

Family Stresses After Pediatric Heart Transplantation

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Parents of ten children who underwent cardiac transplantation at the authors' institution participated in this study to evaluate the effect of heart transplantation on the family. Parents completed the Hymovich Chronicity Impact and Coping Instrument (CICI) and/or the Feetham Family Function Survey (FFFS) 3 to 24 months (mean, 8.4 months) after the transplant. Results indicate that parents face significant psychological and social stresses after their child's heart transplantation related to (1) the uncertainty of the child's future health and well-being, (2) role strain, (3) social isolation, and (4) financial burdens. Recommendations for nursing practice are suggested.



Since 1980, a striking increase in the number of heart transplants in children has occurred across the country, with little examination of the profound psychologic and social effect on the child, parents, and siblings. Limited data about the quality of life or life satisfaction of adult heart transplant recipients suggest that most patients are afforded physical capability for resumption of almost all activities and report good to excellent quality of life.^{1,2} Adult patients after the transplant, however, have expressed concern about role relationships³ and have experienced problems including mood alterations, changes in body image, marital stress, and other family-related problems.⁴ Little is known about the problems facing pediatric patients and their families after heart transplantation. Decisions about cardiac transplantation for children must inevitably be made by parents, rather than the patient themselves. Parents have a duty to protect and nurture their children and to promote their children's well-being in all ways that are open to them.⁵ Parents are,

also therefore, likely to feel responsible for the consequences of their decision regarding transplantation.

In a review by Pennington and associates,⁶ 32 of 36 children were attending school after a cardiac transplant without symptoms referable to the cardiovascular system. At the University of Pittsburgh, eight surviving pediatric patients 4 months to 4 years after heart transplantation have returned to age-appropriate activities, as reported by Fricker et al.⁷ Although these children are no longer acutely ill, it has been apparent that parents expend considerable effort to make the child's life as normal as possible. The purpose of this study is to evaluate the effect of pediatric heart transplantation on the family, especially to identify common stresses and needs of these families with implications for interventions by health professionals.

Methods

During a 42-month period, beginning in June 1984, 13 children from 6 months to 16 years of age (mean, 8.0 years) underwent heart transplantation at our institution (Table 1). There were five girls and eight boys. Seven of 13 children had a cardiomyopathy, 4 had severe ventricular dysfunction with congenital heart disease, and 2 had had Norwood I procedures for hypoplastic left heart syndrome. Our first patient, transplanted at 2 years of age, died suddenly 17 months later, with coronary artery disease found at autopsy. One child with hypoplastic left

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TABLE 1. Pediatric Cardiac Transplants From June 1984 to December 1987

Patient No.	Age at Transplant	Diagnosis	Rejection Episodes	Immuno-suppression	Status
1	2 yrs	Cardiomyopathy	10	C,P,A	Died, 1 yr 5 mos
2	6 mos	Complex CHD with severe ventricular dysfunction	2	C,P	Alive, 3 yrs 1 mo
3	13 yrs	Cardiomyopathy	6	C,P	Alive, 2 yrs 7 mos
4	4 yrs	Cardiomyopathy	7	C,P,A	Alive, 2 yrs 6 mos
5	16 yrs	Cardiomyopathy	6	C,P	Died, 10 mos
6	16 yrs	Cardiomyopathy	7	C,P	Died, 9 mos
7	3 yrs	AS with severe ventricular dysfunction	1	C,P,A	Alive, 10 mos
8	13 yrs	Complex CHD with ventricular dysfunction	1	C,P,A	Alive, 8 mos
9	6 yrs	Cardiomyopathy	0	C,P	Alive, 8 mos
10	2½ yrs	HLHS	0	C,P	Died, 1 mo
11	16 yrs	Cardiomyopathy	1	C,P	Died, 1 mo
12	11 yrs	Complex CHD with severe ventricular dysfunction	2	C,P,A	Alive, 6 mos
13	1¼ yrs	HLHS	0	C,P,A	Alive, 1 mo

C = cyclosporine; P = prednisone; A = azathioprine; CHD = congenital heart disease; AS = aortic stenosis; HLHS = hypoplastic left heart syndrome.

heart syndrome died during the transplant hospitalization after 1 month on ventilatory and vasopressor support. Three adolescents died 1, 10, and 9 months after the transplant, two with rejection and one with Epstein-Barr virus and an associated lymphoproliferative process. Eight children are surviving 1 month to 3 years (mean, 1.4 years) after transplantation with no symptoms referable to the cardiovascular system.

