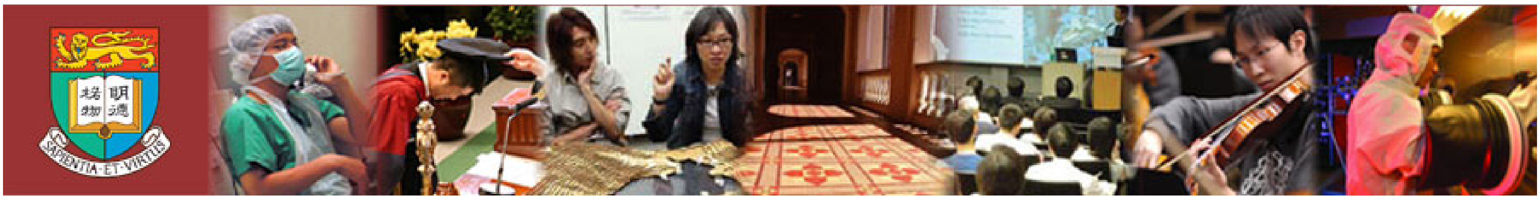

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A Survey of Psychosocial Adaptation in Long-Term Survivors of Pediatric Liver Transplants

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We assessed 41 children and adolescents who had received liver transplants at least 4 years ago, for social, behavioral, and emotional adaptation; physical function; and family stress. We compared their level of adaptive functioning to published data from chronically ill and medically well children. On many measures, transplant recipients had equivalent levels of function to the comparison groups. However, 6- to 11-year-old patients showed mild social and scholastic deficits. Patients' parents report less negative impact of the illness on the family than do parents of other chronically ill children. A listing of medication side effects and the degree to which they are problematic was obtained.

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Liver transplantation is now an accepted treatment for end-stage liver disease, and the number of children who receive transplants continues to grow. In addition, the number of children and adolescents who are long-term survivors of transplantation has increased.

In one of the earliest articles assessing psychosocial adjustment, Starzl et al. (1979) indicated that the progression of rehabilitation among those patients who survived at least 1 year following the transplant was good as long as they were not steroid dependent. Those patients who had many difficulties with rejection and were steroid dependent did not achieve this same level of adjustment. Starzl et al. provided general information regarding the school and vocational pursuits of their patients, and they stated that psychiatric complications were "relatively uncommon" (p. 255). In another study of patients who received transplants prior to 1980, House, Dubovsky, and Penn (1983) reported that pediatric patients frequently suffered from regression, depression, and anxiety about organ rejection and separation from parents. Since the availability of cyclosporin as an immunosuppressant, there has been a decrease in postoperative complications and a reduction of dependence on steroids. It is likely that these factors positively affect the adjustment of liver transplant survivors.

There have been additional studies of pediatric patients' adjustment to cyclosporin as an immunosuppressant. Gartner et al. (1984) reported that, in their group of pediatric patients who had received liver transplantations, most patients appeared to have increased energy and attended regular classes, although some children were noted to have anxiety about the future and fears of organ rejection. Zitelli et al. (1987) also reported on several measures that related to the psychosocial adjustment of 65 liver transplant recipients 2 to 5 years posttransplant. Their sample reported fewer hospitalizations and fewer medications than pretransplant, and a large majority were placed in regular classrooms or were only 1 year behind the acceptable level of performance. In addition, 18 of 20 children examined showed normal or above-average IQ scores 1 or more years posttransplant. All children who were assessed using the Vineland Social Maturity Scales were at or above the age-appropriate norms. Using direct evaluation of intellectual and neuropsychological functions, Stewart et al. (1989) and Stewart et al. (1991) assessed cognitive function and found that there were persistent deficits in intellectual function for those children who had delays pretransplant and in neuropsychological function for the group as a whole. Windsorova, Stewart, Lovitt, Waller, and Andrews (1991) did comprehensive emotional and behavioral assessments of 25 children who had received transplants between 1 and 5 years ago and found that behavioral and emotional adjustment was as good as that of other children with chronic illness. When compared to well peers, however, subtle signs of emotional difficulties were apparent.

