Review: Cognitive and Psychological Outcomes in Pediatric Heart Transplantation

John F. Todaro, PhD, Eileen B. Fennell, PhD, Samuel F. Sears, PhD, James R. Rodrigue, PhD, and Alaina K. Roche, BA
University of Florida College of Health Professions

Objective: To review empirical literature investigating the cognitive and psychological effects of pediatric heart transplantation.

Methods: Electronic and library searches were used to identify empirical studies examining the cognitive and psychological effects of pediatric heart transplantation. Only studies investigating cognitive or psychological outcomes, either prospectively or cross-sectionally, were reviewed.

Results: Preliminary findings suggest that children and adolescents generally functioned within the normal range on most measures of cognitive functioning post-transplant. However, a complicated transplant course caused by infections or rejections may place these recipients at increased risk for cognitive difficulties post-transplant. Studies also suggested that approximately 20%–24% of pediatric heart transplant recipients experienced significant symptoms of psychological distress (e.g., anxiety, depression, behavior problems) during the first year post-transplant.

Conclusions: Research suggests that some recipients are at risk for cognitive and psychological difficulties post-transplant and may require additional academic remediation and/or psychological intervention to address these challenges. Given the limited number of empirical studies available at this time, continued research investigating cognitive and psychological outcomes following pediatric heart transplantation is needed.

Key words: pediatric heart transplant; cognitive functioning; psychological functioning; transplant outcomes.

Heart transplantation has become the treatment of choice for children and adolescents with end stage heart disease. According to the Registry of the International Society of Heart and Lung Transplantation, approximately 3,500 pediatric heart transplants have been performed worldwide since 1982 (Boucek et al., 1997). Medical improvements in heart transplantation have yielded overall 1-year survival rates of 75% to 85% (Boucek et al., 1997; Shaddy et al., 1996) and 4-year survival rates of 60% to 65% (Hosapud, Bennett, Keck, Fiol, & Novick, 1997) in children and adolescents. To date, however, much of the heart transplantation literature has focused on adult patients. Although research examining medical outcomes in pediatric heart transplantation is beginning to move forward, relatively few studies have examined the cognitive and psychological
impact of transplantation in children and adolescents.

Pediatric heart disease must be conceptualized differently than heart disease in adults due to the differing etiologies of children's heart disease. In adults, the most common cause of heart disease is coronary artery disease secondary to atherosclerotic processes. In children and adolescents, however, the most common etiologies for coronary illness are congenital heart disease due to malformations of the cardiovascular system or cardiomyopathy (Baron, Fennell, & Voeller, 1995). In most cases, open and closed heart surgeries are performed to correct these malformations.

Researchers have investigated the cognitive effects of pediatric open-heart surgery. Cognitive outcomes following open-heart surgery have suggested that longer duration of hypoxic states secondary to chronic heart disease (Aram, Ekelman, Ben-Schachar, & Levinsohn, 1985; Newburger, Silbert, Buckley, & Flyer, 1984; O’Dougherty, Wright, Levenson, & Torres, 1985), deep hypothermic arrest procedures (Bellinger et al., 1995; Miller, Mamourian, Tesman, & Baylen, 1979), and longer duration on the cardiopulmonary bypass pump (Branthwaite, 1972; Dickson & Sambrooks, 1979) were associated with greater cognitive and developmental delays. All of these risk factors share the fact that decreased oxygenation, either during the course of chronic heart disease or secondary to surgical repair procedures, increases the probability that children and adolescents will experience cognitive and developmental deficits.

Psychological outcomes following pediatric open-heart surgery have also been investigated. These studies have reported that pediatric open-heart surgery recipients may be at greater risk for developing psychological difficulties post-surgery than same age healthy peers (Casey, Sykes, Craig, Power, & Mullholland, 1996; Utens et al., 1993). These difficulties included both internalizing and externalizing disorders and may, ultimately, interfere with normal academic and social development. However, relatively few studies have examined the psychological functioning of pediatric open-heart surgery recipients, which limits our ability to draw definitive conclusions.

