Prospective Psychological Evaluation of Pediatric Heart and Heart–Lung Recipients

Jo Wray, PhD, and Rosemary Radley-Smith, FRCP
Department of Paediatrics, Harefield Hospital

Objective To study psychological adjustment in children and adolescents before undergoing heart or heart–lung transplantation and to reevaluate them at 6, 12, and 24 months after surgery. **Methods** Previously validated measures of behavior and depression were administered to children, their parents, and teachers. Parents also completed a measure of distress. **Results** Before transplantation, participants and parents obtained significantly higher scores on measures of behavior and psychological distress than children with no health problems and their parents, but 1 year after transplant, there were no significant differences between the two groups. Over time, there were significant improvements in depression and behavior scores in the group who had undergone transplantation. **Conclusion** Despite improvements in psychological functioning over time, a significant minority of children and adolescents undergoing transplantation are at risk for psychological adjustment difficulties. Psychological interventions to reduce morbidity need to be implemented and evaluated.

Key words behavior; heart and/or lung transplantation; psychological distress.

Heart and lung transplantation are no longer new treatment options for children with end-stage heart or lung disease, with over 5,950 such transplants having been carried out worldwide since 1982 (Boucek et al., 2004). One-year survival rates are now 87 and 77% for pediatric heart and lung recipients, respectively (Boucek et al., 2004), and transplantation is considered to be the treatment of choice for children with end-stage disease. However, despite the increasing numbers of children and adolescents undergoing thoracic organ transplantation and the improving survival rates, such patients continue to be a neglected population in the pediatric psychology literature.

Although the majority of patients appear to demonstrate good psychological adjustment after transplant (DeMaso, Kelley, Bastardi, O'Brien, & Blume, 2004; DeMaso, Twente, Spratt, & O'Brien, 1995; Hirshfeld, Kahle, Clark, & Bridges, 2004; Sigfusson et al., 1997), behavior problems, school difficulties, depression, and poor adherence have been identified in a significant minority (Douglas, Hsu, & Addonizio, 1993; Serrano-Ikkos, Lask, Whitehead, & Eisler, 1998; Uzark et al., 1992; Wray, Long, Radley-Smith, & Yacoub, 2001). Such variability in the reporting of psychological functioning reflects limited research (DeMaso et al., 2004), and the lack of prospective, longitudinal studies hinders the identification of predictive factors for longer-term functioning.

At our institution, a research program was implemented with the aim of assessing the psychological impact of transplantation on children and families. Unlike previous research, we have conducted pre- and posttransplant assessments with both heart and heart–lung recipients and have utilized multiple informants in a multimethod design. The objective of this article is to present data collected on a group of 28 children and adolescents who were assessed pretransplant and at 6, 12, and 24 months posttransplant.

All correspondence concerning this article should be addressed to Jo Wray, Children's Outpatient Department, Royal Brompton and Harefield NHS Trust, Harefield Hospital, Harefield, Middlesex UB9 6JH, UK. E-mail: j.wray@rbh.nthames.nhs.uk.

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Methods

Participants

Institutional approval was obtained, and individual consent was obtained from the parents of each child. Those children old enough to assent to the research did so. Children and adolescents were included in the study if they were domiciled in the United Kingdom or Eire, spoke English fluently, and were less than 17 years of age.

Data were collected on 28 children at each of the four time points. Demographic and basic medical data for the sample are given in Table I. Six of the 28 children were less than 2 years of age at the pretransplant assessment, two were between 3.5 and 4.9 years, and the remaining 20 were older than 5 years. Although six of the children were not eligible for completion of any of the behavioral measures before transplant, they were included because of the longitudinal design of the overall study, the fact that their parents completed measures of their own levels of distress, and also to ensure that the sample represented the population of children who undergo transplantation. For comparison, a group of 28 healthy children [mean age 8.29 years, *SD* 5.21 years; 16 (57%) boys] were also seen at two points in time, 1 year apart. Inclusion of a comparison group enabled us to assess whether any changes over time in the group undergoing transplantation reflected developmental changes seen in healthy children or were assessing the impact of transplantation. These children were initially recruited as part of another study into the impact of chronic illness on children and families (Wray & Sensky, 2001, 2004). They were assessed with a number of the same measures as participants in the transplant group.

