Parents’ Perspectives on Caring for Children after Solid Organ Transplant

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Parents’ Perspectives on Caring for Children After Solid Organ Transplant

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Abstract

Purpose
To explore parents’ experiences of the transition from hospital to home and complex chronic illness management following their children’s solid organ transplant (SOT).

Design and Methods
Qualitative component of a larger mixed methods longitudinal study. Parents of SOT recipients were interviewed three times following hospital discharge from five major pediatric transplant hospitals in the United States.
Results
Analysis of parent interviews (N = 48) resulted in three themes that characterized the phases of transition to home and complex chronic illness care. Three themes, corresponding to the three time periods of data collection, included “getting back to normal” at 3 weeks, “becoming routine” at 3 months, and “facing a future” at 6 months. Challenges families experienced over the course of their transition are also described.

Practice Implications
The transition from hospital to home and complex chronic condition care is challenging and changes over time. Nurses are called upon to prepare parents to become knowledgeable and confident to care for the child after hospital discharge. Nurses can best support families in transition after SOT by anticipating and understanding their dynamic challenging complex care needs.

More Americans are living with complex medical health conditions after solid organ transplants (SOTs) than in the past (Cimino & Snyder, 2016; U.S. Department of Health and Human Services, 2016). National Data reported 1,898 SOTs among children less than 18 years of age in 2016, up from 1,609 in 2000, representing an increase of approximately 15% (U.S. Department of Health and Human Services, 2016). Providing supportive nursing care for these complex children is multifaceted both during and after hospitalization (Lerret & Weiss, 2011; Lerret et al., 2014). Education and care coordination delivered by nurses prepares patients and families to successfully self-manage complex care after hospital discharge (Lerret et al., 2015), as parents transition to become their children's primary care provider (Brenner et al., 2015; Lerret et al., 2014).

1 THE COMPLEXITY OF PLANNING THE TRANSITION HOME
As the largest provider of health care, nurses play a pivotal role in discharge planning that can contribute to improving healthcare quality and managing costs (Bobay, Bahr, Weiss, Hughes, & Costa, 2015; Robert Wood Johnson Foundation, 2010; Srivastava & Keren, 2013). A quality discharge transition from hospital to home that prepares families to care for their children is associated with better outcomes after SOT (Lerret et al., 2015). Fostering family self-management of children at all points in time is recognized as the most important facet of care to optimize child and family health (Mavis, Ertl, Chapman, Cassidy, & Lerret, 2015). Family self-management involves managing chronic conditions and actively engaging in a lifestyle that fosters health (Ryan & Sawin, 2009). However, there is limited knowledge regarding the experiences of families during the process of transitioning from the hospital to managing complex chronic conditions in the home environment (Brenner et al., 2015). Specifically, there is a gap in the literature on the discharge experience and complex chronic condition care for families of children with SOT. This knowledge is needed to inform strategies that foster family self-management and provide direction to improve outcomes.

From a family-centered perspective, management of children's health issues are shared by family members. Supporting family self-management involves understanding the parent/caregivers’ role, experiences, and challenges encountered when caring for their children with special healthcare needs. Children with medical complexities are a unique population with specific needs. A better understanding of the parents’ and caregivers’ perspectives on those needs informs interventions to improve the hospital-related care they receive. A randomized controlled trial of children with medical complexity investigated the effect of an enhanced medical home on serious illness and cost of care for pediatric patients. The intervention group showed decreased emergency department visits when families had access to 24/7 medical experts who were familiar with their child (Mosquera et al., 2014). Thus, there is some quantitative evidence on how medical complexity compels us to enhance the medical home model, but there remains limited qualitative information to direct and guide family self-management of chronic conditions during the discharge transition to home and chronic illness care.
The purpose of this study was to explore parents’ perspectives on the discharge transition from acute hospitalization following SOT to long-term management of a complex chronic condition. The time frame for transition to chronic condition care was defined as the first 6 months at home following SOT. The parents’ perspective may be used to inform discharge care and teaching in order to help providers anticipate issues that children and families may experience during the first 6 months after hospital discharge.

2 FRAMEWORK
Meleis’ Transitions theory is a middle-range theory that provides an organizing framework for conceptualizing the transition from hospital to home and chronic illness care (Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000). Transition is defined as a change in health and illness that tends to create a period of vulnerability. There are four major components of transition according to the theory: (1) the nature of the transition, (2) transition condition, (3) nursing therapeutics, and (4) patterns of response (Meleis et al., 2000).

