

Patient and Care Partner Reflections

PX PAPER

The Impact of Bias on Health Equity and the Human Experience

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 PX 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 Lenses:

CULTURE AND 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 the best possible experience and find comfort and joy in every interaction across the organization.

PATIENT, FAMILY & 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 experiences of patients and families are included in all of the organization's processes and executive leadership strategies, patients and families feel respected and valued as both an integral part of their healthcare team and change-agents for the organization.

ABOUT THE AUTHOR



Jeff Cousins is a family-centered care consultant at AdventHealth for Children in Orlando and the parent of a teenager with special needs. His work includes overseeing the patient and family advisory council and fostering good communication between clinical staff, patients and families. Jeff holds a bachelor's degree in radio and TV communications from the University of Central Florida and spent more than 25 years working in TV news.

Being a caregiver to a special needs child led Jeff to a career transition where he could support the parents of hospitalized children. He began serving on AdventHealth Children's Family Advisory Council in 2010 and was chairman for three years before helping to create a full-time position for a parent representative at the hospital. Since joining the staff, he has worked to improve the daily rounding process, grown the patient and family advisory program to four councils and served in the shared leadership and patient safety and quality committee. He has been a member of the Global Patient Family Advisory Board for The Beryl Institute for two years and was part of a workgroup that authored the family experience guidebook, "We Are Not Visitors: Working Together with Family Caregivers and Care Partners" in 2021.

AUTHOR'S PERSPECTIVE

As a hospital employee, I have tremendous respect for the doctors, nurses and other clinicians who devote their lives to improving the health of children in their care. It's not easy work, and it's not hard to understand why the pandemic has led to rampant burnout in healthcare facilities globally.

As the parent of a medically-complex teenager, I have faced bias in our healthcare experiences more often than I would have imagined. This paper helps us understand the different types of bias a patient or family member might encounter, which can be helpful to both identify and address what we are experiencing in the moment.

The paper educates us on how our brains work in decision-making:

Type 1 processes are fast decisions made without conscious thought. *Type 1 thinking processes have helped humans survive imminent danger by making quick, life-saving decisions. In Type 1 processes, our brains use our past experiences or knowledge to make mental shortcuts. If we see a four-legged orange cat with black stripes, we can quickly decide it's a tiger and understand the danger if it's nearby.*

Differently, Type 2 processes are slower and involve conscious thought. *With Type 2 thinking processes, we analyze the information we see instead of making a swift decision. This is where critical thinking reigns. Understanding how the brain works and how thinking happens is immensely important when we talk about bias in healthcare.*

Due to the pandemic, the level of exhaustion and frustration among the healthcare workforce is at an all-time high. As stated throughout this paper, fatigue can be a fertile environment for bias. For example, "When we (human beings) are overworked and tired, those automatic processes –Type 1 thinking – take over." When people are stressed, they're more likely to use quick and automatic processes to make decisions. This can act as fuel for bias.

When time is invested to understand a patient's background through a dialogue about their insight and feelings about what's happening, they'll provide more clues about how best to approach their care. Further, patients will be more willing to work with their care providers toward the shared goal of whole person health. It's a team effort, and that needs to be the goal.

GENERAL SUMMARY

Bias is a human condition that is subconsciously learned, affecting our thinking processes and decision-making. Type 1 and Type 2 processes are the terms for explicit bias and implicit bias, respectively. **Explicit bias indicates awareness of our thoughts and feelings of others, and implicit bias is defined as an automatic reaction toward other people.**

Marginalized groups are most at risk for inequitable care because of bias. In addition to those who experience bias due to gender, race, sexual orientation and more, the disabled and individuals with a limited English language proficiency often experience bias in their healthcare delivery as well.

The manifestation of bias towards patients shows up in clear and tangible behaviors of providers and care teams, for example:

- Profiling
- Righteous attitude
- Disrespectful behavior
- Dismissal of symptoms
- Withholding options
- Establishing power differential
- Using bias to divert care
- Blaming
- Patronizing
- Racism

Loss of trust is a major consequence of bias. “If a patient feels they have been treated unfairly and senses bias is in play, they will walk out and go elsewhere or stop listening and not follow their treatment plan. This will impact how their overall health and lives will look post-encounter,” The Jewish Board’s Chief Diversity, Equity and Inclusion Officer Maxine Legall said.

