RESEARCH ARTICLE

# Provider Perspectives of High-Quality Pediatric Hospital-to-Home Transitions for Children and Youth With Chronic Disease

Carolyn C. Foster, MD, MSHS,[a,b] Elizabeth Jacob-Files, MA, MPH,[b] Kimberly C. Arthur, MPH,[b] Stephanie A. Hillman, MNPL,[c] Todd C. Edwards, PhD,[d] Rita Mangione-Smith, MD, MPH[a,b]

**A B S T R A C T**

**OBJECTIVE:** The objective of this study was to describe health care providers' and hospital administrators' perspectives on how to improve pediatric hospital-to-home transitions for children and youth with chronic disease (CYCD).

**METHODS:** Focus groups and key informant interviews of inpatient attending physicians, primary care physicians, pediatric residents, nurses, care coordinators, and social workers were conducted at a tertiary care children's hospital. Key informant interviews were performed with hospital administrators. Semistructured questions were used to elicit perceptions of transitional care quality and to identify key structures and processes needed to improve transitional care outcomes. Transcripts of discussions were coded to identify emergent themes.

**RESULTS:** Participants ($N = 22$) reported that key structures needed to enhance transitional care were a multidisciplinary team, inpatient provider-patient continuity, hospital resource availability, an interoperative electronic health record, and availability of community resources. Key processes needed to achieve high-quality transitional care included setting individualized transition goals, involving parents in care planning, establishing parental competency with home care tasks, and consistently communicating with primary care physicians. Providers identified a lack of reliable roles and processes, insufficient assessment of patient and/or family psychosocial factors, and consistent 2-way communication with community providers as elements to target to improve transitional care outcomes for CYCD.

**CONCLUSIONS:** Many key structures and processes of care perceived as important to achieving high-quality transitional care outcomes for CYCD have the opportunity for improvement at the institution studied. Engaging key stakeholders in designing quality improvement interventions to address these deficits in the current care model may improve transitional care outcomes for this vulnerable population.

[a]Departments of Pediatrics and [d]Health Services, University of Washington, Seattle, Washington; [b]Center for Child Health, Behavior and Development, Seattle Children's Research Institute, Seattle, Washington; and [c]Department of Patient and Family Experience, Seattle Children's Hospital, Seattle, Washington

Children and youth with chronic disease (CYCD) are patients with either noncomplex chronic disease (defined as having a single chronic condition that is not progressive, varies widely in severity, and results in highly variable health care utilization [eg, type 1 diabetes mellitus]), or complex chronic disease (defined as having a single progressive condition [eg, cystic fibrosis]), or >2 significant chronic conditions that will last at least 1 year, result in high health care utilization, require ongoing treatment, and be episodically or continuously debilitating (eg, infantile spasms and complex congenital heart disease).[1] CYCD are at risk for experiencing disjointed health care delivery because their increased health service utilization.[2–4] Transitioning care from the inpatient to home setting is a vulnerable period for CYCD and their families during which poor care coordination may result in readmissions, adverse medical events, and familial stress.[5,6]

Transitional care includes inpatient activities that prepare patients to go home (eg, family education) and facilitate care once patients have arrived home (eg, communication between inpatient and outpatient providers).[7] Researchers for previous studies have identified that specific transitional care processes are associated with decreased readmissions, improved patient satisfaction, and improved patient health outcomes.[8–12] However, research of adult and pediatric care also suggests that many current transitional care practices remain incomplete, variably implemented, and/or ineffective.[13–15]

While researchers for previous studies have primarily focused on the parent perspective, less is known about hospital and primary care physicians' (PCPs) perceptions of the value and efficiency of current pediatric hospital-to-home transitional care.[16,17] Understanding the perceptions of transitional care from provider stakeholders is critical to developing effective, sustainable interventions. Our objectives in this study were to describe health care providers' and hospital administrators' perceptions of pediatric hospital-to-home transitions for CYCD and to

identify potential future targets for achieving higher quality transitional care outcomes.

## METHODS
### Overview

This was a qualitative study, conducted from August to December 2014, which was focused on inpatient general medicine service providers at a freestanding academic children's hospital and at outpatient PCPs. General medicine inpatient service teams are comprised of an attending physician, 2 to 4 pediatric residents, a social worker, and 2 care coordinators. Care coordinators include nurses who perform clinical tasks (eg, equipment teaching) and nonclinical staff who aid with administrative tasks (eg, appointment scheduling). The institutional review board approved all study procedures.

