Exploring the information needs of adolescents and their parents throughout the kidney transplant continuum

Context — Adolescents are at higher risk for organ loss than are all other age groups, but no studies have been conducted to examine the specific information needs of adolescents. A better understanding of adolescents’ information needs is essential for developing programs tailored to their unique requirements.

Objective — To explore information needs of adolescents who have undergone kidney transplantation in order to inform development of an education program.

Design — A qualitative descriptive design was used. Focus groups (n = 2) were conducted by using a semistructured interview guide. Transcribed data were organized into categories that reflected emerging themes by using simple content analysis.

Participants and Setting — A convenience sample of 8 adolescents (50% female) who varied in age, donor type, and time since transplantation were recruited from a large Canadian tertiary care pediatric center.

Results — Adolescents articulated that the process of undergoing kidney transplant was very stressful and affected all aspects of their lives. In particular, adolescents identified 4 main stressors: changes in body image, wanting to be normal, pain, and breakdown in communication processes. The 2 strategies that assisted adolescents in coping with these stressors were (1) gaining knowledge about the transplantation process and (2) experiencing understanding through social support. They wanted information provided to them gradually throughout the transplant experience with choices given as to how they receive the information.

Conclusion — Adolescents were united in their call for information, self-management strategies, and meaningful social support to better manage their kidney transplant and prepare for transition to adult health care. (Progress in Transplantation. 2011; 21:53-60)

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The diagnosis of end-stage renal disease (ESRD) and the process of undergoing transplantation provoke anxiety and cause stress for children and their families.1 Transplant programs have focused on educating patients about their disease and treatment in order to decrease anxiety and promote the adoption of optimal health related behaviors (ie, treatment adherence) that are critical to improving long-term outcomes. However little research has been done to evaluate these educational programs and whether the information needs of children and their families are being met.2-4 No studies have been conducted to examine the specific information needs of adolescents with ESRD undergoing transplantation. This lack of study is remarkable, given that adolescents are at higher risk for organ loss than patients in all other age groups.5 Therefore, it is imperative that we gain a better understanding of the unique information requirements of adolescents in order to inform the development of programs that can help youth better manage their illness and promote transition to adult health care services.

Adolescence, alone, is a stressful developmental process even for physically healthy teens. Chronic illness further complicates life for adolescents and can adversely affect all aspects of their lives, including physical, cognitive, emotional, social, and vocational functioning.6-8 Adolescents are expected to assume greater responsibility for managing their illness. They must learn to adhere to recommended treatment as their growing independence and autonomy moves forward. However, adolescent adherence to disease management activities is less than optimal. Poor adherence
and inappropriate self-management behaviors may reduce the potential benefits of treatment and could ultimately lead to loss of their transplanted organ.

In summary, no information on the learning needs of adolescents undergoing kidney transplantation has been published, and only limited information is available about the learning needs of parents. In addition, little is known about parents’ or adolescents’ satisfaction with current educational initiatives. Furthermore, findings from the adult literature do not shed any more light on these learning needs. Therefore it is essential to determine what the learning needs of adolescents who are transplant recipients are by asking the end users of these programs. In addition, we need to explore the perceptions of adolescents regarding the most appropriate means and media for the presentation of that information.

Current Program

In 1990, the multidisciplinary team at The Hospital for Sick Children in Toronto, Canada, developed an educational program to prepare youth and their parents for the transplant experience. The aims of this program were to allow informed choice and decrease anxiety by providing information on what to expect across the transplant trajectory, promote active self-care, and teach strategies to prevent complications. Our education program uses a combination of teaching methods including interactive, one-on-one teaching with patients and families that is reinforced with printed material and pictures. The teaching methods used in our program are based on basic principles of adult education and learning. However, this program has never undergone a formal evaluation. Furthermore, it, much like many other education programs, has been developed by health care professionals with minimal involvement from the end-users of these programs. Families have not been asked if our teaching goals are congruent with their needs or tested in anyway to see if we are meeting our goals. Anecdotally, a handful of adolescents seem particularly uninterested in the information provided before transplantation to help to them prepare them for what lies ahead.

