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In my shoes: children's quality of life after heart transplantation

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Abstract

Background—Although heart transplantation has been offered for 2 decades to prolong the lives of children with end-stage heart disease, we know little about how these children view their lives, how they deal with their complicated medical regimen, and how the transplantation affects their quality of life.

Objectives—To examine the quality of life of school-aged heart transplant recipients and to identify the key factors they believe affect their quality of life.

Design—Focused ethnography.

Participants and Setting—Eleven children (7 girls, 4 boys) between the ages of 6 and 12 years (mean 9.1 years) who had received a transplant at least 6 months earlier were recruited from a large children's hospital.

Data Collection and Analysis—Semistructured interviews were conducted in private locations. Data were analyzed using content analysis and constant comparison.

Results—The children described their quality of life as “mostly good,” yet reported that life was “easy and not easy.” Ten factors that affected the children's quality of life were Doing Things/Going Places, Favorite School Activities, Hard Things About School, Being With Friends and Family, Doing Things/Going Places With Friends and Family, Interactions With Friends and Family, Taking Care of My Heart, My Body, The Transplant Team, and Other Health Problems. Based on similarities in meaning, these factors were combined into 3 themes: Doing What Kids Do, Being With Friends and Family, and Being a Heart Transplant Kid. The themes and factors can provide useful direction for interventions aimed at improving the quality of life for children after heart transplantation.

Notice to CE enrollees

A closed-book, multiple-choice examination following this article tests your ability to accomplish the following objectives:

1. Describe the focus of early research conducted around quality of life following pediatric heart transplantation
2. Identify the themes and key factors that pediatric heart transplant recipients believe affect their quality of life
3. Recognize the clinical applicability of the study findings in the care of pediatric heart transplant recipients

For the last 20 years, heart transplantation has prolonged the lives of thousands of children with end-stage heart disease. However, we have relied primarily on anecdotal evidence or data collected from parents and healthcare professionals to inform us about the quality of life (QOL) of children after heart transplantation. We know little about how these children view their lives, how they deal with their complicated medical regimen, and how the transplantation affects their QOL. This information is vitally important because although heart transplantation prolongs life, it is not curative, and pediatric heart transplant recipients now survive for many years after transplantation, with the 10-year survival rate exceeding 50%.¹ Unfortunately, we do not know what it is like for a child to live with a transplanted heart or with the burdens of lifelong immunosuppression, intermittent surveillance for rejection, disfiguring side effects of medication, and an ongoing risk of debilitating and even deadly complications.² Therefore, the purpose of this study was to investigate the QOL of pediatric heart transplant recipients to provide insight into the children's perspectives on life after transplantation.

Literature Review

Early studies of children's QOL after heart transplantation used functional status and psychosocial outcomes as proxies for QOL and relied heavily on data extracted from medical records or collected from parents or professionals. Using functional status to define QOL, researchers reported that 89% to 100% of child recipients participated in or were capable of participation in normal activities for age.^{3,4} In the mid-1980s, using emotional adjustment, self-care ability, exercise ability, and peer and family relationships as indicators, Lawrence and Fricker⁵ reported good QOL in 6-to 15-year-old heart transplant recipients (n=7). However, this team also identified behavior problems in more than 40%; somatic concerns in younger children; and problems with education, coping abilities, and social relationships in adolescents.

More recently, Wray et al⁶ examined the QOL of heart and heart-lung transplant recipients under 17 years of age (n=28) using standardized measures of behavior. This team found that problem behaviors at home decreased significantly after transplantation, but the incidence of persistent behavior problems remained at 20%, twice the incidence in normal controls ($P<.05$). Semistructured interviews with parents and older children revealed additional problems with isolation and self-esteem.

Other researchers have used QOL instruments rather than psychosocial outcomes as proxies for QOL. For example, Apajasalo et al⁷ used age-appropriate measures of QOL to compare QOL in 59 heart, lung, and kidney transplant recipients between the ages of 8 and 23 years to that in healthy controls. QOL for transplant recipients was equivalent to that of controls for all age groups except the group with children aged 8 to 11 years ($P=.03$ overall; $P=.002$ for 8- to 11-year-olds). Children in this group had poorer QOL than controls on the dimensions of eating, making friends, and concentrating ($P<.05$).