### Provider Recruitment and Eligibility

All participants were recruited by e-mail invitation using purposeful sampling, which selects a small group of participants on the basis of their rich experiences within the subject matter of interest.[18] Inpatient general pediatric or hospitalist attending physicians, pediatric residents, nurses, care coordinators, and social workers sampled (hereafter referred to as inpatient providers) were eligible if they had worked full-time in their current position for at least 1 year, were routinely providing transitional care, and primarily served CYCD admitted to the hospital's general medicine services. The general medicine services include both patients with noncomplex chronic disease for whom subspecialists play only a consultative role or no role (eg, patients with eating disorders or asthma) and patients with complex chronic disease who are not admitted to a subspecialty service. PCPs must have worked at their current job for at least 1 year and had at least 1 CYCD admitted within the previous 6 months. Eligible hospital administrators were selected from departments responsible for structures or processes of transitional care including care coordination, information technology, nursing services, and physician services departments.

### Focus Group and Key Informant Interview Facilitation and Content
#### PCP and Inpatient Provider Focus Groups and Interviews

Three mixed provider focus groups (4–5 providers per focus group; total $n = 14$) were conducted in-person for ∼90 minutes by using a semistructured guide (Table 1). The interview guide was developed on the basis of current literature related to high-quality transitional care and revised on the basis of feedback from study team members, experts in CYCD care and/or health services research, and nonparticipating providers and/or administrators. Participating providers were asked to reflect on their experiences caring for CYCD with either a noncomplex or complex chronic disease who were hospitalized in a general medicine service for >3 days and who would likely be rehospitalized within their lifetime.[1] Questions were developed to reflect the Donabedian framework (Fig 1) to elicit providers' perceptions regarding what is needed within the domains of structures and processes of care to achieve high-quality transitional care outcomes for CYCD.[19]

Each group was facilitated together by the principal investigator (C.F.) and 1 nonclinical moderator (K.A. or S.H.) with experience conducting focus groups in health care settings. To include their viewpoints, providers unable to attend a focus group ($n = 4$) participated in 30-minute key informant interviews conducted by the principal investigator, for a total of 18 frontline provider participants.

#### Administrator Interviews

Key informant interviews of departmental administrators were performed in-person for ∼30 minutes ($n = 4$). Administrators were asked their viewpoints on the current state of hospital-to-home transitional care under their purview, the structures and processes of care they would target to create higher quality transitional care, and how transitional care was perceived to fit into the organization's priorities (Table 1).

### Analysis
#### Data Collection

All focus groups and key informant interviews were audio-recorded and

**TABLE 1** Focus Group and Key Informant Interview Sample Guide Structure

Interview Questions

Bedside and Community Provider Questions

Discharge readiness

1. What sorts of things do you take into consideration in deciding a patient is getting ready to go home from the hospital?

2. How is each of you involved in deciding a patient and his or her family is ready to go home?

3. In your experience, how are the different viewpoints and input from inpatient providers and/or staff and family combined to create discharge goals?

4. Once these goals are decided on, how do you communicate about the goals with the other members of the care team?

5. How are discharge goals discussed with families, if at all?

6. How are discharge goals discussed with community or specialty providers, if at all?

Parent education

7. After a patient's discharge is confirmed, how are each of you involved in preparing patients and/or families on what to expect at home?

8. How do you know that the patient and family have had enough instruction?

9. What, if any, physical handouts or online resources do you provide families? How do you choose these handouts or resources?

10. What has been your experience reviewing medication with patients and/or families?

11. What has been your experience practicing home care with patients and/or families?

12. For community providers, what is your opinion regarding how instructions are given to or received by patients and their families?

Home and/or social preparation

13. How do you typically determine that a family will need to make changes or preparations at home prior to discharge?

14. If these changes are identified, how have you gone about addressing them?

15. For outpatient providers, what is your experience with helping families with the changes or preparations needed at home after discharge?

Delay of discharge

16. What do you think contributes to delays in discharge?

Summary questions

17. Overall, what do you think we do well when preparing patients and their families to go home?

18. Overall, what do you think we can do to improve how we prepare families to go home?

Administrator Key Informant Questions

1. What structures or processes involved in preparing and/or sending patients home do you oversee?

2. How have these structures or processes been developed? Are there formal guidelines?

3. What are the barriers to maintaining these structures and processes?

4. What do you think your department does well in preparing for sending patients home? How is there room for improvement?

5. How do you tailor your services to patient's level of medical complexity?

6. What barriers do you think get in the way of providing the best experience for patients and families when it comes to the discharge process?

7. What do you think should be changed about the current processes or systems involved in preparing patients for transitioning home from the hospital?

8. In your opinion, how does care transition and/or discharge care fit with our organizational priorities?

then transcribed. Transcripts were reviewed for accuracy and de-identified. Transcripts were uploaded to a qualitative data program (Dedoose, Version 5.0.11; Dedoose, Los Angeles, CA), which facilitates creation of excerpts and assignment of codes to excerpts for analysis.

