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Caregiver perspectives on the everyday medical and social needs of long-term pediatric liver transplant patients

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Abstract

Objective: Using in-depth interviews, we sought to characterize the everyday medical and social needs of pediatric liver transplant caregivers to inform the future design of solutions to improve care processes.

Approach & Results: Participants (parents/caregivers of pediatric liver transplant recipients) completed a survey (assessing socioeconomic status, economic hardship, health literacy, and social isolation). We then asked participants to undergo a 60-minute virtual, semi-structured qualitative interview to understand the everyday medical and social needs of the caregiver and their household. We intentionally oversampled caregivers who reported a social or economic hardship on the survey. Transcripts were analyzed using thematic analysis and organized around the Capability, Opportunity, Motivation-Behavior model. A total of 18 caregivers participated. 50% of participants reported some form of financial strain and about half had less than 4 years of college education. Caregivers had high motivation and capability in executing transplant-related tasks but identified several opportunities for improving care. Caregivers perceived the health system to lack capability in identifying and intervening on specific family social needs. Caregiver interviews revealed multiple areas in which family supports could be strengthened, including around (1) managing indirect costs of prolonged hospitalizations (e.g., food and parking), (2) communicating with employers to support families' needs, (3) coordinating care across hospital departments, (4) clarifying care team roles around helping families reduce both medical and social barriers.

Conclusions: This study highlights the caregiver perspective on barriers and facilitators to post-transplant care. Future work should identify whether these themes are present across transplant

centers. Caregiver perspectives should help inform future interventions aimed at improving long-term outcomes for children after liver transplantation.

Keywords

health equity; qualitative research; social determinants of health; social adversity

INTRODUCTION

Pediatric liver transplantation offers exceptional survival benefit for children with end-stage liver disease, but long-term outcomes are suboptimal. Though one-year survival is >90%,¹ only a third of children are free of morbidity and have a functioning allograft at three years post-transplant.^{2,3} After the first year of transplant, the focus of care shifts from post-surgical care to chronic disease management—principally ensuring long-term allograft health while minimizing comorbidities related to chronic immunosuppression—which requires coordination between patients/families and the health system.⁴ We and others have described racial and socioeconomic disparities in long-term outcomes, with Black children and children from socioeconomically deprived neighborhoods having increased risk of adverse long-term outcomes.⁵⁻⁸ However, these studies have been at the population level and, therefore, are not granular enough to identify actionable interventions to narrow these disparities.⁹

Understanding and addressing the unique challenges faced by pediatric liver transplant caregivers should lead to improved outcomes by enabling us to identify actionable interventions—those that the health system can implement.⁹ Such interventions may be at the patient/family, provider, health-system, or community-level.¹⁰ Qualitative methods offer a rigorous approach to capturing the caregiver experience after transplant and may uncover opportunities to reduce barriers for patients and their families that ultimately lead to improved long-term outcomes.

In the present study, we aimed to describe the everyday medical and social needs of caregivers of long-term survivors of pediatric liver transplant with a specific focus on how life circumstances impact transplant care and vice versa.

METHODS

STUDY DESIGN

This was a single center study of children who had undergone liver transplant and part of the ongoing Social & Contextual Impact on children undergoing Liver Transplantation Study (SOCIAL-Tx, [NCT04551742](#)). Parents/caregivers of these children were invited to complete a survey designed to capture information about various social needs and to participate in a virtual in-depth 60-minute interview. Briefly, the survey was developed to capture the mid-stream social determinants of health and includes measures of financial strain,^{11,12} material economic hardship,¹³ health literacy,¹⁴ and social isolation^{15,16} (Appendix 1). The survey was primarily self-administered by the participant using paper & pen and completed surveys were stored on an electronic database (REDCap). Health literacy was assessed

with the Newest Vital Sign,¹⁴ which was administered by a research coordinator (A.G.B.) Participants were recruited for the survey portion in the hospital, in-clinic, by phone, or virtually.

The study was approved by the University of California, San Francisco IRB, and all participants provided written informed consent. Child assent was obtained for children 7 years of age. Participants were provided a \$30 gift certificate for their participation. This amount was derived to incentivize participation without being coercive. We adhered to the Standards for Reporting Qualitative Research (SRQR) guidelines in reporting our results (Appendix 2).¹⁷

THEORETICAL APPROACH

We used the Capability Opportunity Motivation Behavior (COM-B) model as our theoretical underpinning for our interview guide as well as initial deductive coding of our qualitative data. The COM-B model¹⁸ seeks to characterize behavior in context by classifying barriers and facilitators to behavior change according to Capability (e.g., knowledge and skills needed for behavior change), Opportunity (e.g., availability of necessary physical and social resources for behavior change), Motivation (e.g., beliefs, attitudes, and emotions related to behavior change behavior). The model is based on multiple theories outlining known domains of behavior change (e.g., post-transplant care), and has been championed by implementation scientists to identify interventions matched to stakeholder needs and preferences.

