

In Conversation with... Beverley H. Johnson about The Role of Patient's Family In Reducing Harm

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Editor's note: Beverley H. Johnson is the president and CEO of the Institute for Patient- and Family-Centered Care (IPFCC). We spoke to her about her experience in [patient and family engagement](#) and improving patient safety, including how to continue to partner with families during pandemics and through technology.

Sarah Mossburg: Welcome. Can you please tell us a little bit about yourself and your current role?

Bev Johnson: Sure, I'm Bev Johnson. I'm president and CEO of the Institute for Patient- and Family-Centered Care (IPFCC). My work, beliefs, and commitment have been shaped by early life experiences. I had polio as a child at the very end of that epidemic, and to this day I have vivid memories of my mom sitting by my side in isolation for almost 10 days with full PPE (personal protective equipment). Of course, we called PPE masks and gowns then. My mom was taught how to safely stay with me in the hospital during that infectious disease epidemic. Fast forward after college, I returned as a nurse and worked at the very same hospital with the same nurse who had cared for me as a child. I worked at that hospital in a variety of clinical teaching and leadership roles for over 10 years, eventually serving as a member of their board of trustees and chair of strategic planning.

It was families who were my teachers at a critical point in my career. I had my first federal grant to develop a guidance publication on caring for children with chronic illness in the community. I gathered families together who were caring for children with a variety of conditions, such as cancer, spina bifida, sickle cell disease, asthma, and cerebral palsy. Just bringing them together then was unusual. I got to see firsthand the power of peer support. But more importantly, as I went into that meeting, I thought I was the expert in the room. I quickly learned that families were the experts. They had expertise and experience that I did not, and they had strengths and capabilities that I had not recognized. That meeting in the basement of the hospital has profoundly shaped my views about healthcare and about patient safety. We need to recognize, respect, and build on the strengths of both patients and families in everything we do.

Sarah Mossburg: What a powerful experience! Thank you so much for sharing that with us. It sounds like that really drove your work with family engagement moving forward. Is that right?

Bev Johnson: Right. I don't usually talk about it as family engagement. I prefer to use the words "partnership" and "collaboration" because they so clearly emphasize that you are working with patients and families, not doing something to or for them. The field has used the term engagement extensively. Collaboration, partnership, engagement—those terms are integrated into everything IPFCC does. But I want to make sure that people understand it's that back and forth. It is through partnership with patients and families that we will achieve the best outcomes and the safest care.

Language and the choice of words have been very important to the evolution of the patient- and family-centered care. We often discover a word or a phrase that conveys a disrespectful or disempowering message. We then realize we shouldn't have said it that way. It is humbling in that regard. But we can change and improve.

Sarah Mossburg: Thank you for sharing that reminder about the importance of language as framing for the way we think about something. I agree with you that this is a partnership with patients and family, and using that language to make it collaborative, centering family and patients, and adjusting the medical model that we've used in the past is important. Can you tell us a little bit about IPFCC and its purpose?

Bev Johnson: IPFCC is celebrating its 30th anniversary this year. We were founded in the spring of 1992. The Institute built on work that I had been leading, related to advancing the practice of family-centered care for children with special healthcare needs, and then later, with women and families affected by the HIV/AIDS epidemic. We worked closely with C. Everett Koop in those years when he was U.S. Surgeon General to develop a standard of care in pediatrics. I always wanted it to be the standard of care for all ages of patients and families. An opportunity arose in the spring of 1992 to make this change. I gathered a group of patients, families, clinicians, leaders, and researchers together, 40 to 45 people. I asked, "is the momentum so great now that family-centered care will just happen, and we can go away, or is there a need for an organization to be the thought leader for extending family-centered care and spreading it across all ages and in all settings where people receive care and support?" The group told us we need to broaden the focus and continue the work.

So that's when the organization was founded. The four core concepts of patient- and family-centered care that guide our work are grounded in mutually beneficial partnerships—respect and dignity; information sharing; participation in care, care planning, and decision making; and collaboration at all levels of care, not just in direct clinical care. Those four core concepts are very important to patient safety. Each one has meaning for how to provide safe healthcare to a very diverse population.

Sarah Mossburg: I agree, thank you. Who are some of the key partners that IPFCC works with?

