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In their own words: Safety and quality perspectives from families of hospitalized children with medical complexity

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CONFLICT OF INTEREST STATEMENT

Dr. Christopher P. Landrigan has consulted with and holds equity in the I-PASS Institute, which seeks to train institutions in best handoff practices and aid in their implementation. Dr. Christopher P. Landrigan has received consulting fees from the Missouri Hospital Association/Executive Speakers Bureau for consulting on I-PASS. In addition, Dr. Christopher P. Landrigan has received monetary awards, honoraria, and travel reimbursement from multiple academic and professional organizations for teaching and consulting on sleep deprivation, physician performance, handoffs, and safety, and has served as an expert witness in cases regarding patient safety and sleep deprivation. Dr. Jennifer Baird has done consulting work for the I-PASS Patient Safety Institute. The I-PASS Patient Safety Institute is a company that seeks to train institutions in best handoff practices and aid in their implementation. The remaining authors declare no conflict of interest.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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Abstract

Background: Children with medical complexity (CMC) experience adverse events due to multiorgan impairment, frequent hospitalizations, subspecialty care, and dependence on multiple medications/equipment. Their families are well-versed in care and can help identify safety/quality gaps to inform improvements. Although previous studies have shown families identify important safety/quality gaps in hospitals, studies of inpatient safety/quality experience of CMC and their families are limited. To address this gap and identify otherwise unrecognized, family-prioritized areas for improving safety/quality of CMC, we conducted a secondary qualitative analysis of safety reporting surveys among families of CMC.

Objective: Explore safety reports from families of hospitalized CMC to identify areas to improve safety/quality.

Designs, Settings and Participants: We analyzed free-text responses from predischARGE safety reporting surveys administered to families of CMC at a quaternary children's hospital from April 2018 to November 2020. Using a qualitative descriptive approach, we categorized responses into standard clinical categories. Three team members inductively generated an initial codebook to apply iteratively to responses. Reviewers coded responses collaboratively, resolved discrepancies through consensus, and generated themes.

Main Outcome and Measures: Outcomes: family-reported areas of safety/quality improvement. Measures: pre-discharge family surveys.

Results: Two hundred and eight/two hundred and thirty-seven (88%) families completed surveys; 83 families offered 138 free-text safety responses about medications, feeds, cares, and other categories. Themes included unmet expectations of hospital care/environment, lack of consistency, provider-patient communication lapses, families' expertise about care, and the value of transparency.

Conclusion: To improve care of CMC and their families, hospitals can manage expectations about hospital limitations, improve consistency of care/communication, acknowledge family expertise, and recognize that family-observed quality concerns can have safety implications. Soliciting family input can help hospitals improve care in meaningful, otherwise unrecognized ways.

INTRODUCTION

Children with medical complexity (CMC) typically have three to four organ system involvement, neurodevelopmental delays, and technology dependence.¹⁻⁵ They require multiple medications, durable medical equipment, specialized formula, frequent hospitalization, and multispecialty treatment. They comprise 1% of the pediatric patient population, but 30% of readmissions and 55% of inpatient costs.^{2,4,5} CMC are frequently followed by six to seven subspecialists, on >10 standing medications,¹⁻⁵ and interface with multiple pharmacies/vendors for medications/durable medical equipment needs. When

hospitalized, CMC is often transferred from one location to another. Due to intricacies of care, CMC are particularly vulnerable to medical errors/adverse events (AEs).⁶⁻¹⁰

Parents/caregivers (“families”) of CMC are well-versed in their children’s needs, providing specialized home care and ensuring continuity in hospital. Families of CMC are adept at identifying errors during hospitalization, including otherwise unrecognized errors.¹¹ However, dedicated studies of the inpatient safety/quality experience of CMC and their families are limited. Additionally, most hospitals do not proactively include families in safety/quality improvement processes.¹²

To address the paucity of research in CMC, and identify unrecognized, family-prioritized areas for improving safety/quality in this understudied population, we conducted a secondary analysis of family survey data from a prospective cohort study about family safety reporting in hospitalized CMC.¹³ We sought to categorize the types of safety reports made by families of hospitalized CMC to better understand their perspectives on inpatient safety/quality and inform future improvement efforts about issues that matter to families and might otherwise be missed. Our findings can help hospitals improve the safety/quality and patient/family-centeredness of care.

