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Transition from Hospital to Home Following Pediatric Solid Organ Transplant: Qualitative Findings of Parent Experience

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Abstract

Transplant providers are challenged to determine appropriate interventions for patients and families due to limited published research regarding the context of the post-discharge experience from the perspective of parents of transplanted children. The purpose of this study is to describe the parent perspective of the transition from hospital to home following their child's solid organ transplant. Within a mixed-methods design, 37 parents of pediatric heart, kidney and liver transplant recipients from three pediatric hospitals responded to qualitative interview questions on the day of hospital discharge and three weeks following hospital discharge. Insight to the discharge preparation process revealed necessary education components. Post-discharge themes were identified for coping, knowledge and adherence. The parents' responses provide awareness as to specific stressors and concerns parents are faced with when their child is discharged from the hospital after solid organ transplant and opportunities for ways the transplant team can provide support.

Keywords

pediatric; solid organ transplant; qualitative

Introduction

National endeavors focus on patient centered care as a crucial component to enhancing and improving health care delivery. National organizations, including the Institute of Medicine and National Strategy for Quality Improvement in Health Care, identified patient-centered care and family engagement as top priorities to improve patient quality of care listed family engagement as one of six priorities.¹ Patient-centered care is defined as "providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions".² Furthermore, the American Academy of Pediatrics highlights the importance of patient-family-centered care in a policy statement speaking to the critical role of collaboration between patients, families and health care professionals.³

Building a partnership with patients and families, particularly those experiencing major transitions to chronic illness management such as solid organ transplant, is critical to promote successful outcomes.⁴ Parents of children with special health care needs report that collaborative relationships with health care providers are a key component of family-centered care.⁵ Although the child and individual family members have different experiences, the role of the entire family is critical to promote successful outcomes and adaptation to chronic illness.^{6, 7} An integrated patient-family-centered care approach can positively impact the perceptions of quality and satisfaction with the care received.^{3, 8}

The post-transplant time period is challenging as the family trades a life-threatening pre-transplant medical illness for a post-transplant chronic medical condition and the associated

uncertainties for potential complications.⁹ Pediatric transplant recipients are medically fragile and present with complex care issues requiring high-level management in the home. Parents of hospitalized children have reported not being prepared for hospital discharge resulting in difficulty managing their child's complex care needs at home.^{10–12}

Pediatric transplantation leads to chronic medical conditions and has been identified as a disease with a high number of readmissions.¹³ Psychosocial components including family resources and family capabilities play a role in the successful management of the child's health condition at home after hospital discharge, even more so for children with complex health conditions.¹⁴ Research on family psychosocial needs following liver transplant has documented that parents of children who had a transplant experience symptoms of emotional trauma.^{9, 10, 15} In our study of the discharge transition for parents of children with solid organ transplant, in which the current qualitative study was embedded, the quantitative findings documented the challenges parents face following discharge from the hospital after pediatric transplantation in terms of difficulty coping, adhering to the medical regimen and overall impact on the family.¹⁶

Studies of families of hospitalized medically complex children highlighting the importance of discharge preparation as an essential component of care.¹⁷ In preparing for hospital discharge, transplant teams work diligently to provide education regarding care required at home including but not limited to illness or disease process, medications and proper administration, monitoring for illness symptoms, and laboratory/clinic follow-up appointments. All members of the transplant team including physician, nurse, coordinator, pharmacist, social worker and dietitian educate patients and families with the goal of adequately preparing families to leave the hospital. Parents provide an important window to the experience of family life and management of the child's medical needs at home, including medication administration and adherence with frequent laboratory/clinic follow-up, that will ultimately impact their success with home management after transplant and the need for return to the hospital.