In general, these studies suggest that children who receive liver transplants show good psychosocial adjustment following their surgery. However, the application of these findings to long-term survivors of pediatric transplantation is limited. Most of the systematic studies either assess patients shortly after transplantation (Gartner et al., 1984; Stewart et al., 1989) or assess a mix of short-term and long-term survivors (Stewart et al., 1991; Windsorova et al., 1991; Zitelli et al., 1987). Indeed, few studies include a substantial number of patients who have received transplants more than 4 years prior to examination.

Studies of the psychosocial adaptation of children who receive liver transplants are notable for the following methodological limitations. Some studies report data that were not obtained using standardized or quantitative measures of adaptation (Gartner et al., 1984; House et al., 1983; Starzl et al., 1979). Several of the more systematic studies do not present data generalizable for the population as a whole because either the examiners restricted their sample to transplant patients who meet specific criteria, such as normal IQ (Windsorova et al., 1991), or their samples comprise a relatively small proportion of the patients at a single center (Stewart et al., 1991). Some studies (House et al., 1983; Starzl et al., 1979) mix pediatric patients with adult patients in their subject groups, obscuring possible differences in adjustment among these two populations. Note that there is little information available on the effects of children's posttransplant status on the caretakers or the family. The substantial impact of the illness on the emotional well-being of the family pre- and posttransplant has been noted in clinical reports (Gold, Kirkpatrick, Fricker, & Zitelli, 1986). Just as the assessment of patients' long-term psychosocial adjustment is an important indicator of the benefits of transplants (Parness & Nadas, 1988), the continued negative impact on the family is an important measure of the cost of this life-saving technology. Finally, although there has been some attempt to assess the impact of patient and disease characteristics on psychosocial adjustment, many variables have not been assessed systematically or have been ignored in many studies. For example, there is evidence that men and women may respond differently to the effects of ongoing illness (Viney, 1982). However, sex differences in adaptation following transplants have not been adequately examined. In addition, variables such as current age, age at transplant, and measures of speed of recovery from the surgery and of recurrent hospitalizations are expected to affect the patient's adaptation. A comprehensive list of persistent side effects of immunosuppressant medications and the degree to which these side effects are experienced as being problematic is lacking.

The primary aim of this study was to obtain information regarding psychosocial adjustment from as broad a group representing long-term pediatric transplant survivors as possible. This study was designed to improve past methodology by using primarily standardized measures of adaptation or quantitative report when such measures do not exist by (a) including a larger proportion of the patients who received transplants at a single center than used in previous studies, (b) assessing the effect of sex differences in adaptation, and (c) including an assessment of the continued impact of the child's disease and transplant on the primary caretakers. Our hypotheses regarding psychosocial functioning were as follows. Children with chronic liver disease who are at least 4 years posttransplant would not differ significantly from other chronically ill children on measures of behavioral adjustment or physical limitations. However, when compared to medically well children, they would show greater social and physical limitations. We also hypothesized that, consistent with findings from other studies that show boys as being more vulnerable to the development of behavioral and emotional problems (Eme, 1978; LaClave & Campbell, 1986), the boys in this sample would show more frequent social and behavioral problems than girls.

A secondary aim of this study was to investigate whether specific variables related to the disease and transplant process may contribute to the psychosocial adjustment of the recipients. These variables were current age, age at transplant, years posttransplant, number of hospitalizations since transplant, and immunosuppressant medication dosage and level. We hypothesized that there would be a positive correlation between years posttransplant and psychosocial function because distance between illness onset and surgery will allow a longer period of normalization. We also hypothesized that number of hospitalizations since a transplant and immunosuppressant dosage and level would correlate negatively with function.

A final aim was to obtain information about the degree to which side effects of immunosuppressant medications are experienced as being problematic.

METHOD

Participants

The participants were children and adolescents 5 to 18 years of age who had received liver transplants 4 or more years prior to participation in this study; all participants were still living at home. Forty-seven children and adolescents met these criteria, and 41 families (87%) participated in this study. One family declined participation, and 5 families were lost to follow-up. The demographic characteristics of the patients are presented in Table 1.

