

# The Family Perspective on Hospital to Home Transitions: A Qualitative Study

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abstract

**BACKGROUND AND OBJECTIVE:** Transitions from the hospital to home can be difficult for patients and families. Family-informed characterization of this vulnerable period may facilitate the identification of interventions to improve transitions home. Our objective was to develop a comprehensive understanding of hospital-to-home transitions from the family perspective.

**METHODS:** Using qualitative methods, focus groups and individual interviews were held with caregivers of children discharged from the hospital in the preceding 30 days. Focus groups were stratified based upon socioeconomic status. The open-ended, semistructured question guide included questions about communication and understanding of care plans, transition home, and postdischarge events. Using inductive thematic analysis, investigators coded the transcripts, resolving differences through consensus.

**RESULTS:** Sixty-one caregivers participated across 11 focus groups and 4 individual interviews. Participants were 87% female and 46% nonwhite; 38% were the only adult in their household, and 56% resided in census tracts with  $\geq 15\%$  of residents living in poverty. Responses from participants yielded a conceptual model depicting key elements of families' experiences with hospital-to-home transitions. Four main concepts resulted: (1) "In a fog" (barriers to processing and acting on information), (2) "What I wish I had" (desired information and suggestions for improvement), (3) "Am I ready to go home?" (discharge readiness), and (4) "I'm home, now what?" (confidence and postdischarge care).

**CONCLUSIONS:** Transitions from hospital to home affect the lives of families in ways that may affect patient outcomes postdischarge. The caregiver is key to successful transitions, and the family perspective can inform interventions that support families and facilitate an easier re-entry to the home.

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**WHAT'S KNOWN ON THIS SUBJECT:** Transitions from hospital to home are stressful for patients and families. If unsuccessful, these transitions can lead to suboptimal patient outcomes, such as hospital readmission. Interventions that are family-centered are key to successful transitions from hospital to home.

**WHAT THIS STUDY ADDS:** Hospital-to-home transitions affect families. This study provides an in-depth look into transition-related experiences, beliefs, challenges, and needs. The family's voice can be used to inform the design of interventions aimed at improving care delivery during the transition period.

The transition from the hospital to the home is a vulnerable time for patients and their families. This experience is associated with increased family stress,<sup>1-4</sup> which can occur with hospitalizations of any duration, including those for common, acute conditions that typically resolve without long-term medical sequelae.<sup>5-7</sup> Stress can impede safe transitions home for children and families. The complexity of the discharge process and disjointed nature of the health care system can further complicate transitions<sup>8,9</sup>; 1 in 5 families report major problems with the transition, which may place children at risk of poor outcomes.<sup>3,10</sup>

Poor transitions may lead to suboptimal patient outcomes. Readmissions may reflect poor hospital-to-home transitions. In children, readmissions occur at a rate of ~13%, considerably lower than that for adults.<sup>11-13</sup> Other consequences include emergency department revisits, medication errors, primary care provider dissatisfaction with communication or confusion regarding discharge care responsibilities, patient or family dissatisfaction, and unanticipated out-of-pocket costs.<sup>14-20</sup> Current care delivery models propagate fragmented transition processes that place undue burdens on patients, families, and the health care system.

The importance of successful transitions is recognized by leading academic societies in medicine, pediatrics, and nursing. These societies have identified the need for novel patient- and family-centered approaches to improve transitions in ways that ensure safe discharge to the home.<sup>15,21,22</sup> Improvement efforts are directed at multiple facets, including communication with families and primary care providers, coordination of care, and family understanding of and comfort with management plans.<sup>21</sup> Ideally, planning for discharge should begin soon after a

patient is admitted and evolve during the hospitalization. The amount of information families receive about new diagnoses or complications of an existing diagnosis, adjusted medication regimens, or need for outpatient follow-up can be overwhelming and affect a family's comfort and adherence to postdischarge care.<sup>23,24</sup> Families may also experience a sense of abandonment if they are unable to contact their inpatient health care providers for postdischarge guidance.<sup>25</sup>

The design and implementation of interventions that address these issues and improve transitions are crucial to avoiding postdischarge complications. We expect that successful interventions will need to be family-centered. Thus, we sought to develop a comprehensive, qualitative understanding of hospital-to-home transitions from the family perspective and to identify commonly experienced barriers to successful transitions. A greater understanding of barriers, from the voice of the family, would allow us to more effectively tailor transition interventions.

## METHODS

### Setting

This is an institutional review board-approved study at the Cincinnati Children's Hospital Medical Center (CCHMC), a free-standing, academic children's hospital with >500 inpatient beds. Approximately 8000 children are hospitalized annually for general pediatric conditions, with ~85% of such admissions staffed by hospitalists.

### Study Design

Focus groups and individual in-depth interviews were selected as the optimal methodology to generate consensus themes about patient and family experiences and preferences during the transition period. Parents

or caregivers of children discharged with common, acute medical conditions were eligible for recruitment if they were English speaking, had a child admitted to Hospital Medicine, Neurology, or Neurosurgical Services, and could attend a focus group within 30 days of discharge. Caregivers of children  $\geq 18$  years of age or those who were hospitalized for a psychiatric diagnosis, discharged to a care facility or institution, in the custody of the county or state, or were already receiving home health services were excluded.