Parent insights provide useful information for individual family planning and for creating parent/family-centric preparatory materials that are relevant to the common experiences of pediatric transplant patients and families. Using a qualitative approach can uncover the specific issues parents face related to coping and impact on family in the home environment, describing the uniqueness and breadth of parental experiences with complex chronic care management that can be hidden in the aggregated quantitative data. Qualitative research plays an important role in moving transplant research forward based on findings of parent behaviors and attitudes that is not accessible through quantitative research.¹⁸

The purpose of this study was to describe the parent perspective of the transition from hospital to home following their child's solid organ transplant. Meleis' Transitions Theory was used as the guiding theoretical framework for this study of parent perspective of the transition from hospital to home.¹⁹ Transition is a change in health and illness that tends to create a period of vulnerability and the hospital discharge is viewed as a transition process because families are moving from one life phase to another.^{19, 20} The qualitative component of the this study sought to describe what are termed 'transition conditions' and 'patterns of

response' to transitional events in Transitions Theory.¹⁶ Discharge preparation can be viewed as a transition condition which can be a facilitator or inhibitor of the transition process. Post-discharge outcomes such as coping difficulty, adherence to medications and treatment plan, and family adaptation are examples of patterns of response by family members to the transitional event.

Methods

Design

The study reported is the qualitative component of a mixed methods study design focusing on predictors and outcomes of discharge readiness for parents of children who received a solid organ transplant. The mixed methods design selected for the study was a primarily quantitative observational study with an embedded qualitative component to complement and provide depth to the quantitative findings.²¹ The quantitative component of the study was previously reported although the qualitative data was collected simultaneously.¹⁶ The design was chosen to capitalize on the strengths of both quantitative and qualitative research methods and focusing on this multi-faceted transition from hospital to home. The combined study was guided by Meleis' Transitions Theory, exploring the theoretical concepts of transitional conditions, nursing therapeutics, and patterns of response in the specific situation of transition to home for parents of children with solid organ transplantation.

This qualitative component used the principles of content analysis, a systematic and rigorous means of describing phenomena,²² and sought to expand on quantitative findings to uncover detailed descriptions of parent perceptions of their experience of the discharge transition process. Understanding the context of quantitative study results is imperative for effective pragmatic research to be understood and ultimately translated to practice.²¹ The discharge transition process was defined for the purpose of this study as both the preparation for hospital discharge as well as the family experience during the first 3-weeks within the home following discharge from the hospital.

Sample

Convenience sampling resulted in the enrollment of thirty-seven parents identified as the primary caregiver of a child who had received a heart, kidney, or liver transplant from three major children's medical centers were recruited between May 2009 and May 2010. Three centers were utilized to enroll a sufficient sample for the quantitative portion of the study¹⁶ within one year's time due to the overall low frequency of pediatric solid organ transplant. Parents were invited to participate based on the following criteria: 18 years of age or older, English speaking, and having a telephone to complete the post-discharge telephone interview. Parents were excluded for the following reasons: the child had 1) a previous transplant or 2) an extreme co-morbid condition resulting in the need for additional skilled nursing care in the home including but not limited to tracheostomy or ventilator dependence.

Data collection procedures

Following Institutional Review Board approval at the three study sites, eligible parents were identified and approached by the transplant coordinator at each participating center to

request voluntary participation and obtain informed consent including a discussion regarding confidentiality. On the day of discharge, the parent self-identified as primary caregiver was asked to complete open-ended questions by the center specific transplant coordinator that were included on forms with quantitative measures for the larger study.¹⁶ The interview questions are listed in Table 1. The qualitative questions focused on education parents received and how ready they felt to leave the hospital. The discharge preparation practices across the three centers included standard transplant education including but not limited to medications, complications (rejection and infection), and the need for close medical follow-up. No parent education interventions or systematic provision of information was employed.

Open-ended questions were also asked 3-weeks following discharge from the hospital in a telephone interview conducted by the research assistant and principal investigator (SL). The post-discharge questions inquired about parent perspective on parent and family coping, education, and medical regimen. These questions were asked based on concepts being studied in the larger quantitative portion of the study.¹⁶ Parents received \$10 for completing each portion of the study (day of discharge and post-discharge). There was no attrition within the study; all 37 parents recruited completed both time points.

Two interviewers, the principal investigator (SL) and a trained research assistant, conducted the 3-week post-discharge interviews using a semi-structured interview form. The telephone interviews were limited to two individuals in order to assure consistency in how questions were asked as parents were enrolled at three separate transplant centers in the United States. The interviewers utilized probing questions beyond the structured interview such as “Could you please explain that more?” in order to receive further information. The interviewers utilized a paper data collection form to document verbatim sentences or phrases. Each interview lasted between 45 and 60 minutes of which 20 to 40 minutes was the qualitative portion. There were no significant issues or adverse events during the study time period and therefore no changes were made to the study.

