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Family and Child Psychosocial Functioning of Infant Heart Transplant Recipients

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Family and Child Psychosocial Functioning of Infant Heart Transplant Recipients

by

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the requirements for the degree of
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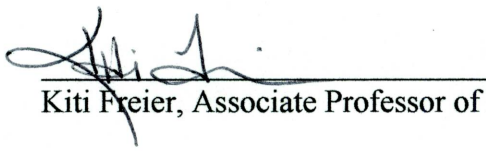
Each person whose signature appears below certifies that this dissertation in their opinion is adequate, in scope and quality, as a dissertation for the degree Doctor of Philosophy.



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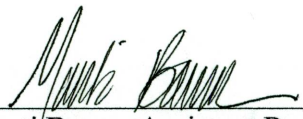

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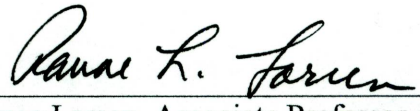

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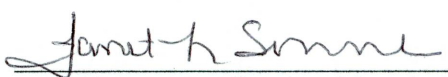

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TABLE OF CONTENTS

APPROVAL PAGE iii
ACKNOWLEGEMENTS iv
TABLE OF CONTENTS v
LIST OF FIGURES vii
LIST OF TABLES viii
ABSTRACT ix

CHAPTER ONE: INTRODUCTION 1
The Infant Heart Transplant Experience 1
Long-term Family Functioning in Infant Heart Transplant Recipients 2
Long-term Psychosocial Development in Infant Heart Transplant Recipients: 3

CHAPTER TWO: REVIEW OF LITERATURE 5
Heart Transplant: Current Issues and Findings 5
Other Transplant Groups 7
Children with Congenital Heart Disease 11
Family Functioning 13
Psychosocial Development 17
Developmental Concerns 20
Statement of the Problem 24
Hypotheses 25

CHAPTER THREE: METHODS 27
Participants 27
Inclusion Criteria 27
Exclusion Criteria 28
Response Rate 28
Methodology 28
Subject Selection 28
Procedure 29
Materials 30
Parent Cover Letter and Consent Form 30
Family Environment Scale 30
Parenting Stress Index 31
Child Behavior Checklist 32
Contest Postcard 32
Design and Data Analysis 33

CHAPTER FOUR: RESULTS 35
Respondent Characteristics 35
Hypothesis One 38
Supplementary Analysis for Hypothesis One 38
Hypothesis Two 42
Supplementary Analysis for Hypothesis One 43

Hypothesis Three 47
Supplementary Analysis for Hypothesis Three 47
Hypothesis Four 50

CHAPTER FIVE: DISCUSSION 53
Limitations 60
Future Research 62

REFERENCES 64

APPENDIX A 70
APPENDIX B 76
APPENDIX C 77
APPENDIX D 78
APPENDIX E 79

LIST OF FIGURES

Figure Page

1. Medians for the Three Study Groups on Measures of Social Competence and Depression.....41

2a. Medians for the Three Study Groups on Measures of Parenting Stress and Family Control.....45

2b. Medians for the Three Study Groups on Measure of Family Cohesion.....46

3. Medians for the Three Study Groups on Measures of Attachment.....52

LIST OF TABLES

Table Page

1. Frequency Information Regarding Demographic Variables Among Infant Heart Transplant Recipients, Children with Congenital Heart Disease, and Non-Clinical Control Children.....37

2. Planned Comparisons between Heart Transplant Recipients, Children with CHD, and Non-Clinical Controls on Measures of Social Competence and Depression.....40

3. Planned Comparisons Between Family Functioning of Heart Transplant Recipients, Children with CHD, and Non-Clinical Controls on Measures of Parenting Stress, Family Cohesion, and Family Control.....44

4. Correlations of Psychosocial Factors and Family Variables Among Individual Study Groups.....49

5. Planned Comparisons between Heart Transplant Recipients, Children with CHD, and Non-Clinical Controls on Measures of Attachment.....51

ABSTRACT

Family Functioning and Long-term
Psychosocial Adaptation of Infant Heart Transplant Recipients

by

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Loma Linda University, December, 1999
Dr. Kiti Freier, Chairperson

With the advancement of medical procedures, heart transplantation has become a viable alternative for infants born with congenital or acquired heart disease. Although these children are thought to experience much improvement in their overall physical functioning post-transplantation, the long-term psychological functioning of these children and their families is currently unknown. This study examines the long-term family functioning and psychosocial development of infant heart transplant recipients in comparison to children with congenital heart disease (CHD) and non-clinical control children. Results indicate that infant heart transplant recipients and their families experience fewer overall problems as compared to the CHD group, and more closely resemble the non-clinical control group. This finding partially contradicts earlier theoretical and empirical research conducted with similar populations. Possible explanations for these results include self-selection bias, defensive responding in the heart transplant group, and methodological issues. It is also possible that after seven years children and families undergoing the transplant procedure have adjusted to the complications inherent in this type of medical procedure. Future research should focus on more direct methods of data collection and should further evaluate the role of depression, developmental stage, and transplant related variables within these children.

CHAPTER ONE: INTRODUCTION

The Infant Heart Transplant Experience

Advances in the field of pediatric heart transplantation during the past 15 years have made possible the long-term survival of infants born with terminal heart disease. These advances in heart transplant procedure, which include the introduction of immunosuppressive drugs such as cyclosporine, and improved medical management both pre- and post-transplant, have resulted in increased survival rates for these infants. Despite these benefits, there are many potential factors that place these children at risk for developmental problems. Often these children are born extremely ill and require life supporting mechanisms and extended hospitalization while waiting for transplantation. Once a donor heart is located the infant must undergo an invasive and complicated surgical procedure carrying a number of medical risks. Post surgery, these children have an existence characterized by a lifetime of immunosuppressive drugs, clinical visits, and, at times, intrusive tests (Stuber, 1993). Their ongoing development and medical health may be further compromised by an increased risk of organ rejection and/or a serious infection (Baum et al., 1997). Combined, these factors not only influence the child but also affect the dynamics of the entire family. Although the long-term prognosis for normal life and development in these children is currently unknown, the number of risk factors these children experience emphasizes the need for research in this area. Consequently, psychologists and medical professionals need information in order to develop appropriate interventions with children and their families aimed at improving overall family functioning, preventing developmental delays, and supporting optimal social-emotional development.

Long-term Family Functioning in Infant Heart Transplant Recipients

Family members, especially parents, play an essential role in all phases of the transplant process. Not only are parents required to give consent for the transplant procedure but in doing so they commit themselves to several years of treatment and follow-up. For this reason Stuber (1993) suggests that parents must not only commit to the transplant procedure itself but also to the prolonged aftercare. During the time surrounding the transplant parents may be required to move near the hospital for long periods of time at the sacrifice of jobs and contact with other family members. Additionally marital strain and financial difficulty are commonly reported problems among these families (Stuber, 1993; Gold, Kirkpatrick, Fricker, & Zitelli, 1986). Although the above issues are more relevant during the early phase of the transplant procedure, their residual effects can last for many years. For example, the high cost of medical care and medications can place ongoing financial strain and increased stress on a family for several years. Additionally, siblings may experience long-term feelings of abandonment or resentment due to the amount of attention placed on the child requiring the transplant.

Once the child is well enough to go home, parents are often faced with a new set of challenges. They are responsible for administering immunosuppressive drugs, for monitoring the child for possible signs of rejection or infection, and for trying to restore some sense of normalcy to their family. This is extremely difficult, especially when the parents may be overly fearful of their child becoming hurt or ill and may lead to a tendency to demonstrate more protective and controlling behaviors such as setting firm rules and procedures for how the child and family will function. Additionally, as these children mature, parents may also be forced to accept that their child has cognitive,

social, and/or psychological delays. This new lifestyle is often a very different one than the anticipated cure many parents had hoped for. In fact, a group of parents stated that after going through their child's transplantation they needed time to adjust to "the new disease called organ transplant" (Zitelli et al., 1987). Combined, these factors can create a great deal of family disruption that can result in a loss of family cohesiveness, inappropriate levels of family control, and an increase in parenting stress. The task for researchers is therefore to develop a conceptual framework for evaluating these families and to determine if interventions are needed to assist with the long-term functioning of the entire family as it moves through the transplant procedure.

Long-term Psychosocial Development in Infant Heart Transplant Recipients:

From a medical perspective, there is no doubt that infants born with terminal heart disease experience a dramatic improvement in physical functioning following heart transplantation. Despite this life-saving intervention, however, these children may be at increased risk for developing problems in psychosocial functioning. Throughout their life these children are likely to have increased dependency on adults and a medical regime. They may experience developmental and/or cognitive delays and may experience alterations in their physical, particularly facial, appearance due to medication side effects. They often miss out on age appropriate activities because of ongoing medical complications or parental overprotection (Lawrence & Fricker, 1987). Two areas of psychosocial development that have attracted the attention of researchers with respect to child heart transplant recipients are social competence and emotional adjustment. Uzark et al. (1992) found that children receiving a heart transplant at age 16 or younger and who were at least 3 months post-transplant displayed less social competence and more

psychological dysfunction as compared to a normative population. Psychological dysfunction was most commonly suggestive of depression and was significantly associated with increased parenting stress and limited family support for managing stress. Similar results have been found among other types of child organ transplant groups (DeBolt, Stewart, Kennard, Petrik, & Andrews, 1995). Further, a unique aspect worthy of research attention specifically related to children receiving transplantation in infancy, is the impact of extended hospitalization during the first year of life on the development of normal mother/child attachment.

CHAPTER TWO: REVIEW OF LITERATURE

Heart Transplant: Current Issues and Findings

The feasibility of heart transplantation was realized in 1967 when Christian N. Barnard, MD, Ph.D., performed the first heart transplant on a 54-year-old male suffering from severe congestive heart failure. Although Barnard's work generated much interest, it was not until the discovery of the immunosuppressive drug, cyclosporine, in 1980 that heart transplantation was accepted as a viable treatment for non-correctable heart disease. With advancements in medical procedures, physicians and researchers began to explore the possibility of conducting heart transplantation with younger patients. In 1978 Loma Linda University Medical Center (LLUMC) developed an intensive research program which included over 400 infant animal heart transplant studies. This research resulted in the first successful human infant heart transplantation performed by Dr. Leonard Bailey in November of 1985. Since this time, over 349 children have received heart transplants at LLUMC with an overall survival rate of 73% as of July 1998. With similar survival rates for adult and child heart transplantation, attention is now beginning to focus on the long-term functioning of these individuals and their families.

Research regarding heart transplantation outcomes suggests that patients experience a substantial improvement in their overall health status. However, the long-term quality of life for these individuals and their families is less clear due to ongoing medical concerns, post-transplant psychological adjustment, and uncertainty regarding the future. Research focusing on the long-term functioning of adult organ transplant recipients has found a number of factors influencing the quality of life in these patients. In a study conducted by Duitsman and Cychosz (1993) questionnaires were administered

to adult patients from five different transplant centers. Findings suggested that satisfaction with family relationships, high self-esteem, and decreased depression were significantly correlated with adjustment of the patient after surgery. In fact, these psychosocial variables accounted for a substantial amount of the variability in determining quality of life as defined by life satisfaction, overall wellbeing, and positive affect.

Other studies of post-transplant adjustment in adults have suggested that these individuals are more likely to experience increases in mood disturbance, and psychological adjustment problems (Bohachick, Anton, Wooldridge, & Kormos, 1992; Dew et al., 1995). Dew et al., (1995) found that although high levels of psychological distress associated with the transplant procedure generally improved during the year following transplant, exceptions were found in recipients who initially presented with one or more of the following characteristics: psychiatric disorder prior to transplant, younger age, lower social support, exposure to recent loss, poor self-esteem, a poor sense of mastery, and the use of an avoidance coping strategy. Individuals presenting with these characteristics continued to experience high levels of anxiety and depressive symptoms.