Five children were lost to follow-up. Characteristics of these patients and their families on pretransplant variables were examined. This pool consisted of three girls and two boys, all of whom were White. They ranged in age from 8 months to 7 years, 8 months at transplant. Two girls showed delays in cognitive function during pretransplant evaluation. All patients lived with both

TABLE 1
Sociodemographic and Transplant-Related Characteristics of Long-Term Survivors of Pediatric Liver Transplants

Characteristic	*M* ± *SD*	*n*	%
Sex			
Male		21	51
Female		20	49
Race/Ethnicity			
Caucasian		35	85
Mexican American		3	7
African American		3	7
Current age	9.63 ± 3.39		
5–7 years		11	27
8–10 years		16	39
11–13 years		9	22
14–16 years		2	5
17–18 years		3	7
Age at transplant	4.76 ± 3.33		
< 1 year		2	5
1–3 years		19	46
4–6 years		12	29
7–9 years		3	7
10–12 years		3	7
> 12 years		2	5
Years posttransplant			
4		17	41
5		11	27
6		13	32
Number of transplants			
1		36	88
2		4	10
3		1	2
Parents' marital status			
Single		2	5
Married		36	88
Divorced		3	7
Number of children in the household			
1		4	10
2		16	39
3		12	29
4+		9	22
Parents' employment status			
Mother			
Employed		25	61
Unemployed		16	39
Unknown		—	—

TABLE 1 *(Continued)*

Characteristic	*M* ± *SD*	*n*	%
Father			
Employed		34	83
Unemployed		2	5
Unknown		5	12
Parents' educational level			
Mother			
< 12 years		2	5
12 years		30	73
16 years		7	17
> 16 years		2	5
Father			
< 12 years		3	7
12 years		21	51
16 years		6	15
> 16 years		6	15
Unknown		5	12
Socioeconomic status level[a]			
I		1	3
II		7	17
III		9	22
IV		15	37
V		9	22

Note. *N* = 41.

[a] According to Hollingshead (1975) Four Factor Index of Social Status.

biological parents. With the exception of one parent, all had completed high school, and one parent had spent some time in college. Four out of five of the families had at least one employed wage earner.

At the time of the study, 40 participants (98%) were prescribed cyclosporin, and 1 child was prescribed FK506. Twenty-four participants (58%) were prescribed prednisone, and 21 (51%) were prescribed imuran. Medication dosage and blood levels were obtained from the children's medical record and are presented in Table 2. Blood levels were available only for cyclosporin. Two participants were not being followed at Children's Medical Center, and information regarding their medication dosage and level was unavailable.

Materials

Psychosocial adaptation can cover several different functions. Boggs, Graham-Pole, and Miller (1991) suggested that social, cognitive, behavioral, emotional, and physical functions are important domains to include when assessing pediatric adaptation. This study was designed to assess these domains using parent report, with the exception of the cognitive domain. Cognitive function is

TABLE 2
Mean Immunosuppressant Dosage and Levels and Steroid Dosage of Long-Term Survivors of Pediatric Liver Transplant Recipients

			Dosage	Level
Medication	*n*	%	*M* ± *SD*	*M* ± *SD*
Cyclosporin	39	100	111.67 ± 95.75	151.85 ± 103.80
Prednisone	24	62	5.19 ± 5.31	
Imuran	20	51	48.00 ± 22.15	

Note. $N = 39$.

accurately assessed only by direct evaluation of the child. However, because an important aim of this study was to include as large a proportion of the geographically scattered subject pool as possible, direct evaluation was precluded.