Content analysis was utilized to examine the interview responses and determine themes from the interpretation and categorization of the data.^{23, 24} This type of qualitative analysis is an iterative process where the resultant themes reliably represent responses provided by the research participants.²³ Two independent reviewers (SL, GS) transcribed parent’s narrative responses verbatim into electronic text documents. Each reviewer has, extensive clinical experience in this population working at one of the participating transplant centers. Although subject to individual bias, qualitative data analysis does not require a separation between data collection and coding.

The reviewers independently examined the transcribed interviews twice and proceeded to code data into categories of responses. Coded statements were systematically compared and those that occurred repeatedly were considered an emergent theme. After independent analysis, the reviewers met to complete coding of data²³ for each qualitative question through a process of generation of initial themes, re-analysis of data, and resultant final themes.²⁵ Rigor was assured by maintaining an audit trail so further conversations regarding the development of final themes could be reviewed line by line. Differences in coding in the

independent review phase were resolved by discussion and consensus between the two reviewers.

Results

Forty-four eligible parents were approached to participate in the study. Seven of these parents declined participation due to lack of interest in the research study. The majority of the sample was parents of heart transplant recipients (n=18), while the remaining were kidney (n=10) and liver (n=9). Parents were also mainly recruited at two of the three pediatric transplant centers, as two of the hospitals enrolled 18 participants each and third hospital recruited one participant. Parents were mostly Caucasian, married and female with a mean age of 38.9 ± 9 years and the transplanted child was 7.9 ± 6 years. Table 2 summarizes parent and child sample characteristics.

Day of Hospital Discharge

Education Content of Discharge Preparation—The first question asked on the day of hospital discharge aimed to gain insight regarding parent's perspectives of the discharge teaching experience (Table 1). The first question focused on topics identified as most important to learn about before going home from the hospital. Three themes emerged: (1) 'Medications', (2) 'Restrictions' and (3) 'Warning Signs'.

'Medication Knowledge': Learning about medications was the focal concern for transplant parents. Specifically, parents stated, "I want to know what side effects to watch for and when to call the doctor" and "I need to know proper medication administration". Parents have a number of medications to administer in the home environment, making education about medications and administration a high priority when in the hospital.

'Restrictions': The 'restrictions' theme represented parental concerns for what the child can and cannot do once in the home environment. One parent stated, "I need to know what my child should avoid...what can [child] be exposed to in the first few months". Another parent echoed similar concerns by stating, "I need to know what my son can or cannot do for a while yet". Parents focused not only on medical care related needs but also considered the impact of medical restrictions on the child's developmental needs, such as resuming normal activities including school; as one parent asked, "Do I need to homeschool?"

'Warning Signs': 'Warning signs' captured parents' concerns for knowing exactly who and when to call with questions or concerns after hospital discharge. One parent stated, "When and who to call at the hospital when there is a problem". The transplant team is a major source of support to patients and families once at home following hospital discharge.

Readiness for Hospital Discharge—The second question asked on the day of hospital discharge focused on parent readiness to provide continued care in the home environment. Parents were asked to identify what helped or interfered with their ability to feel confident to care for the child once at home following hospital discharge. The responses were analyzed separately for "helped" and "interfered" components of the question. "Helped to feel more confident to care for your child after discharge" resulted in two themes: (1) 'Educational

methods' and (2) 'Support'. The same themes emerged for "interfered with feeling confident to care for your child after discharge" in the form of: (1) 'Complexity of education' and (2) 'Need for encouragement'.

'Educational methods': Education was helpful when it was consistent, came from knowledgeable staff, was repetitive, and offered hands on experience. One parent stated, "Everybody was very consistent and very knowledgeable and helpful in every way to make us feel reassured and confident". All transplant team members were instrumental to educating parents, stated by one parent as, "The pharmacist teaching about the medications really helped". Another parent stated, "Hands on experience was key to feeling confident".