Bev Johnson: We have been so fortunate over the years. I think what I value most is the relationships we have with people, with foundations, with health systems, and with agencies. Early on it was the American Academy of Pediatrics, later the American College of Physicians and the American Hospital Association (AHA). I serve on AHA's Quest for Quality Prize Committee, which recognizes the integration of patient- and family-centered concepts with best practice in safety, quality improvement, and more recently with

health equity. Another partner is the Vermont Oxford Network (VON), an organization that partners with families in improving newborn intensive care. VON is an excellent example for how to integrate family partnerships within an organization to improve the quality and safety of care.

There are so many more partners. I think of many federal agencies as partners; we've helped with their mission, and they've certainly helped with ours. In the early days, it was the Health Resources and Services Administration and the Maternal Child Health Bureau who were the real pioneers along with Substance Abuse and Mental Health Services Administration. They understood the importance of partnerships with families for children's health, mental health, and the outcomes, particularly with a focus on children with special health needs.

They were wonderful partners, and they did something that I wish all agencies would do today. They not only funded our work, but they funded their other grantees to learn how to partner with patients and families. They created the expectation that in order to receive a grant, you had to partner with families throughout the project. They not only created the expectation for partnership, they also provided support, technical assistance, and guidance along with best practices, so that grantees could partner in authentic, substantive ways with families. I think this support was critically important to the successes. The Patient-Centered Outcomes Research Institute is another organization that has advanced this agenda. They have changed the conversation in the research community, supporting people to learn how to partner in research planning and to partner with them meaningfully in research.

And last, AHRQ, with its commitment to patient safety, has always conveyed a deep understanding of the essential partnerships with patients and families. IPFCC was pleased to collaborate with the American Institutes for Research® on a series of publications with AHRQ funding. Their team developed guidance documents on partnership and collaboration in hospital safety and quality. One aspect of the work that I thought was particularly important was that AHRQ captured the best practices for how to develop authentic partnerships with families and sustain them. In this AHRQ resource, there is a section on leadership. The leadership of organizations—hospitals, health systems, long-term care communities, ambulatory practices— need to understand and buy into the concept of partnerships with patients and families. These partnerships need to be foundational to the culture of the organization.

Sarah Mossburg: It's really important to get leadership support for this kind of initiative. Otherwise, with so many competing priorities in healthcare, it becomes difficult for staff to identify where to spend their time. One of the things that helps get leadership buy-in and support is impact. Could you speak to the impact that family partnership has on patients and the health system?

Bev Johnson: I'll give you another personal example. I was the coordinator for my mom's healthcare for probably the last 15 years of her life. She lived to almost 105, was dynamic, very engaged, and had a wonderful quality of life.

When my mom had broken her left hip, her left shoulder, and her right hand at the age of 94, she became totally dependent on family. I helped with the transitions of care. Although I'm a nurse by background, I was not working clinically then, and I couldn't keep track of all of my mom's medications. I don't see how anybody does, so I asked for a list. I was expecting pushback, and dismissive talk that I was just a "pushy

family member.” The nurse responded with such respect. She said, “Sure, I’ll print it out for you, and let me show you how it’s organized.” Saying this took her less than a minute, and it gave me such confidence. I think this saved my mom’s life because when we got home, the medication orders were confusing and not accurate. I was able to sort it out because of what that nurse had taught me.

I’m an insider in healthcare. Think about other families who may not understand hospital processes and the important role that families can play. If these people were supported in learning while the patient is in the hospital, they can be supportive and help keep people safe during a hospital stay. But we have mistakenly labeled families as “visitors” when they are really “allies for quality and safety.” Patients determine the role that they want their family members to play as their partner in healthcare. Every hospital, every ambulatory practice, and every long-term care community should have processes in place for a patient or a resident in long-term care to define their family or care partner, and how they want them involved in care. Then during care transitions, when the patient is too sick to share helpful information, staff and clinicians will know with whom to partner.

Another safety strategy that is really important is to listen to the observations of families. They may not have it all right, but we have found, particularly in critical care, that families know their loved one better than staff, and they often pick up subtle changes in mental cognition, or they know how the patient responds to certain medications, and they can pick up early warning signs. Families are safety partners, and by acknowledging this, you convey respect to families.