Measures of social function. The Social Competence scales of the Child Behavior Checklist (CBCL; Achenbach, 1991; Achenbach & Edelbrock, 1983) were used as a measure of social function. The CBCL is a standardized test that measures social competency by parent report. It assesses the amount and quality of the child's participation in three domains: activities, social function, and school function. Norms for the Social Competence scales of the revised version (Achenbach, 1991) were based on children between the ages of 6 and 18 and allow for a comparison of children's profiles with a sample of normal children of the same sex in the same age bracket (ages 6 to 11 and 12 to 18). Social Competence scores on Social and Activities scales for 4- to 5-year-old children were obtained from the earlier version of the CBCL (Achenbach & Edelbrock, 1983), because the revised version does not have normative data for this age group. The test manual provides means for each age group, and *T* scores below 30 are reported to be in the clinical range.

Measures of behavioral and emotional function. The Personal Adjustment and Role Skills Scale III (PARS III; Stein & Jessop, 1990; D. K. Walker, Stein, Perrin, & Jessop, 1990) measures the psychological adjustment and function of chronically ill school-age children by parent report and was used to assess the child's behavioral and emotional function. This scale contains subscales on six dimensions that are associated with patterns of maladjustment in children, including Dependency, Hostility, Withdrawal, Anxiety–Depression, Poor Productivity, and Peer Relations. High scores on the PARS III suggest good behavioral and emotional adjustment. It is appropriate for 5- to 18-year-old children and allows a comparison of a child's scores with a sample of chronically ill children of the same sex in the same age bracket (ages 5 to 11 and 12 to 18).

The PARS III is not as widely used in the literature on behavior problems in children as some other scales (e.g., the CBCL; Achenbach, 1991; Achenbach & Edelbrock, 1983). However, in contrast to the CBCL, which is not recommended for use with a chronically ill population by the author of the test (Achenbach, 1984), the PARS III is considered particularly appropriate for children with a history of chronic illnesses. This is true because items about physical symptoms (which may inflate scores on other similar instruments in this population) have been avoided; the PARS III covers important psychosocial domains and has been found to have good technical properties (D. K. Walker et al., 1990).

Measures of physical function. Physical function was assessed using the Functional Disability Inventory (FDI; L. S. Walker & Greene, 1991). This inventory assesses the impact of illness on children's physical and social functions in everyday activities and is appropriate for chronically ill school-age children and adolescents. Higher scores suggest more difficulty in physical functioning. The authors defined *functional disability* as "difficulty in age-appropriate physical and psychosocial functioning due to physical health status" (p. 40). Means and standard deviations are provided for a normative sample of children diagnosed with recurrent abdominal pain and abdominal pain with organic etiology. In addition, means and standard deviations are reported for well children.

Measures of family impact. The Impact on Family Scale (Stein & Riessman, 1980) was used to assess the impact the illness has on a family and the degree to which the liver transplant process has affected the child's family. This scale includes four subscales: Financial Burden; Personal Strain; Mastery, which relates to the ability to employ coping strategies to face the illness; and Familial/Social, which relates to a disruption in normal social interactions. Higher scores on the Financial Burden, Personal Strain, and Mastery subscales and lower scores on the Familial/Social subscale suggest better adjustment. Means and standard deviations are provided for the normative sample of families with a chronically ill child on each subscale and on total score.

Additional variables related to psychosocial adaptation. Variables that are specific to chronic illness and transplantation and that would be expected to affect psychosocial adjustment (either by removing the child from typical peer contact or by identifying him or her as having a medical condition) were also assessed. These were (a) frequency and duration of hospitalizations since transplant, (b) frequency and duration of hospitalizations within the last year, (c) number of medications, and (d) the degree to which side effects of liver transplant and medication are problematic. Information regarding the number and duration of hospitalizations was obtained from the child's medical records. The number of medications was obtained by parent report. The specific side effects assessed are presented in Table 3. The degree to which side effects of liver transplant and medication are problematic was assessed using a 3-point Likert scale from 1 (*none*) to 2 (*somewhat*) to 3 (*very much*).

Procedure

The study was conducted through telephone interview in order to reach as many families as possible. Interviews were conducted by the senior author who is not a member of the Liver Transplant Program staff and who informed the parents that their reports would be kept confidential and that no child would be identified by name in discussing results with the staff of the Liver Transplant Program. Interviews were generally conducted with the mother or other female primary caretaker. Two fathers, who were not employed and who cared for their child throughout the day, were judged by the investigator (Andrea DeBolt) to be their child's primary caretaker and participated in this study. Verbal consent was obtained prior to each interview, and the parents were informed that they could terminate the interview at any time.