3 DESIGN AND METHODS
In this large, prospective, mixed-methods, longitudinal study, we examined family outcomes after solid organ transplant (SOT) at five major pediatric transplant centers in the United States. This article reports the results from the qualitative interview data. Institutional Review Board approval was obtained at all five pediatric hospitals in the study.

4 PARTICIPANTS
The convenience sample included English-speaking participants who self-identified as the primary caregivers (parent or legal guardian) of a child who had received a heart, kidney, liver, lung, or multivisceral transplant at one of the five participating hospitals. Primary caregivers are referred to as parents for the remainder of this article. Additional inclusion criteria were (a) parent age of 18 years or older and (b) telephone access for the postdischarge telephonic qualitative interviews. The exclusion criteria included parent of a child (a) who had received a prior transplant and/or (b) had a serious comorbid condition. These criteria were excluded, as we determined that they would impact the discharge preparation of the family.

5 STUDY PROCEDURE
Eligible parents were identified by a transplant coordinator or research assistant at the time of hospital discharge at each of the five institutions. After an explanation of the study, participants signed informed consents, completed quantitative instruments, and volunteered to be contacted after discharge home for a series of follow-up telephonic interviews.

The principal investigator or a research assistant contacted participants by telephone at 3 weeks, 3, and 6 months after discharge. The telephonic interviews were conducted using a structured interview guide of open-ended questions that addressed four main topics: (1) challenges and obstacles, (2) participation in medical care, (3) work with the transplant team, and (4) suggestions for improvement. The telephonic interviews were audiotaped. One researcher transcribed the audio tapes verbatim into a word document. Telephonic interviews ranged from 20 to 45 min in length. Participants received a gift card after completion of each interview.

6 DATA ANALYSIS
Transcriptions were entered into NVivo, a software program for qualitative data analysis. One researcher initially coded the data. To begin the analysis, a coding template was created with three main codes: overview, challenges, and needs. As the main codes were applied to the data, subcodes were identified and added. After all transcripts were coded, a report for each main and subcode was generated. The reports were labeled with
the code label and included the respectively coded data from all transcripts. The research team discussed these reports to gain consensus on the words used as code labels and how the labels were applied to the data. Team review and discussion of the coded data led to identification of three themes and description of 10 challenges.

7 RESULTS

Fifty-nine parents met eligibility requirements and of these 51 consented to the study. Forty-eight of the parents completed the first interview at 3 weeks after discharge, 44 completed the 3-month interview, and 42 completed the 6-month interview. Parents had a median age of 34 years (range 19–55 years) and were largely female (n = 41; 85%), White (n = 39; 81%), and married (n = 34; 71%). The children had a median age of 2.8 years (range 3 weeks to 17.5 years) and received a liver (n = 20; 41%), heart (n = 15; 31%), kidney (n = 8; 16%), multivisceral (n = 5; 10%), or lung (n = 1; 2%) transplant. See Tables 1 and 2 for additional sample descriptors.

**Table 1.** Demographics of parents (n = 48)

<table>
<thead>
<tr>
<th>Demographics</th>
<th>N (%)</th>
<th>Median (range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>48 (100)</td>
<td>34 years (19–55)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>41 (85)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>7 (15)</td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
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<td></td>
</tr>
<tr>
<td>White</td>
<td>39 (81)</td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>7 (15)</td>
<td></td>
</tr>
<tr>
<td>American Indian</td>
<td>2 (4)</td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>34 (71)</td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>13 (27)a</td>
<td></td>
</tr>
</tbody>
</table>

*a Includes parents who were single, divorced, or widowed.