The sample was stratified by the family's socioeconomic status because experts in focus group formation have noted that focus group participants are more willing to talk openly when among participants of similar backgrounds.<sup>26,27</sup> Thus, socioeconomic strata were established by mapping participants who resided within socioeconomically similar areas. Census tracts, relatively homogeneous areas of ~4000 individuals, were chosen as our primary geographic unit given their relative homogeneity and their utility in detecting socioeconomic gradients through a linkage to US Census American Community Survey poverty data.<sup>28-31</sup> We defined thresholds that separated individuals into 2 socioeconomically distinct groupings on the basis of the proportion of patients with a home address in a census tract with <15% or  $\geq 15\%$  of the population living in poverty.<sup>31</sup> These cut-points enabled us to ensure an equivalent number of eligible focus group participants within each stratum and diversity in our sample.

### Data Collection

Parents or caregivers were recruited on the inpatient unit during their child's hospitalization. Participants returned to CCHMC facilities for the focus group within 30 days of discharge. Although efforts were made to enhance participation by

scheduling sessions at multiple sites and on weekdays, evenings, and weekends, 4 sessions yielded just 1 participant; thus, the format for those sessions became an individual interview. Child care was provided, and participants received an incentive gift card for attending.

An open-ended, semistructured question guide, developed de novo by the research team, was used to direct the discussion for focus groups and interviews (Appendix). As data collection progressed, the question guide was adapted to incorporate new issues raised by participants. Questions focused on aspects of the inpatient experience, discharge processes, and health system and family factors thought to be most relevant to patient- and family-centered outcomes. An experienced moderator (S.N.S.) used probes to further elucidate responses and expand discussion by participants. Sessions were held in private conference rooms, lasted ~90 minutes, were audiotaped, and were transcribed verbatim. Identifiers were stripped and transcripts were reviewed for accuracy. After conducting 11 focus groups and 4 interviews, the research team determined that thematic saturation<sup>32</sup> was achieved, and recruitment was suspended.

### Data Analysis

An inductive, thematic approach was used for analysis. Transcripts were independently reviewed by a multidisciplinary team of 4 researchers including 2 pediatricians (L.G.S. and A.F.B.), a clinical research coordinator (S.A.B.), and a qualitative methods expert (S.N.S.) to identify emerging concepts and themes related to hospital transitions and experiences. The varied perspectives of team members yielded a nuanced and robust interpretation of results and helped ensure that the data were analyzed in a nonbiased manner via investigator triangulation.<sup>32,33</sup>

During the first phase of analysis, investigators independently read several transcripts before convening to identify and define initial concepts and themes. A preliminary codebook was designed. The team continued to review and code transcripts independently, then met regularly to discuss coding decisions in a collaborative fashion and to resolve any coding differences through consensus.<sup>33</sup> As patterns in the data became apparent, the codebook was modified in an iterative fashion: adding, subtracting, and refining codes as needed and grouping related codes. Coded data were maintained in an electronic database.

During subsequent analyses of the data, the team created a conceptual model that was used to categorize themes and depict relationships between themes. During this phase, findings were also reviewed in multiple forums with key stakeholders (parents, inpatient and outpatient pediatricians, and home health nurses) with the goal of further triangulation.

## RESULTS

### Participants

Sixty-one parents or caregivers of children discharged from CCHMC participated. Of participants, 87% were female and 46% were nonwhite; 38% were the only adult in their household, and 56% resided in census tracts with  $\geq 15\%$  of residents living in poverty (Table 1). These participant characteristics aligned closely with the demographic characteristics of the children and families admitted to the CCHMC.

### Themes Resulting From Focus Groups and Individual Interviews

The initial analysis revealed 12 major themes and associated subthemes. Each of these themes and subthemes are nested within 1 of 4 overarching concepts. The 4 main concepts were as follows: (1) "In a fog" (barriers to processing and acting

**TABLE 1** Participant Demographic Characteristics

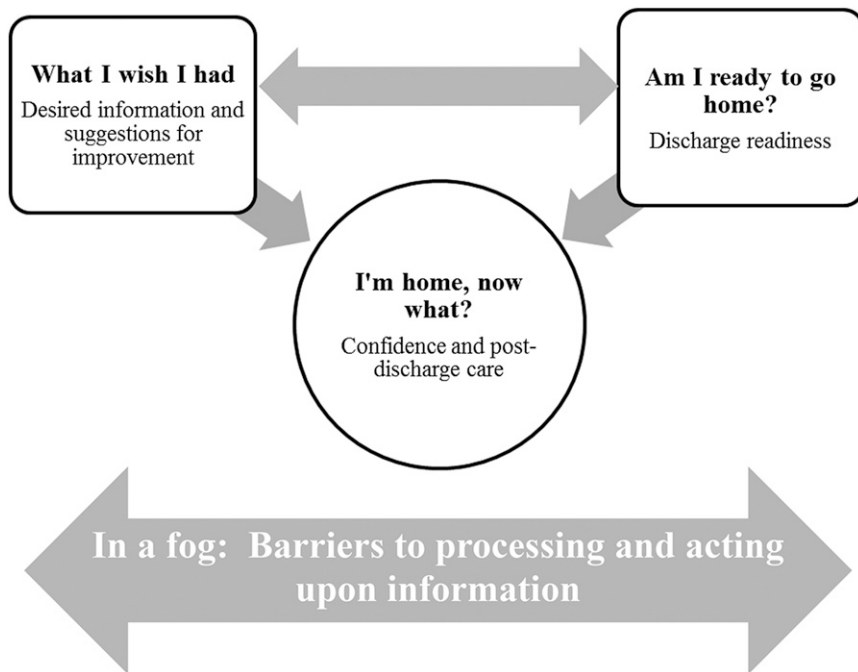
	<i>n</i> (%) <sup>a</sup>
Gender	
Male	8 (13)
Female	53 (87)
Age range	
18–24 years	5 (8)
25–34 years	28 (46)
35–44 years	22 (36)
45–54 years	6 (10)
Marital status	
Single	22 (36)
Single, living with partner	8 (13)
Married	24 (39)
Separated, divorced, widowed	7 (11)
Race	
Black or African American	25 (41)
White	33 (54)
Other	3 (5)
Ethnicity	
Non-Hispanic	59 (97)
Hispanic	2 (3)
Socioeconomic status based on census tract	
High socioeconomic status (<15% below poverty level)	27 (44)
Low socioeconomic status ( $\geq 15\%$ below poverty level)	34 (56)

*N* = 61.

