




2018

First, do no harm: The patient's experience of avoidable suffering as harm

Ashley Bauer MHA

TriStar Health, ashleyzb6405@gmail.com

Follow this and additional works at: <https://pxjournal.org/journal>

 Part of the [Health and Medical Administration Commons](#), [Health Policy Commons](#), [Health Services Administration Commons](#), and the [Health Services Research Commons](#)

Recommended Citation

Bauer, Ashley MHA (2018) "First, do no harm: The patient's experience of avoidable suffering as harm," *Patient Experience Journal*: Vol. 5 : Iss. 3 , Article 3.

Available at: <https://pxjournal.org/journal/vol5/iss3/3>

This Personal Narrative is brought to you for free and open access by Patient Experience Journal. It has been accepted for inclusion in Patient Experience Journal by an authorized editor of Patient Experience Journal.

First, do no harm: The patient's experience of avoidable suffering as harm

Ashley Bauer, MHA, *TriStar Health*, ashleyzb6405@gmail.com

Abstract

Although my entire career has been spent in Patient Experience, nothing I have learned from data, evidence-based practice, or experience-based correlations, has been near as impactful as what I learned from being a patient. This article discusses my own experiences as a patient. I ask readers to consider instances of avoidable suffering as sources of harm that negatively impact patient perceptions, erode trust in care providers and healthcare delivery systems, and create barriers to engaging patients in their care. Recognizing how avoidable suffering creates harm challenges traditional views of Patient Experience as hospitality-based “soft skills” and helps to establish patient perceptions as valid indicators of quality care.

Keywords

Harm, suffering, reducing suffering, avoidable suffering, suffering as harm, patient experience

Experience

When people talk about having children, the conversation inevitably turns to diapers, sleepless nights, first smiles, and how great babies smell. What we do not always talk about is how hard getting to that point can be for some couples or how easily it can all go sideways without a moment's notice. It was late 2008 when my husband and I decided we were ready to start a family, and to our delight it happened right away.

One afternoon nine weeks later, I began spotting and something just seemed off. My doctor could not see me, so she sent us to the Emergency Department as a precaution. I was nervous but rationalized this was a normal experience and I was likely overreacting. We were immediately taken to a room upon arrival and soon after I went back for an ultrasound. When I arrived in radiology, the ultrasound tech introduced herself, as well as another woman in the room. The ultrasound tech explained that the hospital had recently purchased a new ultrasound machine and the visitor was a sales associate there to provide some on-the-job-training. They asked my permission for the sales associate to stay in the room and in my anxious state I quickly agreed. As the ultrasound tech progressed through several pictures, I relaxed little by little. The sales associate began demonstrating all the bells and whistles of the new machine and I knew that everything was okay. Nobody would take 35 minutes to perform an invasive ultrasound for training purposes on an anxious mother if things were not okay. My concern shifted to my husband, knowing he was sitting alone in the room, his anxiety likely rising due to the long wait.

After returning to the room, I assured my husband everything was likely fine and explained the long wait. Soon after, our doctor entered the room with his head down, flipping through some papers, and exclaimed, “It's what I thought. The fetus has aborted.” From there, he immediately launched in to aftercare instructions that neither of us processed, handed us the discharge paperwork, shrugged and said, “It happens. You're young. You can try again.” As I sat there stunned, all I could think was how confused my husband must be. I worked in healthcare, but he did not, and I knew immediately that he would not fully understand what the doctor meant. It sounded so much worse than *miscarriage*. It sounded like my fault.

Avoidable Suffering as Harm

Primum non nocere. “First, do no harm,” is often quoted by healthcare professionals and care providers in reference to providing highly reliable, safe, quality care. In most health systems, doing no harm applies to physical aspects of care – preventable deaths, medication errors, wrong site surgical procedures, etc. – but does not address the ways in which we cause avoidable suffering for patients. As described by Mylod & Lee in a 2013 Harvard Business Review article entitled “A Framework for Reducing Suffering in Healthcare,” unavoidable suffering stems from the physical discomfort or complications related to patients' disease and/or treatment.¹ However, suffering that results from dysfunction in a health care delivery system, such as long wait times, poor communication, or a lack of care coordination, is described as avoidable. Any suffering patients endure that is otherwise avoidable erodes patient trust and compounds existing anxiety, fear and frustration.¹

How we communicate, the words we choose, the ability to connect with patients in a way that acknowledges their suffering is an essential part of doing no harm. The ability to empathize with another person is a vulnerable thing. It requires individuals to open up a part of them to the hurt someone else is feeling – neither easy nor fun to do on a daily basis – but an essential part of caring for patients. Most care providers pursued careers in medicine to help others, to care for them, to improve their quality of life, taking an oath to do no harm. An oath that cannot be upheld without recognizing the importance of avoidable suffering as a common source of harm for our patients.

Moments of Avoidable Suffering

The five years after that Emergency Department experience would be a rollercoaster of love and loss as we welcomed two perfect baby girls amidst two additional miscarriages. Our subsequent pregnancies were not full of joy or late-night conversations about what to name the baby, or what he or she might look like. What we learned in the event of our first miscarriage was to be fearful, to not trust what our care providers told us, to question their motives and intentions, to feel completely alone in this journey. Do not hope. Do not expect a good outcome. Do not expect compassion.

