

EVALUATING THE CARDIAC CAMP EXPERIENCE:
DEVELOPMENT OF THE HUBBARD CAMP OUTCOME SCALE

by

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(Under the Direction of Charlotte Wallinga)

ABSTRACT

The current study described the development and validation of the Hubbard Camp Outcome Scale (H-COS), an instrument designed to assess the benefits of camp for children with congenital heart defects (CHD). 29 campers attended Camp Braveheart, a camp for children with CHD, and completed the RCMAS, CATIS, CDI, PedsQL, PedsQL Cardiac Module, and H-COS. Exploratory factor analysis of the H-COS resulted in a 29-item scale with a total scale score and three subscale scores. Reliability of the H-COS was adequate with an overall alpha of .93. The H-COS appeared to be a valid instrument, with significant correlations with the CDI, PedsQL, and the PedsQL Cardiac Module. No differences were found on gender or age of the child. The data from the current study suggests that based upon this limited sample size, the H-COS seems to be a valuable instrument for assessing the benefits of camp for children with CHD.

INDEX WORDS: pediatric camp, children with congenital heart defects, Camp Braveheart, Hubbard Camp Outcome Scale

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DEDICATION

To all of the amazing children at Camp Braveheart: To conga lines at breakfast time and love that is wider than the miles between you and me.

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For your hours of hard work, gracious listening skills, eye for punctuation, and humorous inspiration, I thank you Charlie a million times over. You have pushed me to achieve my best and inspired me to reach a little further. I only hope that I may be as exceptional a teacher, mentor, and friend that you have been to me. To my committee, Charlie, Kevin, and Ron for the hours of long, hard work, thoughtful comments and encouragement.

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CHAPTER 1

INTRODUCTION

Children face significant challenges in the course of their development. Establishing autonomy, developing a sense of self-esteem, making friends, and navigating the pathways to adulthood are complex issues for most children. Yet, for children with chronic illnesses, these normal developmental tasks are possibly even more problematic. Research by Austin (1989) and Breslau (1985) indicates that children with chronic illness are at a much greater risk for developing psychological difficulties such as behavioral problems, poor self-concept, and social withdrawal. The increased psychological and social risks for children with chronic illness are estimated to be 1.3 to 3 times greater than that for healthy children (Thompson, Zeman, Fanurik, & Sirothkin-Roses, 1992). Due to this increased risk, recent research has focused on identifying factors that account for the greater prevalence of psychosocial health problems in this population (Briery & Rabian, 1999). Lemanek (1994) resonates this point in stating “psychological research involving children and adolescents with chronic illness has been ranked by pediatric psychologists as a priority area for future investigations” (p. 143).

Children with chronic medical conditions are increasingly prevalent in the United States, with estimates indicating that they constitute 10-20% of the general child population (Bowe, 2000). Although there are many childhood chronic medical conditions, research investigating the adaptation to these disorders has been conducted with only a few of the most common conditions (e.g., diabetes, asthma, cancer). The focus of the present study will be on a growing population

of children that have been understudied in the psychosocial literature, children with congenital heart defects (CHD).

Congenital heart defects are the most common birth defect in the United States (American Heart Association [AHA], 2004a). According to the American Heart Association, 9 out of every 1,000 babies or about 36,000 births each year will have a congenital heart defect (AHA, 2004b). Currently, there are at least 15 distinct types of congenital heart defects identified, which range from simple defects to complex malformations, with a majority of these defects able to be corrected or improved with surgery or catheter-based therapy (AHA, 2004b). Yet, even with the advances in surgical procedures and treatments to correct these conditions, heart defects cause more deaths than any other birth defect during the first year of life and nearly twice as many children ages 0-14 years die from CHD each year than all forms of childhood cancer combined (AHA, 2004a).

Mortality associated with congenital defects has been declining (AHA, 2004a). Death rates from all heart defects declined 39% from 1979-1997, with infants under the age of one year accounting for more than 50% of this decrease (AHA, 2002). With the advances in technology and corrective surgery options over the last 20 years, the number of children with congenital heart disease surviving into adulthood has increased dramatically (Bernstein, 2000). In fact, the American Heart Association (2002) estimates that there are more than 1,000,000 American adults and children living with congenital cardiovascular defects today. As more children with CHD are living into adulthood, researchers cannot disregard the rising concern of these children's psychological functioning (Baum & Bernstein, 1993). It is no longer sufficient to solely treat the medical symptoms of these children. Research needs to examine the psychosocial needs of children with CHD as well.

