A CARDIAC CAMP EXPERIENCE: EXAMINING ATTITUDES, EMOTION, AND SOCIAL FUNCTIONING IN CHILDREN WITH CARDIAC ABNORMALITIES

by

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Under the Direction of Ronald L. Blount

ABSTRACT

Twenty-nine children and adolescents with congenital heart defects (CHD) and their families participated in a study evaluating psychosocial functioning and the cardiac camp experience. Baseline levels of psychosocial functioning of children with CHD were significantly lower than healthy peers in most domains assessed. With repeated measures analysis, levels of anxiety reported by the child and separation anxiety reported by the parent decreased as a result of camp. No other significant changes were noted. Statistically significant regression models predicted positive and negative camp outcome. Through examining camp outcome measure scores, it appears that many of the specific deficits that children with CHD experience, such as social isolation and physical limitation, are alleviated while at camp. Future interventions to address pre-camp factors such as negative expectations associated with a difficult time could improve the experience for children who attend camp.

INDEX WORDS: pediatric; cardiology; camping; program evaluation; anxiety; psychosocial adjustment; quality of life; homesickness; chronic disease; children

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INTRODUCTION

Children with chronic medical conditions are increasingly prevalent in this country, with estimates indicating that they constitute 10-20% of the general child population (Cadman, Boyle, Szatmari, & Offord, 1987). Although there are many diseases of childhood, research investigating the adaptation to these disorders has been conducted with only a few of the most common conditions (e.g., diabetes, asthma, leukemia, etc.). The psychological aspects of other childhood conditions have been largely ignored or unsystematically studied. One of these understudied groups is the focus of this current investigation, children with congenital heart defects (CHD).

The psychological literature examining CHD in children is a combination of a small number of quantitative studies, qualitative studies, and anecdotal reports. From these few investigations, it appears that there are a variety of psychological symptoms that arise as a result of living with a CHD. For example, even though the specific pathologies of a child with a CHD are not visible, there may be marked effects on their overall physical appearance and their psychological state. Small stature and cyanosis, a blue skin discoloration, may affect body image. In addition, poor performance at school can result from frequent absences. Further, restrictions placed on physical activities can lead to social isolation and low self-esteem (DeMaso, Beardslee, Silbert, Fyler, 1990; Green & Levitt, 1962). These findings suggest that formal (e.g., psychotherapy) or informal (e.g., making new friends) psychosocial interventions for children with cardiac abnormalities are worthy of research attention.

This paper will review several different areas of research. First, the medical aspects of CHD will be presented. Following this, studies which have assessed children's adaptation to CHD will be reviewed. In order to determine the possible effectiveness of an intervention with these children, the literature on therapeutic camps will then be critiqued. Lastly, the proposed study evaluating the effects of a summer camp for children with CHD will be described.

Children with Cardiac Abnormalities

There are various types of pediatric cardiac abnormalities. By definition, a congenital heart disease exists at birth. It is typically referred to as a defect rather than a disease. A congenital heart defect (CHD) occurs when the heart or blood vessels near the heart do not develop normally before birth. Researchers are still studying the factors that can cause a CHD. Sometimes viral infections or diseases may cause a CHD, other times the etiology may be due to heredity, but often it is difficult to determine the cause and almost impossible to predict who will be born with a CHD. These children will likely undergo surgery within hours of birth. The various surgical procedures they may require include open-heart operations, heart transplantations, installation of artificial valves, and pacemaker implants. Prevalence estimates indicate that 8 of every 1,000 infants born have a heart defect (Bernstein, 2000; Ferencz et al., 1997). Sometimes the defect is so mild that there are no outward symptoms. In other cases, the defect is so severe that the newborn becomes ill soon after birth. In still other cases, signs and symptoms occur only in late childhood. Congenital heart problems account for the majority of all birth defects. The improvement in survival rates for these children is astounding. Before the 1950's when surgery for congenital heart defects (CHD) was introduced, 30% of children afflicted with CHD died within the first year of life. Surgical and medical advances now allow up to 88% of children with CHD to live to adulthood (Ferencz et al., 1997).

There are numerous types of congenital heart defects. For a brief summary they will be described in four broad categories: 1) septal defects, 2) obstruction defects, 3) cyanotic defects, and 4) hypoplastic left heart syndrome (for more information see American Heart Association, 2000). A child born with a septal defect is born with an opening between the wall (septum) that separates the right and left sides of the heart ('hole in the heart') with the most common being atrial septal defects and ventricular septal defects. These defects account for over one-third of all CHD, with these children experiencing little or no symptoms and typically having a good prognosis. With obstruction defects, there is a narrowing that partly or completely blocks the flow of blood, termed stenosis. For example, the most common is aortic stenosis which may have exercise restrictions with life-long medical follow-up. Most children with this condition have no symptoms, but some may have chest pain, unusual tiring, dizziness or fainting. The third broad class, cyanotic defects, result from blood pumped to the body that contains less oxygen than normal causing a blue discoloration of the skin, a condition termed cyanosis. The most common cyanotic defects include transposition of the great arteries, where the two great arteries are in reversed locations, and tetralology of fallot, characterized by four specific heart defects. Tetralology of fallot necessitates heart surgery before school age, has potential episodes of cyanosis with rapid breathing and loss of consciousness. Additionally, during exercise the child may be short of breath and faint. Lastly is hypoplastic left heart syndrome (HLHS), wherein the left side of the heart is underdeveloped. Before the early 1980's, there were no surgical options and typically the infant died before 1-month of age. Now there are two surgical options: 1) the Norwood procedure, which consists of a series of three operations to reconstruct the child's heart or 2) heart transplantation. Virtually all of these children require heart medication with many surgical procedures and the outlook varies dramatically. Treatment may include medications

such as diuretics to help the body excrete water and salts and Digoxin to strengthen the heart's contraction, slow the heart rate, and help remove extra fluid from body tissues. There are numerous surgical procedures that a child with CHD may undergo with the most severe being a heart transplant. However, heart transplantation is not a cure. A transplant is a last option choice and the child requires medication and rigorous follow-up for the rest of his or her life. To prevent the child's body from rejecting the new heart, he or she must take daily medications (immuno-suppressants) for the rest of their life. These medications typically have extensive side effects (e.g., weight changes, acne, and dramatic physical changes). Additionally, these children must undergo biopsies and full cardiac catherizations each year.

The majority of cases of congenital heart disease are diagnosed within the first year of life. When possible, early surgical intervention is carried out. The timing of surgery depends on multiple factors including the child's current symptoms, the complexity of the lesion, and psychosocial considerations (Wray & Sensky, 1998). After surgery, most patients require follow-up at regular intervals, and depending on the status of the lesion a patient may be seen from once a week to once a month or once a year. After corrective surgery, some patients and parents may fear recurrence of heart-related problems or may have unrealistic perceptions concerning physical activity restrictions, creating distress for the child and family (Delamater, 1995). These factors create challenges for the child's psychosocial adjustment.

In addition to CHD, there are also acquired heart diseases and arrhythmias. Acquired heart disease in childhood may include a variety of disorders, and generally results from bacterial and/or viral infections damaging the heart. A child may also have an arrhythmia, a cardiac rhythm disturbance as a result of their CHD; acquired heart disease; or another acquired systemic disorder (Delamater, 1995).

A basic understanding of the various subtypes of cardiac abnormalities and their disease parameters and symptom presentation is crucial in understanding its possible influence on psychological adjustment to disease. Unfortunately, a paucity of literature exists that examines this factor. It is possible that children with more severe defects did not survive in decades past and those who did were asymptomatic, decreasing the likelihood of psychological adjustment difficulties.

Impact of Cardiac Abnormalities: Qualitative Investigations

Little literature exists examining the psychological impact of congenital heart disease, and the few existing studies are a compilation of quantitative and qualitative methodological examination. Bowen (1985) conducted a review of the impact of CHD on children at various developmental stages and its effect on family functioning. She found that during infancy, CHD often necessitates the child's separation from parents. This separation can disrupt parental bonding and child attachment formation and the establishment of a basic sense of trust. Parents may experience guilt, frustration, and a sense of failure, while siblings may experience jealousy and feelings of helplessness. Pre-school and school-aged children with CHD may have difficulty in adjusting to school and relating to peers. In addition, they may view the illness as punishment, show poor self-esteem, and experience severe anxiety. Adolescents with CHD often have problems with peer acceptance, alterations in body image, and difficulty developing independence. CHD commonly leads to parental overprotectiveness and overindulgence and to a disruption in routine and discipline (Bowen, 1985).

Sparacino, Tong, Messias, Foote, Chesla, and Gilliss (1997) interviewed parents of children with CHD. They identified seven common challenges faced by these parents. These included difficulty defining normality for a child with a CHD, dilemmas of disclosure to friends

and family about CHD, the challenges of unknown trajectories for survival in relation to future expectations set for their child, difficulties with relinquishing control of illness management to the child, their child's social isolation as a result of their illness, the impact of the illness on family activities and lifestyles with other family members often feeling neglected, and devising family coping approaches that integrate CHD. From these data, researchers concluded that these parents would benefit from skills in determining what is normal for their child, as well as skills to help them monitor their child's health and safety.

Thomason (1997) attempted to provide an in-depth description of adolescents' experience with significant CHD. Eight themes resulted including physical limitations, normalization, relationships, body image, lack of remembrance, acceptance, physical and emotional pain, and looking toward the future (Thomason, 1997). In a study Gantt (1992) conducted with adolescent and young women about growing up with CHD, core issues these females identified were feeling different from others, parental overprotectiveness, and fears of death. These young women were also concerned and uninformed about the impact of heart disease on fertility, contraception, and pregnancy. Lastly these women reported negative views toward their body size and their surgical scars (Gantt, 1992).

Impact of Cardiac Abnormalities: Quantitative Investigations

Personality, temperament, cognitive development, and time of surgery. Quantitative investigations examining children with CHD began with focusing on the differences between individuals with CHD and their healthy peers. Early studies looked at personality, cognitive development, temperament, and the influence of time of surgery in children with CHD. Using the Cattell 16 Personality Factor (Cattell, Eber, & Tatsuoka, 1970), Garson, Williams, and Redford (1974) compared the scores of child heart patients to those of the normative sample.

Results indicated that children with cardiac problems were more neurotic, as evidenced by greater dependency, over protection, a weaker super ego, more impulsivity, and less ambition (Garson et al., 1974). In another study, Kramer, Awiszus, Sterzel, van Halteren, and Claben (1989) evaluated personality in children with CHD compared to healthy controls. No differences were found for younger children. Among older children (9-14), there was some evidence suggesting increased feelings of anxiety, impulsiveness, and inferiority in CHD patients with physical limitations compared to healthy controls (Kramer et al., 1989).

Children with severe forms of CHD also may be compromised in their intellectual and academic achievement. For the most part, however, these children function in the normal range. If there is more involvement of the central nervous system and cyanosis, more deficits in cognitive functioning might be expected (Delamater, 1995). Cyanosis most likely produces adverse effects because of inadequate oxygenation of the brain during early development (Delamater, 1995). In a recent study by Mahle, Clancy, Moss, Gerdes, Jobes, and Wernovosky (2000), cognitive deficits were related to pre-operative seizures and longer durations utilizing the cardiopulmonary bypass machine during open-heart surgery. The cardiopulmonary bypass machine allows the body to continue to pump oxygen-filled blood throughout the bloodstream during surgery (Mahle et al., 2000). Cognitive development has also been found to be an influential factor in psychological functioning. In an investigation examining children with cyanotic CHD, worse psychological functioning was predicted by the degree of central nervous system impairment and lowered IQ (DeMaso et al., 1990).