Pollock-BarZiv et al⁸ used the Pediatric Quality of Life Inventory and the Visual Analog QOL (VAQOL) scale to describe QOL in 8 heart transplant recipients between 10 and 18 years of age. Scores on the VAQOL indicated excellent perceived overall QOL, with a mean score of 8.7 of 10. The Pediatric Quality of Life Inventory total and subscale scores were equivalent to those of a normative, healthy pediatric population and higher than those reported by other chronically ill children. However, the lowest scores were reported on the physical and school health subscales, suggesting that at least a small portion of this group had difficulties with physical attributes and school that affected their QOL.

Most of the research on QOL has been quantitative. However, Olausson et al⁹ conducted qualitative interviews with 44 heart, lung, liver, or kidney transplant recipients between 4 and

18 years of age to elicit their perceptions of their lives after transplantation. Most children reported living normal lives that did not revolve around the transplant and stressed the importance of social support from friends, family, and health professionals. However, they also described concerns about being unable to keep up with peers and feeling different because of physical appearance and attention they received because of the transplantation. The researchers suggested further qualitative studies of more homogeneous age groups, such as school-aged children, to gain a deeper understanding of pediatric transplant recipients' lives.

In summary, previous QOL research in children after heart transplantation has focused on functional and psychosocial outcomes and collected data largely from medical records, parents, or professionals. Few studies to date have asked these children about their QOL. Because heart transplant recipients are surviving for many years, it is important to develop interventions to maximize QOL early after transplantation to provide the best possible chance for these children to experience full, productive lives. Developing such interventions, however, requires an understanding of the children's QOL and factors that affect it.

Objectives

The objectives of this portion of the study were (1) to describe the QOL of school-aged heart transplant recipients and (2) to identify the key factors that they believe affect their QOL.

Methods

Design

Because little previous research has described the QOL of pediatric heart transplant recipients from the children's viewpoint, this study used a qualitative approach—specifically, focused ethnography—because chronic illness is both a biologic and a cultural experience.¹⁰ In addition, pediatric heart transplant recipients and their parents comprise a cultural subgroup with shared beliefs, meanings, and experiences.¹¹

Setting and Sample

After obtaining institutional review board approval, the principal investigator recruited participants from a large pediatric heart transplant clinic in the mid-South using purposive sampling to increase the likelihood of obtaining a sample diverse in ethnicity, sex, age at transplantation, and years since transplantation. Heart transplant recipients included in this study were between the ages of 6 and 12 years old and it had been at least 6 months since their most recent transplant surgery. All participants were English speaking, resided with a parent, and were followed by the transplant clinic that served as a recruitment site.

The transplant team distributed study flyers to eligible participants on arrival at the transplant clinic and requested parental permission for a researcher to visit them in the clinic. The principal investigator then met with those granting permission to describe the study to the parent and child and to answer questions; the investigator obtained written consent from parents and written assent from children. Parents completed a demographic form providing general information about the child and family including age, income, and transplant history.

Qualitative Interviews

The semistructured interviews were scheduled on the basis of the parent's or child's preference. Seven were conducted in the child's home and 4 were conducted in a private hospital location. The principal investigator, an advanced practice nurse with more than 10 years of experience in caring for children after heart transplantation, conducted all the qualitative interviews to provide consistency. All interviews were audiotaped and transcribed verbatim. The

investigator began by asking each child to draw a picture of himself or herself on a good day. Two of the older children elected to “just talk” and not draw the picture. After asking each child to tell a story about his or her picture, the investigator interviewed each child using a guide adapted from one developed by Hinds and colleagues¹² to explore QOL in children with cancer (Table 1). The main questions were identical to those used by Hinds et al except for the diagnosis label.

The semistructured format allowed children to tell their stories in the manner they chose. Before the study, the interview guide was pilot tested with 6 healthy school-aged children to assess the developmental appropriateness and utility of the questions. All children in the pilot study provided relevant, detailed answers and insights into their perceptions of their lives. Therefore, the research team decided the questions were likely to be appropriate for children after heart transplant.