Parents of ten children who underwent cardiac transplantation participated in this study (Table 2). Parents of three children less than 3 months after the transplant were not included. Seven parents were married and three children had single parents at the time of transplant. Two mothers did not have a high school diploma, five parent participants had a high school education, and three parents had higher education. The parents in the survey ranged in age from 20 to 57 years at the time of transplant. Regarding annual family income, four families had incomes less than \$10,000 per year, two other families had incomes less than \$20,000 per year, and only one family with 11 children had an annual income greater than \$30,000. In three of ten families, the child with a heart transplant was the only child.

To evaluate the effect of heart transplantation on the family, parents completed the Hymovich (1981) Chronicity Impact and Coping Instrument (CICI) and/or the Feetham Family Function Survey (FFFS) 3 to 24 months (mean, 8.5 months) after the transplant. The CICI was developed to obtain parental perceptions of their child's illness or disability and information on how parents cope with difficulties they encounter as a result of their child's condition.⁸ This instrument is intended to provide health professionals with an assessment protocol to identify the needs of families. FFFS is a method of systematically

assessing the many relationships that contribute to or that are affected by family functioning.⁹ Family functioning is measured by the parent's perception of the degree to which the function exists as compared with how much there should be, using the Porter¹⁰ technique. This format

TABLE 2. Sociodemographic Characteristics

Child's age at transplant	
Mean (yrs)	8.4
Range (mos-yrs)	6-16
Child's sex	
Female	4
Male	6
Race	
White	8
Black	2
Parental marital status	
Married	7
Other	3
Parental education	
9-11 grade	2
High school	5
Some college	2
College graduate	1
Family's annual income	
< \$10,000	4
\$11,000-\$20,000	2
\$21,000-\$30,000	3
> \$30,000	1
No. of siblings	
0	3
1-2	4
3-4	2
11	1

TABLE 3. Parental Concerns*
(The Chronicity Impact and Coping Instrument) (n = 9)

	Frequency (%)	Mean Severity*
Uncertainty of child's future	8 (88.9)	4.2
Extra demands on time/energy	8 (88.9)	3.7
Child's happiness	7 (77.8)	3.6
Child's care/parenting	6 (66.7)	3.4
Time alone with spouse (n = 7)	4 (57.1)	3.2
Time for relaxation/recreational activities	7 (77.8)	3.0
Sexual relationships (n = 7)	4 (57.1)	3.2
Inadequate insurance/community support	5 (62.5)	3.2

*In order of degree of concern × frequency.

allows for an indirect measure of the degree of dissatisfaction with functioning, the discrepancy or difference between the amount of reported activity, and the amount desired.

Results

After pediatric heart transplantation, parents identified specific concerns, coping responses, and needs within the family. Table 3 shows the concerns reported by more than 50% of the parent respondents and the mean rating of severity or degree of concern, based on a five-point Likert-type scale (1 = "none," 5 = "a great deal"). The uncertainty of their child's future was the most serious concern (mean, 4.2) of these parents (8 [88.9%]). Another significant problem commonly identified, based on the CICI, related to extra demands on the parent's time with diminished physical energy (8 [88.9%]). Further concerns frequently expressed by parent respondents included worry about their ability to promote their child's happiness (7 [77.8%]) and to provide optimal care for their child (6 [66.7%]), in addition to spending inadequate time alone with their spouse (4 [57.1]) and for relaxation/recreational activities (7 [77.8%]). Five parents also reported concern about having adequate insurance and community resources to meet the child's needs.

When asked about perceived concerns of their spouse, the parent respondents reported similar problems including (1) limited time for relaxation/recreational activities (5 [71.4%]) with extra demands on time and decreased energy because of all the family's needs (6 [85.7%]); (2) having enough time alone/outside the home with spouse (6 [85.7%]); and (3) promoting their child's happiness (5 [71.4%]) and getting to do activities together as a family (6 [85.7%]). Four parent respondents also reported that their sexual relationship was a probable concern of their partner.

TABLE 4. Perceived Spouse Concerns*
(The Chronicity Impact and Coping Instrument) (n = 7)

	Frequency (%)	Mean Severity*
Time for relaxation/recreational activities	5 (71.4)	4.6
Time alone/outside home with spouse	6 (85.7)	3.8
Extra demands on time/energy	6 (85.7)	3.3
Child's happiness	5 (71.4)	3.8
Family activities	6 (85.7)	3.0
Sexual relationships	4 (57.1)	3.0

*In order of degree of concern × frequency.

