The lived experience of parents and guardians providing care for child transplant recipients

Context—Little has been published about the caregiving experiences of the parents or guardians of children receiving liver or liver/intestinal transplants.
Objective—To describe the lived experiences of parents and guardians as they prepared for and provided postdischarge care to a child who received an isolated intestine or a liver/intestinal transplant and to assess the impact of transplants on parents' stress levels.
Design—Semistructured, audio-taped phone interviews of parents' and guardians' perceptions of their experiences preparing to and providing care to a child transplant recipient were transcribed verbatim and analyzed by the research team using established qualitative research methods.
Participants—Five parents or guardians (3 mothers, 1 foster mother, and 1 grandfather) of children who received a transplant between 2000 and 2008 at age 11 months to 6.7 years.
Results—Responses to the interviews gravitated toward 3 focal points: the parents' and guardians' perceptions of their interactions with the transplant team, their interactions with the local health care systems, and caring for themselves and their child at home.
Conclusion—In preparing parents and guardians to care for their children after discharge from the hospital, transplant teams need to be aware of differences between what we think we communicate and how it is interpreted by the parents and guardians, the relationships built between parents and guardians and health care teams, parents' attitudes and levels of stress, and the impact these factors have on care and the parents' and guardians' experience. (*Progress in Transplantation.* 2012;22:393-402)

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The number of transplant surgeries performed in the United States has increased exponentially over the years. According to the US Organ Procurement and Transplantation Network (OPTN), 12 623 transplants across all ages and organ types were performed in 1988 and 28 684 transplants were performed in 2010. Included in this total number of transplants were 1713 liver transplants performed in 1988 and 6291 liver transplants performed in 2010. Children make up 12% to 15% of all liver transplants performed each year.[1] With current survival rates for children undergoing liver transplant exceeding 91%, more families are being faced with the long-term challenges surrounding the care of their child after transplant.[2] The successes seen and the lessons learned in pediatric liver transplant encouraged and fostered interest and growth in pediatric intestinal transplants. Although more children receive liver transplants than intestinal transplants, intestinal transplant has become the accepted treatment for patients with permanent intestinal failure and life-threatening complications of total parenteral nutrition (TPN).[3] In 2000, the Center for Medicare and Medicaid Services approved intestine, liver/intestine, and multivisceral transplants as a standard of care for patients with irreversible intestinal failure and complications of TPN. As of September 2009, the International Intestinal Transplant Registry noted 86 accredited intestinal transplant centers; 2291 transplants were performed in 2061 transplant recipients with 1184 patients being alive with or without a functioning graft.[4] More than 50% of these patients were less than 18 years old.[4] The 1-year patient survival rate is 78% to 85% at experienced centers that use induction immunosuppressant therapy.[5] More than 80% of the current survivors have been able to stop TPN and resume "normal" daily activities. The longest survivor received a transplant more than 20 years ago.

Children do not experience life with a transplant in isolation. Parents and guardians are challenged to deal with their critically ill child before the transplant surgery and must deal with the trials and tribulations after the transplant surgery. With improved survival statistics leading to more transplants, there is a need to understand how families experience and cope with the transplant process. This information can guide health care professionals in finding ways to improve transplant processes.

Transplanting organs is an expensive and complex process for both children with life-threatening end-stage organ failure and their parents, financially, physically, and emotionally. Although transplant surgery treats the complications associated with end-stage organ failure, it leaves the child with a new chronic condition—a transplanted organ. It is assumed that the new chronic condition allows the child to optimize his or her quality of life; however, the child and family have to adapt to long-term health care needs and related stressors.[6] Most child transplant recipients are cared for at home by parents who may be expected to provide highly technical care that in the past would have been provided by health care professionals.[7] As with many lifesaving procedures, the survival of patients drives the initial surge of trials and medical research. Once adequate survival statistics have been achieved, studies begin to look at what happens to survivors and their families initially and long-term after the procedure. However, few reports have been published that look at the impact of transplant surgery on parents and families and specifically at the stress parents experience when their children receive an intestinal transplant and ways for health care providers to try to decrease those stressors through their communications and daily interactions.

