

Constantly responsible, constantly worried, constantly blessed: parenting after pediatric heart transplant

Context—Very little research has focused on the long-term caregiving demands associated with parenting a child after a transplant or on the parents' perceptions of those demands.

Purpose—To describe parents' experiences parenting a school-aged child after heart transplant.

Design—Focused ethnography.

Participants and Setting—Eleven parents of children who had undergone heart transplant 2 or more years before the study were recruited from a large children's hospital.

Data Collection and Analysis—Parents were interviewed in a private location of their choice. Verbatim interview transcripts were analyzed by using content analysis and constant comparison.

Results—The parents described their experiences in positive terms, yet acknowledged hardships. Key themes included (1) constantly responsible, (2) constantly worried, (3) constantly blessed, and (4) coping with life. The identified themes provide direction for interventions to help parents cope with the experience of parenting a child after heart transplant. (*Progress in Transplantation*. 2009;19:122-127)

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With advances in health care, children with heart disease who require heart transplantation now live to adulthood. Although transplantation prolongs life, it is palliative, not curative, and brings with it a whole new set of responsibilities for parents caring for their children. Unfortunately, very little research has focused on the long-term caregiving demands associated with parenting a child after a transplant or on the parents' perceptions of caring for that child. After transplant, parents face many complicated short-term and long-term challenges. Most posttransplant care is now provided at home, which leaves most of the responsibility for care with the parents. The responsibility for medical care, parents' concerns about complications, and the normal tasks and concerns associated with raising a child can combine to place a great deal of stress on parents.

Literature Review

Most of the research focusing on parents of children after heart transplant has focused on the stresses

and needs of parents. Early quantitative work identified parental uncertainty about the child's future, demands on time and energy, and child happiness as key areas of family stress after heart transplant.¹ More recently, a second team of researchers² also used a quantitative approach to compare stress in families of children who had undergone heart transplant with stress in families of children who had cancer ($n = 52$). Parents of children after transplant indicated significant stress in the following areas: communication, managing the child's care, and balancing role function. Of note, although the stresses were more frequent for the parents of children after transplant, they perceived the stresses as less difficult than did the parents of children with cancer. In a larger study that included 204 families of children with heart disease, including 24 who had undergone transplantation, Wray and Maynard³ used a combined quantitative and qualitative approach to evaluate family needs. Twelve percent of the families of children after transplant desired more help with caregiving tasks.

In addition, the parents identified the need for additional medical information (side effects of medication, history, prognosis) and emotional support. Although few studies have focused exclusively on parents of children after heart transplant, research with other groups of solid organ transplant recipients has revealed similar issues and also identified additional concerns such as constant stress, financial worries, and family conflict.^{4,5}

Although the few studies reported in the literature give insight into parenting a child after heart transplant, parents' subjective perceptions of their experiences have received minimal attention. Because parents are increasingly responsible for their child's medical care, as well as the normal developmental parenting tasks, research is needed that provides in-depth insight into their experiences. This in-depth insight is critical to the development of interventions that support and empower parents caring for a child after heart transplant. Therefore, the purpose of this research was to describe parents' experiences parenting a school-aged child after heart transplant.

Methods

A focused ethnographic design permitted in-depth exploration of experiences from the emic (or insider) perspective and provided a cultural portrait of parenting after transplant.⁶ The parents shared rich knowledge of their experiences parenting a child after heart transplant. Therefore, this exploratory study was conducted to give voice to the parents.

Sample Selection

Data reported in this study were collected in a larger study^{7,8} that explored the quality of life of heart transplant recipients between 6 and 12 years of age. Parent-child dyads were recruited through the heart transplant clinic at a regional children's hospital in the mid-South. Recruitment advertisements were distributed to eligible dyads by clinic personnel. Those who expressed interest in learning more about the study then provided permission for the researcher to visit with them in the clinic. The researcher provided information about the study, answered questions, and obtained written informed consent. Parents were included in the project if they: (1) had a child 6 through 12 years old who had received a heart transplant at least 6 months prior and (2) were English speaking.

Data Collection

After informed consent was provided, participants completed a demographic questionnaire that provided background information such as the age of the child, transplant history, racial/ethnic background, family composition, and family income. In-depth qualitative interviews were scheduled at a time and place convenient to the parents.

