

Familial Caregiver and Physician Perceptions of the Family-Physician Interactions During Interfacility Transfers

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BACKGROUND AND OBJECTIVES: Children with special health care needs (CSHCN) have frequent hospitalizations and high specialty care utilization. If they initially present to a medical facility not capable of providing their definitive care, these children often experience an interfacility transfer. This transition has potential to impose hardships on familial caregivers. The goal of this study was to explore family–physician interactions during interfacility transfers from the perspectives of referring and accepting physicians and familial caregivers, and then develop a conceptual model for effective patient- and family-centered interfacility transfers that leverages the family–physician interaction.

METHODS: This single-center qualitative study used grounded theory methods. Interviews were conducted with referring and accepting physicians and the familial caregivers of CSHCN. Four researchers coded the data. The research team reached consensus on the major categories and developed a conceptual model.

RESULTS: Eight referring physicians, 9 accepting physicians, and 8 familial caregivers of 25 CSHCN were interviewed. All participants stated that family–physician interactions during transfers should be improved. Three main categories were developed: shared decision-making, provider awareness of families' resource needs, and communication. The conceptual model showed that 2-way communication allows providers to gain awareness of families' needs, which can facilitate shared decision-making, ultimately enhancing effective coordination and patient- and family-centered transfers.

CONCLUSIONS: Shared decision-making, provider awareness of families' resource needs, and communication are perceived as integral aspects of the family–physician interaction during interfacility transfers. Transfer systems should be reengineered to optimize family–physician interactions to make interfacility transfers more patient- and family-centered.

ABSTRACT

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Dr Rosenthal conceptualized and designed the study, conducted the interviews, analyzed the data, interpreted the results, and drafted the initial manuscript; Dr Li assisted with the data analysis and interpretation of the results; Ms Hernandez conducted the interviews, analyzed the data, and interpreted the results; Dr Alvarez interpreted the results; and Drs Rehm and Okumura contributed to the conceptualization and design of the study, and assisted with the data analysis and interpretation of the results; and all authors revised the manuscript and approved the final manuscript as submitted.

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Children with special health care needs (CSHCN) are a population with a high likelihood of frequent hospitalizations and specialty care utilization beyond that required by children in general.^{1,2} When CSHCN present to a hospital that is not capable of providing definitive care, these children are often redirected to hospitals with specialized care, and they thus experience an interfacility transfer.^{3,4}

Unfortunately, decision-making surrounding aspects of transfers is not always based on patient outcomes but rather nonpatient-centered organizational priorities.^{5,6} Interfacility transfers pose challenges and burdens to the physicians involved.⁵⁻⁸ Physician interactions across facilities frequently involve perceptions of disrespect and mistrust.^{6,8} Physician-physician communication often has missing information and can be time-consuming or cumbersome. It is similarly likely that pediatric patients and familial caregivers experience hardships, particularly because transfers might not prioritize familial preferences and patient-centered outcomes.⁶ Familial caregivers of CSHCN must communicate more medical-related information to physicians and have higher rates of questions than caregivers of children without special health care needs.⁹ Thus, the family-physician interactions for CSHCN are especially important.

Research exploring perspectives of family members of transferred adult patients found that families feel uninformed about the transfer and experience difficulty adjusting to the transition.¹⁰ However, research is lacking that includes perspectives of familial caregivers of pediatric patients experiencing interfacility transfers. We predict pediatric transfers could benefit from systems reengineered to become more patient- and family-centered. A potentially modifiable factor that can make transfers more patient- and family-centered is the family-physician interaction. A first step to making such improvements is to understand the current state of the family-physician interaction from the perspectives of the individuals involved.