STUDY SAMPLE AND RECRUITMENT

English- or Spanish-speaking parents/caregivers of children who had received a liver transplant >1 year prior and were receiving ongoing post-transplant care at our institution were eligible to participate. We purposively sampled families, purposively recruiting patients/families from high deprivation index neighborhoods (i.e., using census-tracts from family addresses) or those that reported the presence of a material economic hardship on the study survey (e.g., food insecurity). First, we approached patients/families who reported social needs or those from high deprivation neighborhoods. Then, we expanded to other patients within our practice. Parents/caregivers were approached during inpatient hospitalizations, clinic appointments, and over the telephone. Consent took place in-person or virtually via Zoom. We continued to enroll parents/caregivers until we reached thematic saturation, that is until no new themes emerged from the interviews. No patients participated in the interviews; we spoke with caregivers of pediatric patients exclusively. Our transplant center currently cares for approximately 200 children annually post-liver transplantation. About half our patients have public insurance. A majority of our patients are white; about a quarter of the patients we care for are Black, Asian, Native American, or Pacific Islander. The median deprivation index for patients at our center is 0.35 (IQR 0.26-0.47). For reference, the national median is 0.36 (IQR 0.27-0.46). We contacted each potential participant up to 3 times (N=44) with requests to participate in the study. 24 families responded to our calls. Of these 24, 4 declined the interview and 2 did not show up for the scheduled virtual interview. Every family that we attempted to recruit had a patient who was

>1 year after transplant. In the excluded group, the median time from transplant was 4 years. Our final sample size was 18 caregivers (Figure 1).

Recruitment of all participants and interviews were completed between 1/2021-9/2021.

DATA COLLECTION METHODS AND ANALYSIS

Interviews were conducted virtually via videoconference (Zoom, Inc). To encourage open and frank conversation, the interviews were conducted by one facilitator who was not part of the clinical care team (A.G.B). The interview included a 60-minute discussion using a semi-structured interview guide (Appendix 3) The interviewer would ask additional customized questions based on participant survey responses and interview responses. For example, if a participant reported financial hardship, the interviewer would ask additional probing questions on managing one's expenses. This semi-structured approach enabled the interviewer the flexibility to gain an in-depth understanding of each caregiver's individual circumstances. The interview guide was developed by the principal investigator (S.I.W.) with additional input from study team members with qualitative research experience (C.R.L. and L.G.). All virtual interviews were recorded, and the audio recording of each interview was professionally transcribed verbatim. Transcripts were coded using Dedoose (Los Angeles, CA).¹⁹ A deductive codebook based on the COM-B model was created a priori. Each transcript was coded by at least 2 separate investigators. Three investigators (S.I.W., A.G.B., and H.S.) conducted all coding. Once a transcript was coded by 2 investigators, they met to review the codes and adjudicate any disagreements. The principal investigator (S.I.W.) periodically served as a third coder to ensure consistent coding. Those same three investigators reviewed the transcripts and met regularly to discuss additional emerging inductive codes. They also discussed emerging themes and only included the theme if consensus was achieved. It was determined that theoretical saturation was reached when concepts and themes were redundant with previous observations. Once themes were identified, they were organized into two categories: a) household-level barriers and facilitators to post-transplant care; and (b) provider/health system awareness and outreach related to those barriers and facilitators. Descriptive statistics (e.g., frequencies) were used to describe survey responses.

RESULTS

DEMOGRAPHIC CHARACTERISTICS

18 participants completed surveys and interviews; all participants were caregivers of pediatric liver transplant recipients. 16 were the liver transplant recipient's maternal caregiver and 2 were the liver transplant recipient's paternal caregiver. All participants were English-speaking, and interviews were conducted in English. All patients were long-term survivors >1 year after transplant with a median of 5 years out from transplant, 60% were non-White, about a third of families had public insurance, and about half reported financial strain. Table 1 presents demographic data for the liver transplant recipients. The study IRB did not allow us to extract additional information about recipients' clinical characteristics from the electronic health record.

THEMES

The major themes that emerged were classified according to household-level themes and Health System-level themes. At the household-level, all families reported an explicit system for monitoring their child's immunosuppression medications but differed in how much they relied on the transplant team for coordinating transplant care. All families reported the added stress of in-direct costs during periods of prolonged hospitalizations. Finally, they reported varying levels of support from their employers for work absences. At the health system level, caregivers reported challenges coordinating appointments with ancillary departments (e.g., radiology appointments) and that there was an unclear understanding as to who was responsible for certain tasks (e.g., securing refills for compounded, liquid tacrolimus).

Household-level Themes—Across the interviews, caregivers described a clear division of transplant-related tasks, including medication administration and care coordination. While caregivers reported high levels of capability (e.g., knowledge of the tasks) and motivation (e.g., highly motivated to ensure proper medication administration), many of the barriers to addressing medical and social needs centered around opportunity.

1. Barriers to medical management at home: Across interviews, caregivers expressed explicit systems for medication administration, including a clear understanding of who is responsible for drawing doses, administering the medications, and obtaining refills when supply runs low. While most households have multiple caregivers who administer the immunosuppressive medications to the child, one parent (usually the mother) is in charge of preparing the immunosuppressive medications and ensuring that there are adequate amounts of medications available in the house. This pattern seems to develop because the parent believes medication errors are less likely if one person oversees all medication preparation.

“I want to be strict about it, so I draw it here and then I take it there, and she gives it there at the same time every day.”

One mother described a time where both she and the patient's father erred by both administering immunosuppression doses. This prompted the family to develop a more explicit system for medication administration.

“I tell my husband, ‘Don't ever pack it, don't ever give it because I'm doing it,’ and that's how it's always been...That concept [remembering new doses] is really easy, but it's not at the same time.”

With regards to blood work, some caregivers reported waiting for the transplant team to call with a reminder, while others had a system in place for keeping track of when labs were needed.

“Blood work, I usually wait for them to call me and say, ‘Hey, he's due,’ and then I take him.”

“I have a calendar on my phone. And then I always take him [to the lab] on a Friday because that's my day off...we kind of have our routine already.”