<sup>a</sup> rounded to nearest whole number.

on information), (2) "What I wish I had" (desired information and suggestions for improvement), (3) "Am I ready to go home?" (discharge readiness), and (4) "I'm home, now what?" (confidence and postdischarge care). Using these concepts, we then created a model through which we could understand the family's experience with the hospital-to-home transition as shown in Fig 1.

Participants described "a fog" as "And you kind of . . . you go into a fog when you come here. You forget what day it is, what time," which pervaded their entire experience and affected their ability to process information (concept 1). The continuous interactions between the 3 remaining concepts reveal that these experiences do not occur in isolation. For instance, a caregiver's confidence in caring for his or her recently hospitalized child is dependent on his or her comfort with discharge and with the information about the diagnosis and care received during



**FIGURE 1** Conceptual model depicting key elements of the family's experience with the hospital-to-home transition.

hospitalization. The themes and subthemes that characterize each of the 4 concepts are depicted by representative verbatim quotes contained in Tables 2, 3, 4, and 5.

#### *Concept 1: In a Fog*

There were 4 major themes nested within this first concept highlighting a caregiver's ability to process information: (1) mental exhaustion (this is too much), (2) handling uncertainty, (3) information overload, and (4) usability of information (Table 2). The emotional toll of having an ill, hospitalized child and the accompanying uncertainty was frequently voiced. The amount of information imparted on families during the transition created additional stress for many families. Regarding the usability of information, there were 2 subthemes: actual content received and the relatively common description of unclear messages.

#### *Concept 2: What I Wish I Had*

There were 2 major themes nested within this second concept: (1)

information desired and (2) suggested improvements in the discharge process (Table 3). Concerning desired information, 2 subthemes were identified. The first, general instructions, describes the basic information caregivers want regarding their child's care. Some caregivers acknowledged that the instructions they were given were too general. Others commented on the content of and mode in which they would have preferred to receive information. The second subtheme, red flags/what to watch for, highlighted a strong desire by caregivers to receive details about when to worry and how to manage their child's recovery postdischarge. On the basis of their own experiences, caregivers also shared suggestions for improvement in the discharge process that included adding discharge coordinators and patient advocates to help ease the hospital-to-home transition. They also recommended that information and plans be reviewed in clearer and more consistent terms by health care team members.

#### *Concept 3: Am I Ready To Go Home?*

There were 2 major themes nested within this third concept: (1) emotional discharge readiness and (2) clinical discharge readiness (Table 4). Emotional discharge readiness was often described in different ways, sometimes by the same caregiver. Many discussed feeling relieved about their child getting better and their associated desire to go home. At the same time, many also identified anxiety from the experience of having a child hospitalized. Others acknowledged their unease and lingering concerns with discharge. Clinical discharge readiness related to a patient's clinical progress. Some noted that parental intuition helped them to know when their child was better and ready to be discharged; others relied completely on the medical team's criteria for discharge. Still others commented on the desire for a complete recovery before discharge and the dissatisfaction felt with being sent home too soon.

#### *Concept 4: I'm Home, Now What?*

There were 4 major themes nested within the fourth concept: (1) knowing who to call, (2) bridging the gap (desiring a call or nurse home visit), (3) caring for a sick child, and (4) confidence in caring for a sick child (Table 5). These themes show the stress accompanying the change from 24-hour in-hospital care delivery by an interdisciplinary team to being home where caregivers are responsible for supporting the child through to recovery. Even knowing who, or how, to call with questions after discharge was often unclear. Those who thought that the inpatient team was the best venue for questions did not necessarily know how to get in touch with them after discharge; others were unsure of what their pediatrician knew about their child's hospitalization. Some expressed a desire for follow-up after discharge via phone or a nurse home visit so as to feel supported and