## Coding

Coding was conducted from a phenomenological perspective by using immersion-crystallization methodology to identify meaning within the transcripts. This method, which has roots in grounded theory, employs frequent meetings to develop a group of codes to facilitate thematic analysis by using detailed immersion into excerpts and then reflection to identify emergent themes.[20] First, the primary investigator (C.F.) immersed herself into the initial focus group transcript to generate a codebook by using open coding, which breaks apart the data into quotes and then delineates concepts to stand for interpreted meaning.[20,21] A second reader, a qualitative researcher (E.J.), then similarly performed an immersive reading of the first transcript by using the initial codebook. The readers met 7 times over 6 weeks to reconcile codes. The refined codebook was then applied as subsequent transcripts were analyzed.

After open coding was complete, a final codebook was organized into pattern codes, which consisted of 3 categories: causes and/or explanations, relationships, or theoretical constructs related to high-quality transitional care.[18] Accepted pattern codes were reapplied to all transcribed data by both coders independently and again reviewed over 3 meetings until an agreement was reached such that no new codes emerged and codes had been developed fully with differential variation.[21]

## Thematic Analysis

Once coding was complete, thematic analysis was conducted by organizing the pattern codes into themes on the basis the Donabedian quality of care conceptual framework relating the structures and processes of care to health outcomes.[19] When reading the coded excerpts, we searched, reviewed, defined, and named the structures, processes, and outcomes and then organized them into themes and subthemes to be represented in a conceptual model (Fig 1).[22]

When a specific provider type (eg, PCPs) offered a unique perspective related to a particular theme, this is highlighted within the results section by indicating the provider type who held the unique opinion.

## RESULTS

### Participant Demographics

Overall, study participants were fairly experienced, with over half working in health care >10 years and about two-thirds of the group having worked at least 6 years or more in their current position. Participants represented an array of perspectives: inpatient nurses (*n* = 3), social workers (*n* = 3), PCPs (*n* = 3), inpatient attending physicians (*n* = 3), pediatric residents (*n* = 3), care coordinators (*n* = 4), and administrators (*n* = 4).

### Structures Needed to Achieve High-Quality Transitional Care for CYCD

The following themes emerged related to structures needed to achieve high-quality transitional care for CYCD: (1) inpatient provider and hospital work environment; and (2) primary care medical home and community resources. Subthemes and supporting quotes can be found within the subsequent text and in Table 2.

### Theme 1: Inpatient Provider and Hospital Work Environment

#### Subtheme: Collaborative Work Culture With Multidisciplinary Input and Clear Roles

In an ideal state, providers emphasized the importance of working in a collaborative team environment with clear roles that encouraged input from each provider type to create individualized patient care plans.

> "Having the input of every team member is so important. It is why there are multidisciplinary team members because everyone is thinking about something different and has skills in different areas."
>
> Social worker

Family-centered rounds and care conferences are structures that providers identified as facilitating this multidisciplinary approach and effective communication with the patient and family.

> "We frequently will have care conferences with families to bring them and the different providers [together]

to make sure we [all agree on] the goals of care for that individual patient."
>
> Attending physician

#### Subtheme: Inpatient Provider-Patient Continuity

Providers articulated that maximizing continuity of inpatient providers with CYCD across re-hospitalizations enhanced providers' abilities to develop rapport with the patient and family. However, participants noted that inpatient provider continuity and role clarity were challenging to achieve in an academic setting with frequently rotating residents and attending physicians (Table 2). Given their often intricate medical and surgical histories, CYCD with medical complexity could benefit from inpatient provider continuity more than CYCD with noncomplex chronic disease.

> "Chronic care patients need continuity because if they don't, things will fall through the cracks by nature. I mean, if you have a workforce that's constantly turning over and the patient isn't, how could you possibly effectively have continuity?"
>
> Physician services administrator

#### Subtheme: Hospital Resource Availability

CYCD often required services provided by inpatient consultants, ancillary staff, or radiologic services to clarify diagnostic questions or advance treatment. Readily available resources progress a patient toward their medical goals to achieve a timely transition home (Table 2). Delays or inaccessibility of hospital resources on evenings and weekends was identified as a barrier to timely hospital-to-home transitions (Table 2).

#### Subtheme: Interoperable EHR

Providers additionally identified that having a facile electronic health record (EHR) that facilitated care tasks (eg, family education) would improve their ability to transition a patient home by enhancing internal communication among inpatient providers.

> "We really need to have a streamlined [electronic] record in that it would display not only home medication reconciliation for our children with

medical complexities [but also] show home nursing, durable medical equipment, and respiratory therapy orders."
>
> Attending physician

Providers articulated frustration that sometimes the EHR led to provider rework and/or miscommunication between providers (Table 2). Notably, administrators added that organizational challenges persist in integrating the inpatient EHR with community practices (Table 2).

### Theme 2: Primary Care Medical Home and Community Resources

#### Subtheme: Provide a Primary Care Medical Home and Community Ancillary Services

Providers noted that successfully transitioning a patient home was reliant on the presence of a community medical home available to provide care for CYCD and the availability of community ancillary health services (eg, home care nursing).