Caregivers mentioned the importance of staying organized so that they could try to coordinate their child's appointments during the school breaks.

“Whenever she has to miss school for any reason, we preemptively try and schedule it during a breaktime.

One caregiver described using a large whiteboard in their house to keep track of her child’s medical care so that everyone in the household could easily reference it. Again, parents typically described one caregiver overseeing this schedule, often keeping track of when appointments needed to be made on notes in their smart phones or adding reminders to their electronic calendars.

2. Financial stressors: Caregivers lamented the financial impact from the indirect costs of seeking care. For instance, prolonged hospitalizations result in increased family expenses, e.g., food and parking expenses. Notably, almost all the participants we interviewed across different socioeconomic status levels mentioned that parking fees, especially during prolonged hospitalizations, added significant financial stress.

“The other stressful thing I think is just when she’s in the hospital, trying to make sure that not only your child is taken care of and eating correctly, but making sure that the family members are taking care of themselves. It does get expensive. We spent probably over \$500 in parking fees during her transplant time.”

“We spent thousands of dollars on parking because we were there every day for hours. I mean we would max out every day.”

To accommodate the increased expenses after liver transplant, most caregivers reported needing to ‘tighten the belt’ on other household expenditures. Most respondents reported developing strict family expense budgets; a few described other strategies for covering the additional expenses. For example, three respondents utilized crowdfunding platforms such as GoFundMe to raise funds to help cover these unexpected costs. However, we did not elicit whether those who donated to the GoFundMe campaign were friends and relatives or strangers. These three respondents were higher income respondents. It was unclear whether lower resourced caregivers had the same social networks (i.e., social opportunities) to use these crowdfunding platforms.²⁰

3. Employment-related barriers: There was variability in how accommodating caregivers’ employers were when the caregiver needed to address a child’s transplant needs. This variability and uncertainty around employers’ responses contributed to added stress. As examples, some parents reported that they had an easy time securing last-minute schedule changes. They also reported an extremely supportive work environment where their colleagues understood the severity of their child’s disease. They stated that their boss was supportive of needing to leave work at the last minute and some participants reported that their colleagues donated paid time off so they could attend to their child’s transplant needs.

“I was very grateful to have a company that rallied together, and employees donated PTO [paid time off] for the entire three months that I was gone.”

However, other families reported that when they needed to make last minute changes, they felt burdened by the responsibility to ensure that their work was delegated and a lack of understanding from their employers around their child’s medical needs. Some caregivers

also believed that there was a possibility that ongoing last-minute cancellations might mean losing their job, but that ensuring their child's health was the top priority.

“I'm like, 'I'm sorry. I have to drop what I'm doing,' I could lose my job, but my kid comes first... just getting my shift covered, it's stressful sometimes. You have to text everybody, 'Can you cover?'"

For some families, they experienced lost wages when they had to take extended leaves of absence. Post-transplant, certain families continued to experience lost wages because they did not feel ready to re-enter the workforce.

“You don't have big savings, but my husband stopped working all the time we were at [the transplant center]. He stopped working and we were just spending the money that we had in our savings account. Then he went back to work and I had to stay with [patient] because I didn't go back to work right after. I was really afraid of leaving her even with my mom.”

While most respondents reported supportive and understanding bosses, there was significant variation in how easy it was for the caregiver to make last-minute schedule changes to their work schedules. This variation in employer support highlighted how caregiver employment may be either an opportunity facilitator or barrier to addressing a child's transplant needs.

Provider/Health System Themes—It was apparent that caregivers had high levels of motivation to attend to their transplant care and to identify resources that could help provide financial and other social support to enable them to do so. In discussing the health system, all respondents had favorable impressions of the liver team, but opportunity and capability barriers also emerged. Participants reported difficulties with care coordination across specialties, challenges with ancillary services (e.g., radiology), and having an unclear understanding of who could help with non-medical issues (e.g., logistical or social issues).

1. Navigating care in larger health system: Coordinating appointments, particularly for children with additional comorbidities and those who traveled from a great distance, was a significant challenge, especially when trying to coordinate appointments for a single day. Caregivers reported having to call each subspecialty office to coordinate appointments and this often resulted in having to make additional calls to finalize a date that was available across subspecialties. While caregivers had a high level of motivation to coordinate care, it emerged that caregivers perceived that the health system lacked capability to aid in care coordination.

“Usually, it's just me calling everyone. I usually start with dental and then I'll call [transplant nurse practitioner] for transplant...The other ones, I'll talk to whoever the scheduling person is and I'll say, 'We're coming on Thursday. Will that work this particular day? If not, then I'll have to call everyone else back and change it.'”

When it came time to schedule clinic appointments with the liver team, almost all caregivers relied on the liver team calling to remind them of the need for an upcoming appointment. In some instances, the liver team helped facilitate other appointments.

“Usually, [liver team] will say, ‘Can you come in next - whatever,’ and I’m like, ‘Sure,’ and [they] makes the appointment for me. Last week I went in, she made the appointment for ultrasound and for clinic and then in-between ultrasound and clinic, he had labs so it’s just like boom-boom-boom. It was just all taken care of in one fell swoop.”

In other situations, caregivers experienced challenges in scheduling appointments with ancillary services. For example, one caregiver complained about scheduling abdominal ultrasounds with radiology. They reported a lack of flexibility in available dates, suggesting that ancillary departments might have capability and/or motivation barriers in coordinating care for children with chronic illness.