Given that open-heart surgery and transplant recipients experience similar disease etiologies and undergo, to some extent, similar medical and surgical procedures, pediatric heart transplant recipients may experience similar cognitive and psychological difficulties. Moreover, the course of transplantation, including the diagnosis and decision-making stage, the waiting period, transplantation and hospitalization stage, and the follow-up and recovery periods (Greene & Sears, 1994; Kuhn, Davis, & Lippman, 1988), may subject children and adolescents to additional stressors more problematic than those experienced by open-heart surgery recipients. The primary goal of this review, therefore, is to summarize the current research pertaining to cognitive and psychological outcomes in pediatric heart transplantation. This review begins with a discussion regarding the cognitive and psychological functioning of pediatric heart transplant recipients. Suggestions for future research pertaining to the cognitive and psychological impact of pediatric heart transplantation will also be provided.

Cognitive Functioning in Pediatric Heart Transplantation

The effects of heart transplantation on neuropsychological functioning in children have not been extensively studied (Table I). Wray and Yacoub (1991), in a preliminary report, compared the neuropsychological functioning of children receiving heart transplantation \( n = 52 \) to children receiving alternative open-heart surgeries \( n = 52 \) and to normal, healthy peers \( n = 45 \). Children less than 5 years of age receiving heart transplantation performed within the average range on measures of development using the Ruth Griffiths Developmental Scales (RGDS; Griffiths, 1970). These researchers noted, however, that RGDS scores for children who received transplantation were significantly lower than those for the healthy control group. Children older than 5 who received transplantation also demonstrated developmental scores in the average range, despite scores being significantly lower than both comparison groups. In addition, transplant recipients demonstrated lower grades at school and significantly higher absentee rates than both comparison groups. Although the finding that poorer school performance in transplant recipients was of concern, these researchers reported that lower academic performance may have been attributable to missing more time at school.

In a second report, Wray, Pot-Mees, Zeitlin, Radley-Smith, and Yacoub (1994) examined the effects of heart and heart-lung transplantation on development, cognitive functioning, and behavioral
status in 65 children diagnosed with various coronary anomalies. The performance of transplant recipients was compared to children receiving other corrective heart surgeries ($n = 52$) and healthy children ($n = 45$). Children who received transplantation between the ages of 0 to 4.5 years performed in the normal range on the RGDS; however, on all of the developmental subscales, these recipients performed significantly lower than the healthy control group. Transplant and open-heart surgery groups did not differ on any of the measures of development. For children ranging in age from 4.6 to 16 years of age, transplanted children demonstrated lower mean IQ scores than both of the two reference groups as measured by the British Abilities Scales (BAS; Elliot, 1983). Performance on measures of specific academic abilities, including arithmetic and reading, were not statistically different from either reference group. Notably, children who received transplantation performed worse than the healthy group on measures of spelling achievement.

Researchers have also investigated the developmental functioning of infant heart transplant recipients. Trimm (1991) examined language, audiologic, psychomotor, and mental development in 54 infant heart transplant recipients ranging in age from 1 week to 4 months. On the Sequenced Inventory of Communication Development (SICD; Hedrick, Prather, & Tobin, 1984), a measure of language development, 10 out 13 infants (77%) demonstrated normal language functioning (77%) and audiologic functioning (90%). Repeated administrations of the BSID occurring every 4 months for a total of 30 months demonstrated stable psychomotor and mental development scores falling in the average range. Variability in psychomotor development was associated with greater rejection episodes requiring steroid medication usage.