Background of the Problem

Stress

Although the number of centers performing transplant surgeries has increased, many families still relocate to centers away from their homes, causing family stress related to disruptions in routines, role changes, and financial hardships.[8-11] It has been noted that child and family stress may be related to poor compliance with medications and subsequently long-term survival.[12] The severity of stress experienced by parents and guardians may subsequently result in signs and symptoms of posttraumatic stress disorder (PTSD) and its associated ramifications.[13-15] Lerett[16] described the pediatric transplant population as a "unique and vulnerable population" that therefore had increased risks of life-threatening complications. The level of support felt by parents and guardians was instrumental in success after hospital discharge, as was how educational information was given and received. Establishing parent-professional partnerships, using open communication, is key to providing family support that helps parents and guardians to assume the responsibility for caring for their child.[17,18]

In 1997, Rodrigue and colleagues[19] looked at a longitudinal assessment of 27 mothers of children undergoing bone marrow, liver, kidney, and heart transplant and their perceptions of stress, coping, and family functioning. The mothers completed a number of psychological instruments during the pretransplant evaluation and at 1 and 6 months after transplant. Their stress levels before transplant were significantly lower than at 1 and 6 months after transplant. More than half of the mothers reported clinically significant levels of parenting stress at 1 month after transplant, with more than one-third of the mothers continuing to experience very high levels of stress at 6 months after transplant, indicating that transplant surgery is not an isolated event with a time-limited impact on parents.

Maternal coping resources reached their peak shortly after transplantation and then diminished in the following months. This may reflect that resources are more available to parents while they are at the transplant center and may be harder to access once the family returns home. Of note is the fact that increased parent and family stress occurred at a time when the mothers reported reduced access to extended family members for support. This may have occurred later in the posttransplant period, when the perception of others was that the emergent medical condition of the child was improving.

Gerson and colleagues[20] focused on medication adherence and psychosocial variables in 7 families of children undergoing kidney transplant. Elevated parental stress, dysfunctional parent-child interactions, and child behavior problems were associated with poorer medication adherence. In another study,[21] psychological functioning, nonadherence, and health outcomes were studied in parents of 38 patients after pediatric liver transplant. Parental distress, decreased family cohesion, and parental psychosocial risk factors contributed to the risk for late rejection, increased numbers of hospitalizations, and death.[22,23] As more intestinal transplants are performed in children, understanding what the parents and guardians experience throughout the process and how their experience affects long-term outcomes must be enhanced.

Posttraumatic Stress Disorder

According to Santacroce,[24] uncertainty is the single most common cause of stress for people affected by serious illness. It affects parents of children with serious illness from the time of diagnosis through treatment and plays a role in PTSD. Young and colleagues[13] looked at the incidence and severity of PTSD symptoms, and contributory factors, in 170 primary caregivers of pediatric solid organ transplant recipients. Data were collected between 10 and 38 months after the initial surgery (mean, 18.2 months; SD, 6.8 months). All measures were completed by using an interview format either before or after follow-up clinic visits when possible; otherwise the measures were completed by telephone.

As for the overall scores on the Beck Depression Index-11, most scores were within the normal mean, suggesting that the caregivers did not exhibit signs of clinical depression. However, 27.1% showed at least mild depression, with 49.8% of these in the moderate to severe range; 50.6% reported symptoms of moderately severe PTSD. Avoidance was the strongest symptom reported in the 46 parents who were considered to have PTSD. Multiple regression analysis showed that PTSD symptoms were most strongly associated with parents' report of their child's health, the impact of the transplant on the family, and parental attitudes toward the medical caregivers.

