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PSYCHOLOGICAL AND SOCIAL EFFECTS OF INFANT HEART TRANSPLANT ON FAMILIES

A Thesis
Presented to the
Faculty of
California State University,
San Bernadino

In Partial Fulfillment
of the Requirements for the Degree
Master of Science
in
Psychology

by
Judy Rick Jacobson
June 1989

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[redacted] 6/12/89
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ABSTRACT

This exploratory and descriptive study was undertaken to obtain information about multiple, selected aspects of the psychosocial adjustment of parents of surviving infant heart transplant recipients. Parents of ten of the first fifteen infants to undergo infant heart transplant at Loma Linda University Medical Center, ten mothers and seven fathers participated in a semi-structured interview, completed a written questionnaire and four psychosocial inventories assessing self-esteem, marital satisfaction, a scale of stresses, and an adaptation and adjustment measure. Interview data was transcripted and content analyzed for adaptive and maladaptive family system functioning and stressors were identified for three critical periods: pre-operative, peri-operative and long-term post-operative. Anecdotal support was found for hypothesis one, that differences in sociodemographics would be reflected in in different adaptation and coping styles and differing levels of compliance to medical protocol. Hypothesis two, that mothers and fathers will cope differently and the differences will be reflected in role expectation and gender role sterotypes was generally supported. Hypothesis three, that parents who evidence higher self-esteem, marital satisfaction and lower stress levels will cope more effectively did not receive support and the correlations failed to identify an adaptive pattern of coping. This research provides an overview of coping and adjustment in parents of infants undergoing heart transplantation and suggests quantitative research to identify long-term psychosocial effects of infant heart transplantation for families.

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INTRODUCTION

For the past two decades increasing attention has been paid to the effect that acute and chronic illness in children has on their families. The present decade has heralded transplantation of various organs in children and the consequent psychosocial effects. While transplantation has become increasingly accepted as a form of therapy, the risk of mortality is still relatively high. Most types of transplantation require prolonged hospitalization. Thus, any family with a child undergoing the transplant procedure will face global issues of readjustment.

As recently as January, 1986, Clochesy, Whittaker and Murdaugh reported a 95% mortality rate for infants with hypoplastic left heart syndrome (HLHS) despite surgical intervention to repair the heart and they believed neonatal cardiac transplantation theoretically would not be successful. However, in October of the same year, Bailey et al. (1986) published three case reports of infants who had received transplants during the neonatal period and survived. The first recipient is now in his third year and is doing well, and the number of parents choosing this alternative for their infant is rapidly increasing. While infant heart transplantation is still considered experimental, the current survival rates appear very promising. Currently, HLHS is the most common defect for which infant heart transplantation is being performed. As of June, 1989, forty-four infants have undergone heart transplant surgery at Loma Linda University Medical Center with 36 surviving.

One area of concern in infant heart transplantation is the psychological sequelae of infant heart transplantion for parents. As with any infant hospitalization, the psychological ramifications for the family are varied in their intensity and impact. With infant heart transplantation, however, the effect on the family may be profound due to the inherent high risk involved as well as the experimental nature of the procedure. Data are not yet available for long-term survivors of infant heart transplant, nor for the long-term effect that immunosuppressive drugs may have on development, nor for the significance this could have for the family system of the children involved.

Many factors contribute to the difficulties experienced by parents who have an infant with a life-threatening heart condition. To begin with, expectant parents anticipate that their baby will be at least normal if not superior. Therefore, a crisis is precipitated for parents at the birth of an infant who is critically ill due to a congenital defect (Kaplan & Mason, 1960). These parents experience intense and conflicting emotions when their expectations of an ideal baby are not met. Not only is the infant's medical condition a shock, their role as parents is limited by the constraints of parenting in a hospital environment. It may not be possible for the parents to provide even the basic functions of caretaking, such as holding and feeding their baby. Hospital staff assume these roles, and the parents may feel confused about what is expected of them in the intensive care setting (Steele, 1987).

The birth of an anomalous infant heightens stress and anxiety for parents at a time when they are already are likely to be physically and emotionally depleted. Following the birth of a child with a congenital defect, parents experience shock, denial, grief, guilt, inadequacy, anger and depression. Denial is especially likely to occur when the child looks "normal and healthy." The parents grieve over the loss of the expected "perfect child," as well as over the defective part of their infant. They also grieve over their own perceived loss of self-esteem, as well as the loss of their illusion of control and invulnerability. Along with the difficulty of accepting additional responsibilities and the continuous burden and stress that comes with caring for a sick infant, the parents experience guilt for being "defective procreators" (Collins-Moore, 1984)

Similarly, Steele (1987) describes the parents as not only grieving for the loss of the ideal birth experience but as experiencing anticipatory grief for the possible disability or death of their infant. The parents need to resolve the feelings created by the discrepancy between the expected and the actual infant, or the consequences will pose a threat to the integrity of the family unit. In addition, Lynn (1986) noted that parents are only able to offer love and support to their child when they have adjusted to the hospital environment. Until parents' needs have been met, they are not able to focus on the needs of the child.

Similarities in feelings between parents who have experienced the death of a child and parents whose newborn is critically ill were reported by Peppers and Knapp (1980). These feelings include denial, shock, anger, hopelessness, powerlessness, depression, confusion, isolation and anxiety. The parents may experience irritability and appetite and sleep disturbances as well as problems with concentration. They may also be preoccupied with thoughts of the baby and have dreams with themes of anxiety, anger and loss of control.

Other defensive coping mechanisms discussed by Vernon (1979) include guilt, feelings of impotence, reaction formation and blaming the physician. Parents may blame themselves or each other for their defective child, or one spouse may try to protect the other from fears and concerns. According to Vernon (1979) the culturally induced male psychological need to deny weakness and to be strong may make it more difficult for fathers to accept a disability in their child.

Blackburn and Lowen (1986) suggest that mothers have more intense reactions than fathers to the grief and stress evoked by their infant's condition. They attribute this reaction to a discrepancy in bonding time, with fathers lagging behind mothers in the bonding process and increasing their degree of bonding at a slower pace during pregnancy. Consolvo (1984) reports additional factors affecting the maternal reaction to an anomalous infant. Mothers view the fetus as a part of "self," and an imperfect baby strikes a blow to the mother's self-esteem and to her maternal role. She may feel angry and anxious when she is unable to provide the nurturance and protection that is considered an integral maternal function.

By contrast, Consolvo (1984) found fathers to react with aggression, withdrawal or stoicism when they are forced to give up their position of control and defer to health-care providers. Because of the male tendency to be less emotionally expressive, fathers may experience difficulty in their efforts to offer support to their wife at the same time they are attempting to bond with their sick infant.

Due to the immediacy of the need for the parents' decision regarding their choice of treatment following the birth of an infant with a potentially fatal heart defect, parents have no time to work through the loss of the expected "perfect" child. The mother and child may be immediately separated with consequent maternal anxiety, guilt and fear. The father may have to visit the infant and the mother in different hospitals as well as make arrangements for siblings (Clochesy et al.,1986)

Patenaude, Syzymanski and Rappeport (1979) describe the dilemma for families forced to decide between an experimental treatment, a palliative treatment or the choice of no treatment and certain death. Many of the questions parents ask have no answers. While there is hope for potential gains with treatment, there are also great emotional costs. Families suffer from the accompanying stresses and reveal problems in their interrelationships which were previously incorporated into the family's successful defensive structure. Parents who remain in a chronic state of crisis with unresolved grief may have serious social adjustment problems and significant relational difficulties (Pepper & Knapp, 1980). Related effects are caused by geographic dislocation, sibling problems due to parental unavailability and altered family relationships. Even families who have not been dislocated geographically must seek much of their emotional support from the medical care-givers, because "outsiders" simply cannot understand the complexities of the procedures sufficiently to provide helpful emotional support. Medical procedures may arouse uncertainty as well as "magical" hopes. Factors affecting family coping include the length of the patients' illness and intercurrent family stresses such as marital conflict, separation or divorce.

The process of organ transplantation for a child has a profound impact on the entire family. Parents are faced with stresses that are unique to the hospital setting. Gold, Kirkpatrick, Fricker and Zitelli (1985) gathered descriptive information from parents whose children had undergone heart and liver transplantation. They report three stages that the parents must endure with respect to their child's organ transplantation: the preoperative stage, the perioperative stage and the long-term post-operative stage.

The preoperative stage is characterized by the parents' loss of control, their denial of the child's medical reality and their attempts to build trust in the medical staff. Stresses mount as they wait for a donor organ to become available. Other concerns include guilt over the death of the donor, the competition for limited organs and the burden of informed consent. Caplan (1983) expressed the possibility for a "charade of consent." This is a consent where the parents' perception of the factual information is touched by desperation and their intense feelings affect their interpretation of facts.

Similarly, Patenaude et al. (1979) found that parents memorized concrete information provided by the medical staff but isolated and denied their emotional reactions and fears. The parents also experienced anger when abandoned by family members or friends and depression over their child's deteriorating condition during the waiting period.

In the peri-operative period the parents experience anxiety, shock and possible exhilaration over the infants' surviving the surgery. They must attempt to realign with their child and emotionally integrate the reality of the transplanted organ. This period is characterized by the fear of organ rejection and infection. Parents often experience feelings of powerlessness and isolation as well as a feeling of dependency on the hospital and medical personnel (Patenaude et al., 1979).

During the long post-operative period, the parents must adapt to a new parenting role and possible readjustment of the family structure. There is an ongoing fear of rejection and uncertainty about the child's future (Gold et al.,1985). Following transplantation there may be fears of contamination or claustrophobia aroused by the sterile isolation required. The possibility of repeated crises for the patient are great, and the dependency on care-givers produces intense and complex relationships (Patenaude et al., 1979).

Family difficulties do not end with the patient's discharge from the hospital. The adjustment after the patient is home may be greater than the family anticipated. The mother is likely to be worried and exhausted. Once home, she is more directly confronted with the physical and emotional differences between the patient and siblings or peers. The father often has had to neglect his work and take time off during the child's hospitalization. He may experience resentment at the child's continuing needs. Siblings feel jealous that the ongoing focus is still the sick sister or brother (Patenaude et al., 1979). According to Freund and Siegel (1986), while mothers may welcome the opportunity to become the primary caregiver, they may be reluctant to assume full responsibility for the child's well-being. It is difficult to relinquish the assistance and intensive support they received from the medical staff.

The post-transplant period may be marked by frequent crises. Patenaude et al. (1979) describe this period as a time of "high stakes limbo," with vacillation between hope, fear and anger. If an iatrogenic condition is induced as a result of treatment, a high potential for parental guilt exists. Psychological support systems are essential during this period.

Pfefferbaum, Lindamood and Wiley's (1977) research studying the psychosocial aspects of pediatric bone marrow transplantation describes these children as a highly vulnerable group with regard to emotional stress. Parent-child interaction was the focus of their investigation and was found to greatly influence the child's well-being. They rated factors such as frequency of parental visits and the degree of emotional support offered to the child, as well as parents' eagerness for the procedure. They found no significant predictor for survival during or after hospitalization and they speculated that the overwhelming nature of the illness outweighed any other factor. Although these factors did not affect outcome in terms of survival, they may be of critical importance in the management of families of transplant patients.

In a study of attitudinal factors in congenital heart disease (Linde, Rasof, Dunn & Rabb, 1965), significant changes in family attitudes were noted that were not necessarily related to the severity of the disease or to the child's incapacity. They found that poorer adjustment and anxiety in the child were related to high maternal anxiety and pampering rather than to the degree of incapacity. It was also noted that maternal anxiety was related to the presence of a heart condition rather than its actual severity. Interestingly, while excessive pampering and anxiety resulted in poorer adjustment in the cardiac child, the opposite effect occurred for siblings who showed better adjustment associated with maternal pampering.

