Patient and Care Partner Reflections

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 lenses of patients and families.

INTENTION

The intention of reflecting on this PX paper through the lenses 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:

Infrastructure and Governance

The "Why"
Effective experience efforts require both the right structures and processes by which to operate and communicate and the formal guidance in place to ensure sustained strategic focus.

The "Impact"
When infrastructure and governance are designed to have the best interest of the patient at heart, patients and families feel welcome, supported and embraced.

ABOUT THE AUTHORS:

The three authors of this reflection are members of The Beryl Institute's Global Patient and Family Advisory Board (GPFAB). Tony Serge and Isabela Castro are the GPFAB Co-Chairs and Aimee Williamson is a board member. Beyond their experience with The Beryl Institute, Tony is the Co-Chair of the Patient and Family Advisory Board at Brigham and Womans Hospital and past Co-Chair for the Dana Farber Adult Patient and Family Advisory Council. Isabela is a global advocate/activist and has been the chair and a member of several boards around the world. Aimee has been a member of the Boston Children's Hospital Family Advisory Council since 2014, serving as Parent Co-Chair from 2020-2022. Their collective experience with healthcare spans over 50 years as patients, caregivers, patient & family advisors (PFAs), and a provider.

AUTHORS' PERSPECTIVE

As patients, caregivers, and patient and family advisors (PFAs), we are struck by the importance of this PX Paper to the field of experience. It provides a strong argument for the importance of a commitment to the human experience, while also addressing the financial value of experience to patients and families, which we all know first hand. It also provides direction and concrete strategies for healthcare institutions to make progress. We appreciate this approach, as well as the importance of culture in driving patient experience and the interconnectedness of workforce and patient experience.

We are also inspired by the fundamental insight of shifting the focus of healthcare from transactional to more relational. While there may have been points in our lives where healthcare was transactional, and that was perfectly okay, our collective experience of over 50 years as patients, caregivers, and PFAs tells us that effective healthcare is dependent on strong relationships—especially during lengthy or complex healthcare journeys.

We have seen and strongly believe that patient experience is a critical component of effective healthcare, including positive outcomes, safety, patient adherence to the care plan, and patient loyalty. Expected quality of care is and always will be a top priority when choosing a healthcare provider or institution, but as this PX Paper reminds us, medicine is part art and part science. Strong communication among patients, caregivers, and providers, along with mutual understanding and respect, help drive positive outcomes and trust. It's not always clear to a patient or caregiver why outcomes may not be as positive as expected, but if the patient and family have developed a

relationship based on trust and mutual respect, it is far easier to navigate those bumps in the road. In addition, healthcare journeys can create feelings of vulnerability or despair and consume a person or family's life. Healthcare professionals recognize this, providing care with compassion and respect to ease the burden.

GENERAL SUMMARY

The *Human Experience Imperative: Practical Insights for Executives on Organizational Structure and Strategy* makes a compelling case for healthcare institutions to invest in experience. The paper provides data-backed rationale for the importance of experience, recognizing the interconnectedness of patient and workforce experience as a broader notion of the *human experience* in healthcare. Experience efforts help advance healthcare outcomes, including "clinical quality, financial viability, workforce engagement, equity, loyalty, and reputation."

The authors call on institutions to focus on structure as a key first step in this process, identifying considerations that revolve around leadership, structure, strategy, and culture. These considerations include investment, access to the C-suite, going beyond metrics, ensuring accountability, and being a champion for human experience across boundaries.

Key Points to Consider as a Patient or Family Caregiver

As patients and caregivers, we can confirm the paper's message about the importance of experience and the elements that drive it. While quality care is our top priority, we know that a better experience drives patient loyalty and improves outcomes. We also know what matters to us—including being treated with respect and empathy, trusting our providers, feeling listened to, and playing an active role in our care.

It was interesting to learn that positive experience also has a quantifiable value on an institution's finances, with one study finding margins almost three percentage points higher. It was also interesting, but not surprising, to read that patients are more likely to share a poor experience than a positive one. While positive patient experiences build loyalty leading to higher margins, the opposite can also be true. Negative experiences may drive us to communicate improvement needs or seek out alternative providers or organizations.

We can also relate to importance of culture, which is felt by patients and caregivers throughout their continuum of care. We would argue that experience is not typically defined by one isolated interaction, although an isolated interaction can derail an

experience almost instantly. We view our care as a journey, characterized by several interactions that come together as an overall patient experience—a notion well reflected in The Beryl Institute's definition of patient experience as "the sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care."