One more observation at the care level: I believe that we would improve healthcare significantly and make it a safer place if we consistently partnered with patients and families in teaching rounds and interdisciplinary rounds. Talking about the patient in the hallway, making decisions, and then coming in the room and talking at the patient or family is not time efficient. We miss important cues. It’s not a good way to teach. If we teach and model for students and trainees how to conduct rounds with the patient and family, they will collaborate in clinical practice and develop a new respect for patients and families going forward. We learned during the pandemic that we can do this virtually—families can participate in rounds from San Francisco when the patient is here in Washington, DC.

Sarah Mossburg: You mentioned partnership at the care level: Do you have thoughts on other levels where partnering with patients and families can improve?

Bev Johnson: Absolutely. I think of it in two basic ways: at the care level and at the organizational level. So much of IPFCC’s work has been to build the capacity of organizations to recognize the importance of the insights and experience of patients and families, and more recently of residents in long-term care. One way to build organizational capacity for partnerships is to create patient and family advisory councils. Patients, residents in long-term care, and families are selected and prepared to be partners. It’s not an advocacy role. It is really a partnership role of sharing with leaders and staff their experiences with safety, quality, and the experience of care, and then work together to improve it.

What we’ve known for a long time, but we haven’t addressed it sufficiently, is that these partners or advisors need to represent the diversity of communities served. In the past, the partnerships have not been as representative as they should be. There’s exciting work going on right now to ensure diversity in

advisory councils.

In addition to advisory councils, there are many other opportunities to improve safety through partnerships. Patient and family advisors should serve on the Patient Safety Committees. They need to be on the Board Quality Committee. To avoid tokenism, we strongly believe that more than one patient or family advisor should be added to these committees. We recommended at least two or three people in a working group of perhaps 12 to 14 people. A good practice is to select, orient, and prepare an alternate, so you'll always have at least two people. I think you also have to prepare staff, leaders, and clinicians on how to partner with patients and families on a Safety Committee or Quality Improvement Committee. It's a new way of working, and sometimes staff, clinicians, and hospital leaders don't understand how to make these partnerships work well. Again, that's something we like to help organizations do; it is a skill set you can develop and use.

Another partnership opportunity at the organizational level, which was set back by the pandemic, is having patients and families serve as faculty, as educators, for students and trainees about patient- and family-centered care, about how to partner, how to listen deeply to patients and families, and how to weave these approaches into your clinical practice. We hear from staff, clinicians, and leaders positive reports about the power of these educational sessions with patient and family faculty. They are often transformational.

Sarah Mossburg: Thank you for sharing these concrete, helpful recommendations. You distinguished between an advocacy role and partnership. Could you explain that difference?

Bev Johnson: Advocates convey a desire for a specific goal or change, but advocacy doesn't necessarily create the opportunity to hear from the other person's perspectives. There's a definite role for patients and families in advocacy. But for patient- and family-centered care, I think of mutually beneficial partnerships. I don't think that we can make care safe if we ignore the experience of clinicians and staff. I think we have to hear their points of view, and they have to hear the points of view of patients and families. Then we work together to create safety and other healthcare improvements.

Sarah Mossburg: Could you speak to the evolution in the way we recognize the role of families in patient care? You talked initially about your own evolution in thinking from your early meetings with children and families. What about at the level of the health system in the United States, how has that evolved and how has that affected patient safety?

Bev Johnson: A couple of examples come to mind that are beyond an individual organization around partnerships with families. One is the work of SIDM, the Society to Improve Diagnostic Medicine. They have wonderful resources available on their website that teach patients and families, and patient and family advisory councils, how to improve diagnostic safety. These resources were developed with patients and families who had experienced diagnostic error. They include strategies for how patient and family advisors and the councils can partner with senior leaders.

Another area in patient safety where patient and family partnership has evolved is medication reconciliation. It has often been staff driven. What about patients and families? They need to be part of the process to make sure it is correct. It is essential to teach and share information about medications for the transition of going home. Patient and family advisors at Beth Israel Hospital in Boston worked with staff and

clinicians for several years to improve transitions of care, and particularly on medication safety. These patient and family advisors said that they needed a detailed list about medications, and that list should be readable and understandable in the languages they prefer. It should include information about why a patient must take this medicine, how to take it, and what he or she should be concerned about. But we also want the “refrigerator list.” A practical, insightful recommendation from advisors—a succinct, clear, practical tool that tells a person when and how to take each medication. That type of list just makes so much sense. Patient and family advisors helped the hospital see a simple, practical approach for sharing information.