The primary researcher, an advanced practice nurse with more than 10 years of experience caring for children and families after transplant, conducted all interviews. Parents were interviewed in their own homes or a private location at the hospital depending on their personal preference and their convenience. Interviews lasted approximately 1.5 to 2 hours, were audio taped, and were later transcribed verbatim. Each interview began with a broad opening question, which was followed by probe questions and follow-up questions. Although the interview guide⁷ was designed to elicit descriptions of their children's quality of life, the broad opening question, "Tell me about your child's life since the heart transplant," allowed parents to tell their child's story, which was intertwined with the parent's own story. Probe questions were used to allow parents to clarify or expand on information related to experiences. The researcher recorded field notes to supplement data obtained from in-depth interviews. The field notes focused on contextual observations.

Data Analysis

All transcribed interviews were first checked for accuracy and then entered into Ethnograph version 5.0,⁹ a qualitative data management program that numbers each line of text and facilitates sorting of data and coding of emerging themes. The research team used content analysis and constant comparison to identify raw data clusters. Two doctorally prepared pediatric nurse researchers (A.G., J.M.) coded data independently and then compared for consistency. Discrepancies in coding were discussed until agreement was reached. Raw data clusters were then combined to form broader themes. Intraparticipant analysis occurred as each transcribed interview was reflected upon, common themes identified, and relevance confirmed. Interparticipant analysis helped the researchers to identify those themes that were common across cases, as well as themes that were unique to particular cases. Finally, the data were analyzed for interrelationships between themes. Theoretical notes were kept throughout the analysis process to maintain an audit trail for conceptual decisions.

Results

An ethnically diverse sample (64% white, 27% black/African American, 9% Asian/Pacific Islander) of 11 parents participated in the study. The average age of the 9 mothers and 2 fathers was 34 years. All parents had at least a high school education, and 3 were employed at the time of the interviews. Nine parents were married and 2 were divorced. The mean age of the children was 9 years (range, 6-12 years), and all of the children had received their transplant at least 2 years before the interviews.

The parents described their overall experience parenting a child after heart transplant in positive

terms, yet they acknowledged hardships. In one parent's words, "I think our overall experience has been really, really positive. I mean if you have to go through it. Yeah, it's hard." They made it very clear that despite any hardship, "considering the alternative, it is more than worth it." Three key themes characterized the parents' experiences: (1) constantly responsible, (2) constantly worried, and (3) constantly blessed. As parents described difficulties they encountered related to being constantly responsible and constantly worried, they also described the ways in which they managed those difficulties. Therefore, a fourth theme, coping with life, emerged. Each of the 4 themes is discussed individually.

Constantly Responsible

Parents described every day as "so much responsibility." In the words of one father, "The work is on us. The maintaining his health. The parents are scheduled to be with him at home and do the job and to make sure that it works okay also. Your work never stops. It's continual." Parents described 2 distinct features of their constant responsibility including, the constant nature of the care and the constant vigilance required to keep their child healthy. All parents acknowledged the around-the-clock nature of their responsibility for their child's health and medical regimen. They also contrasted this to their responsibilities for their other children. According to the mother of a 6-year-old child who had received a heart transplant and a 2-year-old child without chronic medical issues,

Sometimes it's so nice with [2 year old] to not have to remember medicine every morning and every night. I can just put him to bed when he gets tired and not have to be thinking about medicine every 12 hours even on weekends...It's always on your mind and you're always thinking about the time and when you're giving it.

The degree to which this responsibility dominated parents' lives varied along a continuum from something they incorporated into their lives like "brushing your teeth" to something that controlled their lives. Parents in the latter category were in the minority and described the regimen as controlling their lives in these words,

It's a whole different life. You are regulated by your medicine, the times with your medicine. And the health issue. We cannot go here, we have to be careful...It's just something that kind of controls you. Something that you have to revolve your life around.

In addition to being constantly responsible, parents described around the clock vigilance required to

"keep my child healthy." This vigilance involved close monitoring for signs of illness and monitoring of the environment and people in the environment to avoid "situations that I feel are more germey." The major focus of the parents' vigilance was prevention and early detection of infectious diseases.