The psychological literature on children with CHD is a combination of a small number of quantitative studies, qualitative studies, and anecdotal reports. Based upon these investigations, children with CHD seem to experience problems in several areas of psychosocial development (Delamater, 1995). For example, even though the actual medical condition of a child with CHD is not visible, there may be marked effects on their overall physical appearance and their psychological state (Bernstein, 2000). Small stature and cyanosis, a bluish coloring to the skin, may affect a child's body image. Restrictions placed on physical activities can lead to social isolation and low self-esteem (DeMaso, Beardslee, Silbert, & Fyler, 1990). Children with CHD report feeling inferior to their peers (Kramer, Awiszus, Sterzel, van Halteren, & Claben, 1989). Congenital heart defects have the potential for creating disproportionate psychological problems due to the emotional and psychological significance attached to the heart (Wray & Sensky, 1998). These findings suggest that possible psychosocial interventions for children with cardiac abnormalities are worthy of research attention. In fact, according to Delamater (1995), very little intervention research on children with CHD has been reported, reinforcing the need for more investigation in this area.

One intervention that has been explored is camps for children with chronic illness (Rosenbloom, 2001). Summer camps are renowned for the joy and freedom they bring to children. In recent years, summer camp programs have been established for children with chronic health conditions that would otherwise be unable to attend camp because of restrictions imposed by their illness (American Camping Association [ACA], 1998). While summer camps have become a popular means of addressing the psychosocial needs of children with chronic illnesses (Briery & Rabian, 1999), there has been little scientific research conducted that specifically focuses on their camping experience (Thomas & Gaslin, 2001).

Previous research on camps for children with chronic illness has been limited and there has been very little known research conducted on camps for children with cardiac abnormalities. In addition, there are few existing instruments designed to specifically assess the impact of camp for children with chronic illness. In the past, nonstandardized question and answer forms were distributed to children and their parents to collect information about their perceptions of the camp experience (Punnett & Thurber, 1994). These nonstandardized forms lead to largely anecdotal information that did not lend itself to comparisons between groups or across years. In addition, there has been little research detailing children's impressions of camp and few instruments designed to measure children with chronic illness's impressions of the camp experience (Punnett & Thurber, 1994).

As Rosenbloom (2001) has stated, camp can have a profound effect on a child's ability to live with a chronic illness. Therefore, the present study will expand on previous research and examine the impact of Camp Braveheart, a camp for children with congenital heart defects, by developing and testing a quantitative instrument.

Purpose

The purpose of the present study is to describe the development and validation of a quantitative measure, the Hubbard Camp Outcome Scale, to assess children's perceptions of Camp Braveheart. A secondary purpose is to investigate the psychosocial benefits children with CHD may gain by attending Camp Braveheart.

CHAPTER 2

REVIEW OF LITERATURE

The following is a review of the literature on children with cardiac abnormalities and pediatric camps. First, an examination of cardiac abnormalities in children, including the etiology and physical symptoms, will be presented in order to better understand and identify problems in their psychosocial development. Second, research investigating the psychosocial development of children with CHD will be explored. Third, the literature on camps for children with chronic illness will be reviewed. Next, the existing quantitative instruments that have been designed to assess children's experiences at camp will be described. Finally, the hypotheses for the study will be presented.

Cardiac Abnormalities in Children

A cardiac abnormality that exists at birth is classified as congenital heart disease (AHA, 1998). Yet, these abnormalities are typically referred to as congenital heart defects rather than diseases. A congenital heart defect is caused when the heart or the blood vessels surrounding the heart do not develop normally before the child is born (AHA, 1998). While there have been numerous attempts by researchers to identify the causes of CHD, the answers are still inconclusive (Bernstein, 2000). Viral infections and diseases, ingestion of certain drugs during pregnancy, as well as hereditary have been linked to CHD, but the primary cause is still unknown (Bernstein, 2000).

Diagnosing a congenital heart defect is difficult during pregnancy, but 50 to 60% of children are diagnosed with congenital heart disease within the first month of birth. These babies

may be blue in color or have very low blood pressure shortly after birth, have breathing difficulties, feeding problems, and/or poor weight gain. Children with severe heart defects will likely undergo surgery that may include open-heart operations, heart transplantations, or installation of artificial valves and pacemakers within hours of birth. Often, this initial surgery is the first in a long series of required heart surgeries for children with cardiac abnormalities (Bernstein, 2000).

