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Posttraumatic and Parent Stress in Parents of Infant Heart Transplant Recipients

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Posttraumatic and Parent Stress in Parents of Infant Heart Transplant Recipients

By

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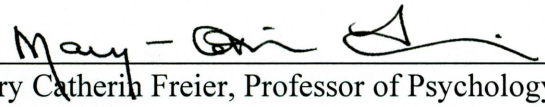
Each person whose signature appears below certifies that this doctoral project in his/her opinion is adequate, in scope and quality, as a doctoral project for the degree of Doctor of Psychology



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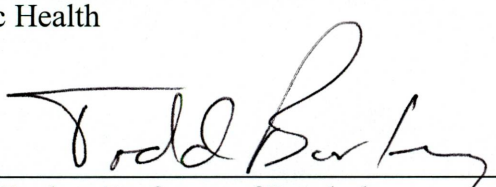

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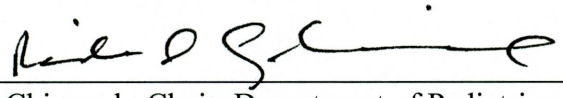

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ABSTRACT OF THE DOCTORAL PROJECT

Posttraumatic and Parent Stress in

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By

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Doctor of Psychology, Graduate Program in Psychology
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Dr. Mary Catherin Freier, Chairperson

Heart transplantation during infancy is a life-threatening event, and when successful, the treatment is a life-long process and the potential for life-threatening consequences never ceases. As a result, parents can be impacted in many ways by this traumatic and demanding experience that begins with the initial diagnosis of their infant and continues into the long-term life course of these children. This life-long process has the potential to cause symptoms of posttraumatic stress disorder as well as elevated levels of stress in parents. This study examined parental self-reported post-traumatic stress symptoms and parental stress in parents of children who received a heart transplant in infancy. A total of 15 biological parents of infants transplanted 7-21 years prior responded to mailed surveys assessing post-traumatic stress symptoms and parental stress. The results demonstrate that even 7-21 years post-infant transplant parents report symptoms of post-traumatic stress and an elevated level of parental stress. It was also found that parental stress was more accounted for by child characteristics than parent characteristics. Further, lower levels of post-traumatic stress symptoms were found to be associated with longer time since transplantation, whereas higher levels of parental stress were associated with longer time since transplantation. In addition, parental stress levels were found to be associated

with post-traumatic stress levels. While the sample size in the current study is small, these results reflect the importance for further investigation in this area and indicate a need to provide support for parents of infant heart transplant recipients throughout the course of their child's life.

Literature Review

First successfully attempted in 1985, pediatric heart transplantation has now become an accepted and widely practiced treatment option for infants suffering from cardiac disease and defects and who are not expected to survive without intervention. In 1984, Dr. Leonard Bailey performed the first xenotransplantion on "Baby Fae" who received a baboon heart and a detailed report of this surgery was released in 1985 (Bailey, Nehlsen-Cannarella, Concepcion, & Jolley, 1985). "Baby Fae" only survived for 20 days; however, the procedure advanced the movement of infant heart transplantation.

In 1986, Dr. Bailey published an article describing three successful heart transplantations with donor human hearts in infants with hypoplastic left heart syndrome (HLHS) (Bailey et al., 1986). The number of successful heart transplantations in the pediatric population has continued to increase worldwide since 1985, however, the number of transplantations have decreased slightly since a peak in the early 1990s (Boucek et al, 2006). Heart transplantation has now been identified as an acceptable and effective treatment option for the infant population (Minami et al., 2005; Pahl et al., 1998).

For infants diagnosed with cardiac problems, modern treatment grants parents the opportunity to choose from three treatment options, which include: supportive care, Norwood (3 Staged) surgical procedure, and/or cardiac transplantation (Claxon-McKinney, 2001). The optimal treatment choice for infant cardiac patients remains controversial and parents are faced with a difficult treatment decision that will impact the life of both the infant and the family. One alternative to heart transplantation is staged

surgical palliation, which was initially accepted as the primary treatment option for these patients.

However, heart transplantation is now receiving more recognition as an effective treatment with acceptable morbidity and mortality rates (Boureck et al, 2006; McGuirk et al., 2006; Minami et al., 2005; and Pahl et al., 1998). Transplantation replaces the "uncorrectable" heart with a normal one. This option offers the best chance of long-term survival, however, issues such as donor shortage, organ rejection, and immunosuppression does not make it an infallible treatment choice (Boureck et al, 2006; Swanson, 1995).

Heart Transplant Survival Outcomes

Survival rates following heart transplantation have increased significantly since 1985 as immunosuppressive regimens and the management of complications have improved. In 2001, the survival rate one year after transplantation was found to be 79%, at 3 years the survival rate was 70%, and 67% at 5 years for all ages and diagnoses (Berg, 2002). Currently at many centers that perform infant heart transplantations, the one-year survival rate is now in the 90% range (Ross et al., 2006).

The heart transplant procedure has now been demonstrated to be a treatment with better survival rates than staged surgery (Jacobs, Blackston, & Bailey, 1998; Jenkins et al., 2000). Although the Norwood (3-stage) surgical procedure has survival rates between 73 and 90%, it remains one of the highest risk procedures in pediatric cardiac surgery (McGuirk et al., 2005). However, due to the mortality risk while awaiting transplantation, the mortality rates for surgery and transplantation are similar. Shaddy et al (1996) studied 191 children who received a heart transplant between the ages of 1 and 18. Survival rate

in this group was found to be 93% at 1 month post-transplantation and 81% at 2 years post-transplantation. Survival rates following heart transplantation vary considerably between institutions, age at transplantation, and pre-transplant diagnoses.

Diagnosis and age at transplant have been found to impact survival rates of heart transplantation. Within the pediatric heart transplant recipient population, transplantation at a younger age was found to be a risk factor for post-transplantation death (Shaddy et al., 1996). The child's cardiac diagnosis has also been associated with the transplant survival rate (Minami et al., 2005). Minami et al (2005) found survival rates were highest for children who underwent heart transplantation due to dilated cardiomyopathy (DCM). Children diagnosed with HLHS were found to have the highest early mortality rates in comparison to children with DCM (Minami et al., 2005). However, post-transplant survival rates in infants with HLHS were not found to differ from post-transplant survival rates in infants being transplanted with other organs (Chrisant et al., 2005). This suggests that diagnosis has an impact on the survival rate both pre- and post-transplantation with infants being at the highest risk of mortality.

Heart Transplant Treatment Decision

Survival rates are improving for heart transplantation, however, the treatment option is not without risk. Therefore, the decision-making process for transplantation is an important consideration. Pediatric patients are designated as candidates for heart transplantation if they have end-stage heart disease, are not expected to survive longer than 12 to 24 months, all other medical procedures and therapies have been exhausted, and/or the life quality is expected to be unacceptable without the intervention (Berg, 2002; Webber, McCurry, & Zeevi, 2006).

Common etiologies for which pediatric patients are considered as heart transplant candidates include congenital heart disease (CHD), cardiomyopathy (CM) and acquired heart disease (Berg, 2002). Complex congenital heart defects and cardiomyopathy together account for approximately 90% of transplantations in children (Boucek et al., 2005). In the infant heart transplant recipient group, congenital heart disease accounts for the majority of cases (Boucek et al, 2006; Shaddy et al., 1996; Webber, McCurry, & Zeevi, 2006). A substantial number of infant heart transplant recipients are diagnosed with a form of congenital heart disease called hypoplastic left heart syndrome (HLHS).

Hypoplastic left heart syndrome. Discovered in 1952 and named in 1958, HLHS is a congenital heart disease that accounts for almost 25% of infant deaths during the first week of life (O'Kelly & Bove, 1997). In newborns with HLHS, the left-sided structures of the heart are inadequate and cannot support the circulation of the system (Claxon-McKinney, 2001). Without early neonatal surgical intervention, this anomaly is fatal. HLHS is a clinically silent disease in utero. Most fetuses with HLHS are asymptomatic prior to birth and come to gestational term without difficulty (Rychik, 2005). Even with HLHS, infants tend to be full term and initially appear as well-developed normal infants (Swanson, 1995). Due to the improved quality of fetal ultrasound techniques and improved obstetric ultrasound operator skills, the diagnosis of HLHS can now be made prior to birth by detecting an absence of the normal 'four-chamber' heart (Rychik, 2005).

Immediately after birth there is a quick decline in the health of the newborn. As the fourth most common critical congenital heart defect, infants born with HLHS will experience severe secondary organ damage and early death without intervention. In the absence of treatment, the infant's ductus arteriosus closes and the infant experiences

metabolic acidosis, decreased systemic perfusion, circulatory collapse, and death (O'Kelly & Bove, 1997). The initial round of treatment is only to stabilize the infant until decisions regarding future treatment can be made. Without any form of treatment, 95% of infants with HLHS will die within a month of birth and the remaining 5% will not survive more than four months (Claxon-McKinney, 2001). Thus, while heart transplantation has become an accepted and successful treatment, due to insufficient donor organs, surgical palliation procedures are more often used in this population.

Donor Shortage as Limiting Factor for Transplantation

When it is decided that a child is an appropriate candidate for heart transplantation, the child is placed on the Network for Organ Sharing waiting list (Berg, 2002). Although data has demonstrated an overall 90% survival to cardiac transplantation (Bourke et al., 2003), a high number of infants die while awaiting a transplantation particularly due to the long wait because of the limited availability of donor organs. Infants diagnosed with HLHS are particularly fragile as they have a higher pre-transplant mortality rate than any other diagnostic group awaiting heart transplantation (Chrisant et al., 2005).

Chrisant et al (2005) looked at 1234 patients that were listed for cardiac transplantation over a 6 year period (1993-1998) and found that infants diagnosed with HLHS made up 21.2% of the waitlist. Of the infants with HLHS, 25% of them died while waiting for transplantation, with 50% of the deaths attributed to cardiac failure. Despite organ awareness campaigns, donor organs have not increased in availability over time (Berg, 2002) and it is likely that the uncertainty of receiving an appropriate organ donation can make the waiting process a particularly stressful time.

The Heart Transplantation Process

The critical nature of an infant in need of a cardiac transplant, the relative newness of the treatment procedure, and the uncertainty of treatment outcome, can make the decision to select a heart transplant a difficult one for parents. Further, approximately one-quarter of all heart transplant recipients are under the age of one, making them too young to participate in the decision for heart transplantation (Webber, McCurry, & Zeevi, 2006). This leaves parents in the decision-making role. Once the decision is made to treat the infant by heart transplantation the family faces the transplantation process. Heart transplantation involves a long and complex course of treatment (Flanagan-Klygis & Frader, 2005) and treatment continues into the long-term postoperative stage.

Transplantation, although emotionally and physically draining for both the patient and the parents, is not a cure and has instead been described as an exchange of one set of symptoms for another (Berg, 2002). It has been likened to a fatal disease (heart disease) that becomes a chronic condition ("a transplanted heart"): "A mother put it very well when she said, 'we traded one disease for another. One day my child had a disease called congenital liver disease and the next day the disease was called liver transplant'" (Gold et al., 1986).

In their study of the psychosocial outcomes of parents and young children following pediatric kidney transplantation, Douglas, Hulson, and Trompeter (1998) found that parents soon realized after transplantation that the kidney transplant was simply the beginning of a long-term effort to prevent rejection or failure of the new organ. LoBiondo-Wood, Bernier-Henn, and Williams (1992) found that there were many long-term health care needs and related stressors that followed a liver transplantation including potential for death, potential rejection of the new liver, long-term medication side-effects,

continued medical expenses, alterations in roles of family members and unknown long term results. The transplantation process brings with it issues, emotions, experiences, and tasks that all become part of the everyday lives of transplanted patients and their families.

Post-Transplant Medical Risks

A significant factor in the long-term survival of heart transplant recipients continues to be chronic rejection and infection (Berg, 2002; Fricker et al, 1987). Rejection is the most common cause of death following heart transplantation in the pediatric group (Shaddy et al., 1996). Further, rejection continues to be a threat years after the transplantation (Pahl et al., 1998). Although the majority of acute rejection episodes tend to occur in the first 6 to 12 months after the heart transplant (Kirklin et al., 1992), a significant proportion of transplant recipients still experience acute rejection episodes one year post-transplantation (Kubo et al., 1995).

In the Pediatric Heart Transplant Study, of those patients who survived one year after transplantation, approximately 25% experienced late rejection episodes (Webber et al., 2003). In a long-term study of 15 infants transplanted prior to one year of age, Ross et al (2006) found 93 rejection episodes in this group. Deaths that occurred more than 5 years post-transplantation were found to be frequently related to acute or chronic rejection (Sigfusson et al, 1997). Early graft failure, infection, and sudden death were also found to be causes of death post-transplantation (Shaddy et al., 1996).