Subsequently, '*complexity of education*' received during the transplant hospitalization was also identified as interfering with parents ability to feel confident to continue care at home. Transplant families receive education including but not limited to medication administration, medication side effects, and signs of rejection or infection. The complexity of education may be overwhelming but is critical in order to ensure accurate medication administration and ability to know when to call the transplant team. One parent summarized as follows, "A lot of the symptoms of a cold or flu are the same as rejection of the organ, so I am a little less confident that I would know when to call the doctor".

'Support': Support from nurses and family was identified as helpful during the hospitalization phase. "Our family support and nurses assured me and my family that we were all doing what we needed to do". Knowing that the transplant team is available allows the family to feel supported. "They [the transplant team] said call anyway anytime so that helped my confidence".

A '*need for encouragement*' from other family members or the transplant team was identified as interfering with the parent's ability to feel confident in going home. Parents describe the need for help at home, "I love to get more help at home with her [transplanted child], I would like to have more help with it all because I don't". One parent described feeling a need for encouragement from the transplant team by writing, "I feel confident but I just feel they [the hospital staff] need to feel more confident in us".

Three Weeks Post-Discharge

Coping at Home After Discharge—Four questions were asked in order to provide insight to parent coping and challenges parents experience in the first three weeks following hospital discharge. The first three coping questions focused on stress, difficulty caring for the child, and challenges with family members (Table 1). Three themes emerged: (1) 'The new normal', (2) 'Watchful waiting', and (3) 'Medications'.

'The new normal': The 'new normal' stemmed from statements about developing a family routine including juggling other children, getting to and from hospital for clinic follow-up and laboratory appointments, ensuring accurate medication administration, and getting back to work or school. "Driving back and forth to the hospital for frequent clinic and laboratory appointments is stressful". The post-transplant regimen posed challenges as parents were

trying to coordinate laboratory and clinic follow-up alongside home care requirements, family routines, and needs of other family members.

Families were trying to “figure it all out” during the first three weeks in order to develop a pattern so the child is receiving the best care possible at home. Parents described trying to find a routine at home and were challenged by the desire to lead a normal life within the context of potential transplant-related restrictions. “It is stressful keeping up with everything”. “It is stressful to process everything, care for my son [transplanted child] and juggling other kids”.

The transplanted child, siblings, and other family members were also trying to get back into a routine. One parent reported how difficult it was for her school-aged child who wanted to return to school and see her friends. Parents reported similar difficulties with managing the other children stating, “I have three other kids...the siblings have different schedules” and “the other kids have a life as well”. The siblings have their own schedules and it is challenging to coordinate the needs of siblings and transplanted child. Siblings also had a difficult time when parents were not around due to dealing with medical issues for the transplanted child. Parents stated, “It is most difficult for siblings because they were not able to see us [parents]”, and “other child has been distanced from the family”. Siblings are a part of the entire family and have particular needs that must be considered and addressed.

One parent described how her husband was having a hard time because he had to go back to work and could not be at clinic appointments, “making him feel helpless”. Other parents reported that relatives helped with general household duties not specific to the transplanted child in order for the family to get into a routine and set up a schedule. The family had to “get into a family routine and learn patience as a family, everyone [three children] wants, and there are three children so they need to take their turn”.

‘Watchful waiting’: Parents were not only managing the daily needs of the transplanted child but also managing day-to-day life. The transition to home is a time to create a new normal that not only incorporated daily tasks that need to be completed related to post-transplant care but also included dealing with the associated worry for unknown complications that may occur.

Parents stated “worried about making sure there is no rejection...just being a worried mom”, “thought of rejection is stressful, I am worried and want to make sure she [transplanted child] is ok”, and “worried about having a good drug level and rejection”. Worry was accompanied by watchful vigilance for signs and symptoms of transplant related complications including the potential for organ rejection, and concerns about obtaining accurate immunosuppression drug levels. Parents reported difficulty not knowing what would happen after transplant in regard to potential complications or hospital readmissions.