**Table 2.** Demographics of children (n = 48)

<table>
<thead>
<tr>
<th>Demographic</th>
<th>N (%)</th>
<th>Median (range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>48 (100)</td>
<td>2.8 years (3 weeks to 17.5 years)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>24 (50)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>24 (50)</td>
<td></td>
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<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>39 (81)</td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>9(19)</td>
<td></td>
</tr>
<tr>
<td>Transplanted organ</td>
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<td></td>
</tr>
<tr>
<td>Liver</td>
<td>20 (41)</td>
<td></td>
</tr>
<tr>
<td>Heart</td>
<td>15 (31)</td>
<td></td>
</tr>
<tr>
<td>Kidney</td>
<td>8 (16)</td>
<td></td>
</tr>
<tr>
<td>Multivisceral</td>
<td>5 (10)</td>
<td></td>
</tr>
<tr>
<td>Lung</td>
<td>1(2)</td>
<td></td>
</tr>
<tr>
<td>Inpatient number of days</td>
<td>48 (100)</td>
<td>13.5 days (4–90)</td>
</tr>
<tr>
<td>Medications at discharge</td>
<td>48 (100)</td>
<td>10 medications (5–21)</td>
</tr>
<tr>
<td>Skilled cares at discharge</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wound care</td>
<td>17 (35)</td>
<td></td>
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</table>
Three themes, corresponding to the three time periods of data collection, characterized the phases of transition to home and complex chronic illness care. Families experienced 10 challenges over the course of their transition. The intensity of these challenges was different in each phase of transition (see Figure 1).

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Enteral/tube feeding</td>
<td>17 (35)</td>
<td></td>
</tr>
<tr>
<td>Central line care</td>
<td>14 (29)</td>
<td></td>
</tr>
<tr>
<td>Drainage tube</td>
<td>3 (6)</td>
<td></td>
</tr>
</tbody>
</table>

Figure 1 Postdischarge challenges for parents of children who have had SOTs

7.1 Theme 1: “Getting back to normal”
The theme “getting back to normal” characterized the families’ phase of transition at 3 weeks after discharge. Parents reported that the extraordinary event of their child's transplant surprisingly turned out to be rather uneventful. A mother of a 2-month-old infant reported:

My son had a heart transplant. It just sounds like a huge deal and it is. But really, it's been so non-eventful. We expected it to be a much bigger deal than it is. It's very bizarre. (mother of a 2-year-old child)

Another parent of a 1-year-old boy, who had had a liver transplant, reported:

A transplant is a huge deal, but it's been so non-eventful...our challenge is getting back to normal. (parent of a 1-year-old boy)

At 3 weeks after discharge, the most common challenge reported by 42% of the parents (n = 20) was establishing new routines to organize their children’s care and meet their other family responsibilities. For example, a mother of a 10-year-old child with a heart transplant stated

...we need to be careful to be organized in a way that works for us. We're scheduling so many appointments – visiting nurses, physical therapy, home schooling tutors, clinic appointments – that it can get to be a little overwhelming keeping everything organized. (mother of a 10-year-old child)

This child required personal care, medications, and treatments at home and also frequent appointments for various health needs. Thus, at 3 weeks after discharge, parents were juggling multiple responsibilities including caring for the child with SOT, returning to work, and attending to siblings needs (e.g., school, activities, and appointments). Parents were working on new routines to manage travel, coordinate schedules, and obtain childcare for siblings when parents were at their child's posttransplant appointments.
The challenge of medication management was reported by 38% of parents (n = 18) at 3 weeks after discharge. For the most part, parents felt adequately prepared and knowledgeable regarding the medications, so lack of knowledge was not a reported source of stress. As this mother of an 18-month-old child with a liver transplant shared:

The hardest thing is probably getting the medications right – and honestly, it hasn't been too bad. The transplant team is really good at making sure we know what we're doing. (mother of an 18-month-old child)

Aspects of medication management that were challenging were establishing a schedule and routine for giving the medications, timely administration of medications, keeping up with dosage changes, and managing side effects.

Just less than one-quarter of parents (n = 11) reported that their self-care was a challenge. For example, one mother of a 4-month-old child with a heart transplant said:

The worst part, for me, was all due to me being in the hospital with her as much as I was – I didn't sleep right, didn't eat right...I just didn't take care of myself. I see now that I should have done more for myself because that first week she was home, I was a mess. After we all got some good sleep and our schedules went back to normal, we're doing great. But that was a rough first week! (mother of a 4-month-old child)

They described that establishing balance between taking care of themselves and taking care of their child was difficult. Parents were physically exhausted from lack of sleep and caring for their children during and after the transplant as well as for other family members. Three parents were organ donors for their children’s transplants and their own recoveries made contributed to their feelings of fatigue. Parents also reported feeling emotional exhaustion as the newness of the situation was stressful; the unknown regarding the future was somewhat frightening.