Many other postoperative complications can impact survival and quality of life of heart transplant patients. Ross et al (2006) also found 17 infection episodes that required hospitalization and 3 cases of graft coronary artery disease in the 15 infants studied. Other long-term complications of heart transplantation include reversible or irreversible

renal failure, hypertension, seizures, allograft rejection, side effects of the immunosuppressive medications, nephrotoxicity, and gingival hyperplasia (Berg, 2002; Fricker et al., 1987). Sigfusson et al (1997) found renal dysfunction due to the immunosuppressive agents, lymphoproliferative disease, other neoplasms, and coronary artery disease in a group of children who survived more than 5 years after heart transplantation.

In a study of 57 infants who received heart transplants, Baum et al (1993) found 19% of infants had abnormal neurological examinations 4 months post-transplant, with the most common abnormality being hypotonia. Although the body of knowledge about the medical and surgical aspects of heart transplantation is now considerable and continually evolving, there are still relatively few data concerning the psychological implications of infant heart transplantation.

Psychological Implications of Heart Transplantation

There is only a small body of research related to the psychological implications of transplantation in children (LoBiondo-Wood, Bernier-Henn, & Williams, 1992). As heart transplants are a fairly recent medical development, the research is lacking even more in the area of heart transplantation. Fine et al (2004)'s review of the literature on the cognitive and psychological functioning after heart, kidney, or liver transplantation in children, found heart recipients to be the least studied group. Much more research has been done on pediatric solid organ transplantation in general.

Emotional integration of a donor heart. Although the emotional experiences have been found to be similar for heart and other solid organ transplantation, there is one important difference. The emotional integration of the heart can be much more difficult than for any other organ (Kaba, Thompson, Burnard, Edwards, & Theodosopoulou, 2005). The heart not only circulates blood, but is a place with which we associate the origination of feelings. "A number of parents have verbalized fears that the new heart would somehow change their child's personality. A mother expressed her fantasy that her son would have to learn 'how to love' all over again. Some parents even give the new organ a first name, almost like a new family member" (Gold et al., 1986, p. 741). Although patients and parents are often taught pre-surgically to think of the heart as merely a pump, the symbolic nature of the heart often complicates their acceptance of its replacement. The heart has many associations to vitality, emotion, and the soul (Kaba et al., 2005).

Heart transplant patients and their parents must cope with both the loss of the infant's own heart and the acceptance of a donor heart (Kaba et al., 2005). Kaba et al. (2005) conducted a qualitative study regarding the psychological problems of adult heart transplant recipients. They found that "somebody else's heart inside me," was the most important issue that faced those with a heart transplant within the post-transplant period. The concerns here related to the patients' concerns about the donor's heart and how getting somebody else's heart might affect their own personality; guilty feelings for the donor's death and feelings of gratitude towards the donor's family; and concerns about their own heart. The patient and family's idea of the organ donor may influence the

perception about the transplantation process and the psychological outcomes of the transplantation (Gotzmann & Schnyder, 2002).

Psychological functioning. Surviving infant heart transplant recipients are living longer and long-term functioning of these children is just starting to be studied. After only a few years of successful pediatric heart transplantations, a study conducted through the University of Pittsburg in 1987 concluded that children who underwent and survived the heart transplantation process were able to adapt to the experience and return to an age-appropriate level of functioning (Lawrence & Fricker, 1987). In addition, on average cognitive development was found to be within normal limits, during the first 38 months of life in a group of infant heart transplant recipients (Freier et al, 2004). However, psychological, cognitive, and behavioral adaptations are currently being found in the recipients of pediatric heart transplants (Baum et al, 2004; Berg, 2002)

The majority of pediatric heart transplant recipients studied by DeMaso et al (1995) also demonstrated good psychological functioning post-transplantation. Wray and Radley-Smith (2006) found that children who underwent a heart or heart and lung transplantation demonstrated good psychological functioning immediately after transplantation. However, a significant minority of the children studied showed some depression and behavior problems within 3 years after transplantation. The results also indicated that early adjustment may be a predictor for later psychological functioning as psychological adjustment at 12 months was found to be associated with psychological adjustment at 3 years (Wray & Radley-Smith, 2006).

Cognitive functioning. While many pediatric heart transplant recipients appear to function with average cognition, there are a number of cognitive problems that are being

found in the pediatric heart transplant recipient population. Wray and Radley-Smith (2004) found that children awaiting heart or heart-lung transplantation demonstrated developmental delay. Evidence of impaired functioning and deterioration in developmental skills has been found in young children post-heart transplantation (Baum et al, 1993; Fleisher et al, 2002; Baum et al, 2000). Further, significant numbers of children who undergo heart or heart-lung transplantation are also demonstrating problems at school post-transplantation (Wray, Long, Radley-Smith, and Yacoub, 2001).

Baum et al (2004) found significant impairments in intellectual functioning in one-third of the infant heart transplant recipients assessed at 5 to 10 years of age. Baum et al (2000) found deterioration in developmental skills after one year of age and increasingly poorer attention to tasks and less social interaction in the second year of life in a group of infants who received heart transplantation. Fleisher et al (2002) found that patients who underwent heart transplantation before the age of two were more delayed in development and more delayed in speech and hearing than children who underwent other types of cardiac surgery requiring cardiopulmonary bypass. Language scores were found to be lower in the infant heart transplant recipient population 5 to 10 years post-transplantation (Baum et al, 2004).

Behavioral functioning. Behavior problems were also reported more frequently at home in children who underwent infant heart transplantation (Baum et al, 2004) and, overall, parents reported the children as more "difficult" than the normative population (Wray and Radley-Smith, 2005).Wray and Radley-Smith (2005) found increased activity levels and increased independence in this group. Depression, which is often expressed in children as behavior problems, has been found post-transplantation in children who

experienced heart or heart-lung transplantation (Uzark et al, 1992; Wray and Radley-Smith, 2004).

Type of diagnosis has been found to be related to post-transplant psychological functioning, with a diagnosis of CHD being a risk factor for greater psychological morbidity post-transplantation (Wray and Radley-Smith, 2006). Children with CHD awaiting transplantation showed significantly lower scores on all areas of developmental assessments except for personal/social skills than children with CM (Wray and Radley-Smith, 2004). Further, no differences were found in levels of depression, post-traumatic stress, or self-concept between children who underwent heart transplantation and those children with congential heart disease who did not receive a heart transplant in a study of infants and children at least six months post-transplant and a comparison group of children with CHD (Aaen, 2005).

Impact of Parental Experience on Outcomes

Parental experience of the transplantation process has been shown to impact the treatment outcome, including the long-term psychological, cognitive, and behavioral functioning of the pediatric patients. Post-transplant emotional adjustment and functioning of children who underwent heart transplantation has been shown to be related to parental stress, pre-transplant emotional functioning, and family functioning (DeMaso et al, 1990; DeMaso et al, 1995). A stable family unit with a reliable parent figure and a relative absence of preoperative anxiety and withdrawal predicted better psychosocial outcomes in pediatric heart transplant recipients (Shapiro, 1990).

Jessop, Riessman, and Stein (1988) found a relationship between the functional status of chronically ill children and the mental health status of their mothers. Children

with more functional limitations had mothers who demonstrated more psychiatric symptoms. Eiser (1990) found an association between chronic childhood disease and an increased risk of adverse repercussions for maternal mental health and family functioning. Maternal anxiety, particularly related to the risk of infection, was associated with post-transplant developmental delay in children as mothers tended to become overprotective and restrict social interactions delaying speech and socialization skills (Wray and Radley-Smith, 2004).

Wamboldt and Wamboldt (2000) looked at the role of the family in the onset and outcome of childhood disorders including chronic illness. The authors found that childhood illness changes family dynamics and family functioning. Specifically, they found that after a childhood diagnosis, family interactions often become more structured and organized and less stimulating and emotionally warm over time. Wamboldt and Wamboldt (2000) concluded that chronic illness influences family functioning primarily to the degree that family change occurs in an effort to deal with the stress of the illness. They found evidence that families cope by becoming more regimented, structured, and organized. Their final conclusion: "families can cause problems, but many times the problems families have are in response to the problems of the child" (Wamboldt & Wamboldt, 2000, p. 1217).

The entire family is involved in, and affected by, the transplantation process and it has been recognized in the literature as a stressful event for everyone involved. However, research has not focused on the specific changes that occur in families of heart transplant patients. Caring for a heart transplant recipient is expected to cause a significant amount

of parental stress. The stressful experience of the heart transplantation process would be expected to impact the long-term outcomes in this population.

Parental Experience of the Transplantation Process

Due to the critical condition of the infant, the unavailability of a clear intervention, and the risks involved with heart transplantation, the transplantation process is considered to be a stressful experience for parents (Swanson, 1995). Parents are likely to feel grateful for a "life-saving" and "miraculous" opportunity that transplantation presents for their child because it was not too long ago when there were no treatments available for children facing life-threatening cardiac diagnoses (Gold, Kirkpatrick, Fricker, & Zitelli, 1986). However, there is also a great deal of trauma and stress associated with the transplantation process. There are concrete issues to deal with such as financial burdens and public involvement as well as emotional issues that arise throughout the transplantation process.

Pre-transplant parental experience. Initial diagnosis and the discovery of a need for treatment can create reactions of shock, discouragement, and depression for parents (Masi & Brovedani, 1999). Parents may develop theories of origin of the problem centered on themes of guilt, such as the need for transplantation as a punishment for bad actions or thoughts (Masi and Brovedani, 1999). Feelings of guilt have been found in some parents of infants diagnosed with CHD and CM due to the congenital nature of these diagnoses (Cohn, 1996).

The option of the heart transplantation process as a treatment is a difficult decision to make for parents. It is the parent who must give the informed consent and the burden of the decision is on them. Parents try to do their best to protect their child from

pain; however, a parent makes the decision to go through with transplantation knowing what lies ahead for their child (Gold et al., 1986).

Pre-transplantation, parents must consent to a painful procedure for their children, await the death of another child for an organ, and compete with other families for limited organs. Gold et al. (1986) explained that there is guilt that accompanies the realization that an available organ for transplantation only occurs with the death of another child. "Parents have talked about an approaching holiday and the increased number of donor organs it will bring from the high rate of automobile accidents" (p. 740). This is also associated with guilt that may arise from a sense of competitiveness that parents may feel.

Although parents may want to befriend and find support in other parents who are sharing the same experience, they may have conflicting feelings because their children are both awaiting a donor (Gold et al., 1986). Parents may find it difficult to be happy for another child receiving organ transplantation as they watch their child deteriorate. A child's hospitalization can be a stressful time for parents. Sormanti, Dungan, and Rieker (1994) found that although parents of children who underwent bone marrow transplantation did not experience long-term psychosocial problems, they did report that their children's hospitalization was a difficult time during the transplantation process. Therefore, although these parents may show good long-term adjustment, the parents are reporting difficulties in the beginning stages.

Post-transplant parental experience. The long-term postoperative stage is the least studied area. Post-transplant, parents must adapt to a new type of parent-child interaction, emotionally integrate a new organ, adapt to a new parenting role, and adjust

to a new family structure (Gold et al., 1986). A long-term fear of rejection, infection, and death may exist for many parents (Gold et al., 1986). From the moment a transplanted child is released from the hospital, parents report that many distressful thoughts are involved in taking home a transplanted child. Parents often feel inadequate to care for their child, fear being alone with the child, fear losing the child, and feel a great responsibility to meet the child's distinctive and individual needs (Gold et al., 1986).

Dudek-Shriber (2004) investigated stress experienced by parents in the neonatal intensive care unit. Dudek-Shriber found that the highest levels of stress experienced were in the relationship with baby-parental role area, and regarding how the baby looked and behaved. The infant characteristic of gestational age resulted in significantly different scores concerning the baby's appearance and behavior. Consistent predictors of stress were length of stay, extreme prematurity, and a cardiovascular diagnosis.

There is also often an issue of bonding and attachment because the parents were rarely alone with nor were they the primary caregivers of the child for the first few months of life and at times parents may actually emotionally detach from their child. A group of infants with congenital heart disease had the lowest proportion of secure infant-mother attachment dyads when compared to a group of infants with cystic fibrosis and a group of healthy infants (Goldberg et al, 1990b). An undeveloped bond is likely to make the difficulty of caring for an ill child even harder (Gold et al., 1986).

There is no doubt that surgery of any kind creates added stress for the child and family. Parents of children who underwent selective posterior rhizotomy (SPR) or functional rhizotomy, which is a treatment for many children with spastic cerebral palsy (CP), showed statistically and clinically significant increases in total parenting stress and

in the parent–child dysfunctional interaction subscale (Miller, Pit-ten Cate, and Johann-Murphy, 2001). Miller, Pit-ten Cate, and Johann-Murphy (2001) found that although the parent-child bond was properly established, the year between surgery and follow-up created a dysfunction in the interaction and threatened the bond. Parents of children who received heart or heart-lung transplantation reported feelings of loss over time as their children became more independent and did not "need" them in the same way pre- and short term post transplant (Wray and Radley-Smith, 2005).

Parental Outcomes Related to the Transplantation Process

According to Gold et al. (1986) parents can take on a number of characteristics when faced with the transplantation process. Parents can attempt to become all things to their child. They may appear to be determined and assertive although at heart they feel guilty, hopeless, and out of control. Other parents may feel tentative and less organized because they have little time to emotionally adjust to such a serious diagnosis. This may change the family dynamics. Parents are likely to feel alone in their experiences as they are pushed through the transplantation process (Gold et al., 1986). Feelings of aggression, hostility, and depression may cause them to distance themselves from their spouse, other family members, and the medical staff.