METHODS

Study design/population

We conducted a qualitative analysis of baseline survey data (collected on paper/electronically before¹³ and after the COVID-19 pandemic) from a prospective cohort study of families of hospitalized CMC on a dedicated complex care service at a quaternary care children’s hospital between April 2018 and November 2020. The hospital has a dedicated complex care program, patient relations department, family advisory council, and voluntary incident reporting system (VIR). Hospitalists with complex care expertise run the program, which admits medical/postsurgical patients hospital-wide with neurological impairment and/or technology dependence, followed by three to four subspecialists. We included all English-/Spanish-speaking families admitted on the complex care program across five inpatient units, excluding patients in residential care facilities, state custody, and international patients. Participants were consented verbally with an information sheet, using in-person/video interpretation as needed. Our hospital’s IRB approved the study. We followed the SQUIRE guidelines for reporting.¹⁴

We surveyed families before anticipated discharge. Surveys inquired about experiences with safety during hospitalization. We provided examples of potential safety events (e.g., medication, equipment, and complications). We asked families about: whether their child’s illness worsened due to medical care; whether their child’s illness worsened because of omissions in care; nonharmful errors; good catches; concerns not being heard; or anything upsetting or that could have harmed their child (Supporting Information: Appendix 1). We captured demographic information including parent/caregiver age, relationship, race/ethnicity, parent activation (P-PAM),¹⁵ and health literacy (Newest Vital Sign).¹⁶ Further survey details were previously published.¹³ Patient demographic/hospital administrative data were obtained from the Pediatric Health Information System.¹⁷

Categorizing family responses

Three trained investigators with complex care, patient safety/quality, and qualitative methods expertise jointly reviewed free-text responses. Responses were first retrospectively categorized deductively using a classification system from prior research,^{13,18–20} with categories including medication, feed, care, and so on.

Qualitative analysis

We next used a qualitative descriptive approach to conduct an inductive thematic analysis^{21,22} of survey free-text responses to describe safety/quality concerns of hospitalized CMC. Investigators created and iteratively refined a codebook. They applied the codebook to concurrently code interviews, resolving discrepancies through consensus. We generated themes describing safety/quality experiences of hospitalized families of CMC, reviewing themes with a multidisciplinary study team (including a parent safety advocate, a parent of a CMC, frontline nurses, nursing leaders/educators, and complex care hospitalists). Dedoose²³ facilitated coding, analysis, text search, and theme development.

RESULTS

Sample characteristics

Overall, 237/251 (94%) families consented and 207 completed surveys (88%). The families' mean age was 48 years (SD = 11), and were predominantly female (82%, $n = 168$) and White (72%, $n = 152$). Nearly half (43%, $n = 86$) had an annual household income <\$50,000, 50% had <4-year college degree ($n = 104$), and 15% ($n = 31$) had limited English proficiency. Patients were majority male (56%, $n = 116$), with mean age of 14 years (SD = 7), and mean length of stay of 10 days (SD = 14); 47.8% ($n = 87$) had public insurance and 85.5% ($n = 177$) had technology dependence. The most common complex chronic conditions were neurologic/neuromuscular (77.3%, $n = 160$) and gastrointestinal (75.8%, $n = 157$) (Table 1a,b).

Event classification

Eighty-three families provided 138 free-text responses. Categories included cares, communication, compliments, delays in care, diagnosis, environment, equipment, feeds, and medications (Table 2). Concerns included contradictory feeding instructions, delayed seizure medications, unplugged oxygen, unclamped G-tube, and incorrect formula.