Data Analysis

The principal investigator entered descriptive quantitative data manually into SPSS 14.0 (SPSS Inc, Chicago, Illinois) and checked for accuracy before analysis. She checked interview transcripts for accuracy and then entered them into Ethnograph 5.0 (Scolari, Sage Publications Software Inc, Thousand Oaks, California),¹³ a data management program that facilitated data sorting. Qualitative data collection and initial data analysis were concurrent. Content analysis was used to identify raw data clusters. Then, using constant comparison, each data cluster was compared with other data clusters and combined to yield 10 global factors. Factors with similar meanings were combined to form 3 broad themes. Two senior nurse researchers with expertise in qualitative methods reviewed and assisted with the analysis.

Results

Findings are discussed in the following order: sample description, overall qualitative findings, and model case. The model case summarizes one child’s story, but her story illustrates the themes described by all of the children.

Sample Description

Eleven racially diverse children (7 girls, 4 boys) participated in the study (Table 2). Although the mean age of the children was 9 years, the majority had received transplants before 4 years of age and only 2 remembered the transplant procedure.

All children were attending school. Ten were attending community schools and 1 was home schooled. Four of the children were in special education classes or had cognitive delays by parent report. All children, including those with cognitive delays, were able to provide answers to most of the interview questions.

Qualitative Findings

Most of the children described their lives in positive terms, such as “mostly good” or “fun.” The only negative response came from a 6-year-old who wrote the word “shots” when asked what it was like to have a heart transplant. However, though mostly positive about their lives, all children discussed aspects of their lives that were “not easy.” Although chronological age and developmental delay affected the children’s descriptive abilities, most were able to describe both positive and negative aspects of their lives.

Numerous data clusters representing key factors affecting the children’s QOL emerged from the interviews. These initial clusters were combined into 10 global factors that children perceived as affecting their QOL: Doing Things/Going Places, Favorite School Activities, Hard

Things About School, Being With Friends and Family, Doing Things/Going Places With Friends and Family, Interactions With Friends and Family, Taking Care of My Heart, My Body, The Transplant Team, and Other Health Problems. On the basis of similarities in meaning, these factors were combined into 3 themes representing important QOL domains for school-aged heart transplant recipients: Doing What Kids Do, Being With Friends and Family, and Being a Heart Transplant Kid (Table 3).

Key Themes

Doing What Kids Do—This theme encompassed data related to opportunities and ability to participate in desired recreational and educational activities and comprised 3 factors: doing things/going places, favorite school activities, and hard things about school. The most important factor was doing things and going places. All the children identified this factor multiple times describing a range of activities including visiting amusement parks, playing outdoors, and watching television. They described both solitary activities and activities with friends and family. The children's good day drawings were consistent with this. Of the 9 good day pictures with discernible figures, 4 were of children doing things or going places such as riding amusement park rides or swimming. Two additional pictures drawn by children who identified enjoying playing outside were of outdoor scenes.

When the investigator asked the children if there was anything they would like to do but could not because of the heart transplant, 3 reported that there were no restrictions on desired activities. However, 5 children reported restrictions on participation in desired activities, including riding roller coasters (n=3), riding horses (n=1), and a future army career (n=1). The remaining 3 children had difficulty answering this question because of their young age or cognitive delay. Two older children described the impact of their limited physical abilities indicating that “the only thing kind of bad about it [the heart transplantation] is like PE or something; I can't do all the stuff that other kids can do.”

Favorite school activities were also part of this theme. All the children in the study were attending, but there were only rare references to academic performance, academic subjects, and behavior in school. Rather, the children's major focus was on enjoyable school activities such as playing on the playground, recess, special occasions at school, and “activities” such as music, art, and physical education. Eight of the 11 children identified favorite school activities. The 3 who did not identify favorite school activities all had developmental delays including cognitive and speech delays.

Six of the children described hard things about school. Some referred to difficulties such as being a grade behind the grade they were “supposed to be in,” homework limiting other activities, and hard work, but most of the hard things were related to being victims of teasing and bullying (n=5). One child described a good day as “whenever people don't try to bully me because I've had a problem with a bully at school for a while.” There were also references to being teased or bullied related to the transplant or medication side effects including “making fun because of my scar,” “kids picked on me in first grade since I took that cyclosporine and it made me really, really hairy,” and “people made fun of me when my gums were huge and my mustache was grown out too.”