Chronic medical illness in a child has been found to increase parental vulnerability to marital discord (Wamboldt & Wamboldt, 2000). Quittner, Espelage, Opipari, Carter, Eid, and Eigen (1998) studied whether mothers and fathers caring for a young child with a chronic illness experience specific stressors including role strain that affects marital satisfaction, intimacy and daily mood. Their results indicated that couples of a child with Cystic Fibrosis reported higher levels of conflict over child-rearing, a

greater discrepancy between the real division and ideal division of role, and fewer positive daily interactions than couples in the comparison group. Greater marital role strain was found for the CF couples than those caring for a child without an illness. They also found significant support for their hypothesis that couples caring for an ill child would have less time for social and recreational activities. Mothers reported higher perceptions of intimacy and more symptoms of depression. They concluded that mothers of chronically ill children are "at risk" for decreased psychological and physical health.

Knafl and Zoeller (2000) focused on parents within the same family and looked at whether mothers and fathers have shared view of their situation and the impact of their child's illness on individual and family functioning with the hope of discovering some of the similarities and differences with regard to how mothers and fathers view childhood illness and its implications for family life. Knafl and Zoeller (2000) found that although some significant differences exist, parents were found to be more alike than different in their responses to their child's chronic illness. Mothers reported significantly higher mood disturbance in the areas of confusion and fatigue and fathers reported higher levels of vigor. However, in general, the mothers' and fathers' scores indicated more areas of similarity than difference. Knafl and Zoeller concluded that parents caring for a child with a chronic illness most often develop a shared view of the illness, its management, and its impact on family life. This shared view is an important factor in coping with the illness and protecting the family from a negative impact.

The transplantation process can be a stressful experience for parents of infant heart transplant recipients. Parents of infants with cardiac disease do report heightened levels of stress compared with parents of healthy infants (Goldberg et al, 1990a; Uzark et

al, 1992). When compared to parents of infants with cystic fibrosis and parents of healthy infants, parents of children with congenital heart disease reported higher levels of parental stress (Goldberg et al, 1990). Parents of children CHD also reported more problems with depression and a lowered sense of competence than parents of healthy infants. Visconti et al (2002) found that parents of children with d-transposition of the great arteries (d-TGA) reported less parental stress than normative samples. It was suggested that the low levels of stress reported in this population may be a result of the view that repair of d-TGA resolves the problem (Visconti et al, 2002). Also, compared to other forms of CHD, children with d-TGA have a lower incidence of associated cardiac and extracardiac anomalies and age at repair is relatively uniform (Visconti et al, 2002). Children who experience heart transplantation may be less uniform and have more complications.

Transplantation is also not considered a "fix" for the problem and involves long-term complications and stresses for the parents. Having a child with a chronic illness or potentially terminal disorder has long been recognized in the literature as a stressful event for the entire family (Kazak, 1989). Heiney, Neuberg, Myers, and Bergman (1994) found evidence that parents whose children experienced a bone marrow transplant experienced symptoms of guilt, misgivings, and anxiety.

They also found that parents experience ambivalence about leaving the hospital in which the child is cared for by medical staff, magical thinking about creating a safe home environment, anxiety about keeping the child well, and unrealistic expectations that the transition from hospital to home would be smooth. These issues and others affect the

parents before, during, and after transplantation, making the entire process a traumatic and stressful one.

Post-Traumatic Stress Disorder

PTSD is a variety of symptoms and psychological reactions that have the possibility to develop after a traumatic experience, such as the diagnosis and invasive treatment of one's child. According to the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV-TR), "the essential feature of Posttraumatic Stress Disorder (PTSD) is the development of characteristic symptoms following exposure to an extreme traumatic stressor..." (p. 463). In response to a traumatic stressor an individual will often experience intense fear, helplessness, or horror. The individual with PTSD will persistently reexperience the traumatic event, persistently avoid stimuli associated with the trauma, experience numbing of general responsiveness, and have persistent symptoms of increased arousal.

Reexperiencing and avoiding the trauma are the two characteristic symptoms of PTSD. In reexperiencing the trauma the individual may experience intrusive and unwanted thoughts and images. Avoiding the trauma may involve both physical and emotional avoidance of reminders of the trauma. Hyperarousal, another common symptom of PTSD, can involve sleep disruption, difficulty concentrating, hypervigilance, and an exaggerated startle response (de Vries & Kassam-Adams, 1999). Symptoms of PTSD will usually present within three months of the traumatic stressor, however, a delay of months, even years may occur.

It is important to note, however, that not all individuals who experience traumatic experiences develop symptoms that are clinically significant enough to warrant a

diagnosis of PTSD. The National Comorbidity Survey found a lifetime PTSD prevalence rate of 7.8% (Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995). The severity of a trauma experience has been shown to be a primary etiological factor for post-traumatic stress; however, it is a universal finding that not all victims of trauma experience symptoms of posttraumatic stress (McKeever and Huff, 2003).

The diathesis-stress model of PTSD states that individuals have a level of predisposing risk factors (diatheses) that will impact the development of PTSD in the face of a traumatic situation (McKeever and Huff, 2003). For this reason, only a minority of people in any given population of victims of traumatic situations will experience post-traumatic stress symptoms. Reported estimates range from 5%-35%, with very few exceeding 50% (McFarlane, 1990; Kulka et al, 1990; Norris, 1992; and Resnick, Kilpatrick, Best, & Kramer, 1992). Ruscio, Ruscio, and Keane (2002) found a dimensional latent structure to PTSD that emphasizes an understanding of PTSD as continuous variable with varying levels of symptom severity and chronicity rather than the consideration of the presence or absence of the disorder.

Post-Traumatic Stress Symptoms in Parents of Pediatric Patients

Any event in which a person (i.e. a parent/guardian) experiences fear, helplessness, or horror because of harm or serious injury to a loved one can develop PTSD after witnessing or learning of his/her child's diagnosis (de Vries and Kassam-Adams, 1999). A qualifying event for posttraumatic stress disorder (PTSD) is learning that one or one's child has a life-threatening disease. Post-traumatic stress disorder suggests that individuals exposed to situations of extreme stress may have maladaptive or abnormal reactions (Ruscio, Ruscio, and Keane, 2002). However, it is normal to

experience at least some symptoms of stress after exposure to a traumatic event and many trauma survivors show PTSD symptom levels that are subclinical, though elevated compared to those who have not been exposed to trauma (Ruscio, Ruscio, and Keane, 2002).

Young et al. (2003) found that over half of the caregivers of pediatric transplant recipients of any kind in their study reported moderate to severe levels of PTSD symptoms. The authors concluded that PTSD seems to be common in this population. These elevated levels of PTSD symptoms were found despite the participants not reporting significant levels of depression or anxiety. Post-traumatic stress symptoms were studied in a group of mothers of childhood cancer survivors. The mother's reported posttraumatic stress predicted general adjustment 18 months later even when stressful life events were considered. Life events did not mediate the association between post-traumatic stress symptoms and general adjustment (Barakat et al, 2000).

Parents of children surviving childhood cancer indicated significantly higher levels of posttraumatic stress symptoms than a group of comparison parents even though the children did not differ from a comparison group of children. Perceived life threat and family and social support resources were the main contributions to the posttraumatic stress reported by these parents (Barakat et al, 1997).

Rizzone, Frederick, Murphy, and Kruger (1994) conducted the first study of posttraumatic stress symptoms in mothers of childhood burn victims. They also investigated how social support influenced the development of PTSD in these parents. Burns, like chronic illness and transplantation, forces an immediate alteration in the present and future lifestyle of the child and his or her family. Adaptation to

psychologically stressful situations is required of these families. Rizzone, Frederick, Murphy, and Kruger (1994)'s study found that 72% of the parents reported experiencing posttraumatic stress symptoms within 6 months of their child's burn injury, with 56% of those parents continuing to experience symptoms years after the trauma. This study found that guilt and self-blame were common in these parents and likely highly associated with the PTSD symptomology.

Azoulay et al. (2005) found that 33% of family members who took on the role of decision-maker of patients admitted to the intensive care unit experienced post-traumatic stress symptoms. Among mothers of children who underwent hematopoietic stem cell transplantation, Manne et al. (2004) found that nearly half of the mothers evidenced significant posttraumatic stress reactions. Further, 20% of the mothers had clinically significant distress reactions and one-third of the mothers met the criterion for persistent distress.

de Vries and Kassam-Adams (1999) studied PTSD symptomology in pediatric traffic accident victims and their parents. They found that 15% of the parents in their study did present with diagnosable PTSD and 44% were reported to have at least minimal impairment from posttraumatic symptoms. Further, they found that parental PTSD symptomology was associated with younger child age, the presence of PTSD in the child, and whether or not the parent witnessed the event. The severity of the injury was not found to be associated with parental PTSD.

Parental Stress and Post-Traumatic Stress Symptoms in Parents of Heart Transplant Recipients

Unlike other traumatic stressors, in the heart transplantation process it is not easy to identify the traumatic stressor(s) as there are a number of potential traumas that occur. At initial diagnosis parents are faced with the fact that their child will die without treatment and may die with treatment. Throughout treatment parents watch helplessly as their child experiences repeated painful invasive procedures, hospitalization, and life-threatening complications. There are disruptions of family life, feelings of helplessness, and recurrent reminders of the child's vulnerability to rejection or infection and/or death (Kazak, Stuber, Barakat, Meeske, Guthrie, & Meadows, 1998). "It is a paradoxical situation. Parents want to maintain their child in the best possible condition. Yet, they are aware that the sickest children receive transplants first. It is tortuous for parents to watch the child deteriorate to be a priority for the limited number of donor organs" (Gold et al., 1986).

In their article, Heiney, Neuberg, Myers, and Bergman (1994), discussed ways in which the experience of a transplant is a traumatizing event. Factors associated with PTSD symptoms were described to be the degree of life threat, duration of the trauma, the degree of bereavement or loss of significant others, the displacement from home community, the potential for recurrence, the role of the parent in the trauma, and the exposure to death and destruction, all of which occur throughout the transplantation process. Farley et al (2007) studied parents of pediatric heart transplant recipients 3 months to 10 years post-transplant and found 10 of 52 parents studied met clinical diagnostic criteria for post-traumatic stress disorder at the time of the study. These parents also reported significant levels of parental stress in the areas of communication

around the child's illness, emotional distress, managing the child's medical care, and balancing role functions.

Kazak (1997) found a great deal of support in the existing literature that substantial parental distress occurs long after the transplantation. Her research found significantly higher number of symptoms of posttraumatic stress in mothers and fathers of survivors of childhood leukemia than in comparison families. Further, they found that many parents experience a chronic subdiagnosis of distressing symptoms. Kazak, Stuber, Barakat, Meeske, Guthrie, and Meadows (1998) found a significant difference in posttraumatic stress symptoms in mothers and fathers of long-term survivors of childhood cancer in comparison to families without children with chronic illness. The authors concluded that mothers and fathers of long-term survivors of childhood cancer are likely to have ongoing and significantly elevated posttraumatic stress symptoms.

Santacroce (2003) explained that when a traumatic event occurs, previously held assumptions about the self and the world are shattered and uncertainty is generated. Traumatic events evoke horror, helplessness, and fear and the development of three types of characteristic symptoms: reexperiencing, avoidance and numbing of emotions, and hyperarousal. Childhood illness results in parental helplessness and an intense fear of the child's potential death. Chronic childhood illness extends beyond diagnosis and the acute threat to ongoing traumas that repeatedly occur throughout treatment and survivorship. Kazak et al. (1998) and Santacroce (2003) both found that parents with chronically ill children often develop PTSD-type symptoms and this is further determined by how the parent subjectively experiences the child's illness.

Landolt, Vollrath, Ribi, Gnehm, and Sennhauser (2003) found that parents of pediatric patients they studied experienced posttraumatic stress symptoms. They also found that parents reported more severe posttrauma symptoms than the children. The authors suggest that this is because the parents experience traumas independent of the children such as feelings of guilt and the exposure as witnesses to the traumatic experiences of their children. This article was the first to compare the posttrauma symptoms in parents of children impacted by acute conditions (e.g. accidents) or those impacted by chronic conditions (e.g. severe chronic diseases). Landolt, Vollrath, Ribi, Gnehm, and Sennhauser (2003) found that the parents with the children who suffered from chronic conditions experienced higher rates of posttraumatic stress symptoms than parents whose children were impacted by acute conditions.

Statement of the Problem

Having an infant who must undergo heart transplantation can be a traumatic experience for parents and can potentially lead to the development of long-term psychological distress responses (Manne et al., 2004). The purpose of this study was to evaluate the prevalence of posttraumatic stress symptomology and parental stress in parents of infant heart transplant recipients post-transplantation. It has been demonstrated that parents of heart transplant recipients do experience a great deal of stress and trauma. It would be beneficial to look specifically at parents of the infant heart transplant population to determine their posttraumatic stress symptomology and parental stress.