Themes

Five themes emerged from family survey responses: unmet expectations of hospital care/environment, lack of consistency, provider–patient communication lapses, families' expertise about care, and the value of transparency (Figure 1).

Theme 1: Unmet expectations of hospital care/environment—Family expectations of hospital care—like resource availability—were not always met, including medications and formulas.

Certain prescribed medicine and basics [are] not available ... we were told milk/formula [are] not available after a certain hour because it was “locked up.” How ridiculous! —Parent 1

Families also described concerns about hospital environment, like fear of infection in double rooms.

Due to his low ANC [and] immune system [he] should have private room ... [this was] very stressful on both patient & parent. —Parent 2

Families also had expectations regarding cares that were not always met.

A ca [clinical assistant] rushed through cleaning the wound ... I don't think she took the time to dry it properly. The moisture was never dried plus he has a fever ... They need to take the [time] to do the job properly. If it's too many patients say something. —Parent 3

Theme 2: Lack of consistency—Families identified a lack of consistency in resources, policies, staffing, and communication in different units. For instance, they noted treatments were variably available, sometimes due to staffing.

The respiratory department was not readily available to do my son's cough assist following his vest treatments ... Most of my son's hospitalization, respiratory nurse was not readily available. —Parent 4

In addition, families noted variability in resource availability from one location to another.

We were told that a certain, common, over the counter med was not carried at the hospital. A bizarre thing on its own but more bizarre because the ER gave my son that same med only hours prior. —Parent 1

Families also noticed practices varied across units, both in stated policies and enforcement.

... my mother has been coming to these appointments with my daughter and they never told us once that there couldn't be more than two people together and they let us get all the way up through security. Once we get up to that floor, we were told and it created issues which led to my daughter having a meltdown due to the separation ... We were also told it was okay by the family center and front desk. —Parent 5

Families described challenges due to inconsistent staffing. For instance, they described performing cares themselves and frequently repeating information to different staff about nuances of care.

Lack of continuum of care. During the stay she had a different nurse and different CA for each shift. Because of the complex nuances of care needed, each staff had to be told about handling issues, feeding issues, not having inhalation therapy, feeding flushes, g-tube handling, nighttime sleep positions. —Parent 6

Theme 3: Provider–patient communication lapses—Families reported various communication challenges in the hospital. These included inconsistencies and delays in

communication, as well as concerns about content, process, and manner of communication. Families also had specific preferences about how communication occurred in their child's presence.

Families described inconsistencies in communication, both with the primary team and between the primary team and subspecialists.

Apparently there was some scheduling confusion and GI physician who was supposed to assist our surgeon was never informed ahead of time ... caused a delay in procedure and added anxiety for my daughter. —Parent 7

Doctors on rounds were not on the same page about the plan. —Parent 8

Families expressed concerns about delays in communication, particularly around subspecialists and weekends.

Could not get timely answers from surgery dept especially on weekend days. —Parent 9

Families also felt their input was sometimes dismissed by providers.

Condisending[sic] feel to Dr like “you don't know” or [being] very dismissive. —Parent 10

Families valued bedside manner and respect from both non-clinical and clinical staff.

There was a receptionist that was kind of rude. I went to the desk to let her know I was leaving, and she looked at me and asked if I could wait a minute. —Parent 11

... the woman that came was clearly aggravated when she walked in the room. She was short with my nurse and when she placed the tube, she was extremely rough despite my many attempts to ask her to slow down or even give my son a break ... that nurse brought her personal stuff into this procedure and my son was traumatized because of her inability to remain calm and professional. —Parent 12

Families discussed the importance of honoring preferences around what is communicated in front of their child.

It would be great for parent and the team to take a few moments when they are introduced the first time to offer to speak privately outside of the child's room. Sometimes, there are things I would have liked to address before the doctors announce them to my son and I together. —Parent 12

Theme 4: Families' expertise about care—Families of CMC described having intimate knowledge of their children's medical needs and care. Often, they were the first to notice changes in status, errors, and near-misses.