Being With Friends and Family—The second most important theme encompassed relationships and time with friends and family and included being with friends and family, doing things/going places with friends and family, and interactions with friends and family. Friends were the second most frequent component of the good day drawings (Figure). Six children made references to being with or seeing friends and family members without mentioning activities or outings. Five of these 6 were girls, suggesting that this factor may be more important to girls than boys in this age range. Time with friends was described most

frequently, with the children describing good days as “seeing” or “hanging out” with friends, most often at school. Although less often than time with friends, the children also described the importance of time with family, including good days because “I get to go and spend the night with my grandmother” or “when my Dad is here” and bad days because of “not being able to see my brother a lot.”

There was an important connection between being with friends and family and doing things/going places. Ten of the 11 children identified the importance of doing things/going places with friends and family. The children described activities such as “go to the park as a family,” “play with my sister,” and “walk down the alley and play basketball with one of my friends.” One of the children described both being with and doing things with friends, saying good days are “seeing my friends at school, talking ... when I go over to their house I like to play games and I like to eat pizza and I like to play with their toys and stuff.”

The older children described supportive interactions with friends and family. For example, in discussing her scars, one girl said, “My Mom and I say that as I grow older, it’s not gonna be this big.” Another child reported that her mother supported her by bringing her medicine to school if she forgot to take it. The children also discussed friends whom they trusted or could talk to. One of the boys described tiring before the other children in physical education class and poignantly reported that “my friend tells me to wait for him so we can run together, side by side.”

Although the children focused primarily on positive time with family and friends, 5 children also identified negative interactions with family members. Most of these interactions were described by girls who complained about being pestered or bothered by their brothers. Two children (1 girl and 1 boy) used the term *bully* to describe an older sibling. When the girl was asked what her brother did to bully her, she replied, “He picks me up or tickles me.” The boy did not provide additional details. There was one reference to getting in trouble with a parent for being mean to a sibling “for no reason.”

Being a Heart Transplant Kid—Although these children valued normal childhood activities and time with family and friends, they also talked about some aspect of the heart transplantation or heart transplant regimen. The theme Being a Heart Transplant Kid included the impact of the transplantation, transplant regimen, and medical problems on the child, and included the factors taking care of my heart, my body, the transplant team, and other health problems. Even though children spent time talking about the heart transplantation, they made it clear that this was not the central focus of their lives. They acknowledged the transplantation and seemed to appreciate it as an important experience. They also worked to minimize it and made comments such as, “When you have the transplant, it’s not really that bad. It’s like any other surgery.” They all described aspects that were “easy and not easy.” However, 3 children reported that their good days and bad days were not related to the heart transplantation. Two others were quick to explain that negative events related to their heart transplantation only made things difficult for “a little while” or “just at recess.” This theme appeared to become more important with cognitive maturity because older children without cognitive delays identified the theme more often.

Only 2 children remembered their transplantation and could describe its immediate impact. A child who had required extracorporeal support before transplantation reported the following experiences after receiving the transplant: “I had to make all new friends and I didn’t really remember anybody. And I had to repeat kindergarten. I didn’t really know anybody except really my family. And I had to learn to walk and talk again.”

The other child was quite ill at home while waiting and reported, “I can breathe better now. When I run and all, I don’t get that tired. I can like run for a very long time and then just take a break.” She also reported with great excitement that she could now ride amusement park rides.

All children described taking care of my heart and the impact of those activities. The most prominent aspect of this factor was painful or scary aspects of medical management. The most commonly identified area of distress was needle sticks (n=6) for phlebotomy, injections, and intravenous lines. The children used language ranging from “I don’t like that” to “I hate blood draws. I scream.” Points of discussion included “hurt like crazy,” “it scares me,” and being stuck more than once. The second most frequently identified area of distress across was biopsies (n=3), including fear, pain when the pressure dressing was removed, and limited mobility immediately afterward. Two of the older children noted the negative impact of not being able to eat foods that they enjoy or that “other kids can eat like crazy.”

Medications were discussed factually: “I take medicine to keep my heart healthy.” However, an older child described difficulties adjusting to medication, saying, “I wasn’t really used to taking medicine,” and reported occasionally forgetting or being late. Two children (1 girl and 1 boy) discussed the negative impact of cyclosporine on their appearance, saying it “made me really, really hairy” and “I didn’t like what it did to my gums.” Also, they described being teased by others or not liking it when others talked about their appearance.