Marino and Lipshitz (1991) examined the temperament of a group of infants and toddlers with CHD. Parents reported ratings of temperament on standardized scales. CHD infants were found to be more withdrawn, more intense in emotional reactions, and had lower thresholds for

stimulation. Toddlers were rated as less active, rhythmic, and intense, and more negative in mood. Lastly, there is evidence that time of surgery is a factor that influences the degree of effects secondary to CHD. Patients who received later surgery were more timid and reserved, less venturesome and more apprehensive that those of patients who had surgery earlier (Baer, Freedam, & Garson, 1984). Additionally, there is evidence indicating that surgery conducted earlier is associated with improved cognitive functioning (Delamater, 1995).

This compilation of research on personality, cognitive development, temperament, and time of surgery has aided in our understanding of children with CHD. Although it is far from exhaustive, it delineates some preliminary differences between healthy children and those living with CHD. As most researchers rely on information provided by parents of children with CHD, it is essential to examine familial perceptions and psychological adjustment from the familial perspective given their child's condition.

Familial perceptions and adjustment. The adaptation and adjustment of families caring for children with chronic illness is important both for an understanding of the disease's impact on each family member as well as how their functioning influences the child's adjustment. DeMaso, Campis, Wypij, and Bertram (1991) examined the effect of maternal perceptions of the severity of their physical condition and actual CHD severity on the behavioral and emotional adjustment of four to ten-year-olds. The children had good overall functioning. Maternal perceptions accounted for 33% of the variance in adjustment while severity of the illness accounted for only 3%. The authors concluded that the quality of the mother-child relationship is more critical than the severity of illness to the psychological adjustment of the child (DeMaso et al., 1991). Another study examined mothers of children with CHD during their child's hospitalization and following discharge. Mothers reported their concerns about medical

prognosis, quality of life, psychosocial functioning, effects on family, and financial issues. During hospitalization, mothers were most concerned about medical prognosis. Mother's anxiety, depressive symptoms, and concerns decreased following discharge. Their perceptions of the medical severity of their child were associated with their level of distress about psychosocial issues after discharge (Van Horn, DeMaso, Gonzalez-Heydrich, & Dahlmeier Erickson, 2001). This further supports the idea that following hospitalization, parent perception of their child's condition may be a more influential factor on parent psychosocial adjustment than the child's actual disease severity. Berant, Mikulincer, and Florian (2001) examined mothers' attachment style and psychological reactions to diagnosis of CHD in their infants. Securely attached mothers appraised motherhood in more positive terms, perceived more available support, were more likely to seek support, and reported less psychological distress than insecurely attached mothers. Maternal coping style and method of problem appraisal mediated the attachment-distress link. More specifically, securely attached mothers reported lower levels of distress and engaged in cognitive-focused coping techniques, while insecurely attached mothers reported greater distress and engaged in emotion-focused coping techniques (Berant et al., 2001).

Although fathers are often ignored in research, Clark and Miles (1999) conducted semi-structured interviews with fathers of infants with severe CHD. Their findings indicate that fathers experience four interrelated conflicting reactions. They have the joy of seeing their child born and becoming a father, with the sadness and loss associated with the infant's illness. They have the challenge of becoming attached while dealing with fears about the infant's vulnerability and potential death. They feel the need to try to maintain control while feeling a loss of control. Lastly, they struggle to remain strong for others while hiding their intense emotions. Although the findings by Clark and Miles (1999) are preliminary in nature, they do indicate that fathers are

equally important to consider when examining family adjustment. Another rarely studied family member is the sibling of a chronically ill child. These siblings have been found to be at increased risk for psychopathological disorders. In a study examining the impact of CHD on the family, 27% of the siblings of children with CHD had unspecified behavioral problems, 13% had psychosomatic disorders and 24% had both (Aply, Barbour, & Westmacott, 1967).

Although there is a paucity of research, these studies indicate the importance of a child's chronic illness on the entire family system. Children with CHD conditions both have an impact on the family system and are influenced by their families' perceptions and level of adjustment.

Adjustment of a child with CHD. A multitude of factors contribute to a child's adjustment to a chronic illness. Congenital heart defects, maybe more than any other individual chronic illness, have the potential for creating disproportionate psychological maladjustment due to the emotional and psychological significance attached to the heart. Therefore, parents and children may be inclined to exaggerate the danger of any symptoms related to the heart and to respond negatively to their misgivings (Pless & Pinkerton, 1975). For a child with CHD, the defect itself is hidden, but there may be quite marked effects on physical appearance. Small stature and cyanosis are features that can affect body image. Poor performance at school can occur in academic areas because of absences, and medical restrictions that place limitations on physical and sports activities may result in social isolation and low self-esteem. Some research indicates that children and adolescents with CHD seem to possess a distorted body image as indicated by drawings of the human figure (Green & Levitt, 1962). A recent study by Gupta, Mitchell, Giuffre, and Crawford (2001) examined anxiety, fears, and behavioral problems in children with asthma, children with CHD, and healthy controls. They also examined the influence of maternal anxiety, time since diagnosis, and severity. Children with asthma and CHD had more medical

fears and physiological anxiety than norms. Increased maternal anxiety positively correlated with the child's anxiety, medical fears, and behavioral problems. Increased severity of asthma or cardiac problem was associated with a higher level of children's physiological anxiety and fears. Less time since the diagnosis of their disease adversely affected the children's social interactions in both groups of patients. Feelings of inferiority have also been reported in patients with CHD (Kramer et al., 1989). One study assessed for behavioral and emotional problems at least 9 years after surgical correction for CHD. These children obtained significantly higher problem scores on the CBCL (Child Behavior Checklist) and YSR (Youth Self Report and Profile) than same-aged peers from a normative reference group. The type of problem behaviors did not differ across cardiac diagnostic groups (Utens et al., 1993).

Psychological adjustment has also been examined across cardiac conditions. As some previous research has indicated, condition severity is predictive of the degree of psychosocial problems (Kramer et al., 1989). Casey, Sykes, Craig, Power, and Mulholland (1996) examined behavioral, academic, and social adjustment of surgically treated complex CHD versus those with a heart murmur. Children with complex CHD were rated by parents as more withdrawn, having more social problems, and engaging in fewer activities, and rated by teachers as more withdrawn than those with less severe heart complications. The families also reported financial and personal strain and greater familial and social stress. The personal strains the family experienced appeared to be the most influential factor, and in turn resulted in a disproportionate amount of parental attention focused on the sick child encouraging the invalid role and discouraging social competencies (Casey et al., 1996). In another study, researchers compared adolescents with cyanotic CHD to those with atrial septal defects. Cyanotic CHD is a more functionally impairing and chronic form of CHD than an atrial septal defect (acyanotic).

Children with the two conditions differed on physical capacity and psychiatric variables, with 42% of cyanotic children given a DSM-III diagnosis versus only 27% of acyanotic receiving a diagnosis. Overanxious disorder and dysthymic disorder were most common. There was also a significant correlation between psychiatric status and physical capacity with greater psychopathology associated with more severe physical impairment (Spurkland, Bjornstad, Lindberg, & Seem, 1993). A subset of children living with heart conditions may undergo heart transplantation. This treatment can cause severe physical impairment and necessitates a complex regimen of care. This form of treatment, unheard of decades before is becoming a viable option for severe congenital defects.

Heart transplantation. When no other medical or surgical option is available to improve heart functioning, doctors opt for heart transplantation. As mentioned previously, a heart transplant does not cure a child's heart disease and the child will need medication and rigorous follow-up for the rest of his/her life. This procedure was performed successfully in children for the first time just over 20 years ago. In recent years pediatric heart transplants have been performed more frequently and techniques have been refined, resulting in increased survival rates and quality of life for those at the end-stage with no alternative (Baum & Bernstein, 1993). For the six years ending in 1993, 1,269 children and adolescents received heart transplants in the US (approximately 10% of all heart transplants performed). Of those children, over 40% were less than one year of age (Stuber & Canning, 1998). Of concern is that approximately 20% of children may have neurological complications as a result of the transplant (Baum, Chinock, Ashwal, Peverini, Trimm, & Bailey, 1993). Uzark, Sauer, Lawrence, Miller, Addonizio, and Crowley (1992) examined psychosocial adjustment following heart transplant in a group of children whose mean age was 10, and who were on average, almost 2 at the time of the

procedure. Based on the CBCL, these children had significantly lower levels of social competence and more behavioral problems than the normative sample, with depression being the most common problem reported. Psychological difficulties were associated with greater family stress and fewer family resources for coping effectively with stress (Uzark et al., 1992). DeMaso, Twente, Spratt, and O'Brien (1995) roughly assessed psychological functioning in a group of children pre- and post-transplant with the Children's Global Assessment Scale (CGAS), similar to Global Assessment of Functioning (GAF), finding improvements in psychological functioning after transplant. Pre-transplant psychological functioning was more strongly related to posttransplant psychological functioning than were the children's medical severity (DeMaso et al., 1995). This study represents one of the only investigations examining psychological functioning in pediatric transplant recipients, and demonstrates the need to examine this parameter more in depth.

In examining the psychological needs and difficulties of children and families who live with congenital heart defects, it is equally important to provide empirical support for programs that seek to alleviate some of those difficulties. Summer camps are renowned for the joy and freedom they bring to children each summer. In recent decades, summer camping programs have been established with the intention to bring some of those fundamental benefits to children with chronic medical conditions who would otherwise be unable to attend camp because of restrictions imposed by their illness. This literature review will examine the overall purpose of a summer camping experience and how that philosophy could benefit a child living with a chronic illness.

Camping as a Tool

The American Camping Association (in ACA, 1997a) defines camping as "A sustained experience, which provides a creative, recreational, and educational opportunity in group living in the outdoors. It utilizes trained leadership and the resources of the natural surroundings to contribute to each camper's mental, physical, social, and spiritual growth" (pg. 1). Surveys conducted by the ACA indicate that camp directors and parents recognize four important contributions that camp has on child development. In rank order they include: 1) self-confidence and self-esteem; 2) getting along with others/teamwork; 3) an appreciation for the outdoor/environmental concerns; and 4) recreational skills (ACA, 1997b).

The camping environment has long been thought to support positive development. Recently Marsh (1999) conducted a meta-analysis from 22 studies providing 37 independent measures of youth self-constructs. Camps that focus on enhancing self, wherein this construct was clearly stated as a focus of the program and camp philosophy, had twice the positive effect as those that did not focus on that aspect. Camp had a positive effect across all ages with a greater effect for younger campers (ages 6-10). These findings support current thinking advocating camp as a positive influence on a child. It is worth noting that in a relatively short period the child's sense of self is influenced. This shift in such a brief amount of time may be partially attributable to the 24-hour total immersion each child experiences in the camp setting.

Although many children appear to enjoy the summer camping experience, some children do not fare as well. It is not uncommon to have a few children who want to call home to parents or who appear miserable throughout camp. Investigators have examined this subset of children to determine why some children appear to have difficulty at camp.