Farley and colleagues[14] looked at parenting stress and parental posttraumatic stress symptoms after pediatric heart transplant. Parents of 52 children seen during routine clinic visits completed questionnaires assessing illness-related parenting stress and symptoms of posttraumatic stress. The children had received a transplant from 3 months to 10 years earlier. Of concern was that 40% of the parents showed moderately severe to severe symptoms of posttraumatic stress. Ten of the parents met clinical diagnostic criteria for PTSD. The authors noted that many of the subjects may not have met full diagnostic criteria for PTSD but had subthreshold symptoms that caused major disruption in their family lives. The phenomenon of subthreshold, but clinically significant posttraumatic stress symptoms has been identified as occurring frequently in parents of medically ill children and affects family health and psychosocial outcomes.[25,26]

More recently, in 2011, Rossi and colleagues[15] examined the quality of life and coping skills of 56 parents of children undergoing heart transplants. Their focus was on family anxiety and depression and the relationship between PTSD as it related to a child's poor response to the disease process and compliance with medical regimens. They included the clinical variables of the sex of the parent, rejection, number of medications, frequency and number of hospitalizations, as well as the child's age at the time of transplant. They demonstrated the presence of PTSD among 52% of the mothers and 40% of the fathers, which correlated significantly with the trait of anxiety and none of the other variables.

These studies, although small in number, show that the impact of transplant on families does not end when a child leaves the hospital but has ramifications for the long-term health and well-being of the child and the child's family. How information is communicated is of utmost importance, as is building relationships with the families, including open honest dialogue. The perceptions of what is being said to parents and guardians and what is being heard need to be better understood. Health care professionals must be aware of mitigating factors that affect families and children and provide appropriate interventions to help them through the process of transplantation.

Communication and relationship building are instrumental in how professionals give information and how parents and guardians receive information that may affect short- and long-term complications and survival.[27] With an increase in the number of children undergoing intestinal transplants, we need to examine the long-term effects on the parents and build in resources to support parents and families over time. The following study is designed to hear the stories of parents and guardians as they prepared for their child's discharge and subsequent return home. The study will expand the body of knowledge on the lived experiences of parents and guardians of a child who received an intestinal transplant. It is the first phase of a multiphase study designed to look at the effects on parents of living with and caring for their child after transplant.

Methods

Design

This study used a qualitative approach that aimed to capture individual parents' and guardians' perceptions of their experience preparing for and providing care to a child after transplant surgery. After the study was approved by the institutional review board, potential participants were mailed a letter of invitation with a return form and envelope for them to indicate their willingness to participate in the study. Phone interviews were used for data collection. Each person who agreed to participate was interviewed once by using open-ended questions focused on the parent or guardian's perceptions of their needs and preparation for serving as a primary caregiver once a child was discharged from the hospital after isolated bowel transplantation or liver/bowel transplant (Table 1).

Parent interviews were tape recorded, transcribed verbatim, and verified for accuracy. The verbatim transcription of each interview was reviewed by the research team, using a recursive process to identify themes. Four nurse experts individually reviewed each transcript to become familiar with the narratives and to perform line by line coding as described by Spradley.[28] Then, the 4 nurses reviewed the transcripts as a research team, comparing their codes, thoughts, and observations

Table 1 Interview guide

Parental open-ended interview

Interview guide (after confirmation of willingness to participate in the study and audio recording)

What was it like getting ready to care for your child after dismissal from the hospital after transplant?

What was most difficult?

What was easiest?

What were your greatest needs at that time?

Who or what helped you the most?

What would you have liked to have seen done that was not?

What recommendations do you have as we prepare other parents to care for their child after transplant?

What was it like returning to your home after transplant?

What was most difficult?

What was easiest?

Who or what helped you the most?

Did you have extended family or friends who were available?

Did they help—why or why not?

The intent is to “hear” what the parents see as their needs.

about the interviews. Shared thoughts and general observations were recorded on flip charts separate from the data as common themes in the narratives were identified.

Various strategies to ensure the rigor of qualitative research were integrated into the team’s work. These included maintaining an audit trail, searching for negative evidence, and maintaining open communication among the members of the research team. If there was concern regarding the strength of the themes as they evolved, the team returned to line by line review of the data for clarification.

