BACKGROUND: Children with medical complexity (CMC) often require complex medication regimens. Medication education on hospital discharge should provide a critical safety check before medication management transitions from hospital to family. Current discharge processes may not meet the needs of CMC and their families. The objective of this study is to describe parent perspectives and priorities regarding discharge medication education for CMC.

METHODS: We performed a qualitative, focus-group–based study, using ethnography. Parents of hospitalized CMC were recruited to participate in 1 of 4 focus groups; 2 were in Spanish. Focus groups were recorded, transcribed, and then coded and organized into themes by using thematic analysis.

RESULTS: Twenty-four parents participated in focus groups, including 12 native English speakers and 12 native Spanish speakers. Parents reported a range of 0 to 18 medications taken by their children (median 4). Multiple themes emerged regarding parental ideals for discharge medication education: (1) information quality, including desire for complete, consistent information, in preferred language; (2) information delivery, including education timing, and delivery by experts; (3) personalization of information, including accounting for literacy of parents and level of information desired; and (4) self-efficacy, or education resulting in parents’ confidence to conduct medical plans at home.

CONCLUSIONS: Parents of CMC have a range of needs and preferences regarding discharge medication education. They share a desire for high-quality education provided by experts, enabling them to leave the hospital confident in their ability to care for their children once home. These perspectives could inform initiatives to improve discharge medication education for all patients, including CMC.
The transition home from inpatient care can trigger failures in care, including miscommunications among health care team members and family, omissions or inaccuracies in medication teaching, and difficulty obtaining necessary equipment. Although research efforts in recent years have been focused on improving hospital discharge processes, there remain few standards for safely shifting the burden of medical care from the hospital team back to the child’s caregiver, usually the parent. Parents have been shown to have variable understanding of discharge medication instructions, including medication names, dosages, and durations. Unsurprisingly, outpatient adverse drug events are common, and many families experience at least 1 medication error after hospital discharge. Children with medical complexity (CMC), those with long-term medical problems requiring multiple specialists and/or technology dependence for survival, are particularly vulnerable to medication errors after hospital discharge compared with children without complex, chronic disease. To minimize these errors, discharge medication education should provide a critical safety checkpoint before medication management is transitioned back to the family. Furthermore, medication education should engage families because their engagement can be a key driver of successful transition home. Standardized discharge-related interventions in the adult population, such as having trained discharge educators engage with patients at multiple touch points before or after discharge, have been shown to reduce the likelihood of hospital readmission. Pediatric studies have examined the transition from hospital to home but have not specifically concentrated on the impact medication teaching has on these transitions. Additionally, family engagement specific to medication education at the time of discharge is understudied, and it is unclear if current discharge processes meet the needs of CMC and their families. The aim of this study was to evaluate the perspectives and priorities of parents of CMC on medication education at the time of hospital discharge, including teaching received, information and materials desired, and challenges experienced. Identifying and describing these priorities and preferences could provide valuable information about specific improvement opportunities for handoff from hospital to family and directly inform improvement efforts concerning medication education at the time of discharge.

METHODS

Research Setting
This study was conducted during April and July 2019 at a freestanding children’s hospital in the western United States, with ~650 CMC receiving outpatient care at the associated complex care clinic. Current discharge processes include providing hospital discharge instructions to families: paper documents with both manually and automatically populated fields, including discharge medications and care instructions for home. Hospital discharge instructions are reviewed with the family before discharge, typically by the bedside nurse. There is no standard procedure for review of discharge medications with the patient and family; this may be performed by the nurse, physician, pharmacist, or advanced practice provider.

Participants and Procedures
Recruitment for each focus group began 2 days before it was scheduled to occur. Participants were parents of currently hospitalized children who met the following criteria by electronic health record (EHR) review: (1) hospitalized on acute-care floors or ICUs, (2) had at least 1 previous hospital discharge, (3) were documented as taking at least 3 medications before admission, (4) had a parent who spoke English or Spanish, and (5) met the definition of CMC according to the Pediatric Medical Complexity Algorithm. With permission from the patient’s treatment team, eligible participants were invited by the study team to participate in a 1-hour focus group, with 2 focus groups facilitated in English and 2 in Spanish. All participants had children who were hospitalized at the time of participation. All participants signed written informed consent at the time of the focus group, including consent for audio recording. Target enrollment was 8 to 12 participants per focus group so as to promote robust discussion. At the completion of the focus group, each participant was given a $20 retail gift card. This study was approved by the institutional review board.

