Human Stories: COVID Lessons on the Importance of Family Presence

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Early in the pandemic there was complexity and ambiguity across our nation's hospitals about COVID transmission and how to keep our healthcare teams safe. This was compounded by PPE (personal protective equipment) guideline confusion and shortages such as masks, gowns, and goggles. The response to this was the elimination of family presence in hospitals. Luminis Health Anne Arundel Medical Center, which has embraced full 24-7 access for patients' families since 2010, found the COVID-19-related visitor restrictions to be disruptive and harmful. In collaboration with the Institute for Patient- and Family-Centered Care (IPFCC), we adopted processes to facilitate the integration of patient, family, and community partners in the planning and decision making to reaffirm and reestablish a patient's family as partners, not visitors.

Building on a long history and culture of caring, in 2010 we formally oriented our practice to patient- and family-centered care models. Patient- and family-centered core concepts include respect and dignity, information sharing, participation, and collaboration.[1] Our hospital was an early leader in the Better Together: Partnering with Families program.[2]

The 2010 work began with patient and family advisors (PFAs), initiation of a patient family advisory council (PFAC), and elimination of visiting restrictions. The goal of patient and family advisors is to systematically engage with leaders and staff and hold a mirror to your organization. This work expanded to specialty patient family advisory councils (PFACs) with focus in women and children, behavioral health, emergency care, cancer care, and partnership with our Latinx community. At times, our work has been driven through appreciative inquiry and building on what is working well. Other work has been driven from a problem orientation and seeking to address concerns.

This partnership and family presence is shown to improve many aspects of care experience, safety, and quality.[3] The key practice is recognizing family members as partners, rather than visitors or external members in care. Lack of family presence contributes to patient and family harm and caregiver distress. Family presence is linked to reduced falls, infections, readmissions, excess utilization, care inequities, and caregiver distress, and improved patient experience and access. Improvements in these constructs align with the seminal STEEEP definition of quality: safe, timely, effective, efficient, equitable, and patient-centered.[4]

With this more than 10-year journey and noted benefits, the abrupt and volatile COVID-19-driven changes in family presence were deeply felt in our hospital.[5] Research studies have demonstrated the impact of these policies on rates of delirium and sedation, ICU length of stay, falls, and psychological trauma and moral distress.[6] We determined the need for a systematic approach to welcome families back to the hospital. Our approach was grounded in PFCC principles and a bioethical decision-making model.[7] The team was led by the hospital President and comprised of direct care providers and community members. Lessons learned included recommitment to family presence as evidence-based and inherent to our values and culture; a renewed understanding of the harm to patients, families, and care teams with limited family presence; and the need for a systematic and sustainable approach to drive family presence improvements. We continue to apply the systematic framework we developed to advance our family presence practices.

Key Board Takeaways

- Patient- and family-centered care (PFCC) improves quality and health system financial outcomes. Family presence thrives within a PFCC infrastructure supported by PFAs (patient family advisors), PFACs (patient family advisory councils), executive leadership, medical staff, and the board.
- COVID-19 resulted in a major disruption to family presence due to healthcare team workload, infection transmission concerns, and personal protective equipment availability.
- The absence of family presence during the pandemic highlighted its importance and harm to patients, families, and the healthcare team.
- Family presence can be systematically returned to pre-pandemic practices.
- Board members can strategically drive PFCC practices in the same fashion they drive other improvements: understand results, variances, and action plans, and hold management accountable for improvement.

"Nothing about Me without Me"

The key difference in patient- and family-centered care models is that care is organized through the principles of respect and dignity, information sharing, participation, and collaboration. This partnership yields work focused on "nothing about me without me" and caring "with" and not simply "for or to."[8] Care practices include open family presence or visiting hours, bedside shift reports, and access to electronic medical records.

More importantly, this model is supported by a foundation that begins with governance practices at the board level that drive leadership structures and processes. The PFACs advise the board and senior leaders on how to make improvements to the model. PFAs have

1 Institute for Patient- and Family-Centered Care (IPFCC), "Patient- and Family-Centered Care Defined" (Web page).
2 Learn more about this IPFCC program at www.ipfcc.org/bestpractices/better-together.html.
3 Daniela J. Lamas, "Families Are Central to Critical Care. But the Waiting Room Is Empty," *The New York Times,* August 17, 2020.
4 Institute of Medicine, *Crossing the Quality Chasm: A New Health System for the 21st Century,* National Academies Press, 2001.
5 Sherry B. Perkins, Ph.D., RN, FAAN, et al., "Family Presence During COVID-19: Learning from One Hospital's Journey," *NEJM Catalyst,* June 22, 2022.
6 See e.g., T.S. Valley, et al., "Changes to Visitation Policies and Communication Practices in Michigan ICUs during the COVID-19 Pandemic," *American Journal of Respiratory and Critical Care Medicine,* Vol. 202 (2020); pp. 883–885; T.K. Gandhi, "Don't Go to the Hospital Alone: Ensuring Safe, Highly Reliable Patient Visitation," *The Joint Commission Journal on Quality and Patient Safety,* Vol. 48 (2022); pp. 61–64.
7 Deborah L. Dokken, M.P.A., et al., *Family Presence During a Pandemic: Guidance for Decision-Making,* Institute for Patient- and Family-Centered Care, 2021.
8 Michael J. Barry and Susan Edgman-Levitan, "Shared Decision Making—The Pinnacle of Patient-Centered Care," *The New England Journal of Medicine,* 2012.

essential roles in work such as medical and nursing staff peer review, root-cause analyses, daily safety huddles, COVID-19 incident command structure, quality councils and board committees, approaches to reducing workplace violence and injury, executive job interviews, review of Web design and educational materials, hospital bill readability and transparency, patient education material, marketing and Web site content, well-being strategies, and wayfinding content and placement.