Sample

Because this was a first-phase pilot study to guide future research with parents and guardians of children who are organ transplant recipients, the research team made a decision to limit the sample for this study. All English-speaking parents and guardians of children who had received an intestinal or liver/intestinal transplant between 2000 and 2008 at our facility and who had returned home and subsequently died were invited to participate in the study. This sample population was purposely chosen so that remaining parents and guardians could be sampled for the next phases of research without concern regarding the effect of these interviews on future responses or willingness to participate in additional studies. Exclusion criteria included parents and guardians who did not speak English or whose child was dismissed for terminal care. The interviews focused on the parents’ perceptions of preparation for their role as a caregiver for their child at the time of discharge from the hospital and upon returning home. The interviews did not focus on the child’s death, and death was not an anticipated outcome for the child upon dismissal from the hospital.

Results

Thirty-nine letters of invitation were mailed to parents and guardians who met the study criteria. From those letters, we received 7 responses (6 accepting and 1 declining); 7 letters could not be delivered because a current address was not available, and 25 had no response. Of the 6 affirmative responses, 5 interviews were completed. One subject was unreachable after multiple telephone attempts. Demographic characteristics of the respondents are shown in Table 2. The participants did provide rich data for qualitative analysis, and it was determined that adequate saturation was reached to enhance our understanding of their lived experience and proceed with plans for future research.

The parents’ and guardians’ responses to the interviews were focused on their perceptions of (1) interactions with the transplant team, (2) interactions with their local health care systems, and (3) caring for themselves and their child. Commonalities within these responses included communications, relationships, and processes. Interviews did not focus on the death experience.

Perceptions of Interactions With the Transplant Team

Communications With Team

The transplant team at a large teaching hospital includes a variety of staff and students that may vary from day to day. The team includes a staff surgeon, transplant fellow, pediatric hepatologist, resident, nurse practitioner, nurse coordinator, social worker, pharmacist, dietician, staff nurse, and students in any of these specialties. Although bringing this number of professionals together for care of the child and family enhances the comprehensiveness of the care, the size of the team can be formidable to families not accustomed to such large teams. Families are informed about the composition of the team, but may be a bit “overwhelmed” by the numbers and/or hesitant to speak up in front of such a large number of people. Conversation among the team that provides education to students and provides for optimal care planning may be confusing to caregivers focused on the specifics of their child. The nurse coordinator often returns after rounds to try to clarify any confusion in the plan of care and make sure that individual family concerns are adequately addressed. Although the transplant team has multiple resources available for families and spends many hours providing education, the perceptions of what is communicated and how it is accomplished varies.

Table 2 Demographics of parents/guardians interviewed

	Parent or guardian				
Characteristic	1	2	3	4	5
Age group, y	50-69	19-30	19-30	50-69	31-49
Relationship to child	Foster mother	Mother	Mother	Grandfather	Mother
Annual income, $1000	40-50	<10	10-20	80-99	40-59
Education	Some college	Less than high school	Some college	4-year college	2-year college
Marital status	Widowed	Single	Married	Married	Married
Child's age	11 months	13 months	11 months	17 months	6.7 years
Type of transplant	Liver/small bowel/pancreas	Liver/small bowel/pancreas	Liver/small bowel/pancreas	Small bowel only	Small bowel only
Age at death	3.6 years	22 months	16 months	6. 4 years	7.4 years
Survival	2.7 years	9 months	5.5 months	5 years	9 months

Parents' and guardians' comments about activities occurring during transplant team rounds and individual communications with members on the team articulated their experiences. Team rounds seemed to be quite chaotic in the minds of the parents and guardians. "Ten to twelve people were on rounds all shooting questions back and forth and parents kind of get left aside." "'Ping, ping, ping' . . . they go down the hallway, slow down at our room and then they would leave and go 'ping, ping, ping' . . . and be gone." "Holy crap, the team was in and out and I wasn't able to ask my questions." "After rounds, I went to the Internet to review [what was said on rounds]." "When you guys made rounds, we had to step in and not try to take control but assert ourselves so that everybody took the time to let us soak it [the information] in." One parent subsequently wrote down agenda items and gave the team a list as they entered the room, asking each doctor to speak separately.

