hope you can find some peace." So, true to form, I went looking.

The talks at Harvard on Monday focused at times on what a patient/family who endures a medical error is searching for from the healthcare establishment, post event. Some words used to define the missing link were "accountability, closure, retribution, knowledge, transparency, and acknowledgement." All these words contain distinct connotations and emotional overtones unique to the individual's perspective. A patient's view is different from a risk manager which is different than a nurse, different than a physician, different than a hospital administrator. Whose point of view is correct? Is there one?

What is taught in my preschool classroom has merit here: Every individual is important and without considering the view of one the view of all is incomplete. (In preschool it is simplified to 'Each one counts!')

In my humble opinion all these perspectives can be surmised in one very big, yet small, word - peace. There is nothing that can disrupt a life more than entering into a war, whether a cold war (stonewalling) or an active one (litigation).

Communication

Being relatively new to healthcare safety discussions, my two exposures in the past four months to large gatherings of stakeholders (National Patient Safety Foundation and Harvard University), my review of professional literature and personal experience maintain two strong underlying themes - communication and sadly, skepticism.

Successful communication has one essential element: that both parties MUST engage for communication to be even possible, let alone successful.

I don't aim to repeat what so many professionals already know. Nor can I argue the complexities and enormity of the task for patient safety. Rather, I would like you to know how I, one family member, attained what I wanted and desperately needed - and it didn't require government, legislation, systems change, or an electronic medical record (though they could have helped my son).

I began by reading again Dr. Lown's decade old "The Lost Art of Healing". In encouraging this read, I am not admitting to understanding or agreeing with all of his positions. For instance, Dr.

Lown discusses at times withholding information from a patient because he surmises it would cause more harm than good. But then he also writes of the disparity in power and information as a cause of much dissatisfaction among health consumers. How can patients appreciate what they are hidden from?

I am not after all a trained medical clinician, lawyer, business executive, plumber or electrician. When I need guidance in any of those specialties I search for guidance I can trust. However, the book's overarching theme of returning medicine to the relationship between doctor and patient is vital to save a patient's life and the doctor's livelihood. Dr. Lown's 50+ year career is a testament to it. The more that muddies the waters between these two parties the more struggles will continue for all. His mother's traumatic death is testament to that.

Trial and tribulation

In the week before going to trial I was offered a settlement deep in six figures accompanied with a confidentiality clause. My counter offer was the opportunity to meet for five minutes with a particular defendant and to have my certain legal costs paid. Costs that were incurred by me to attain the answers the hospital would not give. Costs that the plaintiff's attorney must incur to file the mandated partner to a medical malpractice civil lawsuit: the certificate of merit. However, with a signed Contingency Agreement, my attorney and firm would only be repaid if there was a financial award. My counter-offer was unacceptable. We went to verdict. There was worthy argument for mistrial and strongly-worded encouragement from the judge to appeal. I applied the brakes.

In 1977, Nils Christie wrote about "Conflicts as Property" in the British Journal of Criminology. "Conflicts are taken away, given away, melt away or are made invisible." The "professionalization of conflicts" in our society has led to conflicts not being addressed or resolved by the parties most affected by the original conflict. I continue to have great appreciation and fondness for the lawyer that pulled me through the trauma of finding out the truth in my son's death. However, he as much as the defendants' lawyers provided "the sad moments of truth when [they] told us that our best arguments in our fight are without any legal relevance whatsoever." Our conflict had become the property of the lawyers. Since they were not a party to the goods originally taken away, they would not be able to find a resolve that would promote healing for either party. So, I had my day (actually a whole week) in court that most never get. It did not bring justice nor a feeling that those that caused my harm had heard me. I needed to return to the beginning.

There wasn't one "a-ha" moment. It was the accumulation of the support of a devoted attorney, the dedication to my living children, the empowerment given by another mom to a deceased boy, the responsibility to memorialize my baby in a positive light that prompted me forward. After jumping through nearly six years of hoops, I found a little bit of peace very simply.

Reaching out and finding peace

I had decided to stop this formal process. It was beneficial for the answers I needed but not the peace I sought. I reached out independently to one of the defendant doctors. The reply was a very pleasant surprise.

I had to assure the doc that all legal action was behind us. It took much courage on my part but after a few emails we agreed to a phone conversation. The phone conversation led to a face-to-face meeting – the first since I glanced his way while on the stand. Then, on a sunny summer day, nearly two years post-verdict we sat in a bustling hospital lobby talking. A mother and her son's doctor discussing what happened. A plaintiff and defendant exchanging what the experience was like from their side of the courtroom. Just two people talking.