The purpose of this study was to explore the information needs of adolescents and their parents throughout their kidney transplant experience (before, during, and after transplant) and to determine whether the current kidney transplant education program at the Hospital for Sick Children is meeting these needs.

Methods

Research Questions

1. What are the perceived learning needs of adolescent patients with ESRD and their parents throughout the kidney transplant process?

2. What are health care professionals’ views regarding the perceived learning needs of adolescents patients with ESRD and their parents throughout the kidney transplant process?

Study Design

This study used a qualitative descriptive study design with focus groups. This design uses phenomenological inquiry, which encompasses qualitative approaches to understand a human phenomenon (i.e., perceived information needs) in a context-specific setting (kidney transplantation process). This method is the method of choice when straight description is required. A focus group method was chosen to capitalize on communication and shared interaction to generate data and gain insight into specific issues in more depth than may be possible in individual interviews.

Sample. Five focus groups were separately conducted, 2 with adolescents, 2 with parents, and 1 focus group with health care professionals. All adolescent patients invited to participate were between the age of 13 and 17 years at the time of the study, spoke English, and did not have any major cognitive impairment or psychiatric illness.

Study Procedures. This study received approval from the research ethics board. At each interview, consent was obtained and participants completed a brief questionnaire on demographic characteristics. Focus group interviews lasted between 40 and 75 minutes. All interviews were conducted in a private, quiet room in the hospital clinic or meeting room. Two investigators (M.K. and J.S.) and 2 research coordinators who were trained in focus group methods conducted the interviews. All interviews were audio taped and field notes were made during or immediately after the interview to record the interviewer’s impression of the participants’ responses to the questions and comfort level with the interview process.

A general introductory question was asked, followed by a broad question and probing to encourage the adolescents to elaborate on their experiences (see Table). Questions were compiled from the literature and the research team’s clinical experience. Finally, adolescents were asked about how they would feel about getting transplant management information from an Internet-based self-management program. This list of questions was modified during the course of the research in light of emerging themes. The interview guide was pilot tested for understanding and flow and to determine the quality of the information obtained.

Data Analysis. All data obtained from the focus group, including field notes, were transcribed verbatim.
Information needs of adolescents throughout the kidney transplant continuum