Although no studies have specifically examined family functioning or child psychosocial development in children transplanted at birth, current research with children receiving transplantation before the age of 17 indicated some similarities and differences when compared to the research with adults. As with adult heart transplant recipients there is a continued focus on the child's psychological and social adjustment with the added emphasis of developmental and familial concerns (Baum et al., 1997; Uzark et al., 1992). This is consistent with the wide body of research suggesting that family responses to a child's illness plays an important role in the child's overall well being (Kong et al.,

1986; Lewis & Khaw, 1982; Shapiro, 1983). In one of the few studies directly examining psychosocial functioning in child heart transplant recipients and their families, Uzark et at. (1992) assessed 49 pediatric heart transplant recipients and their families across five different transplant centers. Results indicated that pediatric heart transplant recipients demonstrated significantly less social competence and increased behavior problems as compared to a normative population. Behavior problems were most frequently identified as depression and were significantly related to greater marital stress and a lack of family support for managing stress.

In another study, which relied on parent report, it was found that out of 69 children who had heart transplants, 33% required support for learning and developmental difficulties (Freier et al., 1997). This can be particularly stressful for family members who have already experienced the anxiety and financial pressures of the transplant procedure. Although psychological research with child heart transplant recipients and their family is clearly limited, research with children and families undergoing other types of transplantation procedures has received significantly more research attention.

Other Transplant Groups

An area of research worthy of investigation that shares some commonalties with infant heart transplant recipients and their families includes research with children who have undergone other types of transplantation. Generally these groups have received more research attention and most often include children receiving liver and kidney transplantation. These children share similar medical experiences with heart transplant recipients as both groups experience one or more invasive surgeries, both must take daily

administrations of immunosuppressive medications, and both have similar medical concerns following transplantation.

In one study, DeBolt et al. (1995) examined 41 children and adolescents 5 to 18 years of age who were at least 4 years post-liver transplantation. The researchers assessed for long-term social, behavioral, and emotional adaptation along with the overall impact of illness on the family. Their findings were compared to published data from both chronically ill and medically well children. Results generally indicated that long-term survivors of pediatric liver transplantation had lower social functioning levels than the medically well comparison group and equivalent or better function compared to chronically ill children. Specifically, when compared to well children, transplanted children demonstrated mild social and scholastic deficits and were less physically active. Measures of behavioral and emotional functioning indicated that transplanted children demonstrated better overall functioning than chronically ill children. Unfortunately, the measures did not include comparison norms for medically well children. Finally, the parents of transplanted children reported less negative impact of the illness on the family then parents of other types of chronically ill children as measured by degree of financial burden, personal strain, family coping, and disruption of the family's normal social activities. Once again, however, no comparison with non-clinical controls was available.

In another study, Zitelli et al (1987) followed 51 children both pre- and post-liver transplantation. These children were followed for a minimum of 24 months to a maximum of 60 months post-transplantation and were evaluated on a number of medical variables including number of hospitalizations, days hospitalized, reason for post-transplant hospitalizations, and medications taken. Additionally, psychosocial evaluations included current school placement, reasons for any school delay, cognitive

functioning, behavioral adjustments, and continuing parental concerns. Overall it was found that these children experience improved functioning following transplantation; however, some notable concerns were indicated. With respect to the medical variables, although transplant recipients spent an average in 22 fewer days in the hospital per year post-transplant, only 25% of the recipients required no admissions during the follow-up period. Zitelli et al (1987) noted that the most common causes for hospitalization following transplant were viral infections, rejection, VZ infection, dental work, and retransplantation. In terms of psychosocial indicators, results suggested that although child recipients were performing within normal limits for cognitive, academic, and behavioral functioning, parents continued to express concerns throughout the follow-up period. Specifically, concerns focused on fear of organ rejection, parental overprotection, change in family identity, medication side effects, and continuing medical expenses. Combined, these factors can place families at risk for increased levels of ongoing stress.

Similar results have been found with research involving child kidney transplantation. In a study conducted to Klein and Simmons (1979) 52 children aged 8 to 20 who were an average of two and a half years post-transplant were compared with chronically ill and medically well children. The researchers used both closed and open-ended questionnaires to assess for various aspects of self-image, impact of the illness on the child, and child school and activity adjustment. In general, children receiving kidney transplants exhibited healthy self-images and positive emotional adjustment as compared to non-clinical controls. However, in terms of physical wellbeing and school activity, the transplanted children rated themselves between the normal and chronically ill children. Specifically, the transplanted children were more fearful of further illness and received considerably lower grades in school. These children were also more likely to be

dissatisfied with their looks than both the normal and chronically ill children. Furthermore, the children reporting dissatisfaction with their physical appearance also indicated lower levels of sociability and self-image.

In another study Fukunishi and Kudo (1995) examined the psychosocial effects of the kidney transplant procedure on children and their families. Subjects included 27 children between the ages of 6 and 14, who were from 12 to 23 months post-transplant, and their families. Within this study cohesion is described as the degree of support family members provide for one another, expressiveness refers to the extent family members are encouraged to express their feelings, and conflict is defined as the amount expressed anger among the family members. On measures of family functioning transplant families were similar to non-clinical controls on measures of cohesion, expressiveness, and conflict. However, there was a relationship between low levels of family cohesion and expressiveness and child school maladjustment. Results also indicated that the family environment was less conducive to child independence and achievement orientation. One explanation for these results is offered by Gold et al. (1986) who suggested that parents have a tendency to become over-controlling of their children following organ transplantation. Additional findings from the Fukunishi and Kudo (1995) study indicate that child kidney transplant recipients experience more difficulty with peer relationships as compared to non-clinical controls. In 30% of these children the inability to form satisfactory peer relationships was severe enough to meet the DSM-III criteria for an adjustment disorder.

Of notable mention in respect to the above studies is that depression was not a significant factor among child liver or kidney transplant recipients. However, upon further review, the mentioned studies either used unstandardized and/or indirect measures

of childhood depressive symptoms or did not address the issue of depression within the study (Zitelli et al., 1987; Klein & Simmons, 1979; Fukunishi & Kudo, 1995). The ambiguity of the above research combined with the knowledge that depression is a significant factor for both older child and adult heart transplant recipients suggests that depression among infant transplant populations is a area worthy of additional research (Uzark et al., 1992; Bohachick et al., 1992).

Combined, the above research suggests that children and their families who have undergone the liver or kidney transplantation procedure experience a range of psychosocial outcomes. The most common findings among the children suggest that although they have relatively normal post-transplant adjustment, they tend to show deficits in social relations and ongoing medical concerns. Family factors seem to center around high levels of stress and child overprotection. Although these findings undoubtedly share many commonalties with the infant heart transplant experience, some findings are also likely to be inherently different. In this respect, children with congenital heart disease is another comparison group which may be helpful in understanding how post-heart transplant factors such as organ rejection and increased susceptibility to serious infections relate to long-term functioning of infant heart transplant recipients and their families.

Children with Congenital Heart Disease

Research with children suffering from congenital heart disease (CHD) suggests that family influences play an instrumental role in the child's development (Goldberg, Morris, Simmons, Fowler, & Levison, 1990). These children and their families are thought to undergo similar medical experiences as heart transplant recipients as both

groups of children have a period of intense illness, both experience one or more invasive surgeries, and both are thought to lead a relatively normal life following initial treatment. Differences in CHD and transplant populations relate to the quality of long-term functioning in that families and children with CHD do not have to deal with the additional post-transplant concerns such as the potential for organ rejection and a higher susceptibility to serious infections due to immunosuppressive medications. In this respect it was thought that children with CHD and their families would be an ideal comparison group as they share some common experiences with the heart transplant group while allowing for the assessment of the long-term variables specifically related to the infant heart transplant procedure.

Research with families who have children with CHD indicates a strong relationship between illness and family, in that when an illness occurs it both affects and is affected by the family situation (Paluszny, DeBeukelaer, & Rowane, 1991). One way that this interaction may be played out includes the degree of family control exhibited over the child. Specifically, studies indicate that parents of CHD children exhibit high levels of control in their child-rearing behaviors. Although this may be viewed as an adaptive strategy to protect the child, when used in excess, it may result in developmental and social deficits (Drotar, Crawford, & Bush, 1984).

Parents of CHD children frequently have ongoing concerns about the seriousness of their child's problem (Goldberg et al., 1990). Additionally, they are faced with the physical burdens of illness, including learning new skills for maintaining the health of their child, maintaining their own equilibrium, and providing emotional support for their other children. With these factors in mind, it is no surprise that studies indicate parents of these children consistently reported more stress than those of healthy children (Goldberg

et al., 1990). In one study DeMaso, Campis, Wypij, & Bertram (1991), assessed parenting stress and behavior problems in children with CHD. Results indicated that low parenting stress was significantly related to decreased child behavior problems.

Research with both CHD and heart transplant populations have identified similar issues in respect to family and child functioning. However, it is thought that when comparing the two populations, the heart transplant group will experience increased problems in terms of family functioning and child psychosocial development due to the additional long-term stresses of organ rejection and increased susceptibility to serious infections.

In considering all the sources of research relevant to the long-term functioning of infant heart transplant recipients and their families no clearly identifiable factors emerge. However, the most consistent and/or relevant variables pertaining to this population include degree of family control and parental stress and child factors such as social competence and depression. To fully address the relevancy of these variables, historical aspects of family functioning, child psychosocial development, and developmental concerns need to be examined.

Family Functioning

The long-term functioning of the family undergoing the infant heart transplant procedure has not been addressed in the literature. As a result, theoretical foundations used to formulate hypotheses, develop research methodologies, and analyze outcomes in this area are not established. Questions related to how the functioning of these families might relate to the child's psychosocial development also remain to be addressed. Researchers examining these family factors in the heart transplant population must rely

either on theories describing family functioning in general or more specific theories directly describing families of chronically ill children.

Historically, the study of family functioning has been centered around two primary approaches; family system theories and family stress theories. Traditional family systems theory was originally derived from general systems theory which expanded the simplistic view of direct cause and effect to a more complex and interrelated bi-directional theory (Wong, 1997). Minuchin (1980) further developed this idea into an applied theory stressing the importance of considering the individual within his or her social context. The theory emphasizes the interaction between family members, in that, a change in one family member results in changes in the other family members, causing yet another change in the original family member (Wong, 1997). When problems such as a medical illness occurs, it is the families' ability to adapt to change that is important. Minuchin, Rosman, and Baker (1978) developed a comprehensive model of family functioning specifically addressing the effects of illness on the family. According to this theory these families are at risk of developing maladaptive interactions which are characterized by overprotectiveness, enmeshment, rigidity, and a lack of conflict resolution. These terms refer respectively to the family's over-concern for each other, a lack of appropriate boundaries between the parent and child, the parent's inability to adjust to the child's changing needs, and an inability to resolve family problems. In this respect, the family may demonstrate maladaptive interactions that results in the child being overdependent, therefore fostering delays in the child's development of age-appropriate independence and autonomy (Minuchin et al., 1979).

Family stress theory was first proposed by Reuben Hill (1949) and was designed to examine how families react to stressful events and to identify factors promoting adaptation to these events. According to this theory, stressors can either be predictable such as a pregnancy or unpredictable such as an illness. These stressors are cumulative in that they involve concurrent demands from community, work, and family. Therefore, when a family experiences too many stressful events within a relatively short period, the family can become overwhelmed and their ability to cope is reduced thereby putting them at risk for physical and emotional problems.