“He did an ultrasound, it's always like, “Okay, let us get back to you.” And when would that be? When would the ultrasound clinic be available? So, we don't really have that much of flexibility or choice. We have scheduled time off that will work for us, and we put it there, but it doesn't work that way. We're at the mercy of getting a call for those schedules.”

There was an overall extremely positive feeling towards the liver team amongst the caregivers that we interviewed. The caregivers reported that the team was very responsive to questions, clearly communicated medication changes, and that they were extremely responsive to adjusting clinic appointments to meet their home needs. It also emerged that the liver team, in some instances, helped to bridge the gaps present in other aspects of the health system highlighted above by facilitating appointments with ancillary services (e.g., radiology) but not in other instances, suggesting that the liver team was highly motivated to address these barriers but did not always know who was struggling to coordinate care.

2. Fragmentation in healthcare delivery in addressing both medical and social needs: Several caregivers described believing that helping families overcome some of the social barriers they faced was not the responsibility of the liver team. For example, caregivers reported that compounded tacrolimus is challenging for pharmacies to dispense. Some of the problems that arose in filling these prescriptions included: receiving insufficient volumes, receiving the wrong formulation (e.g., topical vs. oral tacrolimus), and new pharmacy managers unfamiliar with how to compound tacrolimus. Furthermore, caregivers identified additional barriers obtaining early refills in the case of accidental spills. Overcoming these challenges required diligence and sometimes resulted in delays in receiving the medication or additional out-of-pocket costs. However, caregivers felt that resolving these issues were their own responsibility and not the liver team’s. It was unclear whether this perception stemmed from a lack of confidence in the health system or from high caregiver motivation to address these issues.

“They’ve made enough mistakes to where they’ve gotten it down, but it’s still every time I order, I have to...[steps for ordering compounded tacrolimus]. You guys have nothing to do with it, so I’m like, ‘I’m just going to deal with it,’ because I know what the problem is, so I can fix it. It’s just that I wish I didn’t have to go through it, but it’s really nothing you guys can do. It has everything to do with the pharmacy.”

This same idea—that the health care team should not be burdened to support families to overcome select obstacles to care—emerged in some interviews when caregivers discussed barriers to obtaining social services. One caregiver reported receiving public housing supports and occasional assistance from a food bank. She noted that when she brought her housing issues to the transplant team, they were unhelpful and instead she learned about local resources from an area based 211 service. She also noted not understanding what external resources the transplant team could help her family with—suggesting that the liver team and health system may be limited in their capability to address these issues.

“I don’t know what other resources there are for patients who have been transplanted.”

Caregivers also reported that the transplant team was unable to help them identify specific resources that they qualified for. They reported coming to find these resources from other sources (e.g., other transplant families, internet)

“I did not find any of these resources from the team. I didn’t find out about IHSS [in-home support services] through the team. They didn’t talk about CCS [California Children’s Services]. I had to find out all of this myself because his first chunk of meds, I had to pay for out of my pocket...it was \$300.00 as I was leaving the hospital out-of-pocket and I’m like, ‘What?’”

When asked whether the transplant social worker was helpful, most respondents reported that the social worker was unhelpful in identifying these resources, perceiving that the social work team were unable to address these social needs.

“No, all the social workers that I talked to, I told them the same. They were like, “Oh my god, I never knew about that,” and I’m like, “Well, how do you not know? Isn’t that part of your job?” I don’t really think I learned very much at all from my social workers, and we had a lot of them.”

This sentiment extended to more tangible things like the expensive parking fees that respondents reported. Caregivers reported needing to seek out support.

“I don’t think anybody asked us. We, a couple of times, said, “Hey, what can we do about parking?” That’s when we got the voucher thing, but I feel like we had to ask.”

One caregiver perceived a motivation barrier, stating that even when social work was aware of the financial implications of parking, they were not helpful in addressing this cost.

“[Social work] wasn’t that supportive at all, especially with the parking. I had to pay and I was low-income, so she didn’t help with the parking as much as I’d thought.”

It was clear from the interviews that caregivers are highly motivated to address their child’s transplant care and to also make use of external resources that could ease the financial burden of caring for a chronically ill child. However, the caregivers either felt that the transplant team and health system did not ask about their needs, were unaware of the external resources that could be helpful for them, or that it wasn’t their responsibility to help with certain aspects of post-transplant care.

DISCUSSION

Our study is the first qualitative study to explore the everyday needs of long-term pediatric liver transplant families, with purposive sampling of diverse families. Key themes emerged around managing transplant care and identifying external resources to help with logistical and social needs that arise. Notably, while caregivers were able to establish clear roles and responsibilities for medication administration, there were barriers in coordinating care and obtaining social care provisions. These barriers seemed to stem from a lack of understanding as to who was responsible for some of these logistical and social needs, compounded by decreased awareness by the health system about these needs.

We have previously documented that socioeconomically deprived children are at risk of increased medication nonadherence, graft failure, and death following transplant.^{6,7,21} In conducting this study, we attempted purposive sampling of patients from socioeconomically deprived backgrounds or those who have known social needs to ensure that we capture a diverse range of perspectives. Notably, our findings demonstrate that all the caregivers we spoke with were highly motivated and thoughtful in organizing their child's transplant care. However, the added structural barriers that some families encounter in securing time off from work, the fear of lost wages, and spending one's savings combined with the health system's potential barriers in recognizing and intervening on these additional hardships may contribute additional burden to post-transplant care.