According to research by Wells and Schwebel (1987), chronically ill children are not more likely to become disturbed than physically healthy children, but the younger-aged child experiences greater distress. They suggest that children with previous surgical experience may learn adaptive coping behaviors and may reveal a practice effect whereby children and mothers may learn more instrumental behaviors with repeated exposures to hospitalization. They guardedly suggest that the highest risk may be to younger children with fewer previous surgical experiences and with over-involved parents exhibiting high or low parenting stress. These parents appeared to have more anxious and avoidant attachments which may be related to less efficient coping skills and has implications for hospitalized children. Moderately stressed parents were reported to have more secure attachments.

Furthermore, Liakopoulou, Patterson, Samaraweera and Finnegan (1983) report that "the attachment process may be seriously compromised for the infant who is hospitalized for long periods." The mother may find that feelings of inadequacy, anger, rejection and guilt are elicited by the infant's behavior. While assessing temperament in a newborn plagued with stressful physical conditions was difficult, they found that a specific infant temperament profile usually emerged. They suggest that assistance may need to be provided by medical caregivers when "goodness of fit" between the temperament of the mother and baby is not supported by a mother who is repeatedly confronted with a damaged or sick infant. Inherent issues of anger, sadness, denial, guilt and depression accompany the loss of the idealized child and need to be resolved before parental acceptance of the infant can occur.

Likewise, Waechter (1977) found that the crisis precipitated by the birth of an infant with a congenital anomaly could be a major obstacle to the formation of attachment. In addition, the uncertain prognosis of the infant may affect the mother's willingness to establish a relationship with the baby and that even after the beginning bond has been established it could be interrupted by repeated hospitalizations. The infant's perceived vulnerability produced a climate of insecurity and fear for the parents, with resulting stress and a sense of inadequacy. Whether realistic or not, some parents developed an overriding concern that their child could die at any time, thus making oversolicitousness inevitable.

Gabriel (1986) in discussing possible effects of surgery on infants speculated that the brain of the immature infant may provide a "kind of protection to the developing organism that the child may lack" later in life. Liakopoulou et al. (1983) report that children who were expected to die as infants because of serious illness, may evidence separation difficulties and become infantilized due to overindulgence, as well as showing excessive bodily concerns and underachievement in school.

Additionally, Glaser, Harrison and Lynn (1964) report that feelings of inadequacy, guilt and of being punished for sins or victimized by fate may adversely affect the parent-child relationship. Overcompensation for negative and rejecting feelings or excessive anxiety may predispose the mother toward overprotection and indulgence. By contrast, maternal resentment may result in neglectful or inconsistent handling. Parents of a defective infant have not had the opportunity to conceptualize their baby as "normal." Anxiety about the child's symptoms, feelings of disappointment and irritation with their burden, and fear of death as well as problems related to hospitalization have an effect on the parents relationship with the child. This effect was sometimes manifested in making the child the central figure in the family around whom all future plans and living arrangements revolved. Even when parents recognized the problem of siblings receiving less care and attention, there was no easy solution.

Freund et al. (1985) found that some family members equated discharge from the hospital with a "cure." Often this is not the case. An ongoing threat of medical complications with rejection of the new organ is a salient danger. It may be difficult for families to resume former activities after the child's discharge from the hospital. Parents may need time to reestablish a sense of contact and unity as spouses. A mother who had a traditional, dependent relationship with the father prior to the "transplant experience," may discover a new sense of herself as a capable individual who can make competent and independent decisions. The father may have grown in his ability to function as an effective emotional caretaker. Marital tension is likely to ensue if either partner is unable to deal with the changes in the relationship required by their partner's new dimensions and role expansions. Enormous tension can be created by the "dis-synchrony" that is fostered by periods of extended physical separation as well as by differences in perceptions or emotional states.

Furthermore, a strong and intimate bond may have developed between the child and the parent who spent the most time with the child at the hospital. The lack of day to day interaction with other family members may have created a dependent or exclusive relationship for having emotional needs met. It may be difficult for parents to regain a sense of primacy and intimacy in the marital relationship (Freund & Siegel, 1986).

A family's ability to function prior to a crisis appears to be an indicator as to how well they will cope under stress. Copeland (1986) studied families having a child with cancer and reported that families who function well prior to diagnosis are more adaptable to the situation created by a medical crisis and are less vulnerable to long-term effects. On the other hand, families experiencing problems prior to the medical crisis are likely to have a more difficult time and may be more vulnerable to psychosocial problems associated with illness and treatment.

The research discussed above investigated psychosocial issues for families having a premature infant, or a child who underwent heart, kidney, liver or bone marrow transplantation or had cancer. To date no study has empirically investigated the psychosocial sequelae that *infant* heart transplantation has for families. Regardless of the type of organ transplantation or the age of the recipient, it appears that families face similar emotional stresses and use similar coping mechanisms. However, unlike other pediatric transplant recipients, an infant with a severe congenital heart defect does not have the opportunity to be integrated into the family system before his or her medical course begins. Furthermore, while parents with premature infants' may be overwhelmed by the appearance of their child, infants with hypoplastic left heart syndrome or cardiomyopathy (conditions for which transplantation offers an option) present a normal and healthy appearance making acceptance of their life-threatening heart defect more difficult. Also, since the pediatric transplant studies to date examined effects of transplantation on families with older children, it is expected that this difference in timing may have implications for the family system.

Consequently, this descriptive exploratory study was undertaken to obtain information about multiple, selected aspects of the psychosocial adjustment of parents of surviving infant heart transplant recipients and identify stressors that may be unique to this population as well as stressors common to families dealing with pediatric organ transplantation. Although this study was exploratory in nature, expectations based on the literature of acute and chronic childhood illness are included in the following general hypotheses. First, it was hypothesized that the present study will yield findings indicating that differences in socioeconomic status will be reflected in different adaptation and coping skills, as well as differing levels of compliance to medical protocol. Families expected with greater economic resources and a higher level of education were expected to adapt more readily. Second, it was hypothesizedthat mothers and fathers will cope differently, and these differences will be reflected in role expectations and gender role stereotypes. Thirdly, it was hypothesized that parents who evidence higher self-esteem, report marital satisfaction and indicate lower levels of stress will cope more effectively with the stress of their infant's transplant surgery as evidenced by the parents' perceptions of positive changes in their life and the attribution of more positive than negative changes to the transplant experience.

METHOD

Subjects

Parents of the first 12 infants to survive heart transplantation at Loma Linda University Medical Center were contacted and invited to participate in this study. When the study was initiated, 15 infant heart transplants had been performed, with 12 survivors. Parents of ten infants elected to be in the study, ten mothers and seven fathers. In cases where mother only participated, the limited information available about the characteristics of the father who did not participate in the study are included.

Some fathers of the infant heart transplant recipients were unable to participate in the study because they were living a significant distance from Loma Linda, maintaining the family home and income while the mother and child resided in Loma Linda to receive close medical supervision for the year following the transplant (as required by the LLUMC heart transplant protocol). One father participated in the written portion of the study but was unavailable for the oral interview.

Procedure

The parents of surviving infants' who received transplants at Loma Linda University Medical Center prior to May 1988 were contacted by a letter from their physician introducing the study. Subjects were asked to return a form indicating interest, no interest or requesting additional information. Subjects indicating interest or requesting information were then contacted by the investigator, and an appointment was arranged. Informed consent to participate in the study was obtained from all parents by the investigator. Data was collected using a semi-structured interview format and a self-report questionnaire.

In order to protect the confidentiality of patients and their families, each parent participant was assigned a subject identification number. The interview and questionnaire data were identified by subject identification number, and the list of subjects was kept separate from data with access limited to the investigators. While no adverse affects were anticipated, parents who wished to discuss issues raised in the interview would be afforded the opportunity to speak with a licensed therapist.

Interview

Subjects participated in a semi-structured retrospective interview ranging in length from 1 1/2 to 2 hours. The interview took place at a time and location convenient to the subject (most often in the parents' home). Fathers and mothers were interviewed separately, but whenever possible both parents were interviewed the same day. The family system was investigated using a model (Straus,1973) that evaluated parental response to the crisis of the diagnosis of a critical congenital heart defect in their infant in terms of antecedent, precipitating and consequent variables. Among antecedent variables of interest were differences in demographics and subcultural family styles of relating, experiential differences of individual parents, communication styles, role relationships and attitudes toward infant heart transplantation. The precipitating variables consisted of aspects of the crisis that caused distress and tension in the family and consequent variables were comprised of the family coping mechanisms which may reinforce negative response, causing additional crisis. The interview assessed pre and post morbid family system and role function, the decision-making process regarding the transplant procedure, and adaptive and maladaptive responses as well as coping.

The interviews were tape recorded, the recordings were transcribed and content analysis was performed. Material relevant to this study was grouped in broad quantitative and qualitative categories. Three critical periods in psychosocial adjustment were studied: the pre-operative period, the immediate post-operative period (the period of hospitalization that followed the transplant), and the long-term post-operative period (the period up to three years following release from the hospital).

Questionnaire

In addition to the interview, all participants were asked to complete a self-administered written questionnaire that included demographic material, and psychosocial inventories including the Coopersmith Self-Esteem Inventory, the Locke-Wallace Marriage Inventory, the Holmes and Rahe Scale of Stresses, the Straus Conflict Tactics Scale and the Parental Perception Inventory. In addition to the standard inventories cited above, the researcher created a measure of adjustment and adaptation to assess changes in the parents' life perceived as related to the transplant experience.

Instruments

Demographics. Demographic characteristics of the parents were compiled including: age, marital status, ethnicity, education level, employment status, annual income, number of other children in the family, and the interval in months between the transplant surgery and parent participation in the study.

Coopersmith Self-Esteem Inventory. The Coopersmith Self-Esteem Inventory (Coopersmith, 1967) is a 25-item inventory measuring self-esteem, with a score determined for each subject, using Coopersmith scoring procedures. The range of scores on the scale is 0-25, with higher scores indicating higher self-esteem.

Locke-Wallace Marriage Inventory. The Locke-Wallace Marriage Inventory (Locke & Wallace, 1959) measures marital adjustment and satisfaction. The 15-item scale includes both multiple choice and Likert-scale items and allows subjects to rate their marriage in terms of degree of happiness. On the Likert-scale subjects rate their marriage from 1-7, with a score of one registering as "very unhappy" and a score of seven registering as "perfectly happy." Overall score is computed by adding the numbers assigned to each response and determining whether the score fits into a "satisfactory" or "unsatisfactory" category. With a range of total scores between 0-158, a score above 100 indicates a "satisfactory" marriage, and a score below 100 indicates an "unsatisfactory" marriage.

Holmes and Rahe Scale of Stresses. The Holmes and Rahe Scale of Stresses (Holmes & Rahe, 1967) lists events that occur commonly in people's lives. Each of these events has been assigned a mean value that is an indicator of how stressful the event is. Subjects were asked to note the events that happened to them during the previous year and indicate the number of times that a particular event occurred in the past 12 months. The scorer multiplies the event frequency by the mean value to determine the total stress score. A total score between 150-199 indicates a mild life crisis, 200-299 indicates a moderate life crisis and a score of 300 or more indicates a major life crisis.

Straus Conflict Tactic Scale. The Straus Conflict Tactics Scale (Straus, 1979) rates subjects on their response to 20 statements regarding couples response to conflict and are separated into three categories: reason, verbal aggression and physical aggression. In this study, mean scores were not computed, but the tactics used to settle conflicts were noted.