After their child's heart transplantation, parents identified some changes in coping behaviors, in the ways they dealt with problems or concerns which arose because of their child's condition. Parents reported more talking with someone and more praying, but were less likely to get away or to exercise. Parental beliefs were consistent with the responses and concerns described. Most parents (88.9%) perceived little control over their child's condition. Seven parents did believe that talking about one's feelings to others was important. Five parent respondents also believed that it could be helpful sometimes to get away from the stress/situation. Avoidance or denial was not advocated by these parents.

When data from the FFFSs were examined, areas of family functioning in which most families experienced discrepancy after the transplant paralleled the CICI findings described. Among family functioning indicators, problems included time for leisure/recreational activities in seven families, time with spouse/satisfaction with marriage in three of six families, time with neighbors in five of eight families, and disagreements with spouse in six of six families. Consistent with the CICI data, these concerns point toward social isolation and marital strain in families after heart transplantation. Five families again reported financial strain related to the child's heart transplant.

In view of the increased demands and decreased energy reported by parents in the CICI, it was helpful to look at how parents rated their time related to the child with a heart transplant. On a Likert-type scale (0 = "none," 5 = "much"), parents rated worrying about their child highest (mean, 4.5). Since energy is used to cope with stress, this perhaps explains the perceived decreased energy reported by most of the parents. Parent respondents also spent considerable time enjoying their child (mean = 4.4), focusing attention on this child, feeling extremely grateful for being given "a second chance." Parents did seem to feel the burden of their child's frequent medical follow-up after the transplant (mean = 4.0). Interestingly, although parent respondents had felt they had insufficient time alone with their spouse, they spent considera-

ble time talking with their spouse about the child (mean = 4.0). The amount of instrumental and emotional support from relatives varied greatly among the families, but did not differ significantly from the amount of support parents reportedly expected. Only one parent reported that the amount of time with health professionals was slightly less than desired.

Finally, using the CICI, parents indicated their informational needs. Parents especially expressed concerns about their child's emotional needs, specifically how their child would cope with the transplant, medications, and body image issues in the future. Most parents asked for more help and/or information concerning physical care of their child including diet and care of minor illnesses; play or recreational activities; and the child's physical, social, and emotional development.

Discussion

Parents face major stresses after their child's heart transplantation. These stresses are related to the uncertainty of the child's future health and well-being, role strain, social isolation, and financial burdens. It is likely that for most patients and families, the psychologic stresses and adjustments associated with cardiac transplantation originate not during the process of transplantation itself but with the discovery of life-threatening illness.¹¹ However, as noted by Gold and associates,¹² after facing the realization that the transplant does not provide a complete cure, parents experience a new set of stresses and must "adapt to the new disease called organ transplant." Parents who had become adept at recognizing signs of increasing cardiac distress, must live with the uncertainties of rejection, side effects of required medications, and possible adult lifestyle implications. Parents perceive a lack of control and continue to direct their attention and resources toward the child with a heart transplant.

In addition to worries about their child's heart transplant condition, families experience other concurrent stresses which may affect the child and the functioning of the family as a unit. Readjustments in family structure have been observed after pediatric heart transplantation.¹² Role strain occurs when individuals have difficulty meeting other's expectations and fulfilling obligations included in various roles they accept.¹³ Role strain also results when the demands of a role are greater than the individual's personal resources. In this study, parents expressed concern about their ability to meet expectations of parent and spouse roles. Many parents expressed concern about their ability to provide optimal care for their child and to promote their child's happiness. Married parents also worried about not having sufficient time

alone with their spouse and suggested some self- and spouse dissatisfaction with their sexual relationship. Focus on the child may diminish physical energy available for meeting demands of spouse and other roles. Role strain may be minimized, however, through negotiation and role flexibility.

Familial social isolation was also experienced by these families who reported little time for relaxational or recreational activities. It has been suggested that these families believe it is impossible for other people to understand what the experience of the transplantation process is like.¹² Sharing the burdens and stresses with others, however, may be an important coping strategy to minimize the family system's vulnerability to stress. Furthermore, adequate rest and relaxation are valuable resources to facilitate coping with stressful situations and maintenance of family stability.

