

Patient and Family Roles in Safety

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Moving From Engagement to Partnership

Involving patients and families in healthcare decisions about patient care and in hospital and health system policy and programs results in better health outcomes, higher quality of care, lower health system costs, and improved patient safety.¹ This partnering of patients and families with healthcare professionals is often called “patient and family engagement,” although this term does not have a standard definition and may not describe the best practices for achieving partnership. [An environmental scan](#) conducted by the Agency for Healthcare Research and Quality (AHRQ) notes that clinicians and researchers tend to view “patient and family engagement” as activities that they want patients and families to engage in, whereas patients and families tend to view engagement as building on their current activities in health.² Changing the language may help lead to mutually beneficial partnerships among patients, families, and clinicians. Patient safety experts have made the point that patients and families should be regarded as “essential and respected partners in [patient] care and in the design and execution of all aspects of healthcare.”²

To define the [roles of patients and families in safety](#), the Canadian Patient Safety Institute convened patients, families, and providers; during this meeting they proposed that patient safety is not restricted to the absence of medical harm but rather is definable as the presence of collaborative communication and involvement. This thinking aligns with the [resilient healthcare and the Safety-II framework](#), which seeks to define safety by understanding successes rather than failures of care.

Impact of Families on Safe Patient Care

As essential members of the care team, families play a critical role in reducing harm and improving safety for patients. [AHRQ's “Guide to Patient and Family Engagement in Hospital Quality and Safety”](#) reviews evidence that shows that partnering with families and patients results in better patient outcomes, especially on emotional health, symptom resolution, and pain, as well as blood pressure and blood glucose levels. The guide emphasizes two care processes in particular when families can impact safety—nurse bedside shift report and planning for care transitions from hospital to home. Conducting nurse change of shift at the patient’s bedside with families creates an opportunity for bidirectional exchange of information. It is an opportunity to build on the family’s understanding of what occurred during the last shift and of the plan for

the next steps in care. In addition, families can have observations about the patient that are important to care and safety and benefit staff and clinicians. Families can then work collaboratively with nurses to ensure the plan of care is followed.

Evidence reviewed by the guide's authors shows that including patients and families during care transitions reduces harms such as falls and helps catch serious near-misses such as errors in blood compatibility. Partnering with families during the planning for the transition from hospital to home is associated with increased safety, as well as lower health system costs through fewer hospital readmissions. Among the many important safety benefits of family presence is sharing of vital information that, because of illness, patients may be unable to provide.³

As a reflection of the growing awareness of the importance of family in care transitions, more than 42 states have passed the [Caregiver Advise, Record, Enable \(CARE\) Act](#) to assist family caregivers as their loved ones go into the hospital and as they transition home. With the CARE Act, patients are asked to provide a family member or other care partner name for listing in the medical record so that they can receive education and instruction for ongoing care and the transition to home. In 2021, Healthcare Excellence Canada (HEC) merged with the Canadian Patient Safety Institute. During the pandemic, HEC built on its efforts that began with the Institute for Patient- and Family- Centered Care's (IPFCC) [Better Together: Partnering with Families](#) campaign and developed a more comprehensive definition for the roles of patients partners.

Family Presence and Participation During the COVID-19 Pandemic

Most hospitals and health systems responded to the COVID-19 pandemic by establishing rules that reverted to calling care partners "visitors" and restricted family presence. These restrictions were intended to decrease COVID-19 transmission but meant that families could not be at the bedside and were no longer present for nurse shift changes and for planning the transition to home. Patient safety expert Tejal K. Gandhi, noted that these restrictions went against established advice from safety experts; commenting on those restrictions, Gandhi stated that "family members provide an important safety net for patients in the hospital and across the entire continuum of care."⁴

The emotional toll of the loss of family presence was rapidly apparent.⁵ Given the unique role of families in pediatric and neonatal care, and in the care of older adults, the effect of limiting family presence in these environments was noted and commented on in the literature relatively early in the pandemic. In the neonatal context, the importance of parental interaction with neonates is well established for reducing the infant's stress and for establishing bonds.⁶ [Negative effects on older adults from the restriction](#) of family presence in nursing homes and long-term care communities were observed, especially increases in depression and anxiety. Unplanned weight loss, increased incontinence and decreased cognitive function has also been reported with restricted family presence due to COVID-19.⁷ More broadly, an integrative review across patient populations of all ages and care settings found that patient stress, including loneliness and depressive symptoms, was higher during these restrictions and that anxiety and less access to information was reported by families.⁸ In fact, long-standing [evidence](#) suggests that isolation and reductions in family presence increase patient stress and family anxiety, so it is likely that pandemic

restrictions, which have shown variable efficacy in reducing the spread of respiratory illness, are associated with worse outcomes in terms of patient and family well-being. The severe restrictions of family presence and participation had a significant impact on clinicians and staff. For instance, commenting on the impact of the lack of family presence, one physician stated, “It was just so hard to be the kind of physician you wanted to be. And I felt so bad for all of our patients...you know, it was an awful time.”⁹ Given a strong commitment to family partnership and the recognition that families are often holders of vital information, clinicians and staff at many hospitals found creative ways to involve families successfully despite the challenges of the pandemic.³ In recognizing the challenges presented by restricting family presence, IPFCC convened residents and families to identify research topics and a guide to better engage long term care patients and families in future research.¹⁰