Table  Semistructured interview guide for adolescents

<table>
<thead>
<tr>
<th>Broad questions</th>
<th>Probes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Introductory question:</strong></td>
<td></td>
</tr>
<tr>
<td>1. Can you tell me how long you have had kidney disease</td>
<td>What has been the biggest challenge?</td>
</tr>
<tr>
<td>and what it has been like for you?</td>
<td>How have you learned to cope with these challenges?</td>
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<tr>
<td></td>
<td>Consider type of transplant (living or deceased donor)?</td>
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<tr>
<td></td>
<td>Consider impact on siblings?</td>
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<tr>
<td>2. What information do you think it is important for a teenager to know before</td>
<td>About the operation?</td>
</tr>
<tr>
<td>kidney transplant surgery?</td>
<td>About the surgery?</td>
</tr>
<tr>
<td>Please tell me more about that.</td>
<td>About the medicines that you will take?</td>
</tr>
<tr>
<td></td>
<td>About the time you will be in hospital?</td>
</tr>
<tr>
<td></td>
<td>About the follow-up that you will require?</td>
</tr>
<tr>
<td></td>
<td>About the complications of transplant?</td>
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<tr>
<td>3. What information do you think is important to know at the time of surgery</td>
<td>While in critical care unit?</td>
</tr>
<tr>
<td>and while in the hospital after the operation?</td>
<td>When you are back on the unit?</td>
</tr>
<tr>
<td>Please tell me more about that.</td>
<td>About your medications?</td>
</tr>
<tr>
<td></td>
<td>What information do you need about complications/what can go wrong?</td>
</tr>
<tr>
<td></td>
<td>About the time you will spend in the hospital?</td>
</tr>
<tr>
<td>4. What information do you think is important to know before discharge?</td>
<td>About your medications?</td>
</tr>
<tr>
<td>Please tell me more about that.</td>
<td>About the follow-up you will need?</td>
</tr>
<tr>
<td></td>
<td>About complications?</td>
</tr>
<tr>
<td></td>
<td>About how to assess your own health?</td>
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<td></td>
<td>About your diet?</td>
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<tr>
<td></td>
<td>About going back to school and other normal activities?</td>
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<tr>
<td>5. What information do you think is important to know when you come back for</td>
<td>Does this change as you get older?</td>
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<tr>
<td>follow-up?</td>
<td>Do you need reminders of the information you received at discharge?</td>
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<tr>
<td>Please tell me more about that.</td>
<td>If so, how often?</td>
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<tr>
<td>6. In summary, if you had to tell another teenager how to prepare for this</td>
<td></td>
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<td>process, what would be the key things important for them to know?</td>
<td></td>
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<tr>
<td>7. Thinking back to what you were told, please identify any gaps in the</td>
<td>Did you get the right information at the right time?</td>
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<td>information you were given—anything that you know now but would have liked to</td>
<td>Was anything a surprise to you after transplant?</td>
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<tr>
<td>have been told before.</td>
<td>Did you experience anything that you were not told about?</td>
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<td></td>
<td>Did you find the information overwhelming?</td>
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<tr>
<td>8. During the teaching, before and after transplant, you were given booklets</td>
<td>Would you have preferred it to be on a computer?</td>
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<td>with most of the information that had been discussed with you. Are there other</td>
<td>Can you suggest how information should be displayed on a computer</td>
</tr>
<tr>
<td>ways that you would have preferred to receive this information?</td>
<td>program?</td>
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<td></td>
<td>Would you like the computer to ask you questions to check your</td>
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<tr>
<td></td>
<td>understanding of the information?</td>
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<tr>
<td></td>
<td>Where would you like to be able to access this information from?</td>
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<td></td>
<td>What about a PowerPoint presentation?</td>
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<tr>
<td>9. Is there anything else that you would like to tell us about that you think</td>
<td></td>
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<tr>
<td>is important?</td>
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The qualitative interviews were analyzed by using simple content analysis. Using this method, data were analyzed manually. All data were read several times by at least 2 investigators to obtain an overall understanding, identify data codes, and ensure that all comments were carefully considered and included. Codes and themes were generated, categories were identified within the themes, and relationships among themes emerged. Finally, a qualitative expert (EdD prepared) was consulted to review themes and supporting quotes, which provided a further means of data triangulation. In this article, we report only on the adolescents’ perceptions of their information needs.

**Results**

Demographic and Disease Characteristics of the Sample

Of the 62 eligible participants, 15 agreed to participate in the study (response rate, 25%). Because of scheduling issues, medical acuity, and last-minute schedule changes, only 8 adolescents actually participated in the focus groups. Of the 8 adolescents who participated, the current mean age was 15 years and the mean age at the time of transplant was 10 years. The time elapsed since transplant varied: 1 teen was pretransplant, 1 was within the first year after transplant, 1 teen was between 1 and 3 years after transplant,
3 had received their transplant between 3 and 5 years earlier, and 2 teens had received their transplant more than 5 years earlier. All of the patients had experienced at least 1 complication, and 1 patient had experienced many complications.

Views on Transplant Experience

Adolescents described the transplant process as very stressful and articulated 4 major subthemes of stressors. Adolescents also articulated that they learned to cope with these stressors through gaining knowledge about the transplant process and developing meaningful social support (see Figure). To ensure anonymity, quotes are identified by participants’ study code and age.

The process of transplantation was stressful for all the adolescents. In particular, this stress related to body image, wanting to be normal, physical pain and discomfort, and breakdown in communication with the health care team. Each of these subthemes is described here with supporting quotes.

Body Image. The adolescents expressed how much they hated the adverse effects of their medications on their appearance. These changes not only affected their self-image and self-confidence but affected how others treated them. Adolescents provided examples of how they were teased or excluded because of how they looked. Some described going on crash diets to lose weight quickly. The following examples illustrate how 2 adolescents felt about their body image because of their medications. “I really disliked the bloating after prednisone. I got teased a lot too and it really bothered me” (Patient 5, age 17). The other adolescent stated “I was also chubby—looked like a chipmunk. Everybody would call me a “chipmunk” and I would yell back!” (Patient 15, age 17).