**TABLE 2** In a Fog: Barriers to Processing and Acting Upon Information

Major Themes (Subthemes)	Caregiver Quotes
Mental exhaustion: this is too much	<p>"It's been too much. I've been through too much. I just can't do it... I can't do it."</p> <p>"Because, you know, your child is sick, you're upset and you... you're like just overwhelmed with everything. I mean I'm exhausted every time because I'm always working. So, when I come in here, it's like I'm exhausted. I'm trying to remember everything."</p> <p>"Because if we don't get sleep, I don't know if you're like me, but someone could be telling me, 'you need to do this and this and this to your baby.' And I'm like 'uh-huh, uh-huh...'. And as soon as they leave, I'm like, 'what did they say?...' Right. You are totally nonfunctional and you could only survive on adrenaline for so long."</p>
Handling uncertainty	<p>"For me, it's just the overall abruptness is the most difficult part because you don't know what's going to happen, if they're going to get better because it's always a little bit of a mystery why they're sick to begin with, right? And so, that's the hardest part...how do I know that my child is really getting better, how do I know when we take them off the drugs it's not just going to come back and...but those questions have a way of working themselves out, right?"</p> <p>"How do I know when it's a situation that's really bad and how much time do I have? Because in my mind right now, I had pneumonia once when I was younger, too, and it's like, I never felt like I was about to keel over and die, right?"</p> <p>"Because it [patient's condition] was just going up and down and we would make a little progress during the day, and then at night he wouldn't have any urine output at all."</p>
Information overload	<p>"That was my one complaint and only complaint. I came home with a stack of papers. This big...What in the world?!...Look—this is way too much."</p> <p>"They actually gave us a notebook so that we could make notes of, you know, whatever the doctor told us or how he's doing or what they're doing next. There's one of us here at a time, so we couldn't...you can't remember everything they tell you. And also, so we could write down our questions as they came up for the next round where we wouldn't have to worry about remembering what did you want to ask."</p>
Usability of information (Content)	<p>"I was satisfied this time because I knew what to do in new different scenarios, how to do it without having to panic..."</p> <p>"I literally came home like, 'What?'... Because she was coughing really bad. I'm like, 'Oh, my goodness.' ... We didn't even talk about the cold. '[father of child], you didn't remind me to tell them [the medical team] about the cold.' And he was like, 'Well, what's you up there doing?' You know I forget everything. I don't know. I felt like somebody should have said something to me."</p> <p>"I'm a young mom. That's why it's so hard for me to understand every doctor because I only had her, I'm only 19, so my daughter's 3. So, it's kind of hard."</p>
(Unclear messages)	<p>"Like for us, you see I don't understand her problems, you see I can't say nothing about that because I was scared to leave this hospital."</p> <p>"I'm sitting there like, OK, can somebody explain what's going on because you're all saying 2 different things. One saying he needs to stay here on more antibiotic, you all think you all should change antibiotics and figure out what it is. I'm getting confused for a minute."</p>

receive answers to lingering questions. This desire for a phone call or home visit was especially the case

for those who described challenges with keeping up with a child's changing care needs and managing a

slow recovery or a worsening clinical course. In addition, the barriers and challenges faced by caregivers postdischarge greatly influenced their ability to confidently care for a recently hospitalized child.

## DISCUSSION

We used qualitative methods to understand how the transition from the hospital to home is experienced by families, highlighting informational challenges and varying perceptions of discharge readiness and confidence in providing postdischarge care. The family perspective, or voice, is critical as we develop interventions aimed at improving the effectiveness and safety of the hospital-to-home transition. Health care providers and the health care system increasingly place a premium on interventions that can limit the risk of postdischarge complications. With the expectation that the most successful interventions will target the needs and wants of families, the voice of this key stakeholder, the family, is essential to identify and address barriers to successful transitions.

Various studies, many in adult populations, have created interventions to facilitate a safe transition home, generally altering care models with the aim of decreasing postdischarge health care utilization and costs.<sup>34-42</sup> Care transition theory and other models support that engagement and needs of key stakeholders are important to inform systems-level interventions and improve outcomes.<sup>34,43-46</sup> As a result, some have incorporated the family or patient perspective when evaluating previously implemented interventions.<sup>47-50</sup> Others have shown that family-centered interventions improved certain outcomes, such as satisfaction, discharge readiness, and medication adherence and, in some cases, decreased health care utilization. However, a recent review that

**TABLE 3** What I Wish I Had: Desired Information and Suggestions for Improvement

Major Themes (Subthemes)	Caregiver Quotes
Information desired (General instructions)	<p>“...I was asking them clear as day, what am I supposed to do...what’s her home care, you know, what do you want me to do at home for her? <i>Did you feel like you had a clear idea of what to do in the home?</i> No. Because it was like, watch her. ‘OK, I watch her all the time.’”</p> <p>“And you know, shouldn’t we just let her sleep or should we force her to wake up and eat more. I mean the kind of the midlevel instructions to go over, you know, a lot of it printed out in a bullet-point form and then also go over each of those things and answer questions ... but it was only the 3 bullet points for severe conditions.”</p> <p>“I think [I would want to know the] side effects of ... the medicines that they give them, what can cause it and what can happen if they don’t get enough or how long you should give it to them, the milligrams and everything like that.”</p>
(Red flags/what to watch for)	<p>“But I really would like to see it on my discharge papers ... you had to take his antibiotics for 7 days. Well, on day 8, you know he wakes up in the morning and he has a temperature, you know he’s got a fever. And then I’m thinking, did it say a 100 or does it say 101. Do I run to the ER or just call my doctor and, great, it’s Saturday, you know.”</p> <p>“Like the warning, just like the warning ticket, you know, because they say like if, you know, she doesn’t eat, well, she needs to get checked in because she can’t afford to not eat. She’s losing weight. Well, how long does she have to not eat?... Before I need to call them. What about... and she doesn’t have dirty diapers today. How long does it go before we start to get worried about something like that?... And the difference between what’s the warning sign that, you know, you can just call your pediatrician about, what’s the warning sign you need to bypass the pediatrician and go directly to the ED?”</p> <p>“More symptoms. More signs to look for just in case it came back. But I would just take the more information, the better to prevent...you know things to prevent it from coming back. If there are ways to keep it from coming back. The more information the better is to help so that was the point where I just keep my son in the bubble.”</p>
Suggested improvements in the discharge process	<p>“So you see for efficiency they would hire some type of a discharge coordinator.”</p> <p>“Well, I’m going to put a yellow sticker on the window, then there’s a smiley face and it says, I’m getting out today, this is for real. And then it says, my goal is to be out of here by ... and you write down there with when you talk to them about 2 pm so every person that comes by that door knows.”</p> <p>“I think a lot of return visits to the ER or actual visits to the primary care physician could be avoided if the doctors took time to sit there and say... these are the medications we’re giving. These are the side effects that you should look for or, you know, this is what your child was diagnosed with and make sure before you walk out the door that they have answered every single question no matter how stupid they think it is because no question is stupid when it comes to care of my child.”</p>

ER, emergency room.

included pediatric studies involving only emergency department-to-home transitions highlights that, in pediatrics, family-centered interventions are not routinely informed by solicited input from families.<sup>35</sup> Smith and Daughtrey<sup>3</sup> surveyed parental perceptions after discharge to determine their needs and to identify areas necessitating improvement, with results generally supporting our findings; however, this study was limited by the use of phone surveys and interviews. Thus, there remains a gap in the literature with respect to how families view the hospital-to-home transition period and how their input could be translated into targeted family-centered interventions.