Untreated traumatic stress is associated with poor health outcomes in parents of children who experience childhood injury (Winston, Kassam-Adams, Garcia-Espana, Ittenbach, & Cnaan, 2003). Parents play an important role in the adaptation and outcome

of children with health issues (Streisand et al., 2005). Thus, identifying and addressing the issues that parents face as they experience the transplantation process is an important part of long-term infant heart transplantation outcomes. The stress that parents experience and the potential psychological correlates of their stress has received little research attention. Parents whose own well-being is compromised may impact the outcome of their children. By further exploring the areas of stress that parents experience through the transplantation process, interventions can be developed in order to improve psychological and health outcomes for both children and their parents.

Therefore, the aims of the current study were to estimate the prevalence of post-traumatic stress symptomology and parental stress in parents of infant heart transplant recipients and to determine whether or not parental stress is related to post-traumatic stress symptoms in this population. As a result, it was hypothesized that:

1. Parents of infant heart transplant recipients experience posttraumatic stress symptomology in the postoperative stage.
2. Parents of infant heart transplant recipients experience increased levels of parental stress in the postoperative stage.
3. Time since transplantation will not be associated with current posttraumatic stress symptomology.
4. Time since transplantation will not be associated with current parental stress.
5. Higher levels of parental stress are associated with higher number of posttraumatic stress symptomology in parents of infant heart transplant recipients.

6. Parents of infant heart transplant recipients demonstrate higher parental stress scores related to parent characteristics than to child characteristics.

Methodology

Participants

Participants included parents of children who were registered for and received heart transplantation prior to one year of age at Loma Linda University Medical Center. Seventy-five families from the Kids F.A.R.E. research database of children who received heart transplantations prior to one year of age at Loma Linda University were recruited for participation in the study (See Letter of Introduction and Letter of Passive Consent in Appendix A). Both parents were asked to participate, however, when only one parent responded, the family was not excluded from the sample. A total of 11 families participated in this study and the sample consisted of 11 mothers and 4 fathers. At the time of the current study, the child who had been an infant heart transplant recipient was between the ages of 7 and 21.

Criteria for inclusion in the research sample were: the participant was required to be either the parent or guardian of a child who received an infant heart transplant prior to one year of age and was also the child's caregiver and decision-maker at the time of transplantation; the child must have been alive and under the care of the participant at the time of the study; if English was not the first language of the participant, the participant must have spoken/understood English well enough to complete the assessment measures.

Measures

Demographics questionnaire. A demographic questionnaire designed specifically for this study (Appendix B) was used to assess basic demographics of the parents and their situation. The questionnaire asked for the gender and age of the participating parent,

participant's relationship to infant heart transplant recipient, ethnicities of the parent and the child, age of the child, the date of transplantation, information about the occurrences of any complications related to the transplantation, and the gender and age of other siblings in the home. The questionnaire also asked if the respondent was a decision-maker for the child during the transplantation.

The Impact of Event Scale - Revised (IES-R). The IES-R measures the current degree of subjective distress related to the child's heart transplantation (Weiss & Marmar, 1997). It is a 22 item self-report measure written at a 6th grade level. Participants respond to a 5-point scale from (0) "not at all" to (4) "extremely" according to the past 7 days. The wording of the IES-R is not specific to any particular occurrence and can be used for any life event. To make the items on the measure specific to the transplantation process, the heart transplantation process was recorded at the top of the IES-R to be used as a referent for each item. The IES-R taps dimensions that parallel the DSM-IV criteria for PTSD. It taps into symptoms of intrusion, avoidance, hyperarousal, and dissociative-like re-experiencing.

Scores may be obtained for each subscale and for the total scale. The intrusion component includes items such as repetitive behavior, troubled dreams, and unbidden thoughts and images. The avoidance component includes items such as blunted sensation, ideational constriction, and emotional numbness. The hyperarousal component includes items such as anger and irritability, heightened startle response, difficulty concentrating, and hypervigilance. All items are summed for the total score, in which higher scores reflect "more stressful impact." The total score range is 0 to 88. The cutoff score of 30 is often used to indicate clinically significant post-traumatic stress symptoms (Azoulay et

al., 2005). The IES-R is not a tool for diagnosing PTSD, but instead detects symptoms indicating a risk of PTSD. Diagnostic cutoff points have been established, but this measure is most often used to determine a general level of distress rather than a categorical diagnosis of PTSD. The IES-R provides information regarding the presence of stress-related symptoms and higher scores indicate more the presence of more severe post-traumatic stress symptoms (Azoulay et al., 2005).

The IES-R has high internal consistency in all three subscales with coefficients ranging from 0.84 to 0.92 (Weiss & Marmar, 1997). The test-retest reliability has been found to range from 0.57 to 0.94 for the intrusion subscale, 0.51 to 0.89 for the avoidance subscale, and 0.59 to 0.92 for the hyperarousal subscale depending on the interval between testings. The original IES correlated with the PTSD MMPI scale at 0.79 and the SCL-90 at 0.78 (Neal, Busuttil, Rollins, Strike, & Turnbull, 1994). The IES-R has been shown to discriminate a variety of traumatized groups from nontraumatized cohorts, to differentiate between those who receive a PTSD diagnosis and those who do not, and to correlate highly with other measures of posttraumatic stress (Manne et al., 2004).

Parenting Stress Index – Third Edition (PSI). The Parenting Stress Index – Third Edition (PSI) was used to measure parental stress levels (Abidin, 1990). The PSI is a 120 item self-report scale written at a 5th grade level. Participants respond to a 5-point scale from (SA) "strongly agree" to (SD) "strongly disagree". The last 19 items make up the Life Events stress scale which requires participants to respond either yes or no to whether or not 19 life events have occurred within the last 12 months. The PSI takes less than 20 minutes to complete.

The PSI yields 17 scores, including seven Child Domain scores, eight Parent Domain scores, and a Total Stress score, plus the Life Stress score. The child domain (47 items) reflects child characteristics that may be a cause of stress in the parent–child system. The six child characteristics measure adaptability, acceptability, demandingness, mood, distractibility/hyperactivity, and reinforcement. There is also a Child Domain total score. The parent domain (54 items) reflects parent attributes that may be associated with high levels of family stress. The parent domain includes measures of depression, attachment to child, restrictions imposed by parental role, sense of competence, social isolation, relationship with spouse, and parental health. A Parent Domain score can also be calculated. The life stress scale (19 items) indicates an index of the amount of stress that the parent is currently experiencing and that is outside the parent–child relationship and often beyond their control.

According to Abidin (1990), scores greater than the 75th percentile are indicative of stress. Participants can have a normal total score and yet have a specific domain scores in a critical or abnormal range. This can be used to identify specific sources of stress in the parent's life.

Internal consistency estimates of the PSI range from 0.70 to 0.83 for the Child Domain subscales and from 0.70 to 0.84 for the Parent Domain subscales. The reliability coefficients for the Child and Parent Domain scales and the Total Stress scale were 0.90 and higher. Test-retest reliability demonstrated correlation coefficients of 0.63 for the Child Domain, 0.91 for the Parent Domain, and 0.96 for the Total Stress score for retests at 1 and 3 month intervals (Abidin, 1990). The PSI has been found to be highly correlated

with the Parenting Sense of Competence scale, the Family Resources scale, and the Family Adaptability and Cohesion Evaluation Scales among others (Abidin, 1990).

The Adult Self-Report (ASR). The Adult Self-Report for Ages 18-59 (ASR) was collected in order to obtain information about the parents' adaptive functioning and problems (Achenbach & Rescorla, 2003) for further analysis. The ASR is a 126 item self-report scale. Participants respond to a 3-point scale from (0) "not true" to (2) "very true or often true". The ASR takes less than 20 minutes to complete.

The ASR yields eight syndrome scales, six DSM-oriented scales, a substance use scale, internalizing and externalizing problem scale, and a total problem scale. The eight syndrome scales are: Anxious/Depressed, Withdrawn, Somatic Complaints, Thought Problems, Attention Problems, Aggressive Behavior, Rule-Breaking Behavior, and Intrusive. The six problem scales are: Depressive Problems, Anxiety Problems, Somatic Problems, Avoidant Personality Problems, Attention Deficit/Hyperactivity Problems, and Antisocial Problems.

Procedures

Each family was mailed a packet that included two demographic questionnaires, two Impact of Event Scales, two Parenting Stress Indexes, and two Adult Self-Reports. Each packet included an addressed, stamped envelope to return the demographic questionnaire(s), IES-R(s), PSI(s), and ASR(s). The packet also included a letter explaining the study as well as a letter of passive consent (Appendix A). The return of the completed questionnaires acknowledged the parents' consent to participate. The measures and return envelopes contained no identifying information and responses were therefore anonymous.

Results

Subjects

A total of 75 infant heart transplant recipients from the Kids FARE database qualified for the study and their names were provided to the Heart Transplant Institute. All children had already participated in research and developmental follow-ups at Kids FARE and parents had signed consent for contact for other studies. A member of the Heart Transplant Institute sent the study packets to the selected families. Families were only contacted via packet in the mail, which included a letter of invitation to the study. Although packets were sent to 75 families for a total of 150 recruited participants (both parents), only 15 parents from 11 families participated in this study (10% rate of return). Two months passed between the time packets were sent to the families and data analysis began, allotting families ample time to reply to the questionnaires.

Screening the Data

The data were screened for missing data and accuracy of data entry. All participants completed the Demographics Questionnaire. One parent did not return the PSI. All completed PSIs were valid with no missing data. One parent's PSI revealed a defensive approach to the measure. This may have been due to the possible neglect of reading and/or failure to comprehend some of the questions. This profile reflected slight underreporting of symptoms in this participant; however, the data was still used as it was not significantly different from other respondent's scores. One parent did not return the IES-R, however, all completed IES-Rs were valid with no missing data. Only five ASRs were returned, and therefore, ASR scores were not included in the analysis of the study's

results. Following this screening, it was deemed that the data was adequate to show trends in this population for the purposes of this study.

Descriptive Variables

The sample included a total of 11 mothers and 4 fathers. The ethnic make up of the participants was comprised of 13 Caucasians and 2 Hispanics. Median age of participants was 44 years old with a range of 30-52. In regards to marital status, 13 participants were married and 2 were divorced. All participants were the biological parent of the infant transplant recipient. As members of 11 families participated, 11 infant heart transplant recipients are represented in this study. All children were transplanted in infancy with a median age at transplant of 4.5 weeks and a range of 4 days to 6 months and transplants were received between 1988 and 1999. Current median age of the children was 17 with a range of 7 to 21, which reflects that time since transplantation is between 7 and 21 years. Table 1 depicts the demographics.

Table 1

Demographics

Gender	Total
Males	4
Females	11
Ethnicity	
Caucasian	13
Hispanic	2
Marital Status	
Married	13
Divorced	2
Parental Status	
Biological Parent	15

Table 2 provides the medians, means, and standard deviations of the participant age, the age of the infant heart transplant recipients represented, the child's age at transplant, and time since transplant.

Table 2

Participant Presentation

	Median	Mean
Current parent age (years) (n=15)	44	44.2 (SD 5.9)
Current child age (years) (n=11)	17	14.6 (SD 4.9)
Age at transplant (weeks) (n=11)	4.5	8.9 (SD 8.0)
Time since transplant (years) (n=11)	16.8	14.6 (SD 5.0)

Testing of Hypotheses

The first hypothesis proposed that parents of infant heart transplant recipients experience posttraumatic stress symptomology in the postoperative stage. In order to address hypothesis one, a scatterplot was used to represent each parent's score on the IES-R (Figure 1). A cutoff of 30 points indicates a clinically significant level of posttraumatic stress symptoms on the IES-R. As represented by the figure, there is a significant amount of variability in amount of post-traumatic stress reported by parents on the IES-R.

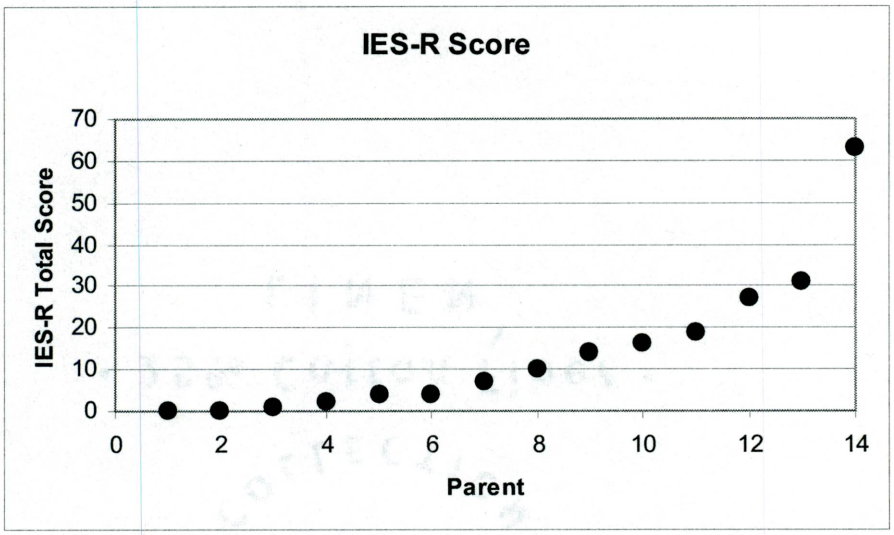

Figure 1. Scatterplot represents each parent's score on the IES-R. A cutoff of 30 points indicates a clinically significant level of post-traumatic stress symptoms of the IES-R.