Struggling at Camp

There is a myriad of factors that mediate the relationship between the child's attitude toward the camp experience and the camp structure itself. Particular factors may result in a poor experience for the camper. If a child comes to camp with pre-existing psychopathology, camp may be more difficult and less enjoyable. Additionally, the child's expectations of their camp experience can have an impact. One dimension that may indicate a negative experience is a child reporting homesickness. Homesickness is defined as the distress or impairment caused by an actual or anticipated separation from home, and is characterized by acute longing and preoccupying thoughts of home and attachment objects (Thurber, 1999). In an investigation examining homesickness in boys attending summer camp, homesickness intensity was negatively correlated with separation experience and age (Thurber, 1999). Additionally, it was most commonly associated with depressive symptomology and internalizing behavior problems. In another investigation examining homesickness in girls, homesickness while at camp was predicted by expectations of homesickness, negative separation attitudes, and little previous separation experience (Thurber, Sigman, Weisz, & Schmidt, 1999). Additionally, expectations about camp may have an impact on each child's satisfaction or dissatisfaction with the camp experience. Thurber and Sigman (1998) tested a causal model for homesickness finding that children with insecure interpersonal attitudes and low perceived control developed an expectation that they would become homesick and dislike camp. From the difficulties identified in the literature for children adjusting to chronic illness and more specifically, cardiac conditions, it would seem that these children would be particularly vulnerable to experiencing these fears or anxieties that may negatively impact their camping experience. Interestingly, research with camps for children with chronic illness has not examined this relationship.

Camps for Children with Chronic Illness

The American Camping Association accreditation standards (ACA, 1998) state that the underlying principle for camps for kids with special needs is to allow these children to participate in all camp activities. Although special medical conditions or needs should not be ignored, they are not the overriding issues while at camp. Camp offers a respite for parents, while allowing children a vacation as well. The camping experience assists in teaching children independence and self-discipline in their approach to their condition and in their approach to life (ACA, 1998). For various camp programs, specific camp goals range from providing a rewarding camp experience as close to normal as possible (Smith, Gotlief, Gurwitch, & Blotcky, 1987) to providing opportunities for a sense of mastery and efficacy in peer relations (Swenson, 1988). The encouragement of normalcy is a key dimension for children who have often been treated as their *illness* rather than as *children*.

The spirit and philosophy of Florida's Camp for Children and Youth with Diabetes (FCCYD) lies in their logo in a diamond that links education, fitness, friendship, and independence over the motto, "I can handle it" (Rosenbloom, 2001). In the early days of FCCYD, the novel opportunities of the camp environment included: the children learning about their disease, the chance to speak with experts, prolonged observation by medical staff, obtaining education away from overdependence and manipulation and participating in camp to facilitate the independence needed to have a complete life. They can also offer the opportunity to teach parents, help medical staff develop better interpersonal skills and understanding, and observe the children in a non-medical environment (Rosenbloom, Grossman, & Malone, 1974). This list remains valid and complete today. In another camp equipped for children with chronic renal failure, camp was a chance to improve the child's self-image, bolster self-confidence, increase

physical endurance, and provide the family with a needed vacation (Primack & Greifer, 1977). In a summer camp for cystic fibrosis, the program structure emphasizes disease management, group support, identification with individuals with similar problems, and temporary parent relief (Kaplan, McKey, Toraya, & Moccia, 1992). From this sampling of camps with dramatically varying disease entities, including chronic renal failure, diabetes, and cystic fibrosis, the goals for the camp are quite similar. The next step is to examine if child and family motivations for going to camp coincide with camp goals.

In the late 1960's, 35% of children at a diabetes camp gave their primary reason for attending as meeting others with diabetes, as did 55% of their parents (Prater, 1969). At the FCCYD in 1999, children reported the following motivations for attending: 48% were either injection related or concerning attitude, independence and responsibility; 17% were to have fun; and 15% to meet others with diabetes, make friends, increase social skills, and recognize that they are not different or alone. Management skills and diabetes knowledge acquisition accounted for 8% of responses, as did improved nutrition (Rosenbloom, 2001). It appears that the goals for attendance and motivation for attending greatly overlap. The next step is to examine the actual impact that illness-specific camp has on these children.

In an asthma camp, feedback from parents seemed to suggest that children seemed more self-sufficient, more knowledgeable about their condition, and more positive concerning their asthma after their camp experience (Punnet & Thurber, 1993). From a separate camp equipped with hemodialysis for children with chronic renal failure, families appreciated the opportunity to be relieved of their responsibilities and the opportunity to spend more time with their other children. Some parents also commented that they were surprised at their child's ability to succeed independently and recognized how they might have been impeding this development by

overprotectiveness (Primack & Greifer, 1977). In a sickle cell summer camp parents valued the camp as an asset in teaching their children independence, coping with new experience, and sharing responsibilities and pleasures with peers (Powars & Brown, 1990).

Across camps, parents are pointing out similar and important benefits derived from the camp experience. Campers themselves have reported what they receive from the camping experience. A group of adolescent females at the end of a camp designed for those with PKU (phenylketonuria) stated, "Camp gives me the strength to make it through the year…Here I am accepted and I don't have to explain anything about PKU" (Singh, Kable, Guerrero, Sullivan, & Elsas, 2000). Additionally, the medical staff who volunteer at the camps report benefits from the camp experience. At FCCYD, medical staff reported learning a true feeling for the emotions and tensions a child experiences when he or she lives with diabetes everyday (Rosenbloom et al., 1974). At a group of diabetes camps in Campania, Italy, the camp gave doctors the opportunity to understand children's behaviors from a completely different viewpoint, allowing the child to share their problems, their fears and anxieties (Misuraca, Di Gennaro, Lioniello, Duval, & Aloi, 1996). The information gained from this experience cannot be found in any textbook. Feedback and commentary provide clues toward generating research questions that hold value to be tested empirically.

Although most of the previous section reported on the results of qualitative research, there have been empirical investigations conducted at camps for children with various diseases. Thus far, more than 100 publications have emerged from studies completely or substantially based at Florida's Diabetes Camp, including a dozen dissertations, mostly by psychology graduate students (Rosenbloom, 2001). However, these studies have not examined the impact of the camping experience per se. Instead, some studies in the camp setting have examined coping

mechanism, family dynamics, acquisition of knowledge, the appropriate ages for disease care tasks, coping methods, and the effectiveness of disease-related teaching methods (Rosenbloom, 2001).

In addition to research at camp for children with diabetes, pediatric cancer patients and their families participated in a longitudinal study to assess the effects of a camp experience on daily activity and family interaction. Based on maternal report, the patient's physical and social activities increased 2-weeks following camp, paired with a decrease in solitary activities. At follow-up, the increase in social activity and decrease in solitary activities persisted (Smith et al., 1987). In this same camp study, siblings reported they also increased the number of activities in which they were involved with the family from pre-camp to during camp assessment. This increase persisted two weeks after camp and at follow-up.

In a summer camp for adolescent girls with PKU, researchers evaluated the effectiveness of an educational intervention. The short-term effect resulted in improved metabolic control associated with improved attitudes, increased knowledge of diet and disease, increased perceived support, and decreased barriers to dietary compliance in a camp setting. Increased knowledge of diet and disease persisted at long-term follow-up (Singh et al., 2000). In a study conducted by Hazzard and Angert (1986), children who had attended a 2-week asthma summer camp were compared to children with asthma who had not attended. Staff reported a positive experience for the children, leading to greater acceptance and greater independence in self-care. However, the children who actually attended the camp did not differ significantly from the non-camper control group on empirical measures of their knowledge about asthma, internal health loci of control, or self-concept (Hazzard & Angert, 1986). In a separate study, Creer (1982) examined the impact of an asthma camp experience on management, attitudes, and behaviors. They assessed the children

before camp, after camp, and at follow-up. They observed a decrease in asthma severity and improved management, as indicated by fewer school days missed and decreased medication usage; an increase in parent's perception of child's independence and maturity in coping; and an increase in child's knowledge of asthma. In addition, the children's attitude toward themselves improved, and there were decreases in anxiety and depression and improvements in self-concept, active coping, and social efficacy.

Rubin and Geiger (1991) examined the effects of a cystic fibrosis summer camp on lung function, nutrition, and self-image. They observed significant gains in weight and improved peak flow. There was a trend toward increasing self-concept during camp, although this number did not reach statistical significance (Rubin & Geiger, 1991). In a study examining nine summer camps in Campania, Italy for children with diabetes, significant improvements in knowledge and self-management of the disease were found following camp. Long-term improvement was observed for those who attended monthly meetings and follow-up checks with parents after the camp. The condition of the non-participants actually worsened (Misuraca et al., 1996). In the United States, a diabetes camp was associated with a marked improvement in adherence behaviors during the children's stay at camp. However, these behavioral and metabolic changes associated with the camp experience did not maintain once the children returned home (Spevach, Bennett-Johnson, Riley, & Silverstein, 1991).

Briery and Rabian (1999) attempted to examine the impact of a summer camping experience on both children's attitudes toward their illness and on their overall levels of trait anxiety. Participants included children attending an asthma, diabetes, or spina bifida camp. Overall, results indicated that children at the end of camp had a more positive attitude toward their illness and their trait anxiety decreased, although it was not specifically targeted in these

camps. Specific analyses yielded differences for new campers and returning campers. For returning campers, trait anxiety actually increased. New campers had better attitudes toward their illness than returning campers. These data support the position that specialized camping experiences can improve attitudes toward illness in children with chronic illness, but these benefits seem to vary depending on the number of times the child has attended camp. These results were across conditions with benefits not specific to any group.

Briery and Rabian (1999) offered a number of reasons for the difference in attitude depending on experience. First, the returning campers may have benefited from their first camp experience, but subsequent attendance did not have a significant effect. Second, although there was not a statistically significant difference in duration of illness in new and returning campers, there was a 1.5 year difference with returning campers dealing with their illness for a longer duration. Briery and Rabian (1999) also did not have a follow-up assessment to examine for maintenance of therapeutic effect. Further, the lack of a control group limited the conclusions that could be drawn from the research.

As Rosenbloom (2001) has stated, more studies are needed that demonstrate what is believed, that camp has a profound effect on the ability to live with a chronic illness. Therefore, this proposed study will take researchers one step further to examine the impact of a camp designed for children with heart defects, Camp Braveheart.

Camp Braveheart

Children's Health Care of Atlanta (CHOA) organizes Camp Braveheart, which is funded through the Michael P. Fisher Endowment. Parents of a child born with a heart defect established this camp in 1994 (CHOA, 2001a). These parents were inspired to make a difference in the lives of other children with similar medical challenges, and today the camp continues in memory of

their daughter. The camp is held at Camp Twin Lakes in rural Georgia. The camp facility was specifically built for children with special needs. The volunteers at camp include medical professionals, parents, and other dedicated volunteers. The camp is designed for children ages 7 to 18 at no cost to families. Their mission is (CHOA, 2001a, pg.2), "To create a positive life experience for all children with complex heart defects through an educational camping program that promotes: self-esteem, socialization among peers, support from families, and so much fun." In 2001, 43 children attended Camp Braveheart for 4 days. In that time, these children participated in swimming, horseback riding, arts and crafts, archery, mountain-biking, and an olympic game competition, activities that any 'normal' child would engage in at camp (CHOA, 2001b). From personal observation, it appears that this camp has a positive impact on children who have CHD, but it would be beneficial to provide empirical evidence to support what many of these campers, families, and volunteers have already reported.