Constantly Worried

The parents also described "a lot of worry." Although they all described that they experienced more stress and worry "in the beginning" (meaning immediately after transplant), they reported that the worries never stopped completely. In the words of one mother,

You have those moments few and far between that make you still feel like you can just not have to deal with something just for a little while. But it never completely goes away. You know, it's in the back of your head the whole time.

Parents' worries focused on their child's health and medical regimen and their child's participation (or nonparticipation in some cases) in normal childhood activities. The mother of a 12-year-old girl described the health-related worries that all parents reported, "Once you get the transplant, you have to worry about infection, outside and inside. You have to worry about medication and you have to worry about the smallest little thing." They also described intense worrying when their child is sick and worrying after biopsy as they awaited results. Another parent described concerns about her daughter wanting to be like everybody else and "not have to do this" (meaning comply with her regimen). Although they primarily described worries about their child's state of health, parents also described worrying about their child's prognosis. The father of a 12-year-old boy reported, "It's a scary deal because you're wondering if everything is going to be all right." Parents were well aware of the risk of serious long-term morbidity:

Dealing with the possibilities of what could happen. Wondering if the smallest little thing happens and she gets sick or whatever—you know—"Oh God, I pray her heart's not rejecting." It wasn't just always totally in the forefront until you just absolutely had to deal with it, until she got sick or something like that.

Parents also described worries about the child's participation in normal childhood activities. Although these worries were less constant in nature, they were difficult for the parents. Most parents described decreased endurance, strength, and/or skill that limited their child's ability to participate in activities. Parents worried about

the effect of the limitations on their children and also experienced distress themselves. One mother said,

The kids are getting big enough now where it's not a thing where everybody gets to play and it's just for fun. It's getting more competitive and there are some aspects he's really good at. He just doesn't have the physical endurance. And it does bother me.

This same mother later indicated "it just broke my heart" when her son chose to leave baseball tryouts, rather than participate because "he knew he wouldn't get picked." For some of the parents, the worries were related to developmental or social delays that either restricted children's ability to participate in activities or resulted in participation with an age appropriate, but not developmentally appropriate, group.

Constantly Blessed

Although all parents described difficulties, they also described the blessings of "having my child with me." Although difficulties and blessings are being described separately here, they were intertwined for the parents. One mother described this so well by saying,

At first you're wondering, what did I do to deserve this? And then it turns into—what did I do to deserve to get all this good stuff that is happening? I get to bring my child home. . . . At first you think you are being punished and then you see people lose their kids and then it turns into you're being rewarded. You don't know what you did to be punished and you don't know what you've done to be rewarded, so you don't even know which one you are anymore.

For one mother, "Any day that I can wake up and look at her, that's great. All of 'em [days] are great to me. Tomorrow's gonna be better than today because I have her here." In addition to the blessing of the child's life, parents also described blessings because of what they had experienced. In the words of the mother of a 6-year-old, "It'll make you a better person and make your family a better family. You'll just have a new perspective on life and just be more thankful that you have what you have." Other parents described that their experiences helped them focus on what is really important. Finally, one mother described the blessing of knowing that her daughter's experiences had encouraged others to consider organ donation.

Coping With Life

As the parents described their experiences, they also identified how they coped with those experiences

parenting a child after transplant. They identified numerous coping strategies, including focusing on the positive, recognizing the lack of choices, faith, support from others, and balancing.

Focusing on the positive included several dimensions: "better than the alternative" and the recognition that there were others who were worse off. As previously discussed, they described any hardship as worth it to have their child with them. One mother described her other children complaining about taking the child who had received a transplant to the doctor and said, "I would tell my kids many times since we were coming up to doctor's appointments, we could be going to visit her in the cemetery." Parents were ever mindful, even many years after the transplant, that the alternatives were or had been "deal with life as it is" or the child's death.

In addition, as they described some of the difficulties associated with the medical regimen, such as restraining a toddler to administer medication, the parents identified that they had "no choice." Even though difficult at times, the parents recognized their responsibility for the medical regimen as "what needs to be done as a parent." Recognizing this as their role and that they had no choice other than to do it seemed to help the parents carry out the parts of the regimen that were difficult.