Our conceptual model (Fig 1) highlights key characteristics of the transition period. Our first concept, related to being in “a fog,” is supported by existing literature related to the stress of hospitalizations on families. It is best described in complex patient populations, including those cared for in NICUs and PICUs.<sup>1,5–7,51,52</sup> Our findings extend this previous work by describing, in detail, why caregivers of a child hospitalized with an acute illness feel enveloped by this “fog” and how its pervasiveness can prevent them from appropriately processing information that may be critical to caring for their child. Understanding how a parent’s potentially limited ability to process information gathered during even a brief hospitalization for an acute illness is important when developing interventions intended to improve both transitions home and patient outcomes.

The second concept relates to information sought by caregivers. The desire for a better understanding of red flags (ie, what to watch for) came through clearly and consistently. This red-flags concept, a type of educational strategy, is well described in adult studies.<sup>8,53–55</sup> Others have

**TABLE 4** Am I Ready To Go Home: Discharge Readiness

Major Themes	Caregiver Quotes
Emotional discharge readiness	<p>"I thought my son was ready. I was more concerned whether or not we were ready.... Well, it was after such a serious illness... We're thrilled he's coming home, but emotionally, 'OK, now, what do we do?'"</p> <p>"Because my daughter had 8, 9 different creams to put on all day long and I'm like, my goodness, I'm about to go home and it's going to start, it's going to be this cream here, this cream there, it's just too much at one time.... So, just too much. I was nervous to go home and to have to deal with all of that."</p> <p>"I think every mother or father, they're always concerned about their child regardless of what the doctors say to you like, 'that's my baby...'"</p> <p>"I ran out of this hospital... with my baby!"</p>
Clinical discharge readiness	<p>"I know he was back to normal because he was acting a fool... I wasn't worried about him no more ... once he started acting silly again. I know he was well, pretty much."</p> <p>"For us, the goal was always when her treatments were 4 hours apart... So we knew that when she would have her treatments 4 hours apart, we would be discharged... So, we just like kept watching the clock."</p> <p>"I didn't have any milestones... No, because one of the goals I thought it would be that she would be fever free [said sarcastically]... But yeah, my problem, you know, I expected her to not have fevers at all... And when we went home, she still had a low-grade fever."</p>

investigated the information desired by patients before discharge, primarily via surveys or qualitative interviews.<sup>3,4,44</sup> In our study, participants expressed a desire for specific details about worrisome clinical signs or symptoms and findings that prompt additional evaluation. Interventions designed to address informational needs and gaps identified by caregivers may improve feelings of discharge readiness and perceived preparation for transition home.

This readiness for discharge is the third concept we address, considered from both a clinical and emotional perspective. A caregiver's perspective on discharge goals typically goes beyond the objective findings of his or her child and incorporates an emotional component. Thus, a caregiver's assessment of his or her child's readiness for discharge may not always align with the health care team's assessment: the health care team may define clinical goals that must be fulfilled before discharge, perhaps with inconsistent family

input. Such misalignment can lead to miscommunication or contention if not proactively identified and addressed. The lack of discharge readiness and/or difficulty with coping skills after discharge is associated with greater odds of health service reutilization.<sup>23,24</sup> Finding ways to enhance a caregiver's readiness for discharge by improving communication and incorporating shared decision-making may decrease undesired postdischarge utilization while also increasing satisfaction.

Many identified their limited understanding of how to care for their child, and their reduced confidence in doing so, as a major postdischarge concern. Many also noted feeling unsure about whom to call with questions after arriving home. As a result, some expressed a desire for a follow-up phone call or postdischarge home nurse visit to help them adjust to their re-entry into the home and to address lingering questions or concerns. There is evidence, primarily in newborn and high-risk adult populations, that

postdischarge home nurse visits or phone calls can improve outcomes such as decreased health care utilization.<sup>35-42</sup> Such evidence, in combination with our findings, reinforces the need for further study of visits or calls that are tailored to meet the needs of families after hospital discharge. Determining their impact on both family-centered outcomes in addition to health care utilization is critical.

We acknowledge limitations to our study. First, this study was conducted at a single academic institution with English-speaking participants. Therefore, the included participants may not be reflective of patients and families who seek care in other more ethnically or linguistically diverse settings. However, at CCHMC, the patient population is diverse both demographically and clinically, which was reflected in focus group and interview participants. Although it was a convenience sample of participants, our sampling strategy ensured socioeconomic diversity. In addition, recall bias is possible because participants were asked to reflect on a discharge experience that occurred in their past. We attempted to minimize this bias by holding sessions no more than 30 days from the day of discharge. Finally, qualitative methods are inherently concept- and hypothesis-generating, not confirming. Still, the interpretive nature of our analysis emerged through multiple analytic iterations that included a diverse team of researchers and added scrutiny and feedback from a larger group of stakeholders.