TABLE 3
Frequency and Severity of Side Effects Experienced by 41 Long-Term Survivors of Pediatric Liver Transplants

		Severity		
Side Effect	*Frequency*	*None*	*Somewhat*	*Very Much*
Surgical scarring	41	38	2	1
Gum overgrowth	34	8	9	17
Short height	31	8	12	11
Mood swings	28	8	13	7
Hirsutism	24	7	12	5
Migraine headaches	17	3	8	6
Low energy level	17	2	13	2
Dental decay	16	2	8	6
Decreased appetite	16	4	11	1
Discolored teeth	15	2	4	9
Bed wetting	14	4	3	7
Chubby face	13	6	3	4
Brittle bones[a]	11	5	6	0
Hyperactivity	9	2	4	3
Excessive weight	4	1	2	1

[a] More than one incident of fractures.

RESULTS

Because a large number of comparisons were made in this study, increasing the likelihood of Type I error, a conservative significance level ($p < .01$) was set.

Measures of Social Function

The results of the Social Competence scales of the CBCL are presented in Table 4. A series of t tests revealed that boys between the ages of 6 and 11 who had undergone liver transplants received scores significantly lower on School and Activities scales than did the normative sample of medically well children. Girls in the 6- to 11-year-old age bracket scored significantly lower on the School scale than did well girls in the same age bracket and received a Social Competence total score that was lower than their well peers' scores. Girls in the 12- to 18-year-old age bracket showed scholastic deficits compared to the normative sample of well girls of the same age.

TABLE 4
Social Competency of 41 Long-Term Survivors of Pediatric Liver Transplants as Measured by the Child Behavior Checklist (Achenbach & Edelbrock, 1983) Compared to the Normative Sample of Medically Well Children

	Boys	*Girls*
Scale	*M* ± *SD*	*M* ± *SD*
Ages 4–5[a]		
Activities	44.00 ± 7.07	50.00 ± 0
Social	37.50 ± 17.68	54.00 ± 0
Total	38.00 ± 14.14	52.00 ± 0
Ages 6–11[b]		
Activities	43.06 ± 6.84*	45.07 ± 8.17
Social	42.00 ± 9.4	46.15 ± 7.12
School	41.00 ± 7.18**	39.16 ± 7.69**
Total	39.63 ± 9.60**	42.54 ± 10.05*
Ages 12–18[c]		
Activities	44.33 ± 4.04	48.50 ± 7.23
Social	43.67 ± 9.07	47.83 ± 7.44
School	40.33 ± 12.70	37.67 ± 9.63*
Total	42.33 ± 11.93	45.83 ± 10.15

Note. Normative sample: $M = 50$ and $SD = 10$.

[a] Boys $n = 2$, girls $n = 1$. [b] Boys $n = 16$, girls $n = 13$. [c] Boys $n = 3$, girls $n = 6$.

*t for comparison of group to normative sample is significant at the $p < .01$ level. **t for comparison of group to normative sample is significant at the $p < .001$ level.

A linear regression was performed to determine whether the following variables would predict function as measured by the previously mentioned scales: (a) current age, (b) age at transplant, (c) years posttransplant, (d) number of hospitalizations since transplant, and (e) socioeconomic status. The results of the linear regression analyses failed to reach significance. Correlations are shown in Table 5.