Parental Perception Inventory. The Parental Perception Inventory (Trause & Kramer, 1983) obtains information on each parent's evaluation of his/her own needs and feelings. The inventory measured self-assessed role performance following the birth of the child who underwent transplant surgery. Responses were recorded in four areas: family support, concerns about the baby, personal feelings and marital functioning. This inventory, previously used with parents of premature infants, was adapted for the current study.

Adjustment and Adaptation. The Adjustment and Adaptation inventory was adapted for this study from an unpublished measure previously used in a cancer research project measuring life changes, abilities and feelings related to the illness, and has two scales. The first scale rates 24 items on a five-point Likert-scale, ranging from "much better" to "much worse." The second scale notes the subject's attributions as "due to the transplant" or "not due to the transplant." Only the changes attributed by the parents to the transplant were considered.

Analysis of Data

Comparisons were made regarding age, marital status, ethnicity, education, annual income, number of other children in the family, whether or not the family had to deal with geographic dislocation, and the interval between the birth of the transplant baby and the parents' participation in the study. Comparisons were also made between mothers scores and fathers' scores on the psychosocial inventories, using either mean scores or percentages as the units of comparison. Correlations were performed comparing each subjects adjustment /adaptation Score (AAS): to his/her inventory score for self-esteem (CSE), his/her marital satisfaction score (LWMS), and his/her stress score (HRSS). The data were analyzed for general patterns of psychosocial adjustment, both adaptive and maladaptive. Objective and subjective measures of adjustment from the psychosocial inventory questionnaire were compared with the content-analyzed interview data. Outcome as related to the infant's physical recovery, sources of family social support and the parents socioemotional and social role adaptation was noted, as well as treatment compliance and the number of rejections and readmissions reported by the parents.

RESULTS

Hypothesis one, that demographic differences would be related to differences in adjustment and coping skills, could not be adequately tested empirically due to the small sample size. Descriptive comparisons of demographic characteristics to coping response were made and aspects of these demographic differences that appeared anecdotally related to coping will be discussed as clinical observations. Descriptive statistics are reported in Table 1, which presents the demographic characteristics of the parent subjects in terms of age, sex, marital status, ethnic origin, education level, employment status, annual income, religious preference, geographic dislocation, and the interval between the transplant infants' birth and parent study participation.

The mean age of the parents was 31 years, with a range from 22 to 44 years. Seven couples (71%) were married, two couples (23%) were living together and one mother was a single parent. The majority of the parents were Caucasian (82%) and four were Hispanic (18%). Religious preference was almost evenly divided between Protestants (47%) and Catholics (41%), with two parents expressing no religious preference. Most parents had some college education (35%) or a college degree (35 %). Forty-one percent of the parents were employed full time (6 of 7 fathers and 1 of 10 mothers). Almost half the families (47%) reported an annual income in the category of $20,000 to $45,000.

Almost two-thirds of the families (71%) had experienced geographic dislocation as a result of the transplant experience. The mean age of the transplant baby at the time the parents were interviewed was 15.1 months. Parents of seven infants were interviewed between the seventh and eleventh month following their child's transplant surgery. Parents of the remaining three infants were interviewed between 23 and 36 months.

TABLE 1. Demographic characteristics of parents of infant heart transplant recipients

Characteristic		n (17)	%
Sex	Female	10	59
	Male	7	41
Marital status	Married	12	71
	Unmarried, living together	4	23
	Separated	1	6
Ethnicity	Caucasian	13	82
	Hispanic	4	18
Religious preference	Catholic	7	41
	Protestant	8	47
	No preference	2	12
Education level	High school or less	5	30
	Some college	6	35
	College degree	6	35
Employment status	Employed full-time	7	41
	Employed part-time	1	6
	Homemaker	6	35
	Leave of absence	2	12
	Public assistance	1	6
Annual income	Under $20,000	4	24
	$20,000-$45,000	8	47
	$45,000-$75,000	5	29
Geographic dislocation	Yes	12	71
	No	5	29
Parents age (years)	Mean = 31	SD = 7.55	Range = 22-44
Interval between birth and study participation (months)	Mean = 15.1	SD = 10.56	Range = 7-36

Five of the families had a child/children older than the transplant child, and two families had a child younger than the transplant child. In four families the transplant baby was the only child. Seven of the transplant babies were male, and three were female. Parents reported that one infant has had no episodes of rejection, three have had one rejection episode, and four have had more than one; several infants were treated for "possible" rejection. Three of the children have not required readmission to the hospital.

All parents described themselves as compliant with the medical treatment offered for their child, and this was generally confirmed by medical records and health-care providers. (Occasionally, parents had requested a delay in some treatment/procedure and felt this had been responded to appropriately by their physician.)

Hypothesis two, that gender differences would be reflected in role expectations and gender role stereotypes was generally supported by the results from the Parental Perception Inventory. As shown in Table 2, fathers were more optimistic (71.4%), were less worried about future pregnancies (57.1%), felt somewhat less helpless about the baby's condition (42.8 %) and experienced significantly less guilt about the babies condition (85.7%). Fathers were less worried about their own ability to cope (71.4%) with the transplant experience and more worried about their spouse's ability to cope (28.5%). Comparatively, the mothers were less optimistic (50%), were more worried about future pregnancies (40%) and felt slightly more helpless about the baby's condition (50%). Mothers also experienced more guilt about the baby's condition (50%). More than half of the mothers were worried about their own ability to cope (60%), but mothers were less worried about their spouse's ability to cope.

Neither mothers nor fathers reported feeling pessimistic about the baby's future, and neither group reported feeling "very guilty" about the baby's condition. The most dramatic difference was reported in their perception of being able to share their thoughts with their spouse. While only 28.9% of the fathers felt they could share all their thoughts with their spouse, 71.4% of fathers kept thoughts to themselves in order not to worry their spouse. Sixty-six percent of the mothers felt they could share all their thoughts and only 33.3% of mothers felt they needed to keep thoughts to themselves.

TABLE 2. Parental Perception Inventory responses shown as percentages (n=17)

Parents Perceptions About:	%	%	%
Baby's Future:	Optimistic	Had Questions	Pessimistic
Fathers	71.4	28.6	none
Mothers	50.0	50.0	none
Future Pregnancies:	Not Worried	Somewhat worried	Very worried
Fathers	57.1	28.5	14.2
Mothers	30.0	30.0	40.0
Helplessness about baby's condition:	Not helpless	Somewhat helpless	Varying level of helplessness
Fathers	50.0	33.3	16.7
Mothers	40.0	50.0	10.0
Guilt about baby's condition:	Not guilty	Somewhat guilty	Very guilty
Fathers	85.7	14.2	none
Mothers	50.0	50.0	none
Own ability to cope:	Not worried	Somewhat worried	Very worried
Fathers	71.4	28.5	none
Mothers	40.0	50.0	10.0
Spouse's ability to cope:	Not worried	Somewhat worried	Very worried
Fathers	57.1	14.2	28.5
Mothers	60.0	20.0	20.0
Sharing thoughts with spouse:	Share all thoughts	Keep some to self so as not to worry spouse	
Fathers	28.5	71.4	
Mothers	66.6	33.3	

Parents' responses on the Adaptation/Adjustment inventory are shown in Table 3. Mothers as a group presented a very different profile from fathers, again supporting the hypothesis predicting gender differences. A significant percentage of mothers reported positive changes in their outlook on life (90%), self-respect (70%), sense of ability (70%) and ability to handle everyday events (50%), compared to fewer positive changes reported by fathers for outlook on life (33%), self-respect (33%) and sense of ability (33%). On the other hand, fathers reported significantly more negative changes

TABLE 3. Percentage distribution of changes attributed to the transplant by fathers and mothers on Adaptation/Adjustment Inventory (n=17)

	Better		Worse	
Category	% Mothers	% Fathers	% Mothers	% Fathers
Outlook	90.0	33.3	00.0	16.6
Self-respect	70.0	33.3	00.0	00.0
Sense of ability	70.0	33.3	00.0	00.0
Sense of peace	40.0	33.3	10.0	16.6
Ability to handle everyday events	50.0	16.6	10.0	00.0
Ability to relax	10.0	00.0	50.0	16.6
Ability to plan future	30.0	16.6	40.0	33.3
Relationship to spouse	20.0	00.0	30.0	33.3
Satisfaction with work	00.0	00.0	00.0	50.0
Ability to be active	20.0	00.0	10.0	50.0
Ability to be independent	20.0	00.0	30.0	50.0

in three areas, namely, satisfaction with work (50%), ability to be independent (50%) and ability to be active (50%), while mothers reported fewer negative changes in these areas and no changes in satisfaction with work. The area representing the most negative changes for mothers was ability to relax (50%), compared to fathers (16.6%). Similarities in number and type of changes for fathers and mothers were seen in their sense of peace, their ability to plan and their relationship to their spouse.

TABLE 4. Distribution of positive and negative changes attributed to the transplant experience by fathers and mothers (n=16)

Group	Changes	Positive	%	Negative	%	Scale Score
Fathers	40	16	40	24	60	.5416
Mothers	108	75	69	33	31	.7425
Combined	148	91	61	57	39	.6672
Positive changes:						
Fathers	Mean = 2.6		SD = 1.9		Range = 1-5	
Mothers	Mean = 7.5		SD = 5.4		Range = 3-22	
Negative changes:						
Fathers	Mean = 4.0		SD = 3.9		Range = 0-7	
Mothers	Mean = 3.3		SD = 3.8		Range = 0-12	

The results from the Adaptation/Adjustment Inventory demonstrated gender differences in coping that had not been hypothesized. As shown in Table 4, mothers reported significantly more positive changes attributed to the transplant experience with an average of 7.5 changes compared to an average of 2.6 changes for fathers. As a group, mothers reported 75 positive changes (69 % of total number of changes for mothers), compared to 16 positive changes reported by fathers (40% of the total number of changes for fathers). By contrast, fathers reported more negative changes attributed to the transplant with a mean of 4.0 compared to mothers with a mean of 3.3. As a group, the fathers reported 24 negative changes (60% of the total number of changes for fathers), compared to 33 negative changes reported by mothers (31% of the total number of changes for mothers).

The percentage of positive and negative changes that parents attributed to the transplant experience as well as scale scores are also presented in Table 4. The scale score consists of a proportion such that the total number of positive changes was in the numerator and the total number of changes was in the denominator. The resulting fraction was converted to a decimal. The scale measures positivity of change with a score of one equaling all positive changes, a score of zero equaling all negative changes, and a score of .5 demonstrating an equal number of positive and negative change.

Further gender differences not hypothesized were also found in self-esteem, marital satisfaction and level of stress. Table 5 presents a summary of group mean subscale scores comparing fathers (n=7) to mothers (n=10) on three psychosocial inventories: the Coopersmith Self-Esteem Inventory (CSE), the Locke Wallace Marital Satisfaction Inventory (LWMS), and the Holmes and Rahe Scale of Stresses Inventory (HRSS). Fathers demonstrated greater self-esteem (21.1) than mothers (16.9), with a SD of 1.6. Fathers scores ranged between 11 and 25, while mothers scores ranged from 5 to 25, with an outlyer of 5. Fathers reported slightly higher marital satisfaction (4.9) compared to mothers (4.1).

TABLE 5. Group mean subscale scores on psychosocial inventories comparing fathers, mothers and parents combined scores.