Efforts to improve post-transplant care should be directed at (1) decreasing the barriers that families encounter when seeking care, and (2) improving the ability of the health system to address non-medical aspects contributing to effective self-management.⁹ As transplant programs look to enhance care coordination and improve the provision of social care, they should consider improving the patient-centeredness of their care delivery. For example, quality improvement or 'waste reduction' business efforts within healthcare settings must be centered²² on the perspective of the patient/family. To achieve improvements in care for our patients/families, we also advocate for participatory-based methods (e.g., N-of-1 trials, human-centered design²³) that incorporate diverse stakeholders, including patients and families, into the research design team. These types of research can provide rapid learning opportunities and simultaneously unlock novel strategies to deliver equitable care.

Efforts to decrease the barriers that families encounter in post-transplant care might start with health care systems looking for specific 'low-lying fruit' to decrease families' care burden. For example, providing free parking and low-cost/no-cost meals for low-income families could reduce the financial burden that families experience during prolonged hospitalizations. Furthermore, simplifying medical regimens (e.g., using tacrolimus pills vs. compounded therapy) is likely to decrease the logistical burdens families face in managing their child's post-transplant care.

Improving the ability of health care systems to address non-medical aspects to effective self-management may require more ambitious health system interventions. It is possible that some of this work could fall to social workers, though more research is needed to understand and strengthen the capacity of social workers on transplant teams. Complementary

workforce models might enable social workers to work on complex cases or mental health needs and additionally engage lay workers, e.g. community health workers or other non-professional navigators, to address families' socioeconomic barriers.²⁴ These types of health workers, often from similar socioeconomic, cultural, or ethnic backgrounds as the patient population being served, are charged with activities such as coordinating medical care treatment, facilitating financial assistance (e.g., tax vouchers), and connecting patients to community resources,^{25,26} with the intention of improving self-management, mitigating social risks, and improving communication between the healthcare system and the family.²⁷ A comprehensive patient navigation approach, with 'interventionists' who are available to a limited number patients/families 24/7, led to reduced diabetic ketoacidosis admissions in children with Type I diabetes²⁷; a limited approach, where a navigator facilitates connecting patients/families with social needs to community-based resources, has been shown to reduce social needs and improve parent-reported child health in pediatric primary care settings.²⁸

While this study is the first qualitative study on the medical and social needs for children after transplant, it is not without limitations. First, this study was conducted at a single center and our sample was limited. Therefore, the experiences that these caregivers relayed may not apply to families from other transplant centers. Furthermore, because of our limited sample, we are unable to stratify these results on the basis of demographic variables (e.g., race, economic hardship). Additional qualitative, patient and family-centered research will help to deepen our understanding of the barriers and facilitators to transplant care across transplant centers and better characterize care gaps that are common across centers. Second, in-depth interviewing techniques are subject to recall bias and may have a performative element.²⁹ While direct observation using ethnography may yield more accurate data, such techniques are time consuming and would not be feasible for this sample size. Third, this study does not characterize the experiences of transplant healthcare team members in identifying and intervening on social adversity. This study lays the groundwork for future studies that explore transplant members' perspectives on care models and systems that facilitate or obstruct the clinical team's ability to intervene on social risks and care coordination. Those studies can complement this family-centered study and help to shape feasible interventions that better meet patient/family needs. Despite these limitations, the interviews revealed important aspects of the patient/family experience following liver transplant.

This study highlighted ways the health system might improve families' post-transplant experiences and therefore can help inform transplant medicine's shift towards more patient-centered care. The many healthcare needs facing post-transplant children—including frequent blood draws, multiple medications, and ongoing clinic appointments with the liver team—are experienced differently by families with fewer resources. As such, addressing the many barriers to accessing this care can be an important target for healthcare systems investing in improving equitable outcomes.

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UCSF Academic Senate Committee on Research

Appendix 1.: Measures of financial strain, material economic hardship, and social isolation

Domain	Measure	References
Financial strain	National Academy of Medicine single financial strain question and supplemental financial resource strain questions (see below)	Prather, et al. 2017 <i>Am J Prev Med</i> & Beck, et al. 2016 <i>JAMA Ped</i>
Material economic hardship	10 question Accountable Health Communities Screening Tool	Alley, et al. 2016 <i>N Eng J Med</i>
Health literacy	The Newest Vital Sign	Powers, Trinh, & Bosworth 2010 <i>JAMA</i>
Social isolation	Berkman-Syme Social Network Index	Berkman L & Syme S. 1979 <i>Am J Epidemiol.</i>

Supplemental financial resource strain questions from Beck, et al. *JAMA Ped* 2016:

1. During the past 12 months was there a time when you wanted to find work but were not able to?
2. During the past 12 months, was there a time when your household did not pay the full amount of rent or mortgage?
3. During the past 12 months, has your household not paid the full amount of any of the utility bills for electricity, heating, or water?
4. During the past 12 months, was there a time when anyone in the household needed to see a doctor or dentist, or go to the hospital or emergency room but did not go?
5. During the past 12 months, was there a time when anyone in the household did not fill a prescription for a medication that they needed?

Indicate any of the things that apply to your situation over the past 12 months. Have you....

1. ...pawned or sold possessions?
2. ...had a creditor call or come see you to demand payment?
3. ...had your home, car or other property repossessed?
4. ...moved in with other people?
5. ...sent one/more of your children to live with someone else?