Another component of this theme was the parent’s emotional investment in watching the child “go through everything” related to the transplant, such as laboratory appointments, clinic appointments, and other transplant related procedures. Parents were not only faced with wondering about possible post-transplant complications but also their child’s reaction

to the diagnosis and treatment for the particular complication. “It is difficult to watch him [transplanted child] go through everything, he is the first person to have medical problems in the family”.

The worry extended to actions having an impact on the entire family as parents reported feeling isolated when they either lived far away from relatives or felt confined to home due to for risk of infection. One parent stated, “We cannot be too close to other family members for parties or gatherings because of transplant precautions”. Additionally, parents stated, “I sanitize everything” and “It is difficult to go out in public places because of sanitation, I use special cleaning wipes to use on restaurant tables”. The concern for germs and the transplanted child becoming sick changed the daily routine of parents as well as the activities parents choose for their family.

Parents were not the only ones who had a difficult time watching the transplant child deal with the post-transplant regimen and worry about the unknown, including potential transplant-related complications. These issues affected the entire family. One of the parents reported “not knowing what the future holds is emotionally hard for the entire family”.

‘Medications’: The main obstacles with medications included frequency, timing and accuracy of medication administration. One of the parents stated, “Before transplant I did not worry about the timing of medications, and now it matters”. Parents stated the following: “Inconvenience to give medications, some you refrigerate and some you do not refrigerate”, “I have two other kids, this is a lot of medication”, “Stressful remembering medications and times”, “Around the clock medications, it is hard to sleep”, and “I am making sure I don’t forget to give medications...need to stay on top of medications”.

The final question regarding coping asked parents to provide specific detail about what may be contributing, both positively and negatively, to their coping after hospital discharge. Three themes emerged from asking parents to report positive influences for coping: (1) ‘Having a pillar’ through both community and transplant team support (2) ‘What I know’ regarding understanding of potential complications and completing care in the home, and (3) ‘Being normal’ by seeing the transplanted child feel better and having fun (Table 3). Parents are supported by individuals and communities, but also knowledge gained from transplant specific education and physical improvements in their transplanted child. Negative influences for coping included: (1) ‘Lifestyle’ and the change in routine and (2) ‘Hospital systems’ as parents found paperwork and miscommunication between medical teams overwhelming. The ability to cope was hindered by parents struggling to develop a new routine that encompasses medical care including medication administration as well as the ability to manage frequent medical appointments for clinic and laboratory draws. Furthermore, inconsistent information from the medical team made it difficult for parents to cope with managing at home. Parent quotes for each of the aforementioned themes are outlined in Table 3.

Parent statements that captured important insight into this stage of recovery included, “I was expecting much worse”, “[it] gets better as time progresses”, and “easier now [after the transplant] compared to before transplant”. Parents remained optimistic despite the

numerous stressors and challenges they face when taking their child home from the hospital including medication administration and worry for potential complications while also trying to develop a new family routine.

Knowledge Needs—Parents were asked to reflect on their level of knowledge on the day of hospital discharge. One theme emerged: ‘Situation specific’.

‘Situation specific’: Parents either stated that they did not need to know anything more before leaving the hospital because they felt very well prepared or indicated the desire for more information related to their child’s unique situation. The specific suggestions included the need for supplies, and better understanding for the importance of hydration after kidney transplant. Other parent responses were related to medications. One of the parents wanted to know “medications that needed to be kept cold while...especially on the drive home from the hospital” and another parent stated “need to know a way to organize the medication list”.

Adherence Difficulty—Three questions were asked in order to learn about challenges adhering to the medical regimen. One theme emerged: ‘Stumbling blocks’.

‘Stumbling blocks’: Parents were asked about adherence difficulty with the medication regimen and follow-up laboratory and clinic appointments in order to provide depth to the challenges they face with this crucial component of managing the medical condition. Medication administration was a familiar task from the pre-transplant period, but parents still reported challenges with medication administration.

The challenges reported with medication adherence are similar to the difficulties parents reported on the more general topic of caring for the child suggesting the centrality of medication management in the lives of post-transplant families. The timing of medication administration can pose significant challenges because there are numerous medications that must be administered at specific times. “The hours are random”, “Getting the schedule is the hardest part”, “Trying to get into the habit of when to take what pill”, “Difficult at the beginning because so many”, “Hospital is 8am and 8pm so it was hard when we got home because we needed to change the medication timing to fit our schedule”, and “Trying to get used to it...take so many”.

