The Pediatric Patient Experience: One Size Does Not Fit All

By Diana Mahoney

Pediatric caregivers don’t need to be told that children are not little adults. They know firsthand that the physical, physiological and developmental needs of children are different from those of adults, and that the clinical care and treatment they receive must be different as well. They may not be aware, however, that when it comes to the overall patient experience, the adult-child distinction is just the beginning.

New data from the Institute for Innovation suggests that the needs of pediatric patients and their families vary considerably, not only from those of adult patients, but also from those of pediatric patients of different ages and developmental stages. Understanding those differences and tailoring the delivery of compassionate connected care accordingly can create value and increase patient loyalty.

“As with all health care, the goal of caring for kids is to alleviate the suffering that is inherent to the child’s illness, condition or treatment and eliminate avoidable suffering caused by system dysfunction by understanding and meeting their needs,” Deirdre Mylod, executive director of the Institute for Innovation and senior vice president of Research & Analytics at Press Ganey, explained in a presentation at the 2017 Press Ganey Pediatrics Executive Leadership Summit. “What we’ve learned is that the overall patient experience is influenced by the degree to which age-related patient needs are met.”

For example, while all families have a need for accurate and thorough information regarding post-discharge care, parents of infants may be more anxious about caring for their sick baby at home than parents of toddlers or school-aged children. Consequently, they may be less likely than parents of older children to give a top-box rating for post-discharge communication, Mylod said. The “fix” in this situation, she noted, is to make sure these parents receive frequent communication about post-discharge care—what to expect, who to call with questions—and reassurance in order to feel prepared.

An Action Framework for Meeting Patient and Family Needs

Before segmenting patient experience outcomes by age, it’s useful to think about the different kinds of needs pediatric patients and families have and how the fulfillment of those needs influences their overall experience, Mylod said. “One way to do this is to look at the drivers of top-box scores on the Child HCAHPS Likelihood to Recommend survey item. This helps identify the issues that most differentiate whether or not your families will recommend your hospital.”

Using data from Press Ganey’s inpatient pediatric patient experience database, Press Ganey researchers identified performance paths for achieving an optimal patient experience based on this loyalty marker. Of note, the single most important consideration for families is teamwork. “The top four paths to an optimal patient experience start with top-box scores for the ‘Staff worked together to care for my child’ item,” Mylod said. “So, what this tells us is that when parents feel as if the care team is working well together, sharing information with each other so everyone on the team knows what is going on and is on the same page, the likelihood that those families would recommend the hospital to families and friends increases.”
When teamwork scores are optimal, the next most important differentiator is the perception that “Doctors listen carefully.” “Parents want to feel as if the physician is listening to what they are saying and respects their knowledge of their own child,” Mylod explained.

And among parents who give top-box scores for teamwork and doctors listening carefully, the perception of whether nurses were attentive to their needs has the most additional influence on Likelihood to Recommend. “It’s interesting that for the best possible experience to occur, we need positive evaluations of teamwork and of two of the more emotional components related to family-provider interactions,” Mylod said. “According to our analysis, if we get those three things, 97% of patients and families will give a top-box Likelihood to Recommend score.”

In other words, Mylod continued, “getting those three items ‘right’ is the quickest path to building trust and reducing stress and anxiety for your families.” And although it sounds difficult, “64% of patients/families nationwide are already receiving that combination of experiences,” she said.

Based on the same analyses, the quickest path to a bad outcome—“the path hospitals want to avoid,” Mylod explained—is the bottom one in the figure, characterized by non-top-box ratings for the items assessing teamwork and nurses listening, and for the discharge preparation item around making parents feel well prepared to care for their child at home. With that combination, only 23% of families give top-box scores for Likelihood to Recommend, regardless of performance on other items.

At each step along the path, however, there are things providers can do to moderate the negative influence of a given item. For example, if teamwork isn’t rated as optimal, feeling listened to by the nurse and receiving courteous and respectful treatment by the doctor can help maintain patient loyalty. “This helps us see how these interpersonal relationships moderate the impact of that bigger issue of teamwork,” Mylod said.