Rationale

Research is lacking that clearly delineates psychosocial issues that face children living with a complex heart defect. In addition, empirically supported interventions intended to improve adjustment for these children are virtually non-existent, and there is no literature on the efficacy of cardiac camps. To help alleviate these deficiencies in the literature, the effectiveness of Camp Braveheart, a summer camp for children with cardiac conditions, was evaluated.

This proposal draws on the literature that has examined children living with a congenital heart defect and findings examining the effects of camps for children with other chronic illness. Data were collected from multiple perspectives: the child living with CHD and the child's parents. The goals of the present study were to 1) validate or contradict previous research describing children living with CHD on measures of depression, anxiety, social functioning and

quality of life, 2) assess the efficacy of a camp designed for children with CHD on their attitude toward their illness, quality of life, and other psychosocial variables, and 3) delineate aspects of the individual that may contribute to improved or poor outcomes at camp.

For this study, it was hypothesized that children with CHD would report greater symptoms of anxiety, depression, social difficulties, and lowered quality of life than normative samples. It was also hypothesized that children with greater disease severity and/or a poor attitude toward their illness would report greater symptomology on the above mentioned measures. When assessing the effects of camp, it was hypothesized that the children's functioning on each of the psychological domains assessed would improve at the end of camp and that these changes would maintain at follow-up. Factors expected to influence the outcome of camp included: expectations for camp, camper status (new vs. returning), attachment style, maternal separation anxiety, and pre-camp psychosocial functioning (e.g., anxiety, depression, social functioning).

METHOD

Participants

The complete sample consisted of 39 children diagnosed with a congenital heart defect and their families. Although recruitment procedures were designed to increase the likelihood of obtaining equal numbers of campers and non-campers, these attempts were unsuccessful resulting in an insufficient number of non-campers (n = 6) to include in statistical analyses. In addition, some children did not complete measures at camp (n = 3) or did not complete self-report forms prior to camp (n = 1). The final sample of campers consisted of 29 children, ages 8 to 17 years of which 52% were male. The sample was predominantly Caucasian (72.4%), with a small proportion of African American (6.9%), Asian (6.9%), and 13.8% who did not endorse any ethnicity. The majority of the sample reported income equal to middle and upper socioeconomic status with 72.3% reporting earning $30,000 or above annually. The PedsQL-Cardiac Module is a quality of life measure specific to cardiac conditions. The Heart-related Physical Symptom subscale, a measure of disease related physical functioning, served as an estimate of disease severity. Participant scores ranged from 17.9 to 100 with a maximum scale score of 100 (M = 65.3, SD = 20.5). The mean for the normative sample was 76 (SD = 17). Fourteen percent of the sample fell below 50, at the lowest level of heart related functioning; 55% between 50 and 80; and 31% were above 80, at the highest level of functioning.

The camp is located in rural Georgia at a facility specifically built for children with special needs. The volunteers at camp include medical professionals, parents, and other dedicated volunteers. The camp is designed for children ages 7 to 18, is conducted at no cost to

families, and is one week in duration. All eligible participants are followed as patients by Children's Healthcare of Atlanta. Of the 60 campers who attended Camp Braveheart, 54 campers were eligible to participate (n = 6 were under 8 years) resulting in a completion rate of 54% for pre-camp and camp intervals. Seven year olds were not asked to participate due to their lower reading ability. The follow-up sample consisted of 18 individuals of the 29 participants represented in these data. No significant differences were found across demographic and disease parameters between the full sample (n = 29) and the follow-up sample (n = 18).

Measures

Demographic and medical survey. The demographic and medical survey asks for: a) ethnicity, b) gross family income, c) parental marital status, d) previous camp experience, e) time previously spent away from home (3 questions), and f) aspects of disease severity. In addition, the child's expectations for camp were assessed using 10 camp-related questions to which each child responded on a 1 to 5 Likert-type scale.

The Child Attitude Toward Illness Scale. The Child Attitude Toward Illness Scale (CATIS; Austin & Huberty, 1993) is a 13-item scale assessing children's attitudes toward their illness or disability. Respondents answer each question on a 5-point Likert-type scale, and attitude toward illness is reflected in the average response/score across items (Austin & Huberty, 1993). Thus, scores generated from the CATIS range from 1 to 5. A score of 1 indicates a more negative attitude and a score of 5 indicates a more positive attitude toward their illness. The scale is reliable, as indicated by an overall alpha for internal consistency across illnesses of .8, with alpha = .74 for children 8-10 years of age and alpha = .86 for children 11-12 years of age. Test-retest reliability over a 2-week period was .80. The construct validity of the CATIS was supported by associations with concurrently administered measures (Austin & Huberty, 1993),

including the Piers-Harris Children's Self-Concept Scale (Piers, 1984) (r = .48, p < .01) and the Child Behavior Checklist (CBCL; Achenbach & Edelbrock, 1983) (r = -.43, p < .01). Further psychometric validation yielded excellent internal consistency, reliability, and good test-retest reliability in adolescents aged 11-17 (Heimlich, Westbrook, Austin, Cramer, & Devinsky, 2000).

Living with Chronic Illness. The Living with Chronic Illness (LCI; Adams, Streisand, Zawacki, & Joseph, 2002) scale is a questionnaire assessing social functioning in children and adolescents with various chronic medical conditions. The LCI scale consists of a Parent form (LCI-P) and Youth form (LCI-Y). The youth form is intended for ages 8-18 years. Both forms include a dichotomous, true/false response format. Items are totaled for a total problem score.

Revised Children's Manifest Anxiety Scale. The Revised Children's Manifest Anxiety Scale (RCMAS; Reynolds & Richmond, 1985) is a 37-item self-report instrument designed to assess the level and nature of anxiety in children and adolescents from 6 to 19 years old. Children respond to each item by marking a 'yes' or 'no' response. The RCMAS consists of five scale scores: Total Anxiety, Physiological Anxiety, Worry-Oversensitivity, Social Concerns-Concentration, and Lie Scale. Reliability estimates range from alpha = .72 to alpha = .85 for internal consistency, the test-retest reliability is fairly stable (alpha = .98, 3-week interval, alpha = .68, 9-month interval) (Reynolds & Paget, 1983). The convergent validity of the instrument is support through a significant correlation between the RCMAS and the A-trait scale (r = .85) of the State-Trait Anxiety Inventory for Children (STAIC; Spielberger, 1973).

Maternal Separation Anxiety Scale adapted. The Maternal Separation Anxiety Scale (MSAS; Hock, McBride, & Gnezda, 1989) is a 28-item measure originally designed for mothers to complete about their own reactions to separations from their infant. Each items is rated on a 5-point Likert-type scale ranging from *1-strongly disagree* to *5-strongly agree*. Responses from the

28 items are totaled, yielding a score from 28 to 140. The version of the MSAS used in this study was adapted and validated by Capps, Sigman, Sena, Henker, and Whalen (1996) for use for mothers or fathers of school-aged children and adolescents. Capps et al. (1996) reported high 4-week test-retest reliability for the MSAS total score (r = .82).

Parental Camp Expectations. This subscale is 5 questions added to the MSAS by Thurber (1999) specifically related to summer camp to assess parent perception of summer camp and expected homesickness in their child. These questions do not contribute to computing the separation anxiety score (1, 4, 31, 32, 33).

Hubbard Camp Outcome Scale. The Hubbard Camp Outcome Scale (H-COS) is a 27-item multidimensional instrument designed to assess children's perception of the pediatric camp experience. This scale was developed and tested for use with children living with cardiac abnormalities, and may be adaptable to other pediatric conditions. Respondents answer each question on a 5-point Likert-type scale. All responses are summed and divided to derive a mean with certain questions reverse coded, resulting in a total scale score reflecting the overall camp experience and three subscale scores: enjoyment/socialization, difficulty/homesickness, and self-esteem/normalization. The reliability and validity for the measure was established in this study (refer to Tables 1 through 5). Item-total correlations were conducted to determine items to retain in a principle components factor analysis ($r > 0.25$). A varimax rotated factor analysis with a minimum eigen value of 2 and factor loading greater than 0.50 resulted in 3 orthogonal factors, the current subscales. Internal consistency estimates for the H-COS were high, ranging from .77 to .93. Test-retest reliability was low to moderate over a two month period, ranging from .31 to .66 indicating that this measure may be sensitive to changes over time. The construct validity of the H-COS was supported by associations with concurrently administered measures, including

the Children's Depression Inventory (CDI; Kovacs, 1992) and the Pediatric Quality of Life-Cardiac Module (PedsQL; Varni, 1998).

Self-Reported Attachment Style Prototypes. The Self-Reported Attachment Style Prototypes (SRASP; Bartholomew & Horowitz, 1991) was adapted for use with children 7-18 (Thurber, Bombar, & Sigman, 1994; Thurber & Sigman, 1998) to assess the security of their interpersonal attitudes towards individuals in their life. The SRASP asks participants to make numerical ratings of how much each of four short paragraphs is an accurate description of them. The paragraphs describe four empirically supported relationship styles: secure, preoccupied, fearful, and dismissing. A composite score of self-perceived relationship security can be derived by subtracting participants' endorsements of the preoccupied, fearful, and dismissing paragraphs from their endorsement of the paragraph describing a secure style. Thus, the higher the composite score on the SRASP, the more the child perceives secure interpersonal attachment. In addition, the child chooses the vignette that most strongly matches to their thinking. No validity or reliability coefficients have been computed for this four vignette measure.

Pediatric Quality of Life Inventory. The Pediatric Quality of Life Inventory (PedsQL; Varni, 1998) is a 23-item measure assessing health-related quality of life in children and adolescents across domains of functioning: physical, emotional, social, and school. Respondents answer each question on a 5-point Likert-type scale. Scale scores are derived for each area of functioning, a psychosocial health summary score, and a total scale score. In one investigation with 291 pediatric cancer patients and their parents at various stages of treatment, the Cronbach's alpha coefficients for the core measure (alpha = .83 for patient and alpha = .86 for parent) were acceptable for group comparisons. Alphas for the patient self-report modules generally ranged from .70 to .89. Discriminant or clinical validity, using the known-groups approach, was

demonstrated for patients on- versus off-treatments (Varni, Seid, & Rode, 1999). In another investigation, the PedsQL was administered to 963 children and 1,629 parents (1,677 subjects accrued overall) recruited from pediatric health care settings. Internal consistency reliability for the Total Scale Score (alpha = 0.88 child, α = 0.90 parent report), Physical Health Summary Score (alpha = 0.80 child, alpha = 0.88 parent), and Psychosocial Health Summary Score (alpha = 0.83 child, alpha = 0.86 parent) were acceptable for group comparisons. The PedsQL distinguished between healthy children and pediatric patients with acute or chronic health conditions, through significant correlations with indicators of morbidity and illness burden, and by displaying a factor-derived solution largely consistent with the a priori conceptually-derived scales (Varni, Seid, & Kurtin, 2001). Additionally, the PedsQL was differentially sensitive to increasing degrees of cardiac disease severity in the cardiology clinic setting and responsiveness to clinical change over time in the pediatric orthopedics clinic setting (Varni, Seid, Knight, Uzark, & Szer, 2002).