An 11-year-old girl described her personal responsibility for taking care of her heart and saw this responsibility as both positive and negative. She reported that a good thing was that “Not only do your parents have to make sure you do it, you have to be responsible. It’s just like being responsible for your pet or doing a chore.” Later, however, she reported that the “hardest thing” about the transplantation was that “Not only your parents have to do it, you have to take care of it too.”

In addition to the 2 children who described changes in appearance related to medication, 2 children discussed their scars. For 1 girl, scars were something people noticed. For the other, the scars were more problematic; she called them “battle scars.” Not only did other children ask about them and tease her about them, but she did not like looking “lopsided sometimes in the mirror.” Of note, most of the children who discussed negative aspects of their appearance were older than 10 years and female.

Three girls identified the transplant team as a positive aspect of their lives. They enjoyed going to the hospital or clinic because they got to see their physicians and nurses and loved “getting attention.” One child reported that the physicians and nurses had “become like family to me.”

Children also identified other health problems as affecting their QOL. One reported that his asthma bothered him more than anything related to his heart transplantation and discussed difficulties keeping up with peers because of the asthma. A second child described bad days when her gastrostomy tube leaked. One of the older children described multiple health problems including leg pain and gastrointestinal issues that interfered with school attendance, and other health problems that “no one can figure out.”

Model Case

Chelsea, an 11-year-old girl, received a heart transplant 2 years earlier. The following are excerpts from the investigator’s interview with Chelsea that provide in-depth insight into her life after transplantation. (Identifying data have been changed to protect her anonymity.)

[Having a heart transplant is] easy and not easy. I can breathe better now. When I run and all, I don't get that tired. I can like run for a very long time and then just take a break. [Good days are] like when we went camping with my mom and my granddad, me and my brother. We went to a little fair and we got to ride the rides. I couldn't do that before because of the sign [those with heart problems may not ride], even though I was tall enough, but I can do it now. [Good days at school are because of] the activities and science. I like art, I like library because you get to get books and I love to read chapter books. I like PE. But I've had bullies and there's one that really ticks me off. She skips counting [on the playground] and is hateful to me. [This makes bad days at school] just at recess. [Bad days at home are because of] Devil boy. He's half angel and half devil [younger brother].

As Chelsea talked, she spent a lot of energy tugging on the center of her tank top pulling it up over her sternotomy scar. She stated that even when she's wearing a shirt people can see her scar and she does not like telling people about it:

[...] usually when I tell those people like the kids and all [...] to me it's like, "We want to know so we can make fun of you" and that's usually what happens. They ask about, not because of the scar, because I had a heart transplant and people think I act perfect when I really don't. They think my life's perfect, but go ahead, get in my shoes. You'll see it's not perfect. You have to watch your fat and your sodium too. You have to take medicine and all and you have scars and all. I can't, like most kids can eat chocolate like crazy. And if you're like me, got all the scars. It kind of makes you look like you are lopsided sometimes in the mirror. I look in the mirror and I'm like UUUUGH. [Good things about being in my shoes are] not only do your parents have to help to make sure you do it, you also have to make sure you watch what you eat and all. You have to be responsible. It's just like being responsible for your pet or doing a chore. You have to be responsible for your heart. And that means not eating so much and drinking like at least 3 glasses of water a day and making sure you put sunscreen on because [...] if you're like me, you're usually gonna have a good chance of getting skin cancer. I actually look forward to [going to the clinic or to the hospital]. I admit it, it's the attention. I've done this forever, ever since I was like a kid and they found out I had it. They've become like family to me. Been there so long, I'm used to doing it. The only thing I wish is no IV. My veins are so small sometimes they have to stick me twice. Sometimes they can't get blood and they gotta stick me again.

Despite her feelings about her scars, this child worked to keep them in perspective. She also worked to minimize other health problems, including those that her mother emphasized as having a negative impact.

[With scars] you start looking at yourself and being sad and all. Sometimes I think, I try to think of them as my battle scars. Because I, because people were saying I was brave doing that and all to have battle scars. I take Miralax [for gastrointestinal problems] and yeah, I have stomach problems. Stomach sometimes queasy. Right now it's hungry [laughs].