Culture is local and carries great power for or against a quality experience. We may not see the investment in structure or strategy firsthand, but we feel the impacts of it. We can tell when a system is designed for us, and conversely, we can tell when it is not and when our care team is experiencing burnout. What we really need to see and to feel is the end result—ideally, that the people are consistently compassionate, helpful, respectful, and good communicators. Hospitals need the investment in structure and strategy to make this happen, but the critical link is that a culture built on attention to experience - both patients and the workforce -is strong enough to make its way to every nook and corner of the organization.

This PX Paper also offers insights that we should heed as patients and caregivers. First, experience requires significant investments of time, resources, structure, and strategy. In other words, it does not come easy to an organizations Healthcare institutions are "big ships," and it takes a lot to change course and move the needle. We must appreciate that this is not an easy task and that a significant investment is required. We can and should provide feedback when warranted but should do so with the understanding that change may not be immediate.

Second, relationships are bi-directional. Patients, families and caregivers are part of the healthcare eco-system, and we must do our part to ensure effective communication that addresses healthcare workers with the same compassion and respect we look for from them. Just as our patient/caregiver experience is made up of "the sum of all interactions," so too is the daily and yearly experience of healthcare providers. How do we, as patients and caregivers, foster that relationship in a way that respects boundaries, yet reinforces a positive experience for patients, caregivers, and healthcare workers?

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

This PX Paper provides important and practical guidance to aid healthcare institutions in efforts to advance the human experience. Some of the points that resonate with us include the idea that C-suite presence is necessary to ensure an integrated strategy that aligns experience with other strategic efforts and the need for experience leaders/offices to be "boundary spanners" in their organizations. From the perspective of patients and families, these approaches are critical, as experience simply cannot be siloed. An organization may want to limit experience to a single person or unit that reviews HCAHPS scores, but as the PX Paper notes, those scores are not drivers of experience but only performance measures of such efforts.

In addition to sharing the paper and reinforcing the principals articulated, PFAs and PFACs can ask themselves and their organizations how they can support, partner, and bring to life the investments in experience recommended by this PX Paper. We offer the following as example applications of this paper's six considerations to PFAs and PFACs:

- PFAs can work with experience leaders and staff to build strong partnerships and support their efforts. Examples include:
    - providing feedback on initiatives before they are launched.
    - sharing experiences to help identify problem areas.
    - applying co-design principals to partner patients and staff on organizational strategy and culture efforts.

- PFAs can bring metrics to life. While the numbers are important, related stories help explain the ratings and motivate change. Stories are data with a soul. Putting patients on a team or having them share stories may increase impact and ensure sustainable change.

- PFAs should understand that experience efforts take time, and changes are not likely to happen overnight.

- PFAs should serve the institution in a way that fosters reciprocal respect and understanding. We must understand the challenges and resource limitations that healthcare organizations face, just as they must understand the challenges we face in navigating their institutions.

- PFAs can also serve as boundary spanners and champions for human experience from the ground up. Every time we walk through the doors of a hospital, we

interact with a wide range of people who represent different lines of a hospital's complex hierarchy—from clinical to non-clinical and from various medical departments to food services and parking.

FINAL THOUGHTS

We appreciate and agree with the six considerations this PX paper makes for healthcare organizations striving for experience excellence. We would suggest adding one more to the list to reflect the increasing recognition that bringing patients and staff together to co-design healthcare processes and policies is a powerful tool:

An experience leader/office should maintain direct connections to institutional avenues for patient and family feedback, actively engage PFAs and PFACs in experience efforts, and adopt a co-design approach to institutional change.

While this PX Paper touches on the importance of engaging patients and families in this work, we believe it is worthy of its own dedicated consideration. This should include developing, strengthening, and investing in patient and family advisory councils (PFACs) and other PFA structures, such as eAdvisor panels.

It also includes a commitment to co-design principals to integrate the patient voice effectively and productively. When such groups are viewed as valuable partners, their voices can be leveraged to identify problems before they make their way to Patient Relations, proactively mitigating problems in the first place.

HCAHPS results are not sufficient to inform experience efforts effectively. Gathering information on experience should come from multiple avenues, including both quantitative and qualitative information. PFAs and PFACs are excellent sources for assessing experience and strong partners for improvements but this too requires investment and support. Investments may include qualified staff to manage PFAs/PFACs, member training, stipends for alleviating barriers to participation or attending patient experience conferences, and access to research and resources from leading patient/human experience organizations.

We conclude with profound appreciation for the work that has gone into this PX Paper. We are committed to do our part to help move this work forward. We encourage healthcare institutions to read it carefully, reflect thoughtfully, and make a concerted effort to invest in the recommended steps to ensure positive experiences, improve quality and outcomes, and maximize their bottom lines.