As an industry, those in healthcare must recognize and accept that bias exists and can be pervasive. The closer we can move to this realization, the quicker we can act to mitigate and ultimately eliminate it.

KEY POINTS TO CONSIDER AS A PATIENT OR CARE PARTNER

Incidents of bias result in a loss of trust with healthcare providers, and rebuilding it can take time. **Socio-economic status, education level and access to good healthcare are not protective factors against bias.**

The effects of bias are personal, painful and poignant. The range of impact to patients can span from emotional turmoil to physical fatal outcomes. Examples of impact include:

- **Creates doubt:** Bias causes a person to question themselves because they are being questioned.
- **Exacerbates stereotypes and ignorance:** It's not uncommon for insensitive jokes and comments about patients and families to end up in the halls of health care facilities. When these biases are exposed, they can become baked into an organization's culture.
- **Delays diagnosis:** Provider sentiments like, "They probably don't have insurance," or "Let's just wait and see," can hold up diagnosis and treatment.
- **Leads to chronic disease:** When a healthcare system does not give a person the quality of care they deserve, chronic disease can result.
- **Life or death:** Experiencing bias makes people less caring about their health, prevents them from taking proactive measures to be healthy and may cause them to avoid the health system altogether.

Healthcare is fundamentally about human beings caring for human beings, but **bias leaves certain patients feeling less than human, degraded and unheard.**

CONCEPTS, IDEAS OR PRACTICES TO SHARE WITH YOUR ORGANIZATION AS A PFA

Key to health equity is making sure diversity is top of mind when adding new members to the PFA Program or Patient & Family Advisory Council (PFAC)

Hospitals have historically required the recommendation of a staff member for an individual to join a patient advisory group. Beginning the journey toward diversity requires council leadership to take a hard **look at the membership and work to mirror the population served.** Consider multiple factors, including race, income, diagnosis, gender and sexual orientation. Look at the structure of PFAC meetings (time of day, accessibility, etc.) and ask if the structure is inclusive to a wide variety of patients and care partners. If the answer is no, work with healthcare leadership to create a PFAC that enables participation from all the populations served.

As PFAC members, **you have the opportunity to talk to leadership about expanding training and opening dialogue.** If it hasn't been done, members can push for the establishment of a Diversity, Equity and Inclusion office.

Bias may occur in the PFAC meetings themselves, so pay close attention to the dynamics of council meetings. Everyone should feel comfortable to share thoughts and opinions. If some members aren't participating, it's important to find out why, and if anyone displays explicit or implicit bias, share it with your chairman or staff liaison as soon as possible.

FINAL THOUGHTS

While the hope is that we're mostly dealing with implicit bias in healthcare, there may be more explicit bias in our communities. Something must change, and the readers of this paper can be the agents to make it happen.

There is no better time to tackle this head on. The actions already being taken in our healthcare facilities show a desire for change, but often a lack of skills or understanding of bias is a barrier to making the transformation.

Some major healthcare organizations, such as AdventHealth, are bringing administrative and clinical leaders aboard to address bias that impacts health equity in their facilities.

You can also take an important step by visiting [TransformHX.org](https://transformhx.org) and sign the Declaration for Human Experience. Once you have signed, ask those in your PFAC to sign, as well as other leaders and healthcare professionals you know.

With greater understanding about our current healthcare environment and our increased awareness of the impact of bias to the human experience, doing nothing is unacceptable. We can view the words of this paper as seeds or sparks to lead us forward to create "a moral universe that will bend toward justice," as pointed out in a quote by Martin Luther King, Jr.

Be hopeful and be part of eliminating bias. Take a hard look at yourself and decide what can be done in your life and in your organization to move forward. Organizations that have focused on eliminating bias have seen improved ratings of care and higher scores for overall experience and likelihood to recommend. Improving health equity will help us regain trust in the healthcare system. Through deepened relationships with our providers and care teams, we can hope to experience that sense of belonging, partnership and loyalty we all desire.