Table I. Demographic and Medical Data of the 28 Transplant Participants

Age at assessment for transplant	
Mean (*SD*) (years)	8.3 (5.1)
Range (years)	0.1–14.9
Gender	
Boys [*n* (%)]	16 (57)
Girls [*n* (%)]w	12 (43)
Ethnicity	
Caucasian [*n* (%)]	25 (89)
Afro-Caribbean [*n* (%)]	3 (11)
Child living	
With both parents [*n* (%)]	21 (75)
With one parent [*n* (%)]	7 (25)
Socioeconomic status	
Nonmanual [*n* (%)]	13 (46)
Manual [*n* (%)]	15 (54)
Diagnosis	
Congenital heart disease [*n* (%)]	10 (36)
Cardiomyopathy [*n* (%)]	11 (39)
Cystic fibrosis [*n* (%)]	5 (18)
Primary pulmonary hypertension [*n* (%)]	2 (7)
Age at diagnosis	
Mean (*SD*) (years)	2.1 (3.6)
Range (years)	0–12
Time between assessment and transplant	
Mean (*SD*) (days)	156 (178)
Range (days)	2–633
Number who had undergone previous cardiac surgery (%)	8 (29)
Types of transplant	
Heart (%)	14 (50)
Heart–lung (%)	14 (50)
Ischemic time	
Mean (*SD*) (min)	201 (70)
Range (min)	35–335
Bypass time	
Mean (*SD*) (min)	91 (29)
Range (min)	31–137
Initial time in hospital after transplant	
Mean (*SD*) (days)	30 (18)
Range (days)	10–76
Subsequent hospitalization during first transplant year	
Mean (*SD*) (days)	19 (21)
Range (days)	0–70
Subsequent hospitalization during second transplant year	
Mean (*SD*) (days)	8 (8)
Range (days)	0–25
Time between transplant and returning to school	
Mean (months)	4.3
Range (months)	3–14
No hospitalization in the first 2 years, other than annual review [*n* (%)]	4 (14)
Infection requiring intravenous antibiotics in the first 2 years [*n* (%)][a]	15 (54)
Rejection requiring steroid treatment in the first 2 years [*n* (%)][a]	15 (54)[b]

There were no differences between the different diagnostic groups or between heart and heart–lung recipients in terms of hospitalization or rejection episodes.
[a]After initial hospitalization.
[b]In 12 cases, rejection treatment involved a 3-day course of methylprednisolone, and in three cases, maintenance steroids for persistent rejection were required.

Procedure

Pretransplant assessments were carried out during the child's admission for medical assessment, and post-transplant assessments were carried out during routine hospital follow-up appointments. Children who were old enough to complete the questionnaires were seen

on their own by the researcher (J.W.), and they completed the questionnaires as part of a larger battery of tests. Parents were also seen on each occasion for a semistructured interview and were given their questionnaires to complete. The healthy children were seen at home.

Measures

Behavior and Mood

Behavior of children aged 5–17 years was assessed with the 31-item Rutter A scales (Rutter, Tizard, & Whitmore, 1970), completed by parents. Internal consistency was satisfactory at each test occasion (Cronbach alpha values ranged from .790 to .919). Owing to the fact that no data on behavior were being collected on children under 5 years, the Child Behavior Checklist (CBCL) (Achenbach & Edelbrock, 1983; Achenbach, Edelbrock, & Howell, 1987), completed by parents of children aged 2–16 years, was introduced after the study had been underway for about a year. Total scores and scores on the broad band scales of internalizing and externalizing behavior will be presented, all of which had good internal consistency (Cronbach alpha: .921 to .955). Behavior at school of children aged between 5 and 17 years was assessed with the 26-item Rutter B scales (Rutter et al., 1970), completed by teachers. Cronbach alpha values ranged from .772 to .894, with the exception of the 6-month score which had poor reliability (Cronbach alpha = .271). Participants aged 8 years and over completed the 33-item Mood and Feelings Questionnaire (MFQ) (Angold, Costello, Pickles, Winder, & Silver, 1987) to assess depression, which exists in separate child (MFQ-C) and parent (MFQ-P) versions. Cronbach alpha values were between .863 and .945 for the MFQ-C and between .924 and .948 for the MFQ-P.

Parental Mental Health

The 30-item version of the General Health Questionnaire (GHQ) was used to assess the mental and emotional state of parents (Goldberg, 1978). Internal consistency was satisfactory, with Cronbach alpha values ranging from .842 to .918 for mothers and from .813 to .912 for fathers.

Information was gathered on social, demographic, and medical factors as well as on issues related to the child's schooling and behavior during the semistructured interview with parents. Particular medical factors included diagnosis, type of transplant, bypass and ischemic times, rejection and infection episodes, and length of hospitalizations.

Data Analysis

Owing to the distribution of the data, nonparametric statistics were used for analysis. Mann–Whitney tests, Chi-squared tests, and Kruskal–Wallis ANOVA were used to compare the different diagnostic groups. Heart and heart–lung recipients were also compared because of the differences in outcome for these two groups, in terms of both mortality and morbidity. Within-group changes over time on the psychological measures were assessed by Friedman's ANOVA. Bivariate analyses of the demographic, medical, and psychological variables were conducted, and Spearman correlation coefficients were computed. The sample size was too small for regression analysis to be carried out.