Measures of Behavioral and Emotional Function

When the total group of patients was compared to the chronically ill normative population on the PARS III, *t*-test results indicated that study patients showed better adjustment on the Anxiety–Depression ($p < .01$) and Withdrawal scales

TABLE 5
Correlations Among Psychosocial Adjustment Scores and Subject's Current Age, Age at Transplant, Years Posttransplant, Total Hospitalizations Since Transplant, and Socioeconomic Status

Psychosocial Adjustment Score	*Current Age*	*Age at Transplant*	*Years Posttransplant*	*Total Hosp.*	*Socioeconomic Status*
CBCL[a]					
Activities	.25	.21	.16	.11	.10
Social Competence	.15	.16	−.02	−.22	.07
School	−.36	−.36	.15	.07	−.14
PARS III[b]					
Peer Relations	.12	.18	−.08	.07	−.12
Dependency	.00	.00	.02	−.03	.14
Hostility	.00	−.01	.16	.00	.21
Poor Productivity	.24	.20	.20	.05	.13
Anxiety Depression	−.01	−.04	.09	−.18	.18
Withdrawal	.69	.62	.83	.45	.20
Total score	.09	.07	.11	−.05	.19
Impact on Family Scale[c]					
Financial	−.02	−.08	.15	−.06	−.30
Familial/Social	.39	.37	−.05	−.17	.90
Personal Strain	.09	.04	.03	−.15	.11
Mastery	.14	.19	−.20	.00	.04
Total score	.27	.23	−.01	−.16	.17
FDI[d]					
Total score	−.18	−.22	.09	.22	.26

Note. Total Hosp. = total hospitalizations since transplant. None of the correlations reached significance at $p < .01$.

[a] Child Behavior Checklist (Achenbach, 1991; Achenbach & Edelbrock, 1983). [b] Personal Adjustment and Role Skills Scale (Stein & Jessop, 1990; D. K. Walker et al., 1990). [c] Impact on Family Scale (Stein & Reissman, 1980). [d] Functional Disability Inventory (L. S. Walker & Greene, 1991).

($p < .001$). Analyses of subgroups divided by age and sex indicated that girls showed better adjustment on the Anxiety–Depression scale (*M* ± *SD* for study patients vs. normative group), with higher scores indicating better function (21.00 ± 2.00 vs. 19.00 ± 3.40; $p < .001$), and on the Withdrawal scale (15.70 ± 0.66 vs. 14.10 ± 2.30; $p < .001$). These differences were present for girls in both the 5- to 11-year-old age group ($n = 14$) and the 12- to 18-year-old age group ($n = 6$).

The results of the analyses regressing PARS III scores on current age, age at transplant, years posttransplant, and number of hospitalizations since transplant were not significant. Correlations are shown in Table 5.

Physical Function

Twenty-eight children in the subject pool fell into the age range of the normative sample (8 to 17 years old) for the FDI. A *t* test revealed that children within this age group who were long-term survivors of liver transplants scored significantly lower than did the normative sample of recurrent abdominal pain ($p < .001$) and organic abdominal pain groups ($p < .001$), indicating that they had less physical difficulty performing the tasks included in this inventory when compared to the normative sample of chronically ill children. However, children who had liver transplants scored significantly higher than did the normative well group ($p < .01$), indicating that they had some difficulty performing common daily activities when compared to the normative sample of well children. A frequency distribution was tabulated to determine which activities were more frequently reported to be physically difficult for these children to perform. In order of frequency, the activities were running the length of a football field (71.4%), doing activities in gym class (57.1%), getting to sleep at night and staying asleep (46.5%), walking the length of a football field (39.2%), being up all day without a nap or break (25%), being at school all day (25%), eating regular meals (21.5%), going shopping (17.8%), walking upstairs (17.8%), doing chores at home (17.8%), reading or doing homework (10.7%), doing something with a friend (e.g., playing a game, 3.6%; walking to the bathroom, 0%; and watching television, 0%).

Sex differences were not significant. In addition, analyses failed to reach significance when FDI scores were regressed on current age, age at transplant, years posttransplant, and number of hospitalizations since transplant. Correlations are shown in Table 5.