In expanding on family stress theories, Patterson (1988) developed a Family Adjustment and Adaptation Response model (FAAR) that according to Drotar (1992), provides a conceptual framework for the study of families with chronically ill children. This model is based on the Double ABCX Model of Family Behavior (McCubbin & Patterson, 1982) which suggests that a stressful event (A) interacts with both the family's crisis-meeting resources (B) and the family's definition of the event (C) to produce the crisis (X). The FAAR model extends this theory by emphasizing the meanings that family attribute to stressors and the level of resources needed for balanced family functioning. According to the FAAR model, families may use various resources and capabilities for meeting demands including financial resources, personal knowledge, systems resources such as family cohesion, and community resources. The model further suggests that more general resources such as family cohesion can be used to meet most demands (Drotar, 1992). Family cohesion is defined as the degree of commitment, help, and support family members are able to provide for one another (Moos & Moos, 1994).

In addition to exploring family functioning as a whole, some researchers have combined theories of family functioning and child psychosocial development in an

attempt to examine the relationship between these variables. For example, Feldman, Nash, & Aschenbrenner (1985) present a family stress model suggesting that multiple stressors such as medical complications and/or low socioeconomic status (SES), combined with poor marital and family relations adversely effect the child's development. This theory supports the idea that chronic illness by itself is not a stressor that causes primary behavioral and developmental disturbances. Rather, the impact of the illness relates to the number of stressors including the severity of the illness, the amount of parental stress, and the degree of family cohesiveness (Bush, Melamed, & Cockrell, 1989).

Parenting stress and family cohesiveness have important implications for the long-term functioning of infant heart transplant recipients and their families. In terms of ongoing stress, parents report daily stressors such as fears regarding episodes of mild to moderate organ rejection, severe infections due to immunosuppressive medications, and ongoing concerns about their child's future (Stuber, 1993). As Gold et al. (1986) point out these fears often result in the parents becoming overprotective of their child as demonstrated by many rules and procedures that the child must follow. This high degree of control also affects the entire family because limitation of the child's activities often limits the family's activities. The above stressors combined with ongoing medical expenses, financial burdens and other life stresses can negatively impact the families' ability to function as a cohesive unit. This can potentially impact the child's psychosocial development as family cohesiveness has been shown to be a protective factor in promoting resiliency in pediatric bone marrow transplant recipients (Phipps & Mulhern, 1995).

Uzark et al., (1992) present the only study specifically using family stress theory to examine family relations and child psychological development in pediatric heart transplant recipients. Based on the double ABCX model, the authors suggest that when faced with a chronic illness, such as heart transplantation, additional family stressors that are not mediated by resources or coping will complicate medical treatment and the long-term adaptation of the child transplant recipient (Uzark et al., 1992). In general, research findings were supportive of this theory in that increased marital stress and decreased family support for managing stress were negatively correlated with depression and social competence in the child transplant recipient (Uzark et al., 1992).

Although none of the above theories have been directly applied to infant heart transplant recipients and their families, they provide a conceptual framework in which to begin addressing this area of research. Important constructs both consistent among the theories and relevant to the infant transplant population include parental stress, family cohesiveness, and family control. An additional area of research attention that is supported by both family systems theory and research using family stress theory is the potential relationship between family functioning and the psychosocial development of the infant transplant recipient.

Psychosocial Development

In examining the long-term psychosocial development of the infant transplant recipient, a number of factors need to be explored. In addition to considering various theoretical approaches, one must also consider the unique experience of the transplant procedure. As pointed out by Stuber (1993), the child receiving a heart transplant in infancy does so before a sense of self is fully developed. In this sense the child does not

experience a loss of a previous functioning but instead a loss of potential options in life. The extent that this affects the future development of these children is not currently known.

From a theoretical perspective, child psychosocial development has been approached from a variety of perspectives with the most accepted child psychosocial theory proposed by Erikson in 1963. This theory suggests that during critical times of development children face core conflicts which either have a favorable or unfavorable solution. Movement to higher stages of development is cumulative and is dependent upon the successful resolution of earlier conflicts. When stages are not successfully resolved the child may experience depression and/or impairments in forming interpersonal relationships. Although Erikson's theory consists of eight stages or conflicts only the first four relating to early and middle childhood are considered here.

The first conflict, trust versus mistrust, occurs from birth to about 1 year. Trust is developed from a consistent and loving caregiver whereas mistrust develops when the basic needs of the infant are inconsistently or inadequately met. When this conflict is successfully resolved the child moves from the basic trust in the parents, to trust in the world, other people, and eventually in oneself. If, however, the conflict is unsuccessfully resolved the child come to expect that the world is painful, stressful, and untrustworthy. The second stage or conflict occurs from about 1 to 3 years of age and is autonomy versus shame and self-doubt. During this time children are attempting to control their bodies, themselves, and their environment. If they succeed in doing things on their own, they gain a sense of self-confidence and self-control. However, if they fail continually or are forced to depend on others once they are capable of assuming control they learn to feel shame and self-doubt (Craig & Kermis, 1995).

Initiative verses guilt, from 3 to 6 years, is Erikson's third stage of psychosocial development. During this time children must learn to take initiative without violating the rights of others or being made to feel that their activities are bad. If their explorations and activities are mostly effective, they learn to deal with things and people in a positive way and obtain a strong sense of initiative. But, if they are severely criticized or punished, they learn to feel guilty. The last stage relevant to early and middle childhood is industry verses inferiority. This stage lasts from approximately ages 6 to 12 and is a time when children are ready to be workers and producers. Achievement orientation and comparison with peers are of major focus. Feelings of inferiority develop as a result of placing excessive demands on the child or when the child believes that he or she cannot measure up to the standards set for them by others (Craig & Kermis, 1995).

In relating Erikson's theory to the long-term development of the infant heart transplant recipient three areas of psychosocial development are of potential concern. These include issues of autonomy, quality of social relationships, and depression. In considering the first of these issues children who undergo the transplant procedure are dependent on their families for long-term care and require a great deal of family support. However, as the child matures and seeks to obtain a sense of autonomy families may be reluctant to allow children to engage in age appropriate behaviors for fear that they will become ill or somehow injure themselves. As Stuber (1993) points out children undergoing transplantation are often treated as fragile and kept in a dependent relationship with their parents and other adults long after it is developmentally appropriate. When this occurs, it has a confounding effect by influencing subsequent stages of development such as the unfolding of social relationships and engagement in age appropriate activities. In regards to infant heart transplantation, it should also be

noted that from a medical perspective there is some necessity to "parental overprotection" as organ rejection and potential for these children to develop a serious infection due to being on immunosuppressive medications remains a real and life threatening possibility.

Infant transplant recipients are also at risk for developing social and emotional disruption at any stage in Erikson's theory as their long-term functioning is continually affected by their medical condition. In this respect the child may experience social delays as a result of not successfully resolving the autonomy verses shame and self-doubt stage as mentioned above or as a result of difficulty with an earlier or later stage. Factors that may affect development in later stages include medication side effects such as dental problems or excessive hair growth, and/or frequent illnesses. These situations are likely to cause the child to feel different, self-conscious, and inferior at a time when social comparison with peers is very important. This in turn may result in emotional problems which are most frequently defined as depression (Uzark et al., 1992). Kazdin (1989) who has extensively studied childhood depression further suggests that the combined effects of many life stressors, as experienced by heart transplant recipients, could independently render a child vulnerable to depressive symptoms regarding themselves and his or her environment.

Developmental Concerns

Despite the growing amount of research conducted on the long term effects of adult and older child organ transplantation, the very young child whose transplant was performed prior to the development of any concept of self has not been adequately addressed (Stuber, 1993). Because these children undergo heart transplantation in infancy, they are most likely to experience developmental disruptions during this stage.

However, they are certainly vulnerable to developmental disruptions at any age, as their dependence on following a specific medical regime is both lifelong and necessary to sustain life. Additionally, their ongoing medical and mental health may be compromised by an increased risk of organ rejection and/or a serious infection. For example, in an unpublished study following the long-term cognitive development of child heart transplanted recipients, it was found that organ rejection and number of serious infections were significantly related to children's overall cognitive ability (Baum et al., 1997). It would be certainly reasonable to expect that these same medical variables may impact to the child's social and psychological development.

As with any research involving children, developmental factors must be considered. In general, research with children receiving organ transplant at various ages suggest that there is a trend for children with earlier onset of disease and/or longer periods of illness prior to transplant to be at risk for developmental problems (Sexsin & Rubenow, 1992). Specifically, Stewart et al (1989) assessed cognitive, motor, and social functioning in 29 children with end-stage liver disease prior to and one year post-transplantation. Findings suggested that in terms of cognitive and motor development the children did not demonstrate a significant improvement. In respect to social functioning, results indicated that children older than four years of age at the time of transplantation demonstrated significant improvement, whereas the younger children did not show this gain. It was suggested by Stewart et al. (1989) that increased parental control, observed more often in the younger children, may encourage dependent behavior and decreased opportunities for children to experience normal development of social skills.

In another study Freier et al. (1997) examined parent's perceptions of their child's development at least two years post-heart transplant. Measured variables included

general personality characteristics such as anxiety, depression, social functioning, and perceived cognitive abilities. The study included 113 children who were at least 3 years of age and received their heart transplant in during the first year of life. Although this was a descriptive study, findings suggested that older children, ages 6-10, had no clinically significant elevations, whereas the younger children, ages 3-5, showed a number of clinical concerns including perceived cognitive delays and high degrees of social isolation. These children tended to play alone, had few friends, and played indoors. Additionally, parents expressed great concern over protecting their child from everyday dangers. The authors hypothesized that poor social skills and perceived cognitive delays, which were significant only in the younger age group, may improve with age as social interaction and academics are introduced.

An additional concern directly related to the infant heart transplant recipient, is the potential disruption to the developmental tasks achieved in infancy. During this period infants are attempting to integrate and regulate many systems necessary for higher levels of biobehavioral organization (Sexson & Rubenow, 1992). According to Sexson and Rubenow (1992) chronic illness in early infancy and/or the transplantation procedure itself may compromise the full development of these tasks. Besides the potential medical risks involved, a prominent concern during this period is the possibility of impaired parent-child relationship.

Bowlby's (1988) theory of attachment is perhaps the most comprehensive explanation for how various parent-child relationships develop and change over time. According to Bowlby, attachment involves the development of an infant-mother relationship that actively responds to the infant's need for food, comfort, play, communication, and sharing of affects. According to this theory, attachment develops

gradually during the first two years of the child's life and once established creates an internal model that influences and relates to later behavior. For example, if an infant's attachment needs are met, he or she learns to trust others and learns how to effectively resolve states of distress. These infants, classified as securely attached, have been found to demonstrate better coping skills, better peer interactions, and increased persistence in approaching school work as compared to infants classified as insecure (Sroufe, 1977). Insecure attachments develop when there is no consistent loving caregiver available to meet the infant's needs. Long-term effects may include poor development of social skills, psychological distress, and/or poor coping abilities.

The theory of attachment has important implication for the infant heart transplant population. During the first year of life when normal attachment is developing, parents and children undergoing the transplant procedure are often dealing with significant separations due to hospitalization, commitment to other children, and relocation. Gold et al., (1985) suggests that during this time parents often spend much time trying to preserve their child's life as opposed to engaging in traditional parenting roles. Additionally, parents may experience an emotional pull between being prepared to deal with the child's possible death and the child's possible recovery. Such factors can disrupt the normal attachment process as it is thought that separation along with emotional distancing can result in the development of an insecure attachment (Bowlby, 1973). This pattern can also continue throughout the post-transplant period and can have detrimental effects on the child's social and/or psychological development.