About 21% of parents (n = 10) reported challenges caring for their other children. Parents felt that they were neglecting the siblings during their children's transplants and still now as the postdischarge care was very time demanding. As a mother of a 13-month-old child with a liver transplant said:

The hardest thing right now is learning how to share our attention with the other kids. Even though she’s doing good, we still feel so consumed with her care, we have to remember the other kids need some time with us too. (mother of a 13-month-old child)

Parents felt sad that siblings endured emotional pain as they feared for lives of the children having the transplants. Parents felt guilty asking the siblings to do more work for the family, especially child care. In cases where siblings were young children, parents were afraid that these siblings could not understand the limitations of children with transplants and might do things to compromise the transplanted children’s health.

Physical care was reported as a challenge by 19% of parents (n = 9). This challenge was only reported at the 3-week time point and referred to the physical demands of caring for their children including lifting, feeding, and bathing. Parents were also performing medical-related cares such as managing urine catheters, broviac devices, or ostomies. Children’s adjustment to their return home was also reported as a challenge by 13% (n = 6) of parents. These parents reported that their children had difficulty sleeping and were still experiencing anxiety.

7.2 Theme 2: “Becoming routine”

At 3 months after transplant, the phase of transition was characterized as “becoming routine.” A father of a 17-year-old who had a kidney transplant said, “I’m finally at a place where I feel like I can take a bit of a breather. Of
course, I'm always going to worry, but she's been doing really well” (father of a 17-year-old). Another father whose 2-year-old child had a kidney transplant said, “Compared to what life was like before transplant, things have been a breeze! It's like coming into the daylight from the darkness” (father of a 2-year-old). Families were confident regarding their children's medications and cares. They were relieved that their child was doing well and the daily work and family routines were becoming more established.

As they are got farther from the pretransplant disease and their posttransplant health stabilized, the challenge of helping children regain their health and function became more prominent and was reported by 48% of the parents (n = 23). Families were addressing delays in multiple areas including gross motor, speech, and growth. Children had issues with eating, activity, overweight, and body image. School-age children were behind academically, with varying needs for remedial work. Some children were displaying challenging behaviors that parents now needed to manage. As one mother of a 9-year-old who had a liver transplant said:

> There were no complications from the transplant, her recovery has been great...it's just the meds. It's tough as a parent, especially when the side effects are behavioral. Sometimes she just doesn't seem like our kid. She's saying things now that she would never have said before. And it's hard to discipline her when you know it's probably the medications talking. (mother of a 9-year-old)

Parents wondered if the new challenging behavior was developmentally appropriate (i.e., temper tantrums of toddlers), side effect of their medications, or secondary to the stress of the children's diseases and treatments.

Another aspect of regaining health and function was accepting that the children were healthy and ready to take part in normal childhood activities. A mother of an 11-year-old child who had a heart transplant stated:

> After everything we've been through, probably the hardest thing for us is letting her go be a kid. We'd like to keep her in our safe little bubble and keep her all to ourselves but she's doing so well and she feels great; it's time to let her be a normal kid. (mother of an 11-year-old child)

Parents felt that at this point, they should begin treating their children as typical children, allowing them to engage in activities, play outside, and play with other kids. At the same time, parents viewed them as vulnerable and expressed worry about injury and infection exposure. For some families, return to normal activities of school and work meant that the children would have to take more responsibility for taking their medications. Parents worried about their children taking medications. As one mother of a 16-year-old heart transplant recipient said:

> I was pretty apprehensive about returning to work but everything seems to be going OK so I've relaxed. I mean, there are still times that I look over at the clock and think, it's 8 am...I hope she's up and taking her meds. (mother of a 16-year-old child)

At this point, the transplant seemed stable and the children were doing well. As parents looked to the future, their focus changed to protecting and maintaining the transplant.

7.3 Theme 3: “Facing a future”

The theme “facing a future” characterized the phase of transition at 6 months after discharge. The personal care and medications were more manageable, routines were becoming established, and children and families were resuming typical activities. A mother of a 15-month-old child who had a liver transplant said, “I'm finally starting to get the sense that I know we're not done, we have a long way to go. But I'm feeling like things are becoming more manageable and not so chaotic” (mother of a 15-month-old child).
In this phase of transition, parents were reorienting to the changes in themselves and their children. A mother of 20-month old child with a liver transplant child said, “This whole experience changes you. You don’t come out the same person you were when it started” (mother of a 20-month-old child).

