

Patient and Care Partner Reflections

WHITE PAPER

The Role of Family Caregivers Throughout the Patient 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 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.



ABOUT THE AUTHOR: Tony Serge



I was a caregiver to my wife for ten years, during which time I also became a patient. Through these experiences, I was personally inspired by the importance of a positive patient, caregiver and family experience and its impact. In my desire to give back, I became a passionate Patient Experience Advisor. I served for three years as a Co-Chair on the Dana Farber Adult Patient and Family Advisor Council. I am now a member of The Beryl Institute's Global Patient and Family Advisory Board and

Patient Experience Policy Forum. My role as a Caregiver has also led me to participate in various Caregiving events. Blending these experiences with my extensive career as a senior level executive, I have enjoyed presenting at Patient and Family Centered Care Conferences, fund raisers and training events.

AUTHOR PERSPECTIVE

This white paper was of special interest to me because, as a former family caregiver, I was drawn to the key insights regarding the real "lived experiences" of a caregiver. It focused on the many challenges and tasks that the family caregiver encounters as they perform their critical role. I encourage family caregivers and PFAs to read this white paper so that they may hear from these caregivers featured in the white paper about their experiences. If healthcare organizations correctly define, address and implement the key points and concerns they talk about, then the "Impact" statement in the Experience Framework (seen on page 1) can be achieved.

GENERAL SUMMARY

At the time of writing of this white paper, there were more than 43 million family caregivers in the United States, however, they have been greatly overlooked in the healthcare system. So, how can family caregivers and PFAs change that? From my personal lived experience, it can start by having a discussion with providers and within healthcare organizations on some of the following points:

- The role family caregivers play in the continuum of care
- The role family caregivers have as part of the Care Team
- The major challenges, important tasks, concerns and issues family caregivers face in caring for the patient.

This white paper, which was written in collaboration with The Beryl Institute and the Caregiver Action Network, addresses these points through the interviewing of seven caregivers who were asked to respond to seven key questions. Their responses offered a thoughtful discussion about their true caregiving 'lived experiences'. It is a very personal and real-life insight into their experiences, concerns and needs. It

clearly exhibited that the role of a caregiver is probably one of the most critical roles in the continuum of care for the patient.

KEY POINTS TO CONSIDER AS A PATIENT OR FAMILY CAREGIVER

The seven questions that these caregivers were asked include:

1. What do you consider your greatest challenge as a caregiver?
2. What is the most important task or role you fulfil as a Caregiver?
3. What advice would you give to someone who is new to caregiving?
4. What is/was your role when your loved one is in the hospital?
5. When you are/were at the hospital with your loved one, do you feel that hospital personnel respect and value your role as a caregiver?
6. Are there times when you would have had a different opinion from you loved one about the quality of care they were receiving in the hospital?
7. What did you fear would happen if you were not there with your loved one during their hospital stay?

As a family caregiver, do you recognize or relate to any of these questions? If so, consider adopting these questions a conversation guide when meeting with and discussing the care of your loved one with their clinicians. Here are some examples for how to utilize these questions to improve care for your loved and get more of the support you need:

What do you consider your greatest challenge as a caregiver (question 1 above)?

- Getting the right information, keeping it organized and coordinating care: As one caregiver said, "Being able to figure out what information you actually need can be challenging..."

Caregivers can be proactive in asking questions and details on caring for the patient. Develop a simple system that helps you organize and easily reference to coordinate care.

What advice would you give to someone who is new to caregiving (question 3 above)?

- Caring for themselves and watching they do not burn out. One caregiver expressed "Everybody knows you've got to take care of yourself, but there aren't any caregivers that know how to do that. They are knee deep into it"

Caregivers can develop a plan for caring for themselves and then reach out for help to implement the plan. Be sensitive to not burning out.

What is/was your role when your loved one is in the hospital (question 4 above)?

- Being the voice of their loved ones... One caregiver said "You are there to speak for them. You are there to be their representative because their job is to get well. So, my job is to speak up for him..."

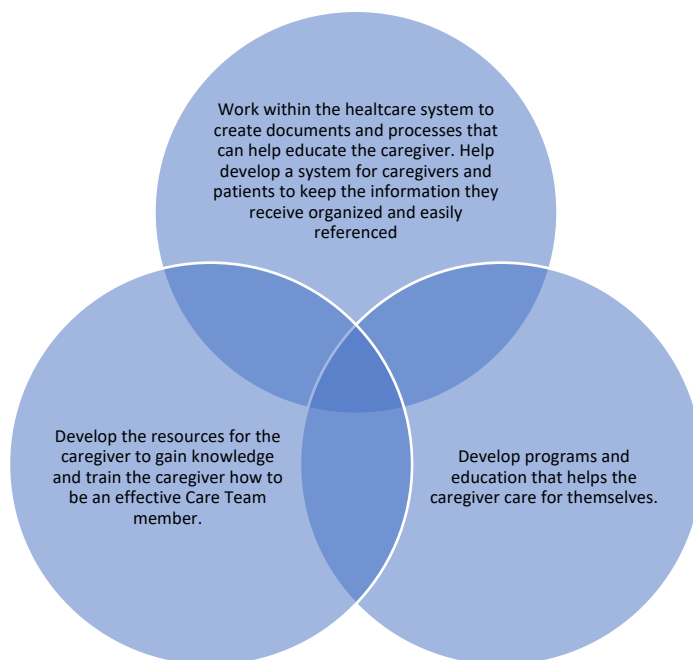
Caregivers can proactively engage with the Care Team to understand and establish your role on the Care Team. Become a knowledgeable Caregiver and contributor on the Care Team.

Finally, this one is very relevant during time of COVID-19. What did you fear would happen if you were not there with your loved one during their hospital stay (question 7 above)?

➤ Fear of bad care... As one caregiver said "I feared that they would get bad care" Caregivers can proactively discuss concerns about the care when you are not there. Setup ways to address these such as pro-active communication.

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

From my personal lived experience and the concerns named in this white paper, below are my reflections on how a PFA can promote solutions to these (and other) items that are of concern to caregivers:



Please also refer to the Conclusion section of the whitepaper. Here there are recommended key elements common in many of the best caregiving practices.

FINAL THOUGHTS

I strongly believe that this is an especially important paper for all family caregivers to read and then proactively engage with their healthcare organization to address their needs. Accomplishing this can lead to becoming an effective member of the Care Team. This true partnership on the Care Team is an important step in the continuum of care for the patient.

As a PFA, it is particularly important that you understand the role of the family caregiver, their issues, and concerns and they how they fit into the Care Team. As their advocate and voice, you play a vital role in influencing the healthcare organization to change processes and strategies on behalf of the family caregiver and the patient.

In summary, maybe by considering these reflections the caregiver can become a true partner on the Care Team and the PFA can effectively represent these Caregivers as their advocate within the healthcare organization. When this is achieved then "The Impact" statement in The Beryl Institute's Experience Framework of "Patient, Family & Community Engagement", can possibly be realized.