This child wanted to do things and go places and be with people who were important to her. She acknowledged the heart transplant and her responsibilities because of it. However, she did not want that to be the central focus of her life. She wanted to keep the importance of her heart transplantation small, so normal childhood activities could dominate. She did not want people to talk about the heart transplant or, worse yet, tease her about it. She wished she could eat "junk food like crazy," but she recognized that she could not. Although the needle sticks bothered her, she still enjoyed visiting the clinic and seeing her "family" there. For Chelsea, the scars were a big deal, but she tried to put them into perspective by calling them battle scars and focusing on the fact that they made other people think she was brave.

Discussion

Much of the previous research on QOL in children has relied primarily on informants other than the children themselves, whereas this study provides important insights into the children's perspectives. As with the subjects in previous studies, the QOL of children in this study was reported as "mostly good." Most children were positive about their lives and valued the normal aspects of life (Doing What Kids Do and Being With Friends and Family). However, the subjects, particularly the older children, spent a lot of time talking about Being a Heart Transplant Kid.

This finding raises the question of whether the dominance of normal aspects of life reflected the children's actual versus their desired realities. It may also reflect that the children have a Shifting Perspectives Model of Chronic Illness¹⁴ and prefer and value aspects of their lives that keep wellness in the foreground. Although they were aware of their heart transplant status, they did not want it to dominate their lives and worked to avoid keeping illness in the foreground. Many of the negative factors related to the transplantation identified by the children in our study, such as pain and limitations, forced a temporary shift from wellness in the foreground to illness in the foreground. However, the children identified many positive factors such as supportive relationships and developmentally appropriate activities that supported wellness in the foreground.

Some of the factors that emerged from these interviews are supported by the work of other researchers,^{5,7,9} including normal childhood activities, peer and family relationships, the transplant team, scars, visible medication side effects, and other health problems. Being bullied, an aspect of hard things about school, is a known risk for children with chronic illness.¹⁵ However, the importance of being bullied to children's QOL after heart transplantation has only recently been recognized.¹¹

Both new factors and new aspects of some of the previously identified factors emerged. The new factors were favorite school activities, negative interactions (a component of interactions with friends and family), and taking care of my heart. Other researchers^{5,6} have discussed emotional adjustment, behavioral problems, and low self-esteem in relation to children's QOL after heart transplantation; however, those factors did not emerge in this study. This discrepancy in findings may be due to other researchers relying on parents or healthcare professionals as informants who as adults perceive those factors as important or perceive the abstract character of those concepts.

Other researchers⁹ have described the importance of feeling different from peers, including feeling different because of physical appearance. Although the children in this study described negative feelings about their appearance, they did not directly compare their appearance to that of their peers. Two children reported difficulty keeping up with peers in physical activities and 1 child reported being unable to eat foods that her peers could eat. However, the children in this study were more focused on their own inability than on feeling different.

Clinical Application

Although this study suggests that children's QOL after heart transplantation is "mostly good," interventions are needed to promote and support the factors that children identify as helping them have good days (doing things/going places, favorite school activities, being with family and friends, and supportive interactions). Such interventions would put wellness, rather than illness, in the foreground. Guidance to parents should focus on the importance of doing things/going places and being with friends and family, and assist them in interpreting activity recommendations in the least restrictive manner. Other important areas of intervention include

early return to school and efforts to minimize school absences, because school is a source of both enjoyable activities and important social opportunities.

These children were mostly positive about their lives, but they also identified areas that were “not easy,” including restrictions or limitations on activities, painful or frightening aspects of the medical regimen, changes in appearance, and being bullied. Interventions should help children identify and focus on activities in which they can participate while helping to eliminate unnecessary restrictions. Although the healthcare team cannot eliminate the need for needle sticks and biopsies, it is important to recognize that many children are distressed by these procedures. Evidence-based interventions are needed to decrease pain with such procedures, such as topical anesthetics for blood draws, injections, or phlebotomy. Many of the children in this study could point to where they got their blood drawn, so parents could apply the topical anesthetic to the site before coming to the clinic to decrease the likelihood of delays associated with this intervention.

Scars after transplantation are another area of concern of these children. Peer support can be an effective way to help children deal with the scars after heart transplantation. In addition, helping children plan how to answer questions about the scars may be helpful. In terms of medication side effects, the children in this study described improvements in appearance when they changed immunosuppressive agents from cyclosporine to tacrolimus. Therefore, advocating for tacrolimus over cyclosporine when medically feasible is important, particularly for children who are troubled by the visible side effects of cyclosporine. This intervention may reduce problems with other children who tease or bully them, as was the experience of 2 of the children in this study.