To further examine posttraumatic stress symptoms, classification of scores into groups of non-significant, low, moderate, and significant levels of post-traumatic stress were constructed to assess the frequencies of scores (Figure 2). The data demonstrates that 14% (n = 2) of respondents endorsed a clinically significant level of post-traumatic stress symptoms. In addition, as represented in the bar graph a total of 50% (n=7) of parents endorsed symptoms of posttraumatic stress (10 points or more) on the IES-R. These results support the hypothesis.

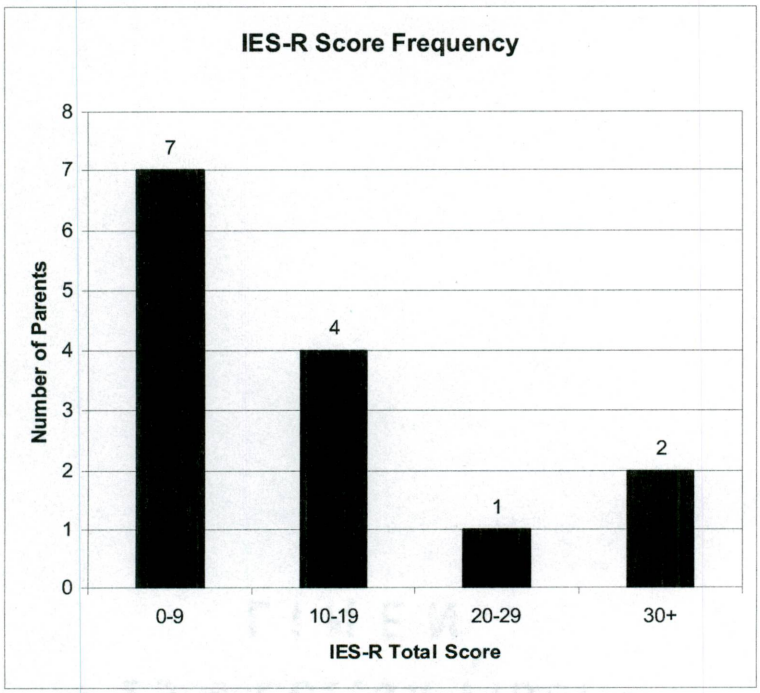

Figure 2. A bar graph represents groups of scores on the IES-R. Scores of 0-9 represent insignificant levels of posttraumatic stress symptoms, scores of 10-19 represent low levels, scores of 20-29 represent moderate levels, and scores over 30 represent clinical levels.

The mean IES-R score for the sample was 14.1, which represents moderate symptomology. However, as noted in Figure 1, there is a high level of variability in scores and the range of scores was 0 to 63.

Hypothesis two proposed that parents of infant heart transplant recipients experience increased levels of parental stress in the postoperative stage. As with the first hypothesis, a scatterplot was used to represent each parent's Total Stress percentile on the PSI (Figure 3). A cutoff at the 75th percentile indicates a clinically significant level of parental stress on the PSI. As with the IES-R, Figure 3 represents the high level of variability in the amount of parental stress reported by parents on the PSI.

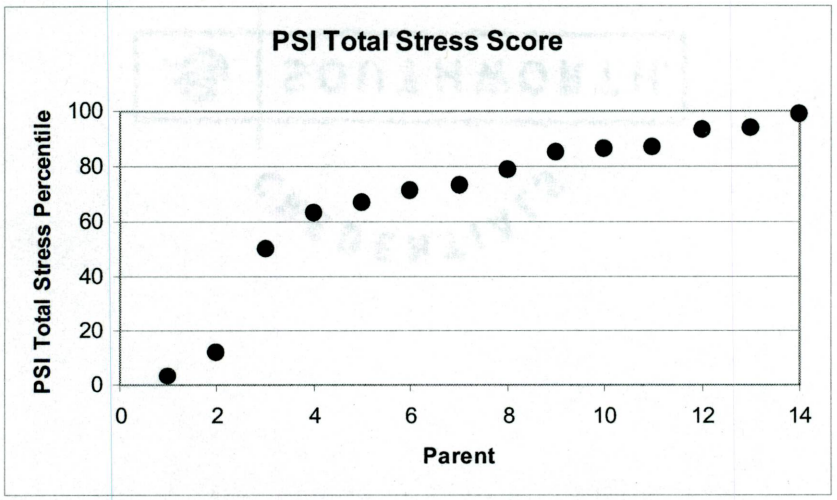

Figure 3. Scatterplot represents each parent's Total Stress percentile on the PSI. A cutoff at the 75th percentile indicates a clinically significant level of parent stress on the PSI.

For a further examination of parental stress endorsed by the participants, PSI Total Stress percentiles were classified into non-significant, moderate, and significant groups and frequencies are represented in Figure 4. As Figure 4 indicates, 50% (n = 7) of parents endorsed a clinically significant level of parental stress on the PSI. Figure 4 also demonstrates that 86% (n = 12) of participants indicated a level of parental stress above the 50th percentile. These results support the hypothesis.

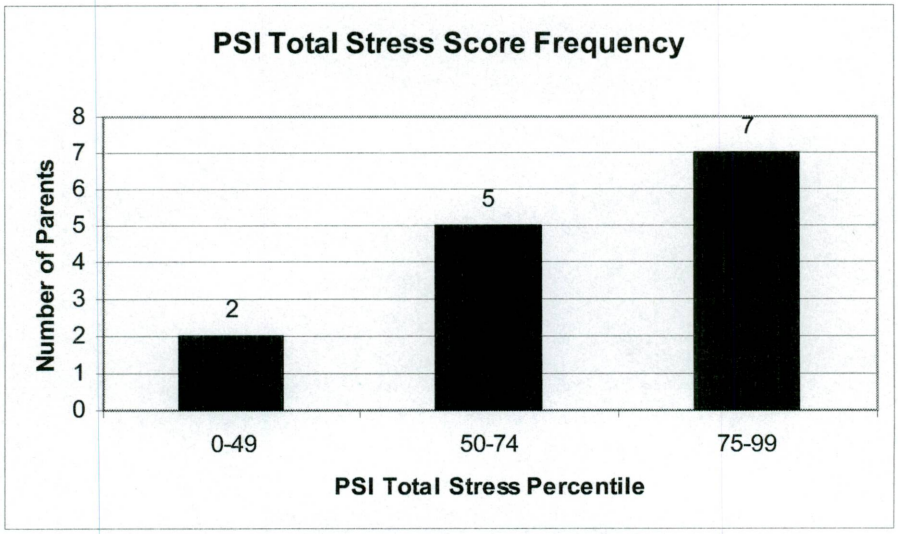

Figure 4. A bar graph represents groups of percentile scores on the PSI. Percentiles ranging from 0-49 represent insignificant levels of parental stress, percentiles ranging from 50-74 represent moderate levels, and scores over the 75th percentile represent clinical levels.

The mean PSI Total Stress score for the sample was at 245.8, which is at the 75th percentile representing a significant level of parental stress. However, as noted in Figure 1, there is a high level of variability in scores and the range of percentile scores was 3 to >99. Table 3 lists the means, standard deviations, and percentiles of the means for the participants' PSI Total Stress and Domain scores.

Table 3

PSI Scores

	Mean	Percentile
Total Stress (n=14)	245.8 (SD 46.2)	75th
Parent Domain (n=14)	125.7 (SD 23.8)	60th
Child Domain (n=14)	120.1 (SD 27.9)	87th

The third hypothesis proposed that time since transplantation will not be associated with current posttraumatic stress symptomology. In order to address this hypothesis, a Pearson correlation was computed to assess the relationship between time since transplantation and participants' post-traumatic stress symptomology. The Pearson correlation coefficient was r = -0.20 for time since transplant and IES-R Total score, reflecting a small to medium effect size. This indicates that 5% of the variance in IES scores is accounted for time since transplantation. This result does not support the hypothesis and Figure 5 displays the small to medium inverse relationship between time since transplantation and post-traumatic stress symptoms. This result implies that greater time since transplantation is associated with lower post-traumatic stress symptomology scores with a small to moderate effect size.

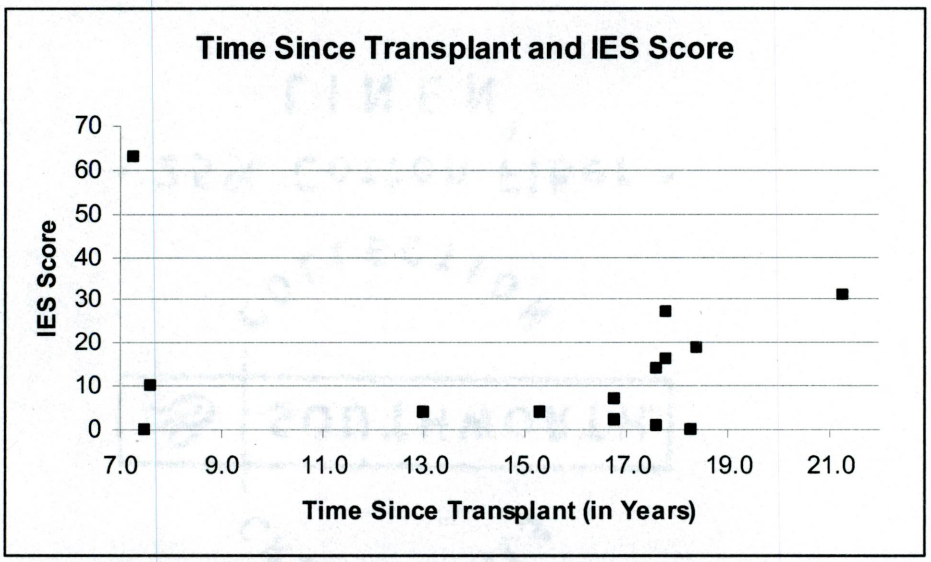

Figure 5. Scatterplot represents each parent's IES Total Score and time since transplantation in years.

The fourth hypothesis proposed that time since transplantation will not be associated with current parental stress. Similar to hypothesis 3, a Pearson correlation was computed to address the hypothesis and assess the relationship between time since transplantation and participants' parental stress. PSI percentile scores were converted to respective T-scores prior to computing a Pearson correlation. The Pearson correlation coefficient was $r = 0.35$ for time since transplantation and Total Stress T-score on the PSI, reflecting a medium to large effect size. This indicates that 12% of the variance in PSI scores is accounted for by time since transplantation. This result does not support the hypothesis and Figure 6 displays the medium to large positive relationship between time since transplantation and parental stress. This result implies that longer time since transplantation is associated with higher parental stress levels with a medium to large effect size.

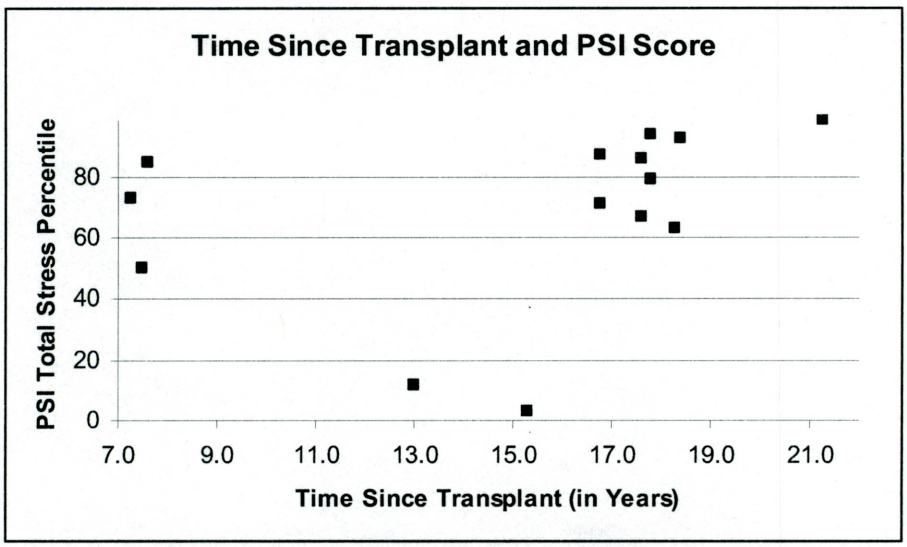

Figure 6. Scatterplot represents each parent's PSI Total Stress percentile score and time since transplantation in years.

Hypothesis five proposed that higher levels of parental stress are associated with higher levels of posttraumatic stress symptomology in parents of infant heart transplant recipients. In order to address this hypothesis, a Pearson correlation was computed to assess the relationship between parental stress and post-traumatic stress symptoms. The Pearson correlation coefficient was r = .33 for Total Stress raw score on the PSI and IES-R score, reflecting a medium effect size. This result supports the hypothesis and Figure 7 displays the medium positive relationship between parental stress and post-traumatic stress symptoms. This result implies that higher parental stress is associated with higher post-traumatic stress symptoms with a medium effect size.