Finally, medical expenses and related financial burdens also contributed to family stress. Even though parents were currently receiving financial assistance with medical expenses when necessary, parents worried about the future adequacy of insurance and community/social services. Parents perceived adequate support from health professionals, but desired additional informational support especially regarding their child's psychologic and social needs.

Conclusion and Recommendations

We conclude that pediatric heart transplantation may have long-term psychosocial effects on the entire family. Although families adapt to the child's chronic condition "heart transplant," there are potential deleterious effects on family functioning. Parents experience chronic stress and tend to focus their attention and direct their energy toward the child with a heart transplant. Role strain can occur when parents have difficulty fulfilling obligations of parent, spouse, and various other roles. Social isolation can further restrict their coping.

Cardiac transplantation seems to be a viable therapeutic alternative for children with terminal congenital and acquired heart disease, as concluded by Fricker and associates.⁷ Further research must be conducted, however, to identify the long-term psychosocial effects of heart transplantation on children and families. A more comprehensive study using a larger sample size from multiple transplant centers is proposed. Currently, clinicians working with these families need to assess family stress and coping to see if families are adapting or if they may need further assistance and professional intervention to enhance coping and improve family life. Besides the instruments used in this study, the Coping Health Inventory for Parents¹⁴ is another valid measure of parental

TABLE 5. Recommendations

- Assess family stress and coping before and after pediatric heart transplantation
- Provide opportunities for family members to communicate their feelings
- Encourage parents to obtain periodic relief from child care activities through utilization of support from other family members, friends, and parents
- Provide anticipatory guidance to parents regarding child's physical care and socio-emotional needs
- Identify resources for long-term psychologic and financial support

coping which could be administered in a nonthreatening manner to parents. Recommended interventions are summarized in Table 5.

Unfortunately, uncertainties about the child's future after heart transplantation cannot be dispelled. Families may benefit, however, from opportunities to ventilate their feelings; periodic relief from child care activities; and anticipatory guidance as much as possible from health professionals regarding their child's physical, social, and emotional needs. Furthermore, we recommend identification of resources for long-term psychosocial support of these children and their families.

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References

1. Baldwin JC, Stinson EB. Quality of life after cardiac transplantation. *Quality of Life and Cardiovascular Care*, 1985;332-335.
2. Lough ME, Lindsey AM, Shinn JA, Stotts NA. Life satisfaction following heart transplantation. *Heart Transplantation* 1985;4: 446-449.
3. Hyler BJ, Corley MC, McMahon D. The role of nursing in a support group for heart transplantation recipients and their families. *Heart Transplant* 1985;4:453-456.
4. McAleer MJ, Copeland J, Fuller J, Copeland JG. Psychological aspects of heart transplantation. *Heart Transplant* 1985;4:232-233.
5. Curtin L, Flaherty MJ. *Nursing Ethics—Theories and Pragmatics*. Maryland: Brady Communications Co, Inc, 1982:226.
6. Pennington DG, Sarafian J, Swartz M. Heart Transplantation in children. *Heart Transplant* 1985;4:441-445.
7. Fricker FJ, Griffith BP, Hardesty RL, et al. Experience with heart transplantation in children. *Pediatrics* 1987;79:138-146.
8. Hymovich DP. The chronicity impact and coping instrument: parent questionnaire. *Nurs Res* 1983;32:275-281.
9. Roberts CS, Feetham SL. Assessing family functioning across three areas of relationships. *Nurs Res* 1982;82:231-235.
10. Porter LW. Job attitudes in management. *J Appl Psychol* 1962;46: 375-385.
11. Christopherson LK. Cardiac transplantation: a psychological perspective. *Circulation* 1987;75:57-62.
12. Gold LM, Kirkpatrick BS, Fricker FJ, Zitelli BJ. Psychosocial issues in pediatric organ transplantation: the parents' perspective. *Pediatrics* 1986;77:738-744.
13. Fife BL. A model for predicting the adaptation of families to medical crisis: an analysis of role integration. *Image: The Journal of Nursing Scholarship* 1985;17:108-112.
14. McCubbin H, McCubbin M, Nevin R, Cauble AE. *Coping Health Inventory for Parents* (1979). In: McCubbin H, Thompson A (eds). *Family Assessment for Research and Practice*. Madison: University of Wisconsin-Madison, 1987:175-192.

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