## CONCLUSIONS

This study gathered rich input from caregivers of pediatric patients admitted with an acute illness. We identified barriers to smooth transitions home, providing an in-depth look at the family experience with hospitalization and re-entry to the home. We developed a conceptual

**TABLE 5** I'm Home, Now What: Confidence and Postdischarge Care

Major Themes (Subthemes)	Caregiver Quotes
Knowing who to call	<p>"Is there a number to call here to talk to somebody? Is there somebody, when you have a question, before you bring them back... just having somebody there to, that you can call without having to ... because your pediatrician is just going to say, 'Go back to the hospital.'"</p> <p>"If there was a problem like we have with the medicine ... and it was not his primary who took care of him ... So who do we call?"</p> <p>"Am I allowed to just call up here [inpatient unit]?"</p> <p>"Even though he'd been out for 2 months, I always call the NICU and ask questions because we kind of bonded with the nurses right there. So I have them and ask questions like, 'do you think this is right, should I do this?'"</p>
Bridging the gap: desiring a call or nurse home visit	<p>"I would have loved someone to call us. 'How are you after you left?' Because they're so caring while you're here."</p> <p>"You still want to feel important like, you know, if someone still cares and which can check up on you. And it's usually the surgical team, the nurse the calls the next day. But in this case it was nothing."</p> <p>"I mean maybe a nurse from Children's would be a little more helpful... Especially if it was like someone that had seen our child ... and like 'OK, well, hey this is nurse such-and-such, we saw you afternoon of Thursday for our daughter you know, we saw how she was doing, you know, is she...you know, we know she is better, is she kind of showing some of those older symptoms when she first got admitted or is she better?'"</p> <p>"Yeah everybody should have a [nurse] home visit."</p>
Caring for a sick child (Routine care needs)	<p>"You know, that was tough because they had me feed him every 3 hours so I was getting up in the middle of the night. I have to set an alarm... Every 3 hours... I was very restless."</p> <p>"He had to take [medicine] every 4 hours, they want me to wake him if he's asleep... And I was like call him at school and call him at afterschool program every time my alarm went off to make sure that either one he went in when he was supposed to or they let him know that it was time. So I think that was one of the hardest things... I got about 8 alarms set on my phone."</p>
(Clinical course)	<p>"She was miserable the whole week... My child screaming and I can't do anything."</p> <p>"And here we are today back to square one. His headache came back today... He's not feeling well again."</p> <p>"No she was like not feeling good. She wanted to be up under me, she wanted to be up under me."</p> <p>"It's a fever of 103.5... I had called the paramedics. They rushed us back here... The day after she spent 1 day at home and then we're back."</p>
Confidence in caring for a sick child	<p>"...when you get home, you're like, OK, now what? Now you finally get in and get settled and you're like, what are we supposed to do again?"</p> <p>"The scariest part when you go home, and everybody's situation is different, depending on the illnesses, for me, it's at the nighttime, initially. It's like, all right, what if, my 2-year-old sleeps in her room, it's like, 'How do I know she's having like some episode in her room and can't breathe?' And so it's kind of hard, so we just had someone to sleep with her the first few nights. That was kind of our solution."</p> <p>"You're hovering over him, you just can't help it. Like, 'Are you sure you're OK?'"</p> <p>"...maybe I need to go to school to be a doctor. I got the machines. I got everything basically what they have here, I have at home. If they're going to give her steroids and Benadryl and say, OK, I can do that myself. Because I carry around with it in my bag."</p>

model that integrates our findings and elucidates connections between experiences, beliefs, challenges, and needs. This model, which

encompasses the voice of the family, can now be used to inform the design of interventions aimed at improving existing systems.

**APPENDIX: FOCUS GROUP AND INDIVIDUAL INTERVIEW QUESTION GUIDE**

- Can you describe how you felt when your doctor or team of doctors told you that your child was ready to be discharged and go home? Walk me through the process when you first heard that your child was going to be going home.
- Did you feel your child was ready to be discharged?
- Did your child's health care team (doctors and/or nurses) ask you if you felt that your child was ready for discharge? AND How did your child's health care team (doctors and/or nurses) involve you in the discussion about discharge?
- Some of you may have had a child (this child or another child in family) hospitalized before. If this is the case, do you remember if your experiences with preparing for discharge were better at that time? Worse?
- What do you think the doctors and/or nurses should make sure you know about when it comes time for you and your child to leave the hospital? What information was crucial for you to know?
- Thinking back to conversations you may have had with doctors/nurses around the time of discharge, how did you feel about them?
- Do you recall asking questions of the doctors about your child's health/discharge processes? Do you recall asking questions of the nurses about your child's health/discharge processes?
- In what ways did you feel that the doctors and nurses in the hospital prepared you for discharge? In what ways did you feel unprepared?
- Overall, how satisfied were you with the transition from hospital to home?



- What was easiest about the discharge process? What was the best part? What was most challenging part about the discharge process? What was the worst part?
- If you were in charge of improving the discharge process for families, what changes would you make, if any? This includes any type of change to make things easier for families, even if it doesn't apply to your situation or recent experience.
- What was it like getting your life back in order after returning home? What was the hardest part for you? What was the easiest part, what went well?
- Did the doctors advise you to follow up with your child's pediatrician or family doctor or another doctor (like a specialist)?
- During the first few days after discharge, what questions or concerns arose? What about a week later? Was there ever a time that you felt uncomfortable taking care of your child? Anything you felt unsure about?
- Did you experience any difficulties related to medications for your child after discharge?
- Did you have concerns about your child's condition getting worse after they got home from the hospital? Several days later?