Data Collection
Focus groups were facilitated by 2 members of the research team, neither of whom was part of any participant’s care team, to ensure participants understood the design of the study and to assist in moving discussion efficiently. Participants were asked to first complete a brief questionnaire, which was used to assess the participant’s age, income, level of education, and preferred language, as well as their child’s age, medical complexity, number of long-term medications, and number of previous hospitalizations. The questionnaire also included a validated single-question assessment of health literacy: “How confident do you feel completing medical forms?” This question was answered with a 5-point Likert scale, ranging from “Extremely” to “Not at all.”

A semistructured focus group guide was devised by the multidisciplinary research team, including physicians (2 pediatric hospitalists and 1 pediatric resident), a nurse practitioner, a pharmacist, and a nurse scientist, and was reviewed by an expert in qualitative methods as well as a parent of a CMC who is a member of the institution’s family advisory council. The guide was translated into Spanish by a professional medical interpreter. The guide was used for all sessions, with the same questions asked of all participants. Questions were divided into 5 sections: (1) individual established routines for medication administration at home, (2) experiences in medication changes and teaching strategies used by providers, (3) previous experiences in medication education at discharge, (4) gaps in medication teaching at discharge, and (5) assessment of both a current state discharge medication list and an alternate discharge medication list. The former was an entirely alphanumerical text-based document, and the latter was augmented by
pictograms (images of pills and syringes for medication type, images depicting the time of day). These medication lists were provided to query parent preference for written or pictographic instructions. The focus group guide can be found in Supplemental Table 3. Focus groups were audiotaped, transcribed verbatim, and translated into English (if conducted in Spanish).

**Analysis**

Responses to the demographic questionnaire were tabulated and presented as percentages and medians where applicable. A qualitative, focused ethnographic methodology was conducted to understand the perspectives of caregivers of CMC in regard to medication education at the time of discharge. The primary aim of focused ethnography is to allow the researcher to investigate a particular phenomenon in a specific setting and/or group of people, which for the purposes of this study was defined as parents of CMC.17,18

One team member was a trained qualitative researcher and all other members received coding training for categories and themes. Every member of the study team reviewed each transcript individually with the development of a shared codebook. Subsequently, focused group coding sessions occurred over multiple meetings with all members of the research team present. Triangulation was used to sort out the “true” information from irrelevant information19 and allow for resolution of discrepancies. Initial coding was used to pull data into pieces such as words, situations, fragments, and focused coding involved analysis of the most meaningful codes.20 Codes were grouped into categories. The overarching themes were defined as abstract entities that brought meaning and unity to the experience of the study participants. Thematic saturation was achieved when no new information was attainable and additional coding was not feasible.21,22

**RESULTS**

Thematic saturation was achieved after the completion of 4 focus groups and repetitive patterns were observed. Approximately 48 patients and/or parents were eligible for inclusion and approached by a member of the study team. Four parents declined participation; 20 parents changed their mind on the day of the focus group; reasons included unanticipated discharge, newly scheduled interventions for their child, or the parent no longer felt comfortable leaving their child’s bedside at the time of the focus group. Twenty-four participants (12 English speaking, 12 Spanish speaking) participated across 4 focus groups. Twenty-three participants partially completed the questionnaire, 19 of whom answered all the questions. Participant characteristics are presented in Table 1. When asked about their confidence in completing medical forms, as an assessment of health literacy, the majority (74.8%) reported they were extremely or quite a bit confident in their ability to complete forms.16

From thematic analysis of the codes generated, multiple themes emerged as parental ideals for discharge medication education: (1) quality of information, including desire for complete, consistent information in preferred language; (2) information delivery, including education timing before discharge, delivery by experts, and sufficiency of time dedicated; (3) personalization of information, accounting for health literacy of parents and level of information desired; and (4) self-efficacy, or the education resulting in the parents’ confidence to conduct the medical plan at home. Themes of the qualitative analysis, as well as illustrative quotes, are presented in Table 2.

**Quality of Information**

Overall, participants described a desire to learn about their children’s medicines, particularly medication indications and possible side effects. Parents also reported lack of consistency between information distributed by medical teams and information provided by pharmacies. There was frequent confusion created between generic and brand name medications and by variations in formulation or concentration between original prescriptions and what was dispensed by pharmacies, as quoted below:

Medications [are] coming in different milligram-sized pills or different concentrations for oral suspensions. And the medications that we’re getting from our outpatient pharmacies aren’t necessarily the same pill size or the same concentration as what we’re getting from inpatient pharmacies or while we’re inpatient.

**Information Delivery**

The discharge process was frequently described by participants as feeling rushed, with inadequate time and space for questions and verification of information. They described instances in which errors in medication reconciliation were not noted until after discharge from the hospital:

When you’re sitting there and you’re wanting to go home after seven weeks and you’re just wanting to get the hell out of there and they’re going over it fast because they are whatever. And I’ve gotten home and looked and there have been, I mean, grave mistakes.