Appendix 2.: Standards for Reporting Qualitative Research (SRQR) checklist

Topic	Item
Title & Abstract	
Title	The title details the topic of study and that it reflects caregiver perspectives.
Abstract	The abstract details key elements of the study.
Introduction	
Problem formulation	Paragraphs 1 & 2 outline the problem.
Purpose	Paragraph 3 specifies the specific objectives of this study.
Methods	
Qualitative approach and research paradigm	The "Study Design" section outlines the approach used for this study.
Researcher characteristics and reflexivity	"Data Collection Methods and Analysis" describes the interviewer and analytic techniques.
Context	"Data Collection Methods and Analysis" describes the context of the interviews.
Sampling strategy	"Study Sample And Recruitment" describes the sampling strategy.
Ethical issues	A statement of IRB approval appears in the "Study Design" section.
Data collection methods	Data collection methods are outlined in "Data Collection Methods and Analysis".
Data collection instruments and technologies	These are described in "Data Collection Methods and Analysis" and are also available in Appendix 1 & 3.
Units of study	These are described in the results section "Demographic Characteristics".
Data processing	These methods are described in "Data Collection Methods and Analysis".
Data analysis	These methods are described in "Data Collection Methods and Analysis".
Techniques to enhance trustworthiness	These methods are described in "Data Collection Methods and Analysis".
Results/findings	
Synthesis and interpretation	The synthesized findings are presented in the results section, titled "Themes".
Links to empirical data	There are example quotes throughout the Results section and also in Table 2.
Discussion	
Integration with prior work, implications, transferability, and contribution(s) to the field	The first 5 paragraphs of the discussion address integration with prior work.
Limitations	Paragraph 6 of the discussion lays out limitations of the current work.
Other	
Conflicts of interest	Conflicts of interest are disclosed in the "Footnotes" section.
Funding	Funding is disclosed in the "Footnotes" section.

Appendix 3.: Interview guide

Medical Questions

1. We're interested in learning more about your day-to-day life. Take me through a weekday routine in your home.
2. What sorts of things are different for your child because he/she had a transplant?

3. Could you tell me about how your child's transplant care needs are addressed in the course of the day?
4. What are the biggest challenges of having a child with a liver transplant?
5. After transplant, children have a lot of medical needs. How do you keep track of all of the information you get from your child's doctors?
6. How do you ensure that your child gets his/her medications?
7. How does it work to get medications from the pharmacy?
8. Can you walk me through how you keep track of when your child needs blood draws or medical appointments?
9. I'm curious to hear about your experience when you come to [your transplant institution]. Can you walk me through your experience of making an appointment, coming in for a visit, etc?
10. Think about a time where you did not understand something about your child's medical care. Can you tell me about it? What did you do?
11. Think about a time when it was hard to communicate with [PATIENT NAME]'s liver team. Can you tell me what happened?
12. What conversations have you had with the liver team social worker?
13. Imagine that you are king/queen for a day and could change anything about your child's transplant care at [TRANSPLANT CENTER], what would you change?

Environmental Context

1. What other family members that help support you or your child? Can you tell me about them?
2. What about family members that live outside of the house who help?
3. Are there other families who also have children dealing with something similar that you talk to?
4. Can you tell me about your neighborhood?
5. What about people in your neighborhood?

Social Needs

1. Has balancing all your expenses ever been a challenge for you?
2. Can you tell me about how health insurance has worked for your child since his/her transplant.
3. Have you had any conversations about [SOCIAL NEED] with your child's transplant team?
4. Would you be comfortable talking about your financial situation with your child's liver doctors or other members of the clinical team?

Abbreviations:

COM-B Capability, Opportunity, Motivation – Behavior

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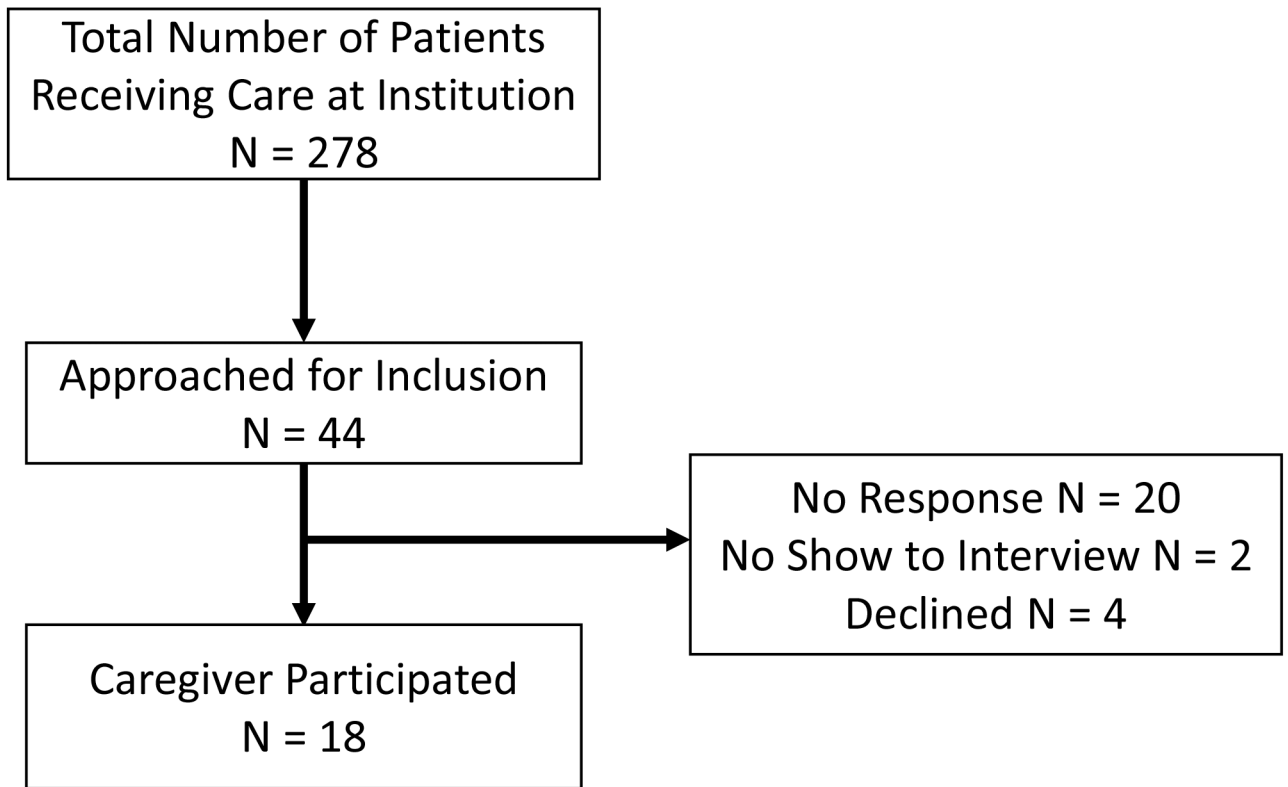