We both attained some peace that day.

In a strange twist, I am now grateful for this doctor....and remorseful that it took so long. I am also wholeheartedly appreciative and in awe of my lawyer who fought long, hard, without compensation while incurring steep costs just so I would find some peace. The road Doc and I had to travel was arduous. And no, I may not agree with all his points of view, nor he mine. However, we are on more of the same pages philosophically than one could imagine. I am open to being wrong so that I may hear the other view. My son, quite unknowingly, gave his life to forward the mission of patient safety. I can give a little of my pride.

There is a shorter road and it would save money, lives and professions - perhaps, naive and simple-minded. However, simple is usually the best way to the safest, most significant healing. Dr. Semmelweis found that a long time ago in discovering how someone so dear to him died.

Physicians and patients will probably always need some extra help and maybe even some "paternalistic protection". In every profession, every walk of life there are individuals who may not understand, may want more, may decide to give away their conflicts. Yet, we do not have to die diagnosed as crazy when we

see an answer to our conflicts. Dr. Semmelweiss tasked his peers to try washing their hands and instruments after autopsies and before labor and delivery. Evidence proves his suggestion was solid.

Physicians and patients who have experienced adverse events know many courtroom dramas are also preventable. Communication and the opportunity for direct conflict resolution between the affected parties are crucial. The Compass of Shame (Nathanson, 1992) is not only for medical professionals after a bad outcome. As a parent whose child died I carried great shame that my child died before I did. I ran away and withdrew from my life as I learned that I made the wrong decisions. I lashed out at people as I realized I didn't ask the right questions or was satisfied with incomplete answers. I isolated myself from others since the mom of a dead baby who was suing men in white coats didn't have a proper and respected place in the culture's landscape. As a parent, I carried great shame that I had to select a 24 inch coffin. I didn't provide much protection for a child that only lasted 11 days here.

Patient-doctor relationships

PEACE in Healthcare will need the coordinated risk taking and trust of doctors and patients to re-direct those who are supposed to be safeguarding these parties (risk managers, hospital administrators, and insurance executives) to make available the option of a doctor/patient (family) non-discoverable "conference" that will not remove any legal rights from either party. This restorative practice has been available in the juvenile justice system for many years. Similar approaches have been successful in conflict-stricken parts of the world like Northern Ireland. Restorative Practices offers appropriate counseling, emotional and professional support before and after a facilitator-guided conference (or "circle") between patient/family and provider. It holds the potential to reduce the number of physicians facing claims, encourage positive changes in defense law, redefine risk management, rewrite liability policies and most importantly, put control and trust back in the patient/doctor relationship.

From 2000-2002, many states (including PA) had doctors marching on state capitals and some patients picketing. Clearly, that tactic was unsuccessful for both parties. The American Medical Association membership is large. I hazard to say the membership of those who have suffered medical errors/adverse events is much larger (Institute of Medicine report, To Err is Human, 1999). These two groups working in union would have great power to stop being the pawns in someone else's chess game.

I have sat next to a variety of physicians from all corners of the nation and from all specialties that are interested in renewing a respectful relationship with their patient. It has been an honor to speak with all of them. I appreciate their willingness to listen, allow my questions, and share their point of view. It is also an honor stained with tears when I speak to another patient or family member that has suffered.

PEACE in Healthcare returns the power to patient and provider directly. Patient and provider are encouraged during the course of treatment and before any invasive therapies or treatments to engage in open dialogue. Patients are instructed to ask their provider: "If something does goes wrong in my care, will you agree to meet with me or my family member within 72 hours after any adverse unexpected outcome and explain what happened as far as you would understand at that point?" Providers are instructed to answer positively. The patient's question concretely displays understanding of the inherent risks that many assume are so low in percentage. Yet, per the IOM report of 1999, the risk is actually much greater. Furthermore, providers are encouraged to return the trust placed in them by remaining in contact with a patient who endured any adverse, unexpected, or mistake in medical care. There are several national and state organizations of peers and patients that can guide this renewed patient-physician relationship. PULSE of PA aims to be one.

At lunch in Annenberg Hall, the attendees were treated to a moving film of medical error victims. As it was to begin, the audience was encouraged to come to the front of the hall for better viewing and appreciation of what they were about to see. Dr. Thomas Delbanco of Harvard's Medical School invited, "Please one person stand, move forward and others will follow."