Statement of the Problem

The long-term family functioning and psychosocial development of the infant heart transplant recipient is a current area of interest for the health professional. As these children approach middle childhood and their social environment rapidly increases, researchers and medical professionals in this field become concerned about how these children and families function long after the transplantation procedure occurs. In an attempt to address these issues, the current study will examine long-term family functioning and child psychosocial development in infant heart transplant recipients as compared to a non-clinical population and families of children with congenital heart disease (CHD).

The literature related to family functioning and the long-term development of the infant heart transplant recipient is conflicted and not well defined. Researchers and theoretical perspectives tend to vacillate between describing these children and families as normal and characterizing them at risk for psychological distress. Part of this confusion relates to the tendency for researchers to either assess for family functioning or child psychosocial development without considering the potential relationship between the two. This study is a first step in examining both of these constructs independently and in relation to each other. Specifically, it is thought that families and children undergoing the transplant procedure will demonstrate more problems in family functioning and more child psychosocial problems then either non-clinical controls or CHD populations. However, it is also thought that improved family functioning can significantly mediate and thereby enhance child psychosocial outcomes across all three groups. In taking into consideration relevant literature and theoretical perspectives the most relevant measures of family functioning in terms of the infant transplant procedures

appear to be degree of family cohesiveness, parental stress, and family control. Relevant measures of child psychosocial development include social competence and depression. Also, the unique aspects of the infant transplant procedure suggest that the nature of the parent/child attachment is a viable topic of research attention.

The goal of this study is to provide insight into issues that families and child transplant recipients face long after the initial crisis of the transplant procedure is over. If it is demonstrated that a relationship exists among these variables, psychologists and medical professionals can utilize this information to better understand the ongoing issues that children and their families face in relation to the heart transplant procedure. In addition, interventions could be developed that specifically address the long-term needs of the child and family who have experienced the transplant procedure.

Hypotheses

1. The first goal of the this study was to examine expected differences in the nature and frequency of psychosocial problems among infant heart transplant recipients, children with corrective CHD, and non-clinical control children. Specifically, it was hypothesized that infant heart transplant recipients would demonstrate significantly more problems with social competence (as measured by the CBC) and depression (as measured by the PSI) as compared to children with CHD. In turn, it was thought that children with CHD would demonstrate significantly more problems in terms of depression and social competence then the non-clinical control children.

2. The second goal of the study was to determine if there were expected differences in family functioning among the three study groups. Specifically it was hypothesized

that families of heart transplant recipients would be more likely to experience inadequate family cohesion (as measured by the FES), increased parental stress (as measured by the PSI), and a higher degree of familial control (as measured by the FES) then the CHD group. Further, it was predicted that the families of children with CHD would be more likely to experience inadequate family cohesion, increased parental stress, and a higher degree of familial control then the non-clinical control group

3. The third goal of this study was to determine if family functioning played a mediating role in the psychosocial development of children undergoing the heart transplant procedure. Specifically it was predicted that any group differences in respect to child psychosocial functioning would be mediated by family variables of parenting stress, family cohesion, and family control.

4. The fourth goal of the study was to examine the nature and frequency of attachment problems in infant heart transplant recipients as compared to children with congenital heart disease and non-clinical control subjects. Specifically, it was hypothesized that infant heart transplant recipients and the congenital heart disease group will demonstrate a significantly higher rate of insecure attachment (as measured by the PSI) as compared to non-clinical control subjects.

CHAPTER THREE: METHODS

Participants

Thirty-one biological mothers whose children received a heart transplant during the first year of life; 6 biological mothers of children diagnosed with congenital heart disease, and 21 biological mothers of non-clinical control children were recruited via mailers through either a hospital database or through a university based medical clinic. All respondents met the following criteria.

Inclusion Criteria

1. The biological mother must be willing to voluntarily participate in the study.
2. Biological mother of a child between the age of 8 and 11 years of age who either received a heart transplant during the first year of life, received corrective heart surgery during the first 18 months of life, or has no identified medical condition other than a normal childhood illness.
3. Biological mother of a child who was either transplanted at Loma Linda University, or is currently being followed by Loma Linda University Congenital Heart Disease Pediatric Cardiology Clinic, or is a non-clinical client of the Loma Linda University FMO Pediatric Children's Clinic.
4. All selected CHD children had uncomplicated diagnoses with good prognoses. Other than regular medical follow-up and possibly administering medication, medically related parent intervention was not required.

Exclusion Criteria

1. Biological mothers who do not read English.
2. Child heart transplant recipients that have an additional medical diagnosis not related to the transplant procedure and not considered a normal childhood illness.
3. Children with congenital heart disease that have an additional medical diagnosis not related to specific CHD factors and not considered a normal childhood illness.
4. Non-clinical children that have any medical condition not considered a normal childhood illness.

Response Rate

A total of 58 biological mothers agreed to participate in the study out of approximately 145 solicitations. Therefore, an overall estimated response rate of 40%was achieved. Among the individual study groups, response rates were as follows; 31 of 73 heart transplant surveys were returned for an estimated response rate of 42%, 6 of 25 CHD surveys were returned for an estimated response rate of 24%; and 21 of 47 non-clinical control surveys were returned for an estimated response rate of 45%.

Methodology

Subject Selection

The heart transplant subjects included all eligible biological mothers whose children are between the ages of 8 and 11 and received a heart transplant at Loma Linda University Children's Hospital during their first year of life. Eligibility, names and

addresses of potential heart transplant subjects were obtained through the hospital database. All identified participants were mailed a packet containing a cover letter/informed consent, all questionnaires (FES, PSI, CDI-P, & CBCL), contest card, and a pre-stamped pre-addressed return envelope.

The congenital heart disease subjects included eligible biological mothers whose children were between the ages of 8 and 11 and received corrective heart surgery at Loma Linda University Children's Hospital during their first 18 months of life. As these children were being followed by Loma Linda University Children's Hospital, Pediatric Cardiology Clinic eligibility, names, and addresses of potential CHD subjects were obtained through the clinic database. All identified participants were mailed a packet containing a cover letter/informed consent, all questionnaires (FES, PSI, CDI-P, & CBCL), contest card, and a pre-stamped pre-addressed return envelope.

The Non-clinical control subjects included eligible biological mothers whose children were between the ages of 8 and 11 who attend routine outpatient pediatric care at the Loma Linda University FMO Pediatric Children's Clinic. Eligibility, names and addresses of potential subjects were obtained through the clinic database. All identified participants were mailed a packet containing a cover letter/informed consent, all questionnaires (FES, PSI, CDI-P, & CBCL), contest card, and a pre-stamped pre-addressed return envelope.

Procedure

Participants wishing to participate in the study were asked to return all questionnaires in the pre-addressed pre-stamped envelopes to Loma Linda University, Psychology Department. Received mailings were examined for completion and scored

by the primary investigator. Scoring of all questionnaires was consistent with standardized instruction provided in the test manuals. All data is stored in a locked filing cabinet at the Department of Psychology, Loma Linda University. Subject names are kept separate from the data and coded to coincide with the subject's address. This allowed the researcher to contact the subjects during the study period. Follow-up phone calls to mothers who either returned forms with missing information or who did not respond to the study were made by the primary investigator two weeks after the initial mailing. All forms returned within six months, beginning from the mailing date, were included in the study. The prize drawing was held on April 30 and the winner was notified through the mail. It should be noted that the Child Depression Inventory-Parent form (CDI-P) was initially to be used in the study. However, as no reliability or normative information was yet available, the measure was not used and all completed forms were sent back to the publishing company for further test development. No personal identifying information was forwarded.

Materials

Parent Cover Letter and Consent Form

A combined cover letter and consent from was sent to all potential subjects (see Appendix A). Return of all questionnaires assumed voluntary participation in the study.

Family Environment Scale

The Family Environment Scale (FES; Moos & Moos, 1994) is a comprehensive instrument used to describe an individual's perception of their current family

environment (see Appendix B). It was used in the current study to assess family cohesion and family control. The FES consists of 90 true-false items that were completed by the biological mother. Raw scores comprising a total of 10 component subscales including family cohesion and family control were used in the analysis. Scoring of family cohesion indicate that raw scores of 6 and 7 represent average functioning whereas on family control the average range of scores is 4 and 5. The FES is a psychometrically sound instrument that has demonstrated good reliability and validity with internal consistency coefficients between .61-.78 and test-retest reliability coefficients between .52-.91 (Moos & Moos, 1994).

Parenting Stress Index

The Parenting Stress Index (PSI; Abidin, 1995) was used to assess the overall degree of stress of the biological mother, parent/child attachment, and child depression (see Appendix C). A total parenting stress score and attachment and mood subtest scores were used. The total stress score includes stresses in the areas of personal parental distress, stresses related to interactions with the child, and stresses that result from the child's behavioral characteristics. The attachment score defines that parent/child relationship as secure or insecure. The mood subscale identifies various symptoms indicative of depression. The PSI is completed by the biological mother using a 5 point scale to describe items (SA = strongly agree, A = agree, NS = not sure, D = disagree, and SD = strongly disagree) with a total of 120 questions. Raw scores were converted into standard scores with a mean of 50 and a standard deviation of 10. High scores are

considered to be scores at or above a standard score of 60. Test-retest reliability indicates satisfactory coefficients ranging from .79 to .96 (Abidin, 1995).

Child Behavior Checklist

Social Competence was assessed using the Child Behavior Checklist (CBCL; Achenbach & Edelbrock, 1983) (see Appendix D). The CBCL is an objective multidimensional questionnaire developed to assess for child behavioral problems and competencies in children between the ages of two and eighteen. Based on the recommendation listed in the manual raw scores were used in the analysis. Generally speaking sores falling below a 3 on the Social Competence scale were considered within the clinical range. Norms for social competence were based on children between the ages of 6 and 18 and allow for comparison with non-clinical control subjects within the same sex and age brackets. The CBCL is a widely used instrument that has demonstrated adequate reliability and validity (Achenbach & Edelbrock, 1983).

Contest Postcard

All subjects were sent a pre-stamped postcard entering them into a drawing to win a $100.00 prize upon the return of the postcard (see Appendix E). Entry into the contest was not dependent on completion of the study and all subjects were welcome to enter the drawing. The prize drawing was held on April 30 and the winner was notified through the mail.

Design and Data Analysis

Data analysis was divided into four sections in order to address the four objectives of the study. First, pair-wise contrast analyses were used in order to examine the nature and frequency of psychosocial problems in infant heart transplant recipients as compared to children with congenital heart disease and non-clinical control subjects. Specifically, individual *t* tests were performed in order to evaluate if there was a significant difference between pediatric heart transplant recipients and children with CHD in terms of social competence and in level of depression. Another set of individual *t* tests was conducted in order to assess the difference between children with CHD and non-clinical control subjects in terms of social competence and level of depression.

The second study objective also used pair-wise contrast analyses to determine if there were differences in family functioning among children who receive heart transplants, as compared to families of children with congenital heart disease and non-clinical control families. Specifically, individual *t* tests were performed in order to evaluate if there was a significant difference between families of heart transplant recipients and families of children with CHD in terms family cohesion, parental stress, and familial control. Another set of individual *t* tests were conducted in order to assess the difference between families of children with CHD and families of non-clinical control subjects in terms of family cohesion, parental stress, and familial control.

Two independent analyses of covariance were initially to be used in assessing the degree to which family cohesion, family stress, and family control mediated differences in the child variables of social competence and level of depression among the three study groups. However, as no group differences in depression and social competence were indicated the examination of covariance was unnecessary. Correlations between family

variables and child psychosocial variables were examined to determine nature of the relationship between these variables.