Figure 1.
Patient enrollment diagram

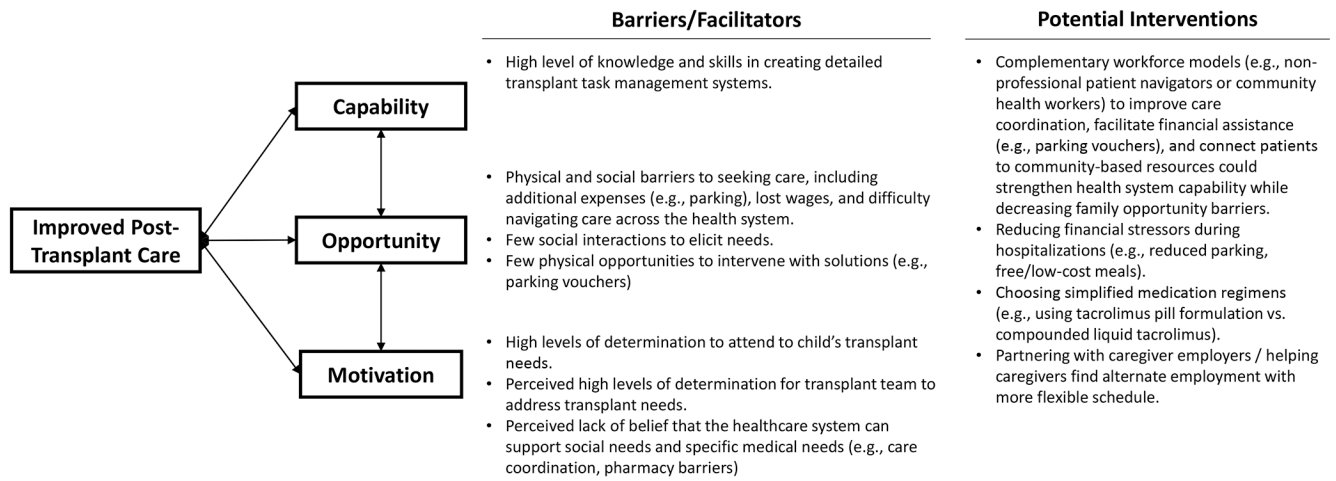


Figure 2. Caregiver barriers, facilitators, and possible interventions organized by the COM-B model

Table 1.

Demographic characteristics of N=18 participants

	N(%) or Median (IQR)
Patient Age at Transplant	1.0 (0.5, 2.5)
Patient Age at Interview	8.5 (3.1, 11.7)
Time since Transplant	5.1 (1.7, 10.9)
Public Insurance (for patient)	6 (33%)
Patient Race/Ethnicity	
Non-Hispanic White	7 (39%)
Hispanic	7 (39%)
Black/African American	2 (11%)
Asian/Pacific Islander	2 (11%)
Caregiver Highest Education Level	
HS or less	3 (17%)
Some College	7 (39%)
4 year college	5 (28%)
>4 year college	3 (17%)
Caregiver Marital Status	
Married	12 (67%)
Single	2 (11%)
Divorced	3 (17%)
Widowed	1 (6%)
Household Income Range	
\$15,000-29,999	1 (6%)
\$30,000-44,999	3 (17%)
\$45,000-59,999	1 (6%)
\$60,000-89,999	4 (22%)
\$90,000-119,999	4 (22%)
>\$120,000	3 (17%)
Neighborhood Deprivation	0.35 (0.17)
Below federal poverty line	2 (12%)
Financial Strain	9 (50%)
Unmet housing needs	1 (6%)
Food insecurity	2 (11%)
Transportation challenges	0 (0%)
Utility needs	1 (6%)
Social Isolation	5 (28%)
Health Literacy	
Limited literacy	1 (6%)
Possible limited literacy	1 (6%)

	N(%) or Median (IQR)
Adequate literacy	16 (88%)

IQR: Interquartile range

Neighborhood deprivation was assessed using a previously validated index of deprivation available at the census tract level.^{7,30} Financial strain was defined based on previous work by Beck, et al.¹² Material economic hardship was determined using the Accountable Health Communities screening tool.¹³ Social isolation was calculated using the Social Network Index.¹⁶

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Table 2.