Pediatric Quality of Life Inventory- Cardiac Module. The Pediatric Quality of Life Inventory- Cardiac Module (PedsQL-Cardiac Module; Varni, 1998) is a 27-item measure assessing health-related quality of life in children and adolescents living with cardiac conditions across domains of functioning specific to their condition: heart problems and treatment, treatment II (medication related), perceived physical appearance, medical treatment anxiety, cognitive problems, and communication. Respondents answer each question on a 5-point Likert-type scale, and it derives scale scores for each area of functioning and a total scale score. Preliminary reliability and validity data comparing the PedsQL-core with the PedsQL-cardiac module demonstrate adequate internal consistency and validity (Uzark, Jones, Burwinkle, & Varni, 2003).

Children's Depression Inventory. The Children's Depression Inventory (CDI; Kovacs, 1992) is a 27-item scale assessing self-reported symptoms of depression with a total score and five subscales: negative mood, interpersonal problems, ineffectiveness, anhedonia, and negative self-esteem. It is designed for school-age children 7 to 17 years old. The scale allows the child to choose from among three alternatives that vary in the symptom described. As a symptom severity measure, the CDI quantifies the magnitude of the depressive complaints. It can also be used as a measure of change to determine if the severity of depressive symptoms has changed following treatment. The CDI has excellent internal consistency, extensive normative data, and correlates positively with self-reported depressive cognitions and negatively with self-esteem. (Kovacs, 1992).

Strengths and Difficulties Questionnaire. The Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) is a 25-item measure that assesses behavioral symptoms across five domains: emotion, conduct, hyperactivity/inattention, peer relations, and prosocial behavior. There is a parent report from for children as young as 5 years and self-report from for children 8 and older. Respondents answer each question on a 3-point Likert-type scale ranging from 0 – *not true* to 2 – *certainly true*. Psychometric investigation confirmed each of the five factors and further found that reliability was generally satisfactory, whether judged by internal consistency (mean Cronbach's alpha = 0.73), cross-informant correlation (mean: $r = 0.34$), or test-retest stability after 4-6 months ($M = 0.62$). SDQ scores above the 90th percentile predicted a substantially raised probability of independently diagnosed psychiatric disorders (mean odds ratio: 15.7 for parent scales, 15.2 for teacher scales, 6.2 for youth scales) (Goodman, 2001). The SDQ has been found to be highly correlated with the CBCL (Achenbach, 1991a). In addition, it has been shown to be significantly better than the CBCL at detecting inattention and

hyperactivity, and at least as good at detecting internalizing and externalizing problems (Goodman & Scott, 1999).

Procedure

To recruit participants for the proposed study, investigators mailed informed consent forms, measures used in the study, and self-addressed stamped envelopes to the family of each 8-17 year old who was invited to attend camp. Each child who participated received a $20 gift certificate as compensation for participating at the pre-camp and follow-up intervals, totaling $40 in compensation for participating at both intervals.

Each participant completed the consent/assent form included in the mailing. Campers completed measures prior to, immediately after, and two months following camp. The packets typically took 60-120 minutes to complete, with longer completion times for younger children.

The initial packet included the human participant consent form (including consent to view medical records), demographic and medical data sheet, Pediatric Quality of Life Inventory parent and child report forms (PedsQL), Pediatric Quality of Life Inventory-Cardiac Module parent and child report forms (PedsQL-cardiac), Living with Chronic Illness parent and child report forms (LCI-P & LCI-Y), Maternal Separation Anxiety Survey (MSAS), Strengths and Difficulties Questionnaire (SDQ), Revised Children's Manifest Anxiety Scale (RCMAS), Child Depression Inventory (CDI), Child Attitude Toward Illness Survey (CATIS), and the Self-reported Attachment Style Prototypes (SRASP) (see Table 6). Specific instructions were enclosed to assist parents in administering the measures to younger children. Families returned the measures by mail, at the clinic, or at registration on the first day of camp. On the evening of the last day of camp, campers completed the RCMAS, CATIS, Hubbard Camp Outcome Scale (H-COS), CDI, PedsQL, and PedsQL-cardiac. Camp staff members were informed of the proper

procedures and monitored administration in order to maintain validity and clarify any questions for the campers. Approximately one to two months following camp, the LCI-P & LCI-Y, PedsQL parent and child versions, PedsQL-cardiac parent and child versions, SDQ, RCMAS, CATIS, and CDI, and H-COS were mailed to participating families with a self-addressed envelope to mail back. The researchers conducted reminder calls to increase the percentage of completed measures.

Table 1

The 27-item Hubbard Camp Outcome Scale Item-Total Correlations (H-COS) (n = 29)

Items (Responses)	*M*	*SD*	Corrected item-total correlation	Alpha if item deleted
Enjoyment/Socialization				
6. How often did you feel like you could do the activities the other kids at camp were doing?	3.8	1.4	.77	.92
7. How happy or sad were you at camp?	4.1	.79	.70	.93
14. How often did you spend time with your friends at camp?	4.2	1.2	.76	.92
15. How often did you have someone to talk to at camp?	4.0	1.2	.67	.93
16. What was it like to make friends at camp?	3.9	.98	.61	.93
17. What was it like to play with kids you did not know very well?	3.5	1.0	.61	.93
18. How often did you play with the other kids at camp?	4.2	1.3	.58	.93
19. How often did you feel like you were part of the group at camp?	4.0	1.1	.78	.92
21. How often did you get along with the other kids at camp?	4.0	1.3	.79	.92
22. How often were you active at camp?	4.0	1.1	.33	.93
23. How often did you feel like you had energy at camp?	3.8	1.1	.55	.93
25. How often did you exercise at camp?	3.6	1.4	.43	.93
27. How much did you like or dislike camp?	4.2	1.1	.54	.93
Self-esteem/normalization				
1. How often did you feel different from the other kids at camp?**	1.9	.92	.40	.93
2. How often did you feel like you fit in with the other kids at camp?	3.8	1.1	.28	.93
3. How did you feel about yourself at camp?	4.1	1.1	.30	.93
4. How often were you proud of yourself at camp?	3.9	1.0	.41	.93
5. How often did you like yourself at camp?	4.2	1.1	.45	.93
Difficulty/Homesickness				
8. How often were you nervous at camp?*	2.2	1.1	.51	.93
9. How often did you worry at camp?*	2.2	1.1	.55	.93
10. How often did you worry about your heart condition at camp?*	2.0	1.3	.67	.93
11. How often were you lonely at camp?*	1.9	1.1	.49	.93
12. How often did you worry about what the other kids at camp thought about you?*	2.2	1.3	.61	.93
13. How often did you feel sad or blue at camp?*	1.8	1.1	.63	.93
20. How often did you feel left out at camp?*	1.9	1.1	.72	.93
24. How often did you feel like you couldn't keep up when you were playing with the other kids at camp?*	2.2	1.3	.42	.93
26. How often did you feel homesick at camp?*	2.2	1.1	.49	.93

Note. * Reverse coded for computing full scale score. **Reverse coded for computing full scale and subscale score. Can replace underlined wording for other pediatric populations.

Table 2
Summary of Factor Loadings for Varimax-Rotated Three-Factor Solution for the H-COS (n = 29)

	Factor Loading			
Item	Enjoyment/ Socialization	Self-esteem/ Normalization	Difficulty/ Homesickness	Communality
6	**.63**	.51	.30	.74
7	**.51**	.48	.34	.60
14	**.81**	.19	.26	.76
15	**.70**	.22	.24	.60
16	**.72**	.05	.24	.58
17	**.75**	.09	.15	.60
18	**.78**	-.16	.25	.69
19	**.80**	.21	.29	.77
21	**.79**	.26	.28	.77
22	**.59**	.05	-.13	.36
23	**.62**	.26	.08	.46
25	**.64**	.14	-.05	.43
27	**.81**	-.18	.13	.70
1	.25	**.74**	-.02	.61
2	-.23	**.57**	.44	.57
3	.05	**.69**	.08	.48
4	.10	**.77**	.15	.63
5	.36	**.58**	.06	.46
8	.08	.02	**.81**	.66
9	.08	.14	**.79**	.64
10	.27	.18	**.74**	.66
11	.25	-.25	**.75**	.69
12	.28	.05	**.73**	.61
13	.30	-.05	**.77**	.68
20	.23	.27	**.80**	.77
24	-.05	.23	**.68**	.51
26	.06	.29	**.61**	.46
Eigenvalue	10.22	2.58	3.66	
% Variance	37.87	9.57	13.55	

Note. Boldface indicates highest factor loadings.

Table 3
Means, Standard Deviations, and Alpha Internal Consistency Values for H-COS Three Subscales and Total Scale Score (n = 29)

Subscale	*M*	*SD*	Alpha
Enjoyment/Socialization	3.93	.83	.93
Self-esteem/Normalization	4.01	.77	.77
Difficulty/Homesickness	2.06	.89	.91
Total Scale	3.95	.66	.93

Table 4

Intercorrelations, Means, and Standard Deviations for H-COS and Psychological Constructs for Concurrent Validity (n = 29)

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	*M*	*SD*
Camp Outcome															
1. Overall Camp Outcome	---	.88**	.56**	-.78**	-.08	-.15	-.44*	-.25	-.42*	-.44*	.35+	.20	.46*	3.95	0.66
2. Socialization/enjoyment		---	.33+	-.44*	-.15	-.07	-.39*	-.07	-.48**	-.38*	.27	.20	.40*	3.93	0.83
3. Self-esteem/normalization			---	-.34+	.00	.02	-.35+	-.51**	-.16	-.31+	.18	.00	.40*	4.01	0.77
4. Difficulty/Homesickness				---	-.03	.26	.29	.22	.20	.32+	-.32	-.17	-.31+	2.06	0.89
Psychological Constructs															
5. Attitude toward illness					---	-.18	-.11	-.18	-.01	-.21	.07	-.02	.06	40.60	3.19
6. Anxiety						---	.39*	.10	.22	.38*	-.71**	-.66**	-.48**	10.28	6.17
7. Depression							---	.59**	.78**	.90**	-.40*	-.36+	-.48**	7.83	5.70
8. Negative self-esteem								---	.16	.46**	-.18	-.14	-.31+	.97	1.24
9. Ineffectiveness									---	.64**	-.22	-.18	-.27	1.90	1.95
10. Anhedonia										---	-.35+	-.33+	-.40*	2.86	2.07
11. Physical functioning											---	.84**	.85**	73.6	21.47
12. Social functioning												---	.71**	69.82	19.65
13. Cardiac quality of life													---	72.29	16.61

Note. $^{+}p < .10$, $*p < .05$, $**p < .01$.

Table 5
Means and standard deviations for at camp and follow-up administrations of the H-COS with the test-retest reliability coefficient (n = 18)

	Time 1		Time 2		
Subscale	Mean	SD	Mean	SD	Reliability Coefficient
Enjoyment/Socialization	3.73	.87	4.31	.45	.31
Difficulty/Homesickness	2.07	.67	1.54	.57	.31
Self-esteem/Normalization	4.05	.81	4.30	.59	.66*
Total Scale	3.85	.71	4.36	.48	.42+

Note * $p < .01$, + $p < .10$.