> "So my frustration [about delays in discharge] is all the work that goes into setting up the home support structure, [in] particular home nursing. Getting approval and staffing [for home nursing] has been [a problem], and it has resulted in multiple ED visits and/or readmissions of patients."
>
> Attending physician

However, addressing the limited availability of community ancillary health services (eg, home care nursing) in rural or otherwise underserved settings was noted as an area to target for transitional care improvements.

> "[Sometimes,] we are really not comfortable sending this kid home over the weekend because they don't have the services in the community, and we are afraid that those community services are not available to [the family]."
>
> Care coordinator

### Processes Needed to Achieve High-Quality Transitional Care for CYCD

The themes that emerged related to processes needed to achieve high-quality transitional care for CYCD were: (1) patient and family needs assessments
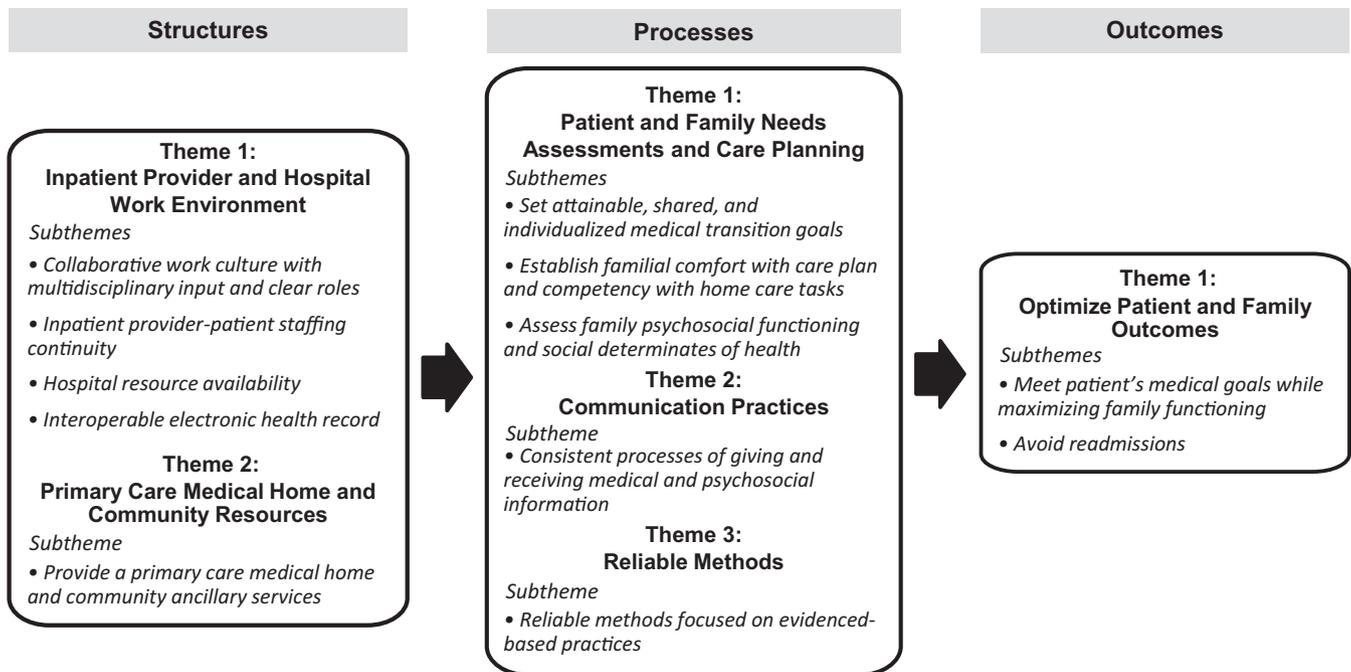
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| Structures | Processes | Outcomes |
|---|---|---|



**FIGURE 1** Conceptual model of provider-identified, high-quality, hospital-to-home transitional care for children with special health care needs.

and care planning; (2) communication practices; and (3) reliable methods. Subthemes and supporting quotes can be found within the subsequent text and in Table 3.

### Theme 1: Patient and Family Needs Assessments and Care Planning

#### Subtheme: Set Attainable, Shared, and Individualized Medical Transition Goals

Providers identified that setting attainable, shared, and individualized medical goals that are used as a metric for when to transition a patient home was a critical process to establishing higher quality transitional care (Table 3).

#### Subtheme: Establish Familial Comfort With Care Plan and Competency With Home Care Tasks

Providers articulated 2 mutually reinforcing but different components of transitional care planning, which were to establish familial agreement and comfort with the care plan, and to ensure competency with home care tasks. For example, a mother needs to agree with the decision ("comfort") that her child must go home with a nasogastric (NG) tube to optimize

nutrition and also have the skill to replace the NG at home ("competency").

