

Patient and Care Partner Reflections

WHITE PAPER

Interconnected: An Exploration of Improvement Efforts Connecting Patient Experience and Communication

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

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I have been working in healthcare throughout my career, in various roles from communications to fundraising and patient experience in hospitals and healthcare charities, but I never really travelled to the heart of healthcare until 2017.

My world changed when I was diagnosed with breast cancer. It was devastating news. I underwent a mastectomy and chemotherapy. Overnight, I went from being a confident healthcare navigator for the family to becoming a cancer patient. Despite my familiarity with healthcare, I was as fearful and worried as any patient. It was from this brush with mortality that I have learnt how different the patient perspective can be from the healthcare professional's.

Through my experience of breast cancer, I looked for meaning and purpose. That was when I became a patient advisor to improve patient experience. Today, I serve as Co-Chair of the SingHealth Patient Advocacy Network (SPAN), a Patient and Family Advisory Council (PFAC) in Singapore's largest healthcare group. In this capacity, I have spearheaded initiatives to bring plain language and compassionate care to healthcare and developed training for patient advisors. I am also a member of The Beryl Institute's Global Patient and Family Advisory Board, and I volunteer in palliative care charities and is a Board Member for Ambulance Wish Singapore, a charity for fulfilling last wishes for terminally ill patients. Today, I am grateful that I get to combine my professional and volunteer work. I am a communications consultant and adult educator in healthcare communications, patient experience, and corporate communications. I am also a Certified Patient Experience Professional (CPXP).

AUTHOR'S PERSPECTIVE

I have been on both ends of the spectrum, working in communications in a hospital and as a trainer for healthcare organisations – and now as a patient receiving care.

Clear and empathetic communication is desired by both patients and health care professionals alike, yet it seems elusive. Whether you are in the U.S., in Singapore, or anywhere in the world, effective communication is integral to a positive patient experience. What resonates strongly with me is that the heart of healthcare is about

human beings caring for human beings. So why is this goal of effective communication elusive?

GENERAL SUMMARY

This White Paper presents responses from 112 respondents in U.S. healthcare organisations. It shares the challenges faced by these organisations in healthcare communications, the perceived barriers to effective communication for clinicians, the impact of cultural diversity and the recommended solution.

As patients, we share our care experience with each other, and communication with healthcare teams – both good and bad – will come up invariably. Patients and families who receive the brunt of poor communication often wonder why it is so hard to get it right, while those who have good experiences may express gratitude for their “good luck” to have a doctor or nurse with “good bedside manner” attend to them. This paper brings to the fore that healthcare communication, good or bad, is not a matter of luck. It sheds light on issues and challenges faced by healthcare providers to bring effective and compassionate communication to their organization.

Key Points to Consider as a Patient or Family Caregiver

Patients and families need to be familiar with these issues that are being grappled with. It is through understanding that we can move the needle and be partners in the conversation to co-design and co-produce solutions that improve communications between us and our healthcare teams.

Having understood the issues faced by healthcare organisations to improve communication in patient experience, what can we do as a patient or family caregiver beyond giving feedback about our experiences? Undoubtedly, several of the challenges faced by healthcare organisations and clinicians are systemic, due to workload and processes. Equally important is each clinician’s skills, knowledge and mindset towards effective and compassionate communication skills.

It may appear that the ball to improve communications is in the court of the healthcare providers, but this is not entirely true, simply because communication is two-directional. If we desire empathetic communication from our healthcare providers, we can start by showing them kindness and empathy, thereby opening the path for them to share empathy with us. This can help clinicians who are facing burnout to feel connected and appreciated. This perhaps is the first step for some to change the mindset. By doing so

consistently, we as patients and families help to plant the seeds for a patient experience that is empathetic and where dignity and respect are conveyed.

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

To be part of the solution to improve communications, Patient Family Advisors (PFA) need to first understand the challenges faced by healthcare organisations and clinicians, which are shared in this paper. Then, we can contribute to co-designing and co-producing the solution.

Here are some suggestions on what you can do as a Patient Family Advisor.

- Share stories with actionable feedback on the impact of communications on your care in internal and external platforms in your organization.
- Help explain, in organizational workgroups and meetings, how effective communication by clinicians affects your care outcome, your safety and your psycho-social well-being.
- Be involved in Communications Training for Clinicians – from design to sharing impactful stories.
- Be involved in helping the organization drive staff resilience and staff appreciation programmes. Empathy starts with us as; an appreciated and happy clinician can lead to effective and compassionate communication.
- Help the organization review and develop patient education materials that are easy to understand and focus on what matters to patients and families.

FINAL THOUGHTS

Perhaps it is time to see clear and empathetic communication as part of a patient's therapeutic treatment, and not as a "nice to have". Time and again, from numerous patient stories and research on compassionate care, it has been clearly demonstrated that patients who receive clear and empathetic communication from their healthcare teams do better. I am grateful that my healthcare team is compassionate and caring, and this has helped me immensely towards my recovery. What I hope for is that receiving clear and empathetic communication from your clinicians will become a "given" rather than a matter of chance. This communication chasm can and should be bridged. It requires all stakeholders, be they patients, families, clinicians, or hospital administrators, to tend to it sensitively and decisively with commitment, compassion and leadership.