There was a sense from this group of parents and guardians that they had to "learn about" the transplant team and facility and vice versa. One parent noted that they had to "learn a new language"—it took some time but they needed to do that plus learn to be "more assertive" in dealing with the team to get the needed information. Another said they felt the "need to be heard" but did not know exactly how to say the things that they wanted to say. One parent felt that not all parents were "up to speed" with the medical problems or complexities and were afraid to ask questions for fear of "finding out the answers." Parents sensed some inconsistencies among the transplant team members. One parent or guardian noted that "if you didn't like the answer given by one team member, ask someone else, and the answer might change."

Relationships With Team

Parents and guardians observed that different health care providers had different styles and attitudes toward their child's care. One parent was appreciative of one physician who always stayed to answer questions, did not appear to be rushed on rounds, and finished the visit by asking, "Do you have any more questions?" Another physician was noted to be "nonchalant about things, and even more so when the patient was critically ill." This parent went on to ask the physician, "Can you take off your doctor jacket and put on your parent's mind and help me understand what you feel you would be doing if this was your child, if we need to think about something else regardless of how unconventional it is?" The response was, "I can't do that." In the eyes of the parent or guardian, this reaction made the physician seem less connected and concerned with the child and family.

There were impressions that the members of the rounding team, including the nurse coordinators and nurse practitioners, were knowledgeable and answered questions, although one parent stated that the nurse coordinator would come back after rounds "only if I looked puzzled." One parent observed that the transplant team became the "family" of the patient and the parents and guardians. "They [the parents and guardians] depend on you for that emotional and professional support." There were comments about the nursing staff. "A lot of the nurses were very helpful, as was the nurse practitioner. They had the most general overall knowledge of the people that I was able to talk to on a frequent basis." Other comments included, "The [staff] nurses were running around a lot with other patients. They were sometimes hard to get a hold of and able to answer only 1 question and then they were off." "The nurses were frustrated with me [during ostomy teaching]. They often wanted to do teaching when I was ready to vomit" (mom was pregnant). Also mentioned was that families turned to each other for guidance and support while in the hospital. "They lean on other families [for support], but another family member may not always be the best resource for them." Family support groups were recognized as an important resource for getting "good information," yet it was also noted that without input from health care professionals, there was a risk for parents to receive "bad information" from members of the support group.

Discharge Process at the Transplant Center

Health care providers know the importance of starting plans for dismissal early in the course of the transplant once patients are hemodynamically stable and their parents or guardians can focus on future needs. Transplant teams often have detailed plans for addressing the complex needs of the child/family involving multiple members of the transplant team. Team members include, but are not limited to staff nurses, coordinators, pharmacists, social workers, dieticians, physical and occupational therapists, child life specialists, and educators. Although standardized plans are in place, the individual needs of each child/family are taken into consideration as part of the discharge process. When asked about preparation for dismissal, the parents and guardians once again had a variety of responses. One said that in looking back, she would have done some more preparation through the Internet, looking up medications and "all that good stuff." "I feel like at that time [of discharge teaching], I was not ready to have that information." One suggestion was to give information about the medications on a more frequent basis. Some said there were no problems with the preparation for discharge: "I had done all of his care up to this point and had gone through this stuff already." "I had all the information when I came back [home]. Everyone told us everything very clearly so I had everything clear when I came back [home]." "The fact that I had a phone number and knew how to contact somebody [after leaving the hospital] who knew my child was very comforting."

Another parent said that "most of the nurses and doctors had given me the idea of what was what." "The nurse showed me really well how to do pretty much everything that I was going to have to do and supplied us with everything we needed once we were gone [from the hospital]." This parent had been doing all the child's care at home before the transplant and opted to "room-in" during the hospital stay, and thus felt that there were not a lot of new things to learn before leaving the hospital.