> "[Knowing if a family is ready to go home] is if the teaching is done and the parents can demonstrate independently that they are able to flush an NG tube, place an NG tube, and that they also voice that they're actually comfortable in doing so."
>
> Nurse

#### Subtheme: Assess Family Psychosocial Functioning and Social Determinants of Health

Providers identified that assessing and then understanding the social, cultural, and economic context of a patient's family was a vital element to providing high-quality transitional care. Providers perceived that a family's degree of psychosocial functioning (eg, parent mental health status), language or cultural factors (eg, limited English proficiency), socioeconomic status (eg, insurance coverage), and living proximity to the hospital might impact the family's ability to return home, to access community services, and to attain the self-efficacy needed to successfully complete care tasks (Table 3). Providers noted that early assessment of these factors was critical for

determining when a patient could go home and whether additional resources were needed.

> "I try to ask: 'Do you have other kids? Are they in school? Does that limit when you can come to [follow-up] appointments? Do you have transportation? Do you have private insurance? Do you have a co-pay? Is that going to affect whether or not you want to follow-up?'"
>
> Care coordinator

However, providers noted that there was no reliable method for identifying social determinants of health, especially because these variables could change during the course of a hospitalization. Providers perceived the unpredictability and liability of these factors as a common source of complications or delays in transitioning a patient to return home (eg, transportation access).

> "I know it's frustrating to other members of the team, as well as myself, that social factors can change overnight. A child can be ready for discharge tomorrow and then something dramatic happens and then the whole plan is disrupted."
>
> Social worker

**TABLE 2** Illustrative Quotes of Provider-Identified Structures of High-Quality Hospital-to-Home Transitions for Children and Youth With Chronic Diseases

| Theme | Subtheme | Quotes |
|---|---|---|
| 1: Inpatient Provider and Hospital Work Environment | Collaborative work culture with multidisciplinary input and clear roles | "I think people here have a very genuine interest in trying to look at all of the different perspectives that are involved in a discharge. When I'm working with any given team on the medical unit, I find they are very welcoming of social work's perspective." Social worker |
| | | "[When discussing how discharge goals are created:] If the social worker is involved, then I usually talk to them about what things do we need to do in order to make sure that this family can get home. If it's the discharge care coordinator, I ask what kind of follow-up is in place. Who do we have to call to make sure if they need to follow-up with the patient? If it is a nurse care coordinator, I ask what sorts of technology might they need at home? Do they need a new suction tube? And can we get that? Or do they have to wait a couple extra days because the company is not there to do it?" Resident physician |
| | Inpatient provider-patient continuity | "Especially with the new system [of resident shift work], you get interns switching almost every week. I think that's where things get lost [referring to details of patient care]. Supposedly the information is in the [electronic sign-out tool] but the information is dense [especially] for the long-term kids." Care coordinator |
| | | "My most recent experience with [the complex care patients] is that I find families are often frustrated with the continual changing of attendings." Social worker |
| | Hospital resource availability | "If [patients] don't get discharged before going into a holiday weekend, they're not going to get discharged until Tuesday or Wednesday even if they're medically ready because so much of the other care coordination, social work services, talking to other providers, or setting up equipment doesn't happen at the same speed over the weekend as it does during the week." Attending physician |
| | | "…Even though we're a 24/7 operation, I think a lot of times we operate on a Monday through Friday basis, recognizing that's not always convenient for families." Care coordinator |
| | | "I think we have great resources. We're a very large hospital… I think our respiratory therapists, occupational therapists, or feeding therapists are amazing resources here… but, I realize that large institutions always have barriers…It's just hard when you work with so many people and on the weekends [with fewer residents working]." Nurse |
| | Interoperable EHR | "In our computer system, you should be able to document everything you've taught the family, under an Education tab, and you should say, 'I've taught this, and they either need to do more or they're free to go.' But, we're just not good at documenting there because you have to scroll a lot [and the information isn't easily accessible]." Nursing services administrator |
| | | "[There is a] whole rigmarole around whether [the discharge summary] is just electronically transmitted and then picked up at the PCP's office to be made available in their chart, or whether we fax, print, and stick in the hand [of the patient and/or family] and say, 'Carry this with you to your pediatrician.' Whatever that is, we will have a health information exchange within the next year [with community PCP practices] and our discharge documents are in scope.…" Information technology administrator |
| | | "Probably the thing that we've had to work with the nurses the most on is that they're printing off a discharge medication list to [review with] the families [that was created by the resident] and confirming if it's accurate, which is great, but then the [electronic] inaccurate one is faxed to the pediatrician…and it must be incredibly complicated for residents to [redo] it right, because nobody's intentionally leaving that list wrong." Nurse |
| 2: Primary Care Medical Home and Community Resources | Provide a primary care medical home and community ancillary services | "There are a group of patients that get readmitted because of poor transition of care to their home. I think what we've come to realize is that the whole thing that brought them here and the whole thing that could bring them back is what happens outside of here [the hospital]… The exciting work of the next several years is thinking about how do we make sure [a family's] home and community is ready to take them and they're ready to interact with their home and community in a way that will make them stay well and not just get sick again." Physician services administrator |
| | | "Who's in charge of managing things when [the patient] is outside the hospital? If you're talking about a chronic condition, then you need to have some continuity [outside of the hospital] that is really well established and you have to have a good communication plan… that prevents them from coming back." Attending physician |

