Patient and Care Partner Reflections

WHITE PAPER

The Experience of Safety in Healthcare: A Call to Expand Perceptions and Solutions

Every individual sees the world through their own lens. In healthcare, the perspectives of patients and families are often different from those who deliver care. Anywhere you see the "eyeglass" icon, enjoy a companion resource written through the lens of patients and families.

INTENTION

The intention of reflecting on this white paper through the lens of patients and families is to support patients, families and PFAs by providing a more relatable entry point for The Beryl Institute's resources. This accessibility through a peer voice enables patients, families and PFAs to be more effective and engaged members of the PX Community.

Each of these reflections fits within the Experience Framework. This reflection falls under the following Strategic Lens:

QUALITY AND CLINICAL EXCELLENCE

The "Why"
Experience encompasses all an individual encounters and the expectations they have for safe, quality, highly reliable, and effective care focused on positively impacting health and well-being.

The "Impact"
When clinical care is excellent, the expectations of patients and families for safe, high-quality healthcare are met, fostering confidence, building trust and cultivating organizational loyalty.

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Over twenty years ago my son, Noah, died at age 4 from a series of medical errors following a tonsillectomy. I went back to school to study how to improve patient safety. Over the years I have been consistently confused by how healthcare creates so many silos. I remember my first discussion with someone about patient experience and realized that they did not see any link to safety or quality. Noah's death impacted the way I perceive healthcare experiences. I no longer see healthcare as service in which I can be a passive recipient. I know that I need and want to be an active advocate for myself and my family. Patients don't silo the various aspects of care, for me safety and experience are intricately combined, and this white paper does a great job of explaining this.

GENERAL SUMMARY

This whitepaper explains in vivid detail the truth that we, as patients, know, even if we have not been able verbalize it: That patient experience and patient safety are inseparable. As patients many of us have seen and felt firsthand how our experience is impacted by the quality and safety of the care we receive. The paper also points out how differently patients define safety from healthcare systems. "Do no Harm" for patients translates into physical as well as emotional or dignity harms.

Healthcare systems often have experience and safety being directed and overseen by two very different departments that may not work together. Because of this the patient, staff and clinician experience and safety are compromised. When healthcare systems think about the two, experience and safety, as being intertwined then there is likely to be increased trust, safety and experience for everyone plus less burnout for clinicians. Understanding how this plays out in our own healthcare systems provides us with insight on how we can be better partners in our own care and as Patient Family Advisors within our healthcare systems to improve safety and experience.

KEY POINTS TO CONSIDER AS A PATIENT OR FAMILY CAREGIVER

This paper points out that as patients or caregivers we may not differentiate between experience and safety. As patients we do not need to become safety experts to make sure we are receiving high quality clinical care, however, we can advocate for ourselves and others when we are being impacted by a culture that does feel safe or welcoming. As the paper speaks to in this quote:

"Patients may not always know what they are witnessing when receiving care within a particular culture, but the culture will reveal itself for better or for worse."

When a less than ideal culture is revealed, and it may only be a "gut" feeling, we have an opportunity to speak out. When we feel harmed by healthcare, as the study in the paper suggests, not by clinical or physical harm but rather by "problems with communication, policies, lack of care coordination and information needs and preferences" then we can we can speak out. Speaking out not only improves things in the moment but also allows the healthcare organizations to see beyond their definitions of safety and harms and to look closer at the lived experience as it unfolds in real time.

There is, as evidenced by the references in this paper, a disconnect in how patient perceive safety, harms and overall experience compared to how staff and clinicians perceive it. As patients we can look to our own activation levels and consider how we might become more activated and a more effective partner in our care. We can ask questions about the specific safety concerns and protocols around current treatment and care plans. We can also share our fears and concerns about what we are experiencing and observing. Working together in partnership, patients, families, staff and clinicians we can all contribute to a culture of safety which will improve the Human Experience.

CONCEPTS, IDEAS OR PRACTICES WORTH SHARING WITH YOUR ORGANIZATION AS A PFA

This paper illustrates many ways that a Patient Family Advisor can be helpful in creating a safer experience throughout healthcare. The following is a long list and not meant to be a step by step guide. You do not need to attempt all of them! Think about how you might bring a few of these suggestions to your PFAC or leadership team.

PFAs Can:	Organizations Can:
PFAC or PFA – included in discussions of developing and adding questions to patient experience survey	If the organization has different departments for safety, quality and experience bring them all together at the PFAC. Have a representative of each area be standing members of the PFAC
PFAs help define safety	Teach the PFAs the intersectionality of safety, quality and experience
PFA involved in all aspects of Human Resources- from hiring to firing decisions	Include PFAs on how to improve clinician and staff experience. They see a different perspective and may have valuable, innovative ideas
Include PFA on all performance improvement cycles	Train and hire PFAs to be the facilitators of EBCD cycles
PFA involved in creating a Just Culture and how to communicate that to the community PFA present to support patients and families at disclosure and apology meetings	Include PFAs on Finance Committees: When wrestling with the very real and difficult decisions having a patient perspective will help with understanding the impact and how to communicate it to the community
Peer support for patients and families who have experienced a significant harm	Include PFAs on Staffing/HR Committees: Helps with understanding some of the impact of staffing decisions
Have the PFAs help develop education materials and initiatives to help patients and families understand safety and how they can help by being advocates for themselves	Include PFAs on Root Cause Analysis or another adverse event analysis: Provides a perspective that is may be provide different ideas of what is at the root of adverse events and ideas to improve

PFAs help assess how the organization is "listening to patients and families and view them as a resource"	Include PFAs on Information Technology Committees: Specifically, when rolling out or using Electronic Health Records, telehealth or other engagement technology
	Include PFAs on Safety Committees: Also include PFAs on Safety Walkarounds and other assessment strategies

FINAL THOUGHTS

During my experience with Noah I did not have a voice. What I was saying and asking for was not seen as important nor a key to preventing an error. Did I know that errors were happening? No. Did I know that what I was asking for would have prevented some of them? No. I didn't know what an activated patient or culture of safety was. I knew that I was scared, and I knew things were not right with my son. I have since learned to speak up even when I don't completely understand the policies or protocols that are in play. I am hopeful as I now see how things have and continue to improve in patient safety and experience. The important take away from this paper is that one of the keys to improvement is including patient and caregivers in creative and meaningful ways.