Psychosocial Inventory	Mean	SD	Range
Self Esteem:			
Fathers (n=7)	21.1	5.0	11-25
Mothers (n=10)	16.9	6.6	5-24
Combination	18.3	6.3	5-25
Marital Satisfaction:			
Fathers (n=7)	4.9	1.6	2-7
Mothers (n=9)	4.1	1.9	1-7
Combination	4.3	1.8	1-7
Stress Scale:			
Fathers (n=6)	272.6	120.9	39-363
Mothers (n=10)	298.6	176.4	176-728
Combination	288.6	154.0	39-728

On a Locke-Wallace Marital Satisfaction scale not presented in table form, 68.7% of parents had marriages rated as satisfactory (with scores ranging between 104-144), and 31.3% were rated as unsatisfactory (with scores ranging from 51-97). Five parents (31.3%) responded that if they had their life to live over, they would not marry the same partner. On the Holmes and Rahe Stress Scale, 25% of parents had scores in the mild life crisis category (150-199), 37.5% of parents scored in the moderate life crisis category (200-299), and 31.3% of parents scored in the major life crisis category. (Three parents omitted stressors on the HRSS that they had reported in the interview. The mother reporting the lowest score, 176, received an adjusted score of 396, one mother scored 728 with an adjusted score of 754, and one father scored 352, with an adjusted score of 398. Adjusted scores were not used in the descriptive statistics.)

Support was not found for hypothesis three. Table 6 shows correlations between the adjustment/adaptation score as measured by changes in the lives of the parents that were attributed to the transplant experience and scores on the psychosocial inventory measures for self-esteem (CSE); marital satisfaction (LWMS); and stress (HRSS). Given the small sample size, these statistical findings are at best only suggestive. Results in these correlations do not offer support for hypothesis three, that parents who evidence higher self-esteem, greater marital satisfaction and lower levels of stress will cope more effectively as evidenced by a greater proportion of positive changes and attributions.

Although there was a significant positive relationship between scores for stress and parents' perception of negative changes in their lives, as might be expected, findings for self esteem were in the opposite direction. There was also a significant positive relation between the total number of negative changes and self-esteem. This correlation

TABLE 6. Correlation between reported changes and psychosocial measure scores (n=17)

Inventory	Total Number of Changes		Total Negative Changes		Total Positive Changes		Proportion (Positive/ Total)	
	r	p	r	p	r	p	r	p
Coopersmith Self-Esteem	.520	.03*	.631	.008*	.139	.60	.295	.267
Locke-Wallace Marital Satisfaction	.217	.41	.241	.368	.103	.70	.196	.466
Holmes-Rahe Scale of Stresses	.319	.22	.651	.006*	.089	.74	.452	.07

may be an artifact that reflects common differences in gender scores for self-esteem and the higher number of negative changes reported by fathers, rather than suggesting a substantive finding that indicates coping with a high number of negative changes leads to higher self-esteem or that high self-esteem is a predictor for the perception of a greater numbers of negative changes, which would make little empirical sense.

Additional Findings:

TABLE 7. Pre-operative, peri-operative and post-operative stressors reported by parents

Period	Stressors
Pre-operative	Diagnosis of infant's heart defect
	Negative or incomplete information from referring physician
	Immediacy of a decision regarding treatment
	Guilt about baby's condition / searching for a reason
	Issues regarding donor baby's heart
	Waiting for donor heart to become available
Peri-operative	Living arrangements in chaos
	Babysitting arrangements for other children
	Keeping friends and relatives informed
	Media attention
	Fatigue
Post-operative	Extended geographic dislocation
	Separation from friends, family and home
	Financial concerns
	Marital stress
	Feelings of isolation / housebound
	Career concerns
	Fear of infant's rejection of donor heart
	Sibling concerns
	Readjustment of family structure following discharge
	Concerns about future pregnancies
	Uncertainty about future/questions with no answers

Analysis of the interview data revealed many common stressors reported by parents for the pre-operative, peri-operative and post-operative period and are delineated in broad categories in Table 7. Half the parents reported that waiting had been the most difficult part of the transplant experience, in particular waiting for a donor heart to become available.

The transplant experience called for many changes on the part of parents. Seven parents (47%) reported changes in their role, of these seven, six were mothers. Until the birth of the transplant baby, 90% of the mothers were employed, and most expected to return to the work force after varying lengths of maternity leave. At the time of the interview only one mother was employed and she worked in a family business out of her home. By contrast, eight of the parents (53%) reported no role change, seven of these were fathers.

Parents who saw themselves "differently" since the transplant reported these differences as positive for the most part. For example, one parent described himself as more confident, several described themselves as "stronger," and some described themselves as more responsible. One mother, referring to her experience with the media exulted, "I have power."

Among changes reported were drastic changes in the parents' social lives. Eighty percent reported a marked decrease in their social life, of these parents, 50% said they had no social life at all. On the other hand, sixty percent described their family as "closer" since the transplant. Fifty percent indicated that their priorities had changed and described themselves as being more appreciative and aware, with more emphasis on the present and family concerns and less emphasis on material concerns.

Although premorbid conflict resolution style was not investigated, in answer to questions regarding conflict tactics used currently in family disagreements, all parents reported that they used reason when conflict began but 88% reported having engaged in verbal aggression themselves while 81% reported verbal aggression by their partner. Thirty-three percent reported some level of physical aggression that included throwing objects, as well as shoving and/or hitting partner.

When questioned about sources of social support, half of the parents felt that the spiritual aspects of their life were very important, and half thought that they were somewhat important. Two couples attended church on a weekly basis. Another reported source of support included counseling. Three parents had seen counselors prior to the birth of the transplant child (one had pastoral counseling following the death of her child, and one couple had family therapy following trauma to an preschool child in their family). Since the birth of the transplant child, 59% of the parents reported having seen a counselor, either a social worker, the transplant coordinator or a pastor. Although all parents interacted with the transplant coordinator on a regular basis, many parents mentioned the transplant coordinator as a source of support and counsel. No parent reported seeing a psychotherapist for issues related to the transplant experience.

When questioned about their health practices, 12 of the parents reported that they did not smoke, but five of the parents who reported smoking before the birth of the transplant baby still smoke. One reported quitting briefly and several try to smoke outdoors. Five parents reported changes in their alcohol consumption with two parents reporting drinking more and three parents reporting that they drink less. Six parents described changes in their exercise habits, with two parents exercising more and four parents exercising less. One parent made significant changes in dietary practices, reporting that before the birth of this child, she and her husband ate out frequently and often ate fast food but since the birth of this child, she has learned to cook and has become mostly vegetarian. However, most of the parents reported that they were aware of nutrition before the transplant and report no significant changes in their diet.

DISCUSSION

Even though the subject population available to be studied was small and heterogeneous, it should be clear at the outset that in spite of differences in coping skills this self-selected subject population was composed of exceptional copers. These parents were pioneers, who opted for transplant surgery for their infants even though this was an extremely new, experimental and controversial procedure. They chose this option often despite initial medical advice to the contrary and pessimistic predictions by referring physicians. This sample included the first survivors of infant heart transplantation; and all these parents, under pressure of time and emotion, made the decision to have transplant surgery for their infant and located a medical center willing to perform the surgery. In many cases, this required uprooting their family in order to make the option of transplant surgery available to their infant.

This study documented the psychosocial sequelae that infant heart transplant had for parents and the data allowed for comparison between the psychosocial status of fathers and mothers. The mean interval between the child's birth and parent participation in the study was relatively short but provided a cross-sectional view of the early participants in this program, including stresses encountered during the pre-operative, peri-operative and post-operative periods. This study did not include parents whose children died following transplant surgery nor does it present information about parents of infants with HLHS who chose not to have transplant surgery for their infant.

The high participation rate by parents exceeded expectations. The demographic and psychosocial characteristics of theses parents provided contrasts in many areas. The parents dealing with this essentially random event represented a twenty-two year age range. The majority were married and quite well educated which may be related to their choice to pursue the stressful option of experimental surgery. All of the fathers but only one of the mothers was employed at the time of the interviews.

Parents' level of self-esteem varied, with fathers scoring higher than mothers. Although the parents reported an overall perception of stability in their marriage/relationships, more than half of the parents reported a level of stress that classified them as being in a moderate life crisis or major life crisis category. Many parents reported significant changes in their life in terms of attitude and adjustment that they attributed directly to the transplant experience. Although all parents found some aspects of the transplant experience to be highly stressful they also reported experiencing very positive effects as well. No parent in the study expressed regret for having chosen to have transplant surgery for their infant. While all the parents said they could recommend the choice of transplant surgery to other parents faced with this dilemma, many said that they would not judge a parent who chose not to have the surgery. Several commented that even if their child had not survived the surgery they would feel better for having made the choice knowing that they had done all they could and the knowledge gained by medical research from their child would benefit other babies. Many of the parents have become actively engaged in promoting donor awareness following their child's heart transplant surgery.

The data from this exploratory study addressed the general hypotheses but due to the small sample size these hypotheses could not be tested using probability statistics. Instead, data was reported using descriptive statistics and findings based on case illustrations and clinical observations.

The first hypothesis, predicting that differences in socioeconomic status, education and culture would be reflected in different coping skills was partially supported. The heterogeneous sample did demonstrate different approaches to coping and adaptation. For example, the decision as to whether the family would relocate of all or part of the family and the differences in adaptation that resulted, appeared to relate to socioeconomic status. Most studies find that stress decreases and psychosocial adaptation increases with economic status and this premise was included in the hypothesis. However, contrary to expectations, families with higher socioeconomic status reported more difficulties and greater strain on relationships. Their career demands were more inflexible, and because they perceived more career and economic risks, their stress actually appears to have been greater than families with fewer financial resources.

A relatively low income couple disclosed that they would not have considered "breaking up the family" even temporarily. In this family, the father was young and a recent employee of a company that gave him an extended leave of absence. Consequently, this family did not find the relocation to be particularly stressful. In contrast, a high income couple who owned a business felt that they could not both be away for a year, so the mother and older child relocated and the father commuted between Loma Linda and the family's distant home as frequently as possible. This family reported serious difficulties in their relationship and great stress involved in relocating. Therefore, even though it appeared that one family placed their desire to avoid separation as a higher priority, the career implications were not comparable. The family with more to lose encountered greater stress and it is possible that the family's usual method of adapting to a crisis may have been interrupted by the extra demands created by their geographic dislocation.

The finding (Cockerham, Lueschen, Kunz & Spaeth, 1986) that lower-status persons are more likely than higher-status persons to be passive recipients of medical services was not given overall support in the current study. Some parents with a higher level of education, and greater financial resources did demonstrate impressive resourcefulness in securing assistance for their family (such as having a computer donated to record their child's medical data) but the lower income families did not appear to be less involved with their child's medical regimen.

A long-term study of this sample may find that families with lower socioeconomic status that appear to cope well initially, may have more difficulty when they return to their home environment; and families with higher socioeconomic status that demonstrate difficulty coping initially, may return to a high level of coping when their added temporary stressors are removed. Another possibility is that families with high or low socioeconomic status will learn new coping skills during the transplant experience that they will maintain over time. The way in which sociodemographics interacted to produce differences in coping response pose questions that have yet to be answered.

Some parents questioned whether they could emotionally and financially tolerate the relocation of all or part of the family for the period of one year as required by the medical center. Although many parents expressed concern about finances, resources available to the families although ranging from very little to quite substantial did not appear to be a determining factor in deciding whether or not to have the transplant surgery. Heuristically, it will be important to compare this finding with reports by parents who decided not to have transplant surgery for their infant.

The prediction that there would be differing levels of compliance related to sociodemographics was not supported with regard to compliance to the infants' medical protocol. All the parents reported compliance with recommended treatment and procedures, and this was corroborated by their medical records. An explanation for this high level of compliance might be found in their reported satisfaction with their relationship with their physician, the transplant coordinators and many of the interfacing health-care providers. Research by DiMatteo and DeNicole (1982) found that social-emotional aspects of patient-physician interaction are central to compliance with medical regimens.