**TABLE 3** Illustrative Quotes of Provider-Identified Processes of High-Quality Hospital-to-Home Transitions for Children and Youth With Chronic Diseases

| Themes | Subthemes | Quotes |
|---|---|---|
| 1: Patient and Family Needs Assessments and Care Planning | Set attainable, shared, and individualized medical transition goals | "We frequently will have care conferences with families to bring them and the different providers [together] to make sure we [all agree on] the goals of care for that individual patient." Attending physician |
| | | "Every patient should have discharge criteria that we set, concrete things... We often do actually sit down with the families and say, 'okay, here are the discharge criteria,' but in order for those to be met we need to establish that there's a safe home environment and that you know how to provide the care." Attending physician |
| | Establish familial comfort with care plan and competency with home care tasks | "[Preparing patients to go home from the hospital should begin when they walk in the door and you think to yourself, 'When they're ready to go home, what are they going to need?' ...then you start figuring out how and when you're going to train them." Nurse |
| | | "...A large component of [a patient's discharge] can also be family caregiver readiness and training of home in DME." Attending physician |
| | Assess family psychosocial functioning and social determinates of health | "[When assessing if a family is ready to go home] you have to start with what's their usual routine and set up at home with their family, and then ask how has it been affected during the hospitalization. What other family or other resources do they have? What demands do they have for work or education that's going to make it hard to organize? And then I rely on social work to [make] those plans." PCP |
| | | "I think [the doctor] has to ask the right question and read the nonverbal cues that a family's not ready to go...because what tends to happen is [the provider] will say, 'Okay, you're ready to go.' ...and then undoubtedly if it's one of those difficult discharges or if a lot of social and contextual factors brought them into the hospital...the parent or the nurse or the social worker will page the resident and be like, 'This family's not ready to go.'" Resident physician |
| | | "[What also leads to delays in discharge is not] assessing social readiness. I ask families to imagine doing [care at home] and incorporating it into the other things that they're doing on a day-to-day basis, and sometimes that uncovers barriers to discharge." Attending physician |
| | | "If you watch nursing students, they have this very clear step-by-step thing that the family's going to do and all the information you're going to give them and say, 'Mrs Smith, this is how you put a nasogastric tube in...,' and life is going to be awesome. What you learn on the job is, people are sleep deprived, it's not the right time, they're not available, they don't speak English, they don't read... What you learn is the true reality of what's it like to send a kid home." Nurse |
| 2: Communication Practices | Consistent processes of giving and receiving medical and psychosocial information | "Where [the hospital] is not as good at communicating, and this isn't because we don't want [to] be or we haven't tried, but we're not as good with school nursing, because there's a lot of challenges with sharing of information and access to information because of the schools' requirements and consents...and what's hard in this state is that each school district has a different process." Care coordination administrator |
| | | "I feel like it is important for me [the PCP] to have input [before discharge] because we have socially high-risk families. So the type of person that you might medically admit or discharge early from a medical standpoint might not be the right person from a social standpoint." PCP |
| | | "[PCPs' practices] admit that their practice wants [to communicate] one way and another practice wants it another way, even when we first started to set up phone calling. But, I think honestly the solution to that is to get rid of the phone call. If we instantaneously gave them a coherent document, I would bet, except for kids who are really fragile, which is different, then you need to talk to somebody...But I think our current process of a third of the patients don't even get discharge summaries and the other two-thirds you get them [late], then the phone call is actually a way around the real problem, which is getting [PCPs] the information." Physician services administrator |
| 3: Reliable Methods | Reliable methods focused on evidenced-based practices | "Even if I was to look at a guideline of care and say, 'Okay, this is an asthmatic [patient] and these are things that [the patient and/or family] needs to go home,' I don't know if 100% of nurses could confirm if RT actually did the discharge [education] sheet [or whether] the parents even know what an asthma management plan is... I wouldn't say it's consistent." Nurse |
| | | "So what I see going well in our discharge for our tracheostomy/ventilator dependent population, is that there's like a specific group of nurses or half of us are trained [to work with] the [tracheostomy/ventilator patients]. So when we discharge those children it's actually pretty organized: they go home with a care notebook that is detailed information on all their systems, we work closely with pulmonary care coordinator, and we also do teaching with the home nurses when they go." Nurse |

DME, durable medical equipment; RT, respiratory therapy.

## Theme 2: Communication Practices

### Subtheme: Consistent Processes of Giving and Receiving Medical and Psychosocial Information

Providers articulated that high-quality transitional care includes timely giving and receiving of information between the inpatient and outpatient settings and includes both medical and social elements (Table 3). Changes to the care plan should be communicated before discharge with PCPs, outpatient specialists, and home-based or school-based services to adequately prepare for a CYCD's return home (Table 3). Previous communication affords outpatient providers the opportunity to give input on the care plan and the ability to reinforce family education in the outpatient setting.