The precise timing that is required with administration of the immunosuppression medication was a struggle verbalized by parents. Parents reported that it is hard to give medications while juggling other responsibilities knowing that immunosuppression drug levels are timed, “All the blood draws are hard” and “You have to come to the hospital in the morning for lab draws.” Parents recognize that early or late medication administration may result in an inaccurate drug trough level.

Parents provided a number of suggestions as to what would help them more easily manage the medications at home. Some of the parents reported it would be helpful to create a schedule for medication administration and talk about the schedule before leaving the hospital. One of the parents stated that a beeper or alarm would be helpful to make sure that medications are always given on time. Another parent expressed the desire for help by

stating, “Have my spouse do some of the medication administration because he doesn’t know how to administer”.

Two statements that did not fall into one of the aforementioned themes, but rather summarize the discharge experience were: “Going home from the hospital is a big deal, it is life changing” and “In the first 12 hours I wanted to rush back to the hospital, but then at 24 hours I knew I could do it”. There was no difference in themes generated based on individual centers or type of organ transplant, indicating that experiences described are not center specific or unique to individual organ groups.

Discussion

The themes emerging from parent responses provide insight to the stressors related to both transplant hospitalization discharge preparation and post-discharge care once at home. Parents need to not only be involved in the discharge process but also receive consistent information from all members of the transplant team. All members of the transplant team including physician, nurse, pharmacist, social worker and psychologist make unique contributions to patient care and can assure each patient and family has the resources needed to successfully continue care at home. Recommendations for improvements to the discharge process by parents of transplant recipients resonate in other discharge transition literature emphasizing the importance of a comprehensive and coordinated discharge from the hospital.^{26–30}

The quantitative portion of this study highlighted the fact that most parents reported receiving good discharge teaching with an average score on the Quality of Discharge Teaching Scale of 8.4 out of 10,¹⁶ but the qualitative data reported here identified opportunities for improvement. The struggle of finding ‘the new normal’ can be an area of focus for the transplant team when preparing families for hospital discharge. A component of discharge teaching should include planning for multiple returns to the hospital and fitting transplant-related management in with normal family related daily activities. The stressor of post-transplant management has also been reported by parents of pediatric bone marrow recipients.³¹ Meetings with families may also need to include a discussion on how going home will impact the family structure and organization once in the home environment. Framing education within the context of the experiences parents may face at home and the decisions to be made within the context of everyday living can help parents to feel confident within the home, without the watchful eyes of the transplant care team.

Findings related to adherence provide insight to both medication and follow-up difficulties after hospital discharge. Parents reported more difficulty adhering to laboratory and clinic follow-up in comparison to the medication regimen in the quantitative portion of the study.¹⁶ The qualitative results provided detail to what some of the challenges were that made it difficult for families to be adherent. The transplant coordinator or pharmacist can provide assistance with medication planning to minimize difficulties with adherence at home. Providing parents with the opportunity to talk through the daily routine at home including timing of medication administration, suggestions for using an alarm or beeper on their phone as a reminder, and identifying another adult that can provide support and

assistance to administer medications before hospital discharge may minimize the stress and anxiety associated with medications once at home. Pre-discharge education should include a specific medication schedule that fits the family routine. Families should discuss their home routine with the transplant team so the medication schedule and support can be tailored to meet each individual family's needs.

Assessments of parents and how the illness impacts the family structure and ability of the family to support the transplanted child³² are important because families that are not functioning well enough put the transplanted child at risk.³³ Although parents reported improved family functioning 3-weeks following transplant in comparison to day of hospital discharge in the larger quantitative portion of the study,¹⁶ families can benefit from a focused conversation regarding life at home. An assessment may include asking families how they are coping resulting in a referral for the family to meet with a pediatric psychologist or social worker.³² Nurses and other members of the transplant team can assess the family impact of transplant and offer support and encouragement to transplant families to promote strong functioning families during the transplant hospitalization, discharge and throughout the transplant journey.