Sarah Mossburg: Recently, I was talking with a patient safety expert about the critical role that family members play in the safety of their loved ones. This person, who has deep experience caring for a loved one in the U.S. healthcare system, cautioned me that healthcare workers should be aware of limitations that families might have based on the situation at hand. For example, if this is a new diagnosis for their loved one, or they’re in a crisis, we need to be careful that we’re not overburdening them or expecting more than they have the capacity to give us in that moment. Many families have been deeply engaged in care for a loved one and are able to play a critical safety role, but many family members are new to this role and don’t have any idea of what that means. What are your thoughts on the range of abilities family members might bring to bear on how involved they can be in safety at the bedside, or at home?

Bev Johnson: I have a great deal of respect for that viewpoint, but I see it a little differently. I’m somewhat less concerned about situational limitation of families. I believe what is most important is to have open communication with patients and families, really an ongoing dialogue. So often we have, as healthcare professionals, made assumptions that families don’t have the capacity or they don’t have the resilience to do something. I don’t want to mistakenly overestimate their capacity. But if you have an ongoing dialogue that’s honest, there are times when families just need a respite, and they could say, “I just can’t deal with this now. I don’t want to know all the details now. Please help me in making these decisions.” I’ve heard patients say they don’t want to know all the information at a particular phase in their cancer journey, or whatever the situation may be. It is the honest, open, and continuing dialogue that I think is really important.

You also touch on another important point, and that is when someone is new to the healthcare system. It is really challenging, particularly for the diversity of patients and families we serve today. In many ways, the pandemic has made it much harder to know how to work together. But IPFCC has a couple of simple tools. With the [Better Together](#) campaign, we developed a one-page information sheet with key bullet points to help a family know how they can be an effective partner in their loved one’s care. You can keep that little list in your pocket. Sadly, what we’ve done in the United States, and in many other countries, is push families away and say, “You’re visitors.” That has become much more extreme during the pandemic.

A group that I admire tremendously is [Healthcare Excellence](#) Canada. This organization has some helpful materials for a program called [Essential Together](#). We worked together with them on the Better Together international campaign to change the concept of families as “visitors.” During the pandemic, they developed amazing resources to prepare and support families to be essential care partners, not “visitors.”

Prior to the pandemic, lots of organizations, including the [American Institutes for Research](#), developed admitting guidance materials: “Welcome to the Hospital” followed by “Helpful Information.” Beyond that,

these materials discuss what the patient's and family's roles are in quality, safety, and the overall experience of care. I think we have to find those guidance documents (which were buried during the pandemic), update them, and make them very available to people so they can learn how to be good partners in healthcare.

Sarah Mossburg: Early on in the pandemic, a lot of healthcare settings limited family presence in order to control the spread of COVID-19. What are your thoughts on that, and what the pandemic showed us about the impact of family presence?

Bev Johnson: Well, we may have to have another interview just on that topic! In the first two to three months of the pandemic, most hospitals and healthcare professionals did not know enough about the virus and how to treat it. Systems and equipment were not in place to handle the situation safely. It came so suddenly and overwhelmed health systems so fast. We were not prepared in so many ways, even lacking adequate personal protective equipment. As a result, health systems and long-term care communities locked down completely, in harsh ways, right away. And while we were in that crisis period, IPFCC presented a webinar on how to partner with families for safety and quality during the pandemic. We were trying to help people think differently, to be very careful and practical, but to recognize the harm from severe restrictions. We know that instances of patient harm have risen because families weren't present in hospitals and long-term care communities. Families weren't able to share vital information that could be helpful to staff and clinicians. Clinicians were having to treat patients, whether they had COVID or some other serious condition, without the information that families might have, and the patient was usually too sick to communicate. I felt really sorry for staff and clinicians, because they knew excluding families wasn't the best way to practice, and how hard that must have been. Technology was some help in making connections with families.

At the beginning of the pandemic, another disappointment for me is that we should have learned from SARS and H1N1. These learnings were described in white papers that IPFCC produced at that time.[1](#),[2](#),[3](#),[4](#),[5](#) In late 2020 and 2021, IPFCC worked with a wonderful ethicist in Canada who shared insight about the impact of locking down healthcare facilities and preventing family access, and what we didn't learn from previous public health crises. Hospitals are beginning to change the concept of families as "visitors," returning to the belief that families are essential care partners. There were some positive lessons learned about family presence during the COVID-19 pandemic. We learned that we could conduct rounds in the hospital with families present via technology. In ambulatory care, we could share a new cancer diagnosis with the patient and family, while the family is in another part of the country, through telehealth. These were positive learnings. I'm confident we're going to do better going forward. But without family presence and participation, patients are at risk for harm in hospitals and other care settings.