Families had expertise in nuances of care and critical historical knowledge that medical teams were not always aware of.

We pushed for Lasix because that is normally how we treat his fluid retention at home, but the residents were reluctant to treat. My son ended up with bilateral

pleural effusions. He continued to get more swollen and the physicians finally began treatment with Lasix to reduce the fluid retention. —Parent 13

My child had similar surgery 6 years ago and ended up with ulcer on her heel. I reminded staff yesterday to be careful of it and staff forgot to put a pillow under her leg. Nurse went to check on it and looked at it this morning and saw that it was a little red. —Parent 14

Families often made good catches and helped partner with staff to double check care. They were adept at the nuances of medications and other therapies.

My son is on the ketogenic diet, and a medication with sugar in it was almost given to him. I caught it and reminded staff that he cannot have liquid medications that have sugar in them.—Parent 13

One of [my] daughters meds [was] left off inpatient list. I noticed it after 1 missed dose and it was corrected. —Parent 15

Though parents reminded the team about mistakes in medications, changes were not always made in a timely fashion.

Ask[ed] about a medicine to re-order that's part of her normal daily bowel regimen and it went through 3 different nurses and still wasn't given. —Parent 16

Family concerns were not always listened to initially. This was a source of distress and led to patient harm in some cases.

I only felt that the team could have acted more timely on my son's medical problems. For 2–3 days, I said something was wrong w/my son b/c his stomach was so distended. —Parent 4

Original reason for coming to the hospital was overlooked through stay until needing to raise the concern, and even when raised, it was quickly dismissed. We had called doctors with our initial concerns prior to coming to the hospital, and it was recommended to bring her in for evaluation. Yet, it seemed like there wasn't much follow-up on these original concerns. —Parent 17

Theme 5: The value of transparency—Families valued transparency, and described varying experiences with it. They expressed frustration with a lack of transparency around diagnoses, plans, and emergency situations.

During the incident we didn't know exactly what caused it and why and getting everyone to come together to help him was not smooth. —Parent 17

Families valued transparency with medical errors and hospital processes, even in challenging situations. When errors or good catches occurred, proactive disclosure helped foster trust.

Missed 2 Ativan doses due to the med route being changed. Was noticed, fixed and [patient] received two rescue doses. Complete transparency on the issue-handled very w[e]ll thank you! —Parent 18

DISCUSSION

In this qualitative analysis of family safety reporting survey data, families of CMC provided rich information about hospital safety/quality. Families described unmet expectations of hospital care and communication challenges and valued consistency and transparency. Although families had specialized expertise about care and were often the first to notice clinical changes, their concerns were not always considered. Our study suggests that unmet expectations, communication lapses, and inconsistency in care can negatively contribute to patient/family hospital safety/quality experience. Greater transparency and recognition of patient/family expertise can improve patient care and trust in providers and hospital systems. By actively soliciting safety/quality input, hospitals can identify unrecognized areas of improvement meaningful to hospitalized patients/families.

While other studies have found that unmet expectations of care contribute to suboptimal patient experience and erosion of provider-patient relationships, most were conducted in outpatient or adult settings.^{24,25} Little is known about unmet expectations of care in inpatient settings, particularly for CMC.

As in the present study, prior studies show that families identify important hospital safety/quality gaps,^{18,26,27} reliably report medical errors/AEs, and identify many nonsafety-related-quality issues.^{11,13,19} We previously found that 9%–26% of hospitalized families report safety concerns, most being medical errors, and many not found in the medical record.^{18,19} When solicited, families reported errors/AEs at equal rates as clinicians and higher rates than VIR.¹⁹

Notably, in the present study, even when a negative event occurred, if handled transparently and addressed appropriately, trust was preserved or rebuilt.^{28,29} Prior studies have similarly found that transparent discussion of errors does not increase malpractice risk.^{28,30} Transparency is known to build trust, a crucial component of the patient–clinician relationship.²⁹

Families in our study noted various medical errors that harmed or could have harmed their children. These ranged from omitted home medications to incorrect doses and routes. As in prior research, seizure medication were particularly error-prone.^{7,9} Families also frequently reported concerns around feeds and equipment. Feeding and medication administration, as well as nuances of equipment use can be unique to each CMC. For example, whether families use the G-tube versus J-tube for feeds, medications, and venting can vary across patients.