Partnerships at the Organization Level

[AHRQ’s “Guide to Patient and Family Engagement in Hospital Quality and Safety”](#) states that “working with patients and families as advisors at the organizational level is a critical part of patient and family engagement and patient- and family-centered approaches to improving quality and safety. Patient and family advisors are valuable partners in efforts to reduce medical errors and improve the safety and quality of healthcare.” The guide has practical tools for developing and sustaining patient and family advisory councils (PFACs). As PFACs have been implemented in hospitals and health systems, evidence shows their impact on safety. [High-performing PFACs](#) are associated with lower rates of 30-day hospital readmissions and better patient experience scores, as well as better outcomes on quality measures in general.^{11,12} The pandemic caused disruption in the functioning of PFACs in some hospitals; however, many hospital staff quickly adapted to virtual methods for work and meetings.¹³ Virtual adaptations were well received, and in some cases virtual options made it easier for PFAC members to participate (for example, they decreased travel time or decreased the need for childcare). Some people found it easier to share their feelings and participate in virtual meetings versus in the hospital setting. Hospitals that continued to engage with patient and family advisors (PFAs) improved safety by cultivating a better understanding of the patient and family experience of the COVID-19 pandemic, including gaps and unmet needs. This partnership and exchange of information was critical during a time when hospitals needed to adapt quickly to changing conditions.

Although pandemic-related virtual adaptations had much unanticipated benefit, families reported that the informal interactions and conversations that take place during in-person meetings are also important.¹³ PFAC hybrid models that include both in-person and virtual meetings may be a next step for PFACs and hospitals to explore. Approaches to PFACs that more fully utilize patient and family partners may help health systems achieve further quality improvements. A recent Cochrane Systematic review found that power imbalances between healthcare providers and patients or families can limit participation in formal partnerships to improve care quality and safety.¹⁴ Leveling the playing field via a virtual platform may have minimized the power imbalances that families felt when engaging in dialogue with providers who were on their “home turf” during conversations in the hospital setting, enabling greater participation in meetings by families. The review notes that addressing these power imbalances is an important path forward for truly successful partnerships with families. A hybrid approach that leverages the benefits and increased participation of virtual meetings while maintaining the advantages of in-person interactions may hold

promise. That PFAs can serve a critical role during an emergency as a conduit of information between hospitals, patients, families, and communities is one lesson learned during the pandemic that hospitals should carry forward.¹³ Furthermore, engaging PFAs in future pandemic planning efforts could help hospitals to adapt quickly to the changing conditions of this type of crisis.

As hospitals gain experience in collaborating with advisors, a potential next step is to engage patient and family advisors as members of hospital committees, even board-level committees. The AHRQ guide offers practical advice for selecting and supporting PFAs to serve on hospital quality and safety committees. To avoid tokenism in working together, it is important to always appoint more than one PFA to these interdisciplinary committees. PFA insights and perspectives can be very beneficial to these working committees, and with the experience of the pandemic, PFAs can be full members with either in-person or virtual attendance. It is important to determine the readiness of quality and safety committees to partner effectively with PFAs before moving forward with collaborative work. Everyone, hospital leaders, clinicians, staff, and PFAs, need orientation and support to work together effectively.

Future Directions and Research

Based on strong evidence of the benefits of family presence for safety and well-being, the Institute for Patient- and Family-Centered Care (IPFCC) created a guide titled “Family Presence During the Pandemic: Guidance for Decision Making.” The guide encourages collaboration among an interdisciplinary team and patient and family advisors to carefully consider any changes, adjustments, or restrictions to family presence in the healthcare settings during a pandemic.¹⁵ IPFCC suggests using an iterative process for assessing and making changes in practices or policies about family presence that seeks to balance relative harms and risks. The IPFCC guide includes helpful tools based on the core principles of dignity, respect, information sharing, participation, and collaboration, which hospitals can use to engage in planning for safe family presence in healthcare settings.

With support from PCORI, [IPFCC recently partnered with key stakeholders](#) in developing topics and themes for future research related to family presence and the impact on social isolation and loneliness in hospitals and long-term care communities. These efforts are meant to inform future decision-making on how best to respond to pandemics while maintaining the safety benefits of partnership with patients and families. Further research may describe how better family and patient partnership will impact the negative outcomes of loneliness, which appear prevalent, as noted in the 2023 Surgeon General’s report.¹⁶ As the impact of loneliness on individual health outcomes becomes better understood, additional benefits of family partnership may be identified.

Restrictions of family presence during the pandemic raised the issue of how essential families’ participation is to safety and well-being. Evidence suggests that family involvement in care can critically improve outcomes, cost, and perceptions of healthcare quality. Improvements can be pursued, to some extent in novel ways, through innovations in the use of technology. A recommitment to patient and family partnership is needed, as care innovations pioneered during the pandemic find their way to broader use, and as we work toward better preparation for future pandemics and health emergencies.

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