### Table 1. Cognitive Functioning in Pediatric Heart Transplantation Recipients

<table>
<thead>
<tr>
<th>Study</th>
<th>$n$</th>
<th>Age of child</th>
<th>Measures</th>
<th>Time of assessment</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wray and Yacoub (1991)</td>
<td>149</td>
<td>Average age</td>
<td>RGDS</td>
<td>Average time of assessment</td>
<td>Study compared three groups: transplant ($n = 52$), open-heart surgery ($n = 52$), and healthy control group ($n = 45$). Although scores were in the normal range, transplanted children demonstrated significantly greater signs of developmental delay than healthy controls. Transplanted children $&gt;5$ years of age demonstrated significantly greater developmental delays than both other groups.</td>
</tr>
<tr>
<td>Wray, Pot-Mees, Zeitlin, Radley-Smith, &amp; Yacoub (1991)</td>
<td>162</td>
<td>Average age</td>
<td>RGDS, BAS, SGST, RBC, RSAB</td>
<td>Average time of assessment</td>
<td>In this follow-up study, three groups were compared: transplanted ($n = 65$), open-heart surgery ($n = 52$), and healthy control group ($n = 45$). In general, cognitive functioning across groups was in the normal range. However, transplanted children $&lt;4.5$ years demonstrated greater developmental delay than the healthy control group. No differences were observed between two surgical groups. Transplanted children (4.6–16 years of age) demonstrated lower intellectual functioning than the two reference groups and worse spelling ability compared to healthy controls.</td>
</tr>
<tr>
<td>Trimm (1991)</td>
<td>54</td>
<td>Ages ranged</td>
<td>SICD, BAER, BSID</td>
<td>Average time of assessment</td>
<td>Transplant recipients demonstrated normal language functioning (77%) and audiologic functioning (90%). Repeated administrations of the BSID occurring every 4 months for a total of 30 months demonstrated stable psychomotor and mental development scores falling in the average range. Variability in psychomotor development was associated with greater rejection episodes requiring steroid medication usage.</td>
</tr>
</tbody>
</table>

SICD = RGDS = Ruth Griffiths Developmental Scales (Griffiths, 1970); BAS = British Abilities Scales (Elliott, 1983); SGST = Schonell Graded Spelling Test (Schonell & Schonell, 1949); RBC = Richman Behavior Checklist (Richman & Graham, 1971); RSAB = Rutter Scales A & B (Rutter, Tizard, & Whitmore, 1970); Sequenced Inventory of Communication Development (Hedrick, Prather, & Tobin, 1984); BAER = Brainstem Auditory–Evoked Responses, BSID = Bayley Scales of Infant Development (Bayley, 1969).
normal language functioning. The remaining three children displayed minor language delays, which were remediated successfully with speech therapy. Likewise, the vast majority of infants (90%) had normal Brainstem Auditory-Evoked Responses (BAER). In addition, psychomotor and mental development, as measured by the Bayley Scales of Infant Development (BSID; Bayley, 1969), were assessed serially at 4, 8, 12, 18, and 30 months. Longitudinal results indicated that infants receiving transplantation demonstrated normal psychomotor and mental development, which appeared to be stable over the course of 30 months. However, increased variability on the Psychomotor Developmental Index of the BSID was associated with rejection episodes requiring steroid medication use, suggesting that organ rejection and its associated treatments (e.g., immunosuppressant medication) may interfere with normal psychomotor development within the first 30 months post-transplantation.

In summary, these studies suggest that most pediatric heart transplant recipients performed within normal limits on measures of cognitive and developmental functioning. However, pediatric heart transplant recipients who underwent a more complex transplant course secondary to post-surgical infection and/or organ rejection demonstrated signs of cognitive and/or psychomotor disturbance. These children were reported to endure additional medical treatments and longer hospital stays, which may have negatively affected their school attendance and academic performance.

**Psychological Functioning in Pediatric Heart Transplantation**

Research examining psychosocial outcomes of children and adolescents receiving heart transplantation is also limited to a few empirical investigations (Table II). In an early study examining the quality of life of pediatric heart recipients, Lawrence and Fricker (1987) described the psychosocial functioning of seven children between the ages of 6 and 15 years old. Although post-operative data were not reported for all transplant recipients, these investigators reported that all children in this small sample were able to return to their normal lifestyles and adjusted well to the stress of transplantation. Specifically, all children were reportedly able to attend to self-care, return to school, and maintain pre-transplant academic performance. Furthermore, six out of eight children were able to develop age-appropriate relationships.