PCP participants added a unique perspective, indicating that they would ideally be involved early in the course of hospitalization rather than only at the time of discharge (eg, by phone for care conferences) given their ability to provide important psychosocial context and information related to the CYCD's physical baseline.

"I think one value to having [PCPs like me] at the care conference about goals of treatment or discharge is that we are the experts about that patient's care... During a hospitalization, I think there's lots of details you can get caught up

in that are not as [relevant when the patient is at home] and that might not pertain to the overall goals, and so it's good to have someone with an outside perspective."

PCP

Although communication was perceived as valuable by the majority of participants, delays in or incomplete communication were identified as barriers to higher quality transitions (Table 3). Ancillary service information and psychosocial issues that might have arisen during hospitalization were not routinely included in transition documentation. PCPs in particular expressed the importance of being updated about new or changing psychosocial concerns relevant to family functioning. Participants also identified the lack of a standard process to establish outpatient and PCP communication preferences for receiving information as a barrier to the hospital consistently communicating with the outpatient setting.

"I feel like [there could be more effective ways] that the resident can specifically contact a patient's primary doctor, rather than talking to the person who's covering that day or [the message] getting lost in the clinic's phone tree. At [clinic name], the PCPs do come out of the room to [answer the phone call], but with other clinics I can never really

actually get a provider on the phone to talk about the handoff."

Resident physician

## Theme 3: Reliable Methods

### Subtheme: Reliable Methods Focused on Evidenced-Based Practices

Providers identified reliable methods focused on evidence-based practices as important to enhancing the effectiveness and efficiency of transition tasks. Reliable methods ensure that any individual can do tasks in a consistent manner. Reliable methods particularly benefit tasks that could be completed by >1 provider type or in >1 manner (eg, medication reconciliation or patient and/or family education; see Table 3).

## High-Quality Outcomes of Transitional Care for CYCD

The theme that emerged related to high-quality transitional care for CYCD was to optimize patient and family outcomes. Subthemes and supporting quotes are within the subsequent text and in Table 4.

## Theme 1: Optimize Patient and Family Outcomes

### Subtheme: Meet Patients' Medical Goals While Maximizing Family Psychosocial Functioning

Providers stated the primary role of the inpatient setting was to help the patient

**TABLE 4** Illustrative Quotes of Provider-Identified Outcomes of High-Quality Hospital-to-Home Transitions for Children and Youth With Chronic Diseases

| Theme | Subthemes | Quotes |
|---|---|---|
| 1: Optimize Patient and Family Outcomes | Meet patient's medical goals while maximizing family psychosocial functioning | "First I do think about the medical aspect. Are [the patient and family] [medically] safe to go home? Are they 'better'?" Resident physician |
| | | "As an attending on service you listen to your team, your residents, your interns and [enable them] to decide when patients are medically stable to go home...If we're saying medically the patients are stable, we have [to also make sure] all of their care coordination, home supply, home nursing, whatever they may be are met." Attending physician |
| | | "A lot of our [medically] complicated kids' families know that we can't fix [all of the child's medical problems] for them. However, the fact that we can convey a sensitivity to that can [make] a big difference in terms of how our families, especially chronic kids, are going to continually be engaging with the medical system and we can establish a foundation [of support for the family] that is hugely important." Social worker |
| | Avoid readmissions | "We try and anticipate a 'bounce back' [slang for readmission within a short amount of time] and try and prevent that." Resident physician |
| | | "...a smooth handoff home makes for less likelihood of readmission." Information technology administrator |
| | | "I feel like I could be helpful and prevent a readmission..." PCP |

through an acute care crisis (Table 4). Therefore, a key outcome of high-quality transitional care is to return the patient to their optimal health status. However, providers also recognized that maximizing family psychosocial functioning and parent readiness was an important outcome of transitional care for the patient to meet his or her health goals.

> "The goal [of transitional care] is to make sure the patients are meeting all of the discharge criteria, that they are medically stable and then a large component of their discharge can also be family caregiver readiness."
>
> Attending physician

### Subtheme: Avoid Readmissions

Providers identified avoiding readmission or return visits to the emergency department as important outcomes in high-quality transitional care.

> "I usually think about what are the things that will keep [patients] out of the hospital for the longest period of time possible, and how do we create that type of support system such that they stay out of the hospital."
>
> Resident physician

### Regulatory Structures and Processes Affecting Transitional Care

Administrators, unlike frontline providers, highlighted the impact of regulatory requirements (especially when tied to financial penalties) on determining the content of transitional care and driving its place among hospital priorities. Administrators specifically noted that a growing emphasis on readmissions and financial risk sharing nationally has driven the hospital to focus on improving transitional care processes (eg, care coordination).