The present analysis comes from a larger study exploring barriers and facilitators to

effective interfacility transfers from the perspectives of physicians and familial caregivers. Previously, we published findings regarding the physician-physician communication during transfers from the perspectives of physicians.⁸ However, an aspect not included in our previous publication was the involvement of familial caregivers during transfers. The present article explores the family-physician interactions during interfacility transfers from the perspectives of referring and accepting physicians and familial caregivers of CSHCN. It then develops a conceptual model for effective patient- and family-centered interfacility transfers that leverages aspects of the family-physician interaction.

METHODS

Study Design

Grounded theory methods were used to conduct this single-center qualitative study.¹¹ Two researchers (J.L.R. and L.H.) conducted semi-structured interviews with referring physicians, accepting physicians, and familial caregivers. We developed an interview guide that asked participants to reflect on the following main topics: (1) their experiences with transfers; (2) their satisfaction with the transfer process; (3) their experiences with transport teams; and (4) their suggestions for improving future transfers.

Participants were asked to reflect on both the recent CSHCN transfer that triggered their eligibility for the study as well as their overall experience of transfers. Initial interview guides were revised as initial data were analyzed and new categories of findings developed. Specifically, interviewers probed more into the topic of family-physician interactions based on preliminary analysis. Interviews were conducted within 45 days of the transfer, in person or by telephone. Each participant verbally consented to participate. Interviews were audio-recorded and transcribed. Interviewers maintained field notes with contextual observations and described verbal and nonverbal cues. Each participant received a \$25 gift card. The University of California, San Francisco, institutional review board approved the study protocol.

Study Population

Study participants were physicians and familial caregivers of CSHCN who experienced an interfacility transfer to a single-center tertiary/quaternary care children's hospital in California between July and November 2014. Participants were identified from an existing hospital transfer center database maintained in real-time as new transfers occurred. We screened the database daily for eligible patients. Eligible patients were those aged 0 to 25 years with a chronic medical or behavioral condition, as defined by components in the CSHCN screener,¹² admitted to a pediatric floor via interfacility transfer (transfer from a different facility's clinic, emergency department, or inpatient hospital).⁸ CSHCN eligibility using the screener was determined by chart review. Non-English-speaking participants were excluded. Potential participants were recruited for participation by telephone, fax, or e-mail after the CSHCN was discharged.

Demographic information of participants and CSHCN was collected by using a participant survey and database review. Familial caregiver characteristics included age and sex. Physician characteristics included age, sex, years of experience, training, transfer practices, and frequency of providing care to CSHCN. Hospital characteristics of the physicians' facilities included freestanding children's status and access to pediatric subspecialists, teaching status, and urban versus rural location. Patient characteristics included age, sex, insurance status, transport distance, originating unit type, and posttransfer service. To stratify the CSHCN according to medical complexity, the number of complex chronic conditions was recorded by using the International Classification of Diseases, Ninth Revision, Clinical Modification, codes identified by Feudtner et al.¹³

Data Analysis

Data were analyzed in an iterative process beginning with open-coding of the transcripts by 4 investigators (J.L.R., L.H., M.J.O., and R.S.R.), which led to development of categories. Two investigators (J.L.R. and L.H.) subsequently performed focused, line-by-line coding of all data to further develop these categories. These investigators coded

the transcripts independently and discussed all discrepancies to ensure consensus regarding the preliminary analysis. During focused coding, new codes, combined categories, and adjusted category definitions were added as the transcripts were analyzed. Data collection continued until the categories were fully developed and demonstrated conceptual coherence around the family–physician interaction during interfacility transfers. Through team meetings and shared analytic memos, the research team reached consensus on the construction of the major analytic categories and development of the conceptual model.

The research team included nurse researchers, inpatient pediatric hospitalists, and an outpatient medicine–pediatrics generalist. Three investigators had extensive qualitative research experience. We used ATLAS.ti. to organize and store coding and for data analysis.¹⁴

RESULTS

This study included 25 CSHCN. From these patient transfers, we conducted twenty-five 45- to 60-minute interviews with referring physicians ($n = 8$), accepting physicians ($n = 9$), and familial caregivers ($n = 8$). Among the familial caregivers, 50% were female, and their mean age was 42 years (95% confidence interval: 33–52). Four familial caregivers had extensive experience navigating transfers as a result of having a child with multiple previous transfers. Two others had some experience given their child's 1 previous transfer, and 2 more had experienced no previous transfers. Characteristics of physician participants, the hospital in which they work, and the transferred patients of the interviewees are provided in Tables 1 and 2.