Results

Mean total scores and numbers of participants or parents scoring above the cut-off on the measures are given in Table II. There were no significant differences between the diagnostic groups on any of the psychological variables. However, heart recipients obtained significantly higher scores at 6 months on the MFQ-P ($Z = 2.084$, $p = .041$) and CBCL total score ($Z = 2.742$, $p = .006$) and lower scores on the total social competence scale of the CBCL ($Z = 2.101$, $p = .033$) compared with heart–lung recipients. At 12 months, heart recipients' total scores were higher on the CBCL ($Z = 2.865$, $p = .003$), and at 2 years, scores were significantly higher for heart recipients on the Rutter A scales ($Z = 2.235$, $p = .022$), child version of the MFQ ($Z = 2.245$, $p = .022$), and CBCL ($Z = 2.361$, $p = .016$). A greater proportion of heart recipients had scores above the cut-off on the Rutter A scales at 2 years ($Z = 2.84$, $p = .016$).

Before transplant, scores on the Rutter A scales and mothers' and fathers' levels of distress were significantly higher ($p < .05$) in the group who had undergone transplantation compared with the healthy group (Table II). One year after transplant, there were no significant differences between the two groups.

Changes Over Time

In those children for whom complete data sets were available, there were significant changes over time on the mean scores for the MFQ-C, CBCL total score, CBCL internalizing scale, CBCL total social competence scale, and fathers' GHQ scores. There were no changes over time in the prevalence of children or parents scoring above the cut-off on any of the psychological outcome measures.

Table II. Mean Total Scores and Numbers Scoring Above the Cut-Off

	Pretransplant	6 months posttransplant	12 months posttransplant	24 Months posttransplant	Healthy time 1	Healthy time 2
Rutter A	*n* = 20	*n* = 19	*n* = 20	*n* = 16	*n* = 17	*n* = 18
Mean	13.6	8.2	10.5	12.3	7.9	7
Number scoring ≥13 [*n* (%)]	8 (40)	6 (32)	6 (30)	6 (38)	2 (11)	2 (11)
CBCL	*n* = 18	*n* = 22	*n* = 23	*n* = 21		
Mean[a]	41.3	28.1	30	35.9	Not given	Not given
Number scoring above cut-off [*n* (%)]	7 (39)	5 (23)	5 (22)	4 (19)		
CBCL: 4–16	*n* = 15	*n* = 20	*n* = 20	*n* = 14		
Internalizing scale: mean[b]	21.1	12.9	13.3	15.6	Not given	Not given
Number scoring above cut-off [*n* (%)]	10 (67)	5 (25)	6 (30)	4 (29)		
CBCL: 4–16	*n* = 15	*n* = 20	*n* = 20	*n* = 14		
Externalizing scale: mean	11.6	11.5	11.9	14.1	Not given	Not given
Number scoring above cut-off [*n* (%)]	1 (7)	4 (20)	4 (20)	4 (29)		
CBCL	*n* = 14	*n* = 19	*n* = 18	*n* = 14		
Social competence items: mean[c]	13.9	15.6	14.2	14.3	Not given	Not given
Number obtaining clinically meaningful scores* [*n* (%)]	11 (79)	9 (53)	12 (67)	8 (57)		
MFQ-P	*n* = 16	*n* = 18	*n* = 16	*n* = 13		
Mean	17.6	8.4	9.3	9.5	Not given	Not given
Number scoring ≥21 [*n* (%)]	5 (31)	2 (11)	3 (19)	2 (15)		
MFQ-C	*n* = 14	*n* = 19	*n* = 19	*n* = 19		
Mean[d]	21.4	11.9	10.9	7.8	Not given	Not given
Number scoring ≥27 [*n* (%)]	4 (29)	2 (11)	3 (16)	1 (5)		
Rutter B	*n* = 14	*n* = 8	*n* = 16	*n* = 14	*n* = 19	*n* = 17
Mean	3.4	5.1	5.4	4.1	5.4	3.7
Number scoring ≥9 [*n* (%)]	1 (7)	1 (13)	6 (38)	2 (14)	5 (26)	2 (12)
GHQ-M	*n* = 28	*n* = 26	*n* = 24	*n* = 21	*n* = 26	*n* = 24
Mean	11.1	4.4	4.3	7.3	3.1	3.8
Number scoring ≥5 [*n* (%)]	20 (71)	9 (35)	5 (21)	9 (43)	5 (19)	6 (25)
GHQ-F	*n* = 19	*n* = 18	*n* = 14	*n* = 13	*n* = 21	*n* = 21
Mean[e]	8.8	8.5	2.8	2.6	1.2	1.1
Number scoring ≥5 [*n* (%)]	14 (74)	5 (28)	2 (14)	3 (23)	1 (5)	2 (10)

CBCL, Child Behavior Checklist; GHQ-F, General Health Questionnaire—fathers; GHQ-M, General Health Questionnaire—mothers; MFQ-C, Mood and Feelings Questionnaire—child; MFQ-P, Mood and Feelings Questionnaire—parents.