Of the 15 distinct types of congenital heart defects identified, each has specific symptomology associated with it, yet several physical symptoms are prevalent across diagnoses (AHA, 2004b). Children with CHD may experience difficulty breathing, profuse perspiration, and poor growth (Bernstein, 2000). They may experience chest pains, unusual lethargy, dizziness, or fainting (AHA, 1998). Exercise and activity restrictions may be placed upon them and they may not be allowed to participate in competitive sports (Bernstein, 2000). In addition to being slightly smaller than other children their age, children with CHD may experience other outward physical symptoms. Often children with CHD have a bluish coloring, especially in their lips, mouth, fingernails, and toenails, and may have clubbing of the fingers and toes (Bernstein, 2000). Children with severe CHD often undergo heart transplants that require a vigorous daily medication routine of immuno-suppressants to prevent their body from rejecting their new heart (Baum & Bernstein, 1993). Immuno-suppressants, while essential for the survival of the child's new heart, may have extensive side effects for children including weight gain, acne, and moon faces (Baum & Bernstein, 1993). Although not all children will experience this physical symptomology, a basic understanding of cardiac abnormalities and their symptom presentation is crucial to understanding the possible influence it contributes to a child's psychosocial development.

Psychosocial Research on Children with Cardiac Abnormalities

As a larger number of children with CHD are living into adulthood, more research needs to be done to investigate the psychosocial impacts of this disease on children (Baum & Bernstein, 1993). The paucity of research on psychosocial adjustment of children with CHD has been noted (Casey, Sykes, Craig, Power, & Mulholland, 1996; Delameter, 1995). It is possible that children with more severe heart defects did not survive in past decades and those who did survive were asymptomatic, decreasing the likelihood that any research investigations would have examined psychosocial developmental issues. The long-term impact of CHD on children's psychological functioning remains unclear (DeMaso et al., 1990). The little research that does exist in the area of the psychosocial impact of CHD on children is a combination of qualitative and quantitative studies. The existing literature in both areas will be reviewed in an effort to identify which if any areas of psychosocial developmental are affected in children with cardiac abnormalities.

Bowen (1985) outlined the impact of CHD on children of various developmental levels and its effect on family functioning. Bowen (1985) described the differential impact of CHD depending on the child's developmental level. Children with CHD were often separated from their parents in infancy, due to medical and surgical needs, causing a disruption in attachment formation, parental bonding, and the child developing a sense of trust. Preschool and school age children reported difficulty adjusting and relating to peers, and experienced poor self-esteem and severe anxiety. Children in this developmental stage often viewed their heart condition as a punishment. Adolescents expressed problems with peer acceptance, alterations in their body image, and difficulty developing their independence (Bowen, 1985).

Thomason (1997) conducted a qualitative investigation that examined the impact of severe CHD on the lives of adolescents. Thomason interviewed male and female adolescents regarding their perception of the illness and their daily life activities. Utilizing qualitative analysis eight common themes were identified: normalization, physical limitations, relationships, body image, acceptance, physical and emotional pain, lack of remembrance and looking towards the future (Thomason, 1997).

Similar themes were reported by Gantt (1992) when she interviewed 13 adolescent and young women, ages of 13-28 years old, who grew up with CHD. Gantt used an unstructured interview to explore what young women with CHD perceived as the impact of their disease on their sexuality, body images, sexual decision-making, and potential pregnancies. Three variables were identified: growing up heartsick, growing up female, and living against the body. Within these three major variables, Gantt (1992) reported several problems for adolescent women with CHD including, feeling different from others, poor self-esteem, poor self-concept, and poor body image. While these themes may be of concern to healthy adolescents at this age, it appears that these issues are particularly troublesome and common for female adolescents with CHD.

In an effort to better understand the dilemmas of CHD from another perspective, Sparacino et al. (1997) interviewed parents of adolescents and young adults living with CHD. The researchers conducted a semi-structured interview with 8 parents, 7 mothers and 1 father, to discover their worries about their child and how the illness had affected them, their perception of their child's relationship with others, and their child's activities. The study identified seven common themes, of which three were related to psychosocial development, including: dilemmas of normality, disclosure dilemmas, and the challenge of social integration versus isolation. Parents indicated their fear that their child often had issues with normality when physically

compared to other children, when playing sports with other children, and when coping with their emotional/mental health issues. Disclosure dilemmas were mentioned surrounding telling a teacher about their child's health for fear it would jeopardize their child's education or cause discrimination, particularly during physical education classes. Finally, parents were concerned with their child's social development indicating fears their child did not have enough friends or spent too much time with parents rather than peers (Sparacino et al., 1997).