Three main categories were developed portraying important analytic themes across the transcripts that pertained to the family–physician interactions during interfacility transfers. These are explored in the following sections, with representative quotes presented in Table 3.

Category 1: Role of the Familial Caregiver in Making Transfer Decisions

Interfacility transfers inherently necessitate multiple decisions to be made during the

TABLE 1 Profile of the Physician Participants

Characteristic	Referring Physicians ($N = 8$)	Accepting Physicians ($N = 9$)
Physician characteristics		
Age, mean (95% CI), y	46 (39–54)	40 (31–49)
Female sex	3 (37.5)	6 (66.7)
Experience, mean (95% CI), y	14 (8–20)	11 (1–20)
Formal training		
Pediatrics, no specialty training	5 (62.5)	5 (55.6)
Pediatrics, with specialty training ^a	1 (12.5)	4 (44.4)
Emergency medicine	2 (25.0)	0
Other	0	0
Transfer practices		
Only refer	1 (12.5)	0
Mostly refer	2 (25.0)	0
Both refer and accept equally	1 (12.5)	0
Mostly accept	4 (50.0)	7 (77.8)
Only accept	0	2 (22.2)
Providing care to CSHCN		
Every day of clinical practice	3 (37.5)	6 (66.7)
Majority of days of clinical practice	2 (25.0)	2 (22.2)
Infrequently during clinical practice	2 (25.0)	0 (0.0)
Unknown	1 (12.5)	1 (1.1)
Hospital characteristics		
Hospital type		
Freestanding children's	2 (25.0)	0
Children's hospital within a hospital	1 (12.5)	9 (100.0)
Non-children's with subspecialty ^b	3 (37.5)	0
Non-children's without subspecialty ^b	2 (25.0)	0
Teaching hospital	4 (50.0)	9 (100.0)
Urban location	6 (75.0)	9 (100.0)

Data are presented as n (%) unless otherwise indicated. CI, confidence interval.

^a Specialty training included fellowship training in specialties such as cardiology, infectious diseases, and gastroenterology.

^b Refers to non-children's hospitals that have and do not have pediatric subspecialty services, respectively. Such services refer to the presence or lack of a pediatric ward or pediatric specialist(s) (eg, pediatric cardiologist, pediatric anesthesia, pediatric surgery).

process. Familial caregiver and physician participants discussed the optimal role of the family in making such decisions. The overwhelming perception was that the family–physician interaction in decision-making should be more collaborative. Many participants discussed the decision-making process of determining whether a transfer was indicated. This key decision was commonly described as made in isolation by the physician and riddled with opposition. Many familial caregivers shared stories of disputes with physicians where families were “arguing” or “fighting” for a

transfer. Of note, no participant described families advocating to remain at the local facility and not transfer. The consequence of lack of shared decision-making for most families was heightened stress for families, increased burdens to families, and hindered family–physician relationships.

Although most physicians and familial caregivers described interactions that lacked shared decision-making, a few individuals explained how some families expedited the decision-making process by facilitating communication between hospital

TABLE 2 Profile of the Transferred Pediatric Patients of the Interviewees

Characteristic	Pediatric Patients (<i>N</i> = 25)
Patient characteristics	
Age, mean (95% CI), y	12 (9–14)
Female sex	8 (32.0)
Medicare or Medicaid	10 (40.0)
No. of complex chronic conditions	
0	11 (44.0)
1	6 (24.0)
≥2	8 (32.0)
Home-to-hospital distance, mean (95% CI), ^a miles	99 (65–132)
Transported distance, mean (95% CI), ^b miles	72 (44–100)
Originating unit type ^c	
Clinic	4 (16.0)
Emergency department	12 (48.0)
Inpatient ward	9 (36.0)
Posttransfer service	
Hospitalist	9 (36.0)
Transplant	7 (28.0)
Pediatric surgery	5 (20.0)
Hematology-oncology	2 (8.0)
Neurosurgery	1 (4.0)
Cardiology	1 (4.0)

Data are presented as *n* (%) unless otherwise indicated. CI, confidence interval.