Parents proposed a designated discharge educator well-versed in the medical history of their child with expertise around their child’s discharge medications. An example is described here:

Maybe someone who is an RN who has that medical knowledge, but that their role is to facilitate the discharges and educate the parents and do whatever needs to be done...

**Personalization and/or Individualization of Information**

Participants expressed appreciation for education tailored to their needs, including color coding of medications for a parent who could not read or write, or simply assessing the amount of information desired.

For some parents they get curious about it [and want to know] what is all this doing? Does she need all of this? Might help just understanding it a little better. Then there’s some that might not want to know just like, “Okay, well if they said so, here we go.”

They also noted their needs changed over time as they adjusted to their child’s illness:
When she was younger and had a lot more medications, I think something more like a spreadsheet would have been easier, especially at the onset of everything...But the papers [that have all the information on them], it gets confusing and it kind of muddles everything. And it's like, okay, I just need highlighted, bullet points of what I need to know and when I have time I can go look at the rest. But half the time I don't even get to looking at the rest because I'm still trying to deal with getting a routine with all."

Self-Efficacy

Self-efficacy was also important to focus group participants.23 Participants expressed a desire to leave the hospital confident in their ability to safely deliver medications to their child at home, as described here:

I want to do whatever it takes to make sure I bring her home and I make her comfortable and however long we have with her, or if God blesses for years to come, then so be it. But I would love to learn, obviously, how we're going to be able to feed her and help her gain weight. What to watch for as far as if we need to take her back to the hospital, and just how to make her grow.

DISCUSSION

Although medication failures, including lack of a clear plan or difficulty filling prescriptions after hospitalization, are commonly reported by families,24 the act of educating parents regarding new or changing medications at time of discharge has been relatively understudied. In our qualitative focus group study of parents of CMC, parents reported shortcomings in discharge medication education. The parents we interviewed reported a broad spectrum of needs and preferences in the timing, content, and delivery of medication education. Parents consistently expressed a desire for high-quality, timely medication education that instills confidence in them to carry out the medical plan at home.

Improving discharge medication education for families leaving the hospital may in turn decrease outpatient adverse drug events and possibly revisits or readmissions.5,25,26 Timing of discharge medication education may play an important role. In a study of medication adherence after stem cell transplant, authors found parents desired teaching earlier in the hospitalization.14 In other publications, authors have described parents as being "in a fog" at the time of discharge and unable to process key information.15 Our focus group participants described medication review and teaching at discharge as rushed; many expressed a desire for the teaching to occur repeatedly and when both the receiver and giver of the information had ample time to absorb the material and ask and answer questions. Our findings build on these previous observations of parental health literacy and self-efficacy being a dynamic and
## TABLE 2  Themes, Categories, and Representative Quotes From Focus Groups

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<tr>
<th>Theme</th>
<th>Category</th>
<th>Representative Quotes</th>
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<tbody>
<tr>
<td>Quality of information</td>
<td>Desire complete and clear information</td>
<td>“Okay, these two heart meds are working together to do what?...We found ourselves looking up and learning about them ourselves...I know they give you that print out...that's with everything in a folder...So maybe they kind of talk to you about it and explained it, which kind of makes you feel more understanding of knowing what this medicine I'm giving to my newborn daughter that's this big and I'm giving her this much medicine it's like, 'What is all this going to do?'”</td>
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<td></td>
<td>Desire consistency of information</td>
<td>“One of my fears is always the side effects. I always, always ask about that.”</td>
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<td></td>
<td>Prefer discharge instructions around medications in their language</td>
<td>“I think they should make sure they just put the same name on the bottle and the paper; because the prescription they give you, sometimes it has one name and on the bottles they give you from the pharmacy it has another name. And so, well, for me it's much more confusing; for everyone, I know. They should coordinate and, please, put the same name.”</td>
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<td>Information delivery</td>
<td>Wish for education at time of discharge to not feel rushed</td>
<td>“I do not understand English well, also trying to have communication with the medical team and nurses and telling them, please can they print it for me in Spanish. Same at the pharmacy, if we go and the bottle is in English, I can say can you change it to Spanish for me?”</td>
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<td></td>
<td>Expert educator desired</td>
<td>“Even nurses, they get confused and...they don't know a lot of why the doctors are giving this. They don't know the history or the story of it or why they're taking this.”</td>
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<td></td>
<td>Desire sufficient time for teaching to allow families to demonstrate understanding</td>
<td>“So it was good to have training. I wish we had a little bit more training. I feel like it was maybe one day...Yes...I could have used maybe another round of it.”</td>
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<td>Personalization and/or individualization</td>
<td>Parents want schedules, lists, and use of graphics tailored to their specific needs</td>
<td>“I mean, it needs to be at least a day ahead of time where no one is feeling rushed and you have a little bit of separation to think of ‘Oh, I didn't ask this...’”</td>
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<td></td>
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<td>“And you're discharged in and out a couple times, is we've had a couple times ask, ‘What times do you do your meds at home now?’ Because coming in and getting discharged can throw off your whole schedule for medications.”</td>
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<td>“I also liked it because it [medication instruction sheet] has like the little picture of the face, how it is and what color more or less and also it tells you—it has very small letters, but it tells you more or less what it has and all of that.”</td>
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|                               |                                             | “…when I left here the first time, when I had many medications; ones from cardiology, the nurses, they gave me options, and I took the most—they
context-dependent state by showing that concerns around timing of education arose for parents with varying levels of education and children with a variety of conditions. For this reason, we advocate for improved processes that allow education to be provided to parents at their preferred time and pace.