Another explanation may be the unique, self-selected nature of the sample; these parents were willing to risk and sacrifice a great deal in order to participate in an experimental procedure in the hope of saving their infant from a terminal prognosis. As this procedure becomes more accepted and common, less effort will be necessary to secure the surgery and rates of compliance may begin to fall, more nearly matching those found for other medical regimens. Therefore, the results of this study may be indicative of the generally high motivation of this particular group.

Parents in the current study reported being asked for their input about their infant's well-being and felt informed and included in many aspects of their child's care. As one father in describing their compliance stated, "Part of the reason was they were asking us 'What do *you* think and why do *you* think or feel that way?'...They (the doctors) said when something isn't exactly right, you may know it before we do." This appears to support DiMatteo and DiNicole (1982) who reported that feeling empowered encourages cooperation and compliance, even with difficult medical regimens.

On the other hand, peripheral compliance by parents did show more variability. Parents were asked to make a number of changes in life style and routines, such as reducing the infant's exposure to the public, observing extra precautions for hygiene and learning to administer medications. In attempting to take control of their child's well-being, some parents compulsively complied, introducing routines that were inflexible and sometimes appeared to go beyond the medical staff recommendations. The guidelines for maintaining a safe home environment for the immunosuppressed baby were invitations to increased compulsivity for these parents and they exhausted themselves with elaborate precautions and rigorous adherence to their interpretation of the recommended guidelines. Others coped by using apparent denial, making few changes even when indicated.

Another contrasting exception to compliance was noted in the area of parents' health practices. Although medical personnel recommended that parents not smoke, no parents in this study stopped smoking. Some parents quit temporarily or tried to smoke outdoors, but in spite of apparent risk to the baby for respiratory problems, parents did not quit. This may provide more evidence of the power of nicotine addiction than for parents' conscious disregard for their baby's well-being since this was the only major area of non-compliance reported by the parents.

The finding in this study, that parents did not make significant changes in their health practices, offers support for the finding by Cockerham, Lueschen, Kunz and Spaeth (1986) who reported that eating properly, participating in exercise, and avoiding smoking and the use of alcohol was not affected by socioeconomic status variables.

Support was offered for the second hypothesis predicting gender differences in coping as reflected in role expectations and gender role stereotypes. Mothers reported a high percentage of positive change in the areas of outlook on life, self-respect and sense of ability which supports Freund's et al. (1985) finding that mothers faced with the crisis of their child's medical condition, may learn that they can cope with this major stress and discover a new sense of themselves as capable individuals. It appeared that mothers often added new dimensions to their role, which increased their sense of efficacy, while fathers' role perception as the provider for family often seemed threatened.

Although most of the mothers were employed before the birth of the transplant child, only one was employed at the time of the interviews. Interestingly, few mothers mentioned this as a stressor. Even mothers who reported that they had always worked did not appear to regard giving up their job as a sacrifice. As one mother stated, "I was the logical one to stay home with the baby." This gives support for the literature (Lipman-Blumen & Leavitt, 1976; Lips, 1988)) that women derive their identity and sense of achievement from their role in relationships and nurturing. Although women suffered greater disruption in their employment status, it appears to be the perception of the women that their role of mother is their most salient role. Miller's (1976) view that "serving others" is the basic principle around which women organize their lives is also given support.

On the other hand, although fathers experienced less disruption in their work, they reported satisfaction with work as one of the significant negative changes attributed to the transplant experience. They described several ways in which their work was affected. First, fathers who relocated to the Loma Linda area usually needed to find temporary employment. Secondly, fathers who commuted between Loma Linda and their home town hundreds of miles away sometimes felt overwhelmed with the added responsibility of maintaining a second home and dealing with their wife's distress at having to make her way in a new environment while she felt alone with the responsibility for the baby. Even fathers whose job/employment stayed the same reported that their career was affected. Speaking of how his career was affected by the transplant baby, one father said, "I watched every plan that I had made go out the window". Fathers reported that their ability to be independent was significantly affected, along with their decreased satisfaction with work, this offers further support for gender role stereotypes that find that men derive their identity/satisfaction from their job/career, as well as the gender stereotype of men as powerful and independent (Lips, 1988).

In spite of mothers' appearing to view caretaking/nurturing as their role, or maybe because of this view, mothers had more concerns than fathers about their ability to cope with the baby's condition. Fathers were more worried about their spouse's ability to cope with the situation. Mothers reported sharing more of their thoughts with their spouse while fathers reported keeping more thoughts to themselves so as not to worry their spouse. This appears to support Consolvo's (1984) finding that fathers react with stoicism or withdrawal when they are forced to give up control to health- care providers, as well as the socialized tendency for men to be less emotionally expressive.

Mothers were more concerned than fathers about future pregnancies and reported more feelings of helplessness and guilt about the baby's condition. This offers support for Consolvo's (1984) view that mothers regard the infant as a part of their "self" and experience anxiety when they are unable to fulfill important functions of their maternal role. Mother's reported inability to stop thinking about the baby offers for support Peppers and Knapp's (1980) finding that mothers are likely to be preoccupied with thoughts of the baby, as well as Blackburn and Lowen's (1986) finding that mothers have more intense reactions to the stress of having a baby with problems beginning at birth.

An additional area of concern for parents centered around their search for understanding the cause of their babies life-threatening heart defect and the attributions that they considered. Although the majority of parents reported that they did not feel guilty about their child's condition, when asked why they thought their child had this heart defect many displayed ambivalence, first stating that there was no known cause but then going on to make various causal attributions. For example, one mother revealed "if I hadn't gotten so angry at my husband when I was pregnant the baby would have been okay," and a father said, "If you do things right, you should get an 'A' ". These responses reflect parents' belief in the "just world" hypothesis (Lerner & Simmonds, 1966) where people believe that what happens to them is determined by their own behavior and worthiness.

Even when parents did not admit feeling directly responsible for having produced a defective child, some parents explained their child's medical problem by drawing on their religious convictions. Some described their baby's condition as "an act of God." One parent admitted, "I used to think that God was punishing me." Another mother attributed the baby's condition to the fact that she and the father were not married and didn't go to church. This may be related to Shaver's (1985) finding that individuals with high religiosity were more likely to attribute more influence to "superphysical causes" (divine influence) which are not equivalent to chance.

Another mother found an external cause. She was convinced that her child's heart defect was caused by the baby's having been conceived near a major power line and she tried to elicit support for her theory from other parents of transplant babies.

Important differences were found between fathers and mothers in terms of cognitive processes in response to crisis and decision-making. Father's decisions appeared to emphasize a cognitive perspective focusing on information gathering and objective criteria while mothers were more likely to process internally, focusing on the subjective emotional-affective aspect emphasizing their connectedness to the infant. For example, fathers made statements such as, "I stepped outside myself...I looked at the success rates," or "I tried to wipe all emotion out and look at it from a quality of life standpoint...what were the babies chances based on a statistics," or "I detached myself and approached it from an objective standpoint." By contrast, mothers made statements such as, "I put myself in the baby's position. . .could I forgive my parents for doing this to me?" or "I thought about how our baby was a fighter," and "She (the baby) showed us that she had such determination to survive."

The third hypothesis, that parents who evidenced higher self-esteem and experienced greater marital satisfaction and lower levels of stress, would be expected to cope more effectively with the transplant experience, was not supported. The correlations failed to identify an adaptive pattern.

Findings of interest, however, include fathers demonstrating higher levels of self-esteem overall, but reporting proportionately more negative changes attributed to the transplant experience than mothers. Although as a group, mothers' self-esteem was somewhat lower, they reported significantly more positive changes attributed to the transplant experience. This gender difference may be an artifact since men in general tend to have higher self-esteem than women. There was some evidence that the mothers in this study had increased their self-esteem by meeting the challenge of coping with the tremendous stress associated with the transplant experience. As one mother describing her experience proudly stated, "I'm not a crazy little girl anymore,... I've grown up,... I've learned to take responsibility. We made it!"

Marital satisfaction did not appear to be related to coping with the crisis with regard to the number of positive changes attributed to the transplant experience. Although some parents reporting a high number of positive changes did report satisfaction with their marriage/relationship, it appeared that other families in which parents (mothers in particular) reported many positive changes had low marital satisfaction. Some of the parents with low marital satisfaction reported putting the difficult aspects of their marriage "on hold" in the hope that these problems were temporary and when the family situation became normalized the problems would disappear or could be dealt with later. It was noted that couples in which both partners had high self-esteem and reported a high degree of marital satisfaction also reported more positive changes than negative changes. It was further noted that couples that had significant differences in their level of self-esteem and couples in which both partners had low self-esteem tended to have lower marital satisfaction and reported more negative changes related to the transplant experience.

There appeared to be a stronger relation between parents' perceived level of stress and positive attributions than to actual reported stressors. For example, two mothers who reported the lowest level of stress, not only appeared to have significantly underestimated their level of stress when information from the interview was compared to their self-report on the stress inventory, but also reported the highest number of positive changes that they attributed to the transplant experience. It is of interest to note that both of these mothers lost infants with heart defects shortly before the birth of the transplant baby. By contrast, the mother with the highest reported level of stress reported the greatest number of negative changes. These examples support the literature on depression (Alloy & Abramson,1979) that asserts that people who are depressed make negative but accurate assessments of their situation, while people who are not depressed make positive but inaccurate assessments about the amount of control they exert over their environment. This appears to be a cognitive distortion that serves as a buffer against stress. There may also be support for Wells and Schwebel's (1987) suggestion that parents with high and low stress appear to have less efficient coping skills, while moderately stressed parents appeared to adapt better.

Further differences in coping response were evident. For instance, one mother with high self-esteem, high marital satisfaction and a relatively low stress score, described their family's method of coping stating, "We incorporated the baby into our lifestyle, and didn't let it (the transplant experience) consume us." Another mother with high self-esteem, low marital satisfaction and a high stress score, reported, "The baby is more and more my priority; she is the focus of my life now". While the first description appears to describe a healthier adaptation, both mothers reported optimism about the future of their family. It is possible that factors such as self-esteem, marital satisfaction and level of stress, while important, may not have as great an affect on coping as hypothesized. Distinctions between coping based on these factors and coping that is based on a positive outcome are difficult to establish. One possibility is that outcome has an even greater effect since all of the parents in this study reported that their baby was doing well. Regardless of level of self-esteem and marital adjustment, would these parents be coping as well if their child had died following surgery? More information needs to be obtained about coping behaviors of parents who appear to have adjusted successfully long-term. This presents a promising area for future research.

Critical stages appear to be important in understanding parents' psychosocial adjustment. Pre-operative stressors for these families included the attitude of the referring physicians with regard to how information was presented, as well as a lack of information by these physicians, and even misinformation. Particularly stressful was a negative perception of transplantion by the physician with regard to probability and outcome. Some parents were told a transplant was impossible, had no chance of success and that they could not expect their infant to have quality of life. Verbal and nonverbal communications on the part of personnel and staff in the hospital setting affected the parents. For example, one father described a nurse averting her eyes from the baby, as well as avoiding eye contact with the parents after sharing her expectation that the baby would not live. Another mother emotionally described her perception that the nurses did not speak to the baby while caring for her and were hostile when confronted by the mother about their disengagement.

Pre-operatively, the most significant stressor was the period of waiting for a donor heart to become available. Parents watching their baby deteriorate were justifiably concerned that the baby's other organ systems could be compromised by the wait, and their feeling of helplessness at this time was especially distressing. The longer wait also meant that the surgery would be done on a sicker baby with the probability of more complications postoperatively. Parents also experienced ambivalence about their fervent wish for an available organ while worrying about "needing a baby to die" so that their child might have a chance to live.