Measures of Family Impact

Parents of children who had undergone liver transplants indicated less negative effect of illness than did the normative sample of parents of chronically ill children on the Familial/Social subscale ($p < .001$) of the Impact on Family Scale. The participants scored lower than did the normative sample on the

TABLE 6
Number and Duration of Hospitalizations of 41 Long-Term Survivors of Pediatric Liver Transplants

Characteristic	*M* ± *SD*	*n*	%
Posttransplant total hospitalizations[a]	7.41 ± 5.05		
1–5		17	44
6–10		12	31
11–15		7	18
16–20		2	5
> 20		1	2
Hospitalizations last year[a]	0.56 ± 1.23		
None		29	74
1–2		8	20
3–4		1	3
5–6		1	3
Days hospitalized[a]	77.41 ± 59.83		
0–30 days		12	31
31–60 days		7	18
61–90 days		7	18
91–120 days		3	8
> 120 days		10	25
Days hospitalized last year[a]	5.92 ± 16.85		
0–7 days		30	77
8–15 days		5	13
> 15 days		4	10
Number of medications currently prescribed	3.88 ± 2.22		
1–2		11	27
3–4		16	39
5–6		8	20
7–8		5	12
> 8		1	2

[a] $n = 39$.

Mastery subscale ($p < .001$), on which lower scores indicate better coping mechanisms. Scores obtained on the Personal Strain and Financial Burden subscales and the total score did not differ.

No sex differences were found. The scores failed to reach significance when regressed on current age, age at transplant, years posttransplant, and total number of hospitalizations since transplant. Correlations are shown in Table 5.

Additional Variables Related to the Psychosocial Adaptation

Number and duration of hospitalizations and medications are presented in Table 6. The frequency of each reported side effect and the degree to which each side effect was problematic is presented in Table 3. Gum overgrowth and diminished height were reported to be at least somewhat troublesome for about two thirds of the patients, with about one third of patients also experiencing mood swings, hirsutism, migraine headaches, low energy levels, and dental decay as somewhat or more troublesome.

Relation Between Immunosuppressants and Side Effects

The results of the correlation analyses are presented in Table 6. No relations were found between the number and severity of side effects with dosages of cyclosporin, prednisone, and imuran. Correlations between specific symptoms known to be related to specific medications and levels of those medications were also not significant.

DISCUSSION

Our findings indicate that, on multiple measures of function, children and adolescents who are long-term survivors of liver transplants live competent lives. As we hypothesized, when study patients had lower function levels than the normative data group, the comparison group consisted of medically well children. When the comparison group consisted of chronically ill children, study patients generally had equivalent and, on some measures, better function. In contrast to our hypotheses, regression analyses did not elucidate the contribution of specific disease and transplant process variables to adaptation.

On emotional and behavioral measures, girls showed fewer difficulties than the normative group of chronically ill children, whereas boys showed equivalent adjustment. Children who are long-term survivors of liver transplants showed some deficits in social competence when compared to well cohorts. Boys spent less time and showed fewer skills in activities such as sports, hobbies, and chores at home. Girls and younger boys had less competent scholastic function, although note that we did not control for school days missed. Also note that, although the differences are generally statistically significant, group scores are within 1 standard deviation of the well population, suggesting that the deficits may not be clinically significant. It is possible that physical limitations faced by these children contribute to their deficits. Some side effects, such as low energy level, may also prevent these children from performing at the level of their peers. In addition, social competence differences may be due to parental restrictions. It has been reported that parents become overprotective of their child following a transplant (Gold et al., 1986). Future studies may investigate the mediation of family function on the adaptation of children following transplants. Finally, these comparisons do not include controls for length of illness, which may be a confounding variable.

The majority of our patients were in the preadolescent age group. Although deficits in adaptation were not found in older age groups, the small number of older participants may be obscuring findings that exist in the older age group as well. Adolescence is undoubtedly a difficult time for children with chronic illness (Cromer & Tarnowski, 1989; La Greca, 1990), and more difficulties may become apparent in this cohort, as the children grow into their teenage years. Longitudinal studies of these children's function may clarify this issue.