^a Refers to the distance between the patient's home and the accepting, posttransfer hospital.

^b Refers to the distance between the referring, pretransfer hospital and the accepting, posttransfer hospital.

^c Refers to the type of unit from which the patient was transferred while at the referring, pretransfer hospital.

burdensome to patients and their families. The distance between the posttransfer hospital and their home imposed multiple hardships. Stretched resources involved finances, lodging, transportation, employment, and child care. Some caregivers described how their resource needs were addressed from services provided by the posttransfer hospital. Services included gas cards, parking vouchers, meal vouchers, and lodging. Others shared how these services were provided inconsistently, leaving some families with no place to sleep or no assistance with transportation to and from the hospital.

A particular challenge arose for families who accompanied their child in the ambulance or flight transport, and consequently had no transportation for the trip home after discharge. Families rarely received assistance with this issue. Familial caregivers perceived that these transportation issues were sources of anxiety and that acknowledging and addressing these issues before the transfer would be a way to minimize the severity of this burden. Although families of CSHCN with a history of multiple transfers were more prepared to coordinate the logistics of a transfer, families with less experience were not as prepared. To prevent all responsibilities being assumed by the familial caregivers, physician participants suggested implementing educational interventions to improve physician awareness of the resource needs of families of transferred patients.

Category 3: Communication With the Familial Caregiver

Communication was discussed extensively by each participant as a vital aspect of creating positive family–physician interactions during transfers. Despite the recognized importance of communication throughout the transfer process, some caregivers perceived few attempts by health care providers to communicate with them. Familial caregivers stated that they were not kept informed and updated. The majority of communication breakdowns occurred at the pretransfer hospital and during transport. Some familial caregivers

providers. They described pretransfer communication between parents and specialty physicians at the receiving hospital with whom they had a previous relationship. When this scenario occurred, posttransfer physicians worked with families to decide whether changes in clinical status warranted admission or transfer, and sometimes instructed families to present to the transferring hospital for a pretransfer evaluation. Families then communicated the desired evaluation results to the referring physician. These familial caregivers who engaged in the transfer process were experienced, assertive individuals. Physicians and familial caregivers reported an appreciation for such interactions, as it left both physicians and families pleased with the outcomes. Particularly, coordination of care was reported to be more streamlined and comprehensive.

Participants also talked about the role of families in deciding other aspects of the transfer, including preferences for a specific hospital and mode of transport. Although some family members deferred such decisions to the physician, caregivers reported that the opportunity to be involved in these types of decisions was important. When families were involved in these decisions, the logistical aspects of the care coordination were more aligned to meet the families' needs. Among physicians who discussed shared decision-making, it was reported to be important. However, it was admittedly not always practiced.

