

Satisfaction, Experience, and Patient- and Family-Centered Care: What Matters Most for Kids?

By Cara Coleman, Program Manager, Family Voices

When I think about the words “patient satisfaction” and “patient experience,” I am reminded of a conversation I once had with my daughter Justice’s providers during a hospitalization. In the context of discussing Justice’s care for the day and how to ensure all “players,” services, and supplies were in order, they shared that they often feel like they are running a hotel. More specifically, they said that they wish they could sometimes say to families and hospital administration, “this is not the Ritz-Carlton!” Somehow our discussion of the *delivery of care* for my daughter had become a discussion of hospitality, as if our experience and satisfaction were the same as the care she received.

Justice had a primary care provider and 16 different specialists, supported by at least 20 advanced care professionals, with care spanning two different health systems. She did not have a shared plan of care—instead the majority of the providers operated in siloes. This resulted in a child with the most “touches” in the healthcare system who received the most fragmented care, which led to poor outcomes. In her last year of life, the poorest outcome was unmanaged pain. After learning that Justice had a pseudo small bowel obstruction, I asked Justice’s gastroenterologist to

Key Board Takeaways

As children’s hospital boards consider their organizations’ commitment to measuring and improving satisfaction, experience, and patient- and family-centered care, they should keep in mind the following:

- PFCC is an action verb, not a noun or adjective. It includes patients, families, and providers *communicating* and *collaborating* for the health and well-being of individuals and families.
- What matters most to kids (quality of life, family well-being, family-centered care) should be married to medical care—as the lens, the basis for care and developed through a shared process of decision making. As Frank Sinatra said in his song “Love and Marriage”... “you can’t have one without the other!”
- Measuring PFCC (going beyond simple verification of interactions taking place) helps us determine how to work together for each child’s health so they can get to the business of being kids. For example, consider measuring:
 - » Whether providers discuss with families how their child’s diagnosis might affect how she/he will be able to participate in school, social, community, and faith-based activities.
 - » In the last year, how often families have felt that their child’s care team members thought about the “big picture” (meaning *all* of their child’s needs).
- Board members need to be made aware of which measurement tools are being used, and hold management accountable for ensuring that those tools are appropriate and specific to children’s hospitals. Specific and high-level PFCC metrics should be included on the board’s dashboard report. Key questions to help board members better understand this issue include how and why do care decisions and communication need to be handled differently with children vs. adult patients?

talk with other providers, including the new palliative care team I had sought out. She indicated that she did not have time, that Justice was “fine,” and that I needed something else to do with my time. She then reiterated the treatment plan (which included more testing, over-the-counter medication at a cost of \$600

a month for our family, and surgery) and left the room. She did not ask what we wanted, why I said Justice was in pain, if we could afford the medication, or even if we wanted to make Justice undergo yet another (her seventh) GI surgery. Her father and I had worked on advanced directives because we realized that

the medical interventions offered caused more harm than good and prevented Justice from being a kid for the short time she had left on this earth. When I attempted to share our thinking so we could collaborate on care, I received more of the same dismissiveness and insensitivity.

From my own lived experience raising, and losing, a child with medical complexity, I can tell you that communication and collaboration/teamwork are absolutely what it is all about. If we do not work *together* as a care team to agree upon what care is being provided, then experience and satisfaction will always be poor... not to mention the quality of life of our children and well-being of our families. We were *satisfied* with most of our providers, and I would check “yes” on HCAHPS surveys that necessary interactions, like daily bedside rounds, occurred in our *experience*. However, the most needed part of Justice’s care, the patient- and family-centered approach (i.e., communication, for example, *sharing* in developing plans of care that balance medical needs and quality of life and *sharing* in decision making) were few and far between. For that reason, Justice couldn’t be a kid when it mattered most. For example, Justice was extremely social and wanted nothing more than to be with her friends and siblings—to do typical kid stuff. However, when treatment decisions were made in a vacuum, without discussion as to how to balance medical and Justice’s quality of life, home regimens were designed that prevented her from attending school because of complexity of care.