The posture expected by executives, medical staff leaders, and board members is a commitment to PFCC principles and ensuring accountability of operational leaders to implement practices and achieve results. Fundamental for me as CNO, COO, and now President has been the knowledge that I do not have to "guess" about the support of leadership as we have enacted changes. Essential to this work is connectivity of PFAs with board members. Our governance structure ensures expectations for PFCC and reporting by PFAs as members at our senior-most governance quality committee.

Luminis Health Anne Arundel Medical Center is a 120-year-old, 453-bed regional health system in Annapolis, Maryland and a Magnet-designated teaching hospital known for excellent care in surgery, obstetrics, orthopedics, oncology, and behavioral health, with one of the busiest emergency departments in the nation.

Aligning Our Journey with DE&I

We strive to lead on topics of anti-racism and demonstrate our commitment to diversity, equity, inclusion, and justice.[9] Our Latinx PFAC arose early in the pandemic from a community concern with family access and language barriers during the most limiting phase of family presence. When family members are present, even with a language barrier, rapport is built, care is witnessed, and trust and partnership grows. This same opportunity doesn't exist without family presence. We acknowledged this gap for family presence and the potential for disparate processes. The yield was strong with a multi-pronged effort driven through our Latinx PFAC; changes included improved interpretation, signage, care planning participation, and financial counseling.

Early in the pandemic when family presence was removed, there was an appreciated ability to "just focus on the patient" in the midst of such uncertainty. This, however, was soon followed by recognition of the clinical harms and caregiver distress generated by lack of family presence. A continued focus has been on team well-being and infection prevention, but with additional focus on support informed by trauma-informed leadership principles.[10]

Community Impact

This PFCC journey and our COVID response has resulted in the engagement of community members beyond patients and families, to the benefit of our organization, patients, families, and communities. In our most poignant example, a long-time community leader, the senior pastor in a church with majority African American membership, became a key partner in our COVID-19 response. She is very engaged in our community and serves as a trusted advisor. She was an early voice for COVID-19 vaccination and we recruited her to be part of our recommitment to family presence. She was instrumental in eliciting parishioner input and raising awareness on potential racial disparities related to family presence. She later became a board member. She describes her critical functions as being where the people are, listening to community members and connecting with management, and acknowledgement of the contribution of "outsideness" she brings with her perspective.

This example and the family presence work we are doing demonstrate the importance of developing human understanding, which is achieved when the organization has gained the ability to treat every patient as an individual. The more work we do in this area, the better healthcare leaders will be able to connect this work with higher-quality care and improved outcomes.

Why Do This? The Business Case

Board members have a responsibility to ensure that the organization's mission, vision, and values are enacted and fulfilled. In doing this, they govern performance and hold leaders accountable to many dimensions. PFCC is as essential as financial stewardship. There is a financial business case demonstrated through organizations such as ours that have strong market position with consumers, medical staff, and employees. This position comes, in part, due to sustained excellent results in quality, patient experience, and workplace environment.

Starting the conversation in the boardroom is the most important first step. Board members need to ask:

- How does a governance decision align with mission, vision, and values?
- What are the links between PFCC practices and financial performance? What can we learn from multi-dimensional indicators such as HCAHPS scores, falls, infections, patient complaints, indicators of disparities, pay-for-performance results, market share, retention of medical staff, executive recruitment, and turnover?
- How might a strategic board conversation be different if a patient or family member was in the room?
- What is the nature of patient family advisors and patient and family advisory council structure?
- What is the digital accessibility for participation in advisors work and PFACs? What is the diversity of participation and leadership in PFACs?
- How are C-suite and medical staff leaders engaged in PFAC work and systematically prioritizing, resourcing, and implementing evidence-based practices?
- In addition to the positive feedback, engagement, and insight that comes from PFAs, what are the challenges and problems the PFACs are addressing (e.g., complexity and harm noted in response to the pandemic or barriers contributing to disparities)?
- How are we individualizing care through principles of respect and dignity, information sharing, participation, and collaboration? How are frameworks such as the 4-Ms (what Matters, Medication, Mentation, and Mobility) driving to "what matters" for individualizing care?[11]

The Governance Institute thanks Sherry B. Perkins, Ph.D., RN, FAAN, President, Luminis Health Anne Arundel Medical Center, for contributing this article. She can be reached at sperkins2@luminishealth.org.

9 "Luminis Health Board of Trustees Approves and Adopts 10 Bold Health Equity, Anti-Racism Recommendations," *The Beacon,* Luminis Health, October 4, 2021.
10 Rose O. Sherman, "Using a Trauma-Informed Leadership Approach," *Nurse Leader*, June 2021; Mary Koloroutis and Michele Pole, "Trauma-Informed Leadership and Posttraumatic Growth," *Nursing Management*, December 2021.
11 Kedar Mate, et al., "Evidence for the 4Ms: Interactions and Outcomes across the Care Continuum," *Journal of Aging and Health*, February 8, 2021.