The immediate peri-operative period was least problematic for the families. Most parents found the surgery less traumatic than the wait for a donor heart. In fact, the surgery often served to relieve anxiety and renew hope. What was stressful was the general chaos in their daily life produced by relocating to be near the medical center. Relocating families found it difficult to set up a second household while spending most of their time at the hospital with the baby. Parents also found it difficult to give adequate time and support to other children in the family who were correspondingly distressed with all the changes in their lives.

During the third stage, the long-term post-operative period, there was again a major adjustment demanded of the families who had relocated. Family members were not only separated from each other in some cases, but they were also removed from other sources of support, such as friends, church and community.

Parents reported child care was frequently a serious stressor during this period. Parents believed that most babysitters would not be able to detect subtle but important symptoms that they as parents had learned to be aware of in caring for the child's special needs. Moreover, even when the parents became secure enough to trust others with the childs's care, they found that babysitters, including grandparents, were often uncomfortable with the responsibility of caring these infant. For many parents, this severely limited their social life as well as their ability to accomplish daily tasks, since parents were advised to be cautious about where they took the baby due to risks posed by immunosuppression. This situation appeared to engender feelings of isolation for some couples and for mothers in particular. For example, mothers made statements such as, "My world has become much smaller, it's just (baby) and me", or "the baby is my whole world right now." One mother despaired, "I feel like I'm in a void".

Yet, the transplant experience was not viewed as an exclusively stressful experience. Many parents felt drawn closer together and believed that their marriage had been strengthened by surviving the transplant experience. Aspects that engendered negative feelings for some parents brought about positive and adaptive responses for other parents that included personal maturation and growth as well as increased family cohesion. Despite the potential for maladjustment, it appeared that most families were able to adapt and resume a relatively normal life after their infant left the hospital.

It is difficult at this early stage of the infant heart transplantation program to evaluate which families have had successful outcomes in terms of psychosocial adjustment. For the families of surviving infants who have returned to their homes, the long-term outlook is not yet known. But the parents of these infants report the baby's well-being in very positive terms and most express the expectation that their family life will return to normal now that they are back in their own environment with their extended family and social support systems in place. The challenge for some parents will be to change the focus from the baby as the central character and balance their family situation in terms of sibling concerns and their marital relationship.

If marital tension persists, the psychological health of all the children in the family is affected. In the future, management of the transplant infant might include an assessment of the family with particular reference to the relationship between the parents with a view to providing intensive support to less stable couples during the highly stressful pre-operative period.

Because of the pioneering nature of this program, parents must live with unanswered questions about their child's future. Long-term side effects of required medications are not known, and data is not available regarding developmental concerns. These are legitimate concerns and will need to be addressed.

Several methodological issues limit the data and the conclusions that can be made from this study, in addition to the the small sample size mentioned previously. Since the birth of a child with a life-threatening condition is rarely anticipated, the information on family functioning is inevitably retrospective and some obvious and well known problems with self-report were evident. Information from medical records included psychosocial data that was sometimes at variance with data from the interview. For example, parents were asked about conflict resolution tactics. One father reported minimal alcohol consumption and no physical aggression, yet his wife says that she fears his violence when he is drinking and there was documented evidence in support of her concerns. Although it was also difficult to assess reports regarding health practices that have a social desirability factor which may have lead to misrepresentation, the data regarding their smoking practices suggests that parents were candid in this area even when their behavior was non-compliant.

Other disadvantages common to self-report scales included missing data, which occurred because subjects failed to complete inventories or failed to understand directions. In this study attempts were made to limit some of these difficulties by interviewing both mother and father when possible and comparing their self-report with medical records. Most of the subjects appeared to be accurate historians, as verified by spouse and medical records.

As with many studies on families with health care considerations, the researcher was presented with challenges. One was the lack of objective data. It is difficult to distinguish between the psychological effects of producing a baby with a life-threatening impairment and the physical burden of the infant's ongoing care. Also, data was not available for parents who did not choose to have transplant surgery, either because they chose palliative surgery or no surgery, or for those parents whose child did not survive transplant surgery. Because of the lack of a control group, the present study could not isolate aspects exclusive to the transplant experience.

The use of an unvalidated, author-constructed questionnaire to measure reactions to the transplant experience could be considered a methodological limitation. This was necessitated by the pioneering aspect of infant heart transplantation with the consequent lack of research in this area. Because the parents in this study were among the first to experience the effects of infant heart transplant on the family, their experience was unique in some ways. For example, the intense media attention, and the longer time families in this study were required to remain near the medical center will not be a significant part of the transplant experience for future families. Therefore the results from this study might be applicable only to those participating early in the experimental phase.

The fact that all the subjects came from one medical center also poses a methodological limitation. Even though the patient population was drawn from a wide area with different demographic characteristics, other centers may provide different psychosocial services which could affect psychological outcome for the families involved.

Because of these limitations, generalizations must necessarily be made with caution. But despite the study's limitations, the in-depth information obtained from the parent interviews provides a rich foundation from which to create a better understanding of parents' experience with infant heart transplant surgery. The descriptive methodology used in this exploratory study allowed the parents the opportunity to offer information about their experience and ways the experience affected their lives.

Future studies need to investigate whether or not these stresses experienced by families have mainly short-term effects. Do families that found geographic dislocation stressful return to their premorbid level of functioning when they return home and can families who appear to cope well initially maintain this level of coping? More extensive exploration of these issues is needed with particular emphasis on the families of long-term survivors. Interpretations of psychosocial outcome data on the long-term survivors will come from studies that gather comparable data on appropriate control populations. To definitively characterize the psychosocial impact on families of infants undergoing heart transplantation, prospective longitudinal research is needed.

A future consideration might be to replicate the study with different populations, for example, parents with a healthy infant, or parents whose infants underwent minor heart surgery. Such a study might lead to a clearer understanding of the variables that appeared most significant in this study.

Although this study suggests that families of survivors have done quite well short-term from a psychosocial standpoint, some of the adverse psychological sequelae may have lasting effects on the family and provide arguable support for routine psychological assessment of families participating in the infant heart surgery program. While there are currently no "markers" for identifying or predicting high-risk families, providing early and ongoing support could prove beneficial. It is likely that the lives of the parents who choose transplantation will be profoundly affected, regardless of their child's medical outcome and it is necessary to determine how to implement the findings by determining effective interventions.

This descriptive study provides an overview of coping and adjustment in parents of infants undergoing heart transplantation. It is imperative that quantitative research be conducted to identify the long-term psychosocial effects of transplantation for families. Family functioning has frequently been neglected in family studies relating to health, but the application of this study by clinicians would be useful in dealing with parents. It is also important to explore the link between psychosocial factors and medical technology in order to determine appropriate and effective interventions that enhance adaptive functioning for the family system.

APPENDIX

INFORMED CONSENT

Research Project on Psychological and Social Effects of Infant Heart Transplants on Families

I agree to participate in the study of emotional response and family adjustment to infant heart transplantation that is being conducted at Loma Linda University Medical Center by researchers from California State University San Bernardino.

I have been told that my participation will include an interview and the completion of a written questionnaire. The interview will be approximately one hour in length and the written questionnaire will take about 1 hour to complete. I also understand that I may be contacted for one or more follow-up interviews of approximately one hour in length. I have been informed that some of the questions I will be asked are of a personal nature, and I understand that my participation is voluntary and my responses will be kept completely confidential. Medical personnel at Loma Linda University Medical Center will not have access to my answers in the interview or questionnaire.

I have been told that my participation is in no way related to my child's medical treatment. I further understand that I may excuse myself from further participation in the study at any time and that my choice not to continue will in no way effect my child's medical treatment.

I understand that information contained in my child's Loma Linda medical records may be reviewed as part of this research. I further understand that all information obtained, including interviews, questionnaires and medical record information, will be strictly confidential.

I have been told that if I have any questions or concerns regarding this research or if I wish to receive information regarding the results of this study I can contact

Dr. Geraldine Butts Stahly, or Dr. Michael Weiss, Department of Psychology, California State University San Bernardino, (714) 887-7226.

I have been told that the interview will be recorded. The tape will be kept in a locked file and after transcription and coding of data the tape will be destroyed.

I have been told that if I wish to contact an impartial third party not associated with this study regarding any complaint I may have about the study, I may contact Larry Stevens, Patient Representative, Loma Linda University Medical Center, Loma Linda, CA 92350. Phone (714) 824-4634, for information and assistance.

I have read the contents of this consent form and have listened to the verbal explanation given by the investigator. My questions concerning this study have been answered to my satisfaction. I have received a copy of this consent. I hereby give voluntary consent to participate in this study.

Date____________________

____

Signature

____

Print Name

____

Investigator

INTERVIEW

Mother_____ Father_____

1. Is__________your first child? __________

If not, how many other children do you have? __________

Could you describe your experience with other pregnancies.

____

____

____

Probes: a) were there complications? ___________________________________

b) did you ever miscarry? ______________________________________

c) have you experienced the loss of an infant? ______________________

2. Describe this pregnancy. ____

____

____

3. Baby's birth date _______________

4. Baby's sex _______________

5. When was the baby's heart problem diagnosed? _____________________________

____

____

6. What did the doctor tell you about your child's heart condition? ________________

____

____

7. When were you referred to LLUMC? ____________________________________

____

8. Could you describe your decision to have this surgery for your child? ____________

Probes: what factors did you consider? ____________

9. Did you consider other alternatives? ____________

Probes: a) no treatment? ____________

b) Norwood procedure (corrective surgery)? ____________

10. Who helped you in this decision? ____________

Probes: a) doctors? ____________

b) transplant coordinators? ____________

c) family? ____________

11. What reservations did you have? ____________

12. Were you and your partner/spouse in agreement? ____________

If not, describe ____________

13. Can you describe what it was like for you while you were waiting for a donor heart to become available for your baby? ______________________________

____

____

____

____

14. How long did your child have to wait after registering with organ procurement for a donor heart to become available? ______________________________

____

____

15. What was the date of your child's transplant surgery? ____________________

____

16. Did you ever choose not to have a recommended procedure for your child? If so, describe. ____

____

____

17. Did you ever choose to discontinue a treatment against medical advice? ________

____

18. How have the following areas of your life been influenced by your child's medical condition:

a) social activities? ____________________________________

____

____

b) family? ____

____

____

c) friends?

d) work?

e) time by yourself?

f) spiritual aspects of your life?

g) plans for the future?

h) life priorities?

i) sexuality?

j) other areas?

k) Have you found that holidays and family events (birthdays, anniversaries etc.) have been celebrated differently? If so, describe. ____________________

19. In what ways has the decision to have transplant surgery for your baby affected your life with regard to:

a) your other children (if any)? ____________________

b) having to live in Loma Linda? ____________________

c) being separated from other members of your family? ____________________

d) separation from friends/your community? ____________________

e) finances? ____________________

f) other? ____________________

20. We've talked about many areas in your life that have been influenced by your baby's heart condition. How has your marriage/relationship been affected by these changes? ____

____

____

Probes: a) your time together? ______________________________

____

____

b) your communication? ______________________________

____

____

c) your sexual relationship? ______________________________

____

____

d) other ways? ______________________________

____

____

21. Are you finding that your role in the marriage/relationship has undergone changes?

____

____

____

Probes: a) mother making decisions alone? ______________________________

____

b) father having more household responsibilities? ____________________

____

c) other ways? ______________________________

____

11. Has your role in your <u>family</u> changed in any way since your child's illness? If so, describe. ______________________________

____

____

13. Have you experienced financial problems associated with the transplant surgery and/or relocation? ______________________________

____

____

22. What member of you family has been most helpful to you since the birth of your baby? Describe. ______________________________

____

____

23. Do you think differently about yourself since the birth/heart transplant of this child?

____

____

____

24. Have you noticed a change in other people's attitude toward you since the birth/heart transplant of this child? ______________________________