They were contemplating the permanent changes and long-term consequences of their children’s transplants for their children and themselves. A mother whose toddler had a liver transplant said:

This underlying state of constant stress has definitely honed my ability to think quickly in all other areas of my life. I have absolutely no trouble making decisions about anything these days. (mother of a toddler)

At 6 months after discharge, the hard work of regaining health and function continued, with 44% (n = 21) of parents reporting this challenge. Families were facing more difficult and long-term needs such as growth, weight, and body image. For example, one mother of a 9-year-old child who had a kidney transplant said:

I think our stress is starting to get a little worse, actually. Now we're battling with our child gaining too much weight. We weren't expecting that. We thought weight wasn't really the issue – we thought it was more about compromised bone composition. We knew they wanted her to be physically active, but we never really pushed it. Now they're telling us we need to get her on a sports team or something where she'll get one hour of exercise per day. I'm a RN and I work nights three times a week and I have other kids. (mother of a 9-year-old child)

Parents expressed concern about their children’s futures. They worried that their children might not be able to afford, or that they would stop, their antirejection medications.

The challenge of vigilant monitoring was reported by 43% of parents (n = 18). Vigilant monitoring referred to parents’ constant surveillance in order to protect their children’s transplanted organs by preventing infections, injuries, and rejection. Parents worked to prevent infections by attempting to limit exposures. As a mother of a 7-year-old child who had a liver transplant said:

He has no immune system. I'm worried about flu season coming up. I was thinking that I'm going to supply his school bus with a giant bottle of hand sanitizer and ask the bus driver to have all the kids use it when they get on the bus! I'll pay for everything myself! I'll do whatever it takes to keep my son healthy! Do you think they'd let me do it? (mother of a 7-year-old child)

With children going back to school and child care settings, parents could no longer be physically present to monitor and limit exposures. They worried about infections and injuries that might happen when the children resumed typical activities of childhood and/or were out of their direct supervision. Parents also expressed concern about organ rejection. They were unsure which signs and symptoms indicated rejection and therefore were distressed when their children showed signs or symptoms of illness. A mother of an infant who had a heart transplant said:

I guess the hardest thing is not freaking out over every little thing. Try to remember the big picture – not everything is transplant related. Like I said, he had a low fever and was uncontrollably crying a few weeks ago and I rushed over to the ER and it turned out he was just teething! Like any normal baby would do! (mother of an infant)

At 6 months after transplant, children were transitioning from their transplant providers to primary care providers and other specialists. This transition was part of regaining health and function as children and families moved toward receiving care in routine settings. Parents felt sad that they were losing their close connection with the transplant team due to less frequent clinic appointments. They also expressed concern about providers
who did not have adequate knowledge about posttransplant care. For example, this mother of a 16-month-old child with a liver transplant stated:

I really feel like I need to be on constant watch because a lot of mistakes have been made. I've gotten to the point that whenever anyone walks into her room, I immediately ask ‘who are you, what are you here to do and who told you to do it?’ The last time we were in the hospital, we had 2 different people who both had different – and WRONG – information! Nights in the hospital are hard! You just have to hold tight overnight until the people who really know your kid come in. (mother of a 16-month-old child)

Parents became aware that they had more specialized knowledge regarding transplants than some of the physicians and nurses who care for their children. This provoked anxiety as parents worried that these providers might compromise their children's health by not providing needed transplant-specific care. Parents displayed vigilant monitoring in their interactions with nontransplant providers.

8 DISCUSSION
This article reported the qualitative component of the first prospective, mixed-methods, longitudinal study to examine parents’ experience of the transition to home and complex illness care after their children's SOT. Parents reported the progression of their adjustment to challenges at the three time points following hospital discharge (3 weeks, 3, and 6 months). The parents’ perspectives are critical to understanding how nurses can best support families in the immediate time after hospital discharge and for the long-term as families confront new challenges along the way.

“Getting back to normal” was the theme that characterized transition at 3 weeks after discharge. Parents described the immediate challenges of learning new skills and routines. Interestingly, families were surprised with how “ordinary” something that they termed “not ordinary” happened and were relieved that the transplant was over. They reported numerous challenges focused on the day-to-day medical care for the transplanted child in the context of also returning to normal home activities including attending to other children and returning to work. This finding is similar to literature on the caregivers of adult liver transplant recipients who report feeling strained as they deal with uncertainty and unpredictability in the immediate time period following transplant (Beckmann, Kunzler-Heule, Biotti, & Spirig, 2016). Furthermore, parents of children hospitalized for an acute care illness (Solan et al., 2015) and SOT recipients have reported similar challenges focusing on medication management and providing care to the child in the first 3 weeks after hospital discharge (Lerret et al., 2014).