Category 2: Addressing Physician Awareness of Families' Resource Needs

Physicians and familial caregivers described extensively that transfers were

TABLE 3 Exemplary Quotes Supporting the Major Categories and Subcategories

Category	Subcategory	Exemplary Quote	
Category 1: Role of the familial caregiver in making transfer decisions	Conflicts and disagreements	"I think that was unfair. You know, that I had to come and argue in order to get my son to where he needs to be." (familial caregiver)	
	Engaged familial caregivers facilitating the transfer	"I was exchanging some e-mails with the nurse coordinator at the other facility and letting her know what was going on and my attempts at making sure people were communicating." (familial caregiver) "We got an occasional call where an emergency room typically referred to [hospital] and they chose to refer to [our hospital] because the family asked." (accepting physician)	
	Importance of involving the familial caregiver	"I think that it should be 'this is where we are thinking of sending you; how do you feel about that?' Not necessarily up to the parent, but I think the parent should have some say in it." (familial caregiver) "I like to give families, if I am sending a kid, choices that are within reason, as to what is appropriate, medically appropriate choices because transportation is usually a barrier for a lot of families." (referring physician)	
Category 2: Addressing physician awareness of families' resource needs	Challenges as result of limited resources	"I am a retiree and my funds are like deteriorated and it was hard for us to get down there." (familial caregiver) "I had some more kids here at the house...it was difficult for us to go back and forth." (familial caregiver) "They are going to this other hospital that is far away and the fears that the parents have in terms of like 'okay, who is going to take care of my kids at home when I drive here and do I have to follow them in the ambulance; can I go in the ambulance'...trying to figure out their own logistics really is a challenge for parents." (referring physician)	
		Value of receiving services to minimize the burdens	"The social worker, oh they were so helpful...they had food cards to get food in the cafeteria and gas cards and they made it so we could feel better so we could be there with my son." (familial caregiver)
		Lack of attention to resource needs	"[Patients and their families] can be understandably anxious about being transferred and transported...not knowing how they are necessarily going to be transported back home, because that is not usually addressed in the transport process." (accepting physician) "We will have these families who have to come back sometimes for 3 or 4 different appointments and each appointment is on a different day... patients have to come back for a really long drive for a 15 min appointment and I wish there was a good telehealth option for that." (accepting physician)
	Need for greater physician awareness of the burdens	"A lot of attendings have no clue—like how much this is impacting the families and how much it is costing them; it is not really something taken into consideration and maybe if there was more learning from a better aspect of what you are asking of families." (accepting physician) "I wonder if there was just better teaching across the spectrum about transfers and how they can be done and kind of what—how much things cost and what families are paying for." (accepting physician)	
Category 3: Communication with the familial caregiver	Effective communication	"Well basically if [physicians] communicate with me it is going to go well. If I don't know and have to keep asking questions, we are not off to the right start; I think informing a parent of what's going on or just communication plays a big role in everything." (familial caregiver) "Being able to know what is going on is probably the biggest thing because you just found out your child has a serious emergency going on right now and your head is spinning, your brain is going a 1000 miles an hour; is he going to be okay, is he not going to be, so just knowing, just knowing what is going on is really—it almost helps with the sanity of the parent." (familial caregiver) "Every time I used [telemedicine] where I was looking at a patient at the emergency department (ED), the referring ED, that it was extremely helpful because they could see me. It was a 2-way communication, families could see me; they could see what I looked like if I was the accepting doctor; they knew I was a pediatrician and often they were at a facility or an ED where there was no pediatrician; so that was often very reassuring to parents." (accepting physician)	

TABLE 3 Continued

Category	Subcategory	Exemplary Quote
	Breakdowns in communication with familial caregivers	<p>"I didn't know if they were going to do surgery the same night or if they were going to do it the next day and I didn't feel like I was much included in anything...I didn't get much information." (familial caregiver)</p> <p>"Not everyone communicates it very well to the parents or the families and sometimes they don't understand what is going on and why." (referring physician)</p> <p>"They don't know exactly what the plan is or why they are being transferred or why it is an emergency or things like that." (accepting physician)</p>

said they did not know what the potential diagnosis was or why tests were performed. From the perspective of the family, even the plan to be transferred was not communicated to them in a timely fashion. Some familial caregivers perceived that communication improved once the transport team arrived. Others believed it improved upon arrival to the posttransfer hospital. Physician participants acknowledged that some physicians do not communicate well with families, leaving familial caregivers uninformed.