____

____

25. What has been the most difficult aspect of the "transplant experience"? __________

____

____

____

26. Are there any positive aspects or experiences that have occurred because of the "transplant experience"? ______________________________

____

____

27. What has been your experience with regard to communicating with the medical staff? ______________________________

____

____

28. Are there been questions you would like to ask your child's doctors but feel reluctant to ask? ______________________________

____

If yes, what are they? ______________________________

____

____

29. Is there any information about your child's condition or treatment that you would like to have that you haven't received? ______________________________

If yes, explain. ______________________________

____

30. Have daily routines at the hospital have affected your relationship with your child?

____

If yes, describe. ______________________________

____

____

Probes: a) what has been the effect of having to mask and gown? ____________

____

____

b) seeing the baby on life support systems? ______________________

____

____

c) any others? ______________________________________

____

____

31. Can you describe what it was like to resume family life after bringing your child home from the hospital? ______________________________________

____

____

____

Probe: a) what was it like for you? ______________________________

____

____

b) for brothers/sisters? ______________________________

____

____

32. How many times has your child been readmitted to the hospital for rejection or complications? ______________________________________

Describe. ____

____

____

33. Was readmission easier or more difficult than the initial hospitalization? ________

____

____

34. Aside from the medical problem, has your experience with this child been different from that with your other children? ____________________

If yes, explain. ____________________

____

____

Probes: a) with discipline, handling, crying, sleeping, feeding, interaction with other members of the family? ____________________

____

____

b) do you find that you are more protective? ____________________

____

c) do you have different rules for this child (less strict)? ____________________

____

____

d) other differences? ____________________

____

____

33. Do you feel that the baby's physical appearance has been altered by medical problems and/or treatment? ____________________

____

____

Probes: a) by immunosuppressive drugs? ____________________

____

b) by anything else? ____________________

____

35. How do others react to your baby/child? ______________________________

____

____

36. Were you contacted by the media in connection with your child's heart transplant?

____

What was that like for you? ______________________________________

____

____

Probe: was it supportive or an intrusion? __________________________

____

____

37. How do you feel about the media now? ____________________________

____

____

38. How do you feel about families making personal appeals for organs via the media?

____

____

____

39. Do you have any idea why your child might have developed a heart condition? If yes, explain. ____

____

____

____

40. Do you think there is anything you could have done to prevent the development of this heart problem? Describe. ______________________________

____

____

41. Is there anything you feel that you can do to help your child's recovery? Describe.

____

____

____

42. What advice would you give to another parent with your child's heart condition?

____

____

____

43. If there anything you would like to share that you have not been asked?

____

____

____

PATIENT PROFILE QUESTIONNAIRE

INSTRUCTIONS: THIS QUESTIONNAIRE ASKS ABOUT YOUR FEELINGS AND EXPERIENCES RELATED TO YOUR CHILD'S TRANSPLANT. YOUR HONEST RESPONSES WILL HELP INCREASE UNDERSTANDING OF SOME OF THE CONSEQUENCES OF ILLNESS AND HELP IMPROVE SERVICES TO PATIENTS AND THEIR FAMILIES.

THERE ARE NO RIGHT OR WRONG ANSWERS. IT IS BEST TO WORK QUICKLY AND NOT LINGER OVER YOUR ANSWERS; YOUR FIRST ANSWER IS PROBABLY BEST.

ALL YOUR ANSWERS ARE STRICTLY CONFIDENTIAL. THE FOLLOWING PAGES WILL BE IDENTIFIED BY NUMBER ONLY TO PROTECT YOUR PRIVACY.

THANK YOU FOR YOUR HELP WITH THIS IMPORTANT PROJECT.

D1. Sex: _____ (1) female
_____ (2) male

D2. Age: __________

D3. Ethnic background:
_____ (1) Black
_____ (2) Caucasian (white)
_____ (3) Hispanic
_____ (4) Asian
_____ (5) Other (describe) ____________________

D4. Marital status:
_____ (1) single
_____ (2) married
_____ (3) divorced
_____ (4) widowed
_____ (5) separated
_____ (6) unmarried, living with partner

D5. List members of household living with you at the present time by:

first name	age	relationship to you
____________________	_____	____________________
____________________	_____	____________________
____________________	_____	____________________
____________________	_____	____________________
____________________	_____	____________________
____________________	_____	____________________

D6. What is the highest educational level you have attained:
_____ (1) have not completed high school
_____ (2) high school graduate
_____ (3) some college, but have not graduated
_____ (4) college graduate (Bachelor's Degree)
_____ (5) graduate degree

D7. Which of the following best describes your current employment situation:
_____ (1) working full-time
_____ (2) working part-time
_____ (3) laid off or on strike
_____ (4) unemployed (looking for work)
_____ (5) unemployed (not looking for work)
_____ (6) retired
_____ (7) disabled, permanent (on permanent disability)
_____ (8) disabled, temporary (on temporary disability)
_____ (9) on public assistance
_____ (10) full-time homemaker
_____ (11) full-time student
_____ (12) other (please describe) ____________________

D8. Has your employment situation changed since the birth of your child:
_____ (1) no
_____ (2) yes (please explain) ____________________

D9. What is your current occupation or your most recent occupation:
_____ (1) doctor, lawyer, professor, natural & social scientist, architect, engineer, etc.
_____ (2) nurse, teacher, accountant, clergy, editor, and technical worker (laboratory technician, computer programmer, etc.)
_____ (3) proprietor, manager or official, self-employed in construction, manufacturing, retail, manager, administrator, inspector
_____ (4) clerical (secretary, bookkeeper, typist, cashier, postal worker)
_____ (5) sales, including real estate and insurance
_____ (6) foreman and craftsman (electrician, machinist, carpenter, mechanic)
_____ (7) operative and apprentice craftsman (bus driver, deliveryman, apprentice carpenter, etc.)
_____ (8) service worker (cook, bartender, maid, etc.)
_____ (9) laborer (including farm: gardener, farm worker, etc.)
_____ (10) other (describe) ____________________________

D10. If you are married or living with a partner, which of the following best describes your partner's current employment situation:
_____ (1) working full-time
_____ (2) working part-time
_____ (3) laid off or on strike
_____ (4) unemployed (looking for work)
_____ (5) unemployed (not looking for work)
_____ (6) retired
_____ (7) disabled, permanent (on permanent disability)
_____ (8) disabled, temporary (on temporary disability)
_____ (9) on public assistance
_____ (10) full-time homemaker
_____ (11) full-time student
_____ (12) other (describe) ____________________________

D11. What is your approximate total family income for one year:
_____ (1) under $10,000
_____ (2) $10,000 - $15,000
_____ (3) $15,000 - $20,000
_____ (4) $20,000 - $30,000
_____ (5) $30,000 - $45,000
_____ (6) $45,000 - $75,000
_____ (7) above $75,000

D12. Check the answer that best describes your financial situation at this time:
_____ (1) cannot make ends meet
_____ (2) can get by with some help
_____ (3) have just enough to get by
_____ (4) comfortable
_____ (5) more than enough to get by
_____ (6) well-to-do
_____ (7) wealthy

S1. Please give your religious preference:
_____ (1) Catholic
_____ (2) Protestant
_____ (3) Born-again Christian
_____ (4) Jewish
_____ (5) Other (describe) ______________________________
_____ (6) No preference

S2. If you attend church, check the answer that best describes your church attendance:
_____ (1) weekly
_____ (2) monthly
_____ (3) less often
_____ (4) rarely

S3. How often do you participate in religious activities:
_____ (1) more than weekly
_____ (2) weekly
_____ (3) monthly
_____ (4) occasionally
_____ (5) rarely
_____ (6) never

S4. How important are the spiritual aspects of your life to you now:
_____ (1) extremely important
_____ (2) very important
_____ (3) somewhat important
_____ (4) not very important
_____ (5) not important at all

S5. Have you sought any professional counseling help (e.g. from a psychologist, social worker, counselor, or religious leader) in the six months before your child's diagnosis:
_____ (1) yes
_____ (2) no

S6. Have you received any professional help since your child's birth:
_____ (1) yes
_____ (2) no

If you received help from any of these people in the six months before your child's diagnosis check Y for yes or N for no:
S7. _____ Y _____ N (1) religious leader/spiritual leader
S8. _____ Y _____ N (2) social worker (in hospital)
S9. _____ Y _____ N (3) psychologist
S10. _____ Y _____ N (4) psychiatrist
S11. _____ Y _____ N (5) other (e.g. transplant coordinator)
(specify) __________________

If you received help from any of these people since your child's transplant surgery check Y for yes and N for no:

S12. _____ Y _____ N (1) religious leader/spiritual leader
S13. _____ Y _____ N (2) social worker (in hospital)
S14. _____ Y _____ N (3) psychologist
S15. _____ Y _____ N (4) psychiatrist
S16. _____ Y _____ N (5) other type of counselor
(specify) _______________

S17. Have you received a referral to any patient support groups:
_____ (1) yes (describe) ______________________________
_____ (2) no

S18. How often did/do you attend the support group:
_____ (1) more than weekly
_____ (2) weekly
_____ (3) monthly
_____ (4) occasionally
_____ (5) rarely
_____ (6) never

S19. How beneficial has the group been:
_____ (1) extremely helpful
_____ (2) very helpful
_____ (3) somewhat helpful
_____ (4) not very helpful
_____ (5) not helpful at all

H1. Before your child's birth, did you smoke:
_____ (1) yes
_____ (2) no

H2. If yes, on the average, how many packs per day in the year before your child's birth: _____

H3. Before your child's birth, did you drink alcoholic beverages:
_____ (1) yes
_____ (2) no

H4. Considering an average month the year before your child's birth, how many days in the month would you drink alcohol:
_____ (1) none of them
_____ (2) some of them
_____ (3) about half of them
_____ (4) most of them
_____ (5) all of them

H5. On a day that you drank, about how many drinks would you usually have: (consider one drink to be 1 oz. liquor, 1 can beer, or 4 oz. wine)

_____

H6. Before the birth of your child, how would you describe your awareness of nutrition:
_____ (1) very aware of nutrition
_____ (2) somewhat aware of nutrition
_____ (3) didn't pay much attention

H7. Before your child's birth, how would you describe the nutrition of your diet:
_____ (1) excellent
_____ (2) good
_____ (3) average
_____ (4) poor
_____ (5) not sure

H8. Before your child's birth, how often did you engage in vigorous exercise?
_____ (1) daily
_____ (2) at least 3 times per week
_____ (3) weekly
_____ (4) occasionally
_____ (5) rarely
_____ (6) never

H9. Since your child's birth/transplant, do you smoke:
_____ (1) yes
If yes, on the average, how many packs per day since your child's birth/transplant: _____
_____ (2) no

H10. Since your child's birth/transplant, do you drink alcohol:
_____ (1) yes
_____ (2) no

H11. Considering an average month in the year since your child's birth/transplant, how many days in the month do you drink alcohol:
_____ (1) none of them
_____ (2) some of them
_____ (3) about half of them
_____ (4) most of them
_____ (5) all of them

H12. On the days that you drink, since your child's birth/transplant, about how many drinks do you usually have:
(consider one drink to be 1 oz. liquor, 1 can beer, 4 oz. wine)

_____

H13. Since your child's birth/transplant, how would you describe your awareness of nutrition:
_____ (1) very aware of nutrition
_____ (2) somewhat aware of nutrition
_____ (3) don't pay much attention

H14. Since your child's transplant, how would you describe the nutrition of your diet:

_____ (1) excellent
_____ (2) good
_____ (3) average
_____ (4) poor
_____ (5) not sure

H15. Since your child's transplant, how often do you engage in vigorous exercise:

_____ (1) daily
_____ (2) at least 3 times per week
_____ (3) weekly
_____ (4) occasionally
_____ (5) rarely
_____ (6) never