While valid variations in care occur across the heterogeneous population of CMC, parents learn over time which approaches work best. Therefore, staff should ask families and not assume a “one-size-fits-all” approach will meet the needs of all complex patients. Staff education about specialized equipment and feeding needs of CMC is critical to providing high-quality care and avoiding potentially harmful errors. Because many CMC have specialized feeding regimens, staff must confirm with families that patients are receiving correct formulas and diets. Particular attention should be paid to patients requiring specialized regimens (e.g., ketogenic diet).

A key theme in our study was that families were often the first to notice issues. They often identified subtle changes in conditions (e.g., abdominal distention, grimacing, mental status) or deviations from care plans and frequently spoke up about potentially harmful issues. This is likely because families possess specialized historical knowledge about what is effective for their children. As a result, families may provide vital contextual information that could help prevent future safety problems. Although families have specialized expertise, their input is not always taken seriously. For instance, one parent informed the medical team that they use furosemide at home for difficulty breathing and pulmonary edema, but the team did not initially implement this suggestion (perhaps because it was not documented clearly in subspecialty notes or care plans).

In addition, due to their expertise and vigilance, families are often the first to identify errors/AEs during hospitalization. Families are also often the first to identify pain, discomfort, and seizures in nonverbal children, who may express pain and seizures in subtle and unique ways that may not follow “textbook” presentations. Listening to families should be a crucial part of decisions around care as families are experts in their child and can detect subtle signs of decompensation that staff/providers may not recognize.^{31,32} Providers should encourage families to speak up and carefully consider family input when formulating treatment plans. Beyond family-centered rounds, hospitals should actively integrate patient/family input throughout hospitalization (e.g., unit transfers, nursing shift changes, multidisciplinary team meetings).

Consistency of care (between hospital and home and across hospital units) is especially valued by families. However, it may not always be possible to replicate home care in the hospital (e.g., administering medications at the same time as home). Being transparent about hospital limitations and processes (including frustrating ones) with patients/families is crucial to improving patient experience. Nurses and physicians can orient patients/families at admission about daily schedules (e.g., shift changes, timing of cares), and unit and hospital limitations. For instance, they can share expected response times to call bells and that medications may be administered at different times than at home. Transparency and compassion about such limitations is essential (e.g., acknowledging families can sometimes provide better, nearly continuous care at home). This transparency can help promote family-medical team rapport and trust.

Families also identified concerns with inconsistency in communication between and across units. Widely implementing standardized communication processes such as I-PASS for handoffs^{20,33} and family-centered rounds^{20,34} can help improve consistency of communication and shared understanding among team members, which has been shown to improve patient safety.

One criticism of family safety reporting is that it may lead families to report many incidents of perceived low importance.¹² However, even seemingly minor family-reported quality issues can have profound safety implications. If hospitals do not take these quality concerns seriously, there is potential to erode trust, impact patient experience, and miss systemic lapses that can lead to patient safety issues. For example, problems with bed rails, objects being left on the floor, and inconsistent policies can all have safety implications. Notably,

these are events that staff may deem too minor to report in VIR, and thus may go unnoticed. However, such concerns are important to families, and may be relatively easy to remedy.