Psychiatric outcomes have also been investigated in a small sample (n = 9) of pediatric heart transplant recipients. Although the average time of assessment post-transplant was not reported, Shapiro and Kornfeld (1989) found that five out of nine recipients experienced post-transplant adjustment difficulties characterized by anxiety, depression, and/or behavior problems using criteria from the Diagnostic and Statistical Manual of Mental Disorders-III-R Revised (DSM-III-R; American Psychiatric Association, 1987). The remaining four recipients reported no major adjustment difficulties. These investigators also reported that many family members of heart transplant recipients exhibited some symptoms of mood disturbance, including anxiety, depression, and anger.

More recently, researchers have examined the psychological adjustment of recipients and their families following transplantation in a larger sample of pediatric heart transplant recipients, (Uzark et al., 1992). Forty-nine pediatric heart transplant recipients and their families at five major heart transplant centers across the United States were mailed questionnaires assessing externalizing and internalizing disorders, self-concept, family stress, and family coping strategies. Results gathered from self-report data suggested that transplant recipients displayed significantly less social competence and more behavior problems compared to a normative population as measured by the Child Behavior Checklist (CBCL; Achenbach & Edelbrock, 1986). Further, behavior problems in transplanted children were significantly correlated with greater family stress and fewer family resources for dealing with stress. In contrast to previous findings reported by Shapiro and Kornfeld (1989), scores on measures of self-concept and anxiety were not significantly different from those of the normative sample. On measures of functional status, 93% of transplant recipients over 8 years of age were attending school and participating in extracurricular activities.

Psychological functioning of pediatric heart transplant recipients has been reported to differ across environmental settings (i.e., home, school). Wray et al. (1994) investigated the behavioral functioning of children who received transplantation compared to open heart surgery recipients and a healthy control group. In the home, transplant recipients were reported to exhibit significant behav-
transplantation who returned to school following transplantation, none exhibited behavior problems in the school setting.

In another study, Demaso, Twente, Spratt, and O’Brien (1995) examined 23 pediatric heart transplant recipients prior to transplantation and at a 1-year follow-up visit. Psychological functioning was measured by the Children's Global Assessment Scale (CGAS; Shaffer et al., 1983), a global rating (0 to 100) measuring children's overall psychological function.

Although the prevalence of behavior problems was not statistically different across groups, a greater percentage of children who received transplantation (24%) were reported to demonstrate clinically significant levels of disordered behavior (heart surgery group = 17%, healthy group = 6%). Of the 30% of children who received transplantation who returned to school following transplantation, none exhibited behavior problems in the school setting.

In another study, Demaso, Twente, Spratt, and O’Brien (1995) examined 23 pediatric heart transplant recipients prior to transplantation and at a 1-year follow-up visit. Psychological functioning was measured by the Children's Global Assessment Scale (CGAS; Shaffer et al., 1983), a global rating (0 to 100) measuring children's overall psychological function.