Wanting to Be Normal. Although part of this stress factor is related to the stress of the body image as just described; the stress of wanting to be normal goes beyond body image and appearance. Adolescents described the stress of not being able to take part in their normal routine. For example, they wanted to be able to attend school and spend time with friends. They described stress associated with special privileges or treatment that made them feel different from their class mates and they wanted reassurance that despite everything they have to go through, they could lead a normal life. The following examples illustrate how one adolescent felt about wanting teachers to treat him like other students who did not have a chronic health condition: “I got more attention than the other kids. . . . I didn’t really like it though. . . . I wanted to be like everyone else, a normal kid; I wanted to be treated equally” (Patient 15, age 17). Another described the effect that her different appearance had on her acceptance by peers: “Oh, well you don’t look like me so, like the popular kids. They’ll be like, ‘Oh you don’t look like me so, why are you coming near me?’ or ‘Why are you hanging out with me?’” (Patient 12, age 17).

Pain and Discomfort. Adolescents described stress relating to the pain and discomfort of surgery, the recovery process, and the various procedures such as a biopsy and starting intravenous catheters. This stress was mostly experienced at the time of the transplant or shortly after. For example, 2 teens stated: “It was just painful. . . . It’s just painful right after: I’m having bladder spasms, as my dad puts it, he’s never seen someone in so much agony” (Patient 4, age 16) and “When you were there, you had to have like a million little like tubes and everything and I couldn’t move” (Patient 14, age 14).

Breakdown in Communication. Adolescents described the stress of being unprepared for procedures or complications and not being listened to by the health care team. Adolescents described that this stress resulted from them not being told what to expect or because what they were told to expect did not happen the way it was explained. This situation is exemplified by 1 adolescent who stated: “I felt they didn’t prepare me enough. They said it wouldn’t hurt, but it did. They said I would be knocked out and I wasn’t” (Patient 5, age 17). In relation to not being listened to and having to have a biopsy, the same teen said “I wasn’t happy with the procedure because I felt they jumped to conclusions too quickly.”

Coping With the Transplant Experience

Adolescents articulated 2 main ways that they coped with the stress of the transplant experience: (1) gaining knowledge and (2) developing meaningful social supports. Gaining knowledge was further broken down into 2 subthemes: (1) the content of the
information they felt appropriate and (2) the process: how they wanted to receive the information.

_Gaining Knowledge._ The participants clearly articulated their interest in acquiring more knowledge about the transplant experience. Most indicated that they primarily learned about what to expect about the transplant experience from their parents and members of the health care team. Overall, they understood and recognized the importance of developing knowledge about their disease and the transplant experience in order to become more independent and to advocate for themselves. In order to do this, they wanted specific information and made suggestions for how this information should be provided.

1. Content: Adolescents overwhelmingly said that they wanted to know everything there was to know about their disease and treatment. They wanted to know about (a) potential complications; (b) side effects of medications and procedures; (c) how to maintain a healthy life style; (d) what the expected outcome was for transplant recipients; (e) prognosis for future and impact on school, job, and family; and (f) information about transition to adult health care services. This need for information was exemplified by 1 patient, who stated “All possible outcomes, like everything that can happen, not just some of it” (Patient 7, age 14). Another teen commented that “I think, definitely about the side effects of the drugs and how they make you physically change and that it’s something that’s really serious” (Patient 5, age 17). They wanted some reassurance that what they were eating and drinking and the types of physical exercise they were doing were positively enhancing their health.

They also thought it was important to let others, who were about to embark on transplantation, know of the serious consequences for not adhering to prescribed medication and other treatment regimes and that failure to comply might negatively affect their health outcomes. For example, 1 adolescent stated that it would be important to “Show them what happens if you don’t take your medication” (Patient 7, age 14). They also wanted to hear stories of hope, that despite all the things they need to learn and do to keep their transplanted kidneys healthy, that they could lead a “normal life.” One teenager, when asked what the most important thing was that he would tell another teenager before a transplant said: “Just listen to music, talk to friends, hang out, have a life that you should, don’t let it, even if you have a kidney transplant, don’t let that hold you back” (Patient 15, age 17).