Our study has several significant limitations. Because the majority of the instruments used in this study were designed to be completed independently by parents, there is some question about the bias introduced by completion through telephone interview. Social desirability effects may be heightened when an examiner is involved in recording the data. The investigators attempted to minimize this effect by informing the parents that the individual gathering the data was not a part of the treatment team and that specific responses would not be provided to the medical team. In addition, there is some question as to the psychometric properties of instruments designed to be completed independently but used in telephone survey format for this study. Again, although this possible bias cannot be eliminated, this limitation is inherent to the broad-based survey method, and it has been used by other investigators who intended to contribute to the literature by providing information from a broad sample (e.g., McCormick, Stemmler, Bernbaum, & Farran, 1986).

Another important limitation is the heavy dependence on parental report alone. Ideally, a study assessing adjustment would include information from several sources, using both in vivo, face-to-face interview and paper-and-pencil measures and including objective measures (e.g., tests of academic achievement) as well as self-report. The data reported in this study were obtained exclusively from a parent, through telephone interviews, using paper-and-pencil measures and relying on self-report alone. Face-to-face interviews are likely to capture more complexities. These limitations can be considered inherent to the goals of our study, which were to provide as comprehensive participation from the subject pool as possible and to broaden existing results from more precise assessments with smaller subgroups of the population.

Finally, a significant limitation is the absence of a control group. We compared our findings to the population from whom the normative data were obtained; this is not equivalent to comparing findings to a matched control group. Our data do not indicate how our group fares compared to children with other comparable chronic illnesses. However, note that there really is no group of children with medical illnesses that would provide an adequate control group for children with liver transplants (Stewart, Kennard, Waller, & Fixler, 1994; Stewart et al., 1989). The best control group for studies such as this one may be the patients themselves prior to transplant. Although we did not gather data on children with end-stage liver disease prior to transplant, the dismal quality of their function is well known to all professionals who work with the population.

IMPLICATIONS FOR CLINICAL PRACTICE

Two observations related to our data may be helpful to the clinician working with families of liver transplant patients. First, preadolescent male transplant recipients may be especially vulnerable to the development of social competence difficulties, and they may benefit from additional long-term support. Our data suggest that it may be worthwhile to evaluate these boys carefully and consider preventive programs on a routine basis. Second, consistent with earlier findings (Stewart et al., 1991), posttransplant children show less competence in school compared to their well peers. Stewart et al. (1991) noted that, although children showed academic deficits, they rarely were identified as being in need of remedial services in the schools. The fact that school difficulties persist may be a result of inadequate early remediation, and this suggests that educational progress should be routinely assessed and remedial recommendations made to optimize these children's school performance. It is our experience that parents frequently ask about the quality of the outcome to be anticipated following liver transplant. Although these questions are occasionally posed before the transplant itself, we have frequently heard parents question their own decision regarding seeking a transplant during the early posttransplant period, when the child and the parents face considerable personal stress. It is usually during this stabilization period that the euphoria of obtaining a transplant diminishes and the families begin to consider what lies ahead now that the major goal has been reached. These data allow the clinician working with the parents to provide some quantitative information regarding psychosocial functioning in long-term survivors of transplants. We have also observed that the major physical changes that result in children following surgery and immunosuppressant initiation can be very troubling to the families and the older children. The fact that only 40% of patients report even one symptom as being troublesome may be of some consolation to these families at this difficult time in their lives.

Important findings are that children's posttransplant health status is not a greater source of personal strain for the primary caretakers than that experienced by parents of other children with chronic illness and that health status does not interfere with social interaction for the family at large. In addition, the primary caretakers appear to have a strong sense of mastery. That is, they are better able to manage the psychological burden and stress of the illness by employing effective coping strategies than are other families with chronically ill children, perhaps as a result of the adversities of the illness. Note that parents had very positive attitudes about their child's present status, with many indicating that they now felt that their child could live a normal life. Certainly, one may speculate about the cognitive mechanisms (e.g., dissonance) that would encourage parents who have made such significant sacrifices to view the outcome as positive. However, when there would be little incentive to focus solely on the positive aspects of the outcome, several parents stated that, despite the intense stress before and immediately following the transplant, the gains experienced by their child as a result of the transplant made the whole process unequivocally worthwhile.

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