As the immediate challenges of learning new skills and routines are managed, parents described the second major theme at the 3-month posttransplant time period of “becoming routine.” This theme captured a new challenge for parents as they reported concerns regarding developmental and psychosocial issues. Parents are now working to re-introduce the transplanted child to daycare or school and address any developmental and/or learning delays. Parents described continued concern for infectious diseases, which is a primary concern when the child returns to daycare or school as reported by parents of heart transplant recipients (Green, McSweeney, Ainley, & Bryant, 2008).

At 6 months after transplant, parents described “facing a future” and the long-term challenge of ongoing monitoring and vigilance and financial concerns. It is essential for the transplant team to identify individual parent and family challenges for these children. The families’ adjustment to accommodate needs of the transplant child is multifaceted and places additional strains on the family routines (Denny et al., 2012). Similarly, caregivers of adult transplant recipients reported a desire for life before the chronic illness as a sense of security (Beckmann et al., 2016) and parents of heart transplant recipients have described the importance of normality (Green, Meaux, Huett, & Anley, 2009). Paying attention to child and family adjustment after SOT
continues after the 6-month time period included in this study, as it has been reported to be an important concern 2–3 years after transplant (Brosig et al., 2014). Nurses can help prepare parents to face the future by helping them anticipate that it is normal to expect vigilance and need for management of finances in long term.

Follow-up after hospital discharge with high-risk populations is a critical component for pediatric discharge care (Berry et al., 2014). The results of this study provide direction for what the follow-up might consist of, including frequent contact with families to include continued education and anticipatory guidance specific to the children's complex medical needs. Education is ongoing and the focus changes over time from managing acute needs in the first 3 weeks, including medication administration and frequent appointments monitoring for complications to managing developmental and neurocognitive issues such as learning and school at 3- and 6-months following hospital discharge.

Frequent medical appointments allow for a unique opportunity to continually assess family functioning and identify needs. Ongoing education with families can also take place, which will include standard transplant education including discussion of medications, laboratory results, and complications but also anticipatory guidance for family functioning and management of complex chronic health condition. Attention should be paid to the important role of family functioning, with assessments for at-risk families with surveys or transplant team social workers.

The parents’ perspectives reported in this study can be used to informs nurses’ care and teaching to anticipate the adjustment at home in the first 6 months after hospital discharge. The results may inform providers’ abilities to anticipate issues, emphasizing the importance of assessing and intervening early. The findings are consistent with literature that exists for other children with other complex chronic conditions including ventilator dependency (Brenner et al., 2015) and congenital heart defects (Schuh et al., 2016).

Limitations to this study exist. Parents who self-identified themselves as the primary caregiver for the transplanted child were interviewed alone; therefore, the results did not capture the experience from other family member's perspectives. The interviews took place over the phone in order to account for participants enrolled at five separate transplant centers, limiting the information that may have been gained from in-person or focus groups with parents together. Probing was used as a technique to obtain more in-depth responses, although it may not have been as successful as in-person interviews. Perspectives of parents whose children did not survive after transplant were not included.

The large sample size for conducting qualitative exploration and conclusion is a significant strength of this study. Parents were enrolled at five major pediatric transplant centers from all of the SOT types across the United States, allowing for variation in practice and experience to be taken into consideration. The study was guided by Meleis’ transitions theory and results focus on nursing therapeutics (Meleis et al., 2000). The findings provide direction for improvements to nursing therapeutics that would help parents in their transition to chronic condition care and help master the care of their child. Qualitative exploration of data is rich and provides a depth of information that cannot be seen in quantitative design alone (Albright, Gechter, & Kempe, 2013).

9 CONCLUSION

The transition from hospital to home and complex chronic condition care is challenging and changes over time. Future research may focus efforts on assessing family functioning and identifying family specific needs to best support parents as they care for the transplanted child.

9.1 How might this information affect nursing practice?

As the number of children with complex medical health conditions after SOTs increases, nurses are called upon to prepare parents to become knowledgeable and confident to care for the child after hospital discharge. Nurses
can provide parents with education for expectations, both medical and psychosocial in the first 6 months after transplant and moving forward to promote optimal care and family functioning after transplant.

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CONFLICT OF INTEREST
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