It was noted that the discharge process could be stressful because the staff nurses had other patients and were not always readily available at the time the parent had questions. The parent felt the need for more time to absorb all the information about the required care and responsibilities for the child. Of note, one parent was pregnant and did not always feel well enough to be actively involved in the care in an attempt to retain information such as wound and ostomy care.

Most of the parents and guardians had mixed emotions about actually leaving the hospital: "thrilled but apprehensive," "happy but nervous," "excited but nerve wracking," "fear of the unknown," and "expected the worst." The things they found helpful were phone numbers to key contacts such as transplant coordinators and home health care nurses. They prepared in ways most suited to their "style." One felt the need to make a detailed daily checklist/record that included such things as the times to do bathing, change dressings, give medications, check vital signs with a detailed record of what the child had in and out (food, tube feeding, fluids, ostomy output, and urine). There was a comfort level while staying in the vicinity of the transplant hospital but an eagerness to go home. Extended family was noted to be of help in transition as were the primary care physicians in the patient's local community.

Perceptions of Interactions With Local Health Care Systems

Communications/Relationships With the Local Team

The parents and guardians generally felt that they had good relationships with their local medical doctors. One said that the local physician "always gave me hope." The local physician was seen as prepared for the child returning home, but not for the severe problems that occurred once at home. "Over here, the [doctor] was good, but the doctors in the [intensive care unit] were thinking I didn't know anything about caring for a transplant patient. They didn't listen to me." One parent felt that the local physician was well prepared to care for the child but, when the child subsequently was admitted to the local intensive care unit (ICU); the ICU physicians were not as informed about the child and/or the transplant as was the primary care physician.

One parent felt like a "bother" to the local physicians. Another was fearful that something was wrong but was unable to describe the problem correctly. The parent felt a need to be "persistent" in returning to see the local physician multiple times before the child was admitted to the hospital. If the child was hospitalized locally, there was a general feeling that parents had to remind staff to give the medications on time and be constantly "vigilant" to make sure all care activities were performed. "They just treat the transplant patient like a regular patient. They shouldn't do that." The parents and guardians also questioned the local physician's knowledge about the appropriate timing to send the child back to the transplant center and wondered if they did not want to call the transplant center because of "fear of being seen as not skilled" enough to care for the patient.

Process at Local Health Care System

Families spend extended time during and after the surgery at the transplant center. They become familiar with the program's personnel, routines, and resources. In general, they had positive experiences attributed to the staff and the lifesaving nature of the procedure. Subsequently, this may have made the transition to home seem more challenging as the people, processes, and procedures changed. At home the parents had concerns about difficulty getting laboratory results back in a timely matter, including identification of types of infection. They noted problems in getting supplies from local home health care companies as quickly as they did when in the vicinity of the transplant center. They did not feel that the unique needs of their child were addressed in the same way as at the transplant center.

Caring for Self and Child

Parents and guardians seemed to have an intense focus on their child and the child's individual needs. They talked about always being "vigilant"—even when the child was hospitalized. "We need to care for them even if it affects adult friends or family relationships" and continued with the need to have "less regard for self" or to "sleep with one eye open, buck up and fight a little harder." There was a thought process to accept medical needs as normal and to organize self and home to support those needs. Yet, the parents felt that their children needed to experience normal childhood activities.

There was an awareness that the transplant did not "fix everything" and not to get comfortable because the "roller coaster ride is not over." Some had extended family members who were helpful, yet even with extended family, one parent noted the need to still do everything for the child "99.9%" of the time. This parent spent hours in the school system on a daily basis in case the teachers needed any help with medications or medical equipment. Another scheduled all activities around the child's medication schedule. Most did not express that their responsibilities were burdensome, and one noted that "being a little sleepy or a little tired is a whole lot better than the alternative." Another thought was, "God gave us the grace to get through . . . one day at a time." One parent was able to take time to "recharge her batteries" with the help of extended family and friends. Only one parent discussed having a significant health problem that was most likely related to the transplant experience and the subsequent death of the child. This parent had a clinical diagnosis of PTSD, was treated with medications and therapy, and had resolution of the symptoms. Two of the parents or guardians experienced the birth of a healthy baby after the death of their child who had a transplant.