Examination of children with CHD in the quantitative literature has found similar results concerning this population's psychosocial functioning. In a study completed in Germany, Kramer, Awiszus, Sterzel, Van Halteren, and Claben (1989) investigated the differences in personality of children with CHD compared to children who were diagnosed with functional heart murmurs and considered healthy. The sample included 217 children, 128 children with cardiovascular defects and 89 control children with functional heart murmurs, between the ages of 4 and 14 years. The CHD group was further divided to include children with physical limitations ($n = 77$) versus those children without physical limitations ($n = 51$), as determined by cyanosis, restrictions from daily and physical activity, and restriction of regular school attendance. Personality factors for younger children, ages 6 years through 7 years, were measured through parent responses on the Marburg Behavior List developed by Ehlers, Ehlers, and Makus (as cited in Kramer et al., 1989) and older children, 10 years through 14 years, were assessed by their response on the Personality Questionnaire for Children developed by Seitz and Rausche (as cited in Kramer et al., 1989). The results indicated no differences on personality factors between groups for younger children; however, older children (10-14 years) with CHD who had physical limitations exhibited increased anxiety, impulsiveness, and inferiority than the healthy controls.

In a recent study, Gupta, Mitchell, Giuffre, and Crawford (2001) discovered similar results when they examined anxiety, fears, and behavioral problems in children with asthma, CHD, and healthy controls. Forty children with asthma and 39 children with CHD, between the ages of 6 and 17 years and who did not display previous anxiety or fears on routine clinical assessment, were recruited from a large children's hospital clinic. The children from both groups completed the Fear Survey Schedule for Children-Revised (FSSC-R; Ollendick, 1983) and the Revised Children's Manifest Anxiety Scale (RCMAS; Reynolds & Richmond, 1985). Parents from both groups completed the Child Behavior Checklist (CBCL; Achenbach & Edelbrock, 1983) and the State-Trait Anxiety Inventory (STAIC; Spielberger, 1973). The child normative sample was derived from standardized scores reported by scale authors on the FSSC-R and the RCMAS. Results indicated that children with CHD had significantly more medical fears and significantly more physiological anxiety than norms. Children with CHD also scored significantly higher than the normative sample on the CBCL total score, the CBCL internalizing score, and the Anxiety/Depression factor of the CBCL.

In another study, Casey et al. (1996) researched the behavioral, academic, and social adjustment of 26 children with surgically treated complex CHD versus 26 children with a mild heart murmur. The children diagnosed with a mild, innocent heart murmur served as the control group and were chosen by researchers as an appropriate healthy control comparison for studying children with CHD. The sample included 26 children with complex CHD, 21 male and 5 female participants, and 26 children who served as controls, with 21 males and 5 females. All of the participants were of school age, with the range between 4.4 and 16.5 years old. Behavioral, academic, and social adjustments were assessed using the parent- and teacher-rated forms of the Child Behavior Checklist (CBCL; Achenbach & Edelbrock, 1983). The physical functioning of

each child was assessed with an objective measure of exercise tolerance, using a symptom-limited graded treadmill exercise test. There was a considerable difference in exercise time between the two groups, with children with more severe CHD having a lower exercise tolerance as displayed by almost 5 fewer minutes on the treadmill than the control group. The researchers found that children with CHD were rated by their parents as more withdrawn, having more social problems, and engaging in fewer activities. Teachers also rated children with CHD as more withdrawn than their classmates.

This examination of the research indicates that children with CHD are affected in several areas of psychosocial development. To review, children with CHD experienced challenges in their psychological development by viewing their illness as punishment, had difficulty developing their independence, had poor self-esteem and experienced severe anxiety (Bowen, 1985). Children with CHD also have reported having a poor body image (Bowen, 1985; Gantt, 1992; Thomason, 1997) and had issues with their self-esteem and self-concept (Gantt, 1992). These children also faced challenges by having more medical fears, anxiety, and depressive symptoms than healthy norms (Gupta et al., 2001). The social development of children with CHD was also affected as shown by these children having difficulty relating and being accepted by their peers (Bowen, 1985; Sparacino et al., 1997; Thomason, 1997), feeling normal or different from others (Gantt, 1992; Sparacino et al., 1997) and experienced feelings of inferiority (Kramer et al., 1989). Children with CHD were also found to be more withdrawn, had more social problems, and engaged in fewer activities than healthy norms (Casey et al., 1996). The limited physical ability of children with CHD also contributed to their social development (Casey et al., 1996; Sparacino et al., 1997) by being unable to keep up with the other children in physical education class or being excluded from activities due to their medical condition.