Our study has practical implications for hospitals and clinicians (Table 3) and led to several local efforts. QI efforts resulting from this project included a family-centered medication reconciliation 24 h after admission to confirm the accuracy of ordered inpatient medications. Additionally, we created an individualized environmental plan (IEP) which outlines patient/family inpatient care preferences (e.g., positioning). Families of CMC frequently identify medication errors, which are ubiquitous. Barriers to medication reconciliation in CMC include medication complexity, number, timings, frequent changes, PRNs, and administration nuances. Thus, particular attention should be given to partnering with families of CMC to confirm medication timing, route, and PRNs. Care must be taken for certain medication types and patients on ketogenic diets. Reviewing medications with families of CMC by problem or category (including seizures, breathing, gastrointestinal, pain, tone, skin, and PRNs) may be helpful. Families should also be asked about their child's "sick day" plans for seizures and respiratory medications so treatments can be escalated appropriately during illness. Further scholarship and QI work are needed to improve medication reconciliation for CMC.

Additionally, hospitals and clinicians can better manage expectations with families about limitations of hospital care on admission. Clinicians should also acknowledge family expertise in their child's medical management and listen when families share concerns. Hospitals can be more transparent about errors and AEs since families are aware they occur, appreciate disclosure, and transparency helps build trust. Finally, while it was conducted in CMC, our study has implications beyond pediatrics into adult and geriatric populations.

Our study's limitations include generalizability, as the study was conducted on a dedicated service for CMC at one quaternary care hospital. We surveyed English-/Spanish-speaking families and excluded international patients. The experiences of other families may vary. Additionally, the onset of COVID-19 made recruitment challenging and necessitated a data collection pause.

CONCLUSION

Families of hospitalized CMC expressed a variety of concerns with safety/quality implications for hospitals, including lack of consistency in care and unmet expectations. Families also experienced communication lapses, both with primary providers and subspecialists. Family expertise was not always considered initially. Ultimately, families valued transparency and communication about safety. Therefore, encouraging open discussion can enhance patient/family trust and experience, even after errors occur. Providers can improve patient experience and safety by managing expectations around limitations of hospital processes; better orienting families; recognizing family expertise; encouraging families to speak up and listen when they do; and being transparent about mistakes. Soliciting input from families of hospitalized children can help hospitals improve safety/quality in ways that are meaningful to families and might otherwise be missed.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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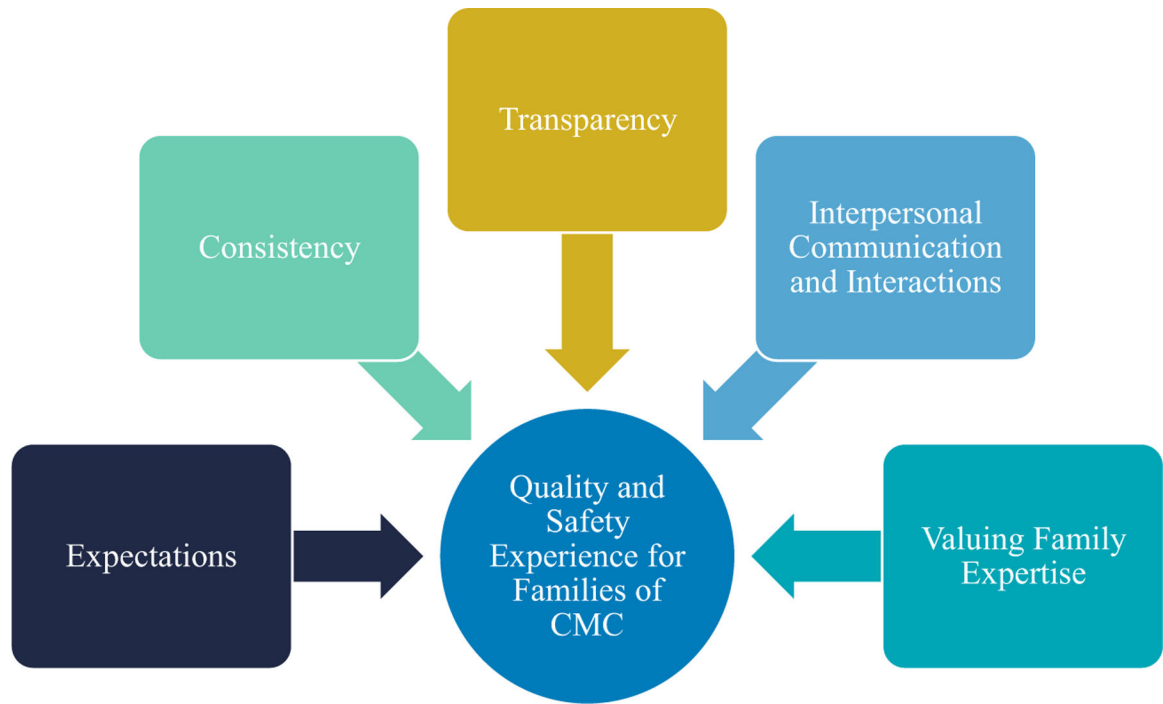