Being informed and updated was perceived to ease the anxiety, uncertainty, and fear felt by many familial caregivers. Parents described the need for information about the clinical aspects of their child's care and also about the transfer process and available resources. Less experienced familial caregivers described being at the posttransfer hospital not knowing how to obtain food or other necessities.

Although some families experienced poor communication, others shared stories of effective communication that was clear, frequent, and bidirectional. In particular, telemedicine use before the transfer was described as a useful tool for 2-way communication between the posttransfer physician and families. Telemedicine not only permitted the posttransfer physician to see the patient and thus have a stronger understanding of his or her clinical severity, but telemedicine permitted the family to feel comforted in seeing and communicating with the specialty physician. Telemedicine additionally assisted with the coordination of care; it increased the referring physicians' ability to provide clinical

management recommendations that could be initiated at the pretransfer facility.

Conceptual Model

Upon review of the categories and the relationships between them, we constructed a conceptual model to illustrate how to foster effective patient- and family-centered interfacility transfers by improving the family-physician interaction (Fig 1). The concepts in the model pertain to the 3 study categories of communication, provider awareness of families' needs, and shared decision-making. Good 2-way communication between physicians and families promotes improved provider awareness of families' needs. When families are informed and when physicians are aware of family preferences and value their input during transfer, both parties are then more prepared to participate in shared decision-making. Each of the 3 categories enhances care coordination throughout the transfer process by addressing the transfer challenges of suboptimal decision-making, imposed burdens, unmet resource needs, and poor communication. We theorized that reengineering interfacility transfers to focus on communication, provider awareness of families' needs, and shared decision-making could lead to more effective coordination between families and providers and ultimately more effective patient- and family-centered interfacility transfers. Importantly, we can improve the family experience by making the process significantly less stressful and taxing.

DISCUSSION

This explorative qualitative analysis examined family-physician interactions

during interfacility transfers from the perspectives of physicians and familial caregivers of CSHCN. We identified that decision-making, resource needs, and communication are perceived to be vital aspects of family-physician interactions. Study participants expressed concerns with current transfer practices. The lessons learned led to the development of a conceptual model for effective patient- and family-centered transfers.

In the present study, familial caregivers expressed concern over the perceived lack of shared decision-making during transfers. They often felt the need to negotiate the transfer by arguing with the referring physician to be transferred. By the same token, previous research describes physician-physician interpersonal conflicts surrounding transfer decisions. Referring physicians report that accepting physicians can be disrespectful and rude.⁸ Referring physicians perceive they need to argue that a transfer is necessary, with the implication that the accepting physician thinks the referring physician is lazy or inept.⁶ It is therefore not surprising that families feel they too have to negotiate the transfer. A potential rationale for the lack of shared decision-making during transfers is that physicians are not aware of the value of such familial involvement; rather, the realm of shared decision-making is mostly thought to apply to clinical management. The findings in this study imply that physicians should take action to engage families in decision-making throughout the process of interfacility transfers. Physicians and families should share information, discuss options, and decide on the best course of

action. These steps pertain not only to clinical treatment plans but also to other aspects, including whether to transfer, where to transfer, when to transfer, and how to transfer.

Our study revealed the familial caregiver and physician perception that most physicians lack awareness of the imposed burdens and resource needs of families during a transfer. Likewise, previous research showed that pediatric providers have a similar lack of recognition of the psychosocial needs and barriers to discharge during the hospital-to-home transition.¹⁵ Recent efforts have been made to recognize and address these discharge needs by promoting standardized frameworks to organize the discharge process.^{16–20} We propose that the interfacility transfer process would benefit from similar standardization. Standardization might bring awareness to and help address the imposed burdens, such as transportation or financial hardships. Addressing the issue of family members having no transportation home to distant locations would reduce burdens to families and minimize discharge delays. We also propose that physicians receive additional training on conducting interfacility transfers. This training would

include how to optimize 2-way communication, recognize family resource needs, and facilitate shared decision-making during interfacility transfers.