The loss of our first pregnancy and the way in which it was handled, without real thought or regard for myself and my husband as *people* who were about to receive devastating news, created avoidable suffering that eroded trust in all future experiences. Through our following four pregnancies, we do have the two moments of overwhelming love and joy when our daughters were born, but the snapshots from those years that stand out the most are littered with moments of suffering that could have been avoided by more thoughtful care providers who saw me as a person and not just a patient to diagnose and discharge:

The ultrasound tech who prioritized on-the-job training without questioning if the moment was appropriate for the new mother on the table who would soon find out she was no longer having a baby.

The ED doctor who called the baby we already loved an “aborted fetus” and told us we could try again as he walked out the door.

The variety of care providers who shrugged and said, “These things happen,” and quoted statistics on how many pregnancies fail before women even know they are pregnant. As if we should find comfort in the fact that we were not alone.

The nurse practitioner who remarked, “I wondered when you were going to cry,” when I teared up as she talked with me about a D&C following my second miscarriage.

The annoyed post-op nurse who shushed me and pulled the curtain as she walked away because I woke up from anesthesia disoriented and crying for my baby after my third D&C.

These moments rise to the surface any time I think about my pregnancies or the birth of my children. They do not drown out the happy moments, but they bob right there on the surface with all the good ones. Diluting the memories of those who did take care to be compassionate and thoughtful in their communication, taking time to acknowledge our individual situation, or express compassion for what we were going through.

“The relationship between doctors and their patients has received philosophical, sociological, and literary attention since Hippocrates, and is the subject of some 8,000 articles, monographs, chapters, and books in the modern medical literature.”²² Despite the longevity of this conversation, I believe care providers (*all* who provide care at the bedside) still underestimate the lasting impression and impact they have on patients and their families – both positive and negative. Patient engagement, making meaningful connections, or being empathetic gets chalked up as soft skills or “the squishy stuff.”

Throughout my career in Patient Experience, I have repeatedly seen these elements of care downplayed or rebutted as irrelevant to providing quality patient care. As a patient, I may not fully understand a diagnosis or how a treatment plan will improve my quality of life, but I do know how you made me feel and that absolutely impacts my desire and likelihood to trust that you have my best interest at heart, that you know what you are talking about, and that I should place my trust – and in some cases, my life – in your hands. All of which directly impact two key drivers of quality care - patient compliance with treatment plans and their resulting outcomes.

Ask of Care Providers

Looking back now, nine years later and eleven years into my career in healthcare, I understand more of where the care providers I encountered as a patient were coming from. Competing priorities, the lack of education that exists around handling complex emotional situations with patients, and the need to create a shield and build their own resiliency against all the suffering they see on a daily basis often supersede the motivation or ability to make real connections with patients. Our care providers – doctors, nurses, techs, anyone working in direct patient care – see some of the worst parts of our lives and they have to learn how to not carry that burden with them. The need to foster that resiliency is real and essential to their own well-being and ability to care for patients. But somewhere between the needs of the patient and the care providers, we have to agree on the importance of doing no harm in the form of avoidable suffering. To know that what

patients need most from their care providers is a connection, a feeling of trust, and to feel *seen*.

The following are recommendations for any person who provides direct patient care, as well as those who provide leadership in our health systems:

1. Commit to the inclusion of avoidable suffering in the concept of “doing no harm.” Include ways in which avoidable suffering occurs in your organization and work group in discussions regarding patient safety, quality of care, and high reliability.
2. Be present in the moment and experience your patient is having. Know that your normal is *not* their normal – they are experiencing life-changing events, often without the medical background or knowledge you possess.
3. Make a conscious effort to eliminate avoidable suffering in the care you provide. Consider the impact your words and approach may have on patients, particularly during highly emotional situations. Take time to connect with your patients and show real empathy. It is okay to acknowledge their situation as something that is painful, difficult, or scary.
4. Reflect on your own experiences as a patient, or the caregiver of a loved one, to identify instances where you feel a care provider or organization dropped the ball. How did that make you feel? How could it have been avoided? How might you have interpreted the situation if you did not possess the medical background and education that you have? Use this self-reflection to establish a personal framework that allows you to better relate to your own patients and their loved ones.

When patients and their loved ones think back on their experiences they will not remember every detail, but they will carry with them snapshots of memories created in moments. The birth of a child, the day they received a terrible diagnosis, their last cancer treatment, the moment they decided to remove life support from a loved one – those snapshots play in a loop that will come to represent these larger experiences. Be present in those moments and intentional in your words and actions. See the person in front of you and choose to do no harm.

References

1. Mylod, Deirdre E. & Thomas H. Lee, MD. “A Framework for Reducing Suffering in Health Care.” November 14, 2013. *Harvard Business Review*.
2. Goold SD, Lipkin M. The Doctor–Patient Relationship: Challenges, Opportunities, and Strategies. *Journal of General Internal Medicine*. 1999;14(Suppl 1):S26-S33. doi:10.1046/j.1525-1497.1999.00267.x.