Inconsistencies in information received from the hospital and the pharmacy is a common occurrence, and the parents we interviewed echoed this. Furthermore, they expressed a desire to have knowledge of both brand and generic names as well as suspension concentrations at their fingertips so they could resolve these discrepancies independently. Knowledge of adverse effects of medications has been shown to be a common gap when parents are queried about their child’s medication after discharge. Parents we interviewed sought this information, suggesting this gap is an opportunity to tailor discharge medication education content. Regarding the delivery of discharge education, adult studies demonstrate that dedicated discharge providers have been associated with lower readmission rates. No pediatric studies to our knowledge have replicated this effect. Despite this, another theme we encountered was the desire for the clinician providing medication education to have expertise in both their child’s care and the medications being prescribed. The positive impact on parents’ confidence in conducting the discharge plan is important to their satisfaction, and in studies of families’ overall discharge experiences, authors have found self-efficacy to be a central focus. The parents we interviewed emphasized value on self-efficacy and wished to be provided tools and education to both implement the medical plan at home and troubleshoot any issues that arose.

The perspectives highlighted in the current study could inform improvement initiatives for quality of discharge medication education. Implementing a discharge checklist, including enhanced medication review, has improved patient satisfaction and family readiness for discharge. A structured discharge team, consisting of providers with medical knowledge of the patient and in-depth understanding of medications, such as a physician, advanced practice provider, or pharmacist specializing in transitions of care, would be well poised to provide this education. Although it may not always be feasible to provide all education well in advance of discharge because some medication changes on the day of discharge may be unanticipated, having a dedicated team may take some of the time pressure off already busy frontline providers, allow for more time for teaching, and promote family engagement. Incorporating photographs into discharge instruction or ensuring multimodal teaching, including in-person education and educational videos, in addition to paper instructions, may improve confidence and parent satisfaction. There are also opportunities within the EHR to provide more complete, concordant, and

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<th>Theme</th>
<th>Category</th>
<th>Representative Quotes</th>
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<tbody>
<tr>
<td>Self-efficacy</td>
<td>Demonstrate use of memory aids</td>
<td>“I use a pill reminder.”</td>
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<td>“And I make a schedule, I make my schedule and I see the times and also on my phone, the alarm can be used.”</td>
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<td>“I took a box of markers and I mark the lid of the bottle and where it has the prescription, where it has the medicine, on this side, I put the same color as the lid and used it like a big box, either another color and the color of the lid. So, when I prepare my medicines, I guide myself with the colors; I do not have to read, because I do not really know how to read, very little.”</td>
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<td>Value self-reliance</td>
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<td>“Just be on top of it. I make sure he knows, too, just in case one day I’m not there, if someone else is giving him something, that he knows also what meds he needs, how many pills are correct. And it’s all in my head. But I also have a small piece of paper where I’ve written it for anybody else who might need to get something.”</td>
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<td></td>
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<td>“Ultimately it comes down to we are responsible for providing our children with the correct medication when they need it. And so we need to have the tools to understand how to figure out on our own that the medication is correct.”</td>
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TABLE 2 Continued
Parents of medically complex children cited barriers to feeling confident in administering medication to their children after hospital discharge and reported a wide spectrum of needs and preferences for discharge medication education. Overall, families of medically complex children want high-quality discharge medication education provided by experts that allows them to leave the hospital feeling confident in their ability to care for their child once home. The next steps already underway at our institution to address the needs expressed by parents in our focus groups include improvements to the literacy level and translation of our EHR-generated discharge medication lists as well as piloting a new discharge pharmacist role.

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Parent Perceptions and Experiences Regarding Medication Education at Time of Hospital Discharge for Children With Medical Complexity
Jessica M. Gold, Whitney Chadwick, Melissa Gustafson, Luisa F. Valenzuela Riveros, Ashley Mello and Annette Nasr
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