Uncertainty of the child's future health and well-being has been reported as a source of family stress for families of pediatric transplant recipients.^{34–36} Parents reported overall little difficulty coping after hospital discharge using the Post Discharge Coping Difficulty Scale reporting an average score of 2 out of 10 with 10 indicating significant difficulty coping on the quantitative portion of the study. However, the highest single rated item on the tool was parents stating how stressful life was after discharge (average 4.7 out of 10).¹⁶ The uncertainties of medical complications including rejection, infection, and medication side effects are stressful and may diminish over time, but likely never completely resolve.³⁷ Families of medically complex children want a single point of contact to address their medical concerns.^{4, 38} Minor mistakes in dose administration, particularly for immunosuppression medication, can result in transplant-related complications and unplanned utilization of healthcare resources.

Transplant coordinators are a consistent and accessible part of the transplant team, and a simple phone conversation between the transplant coordinator and family can continue to provide reassurance and build parent confidence.⁴ The transplant team plays an important role in building parent's confidence to continue care at home after hospital discharge. Transplant providers who develop a meaningful connection with patients and families encourage families to actively participate in the post-transplant care which is essential to successful outcomes.³⁹

Parents should be encouraged to reach out to family, friends and the community for support. Even if parents are close to home or support network, they may feel isolated from family members and friends because of transplant precautions and concerns for complications. Social isolation has been reported in a previous descriptive study of parents of pediatric transplant recipients.³⁶ Specifically, parents of pediatric heart transplant recipients may place unnecessary restrictions on their transplanted children due to fear of infectious diseases.⁴⁰ Parents receive education that their child is at risk for infections, although the

‘restrictions’ theme underscores the importance of educating families regarding recommendations for daily living and activities. The transplant coordinator and social worker can recommend to parents who feel isolated, especially geographically, blogging or using online support groups.

Most importantly, parents were positively affected by watching their child feel better and seeing them physically improve. Parents were happy to see the child having fun and coming home to establish a sense of normalcy. The importance of normality after transplant has been described by parents^{36, 41} as well as pediatric liver transplant recipients.³⁹ Parents are living their lives within the context of having a transplanted child. This study captures the parent experiences of putting disease and life together following hospital discharge after the life-changing event of organ transplantation.

A summary of implications for practice organized by transplant hospitalization and three weeks following hospital discharge is found in Table 4.

Limitations

Qualitative information on the day of hospital discharge was collected through the use of a self-administered questionnaire and 3-week follow-up data was collected by phone interview after completing quantitative measures. Parents were recruited at three different transplant centers for this study and limiting to two interviewers was important for consistency in data collection. A face-to-face interview providing an opportunity to ask open-ended questions regarding how parents feel and their fears about going home may yield more in depth and valuable information on improving the discharge process. In person interviews could be considered specifically in the setting of data collection at a single center. Differences in center specific discharge education and preparation were not accounted for and suggest further work may be warranted to identify areas for improvement in the discharge process.

The study was also limited by interviewing one parent, self-identified as the primary caregiver for the transplanted child. Interviewing parent dyads may provide more specific insight as to how to support the family as a whole. Each parent has a unique role and may need to be supported in different ways in order to assure the best care is being given to the transplanted child.

Small sample size is a limitation as the majority of the sample characteristics included families that are married and Caucasian. The findings reported although reflective of the transplant population may not be generalizable based on demographic differences.

Conclusion

This is the first study to explore parent perceptions of the transition from hospital to home with qualitative data following their child’s heart, kidney or liver transplant. Consistent with Transitions Theory, results point to the transition conditions that facilitate and inhibit a successful transition as well as parent’s patterns of response during early home-based care following discharge.^{19, 20} In addition to educating parents on medications and

complications, parents also have a need for emotional support and guidance in parenting the child with a transplant.³⁰ Some parents cope better than others with the challenges associated with their child's chronic condition, highlighting that it is critical for the transplant team to address the individualized needs of children and their families.⁴² Similar to the emphasis currently being placed on transitions from hospital to home for adult patients,^{43, 44} pediatric transplant families have transitional care needs that require preparation and attention throughout the transition period.