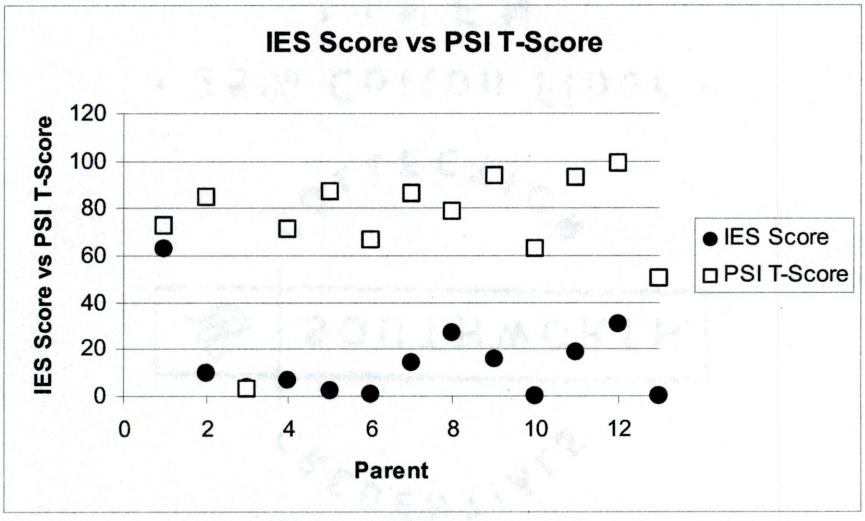

Figure 7. Scatterplot represents each parent's IES score and PSI Total Stress T-Score.

The sixth hypothesis proposed that higher parental stress scores are more related to parent characteristics than to child characteristics. To address this hypothesis, a scatterplot was used to represent each parent's percentile score on both the Parent Domain and Child Domain of the PSI (Figure 8). A cutoff at the 75th percentile indicates

a clinically significant level of parental stress on the PSI. As with the PSI Total Stress, Figure 7 represents the variability in amount of parental stress reported by parents on the parent domain of the PSI. However, less variability is seen in the child domain. Parent domain scores are more similar to child domain scores as parent domain percentiles reach the 60th percentile. Also, the majority of parents indicated a higher level of parental stress related to child domain than to parent domain.

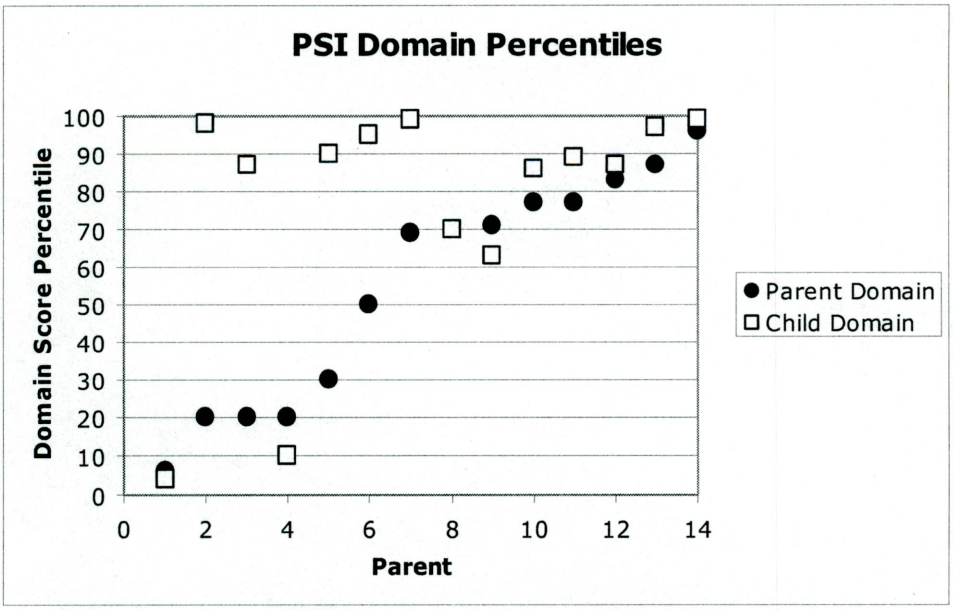

Figure 8. Scatterplot represents each parent's Parent Domain percentile score and Child Domain percentile score on the PSI. A cutoff at the 75th percentile indicates a clinically significant level of parent stress on the PSI in regards to that domain.

For a further examination of parental stress endorsed by the participants by domains, PSI percentiles were classified into non-significant, moderate, and significant groups and frequencies for both Parent Domain score and Child Domain score are represented in Figure 9.

As Figure 9 indicates, 36% (n = 5) of parents endorsed a clinically significant level of parental stress on the Parent Domain, whereas 67% (n =10) parents endorsed clinically significant levels on the Child Domain.

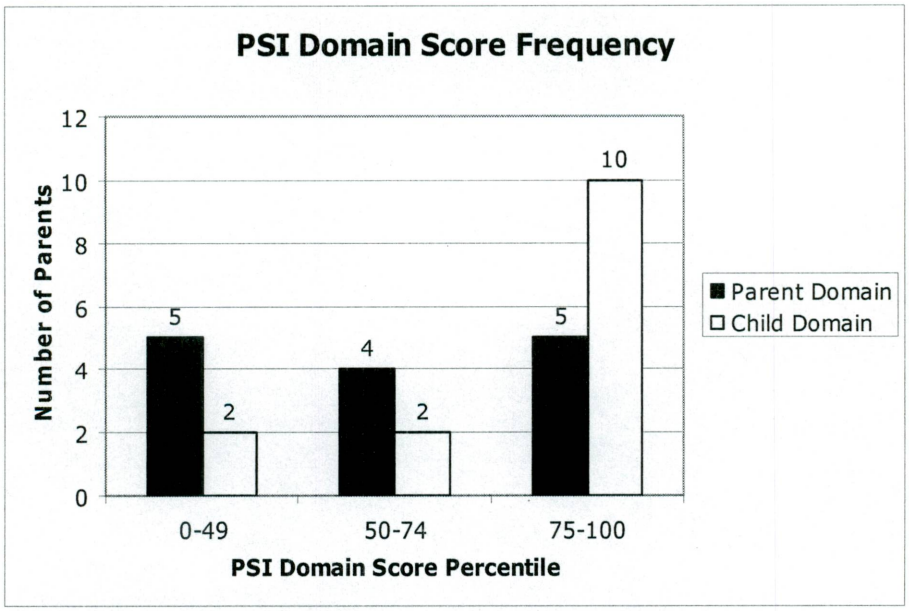

Figure 9. A bar graph represents groups of percentile scores for the Parent and Child domains of the PSI. Percentiles ranging from 0-49 represent insignificant levels of parental stress, percentiles ranging from 50-74 represent moderate levels, and scores over the 75th percentile represent clinical levels.

The mean PSI Parent Domain Stress score for the sample was at 125.7, which is at the 60th percentile representing a moderate level of parental stress. The mean PSI Child Domain Stress score for the sample was 120.1, at the 87th percentile representing a clinically significant level of parental stress. These results indicate that parents are reporting a higher level of parental stress related to child characteristics than parent characteristics, which does not support the hypothesis.

As a supplementary analysis, 8 participants who responded as part of 4 married couples were compared with the remaining participants that included individual

biological parents. A post-hoc analysis comparing means for both groups on the IES-R and PSI Total Score was conducted. For the IES-R, the mean value was 10.1 for the couple group and 18.1 for the individual parents. These results indicate that as a group the individual parents reported more post-traumatic stress symptoms than the coupled parents group. In contrast, the opposite results were observed in regards to reports of parental stress. On the PSI, the mean percentile of Total Stress score for the coupled participants was 70.9 and for the individual parents group the mean percentile was 66.6. In this group the coupled parents reported a slightly, however not significant, higher level of parental stress as a group than did the individual parents group. Due to the small size of the groups, it is not possible to confirm statistically if group differences exist.

The Adult Self-Report was collected in order to obtain information about the parents' adaptive functioning and problems. However, an insufficient number of ASRs were returned by participants. Of those that were returned, no scores were in the clinical range on any scale of the measure. Therefore, the measure was not utilized for further analysis.

Discussion

Infant heart transplantation has become a well-established treatment option for children suffering from cardiac disease and defects and who are not expected to survive without intervention. However, due to the potential variety of long-term medical, cognitive, behavioral, and psychological sequelae associated with the treatment choice, transplantation is considered to be a life-long process. Heart transplantation has been likened to a chronic illness and the long-term course can be a source of stress for the parents. Many of the physical and emotional events that often occur throughout the transplantation process are stressful, and can be considered traumatic experiences. For the parent having a child diagnosed with a life-threatening illness is a qualifying event for the diagnosis of Post-Traumatic Stress Disorder, a condition that involves symptoms of reexperiencing, avoiding, and hyperarousal related to the traumatic experience.

Given the decline in the health of an infant, the need for immediate care in the face of waiting for an organ, the ambiguity of whether a donor heart will be found before the infant dies, the necessity for parents to consent to painful treatments for their infant, the uncertainty of treatment outcome, the risks associated with the treatment, and the adaptation to new roles, it is clear that the infant heart transplantation process is a stressful experience for the parents of these children. This study focused on identifying current post-traumatic stress symptoms and parental stress in parents of children who were infant heart transplant recipients. In order for children to achieve the best possible post-transplant outcomes, it is essential that research focuses not only on the child's psychological experience of the heart transplantation, but also the experience of the

parents as parental stress and their traumatic symptoms can have an impact on long-term outcomes.

Although transplantation is a complex and challenging process at any age, pediatric transplantation in infancy is particularly difficult and risky. Infants have the highest rates of pre-transplant mortality, infants in need of transplants are typically the most fragile patients, and the development of parent-child attachment may be problematical. Diagnosis must typically be followed quickly by treatment without much time for parents to comprehend or accept that their new child has cardiac problems. Parents of these infants are in the decision-making and care-taking role. Infants who have received heart transplants are a significantly understudied population and parents of these children have received even less attention. To-date, no literature is available addressing long-term psychological functioning of parents of infant heart transplant recipients.

It was the purpose of this study to identify, via parent self-report, current post-traumatic stress symptoms and levels of parental stress in parents of infant heart transplant recipients in the long-term postoperative stage. Fifteen biological parents of children ranging in age from 7 to 21 years who received heart transplantations prior to the age of one responded to a survey mailing that inquired about their experience as a parent in the infant heart transplantation process. 11 mothers and 4 fathers completed measures that assessed their post-traumatic stress symptoms and levels of parental stress.

The first hypothesis of this study proposed that parents of infant heart transplant recipients would show elevated scores on a measure of post-traumatic stress symptoms in the long-term post-operative stage. A minority of the sample, 14%, indicated a clinically significant amount of current post-traumatic stress. The measure used to assess

posttraumatic stress symptomology requires parent's to respond regarding their experiences in the past seven days. This indicates that the posttraumatic stress symptoms reported by these parents is not simply a "memory" of the feelings regarding the event, instead are current symptoms.

These results are consistent with a recently published study showing a minority of parents of pediatric heart transplant recipients meeting criteria for PTSD (Farley et al., 2007). Other studies that have also shown elevated levels of post-traumatic stress symptoms in parents of other pediatric transplant recipients (Young et al, 2003), parents of pediatric patients (Landolt et al., 2003), mothers of childhood cancer survivors (Barakat et al, 2000), parents of childhood burn victims (Rizzone et al., 1994), mothers of children who underwent hematopoietic stem cell transplantation (Manne et al, 2004), parents of pediatric traffic accident victims (de Vries and Kassam-Adams, 1999), and parents of chronically ill children (Kazak et al, 1998; Santacroce, 2003).

The result for this hypothesis is also consistent with Azoulay et al (2005)'s study that showed elevated levels of post-traumatic stress symptoms in parents who took on the role of decision-maker of patients admitted to the intensive care unit. In addition, 36% of parents reported symptoms of post-traumatic stress that were not at a clinically significant level, which is consistent with Ruscio, Ruscio, and Keane (2002)'s findings that many trauma survivors show PTSD symptom levels that are subclinical, however, elevated compared to those who have not been exposed to trauma.

It is a universal finding that not all individuals that experience a traumatic event will develop symptoms of post-traumatic stress (McKeever and Huff, 2003). The results of this study are consistent with that finding in that not all parents reported post-traumatic

stress symptoms. However, this study only speaks to those parents who are 7 to 21 years removed from the transplant event and does not speak to the immediate effects of the transplantation process. Parents earlier in the post-operative stage may experience different levels of post-traumatic stress symptoms than the parents represented in this study. Importantly however, it is noted that 50% did report moderate symptoms several years post their child's transplant.

