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:

PATIENT, FAMILY AND COMMUNITY ENGAGEMENT

The “Why”
Central to any experience effort are the voices of, contributions from and partnerships with those receiving care and the community served.

The “Impact”
When the experience of patients and families are included in all of the organizations’ processes and executive leadership strategies, patients and families feel respected and valued as both integral part of their healthcare team and change agents for the organization.
CULTURE & LEADERSHIP

The “Why”
The foundation of any successful experience effort is set on who an organization is, its purpose and values, and how it is led.

The “Impact”
When an organization’s culture is aligned in its purpose and values, patients and families feel that the entire organization was designed to provide them with best possible experience and find comfort and joy in every interaction across the organization.

ABOUT THE AUTHOR: Nikki Charisse Montgomery

I am a patient advocate, patient safety book author and patient-family partner. I hold a bachelor’s and master’s degrees in English, along with a master’s degree in Educational Psychology with research focused on informing and empowering parents of medically fragile children. I completed a graduate certificate in Patient Advocacy and serve on the Board of Directors at University Hospitals Rainbow Babies & Children’s Hospital, where I also sit on the safety committee and am a past-president of the hospital’s Patient and Family Partnership Council. In addition to my work with Ohio’s Solutions for Patient Safety family engagement group, I am part of the Global Patient and Family Advisory Board for the Beryl Institute and the project coordinator for the Beryl Institute’s Patient Experience Policy Forum. As a member of the Center for Medicare and Medicaid Services Person and Family Engagement Committee, I have been recognized for volunteerism and advocacy in the healthcare setting.

AUTHOR PERSPECTIVE

I was inspired to read this white paper because, as an African American woman who has experienced healthcare as a patient, a caregiver and a patient advocate, I have seen and lived the effects of cultural competence, and its absence. Stereotypes have often overlaid my interactions in healthcare, and I have been on the receiving end of microaggressions about my hair, misinformation about my options for care, and blatant dismissals of my concerns. Biases affect the way professionals engage with me and talk to me, from presuming my education level to painful reproductions of black dialect in failed attempts to connect with me personally. These experiences
highlight some of the obstacles I have in finding competent care that addresses my unique needs in the context of my cultural and lived experience.

GENERAL SUMMARY

This white paper focuses on the importance of cultural competence in delivering quality care. Cultural competence is essentially an understanding of how people’s culture, including “language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups” affects how they interact with and within the healthcare system. This paper focuses primarily on the importance of developing cultural competence at the interpersonal level, with patient interactions, in order to support positive patient experiences.

Cultural competence is a necessary component of an excellent patient experience. When professionals connect to patients’ motivations, beliefs, and ways of understanding their health, they can help to improve health and remove barriers. Understanding and respecting culture as the backdrop for the way patients see and experience healthcare, wellness and treatment is important for professionals, but it is essential for patients and their families.

KEY POINTS TO CONSIDER AS A PATIENT OR FAMILY CAREGIVER

Patients want to be treated as individuals; we want to know that the quality of care we receive is not guided by assumptions that are based on identifiers and demographics. We want to know our providers are actively working on dismantling their own biases in order to stop the negative effects those biases have on our health.

Cultural competence has a huge impact on patient outcomes, but patients have no way of knowing a provider’s level of bias or cultural competence. They have no way of knowing whether their provider takes seriously the impact of their cultural competence and biases on the health of patients. Patients walk in blind to our providers’ beliefs about us, which can have a direct effect on the quality and duration of our lives. From microaggressions that subtly erode trust to outright differential treatment, members of marginalized groups experience the gamut of cultural competence failures. Each cultural competence failure has the potential to make a patient feel alienated, objectified, exploited and stereotyped. The collective effect of these experiences over a life span and across the spectrum of care can make patients delay or avoid care, mistrust care plans, and change providers more frequently, which threatens the continuity of care. As providers work to “be sensitive to the preferences and values of others,” they should also consider that the past healthcare experiences of people in some groups might be tainted by negative cultural competence experiences. The work of providers involves building trust by mending the gaps in trust formed by negative healthcare experiences.
CONCEPTS, IDEAS OR PRACTICES WORTH SHARING WITH YOUR ORGANIZATION AS A PFA

Health care disparities persist, despite the many years of study, bias training and cultural competence training for healthcare professionals. While health care systems and professionals are working to improve cultural competence, at any given moment, these individuals and systems have varying levels of cultural competence, which can affect patient experience. Ongoing development of cultural competence skills is an essential part of improving the quality of patient interactions, which is central to an excellent patient experience and the elimination of disparities.

For patients and families and PFAs, it is important to remember that many professionals and health care systems are still building on cultural competence as an organizational value. The white paper advocates for “improving providers’ communication skills” and “developing skills in interacting and responding to individuals from other cultures.” **PFAs can inquire about their organization’s ongoing efforts to improve cultural competence and eliminate bias.**

Patients and health care leaders need ways to understand providers’ levels of cultural competence and how it affects the health and care of patients. PFAs can **find out how organizations are working to actively re-educate providers** about culturally based myths like the idea that pain tolerance, skin thickness and skin thickness are different based on race, gender and ethnicity. **PFAs can also advocate for systemic ways for patients and families to report and remediate concerns about biases and differential care and treatment.**

**PFAs can share their stories and experiences of bias in health care with providers and leaders.** This goes beyond bias training to a better understanding of the concrete effects on patient health and requires diversity in the PFA groups, which can help providers and systems “increase awareness of personal cultures, values, beliefs.” The disparities illuminated by COVID-19 outcomes should compel a focus and commitment to diversity among PFAs and healthcare providers and leaders, whose perspectives on the patient experience can reveal gaps and needs in communities that at are represented inequitably. **PFAs can work with healthcare leaders to ensure that patient and family groups are representative of patient populations and include the voices of historically underserved patients.**
Those voices should be amplified when disparities are identified, as they disparities are likely to affect their families and communities more acutely.

**PFAs can help families evaluate the components of positive healthcare interactions, including those demonstrated in national measures.** Has the provider taken time to talk with me and make eye contact? Has the provider asked about my challenges and needs? Do I feel like more than a chart number? Do I feel seen and heard? Did the provider explain ideas well and engage me in the conversation? Do I understand what great care should look and feel like? Patient focus and insistence upon receiving excellent care can mitigate provider shortcomings in cultural competence.

**FINAL THOUGHTS**

As organizations and professionals build skills in cultural competence, it is important to remember that we are not there yet. We have many opportunities and avenues to continue this work of ensuring that care is equitable and that systems and providers are culturally competent and responsive. In the meantime, we need to help patients navigate the healthcare system and the biases we still experience within it.

All patients want to be seen, valued and humanized in a way that promotes our health and improves our experience. That is the heart of what cultural competence feels like from a patient perspective. Cultural competence and eliminating disparities are not luxuries; they are, quite literally, matters of life and death. Both are necessary in the plight to improve care for all, and the time to act is now.