2. Process: The adolescents described a wide variety of ways that they would like to be educated about the transplant experience. The overarching theme was that they wanted a variety of options on how they received this knowledge. For example, they felt that some teens would want to see pictures of other teenagers undergoing transplant, watch video clips of the transplant surgery, and hear about the complications other patients had experienced, while others teen would not want those things. As one teen said,

I think you should get the decision if you want to see it or if you don’t. Right, so if you want to see the picture, you want to face the facts, sort of right? You can ask to see it, if you don’t, then they can just tell you (Patient 12, age 17).

The teens felt that if information was provided on a Web site or other computer-based teaching program, then teens could choose the medium that met their individual learning style. They felt that a Web-based program would ideally lend itself well to tailoring of information. For example, it could provide a tour of the hospital and step-by-step procedure of what would happen during each phase of the transplant experience, introduce the transplant team members and allow the teens to hear real-life stories from other transplant recipients. However, the teens did not want this at the exclusion of the one-on-one time with the transplant team members, as they felt this was also helpful.

The second main thrust of this subtheme was that the teens wanted to receive the information gradually. They did not want to be overwhelmed with too much information at once. As 1 teenager said “I would rather come back more than having it all thrown on me, and just going crazy from thinking about it too much... not being able to process it” (Patient 4, age 15). Another teenager expressed that it is important for children, who receive a transplant at a young age, to know what they have gone through and understand more about their condition and experience, gradually as they age. He stated:

Well if they’re at a young age, like when I got it at 5, like they probably—10 years old. He deserves to know something that he’s gone through. So, they should tell you slowly, bit by bit, what’s going on, why you’re in hospital, why—why it’s going on (Patient 15, age 17).

_Developing Meaningful Social Support._ The adolescents stated that development of meaningful social support helped them cope with transplantation. They described 2 main types of social support: instrumental and emotional.

1. Instrumental: Adolescents described the need to have access to physical or tangible resources. The
supports they described were the use of Ronald McDonald house to live and go to school in, MSN (Microsoft Network), and their parents. One teen described how her parents acted as instrumental support “My parents helped me a lot in the beginning with the meds, just to remind me” (Patient 7, age 14) and another described how his grandmother had helped him cope with the diet restrictions:

Well, with the diet restrictions, it helped a lot since my uh, my dad’s twin brother had it when he was about 5 or 6… So my grandma and he grew up around it; they knew what to avoid, and all that stuff (Patient 4, age 15).

2. Emotional: These supports provide the adolescents with encouragement and development of self-worth. The supports they described as friends, sometimes parents, and the adolescent medicine physician. One teenager said “And now I just surround myself with people that—like close friends from a long time ago. And my boyfriend. And they all really support me” (Patient 5, age 17). Another teenager described:

Uh, I basically forget about everything. Like now, I just, live my life. Like wake up in the morning, go to school, and come home, and sit around. And on the weekends, hang out with my friends (Patient 7, age 14).

Discussion

In this qualitative study, adolescents clearly articulated the stressful effect that transplantation had on their lives. Body image, wanting to be normal, pain, and breakdown in communication with the health care team emerged as the main stressors of adolescents who had received a kidney transplant. Adolescents coped with these stressors by obtaining knowledge and developing instrumental and emotional support. The adolescents wanted access to all the relevant information about their condition and treatment and they wanted to be able to access the information gradually so as not to be overwhelmed. They indicated that they wanted choices in how information was provided and suggested that many of their needs could be met with the development of an interactive Web-based education program although they felt that one-on-one time with the health care team was also important. Finally, adolescents also wanted opportunities to network socially with other teens who had also received a transplant.

Similar to our findings, a review of the literature regarding the burden of adolescents living with a chronic illness showed that the difficulties experienced were related to developing and maintaining friendships, being normal/getting on with life, experiences of school, and relationship with health care professionals.13 A study10 conducted in adult kidney transplant patients examined stresses associated with the adverse affects of immunosuppression and found themes very similar to those expressed by participants in our study: pain, weakness, weight gain, facial changes, and depression and anxiety. Researchers have also found that educational, cognitive, and social deficits as well as body image concerns contribute to difficulties in psychosocial adjustment in adolescents with ESRD.17-19

Taken together, these findings highlight the stressors that youth with ESRD experience during and after kidney transplant and the need for health care professionals to provide youth with information about the specific disease processes and treatments to promote optimal psychosocial functioning.