The fourth study objective used pair-wise contrast analyses to determine if there were differences in attachment style among children who receive heart transplants and families of children with congenital heart disease as compared to non-clinical control families. Specifically, individual *t* tests were performed in order to evaluate if there was a significant difference between families of heart transplant recipients and families of children with CHD in terms of attachment style. Another set of individual *t* tests were conducted in order to assess the difference between families of children with CHD and families of non-clinical control subjects in terms of attachment style.

Finally, in order to obtain statistical significance the researcher attempted to obtain 21 subjects per group for sensitivity to a large effect size (Cohen, 1992).

CHAPTER FOUR: RESULTS

Respondent Characteristics

Thirty-one mothers of children who received an infant heart transplant, 6 mothers of children who had corrective CHD, and 21 mothers of non-clinical controls responded to surveys regarding their child's and family's functioning. Although no parent demographic information was obtained, child characteristics showed, by design, that all children were between the ages of 8 and 11. Gender was roughly evenly distributed within each group with a majority of the children being Caucasian (see Table 1). A series of ANOVAS were conducted in order to assess for within group differences in terms of gender, race, and ethnicity. A significant difference among the heart transplant group in terms of gender and attachment ($F(1,29)=7.76$, $p = .00$, $\eta^2 = .21$) and gender and family control ($F(1,29)=4.32$, $p = .05$, $\eta^2 = .13$) was obtained. However, both mean scores fell well with the normal range of functioning and were not clinically relevant (Attachment: male, $\overline{X} = 52$, female, $\overline{X} = 42$; Family Control: male, $\overline{X} = 4$, female, $\overline{X} = 5$). No other demographic comparisons were significant. In respect to the above, it can be assumed that identified differences between the three study groups were not related to the demographic variables of age, gender, or ethnicity.

Prior to examining the specific study objectives the possibility of defensive responding was examined via a defensive rating scale on the Parenting Stress Inventory. Results indicted that, although not clinically significant, mother's of heart transplant recipients obtained significantly lower or more defensive scores than mothers of CHD children ($t=-2.81$, $df(35)$, $p=.00$, $\eta^2 = .18$). The mean difference between the heart transplant group and non-clinical controls was not significant ($t=-.029$, $df(50)$, $p=.98$, η^2

= .00). In examining the mean scores for each group (Heart Transplant, $\overline{X}$ =31; CHD, $\overline{X}$ =42; Non-clinical Controls, $\overline{X}$ =31) it appears that mothers of heart transplant recipients have a response style that more closely resembles that of the non-clinical control group when compared to a similar clinical population.

Table 1

Frequency Information Regarding Demographic Variables Among Infant Heart Transplant Recipients, Children with Congenital Heart Disease, and Non-Clinical Control Children

Group	Age				Gender		Ethnicity			
	8 N (%)	9 N (%)	10 N (%)	11 N (%)	Male N (%)	Female N (%)	Caucasian N (%)	African Am. N (%)	Hispanic N (%)	Asian N (%)
Infant Heart Transplant Recipients	12 (39)	10 (32)	7 (23)	2 (6)	12 (39)	19 (61)	25 (81)	1 (3)	5 (16)	0 (0)
Children With Congenital Heart Disease	3 (50)	1 (17)	2 (33)	0 (0)	4 (67)	2 (33)	3 (50)	0 (0)	3 (50)	0 (0)
Non-Clinical Control Children	3 (14)	8 (38)	4 (19)	6 (29)	9 (43)	12 (57)	18 (86)	1 (5)	0 (0)	2 (9)

Hypothesis One

Pair wise contrast analysis was used to examine expected differences in the nature and frequency of psychosocial problems in pediatric heart transplant recipients, children with congenital heart disease, and non-clinical controls. Analysis was conducted in two parts. First, two individual *t* tests were performed in order to evaluate if there was a significant difference between pediatric heart transplant recipients and children with CHD in terms of social competence and level of depression. The results for social competence between the two groups were not significant (t=.657, df(35), p=.52, η^2 = .01). The results for depression were also not significant (t=.149, df(35), p=..88, η^2 = .00).

The second part of the analysis required two additional individual *t* tests in order to assess the difference in social competence and level of depression between children with CHD and non-clinical controls. Results for both social competence (t=-.1.27, df (25), p=..22, η^2 = .06), and level of depression (t=.010, df(25), p=.99, η^2 = .00) were not significant. As shown in Table 2, the above findings contradict the basic hypothesis that heart transplant recipients would demonstrate significantly more problems with social competence and depression as compared to the other two study groups. A comparison of the medians for the three groups in terms of social competence and depression are presented in Figure 1.

Supplementary Analysis for Hypothesis One

An examination of the box plots (see Figure 1) suggests a wide range of variability among the heart transplant group as compared to the non-clinical control

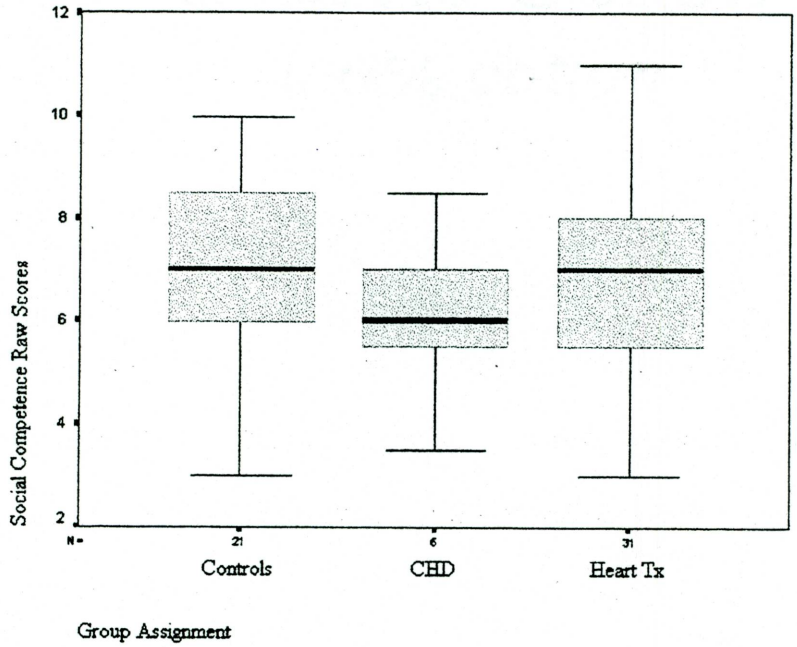
group in terms of depression. Of particular interest was the number of heart transplant recipients reported to have a clinical level of depressive symptoms. In order to assess the relationship between group assignment and clinical levels of depression a Chi-Square was conducted. Results were not significant χ^2 (1,N=52)=3.639,p=056. Examination of the standardized cell residuals indicated that although statistical significance was not reached, more depressive symptoms falling in the clinical range were reported in the transplant group (standardized residual = 1.0; 39%) as compared to the non-clinical control group (standardized residual = -1.2; 14%). These results may potentially have important clinical implications for the infant heart transplant population.

Table 2

Planned Comparisons between Heart Transplant Recipients, Children with CHD, and Non-Clinical Controls on Measures of Social Competence and Depression

Measure	Heart TX Mean (S.D.)	CHD Mean (S.D.)	Controls Mean (S.D.)	*t* value	Significance	Effect Size
Social Competence	6.65 (1.96)	6.08 (1.66)	N/A	.657	.516	.01
Social Competence	N/A	6.08 (1.66)	7.07 (1.69)	-1.27	.217	.06
Depression	51.61 (13.9)	50.67 (16.0)	N/A	.149	.883	.00
Depression	N/A	50.67 (16.0)	50.62 (8.32)	.010	.992	.000

**means for social competence and depression are not clinically significant*



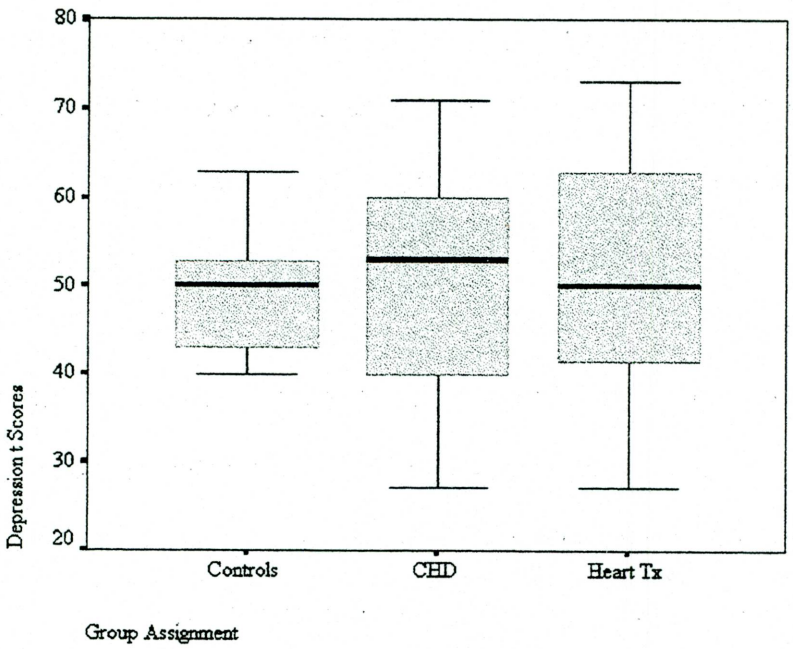


Figure 1. Medians for the Three Study Groups on Measures of Social Competence and Depression

Hypothesis Two

Pair wise contrast analysis were conducted in order to test the second hypothesis that families of heart transplant recipients would be more likely to experience inadequate family functioning then the CHD group, and that the CHD group would experience more problems in family functioning then the non-clinical control group. Individual *t* tests were first performed in order to evaluate differences between families of heart transplant recipients and families of children with CHD in respect to family cohesion, parental stress, and familial control. Results for family cohesion (t=.1.36, df(35), p=.18, η^2 = .50) and family control (t=-1.83, df(35), p=..07, η^2 = .87) were not significant. Results for parenting stress were significant (t=-2.38, df(35), p=.02, η^2 = .14) indicating that mothers of CHD children experience significantly more parenting stress then mothers of heart transplant recipients. It should be noted, however, that although statistical significance was achieved, the PSI cut-off scores indicate that parenting stress was not clinically significant for either group.

An additional set of individual *t* tests were needed in order to fully assess the second hypothesis. Three individual *t* tests were used to determine the difference between families of children with CHD and families of non-clinical control subjects in terms of family cohesion, parental stress, and familial control. Results indicated that there were no differences between the two study groups in terms of family control (t=.1.31, df(25), p=.20, η^2 = .06) and parenting stress (t=1.84, df(25), p=.08, η^2 = .12). Results for family cohesion were significant (t=-2.06, df(25), p=.04, η^2 = .16) indicating that mothers of CHD children reported significantly less family cohesion than mothers of non-clinical control subjects. Once again, despite being statistically significant,

established cut-off scores indicated in the FES manual suggest that results were not clinically significant as both scores fell within the average range of functioning. As shown in Table 3 the above findings do not support the basic hypothesis that the heart transplant group would display more problems than the other two groups. In fact, results indicated that the heart transplant group was comparable to and more closely resembled the non-clinical control group in terms of family cohesion, parental stress, and familial control. A comparison of the medians for the three study groups in terms of parenting stress, family cohesion, and family control are presented in Figures 2a and 2b.