<table>
<thead>
<tr>
<th>Study</th>
<th>n</th>
<th>Age of child</th>
<th>Measures</th>
<th>Time of assessment</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lawrence and Fricker (1987)</td>
<td>7</td>
<td>Ages ranged from 6–15 years of age</td>
<td>PIC, OSQ, ECBI, PD</td>
<td>3 to 34 months post-transplantation</td>
<td>In this descriptive study, children appeared able to adjust to the stress of transplantation and, in most cases, demonstrated adequate or improved quality of life.</td>
</tr>
<tr>
<td>Shapiro &amp; Kornfeld (1989)</td>
<td>9</td>
<td>Average age unspecified</td>
<td>SCID, MMSE</td>
<td>Average time of assessment unspecified</td>
<td>In this descriptive study, 56% of recipients reported adjustment difficulties, including anxiety, depression and behavior problems post-transplant. Family members were described as expressing signs of anxiety, depression, and anger.</td>
</tr>
<tr>
<td>Demaso, Twente, Spratt, &amp; O’Brien (1995)</td>
<td>23</td>
<td>Average age at transplantation unspecified.</td>
<td>CGAS, GARF, DSM-IV Semi-Structured Interview</td>
<td>Average time of assessment 2.1 years post-transplantation</td>
<td>Transplant recipients reported normal levels of self-concept and anxiety. Less social competence and greater frequency of behavior problems were observed in transplant recipients compared to normative samples. Behavior problems were significantly correlated with increased family stress and fewer family resources for managing stress.</td>
</tr>
<tr>
<td>Wray, Pot-Mees, Zeitlin, Radley-Smith, &amp; Yacoub (1994)</td>
<td>162</td>
<td>Average age unspecified</td>
<td>RBC, RSAB</td>
<td>Average time of assessment 10 months post-transplantation</td>
<td>Study compared three groups: transplanted (n = 65), open-heart surgery (n = 52), and healthy control group (n = 45). Twenty-four percent of transplanted children exhibited significant behavior problems. Behavior problems were more prevalent in both surgical groups than the healthy control group.</td>
</tr>
</tbody>
</table>

PIC = Personality Inventory for Children (Wirt, Lachar, Klinedinst, Seat, & Broen, 1982); OSQ = Offer Self-Image Questionnaire, (Offer & Howard, 1972); ECBI = Eyberg Child Behavior Inventory (Eyberg & Ross, 1978); PD = Projective drawings; SCID = Structured Clinical Interview for DSM-III-R (Spitzer & Williams, 1986); MMSE = Mini-Mental State Exam (Folstein, Folstein, & McHugh, 1975); FIRM = Family Inventory of Resources for Management (McCubbin, Comeau, & Harkins, 1979); A-COPE = Adolescent Coping Orientation for Problem Experiences (Patterson & McCubbin, 1987); CHIP = Coping Health Inventory for Parents (McCubbin, McCubbin, Nevin, & Cauble, 1979); CICI:PQ = The Chronicity Impact and Coping Instrument: Parent Questionnaire (Hymovich, 1983); CBCL = Child Behavior Checklist (Achenbach & Edelbrock, 1986); STAIC = State Trait Anxiety Inventory for Children (Spielberger, 1970); PHSCS = Piers Harris Children’s Self-Concept Scale (Piers, 1984); CGAS = Children's Global Assessment Scale (Shaffer, et al., 1983); GARF = Global Assessment of Relational Functioning Scale (American Psychiatric Association, 1994); RBC = Richman Behavior Checklist (Richman & Graham, 1971); RSAB = Rutter Scales A & B (Rutter, Tizard, & Whitmore, 1970).
functioning. These investigators used a cutoff score of 70 to indicate “pathological” psychological functioning. Psychological adjustment, as measured by the CGAS, appeared to improve at 1 year post-transplant, with significantly fewer children functioning in the pathological range (pre-transplant = 43.5%, post-transplant = 21.7%). Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV; American Psychiatric Association, 1994) criteria were also gathered pre- and post-transplantation. Results of the pre-transplant evaluation indicated that 35% of the sample met diagnostic criteria for Psychological Symptoms Affecting Medical Condition with only 4% of the sample meeting these criteria at the post-transplant evaluation. Additionally, pre-transplant evaluations revealed that 13% of the sample met diagnostic criteria for Mood Disorders Secondary to Medical Condition with 0% meeting criteria 1 year post-transplant. Taken together, the results of this study suggest that the psychological functioning of many children improved 1 year post-transplant; however, approximately 20% of pediatric transplant recipients still demonstrated symptoms of psychological distress, although not in the diagnostic range at follow up.