**Segmentation Puts Patient/Family Needs in Focus**

These findings can help paint a broad picture of where improvement efforts might have the most impact on patient loyalty. Segmentation by age and developmental stage helps zoom in on the specific needs of patients and families.

For example, in an analysis of performance on the two HCAHPS global outcome measures of Overall Hospital Rating and Likelihood to Recommend, only 71% of families with a child in the newborn to 2-year-old range gave a top-box Overall Rating score, compared with 75.3% of families with a 3- to 5-year-old, 80.3% of those with a 6- to 12-year-old, and 78.6% of those with a 13- to 18-year-old. A similar distribution was seen for Likelihood to Recommend scores. The respective percentages of top-box ratings for 0–2, 3–5, 6–12 and 13–18 were 78%, 83.4%, 86.9% and 85.5%.
“What this tells us is that these groups of patients have completely different experiences,” Mylod said. To better understand the drivers of these differences, the Press Ganey researchers looked at the national data for all of the measures from Child HCAHPS and the Press Ganey pediatric inpatient survey and grouped the measures based on patients’ needs, and then further grouped the needs based on the Compassionate Connected Care framework, which identifies strategies for meeting the challenges of connecting with patients and reducing suffering.

“In the Compassionate Connected Care framework, needs fall into four categories: clinical, operational, behavioral and cultural,” Mylod explained. For example, meeting some needs requires changing clinical practice, such as streamlining the discharge prep process, while others are sensitive to caring behaviors, such as listening carefully or showing empathy, she said.

Grouping patients’ needs in this way painted very different pictures for each age category. For example, the evaluation of the care experience for newborn to 2-year-olds was lower than any of the other age groups on nearly every measure. “On the clinical side, pain management shows up as a huge issue for these families,” Mylod said. “It’s very stressful for parents to see their children in pain and feel like not enough is being done to help them. And babies can’t talk, so it’s hard for a parent to disentangle what might be actual pain from something else. These parents need empathy and reassurance that everything that can be done to manage their child’s pain is being done.”

Concern about whether providers are doing everything they can to control the child’s pain continues to be an issue for families in the 3- to 5-year-old group, but it becomes less important for the two older groups. “It’s not as terrifying for parents when older kids are dealing with pain because you can speak with them and explain things about how their pain will be managed, so there’s less anxiety,” Mylod said.

Similarly, families of patients in the youngest age group are also more likely than those of older children to feel as if they have not been sufficiently prepared to take care of their child at home or that they have not been well informed about possible medication side effects.

In the middle two age groups, one concern that arises more frequently than in the other groups is that staff are not communicating enough with the patient. “This probably represents some of those discussions about how much information and what information is right for the child, but it also suggests that providers may be more focused on addressing parents’ needs without giving the child the opportunity to be heard,” Mylod said. “It’s also possible that parents are not able to convert the information they are receiving into language that can help a 4-year-old or a 7-year-old understand what is being said, and they need help.”

In the oldest age group, which has some of the highest scores for many of the items, performance dips can be seen on some of the discharge items. “My suspicion,” Mylod said, “is that some of this relates to the transfer of power. ‘Do I as a parent feel ready or do I feel like my child is ready for the necessary self-care?’ That is probably worth exploring and talking about with these patients and families.

“Segmenting data in this way offers a level of insight that can’t be seen by viewing the population as a whole,” Mylod said. “In addition to age, the data can be segmented based on other considerations, such as geography, clinical condition, ethnicity or anything else where there are groups of patients who might have similar needs to each other, but whose needs are different from those of other people.”

Looking at the segmented information through the lens of the Compassionate Connected Care framework, Mylod said, “offers a road map for developing targeted improvement strategies and implementing practice changes that can help pediatric providers better meet the needs of all of their patients across the care continuum.”