Supplementary Analysis for Hypothesis Two

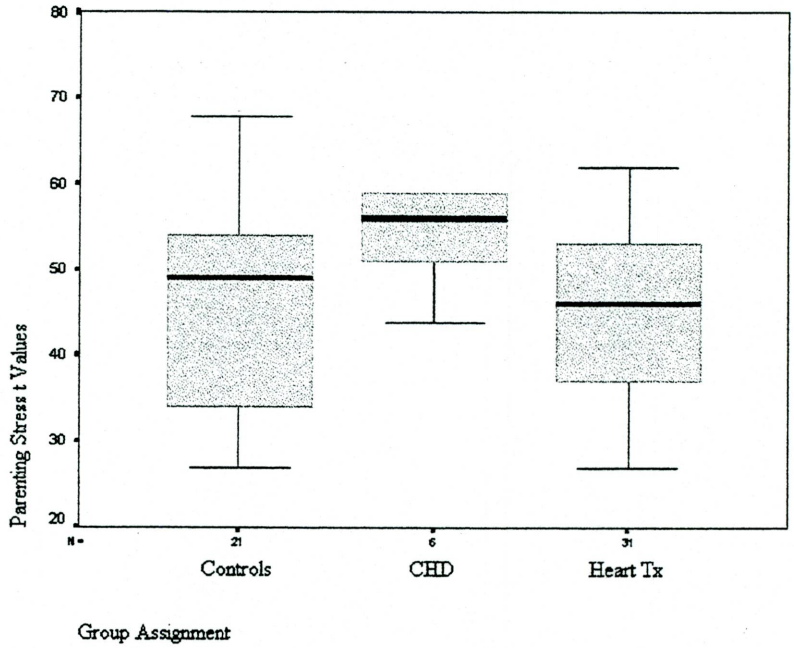
An examination of the box plots (see Figure 2) suggests a wide range of variability among the heart transplant group as compared to the non-clinical control group in terms of family control. Of particular interest was the low level of family control demonstrated in the heart transplant group. In order to assess the difference in level of family control in the heart transplant group in relation to the non-clinical control group a Chi-Square was conducted. Results were not significant $\chi^2(2, N=52)=1.72$, $p=.424$. Examination of the standardized cell residuals indicated that there were no significant group differences in the number of individuals reporting low family control, average family control, and/or above average family control. However, the differences in variability among the two groups is interesting and worthy of future investigation to determine if this is an anomaly or if there is a different response pattern among the heart transplant and control groups. The CHD group was not considered in this analysis due to the low number of respondents.

Table 3

Planned Comparisons Between Family Functioning of Heart Transplant Recipients, Children with CHD, and Non-Clinical Controls on Measures of Parenting Stress, Family Cohesion, and Family Control

Measure	Heart TX Mean (S.D.)	CHD Mean (S.D.)	Controls Mean (S.D.)	*t* value	Significance	Effect Size
Parenting Stress	45.68 (10.3)	56.50 (9.65)	N/A	-2.38	.023	.14
Parenting Stress	N/A	56.50 (9.65)	45.81 (13.2)	1.84	.078	.12
Family Cohesion	7.54 (1.59)	6.50 (2.43)	N/A	1.36	.184	.05
Family Cohesion	N/A	6.50 (2.43)	7.90 (.94)	-2.21	.037	.16
Family Control	4.84 (1.70)	6.17 (1.17)	N/A	-1.83	.076	.09
Family Control	N/A	6.17 (1.17)	5.28 (1.52)	1.31	.204	.06

**means for parenting stress, family cohesion, and family control are not clinically significant*



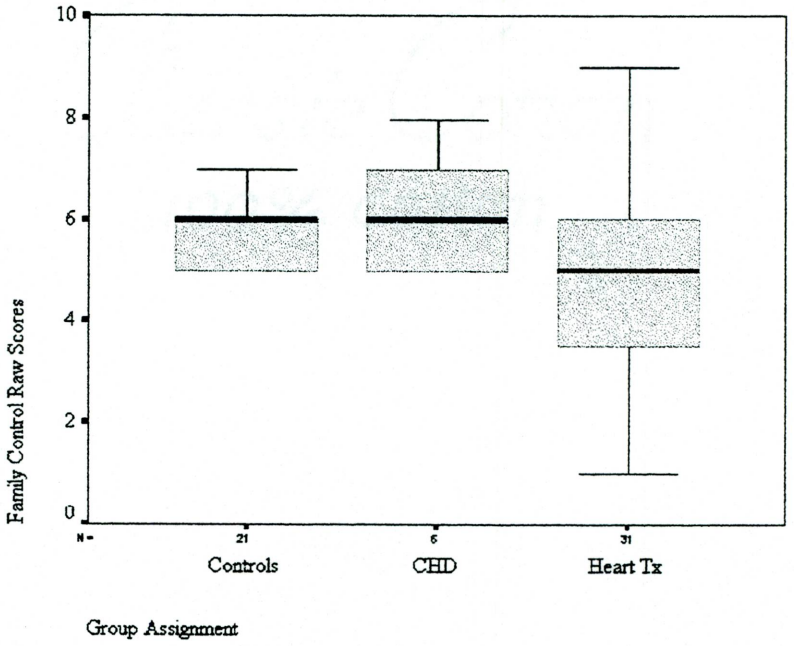


Figure 2a. Medians for the Three Study Groups on Measures of Parenting Stress and Family Control.

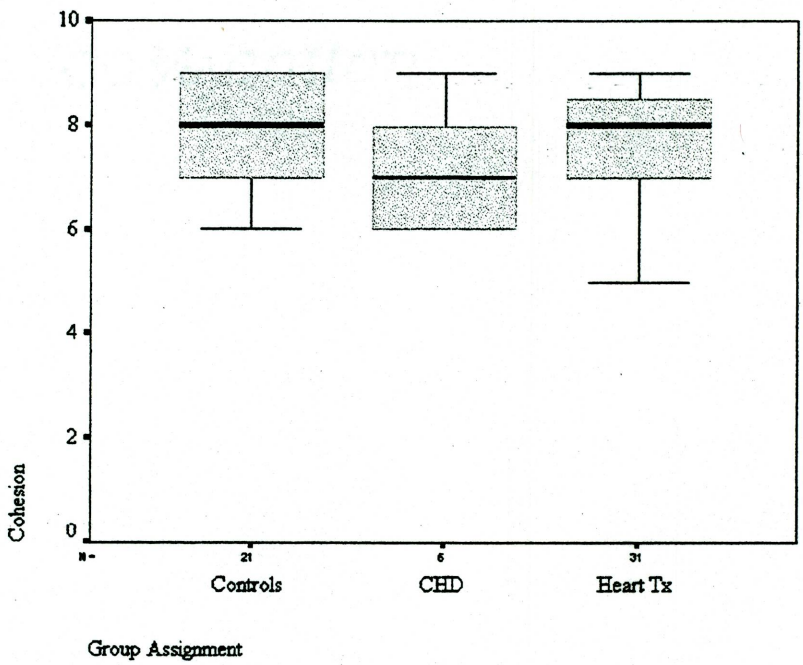


Figure 2b. Medians for the Three Study Groups on Measure of Family Cohesion.

Hypothesis Three

The third objective of the current study was intended to assess the degree to which family cohesion, family stress, and family control mediated differences in the child variables of social competence and level of depression among the three study groups. However, the value of assessing the hypothesis was brought into question because there were no significant group differences in terms of child psychosocial variables. Therefore, the need to account for the covariance of family variables was unnecessary. Correlations among child psychosocial functioning and family variables for both the heart transplant group and the non-clinical control group were examined and are reported in Table 4. The CHD group was not included because of the low number of respondents. Of particular interest in examining the correlations was the strong relationship between depression and parenting stress in the non-clinical control group ($r=.66$, $p<.01$) and the lack of relationship between these variables in the heart transplant group ($r=.19$). This suggests that group assignment is moderating the relationship between parenting stress and depression.

Supplementary Analysis for Hypothesis Three

Two multiple regressions were conducted in order to determine if family functioning and group relationship were significant predictors of mother perceived child depression and mother perceived child social competence. The CHD group was not included in this analysis because of the low number of respondents. The first multiple regression was performed between the degree of perceived child depression as the dependent variable and group assignment, parenting stress, family cohesion, and family

control as independent variables. R for the regression was not significantly different from zero F (4,47) =2.391, p =.064. This finding indicates that none of the independent variables significantly contributed to the prediction of perceived child depression.

A second multiple regression was performed between perceived social competence as the dependent variable and group assignment, parenting stress, family cohesion, and family control as independent variables. R for the regression was significantly different from zero, F (4,47) = 3.996, p =.007. Of the 4 IVs only parenting stress (sr^2=.09) significantly contributed to the prediction of perceived social competence. The three other IVs in combination contributed another .16 in shared variability. Altogether, 25% (19% adjusted) of the variability in perceived social competence was predicted by knowing scores on the four IVs. It should be noted that although the correlation between perceived social competence and family cohesion was .38, family cohesion did not contribute significantly to the regression. Post hoc evaluation revealed that although the correlation was significantly different from zero, (F (1,50) = 8.290, p =.0.006) when only the unique variance was considered family cohesion did not make a significant contribution in predicting social competence

In summarizing the above results there are four important findings requiring attention. First, the relationship between depression and parenting stress appears to function differently in the heart transplant group as compared to the non-clinical control group. Second, the variable of parenting stress appears to be an important factor in predicting social competence in some children. Third, when considered with the other independent variables, group assignment, family control, and family cohesion were not reliable predictors of perceived social competence in children. Finally, neither group assignment or family variables were predictive of perceived child depression.

Table 4

Correlations of Psychosocial Factors and Family Variables

Among Individual Study Groups

Subscale	1	2	3	4	5
		Heart Transplant Group (n=31)			
1. Social Competence	--	-.402 *	-.444 *	.397 *	-.058
2. Mood		--	.189	-.335	-.052
3. Parenting Stress			--	-.396 *	-.175
4. Family Cohesion				--	-.059
5. Family Control					--
		Non-Clinical Control Group (n=21)			
1. Social Competence	--	-.433 *	-.369	.302	-.232
2. Mood		--	.662 **	-.387	-.260
3. Parenting Stress			--	-.463 *	-.171
4. Family Cohesion				--	-.224
5. Family Control					--

* Correlation is significant at the .05 level (2-tailed).
** Correlation is significant at the .01 level (2-tailed).

Hypothesis Four

The fourth study objective examined difference in attachment style among children who received heart transplants and families of children with congenital heart disease as compared to non-clinical control families. Two individual *t* tests were performed. Results of the first *t* test indicated that there was no individual differences between families of heart transplant recipients and families of children with CHD in terms of attachment style (t=-.813, df(35), p>.05, η^2 = .02). Results of the second individual *t* tests also showed no difference between families of children with CHD and families of non-clinical control subjects in terms of attachment style (t=.635, df(25), p>.05, η^2 = .02). An examination of the means as seen in Table 5 show that the CHD group demonstrated the least optimal attachment styles among the three groups. Attachment in the heart transplant and non-clinical groups were almost identical, falling slightly below the CHD group. It should be noted that lower scores represent more secure attachment styles and that despite slight mean differences all group attachment scores fell within the average range and were not clinically significant. A comparison of the medians for the three study groups in terms of attachment is presented in Figure 3.