Table 6

Study Measures and Intervals of Administration

	Time Intervals		
Groups	Pre-Camp/Baseline	End of Camp	Follow-up
Campers	SRASP RCMAS CATIS CDI PEDSQL-G & C LCI-Y	RCMAS CATIS CDI PEDSQL-G & C H-COS	RCMAS CATIS CDI PEDSQL-G & C LCI-Y H-COS
Parents of Campers/ Non-Campers	DEMOGRAPHICS MSAS PEDSQL-G & C LCI-P SDQ		MSAS PEDSQL-G & C LCI-P SDQ
Non-Campers	SRASP RCMAS CATIS CDI PEDSQL-G & C LCI-Y		RCMAS CATIS CDI PEDSQL-G & C LCI-Y

Note. Parent forms: DEMO/INFO = Demographic and Medical Survey; MSAS = Maternal Separation Anxiety Survey adapted; PEDSQL = Pediatric Quality of Life Inventory generic and cardiac module, Parent report; LCI-P = Living with Chronic Illness, parent report; SDQ = Strengths and Difficulties Questionnaire. Child forms: SRASP = Self-Reported Attachment Style Prototypes; RCMAS = Revised Child Manifest Anxiety Scale; CATIS = Child Attitude Toward Illness Scale; CDI = Child Depression Inventory; PEDSQL = Pediatric Quality of Life Inventory generic and cardiac module, Self-report; LCI-Y = Living with Chronic Illness, Youth form; H-COS = Hubbard Camp Outcome Scale.

RESULTS

Psychosocial Adjustment

It was hypothesized that children with CHD would report greater symptoms of anxiety, depression, social difficulties, and lowered quality of life than normative samples. To evaluate this hypothesis one-sample t-test comparisons were conducted to test for significant differences between all participant data collected prior to camp and healthy norms as provided through normative data on the SDQ (parent report), RCMAS, CDI, LCI (child and parent versions), PedsQL (child and parent versions), and PedsQL. Findings are displayed in Tables 7 through 10. According to the parent-completed SDQ, children with CHD had significantly greater behavior problems, greater emotional difficulties, more symptoms consistent with Attention-Deficit/Hyperactivity Disorder (ADHD), and higher levels of peer problems than healthy norms. Conversely, based on child report on the RCMAS and CDI, levels of anxiety and depression are no different or are significantly lower, respectively, than healthy norms. Parent and child report of overall quality of life and cardiac-specific quality of life indicated statistically significant lower scores in the majority of domains assessed on these measures of physical functioning and psychological factors, such as social relations and perceived physical appearance. Lastly, parent and child item reporting on several domains of social functioning indicated significantly more difficulties compared to other chronic illness samples (e.g., sickle cell disease, lupus) in areas such as social participation and social normalization.

Influence of Disease Severity and Attitude toward Illness

It was hypothesized that children with greater disease severity and/or a poor attitude toward their illness would report greater symptomology on measures of psychological and social functioning. This hypothesis was examined using Pearson product moment correlational analyses to determine whether greater disease severity and poor attitude toward illness were positively related with children's psychological symptom reporting.

Self-reported attitude toward illness did not significantly correlate with any measures of psychological functioning. However, greater disease severity was related to higher levels of child reported anxiety, $r(27) = .39$, $p = .039$, lower levels of general quality of life as reported by the parents, $r(27) = -.53$, $p = .003$ and children; $r(26) = -.40$, $p = .035$, lower levels of cardiac quality of life as reported by parents, $r(27) = -.44$, $p = .018$; and children, $r(27) = -.41$, $p = .027$; who reported limited physical functioning, $r(26) = -.46$, $p = .013$ There were also marginally significant associations between disease severity and lowered social functioning, $r(26) = -.34$, $p = .077$; greater medical treatment anxiety, $r(27) = -.33$, $p = .084$; and difficulty communicating with medical professionals, $r(26) = -.35$, $p = .061$. Disease severity was not significantly related to child reported levels of depression, child attitude toward illness, attachment style, and domains assessed on the SDQ (emotional functioning, conduct problems, symptoms consistent with ADHD, peer difficulties, and prosocial behaviors).

Impact of Camp

It was hypothesized that children with CHD would improve across psychological domains assessed at the end of camp and that these changes would maintain at follow-up. To evaluate this hypothesis, a repeated measures ANOVA was conducted to examine within group changes on self-reported attitude toward illness, levels of anxiety, quality of life, and children's

social functioning at the end of camp and two months following camp. There was no significant change in a child's attitude toward his/her illness, level of depression, quality of life, and social functioning. Campers did report a statistically significant decrease from pre-camp (M = 12.0, SD = 7.0) to at-camp (M = 10.3, SD = 6.2) on levels of anxiety, $F(1, 28) = 4.95$, $p = .034$. No significant changes were noted from at-camp to follow-up on attitude toward illness, levels of anxiety and depression, quality of life, and social functioning.

In addition, a repeated measures ANOVA was conducted with parent completed measures of parental separation anxiety, observed social functioning, quality of life and overall psychological functioning (SDQ) of their child completed prior to camp and two months following camp. No significant changes were observed on parental reports of their child's social functioning, quality of life, and overall psychological functioning. Parents did report a statistically significant decrease from pre-camp (M = 62.9, SD = 9.7) to follow-up (M = 59.1, SD = 10.2) on parental separation anxiety, $F(1, 17) = 4.81$, $p = .042$.

Lastly, a repeated measures ANOVA was conducted on children's reports on the overall camp experience. A statistically significant increase was found in scores from at-camp (M = 3.9, SD = .71) to follow-up (M = 4.4, SD = .48) on self-reported overall enjoyment of the camp experience, $F(1, 17) = 10.23$, $p = .005$. Children's reports of their socialization experience also increased from at-camp (M = 3.7, SD = .87) to follow-up (M = 4.3, SD = .45) on the socialization/enjoyment subscale, $F(1, 17) = 8.38$, $p = .010$. In addition, there was a statistically significant decrease in children's scores from at-camp (M = 2.1, SD = .67) to follow-up (M = 1.5, SD = .57) on self-reported difficulties and feelings of homesickness at camp, $F(1, 17) = 9.43$, $p = .007$. No significant change was observed in the domain of self-esteem and normalization from at-camp to follow-up.

Predicting Camp Outcome

Factors hypothesized to influence the outcome of camp included: camper status (new vs. returning), prior separation experiences, age, attachment style, expectations for camp, paternal separation anxiety, and pre-camp psychosocial functioning (e.g., anxiety, depression, social functioning). To evaluate this hypothesis, bivariate correlational analyses were first run to determine which variables were significantly associated with camp outcome. Several potentially important demographic and medically related variables including gender, family income, disease severity, and camper status were not significantly associated with camp outcome. Therefore, these variables were not included in subsequent analyses. Table 11 represents means, standard deviations, and correlations among camp outcome variables, parental factors, and child psychosocial factors considered for inclusion in the regression analyses.

Following theoretical rationale (Thurber, 1999; Thurber, Sigman, Weisz, & Schmidt, 1999), variables hypothesized to predict scores on the domain of difficulty at camp/homesickness included parental factors of perception of the separation experience and parental camp expectations, and child factors of age, previous separation experience, attachment style, and levels of anxiety and depressive symptoms (see Table 12). The full theoretical model was not statistically significant, but the trimmed model that included parental camp expectations and child camp expectations was significant, accounting for 33% of the variance in scores on the difficulty/homesickness at camp subscale, $F(3, 26) = 6.26$, $p = .006$.

No current theories exist for predicting overall camp outcome on the domains of self-esteem/normalization and socialization/enjoyment at camp. Therefore all parental factors and child factors that were marginally ($p < .10$) and statistically significant were entered for each outcome variable to determine the best predictive model. Each model was trimmed to establish a

statistically significant model (refer to table 14). The final overall camp outcome model included parental perception of the separation experience, the child's expectations for camp, and pre-camp negative emotionality, which accounted for 34% of the variance in the child's reported camp experience, $F(3, 25) = 4.23$, $p = .015$. The final socialization/enjoyment at camp model included pre-camp negative emotionality as the sole marginally significant predictor, accounting for 13% of the variance in the child's reported socialization experience at camp, $F(1, 27) = 4.05$, $p = .054$. The final self-esteem/normalization at camp model included parental camp expectations, attachment style, attitude toward illness, and negative self-esteem, which accounted for 46% of the variance in the child's reported self-esteem and sense of normalization at camp, $F(3, 25) = 4.23$, $p = .015$.

Table 7
Comparisons between SDQ, RCMAS, and CDI Normative Data for Healthy Children and Participants with CHD

	Cardiac Sample			Healthy Sample				
Scale	*N*	*M*	*SD*	*N*	*M*	*SD*	Difference	*t*
SDQ								
Behavior Problems	29	11.2	6.6	9878	7.1	5.7	4.1	3.33**
Emotional Problems	29	2.6	2.0	9878	1.6	1.8	1.0	2.74*
Conduct	29	1.45	0.32	9878	1.3	1.6	0.15	0.46
Hyperactivity	29	4.7	3.0	9878	2.8	2.5	1.9	3.31**
Peer Difficulties	29	2.5	2.1	9878	1.4	1.5	1.1	2.74*
Prosocial Behaviors	29	8.48	1.8	9878	8.6	1.8	-0.12	-0.35
RCMAS								
Overall Anxiety	29	12.0	7.0	4379	14.3	6.8	-2.3	-1.76+
Physiological Anxiety	29	3.4	2.4	4379	4.0	2.4	-0.6	-1.29
Worry/ Oversensitivity	29	3.8	3.2	4379	4.7	2.9	-0.90	-1.46
Concentration Problems	29	2.1	1.7	4379	2.75	2.0	-0.65	-2.05*
CDI [a]								
Depression	29	6.96	4.4	1,226	9.98		-3.01	-3.69*
Negative Mood	29	1.1	.87	1,226	2.2		-1.1	-6.60**
Interpersonal Problems	29	0.48	.78	1,226	0.77		-0.29	-1.97+
Ineffectiveness	29	1.69	1.6	1,226	1.9		-0.21	-0.73
Negative Self-Esteem	29	.90	1.2	1,226	0.89		0.01	0.0080

Note. SDQ Norms based on the 2001 National Health Interview Survey (NHIS). RCMAS norms based on the average of White males and White females in the RCMAS National Normative Data (Reynolds & Paget, 1983). CDI norms provided in CDI manual (Kovacs, 1992).
[a]No standard deviations were provided with the normative data.
+ $p < 0.10$, * $p < 0.05$, ** $p < 0.01$.