Ruscio, Ruscio, and Keane (2002)'s explanation of post-traumatic stress disorder as a dimensional structure with varying levels of symptom severity supports these findings. The 14% of parents in this sample that indicated a clinically significant level of post-traumatic stress is similar to reported estimates of frequencies (5-35%) of post-traumatic stress symptoms in any given sample of victims (McFarlane, 1990; Kulka et al, 1990; Norris, 1992; and Resnick, Kilpatrick, Best, & Kramer, 1992). These results from this study describe this population as slightly higher than the rate of PTSD in the normative population. Lifetime prevalence of PTSD in the adult population is 8% (DSM-IV TR).

Although the number of participants was very small and these finding should be interpreted with caution, the results demonstrate that a minority of parents of infant heart transplant recipients are currently experiencing trauma symptoms related to their children's heart transplantation. These findings demonstrate that a number of parents may experience the transplantation process as traumatic and develop symptoms and psychological reactions. However, it is important to consider that the sample represents children that were transplanted in 1988 to 1999 and are some of the pioneer parents of heart transplanted infants. These parents were the first to undergo the transplantation

experience and may have different levels of trauma associated with the transplantation process than parents who are experiencing the transplant process with models to observe. The procedure has also been enhanced, decreasing risks and improving survival rates, possibly making the experience less traumatic for current parents as well.

Given the results in this small sample, a larger sample would more accurately reflect the percentage of parents experiencing significant levels of post-traumatic stress in the population of parents of infant heart transplant recipients. An important consideration when evaluating the results of this study is that the current sample is in the long-term post-operative stage. All parents are at least 7 years post the significant event and for some it has been 21 years since their child's heart transplantation. This sample may be significantly different from parents who are much earlier into the post-transplant phase.

The second hypothesis in this study posited that parents of infant heart transplant recipients would report elevated levels of parental stress. It was found that half of the sample scored in the clinically significant range on a measure of parental stress. Furthermore, the majority of the sample (86%) endorsed a level of parental stress above the 50^{th} percentile. These results are consistent with heightened levels of parental stress found in parents of pediatric heart transplant recipients (Farley et al., 2007) and other pediatric populations such parents of children with cystic fibrosis (Goldberg et al, 1990; Quittner et al, 1998), parents of neonatal intensive care unit patients (Dudek-Shriber, 2004), parents of children who underwent selective posterior or functional rhizotomy as a treatment for spastic cerebral palsy (Miller, Pit-ten, and Johann-Murphy), and bone marrow transplantation (Heiney et al., 1994).

In contrast, Visconti et al (2002) found less parental stress in parents of children with d-transposition of the great arteries (d-TGA) than in normative samples. These results are inconsistent with the current findings. However, there are important differences in the two populations. Repair of d-TGA typically resolves the problem and children with d-TGA have a lower incidence of associated cardiac and extracardiac anomalies. Transplantation involves long-term treatment and complications and infants who experience heart transplantation may be less uniform and have more complications than children with d-TGA. For these reasons, it is understandable that parents of infant heart transplant recipients would report more parental stress as a group than parents of children with d-TGA.

It must be acknowledged that due to the small sample size these results can only be considered as trends in this population. When considering trends for clinically significant concerns in the studied sample, it appears that within this group parental stress is notable in these parents. These results imply that parents of infant heart transplant recipients may be experiencing an elevated level of stress, many at a clinically significant level long after the transplantation. The stress levels are even more notable in that the parents in this study are 7 to 21 years removed from the transplant surgery. This further supports the idea that heart transplantation is a life long process with continued stresses long into the post-operative stage. Many parents in this study indicated post-treatment complications experienced by their children. These long-term complications can be a source of new and/or continued stress for these parents. In fact, it is possible that some of these parents may be looking at issues of re-transplantation seen in some children several years post their infant heart transplantation. Further research with a larger study sample

could better elucidate the nature of parental stress in this population of parents of infant heart transplant recipients.

In addition, prior research has identified increased levels of parental stress in parents of infants with cardiac disease compared to parents of healthy infants (Goldberg et al, 1990a; Uzark et al, 1992). Those findings are comparable to the current findings that parents of infant heart transplant recipients experience stress. However, further research could differentiate the stress related to the transplantation process from the stress of having a child with cardiac disease. In addition, Dudek-Shriber (2004) found a cardiovascular diagnosis to be a predictor of parental stress in parents of infants in the neonatal intensive care unit. This further suggests that some of the parental stress found in this study may be accounted for by the cardiac diagnosis these infants receive.

Hypotheses three proposed that time since transplantation would not be associated with current posttraumatic stress symptoms, suggesting that no relationship would be found between time since transplantation and scores on a measure of post-traumatic stress symptomology. This hypothesis was not corroborated. A small to medium negative relationship was found to exist between time since transplantation and post-traumatic stress symptomology in the studied sample. This result implies that greater time since transplantation is associated with lower post-traumatic stress symptomology scores with a small to moderate effect size in this group. The small to medium effect size indicates that although lower scores tend to appear in later years, some parents do experience significant amounts of post-traumatic symptoms years after transplantation. This finding is supported by other studies that report post-traumatic stress symptoms in parents years

after a children's burn injury (Rizzone et al, 1994) and in parents of long-term cancer survivors (Kazaket al, 1998).

The threat of death from rejection (Ross et al, 2006), sudden death (Shaddy et al, 1996), and other complications (Sigfusson et al, 1997) have been found to continue years into the post-transplant stage. The results of this study reflect trends that suggest the level of post-traumatic stress may not be elevated by these threats as much as by events in the early stages of the transplantation process. The initial stages of the transplantation process have been shown to create the most reactions of shock, guilt, discouragement, and depression for parents (Cohn, 1996; Masi & Brovedani, 1999). Additionally, a few studies have shown that the majority of pediatric heart transplant recipients have demonstrated good psychological functioning post-transplantation (DeMaso et al, 1995; Wray & Radley-Smith, 2006). The positive psychological outcomes may decrease the perception of the trauma and decrease the traumatic symptomology over time.

It is important to consider that this was a cross-sectional study with a small sample size; therefore, the results must be interpreted with caution. The results indicate a trend for longer time since transplantation to be associated with lower reported post-traumatic stress symptoms in parents. Future longitudinal studies with a larger sample size can determine if post-traumatic stress symptoms decrease over time. Further studies should also consider factors that may contribute to the level of post-traumatic stress in parents.

The fourth hypothesis was similar to the third hypothesis and stated that time since transplantation would not be associated with current parental stress, suggesting that no relationship would be found between time since transplantation and scores on a

measure of parental stress. This hypothesis was also not corroborated. A medium to large positive relationship was found to exist between time since transplantation and parental stress in the studied sample. This result implies that greater time since transplantation is associated with greater reported parental stress in this group with a medium to large effect size. These results are consistent with research demonstrating that parents report elevated levels of parental stress 3 months to 10 years following their child's heart transplantation (Farley et al, 2007).

Many studies have documented that the heart transplantation process in a long and complex course of treatment and numerous medical events can occur in the life of a transplanted child, such as late rejection episodes, chronic infections, and other complications (Flanagan-Klygis & Frader, 2005; Ross et al, 2006; Sigfusson et al, 1997; Webber et al., 2003). The current results may be explained by these occurrences. Parental stress may continue if children are still experiencing medical effects. These children become more similar to children with chronic illness and research has demonstrated increased levels of parental stress in children with chronic illness (Goldberg et al, 1990; Quittner et al, 1998).

Infant heart transplant recipients are also being found to develop long-term cognitive and developmental delays (Baum et al., 1993; Baum et al, 2000; Fleisher et al, 2002; Wray & Radley-Smith, 2004), school problems (Wray et al, 2001), behavioral issues (Wray & Radley-Smith, 2005), and mood disturbances (Uzark et al, 1992; Wray and Radley-Smith, 2004). Research supports an association between elevated levels of parental stress in parents and children who demonstrate developmental delays, behavioral

issues, and mood disturbances (Plant & Sanders, 2007; Walker & Cheng, 2007). These later experiences post-transplant may be sources of new and continued stress for parents.

As with hypothesis three, it is important to consider that this was a cross-sectional study with a small sample size; therefore, the results must be interpreted with caution. Other factors such as the current age of the child (i.e. does adolescence increase parental stress) and potential re-transplantation or other medical consequences may be impacting these results as well. The results do, however, suggest a trend for greater time since transplantation to be associated with greater parental stress in parents. Future longitudinal studies with a larger sample size can determine if stress symptoms remain stable or increase over time. Further studies should also consider factors that may contribute to the level of parental stress in parents.

It must be noted that time since transplantation also reflects age in this study as all infants were transplanted within one year of birth. The participants with longer time since transplantation in this sample represent a sample of teenagers and young adults. It is possible that the elevated stress levels may be accounted for by expected parent-teenager issues. However, there may also be an added issue in that these are teenagers that have experienced heart transplantations and this may increase parents' anxiety regarding the children's transitions into young adulthood. Further, this is a pioneer group as these infants are the first to have experienced heart transplantation and survive into the teenage years. As the future is unknown for these children, parental stress levels may increase with time.

The fifth hypothesis stated that higher levels of parental stress are associated with higher levels of post-traumatic stress symptoms, suggesting that a positive relationship

would be found between parents' scores on a measure of parental stress and scores on a measure of post-traumatic stress. This hypothesis was supported and a positive relationship was found to exist between parental stress and post-traumatic stress in the studied sample with a medium effect size. As expected, the result reinforces the view that higher levels of parental stress should be associated with higher post-traumatic stress symptoms. Farley et al (2007) recently found that parents of pediatric heart transplant recipients both met criteria for post-traumatic stress disorder and had elevated parental stress levels.

The sixth hypothesis stated that higher parental stress scores are more related to parent characteristics than to child characteristics. Contrary to the hypothesis, results indicated that more parents in this study reported higher levels of stress related to child characteristics, such as demandingness, mood, and distractability/hyperactivity, than they reported stress related to parent characteristics, such as depression, attachment to child, restrictions imposed by parental role, and social isolation. Furthermore, whereas the majority of the parents in this study reported significant levels of parental stress related to child characteristics, there was a high variability in parent scores on the parent domain. This suggests that parents more consistently report parental stress related to child characteristics.

These results may be accounted for by research demonstrating that the functional status of children impacts the mental health of parents as well as family functioning (Eiser, 1990; Jessop, Riessman, and Stein, 1988). Therefore, the children's needs and problems possibly associated with long-term outcomes may account for more parental stress than parental characteristics related to the transplantation process. Further, as

would be expected, parent domain scores are more associated with child domain scores as parent domain percentiles reach significant levels indicating that parents who are experiencing higher levels of stress overall report stress in both child and parent domains.

In addition to the original six hypotheses of the study, a post hoc analysis was conducted in response to the data received by participants. The additional analysis examined group differences between four married couples (8 parents) who are both biological parents and participants where only one biological parent responded (6 parents). It was expected that the coupled participants may differ from others in that both parents were willing to discuss their experiences of the transplant experience. These parents are likely communicating and working together as evidenced by both parents participating in the study. This may also mean that both parents feel they have an active role in the child's care.

To analyze the group differences, the mean group scores from the IES-R and the PSI were utilized to determine if differences between groups existed in the level of parental stress and post-traumatic stress symptoms reported. The data demonstrated that the 8 coupled parents differed from the individual parents on both measures. The coupled parents overall reported lower post-traumatic stress symptoms than the individual participant group. This finding is supported by research that found couples caring for a child with a chronic illness that develop a shared view of the illness, its management, and its impact on family life demonstrated better coping and the illness had less negative impact on the family (Knafl and Zoeller, 2000). This suggests that these parents may have experienced the process as less traumatic, possibly due to a supportive spousal relationship or less isolation in the process.

In contrast, results further demonstrated that parents in the coupled group overall reported a slightly higher level of parental stress than the individual parents group. This result indicates that in this sample the coupled parents are reporting a somewhat higher, although not significant, experience of parental stress compared to the individual participants.

It is important to note that there were a small number of participants in both groups and therefore results must be interpreted with caution. A trend was found between families in which two parents responded and families in which only one parent responded. The coupled parents revealed a lower level of post-traumatic stress symptoms and a slightly higher level of parental stress as a group. There may be differences between these two groups; however, the groups were too small to draw conclusions but indicate that this may be an area of further research interest. A larger sample can shed more light on the differences that may exist between these two groups. Importantly, individual respondents made up a heterogeneous group in relation to marital status. A larger sample of couples, as well as a more homogenous comparison group would better indicate whether the parents who are still married to the biological parent of the infant heart transplant recipient and who are both willing to discuss the transplant experience have differing levels of post-traumatic stress symptoms and parental stress when compared to other groups.

This study was unable to consider the parent's adaptive functioning and problems as related to parental stress and posttraumatic stress symptomology as many parents did not return the measure anticipated to provide this information. It is expected that the low return rate of this measure was related to the measure's length and the personal material

involved in the questions. Parents may have felt comfortable responding to the measures that asked about their role as a parent. The Adult Self-Report asks questions that are personal to the respondent and this may have caused discomfort and less willingness to return the measure.

Overall, the current study, while small in sample size, provides important information regarding the psychological functioning of parents of infant heart transplant recipients. Taken as a whole, parents of infant heart transplant recipients report symptoms of post-traumatic stress and an elevated level of parental stress even 7 to 21 years later. Further, parental stress was more accounted for by child characteristics than parent characteristics in this sample. It was also found that lower levels of post-traumatic stress symptoms were associated with longer time since transplantation, whereas the opposite was true for levels of parental stress. Higher levels of parental stress were associated with longer time since transplantation.