Transplant teams may consider an additional dimension to education that focuses on managing day-to-day life after transplant, especially in families that include other children. If parents are not able to successfully manage this stressful transition, their child is likely at higher risk of experiencing post-operative complications which are burdensome to the family and health care system.⁴⁵ The qualitative component of this study extended the understanding of the phenomena of discharge preparation, discharge readiness, and post-discharge outcomes and offers vision to designing a discharge intervention program. More rigorous qualitative investigation to explore these themes may provide further insight to how parents adapt to this stressful life experience and have important implications both short and long-term patient survival.

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Table 1

Qualitative Questions

Day of Hospital Discharge	
Education	1 What were the most important topics for you to learn about in preparing to go home?
Readiness for Discharge	1 What helped or interfered with you feeling confident to care for your child after discharge?
Three Weeks Post Hospital Discharge	
Coping	1 What has been stressful? 2 What has been difficult about your child's recovery and managing their condition? 3 What has been difficult for your family members or other close persons? 4 What positively or negatively affected your ability to cope in the last 3 weeks following hospital discharge?
Knowledge	1 What do you know now that you would have liked to know before discharge from the hospital?
Adherence	1 Tell me about the challenges, if any, you have with medication administration? 2 What, if anything, would help you to better or more easily manage your child's medications? 3 Tell me about the challenges, if any, you have had following up with clinic and laboratory appointments?

Table 2

Parent and child demographics

Demographics	
Parent gender	Female = 27 (73%) Male = 10 (27%)
Parent age	Mean 38.9 years $\pm$ 9 years (range 22–55)
Parent marital status	Married = 28 (75.7%) Single = 6 (16.2%) Divorced = 3 (8.1%)
Child gender	Female = 16 (43.2%) Male = 21 (56.8%)
Child age	Mean 95.2 months or 7.9 years $\pm$ 71.5 months (range 3 months to 18 years)
Parent and Child Race	White = 25 (67.6%) Black = 7 (18.9%) Did not answer = 3 (8.1%) Asian = 1 (2.7%) Alaskan or American Indian = 1 (2.7%)

Table 3

Positive and Negative Influences on Coping

	Family	Transplant Team
Positive Influence on Parent Coping	<p><i>Having a pillar:</i></p> <ul style="list-style-type: none"> • “Stay at [transplant residence] house” • “Support from family and friends” • “Support from blog” • “Support from (patient’s) school” • “Support from coordinators physicians and social workers” • “Coordinators answer questions” • “Physicians sitting down to explain things” • “Nurses always available to explain everything” <p><i>Being normal:</i></p> <ul style="list-style-type: none"> • “Watching my child feel better” • “Seeing my child improve physically” • “Seeing my child having fun with life” • “Coming home in general and trying to be normal” 	<p><i>Discharge Teaching and Preparation:</i></p> <ul style="list-style-type: none"> • “Preparation and organization” • “Knowing that something bad could happen” • “Nurses gave me [mom] tools to know what to do and be confident in providing care to patient” • “Consistent and good education” • “24 hour preparation test in the hospital” • “They (the hospital) did everything they could do to prepare us”
Negative Influence on Parent Coping	<p><i>Lifestyle:</i></p> <ul style="list-style-type: none"> • “Can’t just get up and leave because everything is much more scheduled” • “Everybody who was helping when we were in the hospital now wants our time that we are now home” 	<p><i>Hospital systems:</i></p> <ul style="list-style-type: none"> • “Too much paperwork at discharge, Recommend streamlining discharge process” • “Miscommunication between team members leaving it confusing and wondering who was in charge” • “Different doctors who do not know him/her well results in more tests” • “Inpatient is an emotional rollercoaster”

Table 4

Summary of implications for practice

Time Point	Implications for Practice
Transplant hospitalization	<ul style="list-style-type: none"> • Discharge education to include role playing with families how to manage care of child within the family routine • Individualized medication planning between family and transplant team • Discharge education to include role playing with families how to manage care of child within the family routine
Three weeks following hospital discharge	<ul style="list-style-type: none"> • Utilization of alarms as reminders for medication administration • Social work or psychology assessment regarding family coping • Encourage use of family, friends and transplant team as support • Transplant coordinator as main contact person for families