Sarah Mossburg: I agree. You had mentioned earlier being able to engage family members in partnership via virtual rounds during the pandemic. One thing that became apparent, unfortunately, during the pandemic was the disparity in technology access. I'm wondering if you are aware of any negative impacts from trying to engage family members via technology during the pandemic?

Bev Johnson: Certainly, we need to increase access to broadband everywhere and teach people how to use it. I'm going to shift your question a little bit. I think we learned some ways to make technology work for

more people. I have a wonderful example right here in Washington, DC. Children's National Hospital has a "Navigator Program" for families caring for children with complex needs. These parent navigators provided peer support and frontline support to help other families use telehealth effectively as a way to obtain critically important healthcare for their children. Thus, for the families who were not familiar with Zoom or did not have internet access, the parent navigators made it work so these families could keep their children safe.

The other example is with patient and family advisory councils (PFACs). Some places just shut down their PFACs. And that's sad because they didn't tap into the value of having patient and family partners participate in pandemic planning and ongoing quality and safety during the pandemic. The good news is that many patient and family advisory councils switched almost immediately within the first couple of months of the pandemic to virtual meetings. What IPFCC began to see was greater attendance and more engagement. Many PFACs shared that virtual meetings saved families time; people didn't have to drive in traffic and park. It was less expensive. I think that some people felt more comfortable speaking up from their kitchen table, on their turf, not the hospital's turf. Going forward, I believe that we will see a hybrid model for many PFACs because it is easier for many families, especially those from diverse and underserved communities, to participate. Staff liaisons for patient and family advisory councils reached out to advisors and provided extra support to use technology. They shared iPads, taught people how to use them, and helped with internet access. They overcame barriers because they knew the benefit of having those voices at the table.

Sarah Mossburg: So you saw examples where hospitals were making strides to overcome inequities in access to technology.

Bev Johnson: Wonderful leadership at all levels, commitment to overcome inequities, and for family leaders to provide support to other families. There was one area where most organizations missed the opportunity to partner with families, patients, and residents in long-term care communities: that was in planning responses to the pandemic, especially for how to support some level of family presence in safe ways to reduce transmission risk. Some places did it well. I'd love to share just a couple of quick examples with you.

One hospital created a group of advisors, about six or eight people, who would respond to a request from hospital leaders within 2 hours. In the pandemic, you couldn't wait for a monthly meeting. Leaders in healthcare organizations were making changes every other day, or every day, or even hourly. In Canada, across the entire province of Alberta they had two Rapid Response Teams of patient and family advisors to respond to changes in policy at the provincial level.

One more example—during the first week of the pandemic in Canada, senior leaders at Kingston General Hospital reached out to experienced patient and family advisors and asked to meet at a local coffee shop. These senior leaders said they wanted to plan together with these advisors about how to respond to the pandemic. These collaborative coffee shop meetings lasted throughout the pandemic and are continuing to this day. When you have leadership commitment to partner substantively with patients and families, this is what it can look like.

Sarah Mossburg: Those are really great examples, and I really love the fact that you called out the opportunity for pandemic planning and partnering with patients and families for the future. Is there anything else that you can speak to on what we learned from the pandemic related to partnering with patients and families that we didn't know before?

Bev Johnson: As we emerge from the pandemic, we need a substantive recommitment to patient- and family-centered practice. We have had 3 years of working in a different way that has been very traumatic to the workforce. Recommitting to patient- and family-centered care, with its foundation in respect and dignity for all and mutually beneficial partnerships, could be healing for the current workforce. I have a concern about patient safety. Our current workforce, and new members of the workforce coming in, have not had the opportunity to learn about patient- and family-centered care and how to partner with patients and families. They need help in developing communication skills beyond the cell phone and texts, to talk to and collaborate with real people. This is an opportunity to advance the practice of patient- and family-centered care, and it aligns well with work related to diversity, equity, and inclusion. I think we'll go forward better. I'm optimistic.

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