Discussion

Transplantation is an expensive, complex process; financially, physically, and emotionally. Survival rates continue to improve, yet children and families continue to face unique stressors and challenges. Contributing to these challenges are the ups and downs associated with ongoing medical cares, multiple medications and complications, and the involvement of many different health care providers and systems in different locations. The experiences of the parents and guardians in this study suggest that we may be able to improve communications, relationships, and processes during and after transplant. By doing so we may be able to better address parental levels of stress and improve the quality of care provided to children and their families.

Transplant centers are often associated with large teaching hospitals. Therefore the daily team rounds include a number of health care providers: students, resident physicians, medical and/or surgical fellows, attending staff physicians, nurse coordinators, staff nurses, pharmacists, dieticians, and social workers. Although we may tend to see our teams as focused on patients and their families, we need to realistically ask ourselves if that is truly the perception of parents and guardians. The parents and guardians need to feel that the central focus of rounds is directed toward the individual patient and family and not confused by the general education of the students. It is imperative to ensure that all questions are asked and answered; that the family does not feel "rushed" to voice opinions, questions, or concerns; and that they understand the thoughts and plans initiated by the team.

Generally the discharge process begins once patients are hemodynamically stable and parents have the time to focus on future needs. Staff nurses continually provide education about medications, routine care such as bathing, catheter care, ostomy care, and complications of transplantation. The transplant coordinator sees the family on a daily basis to assess needs and has 3 or more individualized education sessions with the family to reinforce medication teaching, awareness of potential complications, identification of situations requiring immediate contact with the transplant team (or the local physician once at home), and phone numbers to reach the team at any time. The dietician frequently reviews formula and fluid needs, including how to properly mix different formula preparations and calculate fluid replacement requirements. The pharmacist also reviews each medication, mechanism of action, common side effects, timing of administration, and so on before the patient is discharged. During this time, the pharmacist has the actual medication containers, so parents have written information and can actually see the medications before discharge. Discharge teaching involves having multiple providers dispense complex information to parents. The information needs to be communicated in ways best suited to the learning styles of the parents and guardians and starts with developing a trusting relationship and supportive environment.

The local physicians are notified by the transplant coordinator when a child receives a transplant, any time a child goes back to the operating room or ICU, and when the child is discharged from the hospital and ready to return to the family's local area. A packet of information is prepared for all local physicians that includes the following: history and physical examination reports, discharge summaries, operative reports, biopsy reports, recent radiological reports, a list of medications, current laboratory results and a detailed letter about the specifics of caring for a child with a transplant, including how to deal with fever in an immunocompromised patient.

It is important for the transplant team to build trusting relationships with patients' families that include professional opinions and personalized care and support. Transplant teams should develop the appropriate processes to achieve optimal outcomes; building positive relationships with families; ensuring that they have information geared toward their specific needs; the time and environment to support learning about medications, acquiring technical skills, and recognizing signs and symptoms of infection and rejection; and the development of organizational skills to make a smooth transition to the outpatient setting and home.

The literature suggests that the long-term nature of transplantation and medical care after transplant can create more stress than is typically encountered by patients and their families faced with a single surgical event. As noted by Sactacroce,[24] chronic illness either in oneself or one's child has been viewed as a potentially traumatic event resulting in a continuum of stress reactions including posttraumatic stress syndrome and PTSD. The 3 categories of symptoms for posttraumatic stress syndrome include arousal (hypervigilance), reexperiencing, and avoidance. Some of these symptoms were possibly evidenced in the interviews. Hypervigilance was evidenced as parents voiced the need to do most of the cares, not asking others for help, making detailed charts of intake/outputs and/or who was coming and going from the child's room, and "persistence" in getting doctors to respond to their needs. That stress is an ongoing problem is reflected throughout the interviews of the parents and guardians. It starts in the hospital setting (and even before admission) and persists into the outpatient and home environment as families are forced to interact with different staffs, institutions, and processes. It is unknown why 25 subjects chose not to respond to the interview and/or if they had different experiences/or perceptions than the persons who chose to respond had. The death experience of their child may have played a part in the willingness of potential subjects to participate. However, given the review of the literature, a component of stress or posttraumatic stress may have influenced their ability or willingness to respond.