Table 8

Comparison between PedsQL Generic Version and PedsQL Cardiac Module Norms for Child and Parent Report and Participants with CHD

	Cardiac Sample			Healthy Sample				
Scale	*N*	*M*	*SD*	*N*	*M*	*SD*	Difference	*t*
PedsQL child								
Total score	28	73.8	17.3	960	79.6	15.3	-5.8	-1.79^{+}
Physical Health	28	76.3	20.2	959	80.2	19.3	-3.9	-1.03
Psychosocial Health	28	72.9	17.1	958	79.4	15.7	-6.5	-2.00^{+}
Emotional Functioning	28	74.4	20.3	958	78.1	20.7	-3.7	-0.98
Social Functioning	28	75.7	19.5	958	84.1	18.5	-8.4	-2.27*
School Functioning	28	68.8	18.0	933	75.9	19.7	-7.1	-2.10*
PedsQL parent								
Total score	29	67.9	18.6	1622	80.9	16.7	-13.0	-3.76**
Physical Health	29	70.4	23.7	1613	81.4	23.2	-11.0	-2.49*
Psychosocial Health	29	67.1	19.3	1621	80.6	16.5	-13.5	-3.77**
Emotional Functioning	29	71.7	22.4	1622	78.0	20.7	-6.3	-1.50
Social Functioning	29	66.4	23.3	1615	85.4	19.2	-19.0	-4.39**
School Functioning	29	63.1	27.2	1417	77.8	22.0	-14.7	-2.91**
	Cardiac Sample			Other Cardiac Children				
PedsQL-cardiac child								
Heart problems-symptoms	29	69.4	21.5	248	76.0	17.0	-6.64	-1.67^{+}
Perceived physical appearance	29	69.5	25.7	239	79.3	25.3	-9.8	-2.05*
Treatment anxiety	29	73.1	24.6	247	82.3	22.2	-9.2	-2.01*
Cognitive problems	29	66.2	19.9	245	75.7	20.6	-9.5	-2.55*
Communication	29	70.4	26.1	217	78.8	23.0	-8.4	-1.74^{+}
PedsQL-cardiac parent								
Heart problems-symptoms	29	65.3	20.5	343	79.6	17.6	-14.3	-3.76**
Perceived physical appearance	29	58.3	30.5	336	82.9	23.0	-24.6	-4.34**
Treatment anxiety	29	67.2	25.6	338	71.2	28.8	-4.0	-0.84
Cognitive problems	29	59.5	27.2	338	71.2	25.7	-11.7	-2.32*
Communication	29	69.5	25.7	273	74.6	26.8	-5.1	-1.06

Note. Norms for PedsQL 4.0 from Varni, Seid, & Kurtin, 2001. Norms for PedsQL 4.0 cardiac module from Uzark, Jones, Burwinkle, & Varni, 2003.

$^{+}$ $p < 0.10$, * $p < 0.05$, ** $p < 0.01$.

Table 9
Comparison between LCI Parent Report for Normative Sample and Participants with CHD

LCI-Parent	Cardiac Sample (*n = 29*) %	Chronic Illness Sample (*n = 88*) %	Difference	*t*
School				
Misses school	44.8	32.3	12.5	1.33
Does not take part in school activities	24.1	15.3	8.8	1.09
Is treated differently than classmates by teachers	13.8	8.2	5.6	0.86
Has school grades below average	10.3	4.2	6.1	1.07
Physical Exertion				
Does not play team sports	62.1	26.5	35.6	3.88***
Does not take part in outdoor exercise sports	20.7	7.1	13.6	1.78+
Does not do as many activities as siblings do	41.4	6.3	35.1	2.77**
Does not play outside often	37.9	10.3	27.6	3.01**
Does not regularly take part in physical education classes	20.7	11.3	9.4	1.23
Does not do chores at home	31.0	4.1	26.9	3.08**
Isolation				
Left out from activities with other children	21.4	15.3	6.1	0.78
Is not invited to play or take part in fun activities	20.7	3.1	17.6	2.30*
Is ignored by other children	10.3	4.1	6.2	1.09
Has fewer friends than classmates do	31.0	8.2	22.8	2.61*
Does not take part in social activities after school	27.6	9.1	18.5	2.19*
Does not take part in social clubs or organizations	41.4	9.3	32.1	3.45**
Does not take part in many family activities	6.9	2.0	4.9	1.02
Teased/Feels Different				
Is teased by other children about appearance	41.4	9.1	32.3	3.47**
Is teased by others	41.4	8.2	33.2	3.57***
Feels different from other children the same age	31.0	19.4	11.6	1.33
Does not like others to know about diet, medications, etc.	34.5	15.5	19.0	2.11*
Is not as independent as children the same age	31.0	11.1	19.9	2.28*
Ease of Social Interactions				
Has problems making or keeping friends	24.1	8.2	15.9	1.97+
Does not get along with children the same age	17.2	3.1	14.1	1.98+
Does not get along with people outside the family	3.5	1.0	2.5	0.71
Has problems getting along with family	20.7	4.1	16.6	2.17*
Feels uncomfortable or uneasy in social events	6.9	8.1	-1.2	-0.25

Note. $^{+}p < 0.10$, $^{*}p < 0.05$, $^{**}p < 0.01$, $^{***}p < 0.001$.

Table 10
Comparison between LCI Child Report for Normative Sample and Participants with CHD

	Cardiac Sample (*n = 29)*	Chronic Illness Sample (*n = 88)*		
LCI-Child	%	%	Difference	*t*
School				
Misses school	48.3	18.0	30.3	3.21**
Does not take part in school activities	31.0	5.1	25.9	2.97**
Is treated differently than classmates by teachers	27.6	3.1	24.5	2.90**
Has school grades below average	6.9	3.1	3.8	0.79
Physical Exertion				
Does not play team sports	62.1	10.0	52.1	5.68***
Does not take part in outdoor exercise sports	24.1	3.0	21.1	2.61*
Does not do as many activities as siblings do	51.7	3.2	48.5	3.80***
Does not play outside often	27.6	1.1	26.5	3.14**
Does not regularly take part in physical education classes	37.9	7.2	30.7	3.35**
Does not do chores at home	31.0	1.0	30.0	3.44**
Isolation				
Left out from activities with other children	24.1	8.0	16.1	2.00+
Is not invited to play or take part in fun activities	17.2	2.0	15.2	2.14*
Is ignored by other children	20.7	3.0	17.7	2.31*
Has fewer friends than classmates do	24.1	1.0	23.1	2.86**
Does not take part in social activities after school	24.1	7.2	16.9	2.09*
Does not take part in social clubs or organizations	46.4	2.0	44.4	4.63***
Does not take part in many family activities	13.8	1.0	12.8	1.96+
Teased/Feels Different				
Is teased by other children about appearance	37.9	5.0	32.9	3.59***
Is teased by others	34.5	8.2	26.3	2.93**
Feels different from other children the same age	27.6	5.1	22.5	2.66*
Does not like others to know about diet, medications, etc.	31.0	6.1	24.9	2.85**
Is not as independent as children the same age	17.2	5.0	12.2	1.71+
Ease of Social Interactions				
Has problems making or keeping friends	24.1	3.0	21.1	2.61*
Does not get along with children the same age	10.3	0.0	10.3	1.80+
Does not get along with people outside the family	6.9	1.0	5.9	1.23
Has problems getting along with family	24.1	2.0	22.1	2.74*
Feels uncomfortable or uneasy in social events	10.3	4.1	6.2	1.09

Note. + $p < 0.10$, * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Table 11

Intercorrelations, Means, and Standard Deviations for Camp Outcome, Parental Factors, and Child Factors

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	*M*	*SD*
Camp Outcome																			
1. Total score	---	.88	.56	-.78	-.06	.28	.31	.10	.01	.32	.24	.12	-.24	-.41	.07	.29	.33	3.95	0.66
2. Socialization/enjoyment		---	.33	-.44	-.08	.21	.14	.07	-.21	.16	.19	.10	-.11	-.36	.18	.25	.28	3.93	0.83
3. Self-esteem/normalization			---	-.34	.15	.15	.30	.20	.11	.17	.46	.29	-.10	-.36	-.47	.33	.33	4.01	0.77
4. Difficulty/homesickness				---	.09	-.27	-.37	-.03	-.25	-.41	-.06	.01	.35	.26	-.13	-.14	-.19	2.06	0.89
Parental Factors																			
5. Parental separation anxiety					---	.08	.17	-.26	-.09	-.23	-.19	-.02	.30	.10	-.04	-.25	-.40	63.5	10.3
6. Perception of separation experience						---	.78	.32	.29	-.11	.12	.10	-.15	-.13	-.10	.27	.27	29.0	4.8
7. Parent camp expectations							---	.08	.25	-.07	.11	.02	-.32	-.12	-.11	.22	.44	13.1	2.3
Child Factors																			
8. Age								---	.52	.17	.23	.40	-.16	.27	-.18	.20	.25	12.3	2.7
9. Previous separation experiences									---	.28	.32	.14	-.37	-.01	-.24	.15	.26	5.1	2.0
10. Positive expectations										---	.30	-.11	-.35	-.26	.04	.50	.24	33.6	3.3
11. Attachment style											---	-.01	-.18	-.49	-.32	.54	.56	0.52	0.51
12. Attitude toward illness												---	.08	.14	-.01	-.03	-.03	40.2	3.3
13. Anxiety													---	.39	.16	-.43	-.72	12.0	7.0
14. Negative mood														---	.25	-.42	-.56	1.14	0.88
15. Negative self-esteem															---	-.31	-.18	0.90	1.2
16. Perceived Physical Appearance																---	.45	69.5	25.7
17. Social functioning																	---	75.7	19.5

Note. $n = 29$. Correlations greater than .31 are significant at $p < .05$ and greater than .24 are marginally significant at $p < .10$, one-tailed

Table 12
Summary of Regression Analyses for Variables Predicting Difficulty/Homesickness Subscale Score on the H-COS (n = 28)

Variable	*B*	*SE B*	β
Full Theoretical Model			
Parental Factors			
Perception of separation experience	-.04	.06	-.18
Parent camp expectations	-.08	.13	-.21
Child Factors			
Age	.02	.08	.06
Previous separation experiences	-.06	.10	-.14
Camp expectations	-.12	.06	-.42*
Attachment style	.50	.44	.28
Anxiety	.00	.03	.03
Negative mood	.27	.28	.26
Trimmed Model			
Parental Factor			
Parent camp expectations	-.16	.06	-.40*
Child Factor			
Camp expectations	-.12	.04	-.44*

Note. Full model, $R^2 = .36$ Trimmed model, $R^2 = .33$
$^{+}p < 0.10$, $^{*}p < 0.05$.

Table 13
Summary of Regression Analyses for Variables Predicting Camp Overall Outcome Scale, Socialization/Enjoyment Scale, and Self-esteem/Normalization Scale Scores on the H-COS (n = 28)

Variable	*B*	*SE B*	β
Camp Overall Outcome Scale			
Parental Factor			
Perception of separation experience	.049	.023	.35*
Child Factors			
Camp expectations	.051	.035	.25
Negative mood	-.30	.13	-.39*
Socialization/Enjoyment Scale			
Child Factor			
Negative mood	-.34	.17	-.36+
Self-esteem/Normalization Scale			
Parent Factor			
Parental camp expectations	.076	.051	.22
Child Factors			
Attachment style	.51	.24	.34*
Attitude toward illness	.067	.035	.29+
Negative self-esteem	-.213	.10	-.33*

Note. Total scale score trimmed model: $R^2 = .34$
Socialization/Enjoyment scale score trimmed model: $R^2 = .13$
Self-esteem/Normalization scale score trimmed model: $R^2 = .46$
$^{+}$ $p < 0.10$, * $p < 0.05$.