## H2O STUDY GROUP

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## ABBREVIATION

CCHMC: Cincinnati Children's Hospital Medical Center

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## REFERENCES

1. Bent KN, Keeling A, Routson J. Home from the PICU: are parents ready? *MCN Am J Matern Child Nurs.* 1996;21(2):80–84
2. Melnyk BM. Intervention studies involving parents of hospitalized young children: an analysis of the past and future recommendations. *J Pediatr Nurs.* 2000;15(1):4–13
3. Smith L, Daughtrey H. Weaving the seamless web of care: an analysis of parents' perceptions of their needs following discharge of their child from hospital. *J Adv Nurs.* 2000;31(4): 812–820
4. Snowdon AW, Kane DJ. Parental needs following the discharge of a hospitalized child. *Pediatr Nurs.* 1995;21(5):425–428
5. Lapillonne A, Regnault A, Gournay V, et al. Impact on parents of bronchiolitis hospitalization of full-term, preterm and congenital heart disease infants. *BMC Pediatr.* 2012;12:171
6. Leidy NK, Margolis MK, Marcin JP, et al. The impact of severe respiratory syncytial virus on the child, caregiver, and family during hospitalization and recovery. *Pediatrics.* 2005;115(6): 1536–1546
7. Diaz-Caneja A, Gledhill J, Weaver T, Nadel S, Garralda E. A child's admission to hospital: a qualitative study examining the experiences of parents. *Intensive Care Med.* 2005; 31(9):1248–1254
8. Davis MM, Devoe M, Kansagara D, Nicolaidis C, Englander H. "Did I do as best as the system would let me?" Healthcare professional views on hospital to home care transitions. *J Gen Intern Med.* 2012;27(12):1649–1656
9. Institute of Medicine, Committee on Quality of Health Care in America. *Crossing the Quality Chasm: A New Health System for the 21st Century.* Washington, DC: National Academies Press; 2001
10. Co JP, Ferris TG, Marino BL, Homer CJ, Perrin JM. Are hospital characteristics associated with parental views of pediatric inpatient care quality? *Pediatrics.* 2003;111(2):308–314

11. Berry JG, Toomey SL, Zaslavsky AM, et al. Pediatric readmission prevalence and variability across hospitals. *JAMA*. 2013; 309(4):372–380
12. Gay JC, Agrawal R, Auger KA, et al. Rates and impact of potentially preventable readmissions at children's hospitals. *J Pediatr*. 2015;166(3):613–619, e615
13. Joynt KE, Orav EJ, Jha AK. Thirty-day readmission rates for Medicare beneficiaries by race and site of care. *JAMA*. 2011;305(7):675–681
14. Karaca-Mandic P, Jena AB, Joyce GF, Goldman DP. Out-of-pocket medication costs and use of medications and health care services among children with asthma. *JAMA*. 2012;307(12):1284–1291
15. Lye PS; American Academy of Pediatrics Committee on Hospital Care and Section on Hospital Medicine. Clinical report—physicians' roles in coordinating care of hospitalized children. *Pediatrics*. 2010; 126(4):829–832
16. Kaushal R, Jaggi T, Walsh K, Fortescue EB, Bates DW. Pediatric medication errors: what do we know? What gaps remain? *Ambul Pediatr*. 2004;4(1):73–81
17. Kaushal R, Bates DW, Landrigan C, et al. Medication errors and adverse drug events in pediatric inpatients. *JAMA*. 2001;285(16):2114–2120
18. Ruth JL, Geskey JM, Shaffer ML, Bramley HP, Paul IM. Evaluating communication between pediatric primary care physicians and hospitalists. *Clin Pediatr (Phila)*. 2011;50(10):923–928
19. Florin TA, French B, Zorc JJ, Alpern ER, Shah SS. Variation in emergency department diagnostic testing and disposition outcomes in pneumonia. *Pediatrics*. 2013;132(2):237–244
20. Morse RB, Hall M, Fieldston ES, et al. Hospital-level compliance with asthma care quality measures at children's hospitals and subsequent asthma-related outcomes. *JAMA*. 2011;306(13): 1454–1460
21. Snow V, Beck D, Budnitz T, et al. Transitions of care consensus policy statement: American College of Physicians, Society of General Internal Medicine, Society of Hospital Medicine, American Geriatrics Society, American College of Emergency Physicians, and Society for Academic Emergency Medicine. *J Hosp Med*. 2009;4(6):364–370
22. Cipriano P; American Academy of Nursing on Policy. The imperative for patient-, family-, and population-centered interprofessional approaches to care coordination and transitional care: a policy brief by the American Academy of Nursing's Care Coordination Task Force. *Nurs Outlook*. 2012;60(5):330–333
23. Weiss M, Johnson NL, Malin S, Jerofke T, Lang C, Sherburne E. Readiness for discharge in parents of hospitalized children. *J Pediatr Nurs*. 2008;23(4): 282–295
24. Lerret SM. Discharge readiness: an integrative review focusing on discharge following pediatric hospitalization. *J Spec Pediatr Nurs*. 2009;14(4):245–255
25. Coleman EA, Mahoney E, Parry C. Assessing the quality of preparation for posthospital care from the patient's perspective: the care transitions measure. *Med Care*. 2005;43(3):246–255
26. Crabtree BF, Miller WL. *Doing Qualitative Research*. 2nd ed. Thousand Oaks, CA: Sage Publications; 1999
27. Stewart D, Shamdasani P, Rook D. *Focus Groups: Theory and Practice*. 2nd ed. Thousand Oaks, CA: Sage Publications; 2007
28. Krieger N, Chen JT, Waterman PD, Rehkopf DH, Subramanian SV. Painting a truer picture of US socioeconomic and racial/ethnic health inequalities: the Public Health Disparities Geocoding Project. *Am J Public Health*. 2005;95(2): 312–323
29. Krieger N, Chen JT, Waterman PD, Soobader MJ, Subramanian SV, Carson R. Geocoding and monitoring of US socioeconomic inequalities in mortality and cancer incidence: does the choice of area-based measure and geographic level matter? The Public Health Disparities Geocoding Project. *Am J Epidemiol*. 2002;156(5):471–482
30. Krieger N, Waterman P, Chen JT, Soobader MJ, Subramanian SV, Carson R. Zip code caveat: bias due to spatiotemporal mismatches between zip codes and US census-defined geographic areas—the Public Health Disparities Geocoding Project. *Am J Public Health*. 2002;92(7):1100–1102
31. US Census Bureau. American Factfinder. 2012. Available at: <http://factfinder2.census.gov/faces/nav/jsf/pages/index.xhtml>. Accessed March 1, 2015
32. Patton MQ. *Qualitative Research and Evaluation Methods*. 3rd ed. Thousand Oaks, CA: Sage Publications; 2002
33. Miles MB, Huberman AM, Saldaña J. *Qualitative Data Analysis: A Methods Sourcebook*. 3rd ed. Thousand Oaks, CA: Sage Publications; 2014
34. Auger KA, Simon TD, Cooperberg D, et al. Summary of STARNet: Seamless Transitions and (Re)admissions Network. *Pediatrics*. 2015;135(1):164–175
35. Desai AD, Popalisky J, Simon TD, Mangione-Smith RM. The effectiveness of family-centered transition processes from hospital settings to home: a review of the literature. *Hosp Pediatr*. 2015;5(4): 219–231
36. Auger KA, Kenyon CC, Feudtner C, Davis MM. Pediatric hospital discharge interventions to reduce subsequent utilization: a systematic review. *J Hosp Med*. 2014;9(4):251–260
37. Brett J, Staniszewska S, Newburn M, Jones N, Taylor L. A systematic mapping review of effective interventions for communicating with, supporting and providing information to parents of preterm infants. *BMJ Open*. 2011;1(1): e000023
38. Cibulskis CC, Giardino AP, Moyer VA. Care transitions from inpatient to outpatient settings: ongoing challenges and emerging best practices. *Hosp Pract (1995)*. 2011;39(3):128–139
39. Hesselink G, Schoonhoven L, Barach P, et al. Improving patient handovers from hospital to primary care: a systematic review. *Ann Intern Med*. 2012;157(6): 417–428
40. Hansen LO, Young RS, Hinami K, Leung A, Williams MV. Interventions to reduce 30-day rehospitalization: a systematic review. *Ann Intern Med*. 2011;155(8): 520–528
41. Leppin AL, Gionfriddo MR, Kessler M, et al. Preventing 30-day hospital readmissions: a systematic review and meta-analysis of randomized trials. *JAMA Intern Med*. 2014;174(7):1095–1107
42. Lopez GL, Anderson KH, Feutchinger J. Transition of premature infants from hospital to home life. *Neonatal Netw*. 2012;31(4):207–214
43. Geary CR, Schumacher KL. Care transitions: integrating transition theory