C1. Think of the most serious problem you/your family faced prior to your child's birth with heart condition. What was the problem: ______________________

____

____

C2. What action did you take to deal with this problem: ______________________

____

____

C3. How helpful was that action in taking care of the problem:

_____ (1) extremely helpful
_____ (2) very helpful
_____ (3) somewhat helpful
_____ (4) not very helpful
_____ (5) not helpful at all

C4. Did you ask anyone for help or advice in dealing with this problem:

_____ (1) yes
_____ (2) no

C5. If yes, who: ________________________

C6. How adequate was the advice or help you received:

_____ (1) extremely adequate
_____ (2) very adequate
_____ (3) somewhat adequate
_____ (4) not very adequate
_____ (5) not adequate at all

C7. Thinking about your family during the year preceding the birth of your child, please list the three most important conflicts or disagreements you remember between you and your spouse:

(1) ____
(2) ____
(3) ____

The following list describes what you and your spouse/partner might have done when you had a conflict in the year before the birth of your baby. Taking into account all disagreements (not just the most serious ones), choose an answer from the list below that describes how often these happened:

0 = Never
1 = Once
2 = Two or three times
3 = Often, but less than once a month
4 = About once a month
5 = More than once a month

		YOU	PARTNER
A.	Tried to discuss the issue relatively calmly	0 1 2 3 4 5	0 1 2 3 4 5
B.	Did discuss the issue relatively calmly	0 1 2 3 4 5	0 1 2 3 4 5
C.	Got information to back up his or her side of things	0 1 2 3 4 5	0 1 2 3 4 5
D.	Brought in someone else to help settle things (or tried to)	0 1 2 3 4 5	0 1 2 3 4 5
E.	Argued heatedly but short of yelling	0 1 2 3 4 5	0 1 2 3 4 5
F.	Yelled and/or insulted	0 1 2 3 4 5	0 1 2 3 4 5
G.	Sulked and/or refused to talk about it	0 1 2 3 4 5	0 1 2 3 4 5
H.	Stomped out of the room	0 1 2 3 4 5	0 1 2 3 4 5
I.	Threw something (but not at the other) or smashed something	0 1 2 3 4 5	0 1 2 3 4 5
J.	Threw something at the other	0 1 2 3 4 5	0 1 2 3 4 5
K.	Pushed, grabbed, or shoved the other	0 1 2 3 4 5	0 1 2 3 4 5
L.	Hit (or tried to hit) the other person, but not with anything	0 1 2 3 4 5	0 1 2 3 4 5
M.	Hit or tried to hit other with something hard	0 1 2 3 4 5	0 1 2 3 4 5
N.	Other (please describe below)	0 1 2 3 4 5	0 1 2 3 4 5

SELF ESTEEM (Coopersmith)

Read the statements below. If the statement describes you, mark <u>LIKE ME</u>. If the statement is not descriptive of you, mark <u>UNLIKE ME</u>.

		LIKE ME	UNLIKE ME
1.	I often wish I were someone else.	_____	_____
2.	I find it very hard to talk in front of a group.	_____	_____
3.	There are lots of things about myself I'd change.	_____	_____
4.	I can make up my mind without too much trouble.	_____	_____
5.	I'm a lot of fun to be with.	_____	_____
6.	I get upset easily at home.	_____	_____
7.	It takes me a long time to get used to anything new.	_____	_____
8.	I'm popular with people my own age.	_____	_____
9.	My family expects too much of me.	_____	_____
10.	My family usually considers my feelings.	_____	_____
11.	I give in very easily.	_____	_____
12.	It's pretty tough to be me.	_____	_____
13.	Things are all mixed up in my life.	_____	_____
14.	Other people usually follow my ideas.	_____	_____
15.	I have a low opinion of myself.	_____	_____
16.	There are many times when I'd like to leave home.	_____	_____
17.	I often feel upset about the work I do.	_____	_____
18.	I'm not as nice looking as most people.	_____	_____
19.	If I have something to say, I usually say it.	_____	_____
20.	My family understands me.	_____	_____

		LIKE ME	UNLIKE ME
21.	Most people are better liked than I am.	_____	_____
22.	I usually feel as if my family is pushing me.	_____	_____
23.	I often get discouraged at what I am doing.	_____	_____
24.	Things usually don't bother me.	_____	_____
25.	I can't be depended on.	_____	_____

LOCKE-WALLACE MARITAL SATISFACTION TEST

1. Check the box on the scale below which best describes the degree of happiness, everything considered, of your present marriage relationship. The middle point, "happy", represents the degree of happiness which most people get from marriage, and the scale gradually ranges on one side to those few who are very unhappy in marriage, and on the other side, to those few who experience extreme joy in marriage.

_____	_____	_____	_____	_____	_____	_____
Very Unhappy			Happy			Perfectly Happy

State the approximate extent of agreement or disagreement between you and your mate on the following items. Please check each column.

Item	Always Agree	Almost Always Agree	Occasionally Disagree	Frequently Disagree	Almost Always Disagree	Always Disagree
2. Handling family finances	_____	_____	_____	_____	_____	_____
3. Matters of recreation	_____	_____	_____	_____	_____	_____
4. Demonstrations of affection	_____	_____	_____	_____	_____	_____
5. Friends	_____	_____	_____	_____	_____	_____
6. Sex Relations	_____	_____	_____	_____	_____	_____
7. Conventionality (right, good, or proper conduct)	_____	_____	_____	_____	_____	_____
8. Philosophy of life	_____	_____	_____	_____	_____	_____
9. Ways of dealing with in-laws	_____	_____	_____	_____	_____	_____

10. When disagreements arise, they usually result in:

_____ Husband giving in
_____ Wife giving in
_____ Agreement by mutual give and take

11. Do you and your mate engage in outside interests together:

_____ All of them
_____ Some of them
_____ Very few of them
_____ None of them

12. In leisure time do you generally prefer:

_____ To be "on the go"
_____ To stay at home

Does your mate generally prefer:

_____ To be "on the go"
_____ To stay at home

13. Do you ever wish you had not married:

_____ Frequently
_____ Occasionally
_____ Rarely
_____ Never

14. If you had your life to live over, do you think you would:
_____ Marry the same person
_____ Marry a different person
_____ Not marry at all

15. Do you confide in your mate:
_____ Almost never
_____ Rarely
_____ in most things
_____ in everything

SCALE OF STRESSES

(Holmes & Rahe)

Which of the following have you experienced in the last year (place a check in the appropriate blanks):

	YES	# OF TIMES
Marriage	____	____
Change in number of arguments with spouse	____	____
Marital separation/ break in relationship	____	____
Marital reconciliation	____	____
Sex Difficulties	____	____
Trouble with in-laws	____	____
Divorce	____	____
Pregnancy	____	____
Death of Spouse	____	____
Death of a close family member	____	____
Death of a close friend	____	____
Personal injury or illness	____	____
Change to different line of work	____	____
Change in responsibilities at work	____	____
Trouble with boss/co-workers	____	____
Changes in work hours or conditions	____	____
Fired from job	____	____
Wife beginning or stopping work	____	____
Change in financial state	____	____
Outstanding personal achievement	____	____
Change in living conditions	____	____

	YES	# OF TIMES
Revision of personal habits	____	____
Change in residence	____	____
Change in schools for children	____	____
Change in recreation	____	____
Change in church activities	____	____
Change in social activities	____	____
Change in sleeping habits	____	____
Change in number of family get-togethers	____	____
Change in eating habits	____	____
Minor violations of the law	____	____
Jail term	____	____
Financial problems	____	____
Foreclosure of mortgage/loan	____	____
Mortgage or loan of over $10,000	____	____

PARENTAL PERCEPTION INVENTORY

Circle the answer that best describes you. Please answer all the questions, but feel free to write comments about your thoughts/feelings that were not covered by the answers provided.

1. Since our baby's birth, I have
    - a. only thought about the baby once in a while
    - b. thought about the baby quite a bit
    - c. not been able to stop thinking about the baby
2. Since our baby's birth, I have
    - a. cried a lot
    - b. cried occasionally
    - c. not cried at all
3. Since our baby's birth, I have
    - a. frequently wanted to be held
    - b. sometimes wanted to be held
    - c. not wanted to be held
4. Since our baby's birth, I have
    - a. not wanted to be alone
    - b. sometimes wanted to be alone
    - c. frequently wanted to be alone
5. Since our baby's birth, finances have
    - a. been a major concern for me
    - b. been a concern for me
    - c. not been a concern for me
6. Since our baby's birth, I have
    - a. not felt I needed more time alone with my spouse/partner
    - b. sometimes felt I need more time alone with my spouse/partner
    - c. often felt I needed more time alone with my spouse/partner
7. Since our baby's birth, I feel my parents have
    - a. helped get things done and understood our needs
    - b. helped get things done but not understood our needs
    - c. neither helped get things done nor understood our needs
8. Since our baby's birth, I have
    - a. not felt worried about my ability to take care of our family
    - b. felt somewhat worried about my ability to take care of our family
    - c. felt extremely worried about my ability to take care of our family

9. Since our baby's birth, I have
    a. not felt neglected by my spouse/partner
    b. sometimes felt neglected by my spouse/partner
    c. often felt neglected by my spouse/partner

10. Since our baby's birth, I feel my spouse's/partner's parents have
    a. helped get things done and understood our needs
    b. helped to get things done but not understood our needs
    c. neither helped to get things done nor understood our needs

11. Since our baby's birth, I have
    a. been optimistic about our baby's future
    b. had questions about our baby's future
    c. been pessimistic about our baby's future

12. Since our baby's birth, I have felt
    a. much closer to my spouse/partner
    b. somewhat closer to my spouse/partner
    c. as close to my spouse/partner as before

13. Since our baby's birth, I have
    a. felt very guilty about our baby's condition
    b. felt somewhat guilty about our baby's condition
    c. not felt guilty about our baby's condition

14. Since our baby's birth, I have
    a. not felt helpless
    b. felt somewhat helpless
    c. felt totally helpless

15. Since our baby's birth, I have
    a. been very worried about future pregnancies
    b. been somewhat worried about future pregnancies
    c. not been worried about future pregnancies

16. Since our baby's birth, I
    a. panic when the telephone rings
    b. am afraid when the telephone rings
    c. am not afraid when the telephone rings

17. Since our baby's birth, I have
    a. often feared losing touch with reality
    b. sometimes feared losing touch with reality
    c. not feared losing touch with reality

18. Since our baby's birth, seeing the other babies in the nursery/hospital has
    a. been upsetting to me
    b. not particularly affected me
    c. been encouraging to me

19. Since our babies birth, seeing the equipment in the nursery/hospital has
    a. been reassuring to me
    b. not affected me
    c. been frightening to me

20. Since our baby's birth, I have wanted to talk to
    a. friends
    b. hospital staff
    c. someone who has "been there"

21. Since our baby's birth I feel the nurses and staff have
    a. been evasive
    b. answered our questions
    c. been informative and given us insight into our baby's problems

22. Since our baby's birth, I have
    a. been very worried about my spouse's/partner's ability to cope with the situation
    b. been somewhat worried about my spouse's/partner's ability to cope with the situation
    c. not been worried about my spouse's/partner's ability to cope with the situation

23. Since our baby's birth, I have
    a. been very worried about my ability to cope with the situation
    b. been somewhat worried about my ability to cope with the situation
    c. not been worried about by ability to cope with the situation

24. Since our baby's birth, I feel I
    a. can share all my thoughts with my spouse/partner
    b. must keep some thoughts to myself so as not to worry my spouse/partner
    c. must keep most thoughts to myself so as not to worry my spouse/partner

25. How is your baby doing now? ____________________________________

____

____

____

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