Another area that may illuminate some of the findings in this study relates to marital status. The sample of participants in this study represents a high proportion of married individuals as the majority of respondents to the current study were married. Therefore, the sample represented in this study may be different than the population of parents of infant heart transplant recipients that are divorced or remarried. Being that the majority of parents are married, the current sample may have more support and therefore experience less stress than would a group of single and/or divorced parents. This may have resulted in an underestimate of the frequency and severity of post-traumatic stress symptoms and parental stress in the population of parents of infant heart transplant recipient.

However, parents of children with chronic illness have been shown to have increased levels of marital conflict and a greater experience of specific stressors related to the family (Quittner et al, 1998; Wamboldt & Wamboldt, 2000). This finding suggests that the study sample may overestimate parental stress due to the participants of this sample being over-representative of married parents. The results of the post-hoc analysis in the current study, which found that parents from the same family reported a higher level of parental stress further supports this thought. Given the majority of the participants in this study are married; further research should compare married parents and single parents in their levels of parental stress. In addition, all parents in this study were the biological parents of the infant heart transplant recipient. Further research may reveal differences in parental stress in re-married couples or single non-biological parents.

When reflecting on the results of the current study, consideration needs to be given to age at transplantation. Although this study was interested in the experiences of parents of infants transplanted prior to one year of age, the median age at transplantation was 4.5 weeks. This indicates that the infants of the parents in this sample were transplanted relatively quickly. The levels of posttraumatic stress symptoms and parental stress reported in this study may be an underestimate for the population as those parents who experienced longer wait times for transplantation were underrepresented. A study with a sample that has longer wait times till transplantation may find even more reporting of post-traumatic stress symptoms and parental stress in parents of infant heart transplant recipients.

Implications

The current study revealed that parents of infant heart transplant recipients do report post-traumatic stress symptoms and elevated levels of parental stress post-transplantation. The implications of these findings include a greater understanding of the psychological experience of an infant's heart transplantation for parents in the long-term post-operative stage. Importantly, this study is very different than other studies that have previously looked at the immediate outcomes of parents of children who underwent an infant transplant in that this study is the only one that looks at very long-term outcomes with it being at least 7 to 21 years since transplantation. Thus, the levels of parental stress and post-traumatic stress symptoms are important here as this implies that many parents are still affected by the transplantation after such a long period of time. This indicates the need to make support and intervention available to these parents for the life-long process the transplantation entails.

Long-term adaptation for children and transplantation outcomes have been found to be correlated with parental trauma responses (Barakat et al, 2000) and early post-transplant family functioning (DeMaso et al, 2004). This implies that the parental symptoms identified by the parents in this study may impact family functioning and further impact later emotional adjustment of the pediatric patient. For example, parents have been found to react to anxiety by limiting a child's experiences and limiting a child's experience influences development in children (Masi & Brovedani, 1999).

Therefore, posttraumatic stress symptoms and parental stress should be assessed for and managed early in the transplantation process to avoid any negative impact they may have on transplantation outcomes for these children. The results of this study

indicate that steps should be taken to prevent, or at the very least relieve, the symptoms of anxiety that appear to exist in these parents long into the post-transplantation stage. Involving parents in the treatment, explaining procedures and expected outcomes, providing support groups, and educating parents on the transplantation process may decrease anxiety about the process early on in the transplantation process. However, an important implication of this study is that parents may need continued support and assistance over the life course of their child and not just in the early years. The psychosocial needs of parents of infant heart transplant recipients need to be addressed at time of transplantation and throughout the child's life.

Limitations

The most significant concern in regards to the limitations of this study was the small sample size. The small sample size does not allow the generalizability to the larger targeted population. With that in mind, only inferences could be made from the results and significance could not be evaluated. Another limitation of this study is the low response from recruited families. Low response rate is an issue commonly faced by survey research; however, the response rate in this study was particularly low. The families were invited to participate in the study through a mailed letter. The methodology likely contributed to the low response rate, especially since it was anonymous and parents may not have felt a commitment to participate. Further, some families may have not received the invitation due to changed addresses or extended time away from home. However, other parents chose not to participate in the study. These parents may have represented a subgroup of the population which has been negatively affected and did not want to speak about the experience or a subgroup that may not be experiencing stress and

therefore felt no need to discuss the experience. We do not know if these two subgroups may have very different profiles of parental stress and post-traumatic stress symptomology from the parents who chose to respond.

The methodology itself may have created limitations to the study. Due to the questionnaires being mailed out, no controlled environment was provided for the respondents to answer the questions. Although instructions were written on the measures themselves, it is not guaranteed that the instructions were followed or understood by participants. Questionnaires are commonly used to measure post-traumatic stress symptoms and parental stress. However, questionnaires cannot as accurately capture the true levels of symptoms and stress as an interview is able to. Yet in this study many parents endorsed significant issues of stress and post-traumatic symptoms, thus making this limitation less likely. Another possible limitation of the current study was that the measures may have not been specific enough to the child's medical condition or current experience and may have made it difficult for parents to accurately identify issues of concern to them.

Future Direction

Overall, the current study suggests several important factors relating to long-term psychological functioning in parents of infant heart transplant recipient population. Most importantly, further study of these trends with a larger sample size and a more representative sample of parents is warranted. Further, future research should focus on reaching a higher percentage of the infant transplant population as well as a greater range in current age and age of transplant to better understand the parental experience. As well,

a longitudinal study would provide greater information regarding the development of, and changes in, the parental stress levels and post-traumatic stress symptoms in these parents.

One area of unique interest for further investigation is gender differences. Future studies can allow for comparisons of stress levels experienced by mothers and fathers to provide insight into differences that may exist in the experience of the parenting process between mothers and fathers. Marital status could also reveal potential differences regarding the emotional experiences of these parents as this study found slight differences between the groups of parents who responded individually and those families in which both parents chose to participate. This suggests that married biological parents may experience differing levels parental stress and post-traumatic stress symptoms than divorced or remarried parents.

Further studies could more closely analyze what parts of the transplantation process are most traumatic for parents as well as the percentage of parents that may qualify for a diagnosis of PTSD. It is also important to determine how these symptoms may impact the outcomes of the transplantation process. In addition, examining and evaluating supportive factors and resiliency in this population would be beneficial given that not all parents reported post-traumatic stress symptoms and/or elevated parental stress levels in this study. According to the diathesis-stress model, parents who have greater degrees of diathesis variables would be at the greatest risk of developing post-traumatic stress symptoms (McKeever and Huff, 2003). Further research could provide valuable insight into the individual differences that may determine risk factors for parents who experience the transplantation process.

In conclusion, parents of infant heart transplant recipients in the current study reported experiencing heightened levels of parental stress and moderate levels of post-traumatic stress symptoms, 7 to 21 years after their child's heart transplant. This is an important finding for the population as it identifies the need to consider the emotional experience of parents throughout the course of the child's life as well as develop strategies to decrease stress symptoms for these parents.

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Letter of Introduction and Letter of Passive Consent

LOMA LINDA UNIVERSITY

'aduate School
ds F.A.R.E.

164 West Hospitali · Lane, Suite 3
San Bernardino, Ca 'ifornia 92408
Phone: ('09) 558-7290
Fax: ('09) 379-1517

Dear Parent:

You are invited to participate in a study examining the parent's experience of a child having an infant heart transplantation to be conducted by Jessie R. Stevens and Dr. Kiti Freier of the Departments of Pediatrics and Psychology at Loma Linda University as part of a doctoral resea :h project. The purpose of this study is to help us understand what the experience was like and the levels of stress in parents who have experienced the infant heart transplantation process and hav : cared for a child who underwent transplantation. It is important to obtain information from pare ts in order to learn how to best help them cope with stress and assist those that will face the proces : in the future.

Procedure

Participation in this study will take approximately 45-60 minutes to fill out four questionnaires relating to your current experiences of the transplantation process, your current level of stress, a id symptoms you may be experiencing related to parenting a child who underwent heart transplantation as an infant.

Risks

Thinking about the transplantation process may bring up experiences or some of the feelings associated with the process. Participation is voluntary and you may quit at any time. However, l ter should you experience any distressing thoughts or feelings of anxiety, you may contact: Loma Linda University Psychological Services at (909) 558-8576, Loma Linda University Departmen of Psychiatry at (909) 558-6080 or your local mental health clinic.

Benefits

Since this is a research study, we will be unable to give you individual scores/results. However, general results regarding posttraumatic stress and parental stress in parents of infant heart transp ant recipients may be obtained after the completion of this study by calling Dr. Kiti Freier at (909) 3 79-1507. This study will help to increase the awareness of stress symptomology and levels of pare tal stress in parents of infant heart transplant recipients and may prove useful for future interventio s.

Participants' Rights

Participation in this study is completely voluntary and your decision to participation or will in n way affect your care or relationship with the Loma Linda University Heart Transplantation Insti ute.

Loma Linda University
Adventist Health Sciences Center
Institutional Review Boar l
Approved ١٠/٩/١١

Confidentiality

Since names are not needed in this study, the information collected is anonymous. Please do not write your name on any of the questionnaires. A number is written on the envelopes that you return in order for researchers to know that you returned the packet and allow us to send you a thank you letter. No information that you return will be associated with your identifying information.

Additional Costs

There is no cost to you for participating in this study.

Reimbursement

There is no reimbursement or inducements for participating in this study.

Impartial Third Party Consent

If you wish to contact an impartial third party not associated with this study regarding any complaints you may have about the study, then you may contact the Office of Patient Relations; Loma Linda University Medical Center; Loma Linda, CA 92354 at (909) 379-1507 for information and assistance.

Informed Consent Statement

Once you have read the contents of this informational letter, your completion of the questionnaires will indicate your voluntary consent to participate in this study. Please keep this letter for your future reference. Participation in this study involves: *1) reading this consent form, 2) filling out the four questionnaires, and 3) placing the completed questionnaires in the stamped envelope provided and placing it in any mail location.* You may contact Dr. Kiti Freier at (909) 558-8725 during routine office hours if you have additional questions or concerns.

Thank you so much for taking time to consider participating in this study,

Kiti Freier, Ph.D.
Director of Kids FARE; Professor of Pediatrics and Psychology
Loma Linda University and Childrens Hospital

Jessie Stevens

Jessie R. Stevens, Graduate Psychology Student
Research Assistant, Kids FARE
Loma Linda University, Psychology Department

February 26, 2007

Dear Parent(s),

My name is Jessie Stevens and I am a graduate student at Loma Linda University. I am conducting a research study through Loma Linda University Children's Hospital and am interested in your experience of your child's heart transplantation process. Your participation is much needed and will be greatly appreciated. Participation involves filling out 4 surveys and should only take approximately 30-45 minutes. Your names will not be included on any of the measures and your responses will be vitally important to this study. There are two packets included in this mailing, one for each parent if applicable. In order to participate, please complete a packet that includes:

1. The Consent Form is for you to read and keep. This document explains the study and your participation.

2. Demographics Questionnaire

3. The Impact of Event Scale. This is a two-sided survey with directions written on the top of the sheet.

3. PSI. This includes an item booklet with instructions and questions. An answer sheet is attached. Please circle your responses on the answer sheet.

4. The Adult Self Report. Instructions are on the survey. Please fill out without including name or identifying information.

When completed, return the four measures in the postage-paid envelope provided as soon as possible. Please do not include your name on any of the documents. Again, your participation will be greatly appreciated! If you have any questions when filling out the forms, feel free to call (909) 519-8732.

Thank you for your time,

Jessie Stevens

Jessie R. Stevens, B.A.
Graduate Student
Loma Linda University

February 26, 2007

Dear Parent(s),

My name is Jessie Stevens and I am a graduate student at Loma Linda University. I am conducting a research study through Loma Linda University Children's Hospital and am interested in your experience of your child's heart transplantation process. Your participation is much needed and will be greatly appreciated. Participation involves filling out 4 surveys and should only take approximately 30-45 minutes. Your names will not be included on any of the measures and your responses will be vitally important to this study. There are two packets included in this mailing, one for each parent if applicable. In order to participate, please complete a packet that includes:

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Thank you for your time,

Jessie Stevens

Jessie R. Stevens, B.A.
Graduate Student
Loma Linda University

Demographics Questionnaire

Gender of Parent: Male Female

Age of Parent: _____

Marital Status: Single Married Divorced Living with Partner

Relationship to Child: Biological Parent Stepparent Adopted Parent Guardian

Foster Parent Other (please explain): _____

Ethnicity of Parent: _____

Ethnicity of Child: _____

Current Age of Child who Received the Heart Transplant: _____

Date of Transplantation: _____

Age of Child at Time of Transplantation: _____

Describe Any Medical Complications Your Child Has Had Related to the Transplantation (date, type of complication, hospitalizations, length of stay, etc):

_____

_____

_____

_____

_____

Please list the age and gender of other siblings living in the home:

Age Gender

___ _____ ___ _____

___ _____ ___ _____