Table of quotes organized by theme

Theme	Quote
Caregiver/ Household Medical Management	
Medication Management	My mom takes care of [patient] so she comes to my house and I have to have her medications ready, packed in little baggies. Just like at the hospital, they have to have names on them, labels.
	So, what I do is normally, once a week, I'll draw up all of his meds and I have a little unit that has drawers in it and I put the syringes full of whatever med in this corresponding drawer. My mom goes in the drawers and grabs what she needs.
	I give it when I'm home but, when I'm working, my mom – I will prep his CellCept and his Prograf. I put my gloves on, I prep it, I write the dosage, I put it in refrigerator and I say, "Give him at this time." My mom doesn't want to touch it because she thinks she's going to mess up.
	I still draw it because I just want to make sure. I'm really like you want to be strict about it, and so I draw it here and then I take it there, and she gives it there at the same time every day.
Lab draws	I just usually wait for them to call me and say, "Hey, he's due," and then I take him.
	We're doing every month, so if this month, I need to bring her 2 nd rd, so I will get the phone to remind me to bring her to the lab.
	We do have a calendar in our kitchen and our labs should be every month, so we just have a sticker when it comes to the fourth week and I let her pick which day she wants to go according to her school schedule.
Clinic appointments	We normally just get a call from them [transplant team], and then they schedule it in advance.
	Usually, [nurse practitioner] will say, "Can you come in next - whatever," and I'm like, "Sure," and she makes the appointment for me.
Caregiver/ household Financial Stressors	I understand why a lot of parents have to quit their job because it is a full-time work to get to all of these appointments.
	I mean, people get by on food, people bring them stuff. But the parking was the other issue. I do know we spent probably over \$500 in parking fees during her transplant time.
	I had to just charge the \$750 on my credit card and ask for reimbursement from my insurance company [for immunosuppression].
	Insurance can take two days, three day, and [patient] won't be able to have that medication for those three, two days, so we try to pay out of pocket.
	One of our biggest hardships then really was parking. We spent thousands of dollars on parking because we were there every day for hours... Then meals, we had to pay for all our meals for a year in the hospital.
	Like even [transplant center] parking lot is super expensive for a day.

Theme	Quote
Caregiver Employment-related Barriers	<p>[Mom working part time] It's mostly because of his illness, because we couldn't put him in daycare. At the same time, it's like the challenge of medications. My team has been very helpful. I used to stay at work until 7:00 PM, and now at about 3:30, they literally kick me out of here and they're like, "Go home. Is [patient] at home? Go home," and they pick up a lot of the little chores that I do...My team actually handed me \$3,000 to cover medications, which we would have been fine, but it was great.</p> <p>I was only working two months before I have to go on leave again, and so I have to ask for PTO donations from my work because I didn't have enough time.</p> <p>Coming home trying to get back in the routine of things. Work was hounding me to come back.</p> <p>Taking time off, at least, you know, they're more understanding, they know that it's important. So we do get that support. It doesn't take off the load the workload, we still have the same workload, and it's just about us trying to manage it, you know?</p>
Navigating Care in Larger Health System	<p>I guess it's just like notes where I just put all her specialists, how many times a year we have to see them, and then what month that is, and then I just try to stick with it. What I really try to do is make the appointment at the appointment, right? We go to pulmonology and then I want to make the next appointment for a year, six months or whatever. That makes it easy. When they're not available, it makes it super hard because, yes, I try to remember and sometimes I'm a couple months late or something, but that makes it difficult. It would be really nice if there was somebody at the hospital who could help me organize and call me and say, "Hey, let's schedule this. Hey, let's schedule that,"</p> <p>If she needs the appointment, they will call us about like last year we need to meet [liver team], so they have people call us.</p> <p>There's a coordinator who helps set up those appointments, and makes contact with the various departments and tries to get them all lined up on one day for us. Sometimes, they've been really helpful about being flexible with their schedule.</p> <p>I feel like calling is a big, big hassle because there're so many phone trees and your call gets lost somewhere. For example, if we have an ultrasound, I call and then I make the appointment after I go through the big phone tree.</p> <p>I don't know his social worker. I don't know what other resources there are for patients who have been transplanted, so that's all the information I have.</p>
Fragmentation in Healthcare Delivery	<p>I was in the process of getting housing assistance and during that time I wanted him to have his own separate room and she stated they couldn't sign off on it, and I just felt like that wasn't being supportive because he has immunosuppressive medication and I just felt like him sharing a room with his sister would not be the best option.</p> <p>But by now, they've made enough mistakes to where they've kind of gotten it down a little bit, but it's still every time I order, I have to... You guys really have nothing to do with it, so I'm like, 'I'm just going to deal with it,' because I know what the problem is, so I can fix it. It's just that I wish I didn't have to go through it, but it's really nothing you guys can do. It really has everything to do with the pharmacy.</p> <p>I mean quite honestly, social work and - I did not find any of these resources from the team. I didn't find out about IHSS through the team. They didn't talk about CCS. There was nothing after he had his Kasai. I mean I had to find out all of this myself because his first chunk of meds, I had to pay for out of my pocket and that was really unexpected because he had his inpatient stay when he had his Kasai and then it was \$300.00 for his meds as I was leaving the hospital out-of-pocket and I'm like, "What?"</p> <p>It's just that I don't know, will they [social worker] be able to help out with this insurance issue? I don't know. Like, I don't know, the scope of where they can help.</p>