Moving beyond Satisfaction and Experience Measures

Measurement of the work we do in healthcare is absolutely critical, but are we measuring the right things for kids? The Triple—and

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Quadruple—Aim¹ provides lofty goals for care for everyone in the healthcare system, but they were not designed with the unique needs of children. I worry that the focus on measuring, and then advancing, experience and satisfaction, gets us so caught up in certain interactions, expectations, and the business of healthcare that we lose sight of what matters most and the whole reason we provide pediatric care: to ensure kids can be kids. Quality of life and family well-being are critical parts of the equation for children, even (especially) for those who are most sick and have disabilities, and must be married with how we design, provide, and measure the delivery of pediatric care.

Is there a difference between patient satisfaction, patient experience, and patient- and family-centered care? You bet! Are these measures often related? Of course—as they should be! I very strongly believe in the need for quality measures. HCAHPS is a good *start*. However, I am concerned that by not measuring patient- and family-centered care just as we measure satisfaction and experience, we are in fact missing key measures that help us determine whether the care provided for children balances medical/clinical needs, quality of life, and family well-being (i.e., ensures focus is

always on what matters most...being a kid).

Patient satisfaction and patient experience are often used interchangeably, but they are not the same thing.² Patient *satisfaction* measures whether *expectations* of a healthcare encounter were met, whereas patient *experience* assesses whether or not the range of *interactions* that patients and families have (or should have) with the healthcare system occurred. Patient- and family-centered care (PFCC) is an approach to the planning, delivery, and evaluation of healthcare that is grounded in mutually beneficial *partnerships* among healthcare providers, patients, and families.³ It redefines the *relationships* in healthcare by placing an emphasis on *collaborating* with people of all ages, at all levels of care, and in all healthcare settings. A key goal is to promote the health and well-being of individuals and families. This approach is guided by four key concepts: dignity and respect, information sharing, participation, and collaboration. PFCC is, in essence, a verb defined by patients, families, and providers through the shared acts of communication and collaboration. Indeed, there is

1 Many experts have expanded the IHI’s Triple Aim concept (simultaneously improving care and experience for patients while lowering costs) with a fourth aim of enhancing the caregiver experience as a necessary aspect of enhancing quality of care.

2 Agency for Healthcare Research and Quality, “What Is Patient Experience?” (available at www.ahrq.gov/cahps/about-cahps/patient-experience/index.html).

3 Institute for Patient- and Family-Centered Care, “Patient- and Family-Centered Care” (available at www.pfcc.org/about/pfcc.html).

a mounting body of evidence as to how meaningful involvement of patients and families in care leads to improved care and outcomes.⁴ In children's hospitals, the effects of PFCC are most readily seen in efforts engaging patients and families in safety and quality of care, with "family-centered rounds" being a hallmark program.

Assessing family-centered care⁵ or measuring integration of care⁶ helps us all move beyond merely verifying an interaction to that active approach of collaboration, and how to do it for a child's health, with questions that explore types of communication, how they are occurring, and with whom. Consider the difference between asking, "Did your care team

explain the treatment plan to you?" and questions such as, "How often did you decide together on a plan? Did you feel a provider knew about the advice of other providers? Or did a provider explore what is difficult (or what works/does not work) in providing care for your child or how it affects the family?" In nearly all my experiences of care with Justice, I could have answered in the affirmative for the first question. Yes, a plan was explained to me, sometimes as a team stood around her bed in "family-centered rounds." However, my answers to the latter set of questions were more varied.

These measurements stand in stark contrast to each other and fall far short of the whole reason why we provide medical care...to help kids be kids!

4 Committee on Hospital Care and Institute for Patient- and Family-Centered Care, "Patient- and Family-Centered Care and the Pediatrician's Role," *Pediatrics*, American Academy of Pediatrics, February 2012 (available at <https://pediatrics.aappublications.org/CONTENT/129/2/394>).

5 National Center for Family Professional Partnerships, A Project of Family Voices, Family-Centered Care Assessment for Families (FCCA-F) (available at <https://medicalhomes.aap.org/Documents/FCCAquestionnaire.pdf>).

6 Boston Children's Hospital, "Patient & Family Experience Outcome Measurement: the Pediatric Integrated Care Survey" (available at www.childrenshospital.org/integrated-care-program/patient-and-family-experience-outcome).

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