For those with complete data sets:

[a]$X^2 = 9.46$, $p = .024$.

[b]$X^2 = 8.57$, $p = .036$.

[c]$X^2 = 10.70$, $p = .013$.

[d]$X^2 = 12.56$, $p = .006$.

[e]$X^2 = 13.56$, $p = .004$.

*Lower scores denote poorer social competence.

Bivariate Correlations

The only demographic or medical variable that was significantly correlated with any of the psychological outcome variables was age. Younger age was associated with higher MFQ-C total scores pretransplant ($r = -.631$, $p = .016$) and at 6 months posttransplant ($r = -.611$, $p = .005$), with higher scores on the Rutter A scales ($r = -.467$, $p = .038$), Rutter B scales ($r = -.586$, $p = .017$), and the GHQ for mothers ($r = -.598$, $p = .002$) at 12 months and higher Rutter B scores ($r = -.539$, $p = .047$) at 24 months.

CBCL total scores at each test occasion were all significantly correlated (all *p*-values <.01). Mothers' GHQ scores were significantly correlated with CBCL scores ($p < .05$) before and at 6 and 24 months after transplant.

Discussion

This study supports previous findings of healthy psychological adjustment in the majority of children and adolescents who have undergone transplantation (DeMaso et al., 1995, 2004; Hirshfeld et al., 2004;

Sigfusson et al., 1997). Whilst pretransplant scores were significantly higher than those of an age-matched healthy group, there was a trend for an improvement in psychological functioning from before transplant to after transplant, as found previously (DeMaso et al., 1995, 2004), with this change most apparent in the early postoperative months. One year after transplant, there were no significant differences between the group who had undergone transplantation and the healthy group. The differences between the groups at the first assessment support the well-documented findings of higher rates of psychological adjustment difficulties in ill compared with healthy children (Lavigne & Faier-Routman, 1992). Stratifying the participants by diagnosis did not elicit any significant differences between the groups on any of the psychological parameters, but comparison of heart and heart–lung recipients indicated higher scores in the heart recipients on some of the behavioral and depression measures after transplant. This latter finding is in contrast to those of Serrano-Ikkos et al. (1998), who found no differences in psychological adjustment between heart and heart–lung recipients, but our results must be interpreted with caution due to the sample size, heterogeneity of diagnosis within the two groups of recipients, and wide age range.

The results for social competence suggest that many of the children are performing poorly. Questions focus on areas such as participation in social groups, sports, relationships with peers, and academic performance at school. Many children, particularly in the early posttransplant months, are restricted in playing sports and socializing—for medical reasons, parental anxiety, or both. All the children had missed some school, and for some this amounted to many months of lost education, with resulting academic difficulties. Social competence results therefore need to be considered against this background of confounding factors—although it will be important to monitor this in the longer term.

Patient numbers were too small for regression analysis to be carried out, which is a limitation of the study, but the significant correlations between pre- and posttransplant scores on the CBCL, together with the lack of correlation between psychological and medical parameters, suggest that psychological rather than medical factors are more important in determining posttransplant psychological adjustment, supporting the findings of DeMaso and colleagues (1995, 2004). A further consideration in the reporting of behavior problems by parents is the parents' own mental state. Maternal levels of psychological functioning may influence mothers' reporting of their children's behavior, and in our study, correlations between mothers' distress and CBCL scores were significant before and at 6 and 24 months after transplant.

The results of our study suggest that a significant minority of patients do experience psychological difficulties at some stage after transplant, which supports the findings of others and the need for continuing psychological evaluation of this patient group. The traumatic nature of this type of surgical intervention and subsequent follow-up is never going to be negated, and if psychological morbidity and possibly mortality are to be reduced, patients at risk for poor psychological outcome need to be identified and interventions implemented early in the transplant journey. The associations between child and parent functioning indicate that such interventions need to be family focused and address issues such as adaptive coping, realistic expectations concerning transplantation, and parenting of sick children who undergo successful surgical intervention. At the same time, it is also important to recognize and identify those factors that may moderate or mediate good psychological adaptation, such as adaptive parental coping and adjustment, high self-esteem, supportive peer relationships, and good adherence, and to emphasize the encouraging fact that the majority of pediatric and adolescent patients demonstrate healthy psychological functioning, at least in the short term after transplant.

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