Because the children commonly described living with a heart transplant as “easy and not easy,” it may be informative to ask children during clinical visits what is easy and what is not easy for them. Such questions could elicit areas for individualized intervention to improve the child’s QOL. Finally, many school-aged transplant recipients received transplants in infancy and therefore did not participate in the formal education that occurred at the time of transplantation. Although healthcare teams educate the children during clinic visits, a formal education program for school-aged children may be helpful. These children’s discussions of their health and medical regimens indicated both interest and ability to understand the information. Thus, school age may be a prime time for an educational intervention.

Summary

Although this study focused on a small sample of heart transplant recipients from a single center, important information was gained about children’s perceptions of their QOL and factors that affect their QOL. However, there is much more to be learned. Further research is needed to explore the factors that affect QOL for school-aged heart transplant recipients, using larger sample sizes and participants from multiple centers. Longitudinal studies are needed to explore how QOL and the factors that affect it change over time. Finally, researchers need to develop and test interventions that improve QOL for this high-risk group.

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Figure.
"Good day" drawing by an 8-year-old girl.

Table 1

Interview guide

Lead in/global questions	Draw a picture of yourself on a good day. Tell me a story about the picture you drew of yourself.
Main questions	What makes a good day for you? What makes a bad day for you? Are there some things you would like to do that you can not? How has having a heart transplant been for you? Is there anything else you would like to say?

Table 2

Characteristics of sample (N = 11)

Characteristic	No. (%) of subjects
Age, y, mean 9.1 ± 1.95 (range 6–11)	
<10 years old	5 (45)
≥ 10 years old	6 (55)
Ethnicity	
White	7 (64)
Black	3 (27)
Native Hawaiian or Pacific Islander	1 (9)
Sex	
Female	7 (64)
Male	4 (36)
Reason for transplantation	
Congenital heart disease	10 (91)
Cardiomyopathy	1 (9)
Age at transplantation, y, mean 2.3 ± 2.75 (range 0.07–9)	
<1 year old	6 (55)
1–4 years old	3 (27)
≥5 years old	2 (18)
No. of daily medications per child	Mean 6 (range 4–14)
No. of children attending school	
Community school	10 (91)
Home school	1 (9)
Annual family income ^a	
<\$10 000	1 (10)
\$20 000–\$29 999	1 (10)
\$30 000–\$39 999	4 (40)
\$40 000–\$49 999	4 (40)

^aNot answered by 1 participant.

Table 3

Key themes and factors affecting children's quality of life after heart transplantation (N = 11)

Theme	Factors (No. of children)	Quotes
Doing What Kids Do	Doing things/going places (n = 11)	Good days: "I get to go to the water park," "I get to play video games," "I get to play basketball with my friends" Bad days: "There are people telling me there's something I couldn't do," "There are things I can't do," "Mostly I get tired before they [other kids] do"
	Favorite school activities (n = 8)	"I like art and library because you get to get books," "PE," "Play on [the] playground," "When we get popsicles for treats," "See friends"
	Hard things about school (n = 7)	"Hard because I have to work all day," "Having to do my homework because then I can't do anything else," "Math," "When people are mean like when they call you names or something"
Being With Friends and Family	Being with friends and family (n = 5)	Good days: "Hang out with my friends," "Go to school and see my friends"
	Doing things/going places with friends and family (n = 10)	Bad days: "People I can't see, like my grandparents, Dad, and brother," "When it's raining and I can't see my friends"
	Interactions with friends and family Supportive (n = 3) Negative (n = 5)	Good days: "Go fishing with my Grandpa," "Play games with my friends" "She is like my best friend that I always talk to" "My bubba bothers me"
Being a Heart Transplant Kid	Taking care of my heart (n = 11)	"The only thing I wish is no IV," "On biopsy days, I'm stressing, my head starts to hurt, and it's like really scary"
	My body (n = 4)	"Look lopsided in the mirror," "Really, really hairy," "Gums were huge"
	Transplant team (n = 3)	"Going to the hospital or clinic is kind of fun like when I go to see my nurses and all my different doctors"
	Other health problems (n = 3)	"My ankle pops and hurts in the mornings and sometimes it'll get so bad that I'll cry about it," "[A] good day is not having to worry about button leaking"