DISCUSSION

Review of Findings

Psychosocial adjustment. In examining the overall adjustment in children with CHD on the SDQ, parents reported significantly greater levels of behavior problems, emotional difficulties (e.g., sadness, worry), hyperactivity, and peer difficulties when compared to healthy peers. This is consistent with prior investigations which also found that children with CHD obtained higher problem scores on the CBCL (Utens et al., 1993), parental reports of children having difficulty relating to peers (Bowen, 1985), and increased impulsivity (Kramer et al., 1989). In contrast, child self-reported levels of depression and anxiety were indistinguishable or lower than those reported by healthy normative samples (Kovacs, 1992; Reynolds & Richmond, 1985). This finding runs counter to prior investigations examining children with CHD on levels of anxiety (Gupta et al., 2001; Kramer et al., 1989) and depressive symptoms (Spurkland et al., 1993).

Parents and children indicated significant levels of impairment across physical, social, and school quality of life domains, with parent reports indicating greater levels of difficulty than the children's report. These findings support previous research outlining significant physical limitations experienced by this population (Thomason, 1997) and school adjustment problems (Bowen, 1985). A recent investigation by Uzark and colleagues (2003) also found significant deficits across all domains of quality of life in children with heart conditions, except physical functioning, when compared to healthy peers. Both parents and children in this sample reported significantly more difficulties with perceived physical appearance and cognitive problems than

another sample of children with cardiac conditions (Uzark et al., 2003) Children reported significantly greater medical treatment anxiety than was reported by parents, while parents reported more heart related physical problems than reported by children. These discrepancies between child and parental report may be due to the fact that children may be better reporters of their own fears, such as treatment anxiety, and parents may attribute the severity of the physical symptoms they observe in their children to a more severe cardiac condition.

The final aspect of overall adjustment examined was restrictions on social functioning. Parent and child reports were compared with reports of parents and children with other chronic medical conditions. The number of difficulties reported across domains by each child was similar to reports by their parents, and was often significantly greater than child self-reports in other pediatric chronic illness groups (Adams et al., 2002) including patients with seizure disorder, cancer, and asthma. Child and parent reports of social limitations related to physical exertion were quite consistent and were greater than children with other chronic medical conditions. Children with CHD reported more instances of isolation and teasing or feeling different from the comparative sample, with some reported difficulties in social interactions with peers and family members. These findings are consistent with prior self-reports of social isolation (Sparacino et al., 1997), relationship difficulties (Thomason, 1997), and feeling different from others (Gantt, 1992). In addition, it further supports parent reports of their child experiencing more social problems, engaging in fewer activities, and being more withdrawn (Casey, 1996). Children with CHD reported significantly more problems with social difficulties at school than children with other chronic pediatric illnesses. However, their parents and parents of children with other disorders did not differ in their reports of social problems at school. Altogether, these findings support prior literature that children with CHD experience a variety of adjustment difficulties.

Influence of disease severity and attitude toward illness. The hypothesized relationship between greater disease severity and psychological maladjustment was only partially supported. Although disease severity was associated with higher levels of anxiety and lower levels of quality of life, with specific deficits in physical functioning and social functioning, no relationship materialized for all other adjustment measures (e.g., levels of depression, behavior problems, attachment style). In addition, attitude toward illness was not associated with any psychosocial constructs. The lack of significant findings may be due to the limited variability of responding in this sample on this attitudinal measure, thus diminishing the ability to differentiate individuals based on their attitude toward illness.

Impact of camp. In support of the hypothesis that psychological improvement could be observed at camp, self-reported levels of anxiety decreased. This finding is consistent with similar studies conducted an asthma camp (Creer, 1982) and camps for children with diabetes, asthma, and spina bifida (Briery & Rabian, 1999). Attitude toward illness did not change significantly as a result of camp, which departs from the investigation conducted by Briary and Rabian (1999) and Punnet and Thurber (1993). Attitude toward illness may be a variable of questionable validity. In this study, it neither changed as a result of camp, nor was it associated with any other psychosocial variable. The lack of a significant decrease in depression is not surprising given previous non-significant findings (Hazzard & Angert, 1986; Rubin & Geiger, 1991) and the low levels of symptoms reported by this sample. No published research has measured quality of life as a change variable in the camp setting. It may be that quality of life is not responsive to change due to this one week intervention. Surprisingly, social functioning did not significantly change. This may be attributed to the negative phrasing of these questions on the LCI and the PedsQL (e.g., other kids don't want to be my friend) that may have diminished

sensitivity to increases in positive social interaction at camp. Scores reported on the camp outcome measure may support this idea. Children indicated that camp was a positive social experience, with an average of 3.9 out of a possible 5 on the Enjoyment/Socialization subscale of the H-COS.

Parents did not observe any significant psychosocial changes in their children two months following camp, but did report a significant decrease in their anxiety about separating from their children. This may correspond to previous reports of parent's surprise at their child's ability to succeed independently at camp (Primack & Greifer, 1977) and reports of children's increased independence following camp (Punnet & Thurber, 1993). Parental separation anxiety related to pediatric camp participation is an area deserving of further research.

An interesting pattern emerged with children's reports on their camp experience. Significant changes were noted from the end of camp to the follow-up assessment, with increases in overall enjoyment of the camp experience, increases for socialization, and decreases in difficulties and feelings of homesickness at camp. Improvements of children's attitudes toward the camp experience over time could potentially be explained in two ways. Positive reporting concerning the camp experience may increase as the positive impact of the camp persists in their life. Also, as children reflect on their experience at camp, they may focus less on small nuisances at camp, such as the insects and their snoring neighbors, and put more emphasis on the overarching themes of camp, such as a sense of group support and making friends. Although there was an increase on the self-esteem and normalization subscale from camp to follow-up, the high camp scores created a ceiling effect, with a mean of 4.0 out of a possible 5 for at camp, thus prohibiting statistically significant change. Reports on this subscale indicate that the majority of children experienced a positive sense of self and felt like they fit in at camp. This supports the

goals of Camp Braveheart (CHOA, 2001a) and indicates that either children who attend camp have a positive sense of self or that camp helped them meet that goal.

Predicting camp outcome. Although in previous investigations homesickness was predicted by a host of factors such as number of separation experiences, attachment style, and anxiety, in this study the model that predicted difficulty/homesickness at camp included parental camp expectations and the child's camp expectations. These two factors are supported by previous research (Thurber, 1999; Thurber et al., 1999). These are important and potentially malleable variables that could be changed using pre-camp orientation presentations. Child reports of the overall camp experience were significantly predicted by parents' perception of the separation experience on the child and the children's lack of negative mood prior to camp. This model supports the importance of the child's psychological state and parental perceptions prior to camp. Socialization at camp was significantly predicted by the lack of negative mood as reported by the child. Thus, not surprisingly, it appears that negative mood may persist during camp and interfere with engaging in and enjoying the social benefits of camp. Lastly, self-esteem/normalization at camp was significantly predicted by attachment style, attitude toward illness, and a lack of negative self-esteem prior to camp. Attachment style may be a difficult variable to manipulate. However, attitude toward illness and self-esteem may be malleable, and as such, provide possible suggestions for future intervention. Contrary to prior investigations, camper status (Briery & Rabian, 1999) and age (Thurber, 1999) was not associated with camp outcome. This may be attributed to the small number of first time campers to serve as the comparison group (n = 6) and the inclusion of campers only 8 years and above.

Limitations

The findings of this study should be tempered in light of its limitations. The initial

portion of this study was dedicated to describing the adjustment of children with CHD, but it is essential to keep in mind that this sample simply represents only a subset of the population with CHD who chose to attend a camp for children with those specific disease parameters. This sample represents children with moderate to severe CHD who must be followed regularly by CHOA in order to be invited to camp. Children with less severe cardiac conditions may not experience the same degree of adjustment difficulties. However, this investigation does indicate the need for clinicians to be particularly attentive to psychosocial issues with CHD patients similar to these participants. Another potential limitation involves the means of data collection. All pre-camp measures were mailed to families, therefore, no supervision during administration was provided to verify the integrity of responding or to clarify any questions during completion. Having children and parents complete measures during a pre-camp orientation for all potential campers would allow investigators to monitor administration and answer potential questions. This approach may even increase the participation rate, as mailing surveys frequently results in lower participation rates. A goal of this study that was not realized involves the collection of data from a non-camper CHD patient control group. This limitation seems to be representative of research in this area, with no non-camper data published in this literature. One-on-one recruitment during patient appointments may be the only way to increase non camper participant numbers, since this small financial compensation offered in this study had no effect. Determining the characteristics that differentiate campers from non-campers remains an illusive goal for future research in this area.

An additional goal of the investigation was to develop a measure of camp outcome. This was accomplished through the design of a face valid test with high internal reliability and validity. In addition, the construct validity of the measure was supported through concurrently

administered measures of psychosocial inventories. However, thus far the H-COS has not been used with any other population to confirm its properties. With promising psychometric properties, future investigations should assess the validity of this measure of camp outcome with other pediatric samples.

Implications and Future Directions

This study provides some implications and future directions for research on the adjustment of children with CHD and the impact of camp for children with CHD. Many of the most pronounced impairments that children with CHD experience are directly addressed at camp. A significant proportion of children who attended camp reported physical exertion limitations, feelings of isolation and persecution, and feeling different from other children. The positive socialization experience, increase in physical activity, sense of normalcy, and positive self-esteem boost that camp provides is a well-suited intervention for addressing those needs. Currently, no specific psychosocial programming exists to target adjustment at camp. The positive effects of camp could potentially be supplemented through group activities that teach social skills and focus on building a positive sense of self. In addition, the goals of camp should perpetuate throughout the year. Children regularly followed by CHOA are readily accessible, making recruitment and the creation of year-round group activities much easier. Activities such as weekend events or support groups could provide a continuity of care. As observed from increases in positive attitudes toward camp during the follow-up period, the excitement does not diminish and providing a means of reuniting these children and families may intensify the benefits. Lastly, some children in this investigation are struggling with significant social and emotional difficulties. Developing therapeutic interventions that address the struggles these children experience would be beneficial. A group therapy format that addresses adjustment to

illness, social impairments, coping skills, and issues of normalcy could provide favorable outcomes for children with CHD.

Although these children did not report clinically significant anxiety levels, the reduction in anxiety observed during the camp experience provides support for the psychological benefits of camp and an incentive for children who have never attended to potentially reap the same positive benefits. Also, the reduction in parental separation anxiety is an encouraging finding. A frequently cited difficulty for parents of children with chronic illness, and more specifically, parents of children with CHD, is struggling with parental overprotectiveness (Bowen, 1985) and difficulty relinquishing control (Sparacino et al., 1997). Reductions in separation anxiety may directly correspond to decreases in parental overprotection and help promote concomitant increases in appropriate independence by the children.

Lastly, the predictors for difficulty at camp provide invaluable information for camp organizers, future campers, and parents. Both predictors, parental camp expectations and child camp expectations, are changeable variables. Efforts to prepare parents and children prior to camp may improve expectations and, in turn, may decrease difficulties and increase the benefits derived by the children at camp, as well as by the parents who are left at home. Interventions may include a pre-camp orientation to meet current campers and parents to discuss the camp experience and coping with homesickness while at camp, practicing separations prior to camp, and discussing the decision to attend camp as a parent-child team. In addition, camp counselors may provide supplemental support at camp for children identified as having negative expectations. This could be accomplished through interventions such as reinforcing positive attitudes, providing immersive distractions, letter writing, and setting up a buddy system at camp to facilitate friendships. By simply assessing the construct of camp expectations and providing

these straightforward interventions, we could alter children's camp experience.

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