FIGURE 1. Five themes emerged that influence the quality and safety experience for families of children with medical complexity (CMC).

TABLE 1a

Participant characteristics ($N = 207$).

Characteristic	<i>n</i> (%)
Relationship to patient ($n = 205$)	
Parent	190 (92.7)
Grandparent	4 (2.0)
Guardian	7 (3.4)
Foster parent	3 (1.5)
Other ^a	1 (0.5)
Age in years ($n = 201$)	
Mean (SD)	48 (11.0)
Gender ($n = 205$)	
Female	168 (82.0)
Male	37 (18.0)
Race and ethnicity ($n = 205$)	
American Indian or Alaskan Native, non-Hispanic	1 (0.5)
Asian/Pacific Islander, non-Hispanic	5 (2.4)
Black/African American, non-Hispanic	9 (4.4)
White, non-Hispanic	152 (74.2)
Other, non-Hispanic ^b	4 (2.0)
Multiracial, non-Hispanic ^c	4 (2.0)
Hispanic	30 (14.6)
English proficiency ($n = 205$)	
English proficient	174 (84.9)
Limited English proficient	31 (15.1)
Education ($n = 206$)	
8th grade or less	6 (2.9)
Some high school, but did not graduate	5 (2.4)
High school graduate or GED	33 (16.0)
Some college/university or 2-year degree	61 (29.6)
4-year college/university graduate	56 (27.2)
More than 4-year college/university degree	45 (21.8)
Annual household income ($n = 199$)	
<\$50,000	86 (43.2)
\$50,000–\$100,000	52 (26.1)
\$100,000	61 (30.7)
Health literacy (newest vital sign) ($n = 178$)	
High likelihood (50% or more) of limited literacy	11 (6.2)
Possibility of limited literacy	26 (14.6)
Adequate literacy	141 (79.2)
Parent–patient activation measure score ($n = 191$) ^d	
Mean (SD)	77.3 (17.1)

^aThe other relationship to patient category includes adoptive parent (1).

^bThe other non-Hispanic category for race and ethnicity includes Cape Verdean (1); Somalian (1); Portuguese and American (1); Unknown (1).

^cThe multiracial category includes Black/African American and Caribbean (1); American Indian or Alaskan Native and White (2); American Indian or Alaskan Native and Asian Indian (1).

^dParent activation was measured using the parent–patient activation measure (P-PAM), which assesses a parent/caregiver’s knowledge, skill, and confidence in managing their child’s care.¹⁵

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TABLE 1b

Patient characteristics.