The adolescents in the study described coping with their stress by becoming informed and by developing emotional and instrumental supports. The importance of developing social support to aid psychological adjustment has been described in a variety of studies looking at chronic illness in adolescence.20-42

Whether as emotional or instrumental support or both, the literature suggests that support from parents, health care professionals, and peers has improved adherence, health, and well-being in adolescents with chronic illness.23,25 Snetten and colleagues27 conducted a study to explore coping strategies in adolescents with ESRD compared with healthy youth. Adolescents with ESRD in that study described a variety of instrumental and emotional supports that they used significantly more than healthy adolescents; specifically, venting feelings, seeking professional support, and relaxing. Avoidance types of coping mechanisms, which typically lead to poorer outcomes, were more commonly used by younger adolescents with ESRD.

The literature suggests that personal resources also influence ability to cope and younger adolescents tend to have less developmental competencies and ability to act independently.28 These findings highlight the importance of helping adolescents undergoing transplantation to develop healthy coping skills. Such help can be provided in a number of ways: peer support, teaching and support from health care professionals, and teaching active rather than avoidant or passive coping skills (problem solving, anger management), which will strengthen adolescents’ ability to deal actively with the transplant experience.

Teenagers in our study had clear ideas of how they wanted information provided to them (interactive, choice, personal stories) and that they wanted the information provided gradually over the course of the transplant experience (before, during, and after). Barriers such as distance from the hospital, busy work and school schedules, poor state of health, and multiple
family responsibilities reduce the ability of teenagers and family members to come to the hospital frequently for discussion, education, and support regarding transplant.

Recent statistics on Internet use in teenagers indicate that 87% of teenagers 12 to 17 years of age use the Internet, 51% use the Internet on a daily basis, and 31% use it to access health-related information. Therefore, the Internet is an acceptable medium to improve the accessibility and availability of transplant education and self-management strategies for teens with chronic health conditions. In addition, it can offer more visual or graphic options for receiving information compared with text-based materials, and teenagers would then have an individual choice as to how they receive this information. Current information available on the Internet is mostly aimed at adults and may contain inaccurate information and be too complex and difficult for teenagers to understand. An Internet-based educational program would overcome some of the current barriers and enable teens to access it when they are ready to learn.

Few self-administered multimedia programs for adolescents with chronic illness have been developed and validated compared with such programs for adults; however, some early evidence indicates that computer-based self-administered treatments for children and families have produced positive results in children with asthma, diabetes, and headaches. Teenagers suggested that in addition to providing an opportunity to obtain information about their disease and treatment, such a program would provide an opportunity for peer support by means of discussion boards, narration of personal experiences, and mentoring. Teenagers were very clear that although they felt a Web site would be helpful, they did not want it to replace the face-to-face time with their health care team members. Time still must be set aside at the hospital to discuss what has been learned and to answer any questions generated. Providing written material, one-on-one education time with health care professionals, and a Web site would allow individual teens to choose the method of learning they prefer.

Limitations

A few potential limitations of our study must be addressed. The study was conducted at 1 tertiary pediatric transplant center and the sample was relatively small, which could be considered a threat to the generalizability of the results. Although the sample was small, it was quite heterogeneous in terms of age range and time since transplant, and costs prohibited us from using multiple transplant centers. We would encourage other centers to consider conducting similar needs assessments. However, the rigor of this study was enhanced by the use of multiple data sources—parents, adolescents, and health care professionals—and by using several researchers for data analysis, including an expert qualitative researcher. This triangulation provided validity checks and reduced the likelihood of bias.

Conclusion

Exploring the information needs of adolescents as they undergo transplantation is a necessary first step in creating an evidence-based education tool for teenagers. Technological advancement and the wide availability of computers makes an Internet-based education tool the ideal medium to meet this need. Furthermore, these resources must include information on how to receive and how to develop instrumental and emotional supports as well as self-management strategies. Such an educational tool will enable adolescents who have received a renal transplant to take more control over managing their illness. The next step will be to develop and test such a program's ability to improve health outcomes.

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