This study shows that stressors surround the transplant and discharge processes, yet many questions remain unanswered. As noted in the work by Lerret and colleagues,[16,27] effective communication and developing trusting relationships are key factors for future research. It may not be unexpected that parents and guardians would experience a different relationship with their local physician than with unfamiliar staff within local hospital systems. Smaller community hospitals may not have the ready access to resources afforded to patients at transplant centers, which may account for some of the parents' perceptions and stressors as well as transitioning families from one phase of transplant to another—hospital to outpatient to home. How we communicate, what we say, how it is said and how it is received, plus the written information we provide, is crucial to the success of these transitions and affects the relationship among transplant team, patient's family, and local care providers, and ultimately the care of the child transplant recipient.

More research studies focused on effective communication (both verbal and written), family perspectives, and building relationships will improve the way we provide care to children and families undergoing transplant. Going forward, a number of studies are proposed to build on our current findings and address some of these concerns. These studies include studies of ways to improve teaching of families about medication management, studies assessing caregiver burden in the adult transplant population, and longitudinal studies looking at the needs of adult and pediatric transplant patients and their families. No doubt ongoing studies in these areas will lead to additional questions and areas of investigation to promote quality care.

Study Limitations

The tendency is for authors to list small sample size as a study limitation. Although our sample included only 5 participants, adequacy of sample size in qualitative research is driven more by data saturation than by numbers. This study was started as a pilot to determine if we could reach saturation with the number of individuals who participated. After data analysis, the team was comfortable with the adequacy of our sample. The fact that the children of the persons interviewed had died could also be a concern, but this did not seem to materialize as a problem because the interviews were focused on preparation for discharge, not on the death. In addition, no parent or guardian was included if the death of the child had been recent. The limitation of data collection to patients treated at one institution is important to note. It is hard to determine if the experiences were specific to this transplant program. Replication by other facilities could help to address that concern. In addition, the future phases of this research program will provide quantitative data about stress and other concerns identified in the literature.

The demographics of the study participants may not be representative of our normal population base, which tends to be younger, unmarried, and have fewer financial resources, and that difference could influence the findings. Perhaps this segment of our population did not feel motivated to respond to the invitation to participate. Because the need for transplantation crosses all age, racial, and socioeconomic strata, we need to be cognizant of how transplantation affects people in all spheres of life.

Conclusion

This study adds to the body of literature about the experiences of parents and guardians after transplant and supports the need for ongoing research regarding how we can provide better care to the parents and guardians of transplant patients. From these interviews, we ascertain that parents and guardians of child transplant recipients do have experiences that could contribute to stress during the transplant process and the subsequent return to home. The stress involves perceived inconsistencies that exist within the transplant program itself (eg, multiple members involved with rounds, different team personalities and communication styles, use of medical terminology that may be difficult to understand, timing of discharge preparation), medical complexities of each individual patient, change in procedures and staff between the transplant hospital and the local hospital, mechanics of organizing home care resources, and the change in home routines once a child returns home. Parents report symptoms of acute stress in their need to provide most of the hands-on care, accept minimal help from family and friends, but maintain most of the control, sleep with one eye open, and wait for the next shoe to drop.

This study looks at the lived experience of parents and guardians caring for children after transplant. The subjects had a story to tell. It is our responsibility to listen, ponder, and continue to identify approaches for increasing the knowledge of care providers to improve outcomes and relieve the stress of the experience. The results of this study will contribute to future studies that will build on these findings.

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