Characteristic	(<i>n</i> = 207) <i>n</i> (%)
Admit age in years (<i>n</i> = 207)	
Mean (SD)	14 (7)
Gender (<i>n</i> = 207)	
Female	91 (44.0)
Male	116 (56.0)
Race and ethnicity (<i>n</i> = 203)	
Asian/PI, non-Hispanic	2 (1.0)
Black, non-Hispanic	20 (10.9)
White, non-Hispanic	146 (71.6)
Other, non-Hispanic	5 (2.46)
Multiracial, non-Hispanic ^a	1 (0.5)
Hispanic	29 (14.2)
Stayed at ICU (<i>n</i> = 207)	
No	148 (71.5)
Yes	59 (28.5)
Length of stay in days (<i>n</i> = 207)	
Mean (SD)	10 (14)
Range	[1–88]
Lifetime overnight hospitalizations (<i>n</i> = 207)	
Mean (SD)	22 (24)
Range	[0–200]
Years part of complex care program (<i>n</i> = 207)	
Mean (SD)	7 (6)
Range	[0–30]
Insurance (<i>n</i> = 206)	
Commercial	101 (49.0)
Public	105 (51.0)
Other	0 (0.0)
Complex chronic condition, number (<i>n</i> = 207)	
Mean (SD)	4 (1)
Range	[0–7]
Complex chronic condition, type (<i>n</i> = 207) ^b	
Cardiovascular	16 (7.7)
Gastrointestinal	157 (75.8)
Hematologic or immunologic	17 (8.2)
Malignancy	1 (0.5)
Metabolic	58 (28.0)
Neurologic and neuromuscular	160 (77.3)
Other congenital or genetic defects	57 (27.5)

Characteristic	(n = 207) n (%)
Renal and urologic	30 (14.5)
Respiratory	37 (17.9)
Premature and neonatal	5 (2.42)
Technology dependent	177 (85.5)
Transplant	0 (0.0)

^aThe multiracial non-Hispanic category for race and ethnicity includes White and Other (1).

^bNumbers in each category are not mutually exclusive.

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TABLE 2

Categories of family safety concerns.

Categories	Examples
Cares	“They did not clean properly between his fingers and toes. It smelled really bad. After I mentioned [they] made the effort to clean him better, like shampooing his hair...”
Communication	“As they are telling me I’m not allowed to feed him, I’m feeding him. Within 2 min they had received the order to feed him ... Major communication issue between doctor and staff. Spoke with charge nurse and immediately had the doctor in there ... She came in and said “I don’t know what the problem was, I had wrote this order 3 days ago.”
Compliments	“Some of the nurses know my child better than some of the doctors, so they are reminded that when you give her ativan, it can be a lot and knock her out. One nurse is great with this and is on it with telling the doctors.”
Delays in care	“He received his seizure meds later than scheduled. He then had seizures in the morning...”
Diagnosis	“They took a while to find the right bacteria to be treated and my son had so much [of] the wrong antibiotic before.”
Environment	“I came in my daughter’s room to find her in the room by herself, face flat on her bed and g-tube not secured”
Equipment	“Oxygen was unplugged” “G-tube/feeding bag clamped incorrectly”
Feeds	“The formula was given at the wrong amount. Formula was not the home formula - they said they would change it if the hospitalization went on. It did and no change was made.”
Medications	“One seizure med was missed at 2 pm caught by nurse and administered then which was 5 h later. They gave 3rd dose midnight to at home[sic] him up. This could have caused breakthrough seizure.”

Clinician and hospital strategies to partner with families in the inpatient setting to improve safety and quality.

TABLE 3

Strategies	Examples
Manage expectations with families about limitations of hospital care	"We may not be able to give medications at the exact same times you do at home."
Orient patient/families at the start of the shift about what to expect	"Here's the schedule for the day. First, the nurses will change shift at 7 a.m., then they will give 8 a.m. meds. Then the medical team will stop by for rounds between 9 a.m. and 12 p.m."
Listen to and acknowledge family expertise in their child's medical management	"You are an expert in your child's care. We want to hear your thoughts."
Be transparent about errors and adverse events	"We wanted to let you know that the delay in your child's medication was because the nurse realized that the pharmacy sent up the wrong dose. We reordered the right dose before giving it to your child."
Improve the consistency of care and communication	"Please let us know if your child has any specific needs that you want to make sure get passed along from one provider to another. For instance, positioning, room temperature, bathing, and medication flushes."