> "In the current payment model, we don't get paid for all the [care coordination] that is happening out in the community. The first thing that will happen [with health care reform] is we'll start to get penalized when [patients] get readmitted, so we'll get a negative consequence or we won't get paid, so we'll do it to lessen our hurt..."
>
> Physician services administrator

## DISCUSSION

In this study, we identified the critical structures, processes, and outcomes related to high-quality transitional care from the perspective of frontline providers and hospital administrators and provided new insights regarding how to approach improving the quality of hospital-to-home transitions for CYCD. Specifically, we identified improvements to health care transitional structures and processes needed to achieve high-quality outcomes for CYCD including meeting their medical goals, maximizing family functioning, and avoiding readmissions.

Our findings are consistent with previous literature in which the value of a family-centered multidisciplinary team approach to inpatient care is established.[23–25] We additionally suggest interventions for improving structures of care that emphasize continuity for CYCD (Table 2). One potential approach to optimizing inpatient provider-patient continuity, specifically for the subset of medically complex CYCD, would be to develop a dedicated inpatient service for them with a defined group of providers. Another potential structural intervention might involve developing secure cloud-based, electronic linkages and availability of CYCD's medical and surgical histories and ancillary care services to facilitate more seamless information sharing across the continuum of care.

Our participants also highlighted that successfully transitioning a CYCD home was contingent on the availability of a primary care medical home and community resources. Without broader insurance reform and state-based policies that support increasing the accessibility of high-quality community resources for pediatric chronic disease (like home nursing), inpatient providers and hospital-focused programs may be limited in their ability to improve transitional care. Therefore, policies and initiatives to achieve transitional outcomes, including minimizing readmissions, need to focus on the entire continuum of care.[26]

Our findings regarding care processes including the importance of setting shared transition goals and conducting patient and family needs assessments that include both comfort and competency with care tasks (Table 3) are congruent with recent evidence that parents want to be involved in care planning and establish self-efficacy with home care before transitioning.[16,17,27] Previous work has already addressed including families in care planning; however, more robust processes may be needed to assess competency with home care tasks, including standardized protocols for home care teaching and rigorous "rooming-in" practices in which parents assume full care before discharge for all CYCD.[23–25]

We also found that although frontline providers valued assessing family psychosocial functioning and social determinants of health when conducting care planning, they did not have standard processes to assess these factors. Recent studies by Beck et al[28,29] revealed that families of lower socioeconomic status experience challenges and stress from hospital-to-home transitions, and proactively addressing these challenges may prevent adverse events and reduce postdischarge disparities. Their work, and ours, support policies that integrate social risk factor assessment with hospital-based pediatric chronic disease care as a way to improve family readiness for discharge and minimize preventable readmissions.[30] Possible future interventions might include utilizing a standardized screening tool to proactively identify psychosocial barriers to successful transitions home, assess parents' subjective agreement with the plan to be discharged, and assess their competency with home care tasks.[31,32] Such screening could facilitate social workers or other staff in providing targeted transition supports ultimately improving family self-efficacy and potentially reducing readmissions.[33]

Another key finding in this study is that communication practices require consistent processes of both giving and receiving medical and psychosocial information. Our study participants highlighted that because of CYCD's frequent and manifold health care interactions, there is a heightened need to consistently communicate care plans with

outpatient, specialty care, inpatient, school-based, and ancillary care service providers to avoid readmissions.[34–36] Creation of health information exchanges, defined as the process of sharing reliable, confidential, and interoperable electronic health-related information, may provide 1 approach to the sharing of a child's care plan across settings.[37–39]

Lastly, we found that a lack of reliable methods focused on evidence-based practices may hinder providers' ability to deliver high-quality transitional care. Currently, no comprehensive evidence-based standards for pediatric transition care exist. However, the authors of a recently published framework outline a general approach to transitional care and new quality measures have been developed to evaluate pediatric transitional care.[5,40] Further research is needed to understand which specific aspects of transitional care might benefit from standardization and which are specific to CYCD versus all children.

This study has some limitations. The data were self-reported from a limited number of participants who were purposely selected at a single institution and thus are not generalizable and subject to selection bias. However, qualitative analysis of focus group and key informant interview data allows for in-depth evaluation of experiences of participants unavailable through other methods. Participants were not asked to prioritize which structural or process improvements were most important to achieving high-quality transitional care, thereby limiting our ability to weigh the various themes identified. However, we provide insights into the structures and processes of transitional care that may be high-value targets for further study and quality improvement.

## CONCLUSIONS

In this qualitative study of hospital-to-home transitional care for CYCD, we found that many key structures and processes perceived as important to achieving high-quality transitional care have opportunity for improvement at the institution studied. This may partially explain the challenges families often experience with transitional care and higher readmission rates commonly observed in CYCD. Engaging key stakeholders in designing quality improvement interventions to address these deficits in the current care model may improve transitional care outcomes for this vulnerable population.

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