Table 5

Planned Comparisons between Heart Transplant Recipients, Children with CHD, and Non-Clinical Controls on Measures of Attachment

Measure	Heart TX Mean (S.D.)	CHD Mean (S.D.)	Controls Mean (S.D.)	*t* value	Significance	Effect Size
Attachment	45.71 (10.5)	49.33 (6.44)	N/A	-.813	.422	.02
Attachment	N/A	49.33 (6.44)	46.10 (11.8)	.877	.394	.02

**means for attachment are not clinically significant*

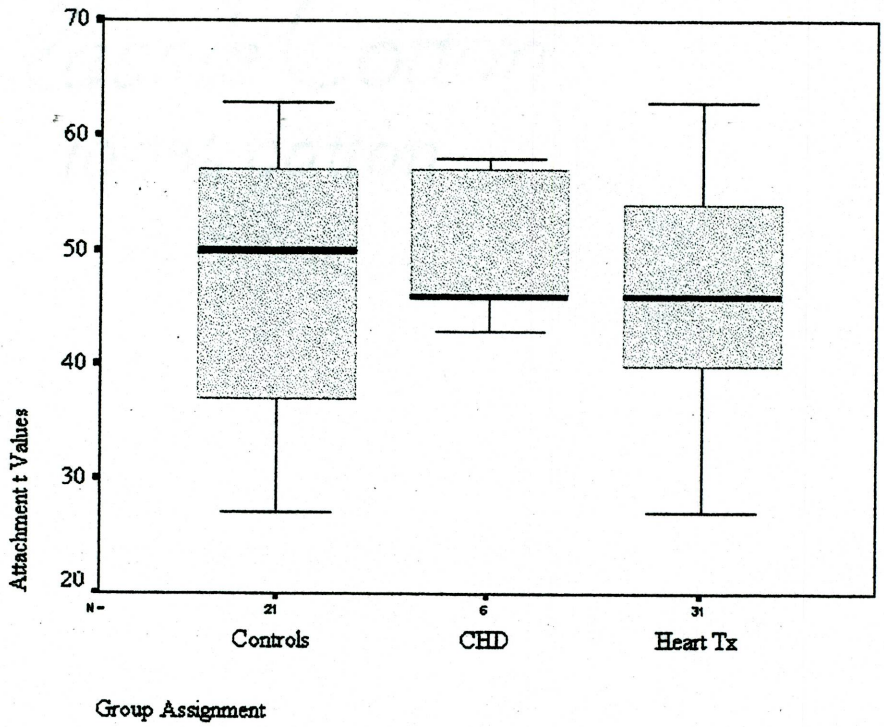


Figure 3. Medians for the Three Study Groups on Measures of Attachment

CHAPTER FIVE: DISCUSSION

The overall goal of this study was to gain a better understanding for how various psychosocial and family functioning factors related to infant heart transplant recipients seven to ten years after transplant. Results indicated that, in general, most infant heart transplant recipients and their families are functioning well several years following the transplant procedure. The first hypothesis of this study explored various psychosocial issues among three different groups of children. Specifically, it was thought that infant heart transplant recipients would demonstrate more problems with social competence and depression as compared to children with CHD, and that the CHD children would experience more problems in these areas then the non-clinical control children. This hypothesis was not supported and contradicts theoretical and experimental findings suggested in previous research. For example, Erikson's (1963) theory of child development predicts that interruptions such as invasive medical procedures, medication side effects, and lengthy hospitalization, as experienced by infant heart transplant recipients, are likely to result in child social and emotional problems. This idea is further supported by Kazdin's (1989) theory of depression that suggests the combination of many life stressors, also experienced by heart transplant recipients, could render a child vulnerable to depressive symptoms.

The current study results are also inconsistent with empirical evidence offered by Uzark et al., (1986) who found that children receiving a heart transplant demonstrated decreased social competence and increased depressive symptoms. A fundamental difference between the findings of Uzark et al., and the results of the current study was the age of transplantation. Whereas the current study was limited to children receiving a

transplant during the first year of life, the study by Uzark et al., included any child receiving a transplant before the age of 17. It is certainly possible to expect that age of transplantation may relate to differences in child development. This idea was addressed by Stuber (1993) who suggested that because a child receiving a heart transplant in infancy has not fully developed a sense of self he or she may not experience a loss of previous functioning but instead a loss of potential options in life. In a slight variation of this idea it is also possible that infant heart transplant recipients experience no loss of future potential options but instead experience their circumstances as "normal" as they have never known a different way of life. It is also possible that the transplant recipients in the current study were still too young to fully understand how their life might be affected by the transplant procedure. This idea is supported by results by Freier et al. (1997) who found no clinically significant problems in infant heart transplant recipients between 6 and 10 years of age in terms of personality functioning, adjustment, achievement, and cognitive status.

In respect to the above, it may be more reasonable to expect problems in emotional and social functioning to emerge in adolescence when there is a heightened awareness of differences and peer relationship take on more importance. Support for this idea is provided by Bernstein (1977) who examined long-term adjustment in children and adolescents undergoing kidney transplantation. Results of that study suggested that pre-school children were able to make rapid gains in terms of physical and social development whereas adolescents experienced the most complicated adjustment. Problems were most commonly associated with concern about physical appearance and growth delays caused by medication side effects.

The second hypothesis that infant heart transplant recipients would exhibit the

most problematic functioning in terms of family cohesion, parenting stress, and family control was also not supported. In fact, the CHD mothers reported the most problems in that results indicated that these families were perceived to experience significantly more parenting stress as compared to families of infant heart transplant recipients and significantly less family cohesion as compared to families of non-clinical control children. It should be noted, however, that although statistically significant, the means for the three groups in terms of parenting stress, family cohesion, and family control fell within the average range and were not clinically significant. In respect to infant heart transplant families, an examination of the means for all three groups revealed that the infant heart transplant group reported slightly lower levels of parenting stress and family control than the other two groups. Also, the level of family cohesion was equivalent to that of the non-clinical control group. Taken together these findings suggest that in terms of parenting stress, family control, and family cohesion the transplant group more closely resembled that of the non-clinical control population.

As indicated above, these findings contradict the theoretical idea expressed in hypothesis two that families of heart transplant recipients would experience difficulty in adapting to the long-term and ongoing effects of the transplant procedure. Of the three examined family variables the most surprising findings were the lack of clinical difference among the three groups in terms of family control and parenting stress as both variables have been shown to be significant factors within the heart transplant population. For example, results of the current study contradict the findings of Gold et al., who, based on informal interviews of parents who's children were recently released from the hospital, identified child overprotection and ongoing parenting stress as significant factors in child heart transplant recipients. The results of the current study also contradict

the findings of Uzark et al., (1986) who found that families of pediatric heart transplant recipients, who were at least three months post-transplant, reported significantly greater family stress than non-clinical control families. Possible explanations for the difference in findings in the above-mentioned studies and in the current study may relate to the length of time since the transplant. All children in the current study were at least 7 years post-transplant whereas the children in the Gold and Uzark studies were only a few months post-transplant. It is certainly reasonable to expect direct and/or indirect stressors related to the transplant procedure to dissipate over time. Support for this idea is provided by Freier et al. (1997) who found that whereas parents of infant heart transplant recipients younger than 5 years of age (1 to 4 years post-transplant) tended to be overprotective, parents of older children between the ages of 6 and 10 years (5 to 9 years post-transplant) did not demonstrate this same tendency. Additional support for this idea is provided by Fukunishi et al. (1995) who found that families of children who were at least one to two years post-kidney transplant were similar in terms of family cohesion and family conflict as compared to non-clinical control families.

Another area that may have improved with time is the family's ability to function as a cohesive unit. Stressors such as marital strain and financial difficulty that are commonly reported during the early phase of the transplant procedure may resolve and the family may return to a previous or improved level of functioning. Also, the high rate of family cohesiveness, as observed in the current study, may be acting as a protective factor by increasing the family's ability to adapt to the ongoing stresses brought about by the heart transplant procedure. This explanation is consistent with family systems theory (Minuchin, 1980) and family stress theory (Patterson, 1988) which suggest that it is the families ability to adapt to a crisis that is important and that resources such as family

cohesion can be used to mediate most demands.

Of notable mention is the higher rate of parenting stress and lower levels of family cohesion observed in the CHD population. These results were particularly surprising as this group was predicted to have better long-term outcomes than the heart transplant group. Possible explanations for these findings are the high probability that the results are unreliable due to the low number of respondents, and the observation that 4 of the 6 respondents were reportedly receiving special education services for significant cognitive delays. This factor alone can be a significant long-term stressor for both child and parent. However, it is important to reiterate that all scores for the CHD group fell within the average range of functioning and were not indicative of any family or child dysfunction.

The third hypothesis predicted group differences in that child depression and social competence would be mediated by the family variables of parenting stress, family cohesion, and family control. However, as there were no significant group differences in terms of child psychosocial development, the need to account for the covariance of family variables was unnecessary. An examination of the within group correlations between family variables and child psychosocial development yielded some interesting results (due to the small number of respondents the CDH group was not included in this analysis). With the exception of the significant relationship between parenting stress and depression in the non-clinical control group, the relationship between all other and family variables and child psychosocial variables were similar in magnitude and direction in both the transplant and non-clinical control groups. Further analysis determined that when considering the two groups together parenting stress was the only reliable predictor of child social competence and that none of the family functioning variables or group

assignment was able to predict child depression. These findings are interesting in the sense that there was no relationship between belonging to the transplant group and the child psychosocial variables of depression and social competence. This supports the family stress theory of Feldman, Nash, & Aschenbrenner, (1985) that it is multiple stressors and not just chronic illness by itself that causes primary behavioral and developmental disturbances in children. Additionally, the ability of parenting stress to predict child social competence and the significance of the correlation between family cohesion and social competence in the transplant group suggests that these variables may represent important protective factors. This idea, supported by Molassiotis, Van Den Akker, and Boughton (1997), suggests that healthier family relationships may create an environment that allows family members, especially the transplant recipient, to work through uncertainties, worries, related to the transplant procedure; thereby contributing to better post-transplant adjustment.

Another interesting finding that resulted from the analysis examined in hypothesis three was the difference in the relationship between parenting stress and child depression within the heart transplant and non-clinical control groups. Whereas these variables showed a strong relationship in the non-clinical control group there was virtually no relationship seen in the transplant group. This suggests that for some reason group assignment is moderating the relationship between parenting stress and mood. A possible explanation for this finding may be the type of parenting stress experienced by the child. For example, if the parenting stress is perceived as concern for the child's health there may not be a relationship between the stress and child depression. If however, parenting stress is perceived as relating to the child's behavior or some other internal characteristic the child could possibly feel depressed and unloved. It is also possible that child heart

transplant recipients have simply habituated to their parents' stress. Whether the true explanation for this finding relates to one of the above ideas or to some other unknown factor, the lack of relationship between parenting stress and child depression, as seen in the transplant group, is a necessary and interesting area for future research. It is also necessary to explore various correlates of child depression as none of the factors assessed in this study demonstrated a significant relationship. This is especially important as mothers reported clinical levels of depressive symptoms in 39% of infant heart transplant recipients; thereby indicating that depression is a relevant factor for at least some of these children.

The fourth hypothesis explored the overall quality of the parent-child relationship in terms of attachment. Although the hypothesis was not supported, it was thought that child heart transplant recipients and children with CHD would demonstrate higher levels of insecure attachment as compared to non-clinical control children. These findings are contrary to the research of Bowlby (1973) which suggests that parent-child separation along with emotional distancing, as thought to be experienced by heart transplant recipients and CHD children, can result in the development of insecure attachments. These results are also inconsistent with the theory of Gold et al., (1985) which states that impairment in parent-child attachment may occur because parents of children undergoing transplant are often focused of saving their child's life as opposed to engaging in traditional parenting roles. Additionally, parents may experience an emotional pull between bonding with the child and being prepared to deal with the child's possible death.