In summary, it appears that most pediatric heart transplant recipients demonstrated adequate psychological adjustment within 1 year post-transplant. This is evidenced by significantly fewer recipients meeting diagnostic criteria for psychological difficulties, exhibiting fewer symptoms of poor psychological adjustment post-transplant, and many children returning to school. It appears, however, that a proportion of pediatric heart transplant recipients experienced significant levels of poor psychological adjustment following heart transplantation compared to normal, healthy peers. Although based on only a few published studies, 20%-24% of pediatric heart transplant recipients still demonstrated symptoms of psychological distress, although not in the diagnostic range at follow up.

Conclusions and Future Directions for Research

The existing literature on cognitive outcomes following pediatric heart transplantation has indicated that most recipients appear to be functioning within normal limits when assessed post-operatively. These data are encouraging since many recipients were able to return to school and pursue additional academic goals. However, Wray and Yacoub (1991) reported an exception whereby pediatric heart transplant recipients demonstrated lower performance on measures of mental development and school performance, possibly due to higher absentee rates from school. Additionally, variability in developmental functioning within the first 30 months post-transplantation was associated with rejection episodes requiring additional immunosuppressant medication (Trimm, 1991). While cognitive functioning for most recipients appears to remain intact, children and adolescents who experienced infections and rejections post-transplant appeared to have been at increased risk for cognitive and academic delays, since their disease course required additional medical management and longer hospitalizations.

Research examining psychological functioning in pediatric heart transplant recipients suggested that, within the first year post-transplant, the majority of pediatric transplant recipients adjusted well to the psychological stress of transplantation (Demaso et al., 1995). The significant reduction in psychological distress at 1 year follow-up suggested that, with time, children and adolescents may have been able to gather sufficient emotional resources to cope adequately with the effects of heart transplantation. However, this is not true for all pediatric heart transplant recipients. Although conclusive rates of poor psychological adjustment cannot be determined from the existing research, preliminary findings suggested that 20%-24% of pediatric heart transplant recipients are at increased risk for cognitive and academic delays, since their disease course required additional medical management and longer hospitalizations.

These preliminary findings raise a number of implications for clinical practice. First, the pre-transplant assessment offers health care providers an opportunity to gather valuable baseline information pertaining to the recipients’ pre-transplant
functioning. In adult heart transplant candidates, most transplant centers utilize a clinical interview and a formal assessment battery of self-report questionnaires to assess baseline cognitive and psychological functioning (Levenson & Olbrisch, 1993). We recommend that similar practices be used with pediatric transplant populations. Four broad areas of functioning should be assessed: (1) developmental, cognitive, and academic functioning; (2) emotional and behavioral functioning; (3) medical compliance; and (4) quality of life. The assessment instruments used to measure cognitive and psychological functioning will vary depending on the age and developmental level of the recipient. Although a comprehensive clinical interview can provide important information regarding these domains of functioning, standardized assessment instruments completed by heart transplant recipients or proxy raters (e.g., parents, guardians) for those children who are too young to complete self-report measures on their own would increase the validity and reliability of the overall assessment. Second, given that a proportion of pediatric heart transplant recipients are at risk for cognitive and psychological problems, parents of these children and adolescents should be educated on how to monitor their children’s psychological status. Early detection of poor psychological adjustment could be brought to the attention of mental health providers to provide preventative care and limit the exacerbation of the problem. Third, since pediatric heart transplantation likely has a bidirectional impact on both the functioning of the child and the family system, broader interventions simultaneously targeting children and families are needed (Kazak, 1989). Family-based interventions focused on disease education, preventative health care, coping strategies, and enhancing family communication and interpersonal relationships have been used with other disease populations (Kaslow et al., 1997; Streisand, Rodrigue, Houck, Graham-Pole, & Berlant, 2000). In many cases, these family interventions could be provided during hospitalization and/or shortly following discharge in order to maximize the adjustment of children and families during the early stages post-transplantation.