- and complexity science concepts. *ANS Adv Nurs Sci.* 2012;35(3):236–248
44. Anthony MK, Hudson-Barr D. A patient-centered model of care for hospital discharge. *Clin Nurs Res.* 2004;13(2):117–136
  45. Rhodes KV. Completing the play or dropping the ball? The case for comprehensive patient-centered discharge planning. *JAMA Intern Med.* 2013;173(18):1723–1724
  46. Harrison A, Verhoef M. Understanding coordination of care from the consumer's perspective in a regional health system. *Health Serv Res.* 2002;37(4):1031–1054
  47. Klassen AF, Dix D, Cano SJ, Papsdorf M, Sung L, Klaassen RJ. Evaluating family-centered service in paediatric oncology with the measure of processes of care (MPOC-20). *Child Care Health Dev.* 2009;35(1):16–22
  48. Wilkins A, Leonard H, Jacoby P, et al. Evaluation of the processes of family-centered care for young children with intellectual disability in Western Australia. *Child Care Health Dev.* 2010;36(5):709–718
  49. Cawthon C, Walia S, Osborn CY, Niesner KJ, Schnipper JL, Kripalani S. Improving care transitions: the patient perspective. *J Health Commun.* 2012;17(suppl 3):312–324
  50. Horwitz LI, Moriarty JP, Chen C, et al. Quality of discharge practices and patient understanding at an academic medical center. *JAMA Intern Med.* 2013;173(18):1715–1722
  51. Graves JK, Ware ME. Parents' and health professionals' perceptions concerning parental stress during a child's hospitalization. *Child Health Care.* 1990;19(1):37–42
  52. Shaw RJ, Deblois T, Ikuta L, Ginzburg K, Fleisher B, Koopman C. Acute stress disorder among parents of infants in the neonatal intensive care nursery. *Psychosomatics.* 2006;47(3):206–212
  53. Markley J, Sabharwal K, Wang Z, Bigbee C, Whitmire L. A community-wide quality improvement project on patient care transitions reduces 30-day hospital readmissions from home health agencies. *Home Healthc Nurse.* 2012;30(3):E1–E11
  54. Coleman EA, Smith JD, Frank JC, Min SJ, Parry C, Kramer AM. Preparing patients and caregivers to participate in care delivered across settings: the Care Transitions Intervention. *J Am Geriatr Soc.* 2004;52(11):1817–1825
  55. Coleman EA, Parry C, Chalmers S, Min SJ. The Care Transitions Intervention: results of a randomized controlled trial. *Arch Intern Med.* 2006;166(17):1822–1828

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