One possible explanation for the lack of expected group differences in terms of attachment is that despite experiencing early medical problems and lengthy

hospitalizations, the transplant and CHD children had their basic needs met for affection, touch, stimulation, and survival. This is supported by the fact that all parents of transplant and CHD children were required to undergo a pre-treatment evaluation and from the beginning were required to actively participate in their child's treatment. It is also supported by the fact that parents have the choice of deciding for or against the transplant procedure. It is reasonable to expect that parents opting for the surgery have a vested interest in their child's health and overall wellbeing.

Another possible explanation for the lack of attachment problems observed in the transplant and CHD groups is that the formulation of attachment is a gradual process that develops over the first few years of life. Because the children in these groups received their respective medical interventions prior to or around the first year of life, even if the treatment procedure interfered with the normal development of attachment there would still be several opportunities to establish the parent-child bond. In other words, there are many chances both pre- and post- surgery for a secure parent-child attachment to occur.

Limitations

This study provides a first attempt to address family functioning and child psychosocial development in infant heart transplant recipients. It has several limitations. First, although an overall response rate of 40% was achieved it is reasonable to suggest that individuals choosing not to participate in the study may represent a sub-group with different characteristics. For example, it is possible that individuals presenting with the most severe problems chose not to participate in the study. Also, despite meeting the minimum statistical requirements for number of subjects in the transplant and control groups, the collection of more subjects would have certainly increased the overall range

of scores obtained within each group. More subjects within the CHD group were needed in order to have confidence in the results obtained. With such a low number of respondents there is some question as to the reliability of the findings regarding the CHD group. Combined, the limited number of study participants and the possibility of not having a representative sample may have limited the amount of variability among the groups and contributed to the overall lack of significant findings.

Another limitation of the study was the possibility of underreporting among the mothers of the heart transplant recipients. This is evidenced by the fact that these mothers consistently reported fewer family functioning and child psychosocial problems than either CHD families or non-clinical control families. Given the degree of initial and ongoing stress these families experience in relation to the transplant procedure, this result is surprising. Further support for this finding is that mothers of heart transplant recipients demonstrated a similar response style on the PSI as non-clinical control mothers and a significantly different response style than that of the CHD group. This difference in response style among the heart transplant and CHD groups was surprising as both groups are thought to undergo similar medical procedures and experiences. Given this information, it is certainly possible that some mothers in the transplant group tried to respond to some of the questionnaires in a socially desirable way. It is also possible that given the drastic life saving measures these families choose to take, they may feel the need to defend their action by either consciously or unconsciously presenting their child in a more positive light than actually exists.

A final limitation of the current study is the use of mothers' perceptions of family and child functioning. A more comprehensive assessment of the perceptions of all family members may have been more informative and may have reduced the potential for

defensive responding. Also, a more direct measure of family functioning and child psychosocial development would potentially provide more accurate and beneficial information. It would be particularly important to gain information directly from the child and to also assess other potential sources of information.

Future Research

Despite the overall finding that infant heart transplant recipients and their families are doing well, the question as to whether family functioning and child psychosocial development are important issues within this population remains open. Given the potential for defensive and/or inaccurate responding, future research should include methodological variations such as more precise measures, the use of direct child observation, and parent interview. It may also be beneficial to include other sources of information such as the child's teacher. When taken together these methods are likely to yield more accurate and useful information directly relating to the population being measured.

Future research should also explore why the relationship between parenting stress and child depression was different in the heart transplant group as compared to the non-clinical control group. An additional explanation is needed for why a larger percentage of transplant recipients were perceived as having a clinical level of depressive symptoms and for why the heart transplant group reported more variable scores in terms of family control as compared to the non-clinical control group. Future studies are also needed to assess transplant recipients as they proceed through adolescence. It is at this point that they become fully aware of their differences and issues such as depression, self-concept, physical appearance, and peer relationships take on new importance.

Other areas of future research should include a broader range of variables that may be important within the transplant population. Such variables may include the overall health of the child, the number of rejections, and the number of serious infections. It may also be beneficial to assess the family closer to the time of transplant when the actual changes in family functioning are occurring. Variables that may be particularly relevant at this time include fear of rejection, parental overprotection, changes in family identify, and stressors related to financial and medical expenses. These variables are thought to relate to the family's ability to adjust to the transplant procedure and to the level of dysfunction in the home. Finally, longitudinal studies are needed to assess the critical periods of development that are affected by the transplant procedure so that effective methods of providing psychological support for these children and their families can be developed.

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APPENDIX A

Consent Form for the Heart Transplant Group

Dear Parent/Guardian:

You are invited to participate in a study examining the potential long-term differences in family functioning and child behavior among child heart transplant recipients as compared to children who have had corrective surgery for congenital heart disease and children with no history of medical complications. The purpose of this study is to identify factors that may be related to improving overall family functioning, preventing developmental delays, and supporting optimal social-emotional development in children with serious heart complications.

In order to complete this important study Loma Linda University Children's Hospital and the Department of Psychology are requesting that the mother of the family fill out the attached four questionnaires. We recognize that fathers are sometimes the main caregiver of the family but in order to maintain test uniformity we are only surveying mothers at this time. Two of the questionnaires will ask how family members relate to each other and the amount of stress experienced as a parent. The other two questionnaires will ask about your child's behavior and participation in activities. It will take approximately 1 hour and 30 minutes to complete all questionnaires. Once complete mail the questionnaires back in the pre-addressed pre-stamped envelops. Once the questionnaires are received, all identifying information will be removed and the questionnaires will be number coded. A master sheet with names, addresses, and code numbers will be kept separate from the questionnaires in case we need to contact you in the future regarding this study. A copy of one questionnaire, the CDI-P, will be sent back to the publishing company for test development once all identifying information is removed and coded.

There is no risk for participating in this study and no direct benefit to you by participating. However, the information you provide may help us better understand ways to provide more effective health care for children who have had heart problems. Participation in this study is entirely voluntary. Your decision whether or not to participate or to terminate involvement at any time will not affect your or your child's present or future medical care. If you wish to contact an impartial third party not associated with this study regarding any concern you may have about the study, then you may contact the Office of Patient Relations, Loma Linda University Medical Center, Loma Linda, CA 92354, phone (909) 558-4647 for information and assistance. If you have any questions directly related to the study you may contact Dr. Kiti Freier at (909) 478-8577. The return of the questionnaires assumes voluntary participation in this study. You may keep this letter for you records.

Complete and return the included postcard in order to enter a drawing for a $100.00 cash prize.

Thank You,

Marti Baum, M.D.
International Heart Institute
Loma Linda University Children's Hospital

Kiti Freier, Ph.D.
Chair, Department of Psychology
Loma Linda University

Kimberly Freeman, Graduate Student
Loma Linda University, Psychology Department

Consent Form for the Congenital Heart Disease Group

Dear Parent/Guardian:

You are invited to participate in a study examining the potential long-term differences in family functioning and child behavior among child heart transplant recipients as compared to children who have had corrective surgery for congenital heart disease and children with no history of medical complications. The purpose of this study is to identify factors that may be related to improving overall family functioning, preventing developmental delays, and supporting optimal social-emotional development in children with serious heart complications.

In order to complete this important study Loma Linda University Children's Hospital and the Department of Psychology are requesting that the mother of the family fill out the attached four questionnaires. We recognize that fathers are sometimes the main caregiver of the family but in order to maintain test uniformity we are only surveying mothers at this time. Two of the questionnaires will ask how family members relate to each other and the amount of stress experienced as a parent. The other two questionnaires will ask about your child's behavior and participation in activities. It will take approximately 1 hour and 30 minutes to complete all questionnaires. Once complete mail the questionnaires back in the pre-addressed pre-stamped envelops. Once the questionnaires are received, all identifying information will be removed and the questionnaires will be number coded. A master sheet with names, addresses, and code numbers will be kept separate from the questionnaires in case we need to contact you in the future regarding this study. A copy of one questionnaire, the CDI-P, will be sent back to the publishing company for test development once all identifying information is removed and coded.

There is no risk for participating in this study and no direct benefit to you by participating. However, the information you provide may help us better understand ways to provide more effective health care for children who have had heart problems. Participation in this study is entirely voluntary. Your decision whether or not to participate or to terminate involvement at any time will not affect your or your child's present or future medical care. If you wish to contact an impartial third party not associated with this study regarding any concern you may have about the study, then you may contact the Office of Patient Relations, Loma Linda University Medical Center, Loma Linda, CA 92354, phone (909) 558-4647 for information and assistance. If you have any questions directly related to the study you may contact Dr. Kiti Freier at (909) 478-8577. The return of the questionnaires assumes voluntary participation in this study. You may keep this letter for you records.

Complete and return the included postcard in order to enter a drawing for a $100.00 cash prize.

Thank You,

Renae Larsen, M.D.
Pediatric Cardiology Clinic
Loma Linda University Children's Hospital

Kiti Freier, Ph.D.
Chair, Department of Psychology
Loma Linda University

Kimberly Freeman, Graduate Student
Loma Linda University, Psychology Department

Consent Form for the Non-Clinical Control Group

Dear Parent/Guardian:

You are invited to participate in a study examining the potential long-term differences in family functioning and child behavior among children with no significant history of medical complications as compared to families who have had a child born with a serious heart problem requiring either transplantation or corrective surgery. The purpose of this study is to identify factors that may be related to improving overall family functioning, preventing developmental delays, and supporting optimal social-emotional development in children with serious heart complications.

In order to complete this important study Loma Linda University Children's Hospital and the Department of Psychology are requesting that the mother of the family fill out the attached four questionnaires. We recognize that fathers are sometimes the main caregiver of the family but in order to maintain test uniformity we are only surveying mothers at this time. Two of the questionnaires will ask how family members relate to each other and the amount of stress experienced as a parent. The other two questionnaires will ask about your child's behavior and participation in activities. It will take approximately 1 hour and 30 minutes to complete all questionnaires. Once complete mail the questionnaires back in the pre-addressed pre-stamped envelops. Once the questionnaires are received, all identifying information will be removed and the questionnaires will be number coded. A master sheet with names, addresses, and code numbers will be kept separate from the questionnaires in case we need to contact you in the future regarding this study. A copy of one questionnaire, the CDI-P, will be sent back to the publishing company for test development once all identifying information is removed and coded.

There is no risk for participating in this study and no direct benefit to you by participating. However, the information you provide may help us better understand ways to provide more effective health care for children who have had heart problems. Participation in this study is entirely voluntary. Your decision whether or not to participate or to terminate involvement at any time will not affect your or your child's present or future medical care. If you wish to contact an impartial third party not associated with this study regarding any concern you may have about the study, then you may contact the Office of Patient Relations, Loma Linda University Medical Center, Loma Linda, CA 92354, phone (909) 558-4647 for information and assistance. If you have any questions directly related to the study you may contact Dr. Kiti Freier at (909) 478-8577. The return of the questionnaires assumes voluntary participation in this study. You may keep this letter for you records.

Complete and return the included postcard in order to enter a drawing for a $100.00 cash prize.

Thank You,

Marti Baum, M.D.
FMO Pediatric Children's Clinic
Loma Linda University

Kiti Freier, Ph.D.
Chair, Department of Psychology
Loma Linda University

Kimberly Freeman, Graduate Student
Loma Linda University, Psychology Department

APPENDIX B

Family Environment Scale

APPENDIX C

Parenting Stress Index

APPENDIX D

Child Behavior Checklist

APPENDIX E

Contest Postcard

Return of this postcard automatically enters you into a drawing for a $100.00 cash prize. Entry into the contest is not dependent on completion of the study and all study participants are welcome to enter. The prize drawing will be held on April 30 and the winner will be notified through the mail. Be sure to include your name and address on the other side of this postcard. Good luck and thank you again for your interest in this study.