Investigating the cognitive and psychological functioning of pediatric heart transplant recipients presents a number of challenges to researchers. First, given that few numbers of children and adolescents receive heart transplantation, most studies are limited to using small sample sizes. Multicenter studies may allow investigators to study larger groups of children and adolescents. Second, because many children undergoing heart transplantation are too young to complete self-report instruments, it may be difficult to use standardized self-report instruments with all children. In that case, it may be helpful to use proxy raters to report on behalf of the recipient regarding their emotional well-being. Third, given that pediatric heart transplant recipients can range in age from 0 months to 17 years, researchers must carefully attend to several developmental issues. For instance, the impact of delayed physical development on subsequent psychological functioning must be considered. Further, given that pediatric heart transplantation increasingly occurs during early childhood, researchers should be encouraged to examine the degree to which transplantation and lifelong immunosuppression interferes with normative developmental tasks of childhood.

Within the cognitive domain, conclusions regarding the effects of heart transplantation on cognitive functioning of children and adolescents are limited by various methodological problems, such as small sample sizes, incomplete assessment batteries, and poor control for disease type and duration. Replication studies addressing these limitations are needed to better explain the potential cognitive deficits experienced by heart transplant recipients. Furthermore, additional longitudinal investigations examining the long-term impact of pediatric heart transplantation on cognitive functioning are needed. Moreover, many domains of neuropsychological functioning have not been examined in these patients. Given the impact of cardiac dysfunction on higher brain functions, future research should utilize comprehensive neuropsychological test batteries, including measures of memory and learning, executive abilities, motor functions, and visual-perceptual skills to assess a broader range of cognitive and motor abilities. Finally, as many of these transplant recipients have been reported to have high absentee rates from school, the impact of their disease on school achievement should also be examined.

Some evidence suggests that a proportion of children and adolescents may experience psychological difficulties, such as anxiety, depression, behavior disorders, and poor self-concept following transplantation. Future studies should continue to
assess the prevalence of psychological difficulties in pediatric heart transplant populations. Previous research with adult heart transplant recipients has indicated that symptoms of anxiety and depression are prevalent and may affect long-term outcomes, such as medical compliance (Dew, Roth, Thompson, Kormos, & Griffith, 1996) and quality of life (Sears, Rodrigue, Greene, & Mills, 1995). However, in the pediatric heart transplant literature, these issues have been relatively unexplored and require further investigation. Studies examining positive factors influencing pediatric heart transplant outcomes are also needed. For example, future studies could examine the influence of positive psychological constructs such as optimism, hope, and spirituality on pediatric transplant outcomes. In addition, we know little about the psychological adjustment of pediatric heart transplant candidates and families who are waiting for donor hearts to become available. Research is needed to investigate the impact of the waiting period on candidates and their families. Finally, the effectiveness of psychosocial interventions aimed at assisting children, adolescents, and families in coping with the stress associated with transplantation remains to be studied.

This literature review offers health care professionals a chalkboard full of empirical questions pertaining to the cognitive and psychological impact of pediatric heart transplantation. In many ways, psychosocial research with pediatric heart transplant recipients is in its infancy compared to research with adult recipients. Pediatric researchers, however, may glean research questions and methodologies from our colleagues investigating similar psychosocial issues with adult heart transplant candidates and recipients (Dew, 1998; Rodrigue, Greene, & Boggs, 1994). However, these investigations must include research issues with specific developmental emphases (e.g., peer relations, school achievement, cognitive development). Hopefully, in the future, research on transplantation in children and adolescents will provide greater knowledge about the concomitant medical, psychological, social, and academic functioning of heart transplant recipients and their families.

Acknowledgments

We thank Jannette Rey for her continued support throughout this research and her helpful comments during preparation of this manuscript.

Received August 25, 1998; revisions received December 29, 1998; April 20, 1999; July 1, 1999; September 1, 1999; accepted September 13, 1999

References