Parents also described key sources of support that helped them cope. These key sources of support included faith, family, friends, and the health care team. In the words of the mother of a 6-year-old boy, "There's a lot of things worse than your child having a heart transplant. You know, get all the support you can and say a lot of prayers and [have] a lot of faith." Family and friends were the most important sources of emotional support. Family members, most often grandmothers, also provided assistance with the care of the child after transplant and his or her siblings. This respite was very helpful to parents. However, because family and friends did not always understand the implications of transplant, other sources of support were especially important. The parents described needing support from the health care team and parents of other children who had received a transplant. According to one mother, "Parents need other parents to talk to. Somebody who can say life is good." The role of faith "in God" was described by over half of the parents. They described that their faith made them feel less helpless and gave them hope.

Finally, parents described learning to balance the care the child needed with the desire for the child to have a normal life. This balance was very important in parental decision making about activities for the child and family and helped them cope. They applied this process to decisions about birthday parties in public places, participation in family holiday activities, and

participation in school and recreational activities. Most often, the care the child needed revolved around protection from infectious diseases. As one mother stated, "It's little things like that. You want to shelter him from things like that [infectious disease risk] but sometimes you want to let him be a 6-year-old little boy."

Discussion

The findings of this study emerged from a larger study focusing on the quality of life of school-aged transplant recipients. Initially parents were not asked about their experiences, yet they discussed them as they discussed their child's experiences. Therefore, to give voice to the parents, probe questions were added to help us better understand the parents' experience. Parents in this study described both positive and negative aspects of their experiences parenting a child after heart transplant. Although they identified the constant nature of the responsibilities and worries as negative, the blessing of their child's life more than balanced those difficulties.

One of the key issues parents identified was the constancy of the responsibilities and worries, even though the children in the study had received their transplants at least 2 years earlier and were doing well medically. Previous research has described the stress experienced by parents related to the demands of their child's care.^{1,2} In this study, parents described a range of ways of managing the responsibilities for the child's care, from those who integrated the responsibilities into their life to those whose lives revolved around the responsibilities. Developing and implementing interventions to help parents integrate the responsibilities for their child's medical care into their lives are key to long-term mental health for parents, particularly because the inability to do so has been described as a predictor of posttraumatic stress symptoms and posttraumatic stress disorder.² The constant vigilance required to keep their child healthy was mostly focused on infection prevention. Although infection prevention is a critical aspect of home care, many of the parents described extreme measures, such as not allowing their child to leave the house for the first year after transplant or not allowing their child to play on public playgrounds. Professionals can help parents learn to protect their child yet promote a healthy lifestyle by giving specific, developmentally appropriate instructions for activities initially and with subsequent outpatient visits as the child matures.

The parents in this study described themselves as chronically worried about their child's health, the medical regimen, and the child's ability to participate in developmentally appropriate activities. Much of the worry centered around uncertainty related to risk of complications and long-term prognosis, as has been described previously.¹ Providing information that

helps parents realistically appraise the risk of complications and understand the long-term prognosis is critical. However, uncertainty will most likely persist, given the nature of the child's medical condition. Emotional support, particularly from other parents of children with a transplant, may help parents deal with that uncertainty. Parents also described worries about their child's participation (or the lack thereof) in activities related to the child's physical or social limitations. Encouraging parents to help children identify and participate in activities that they enjoy from an early age is very important. Given the limitations in endurance and strength described by these parents and the impairments in exercise performance described by other researchers,¹⁰ there will most likely be activities that the children cannot participate in both short and long term, and parents should be made aware of that. Cardiac rehabilitation should be a priority to help children develop the strength and endurance to participate in developmentally appropriate activities, which is both a key factor in children's quality of life after transplant⁸ and a key area of concern for parents.

Finally, parents desired more opportunities to interact with parents of other children with a transplant. Therefore, facilitating those interactions, either through formal support groups or more informal interactions, may be very helpful for parents. In addition, professionals can help parents recognize the importance of supportive relationships with family and friends and encourage them to maintain those despite the demands of their child's medical regimen.

Future Directions

Few studies to date have focused on the experience of parenting a child after transplant. This study provides a glimpse into that experience and provides direction for clinical intervention and future research. Particular attention is needed to assist parents with integrating their child's medical care into their daily lives and to help them obtain peer support. In addition, parents need ongoing education to help them accurately appraise the risk of infectious disease associated with developmentally appropriate activities.

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