Improvement efforts to make transfers more patient- and family-centered could target 2-way communication. Based on results in the present study, improvement efforts should prioritize the communication at the pretransfer hospital. Telemedicine was discussed by multiple participants as a useful communication intervention to improve the family–physician interaction during interfacility transfers. Pretransfer 2-way telecommunication between the accepting physician and the patient and family was perceived to provide reassurance to families. The use of telemedicine has been shown to be well accepted by parents of children with serious chronic conditions.²¹ As part of standardizing the interfacility transfer process, telemedicine could be a potentially valuable tool. Because telemedicine has been largely used for critically ill patients,^{22–24} further research is required to determine the effects of incorporating telemedicine into the interfacility transfer process for noncritically ill pediatric patients.

The present study aimed to explore perspectives of physicians and familial

caregivers of CSHCN. Although the physician participants were identified for having transferred patients meeting CSHCN criteria, these physicians provide care to the broader group of all pediatric patients. Their experiences and therefore results of the physicians' perspectives pertain to the broader group of transferred pediatric patients. However, the experiences and thus results of the familial caregivers' perspectives pertain specifically to CSHCN. Before applying results of this study to non-CSHCN, additional research should examine the family–physician interaction during interfacility transfers of the broader population of all pediatric patients.

Our study has several limitations. Transferability was limited by use of a single receiving facility. Participants were limited to English-speaking individuals only; thus, issues pertaining to communication and shared decision-making might be amplified in the setting of language barriers. Participants could have recall bias. The number of referring providers in this study with no pediatric background was low, which may have influenced their perceptions of caring for CSHCN and thus affected the results. In addition, participants who agreed to be in this study could have polarized perceptions due to extreme interfacility transfer experiences.

CONCLUSIONS

Referring and accepting physicians and familial caregivers in our study perceived decision-making, provider awareness of families' resource needs, and communication to be important aspects of the family–physician interactions during transfers. Optimizing communication, provider awareness of family needs, and shared decision-making may potentiate improved care coordination and ultimately transfers that are more patient- and family-centered. The framework developed in this study can potentially guide future interventions to enhance interfacility transfers. By addressing domains identified in our model, we may improve family–physician interactions, the delivery of care we provide, and the health outcomes of children who experience hospital-to-hospital transfer.

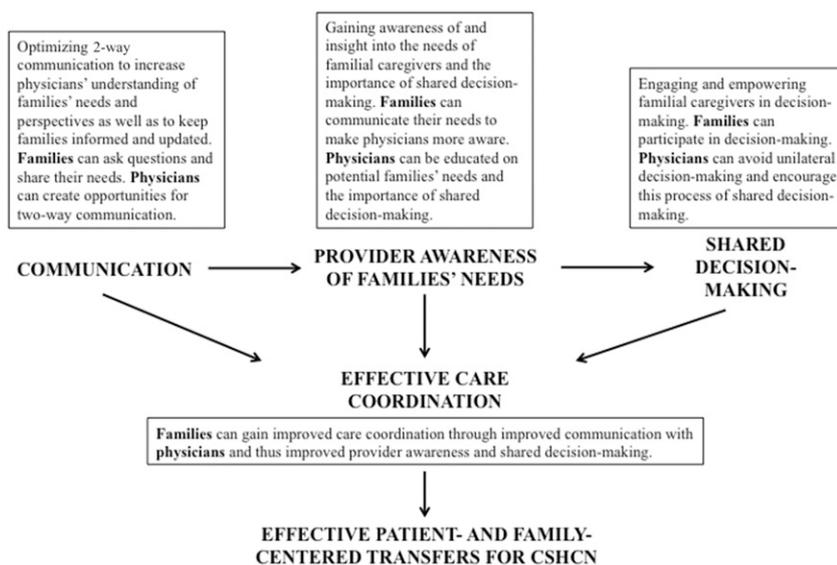


FIGURE 1 Conceptual model for effective patient- and family-centered interfacility transfers for CSHCN

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