When considering the psychosocial development of children with CHD, it is equally important to provide empirical support for programs that seek to address these concerns. In recent decades, summer camping programs have been established with the intentions of bringing some of the fundamental benefits of camp to children with chronic medical conditions who would otherwise be unable to attend because of restrictions imposed by their illness. The overall purpose and philosophy of a summer camp experience, including its role as an intervention for children with cardiac abnormalities, will be reviewed.

Camps for Children with Chronic Illness

Camping is defined by the American Camping Association (ACA, 1997a) 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” (p. 1). In addition to accomplishing this main goal, surveys conducted by the ACA indicated that camp directors and parents recognized four important contributions that camp had on a child’s development. In rank order, they indicated that camp a) contributed to a child’s self-confidence and self esteem, b) assisted children in getting along with others/teamwork, c) instilled an appreciation of the outdoor/environmental concerns, and d) enhanced recreational skills (ACA, 1997b).

The ACA accreditation standards (ACA, 1998) stated that the underlying principle for camps for children with special needs was to allow these children to participate in all camp activities. The ACA reported that there were 12,000 camps across the country and more than 5,000 of these camps directly served these children with special needs (ACA, 2003). The camping experience assisted in teaching children independence and self-discipline in their approach to their condition and in their approach to life (ACA, 1998).

At these camps, mental, physical, and medical conditions or needs were addressed; yet, they were not the principle issues for children at camp. Although the specific goals of camps for children with chronic illness varied from providing a rewarding camp experience as close to normal as possible (Smith, Gotlieb, Gurwitch, & Blotcky, 1987) to providing a sense of mastery and efficacy in peer relations (Swenson, 1998), the underlying theme was to provide normalcy to these children, outside the parameters of their illness (ACA, 1998). Camps were designed to provide an environment that fostered normalization by accommodating children typically between 6 and 18 years old who had been diagnosed with a specific medical condition. In this environment, children were exposed to peers that had been living with the same disease and could relate to the manifestation of the illness and the emotional, physical, and psychological issues they were facing (Rosenbloom, 2001). For instance, at the end of a camp designed for children with hemophilia, a camper reported, “I think everyone with hemophilia should come to camp” (Thomas & Gaslin, 2001, p. 261). Pediatric camps have addressed many areas of psychosocial functioning by creating an environment where children were free to swim, boat, and play kickball without concern about being different from their peers.

Previous researchers examined the advantages of camps and reported benefits in areas including family dynamics, acquisition of knowledge, the appropriate ages for disease care tasks, and the effectiveness of disease-related teaching methods (Rosenbloom, 2001). Additional research has looked at the effectiveness of the camp environment to educate children about their illness and teach self-management techniques (Misuraca, Di Gennaro, Lioniello, Duval, & Aloi, 1996) as well as children’s knowledge, attitudes, and health benefits relevant to nutrition management (Singh, Kable, Guerrero, Sullivan, & Elsas, 2000). Studies have also investigated camp settings in relation to children’s weight gain and pulmonary functioning (Kaplan, McKey,

Toraya, & Moccia, 1992; Rubin & Geiger, 1991) medical complications (Powars & Brown, 1990) and adherence behaviors and diabetic control (Spevack, Johnson, Riley, & Silverstein, 1991). Since the focus of this study is on the psychosocial aspects of camp for children with chronic illnesses, this review will be limited to the literature related to this topic.

There is little literature about the effectiveness of camps in addressing psychosocial development for children with chronic illness (Thomas & Gaslin, 2001) and the research that has been conducted has been largely anecdotal (Briery & Rabian, 1999). The limited quantitative research that does exist supports the idea of camp as a means of addressing psychosocial development in children with chronic illness (Briery & Rabian, 1999; Punnett & Thurber, 1993; Smith et al., 1987; Thomas & Gaslin, 2001).

Smith et al. (1987) completed a longitudinal study on a group of patients with pediatric cancer and their families to assess the effects of a camp experience on daily activity and family interactions. The sample consisted of 18 children with cancer, between the ages of 6 and 12 years, and their mothers and siblings who participated in a one week summer camp. Mothers completed the Interaction with Environment Checklist (Tittler, Friedman, Blotcky, & Stedrak, 1982) which was a self-report of the types of activities the child engaged in the previous week and the Daily Activity Scale (Smith et al., 1987) which assessed the hours children spent in physical, social, and self-engaged activities at three different sampling periods. Mothers completed these instruments two weeks before camp, two weeks following camp, and again four weeks after camp. Results indicated that the child's physical and social activities increased in the two weeks following camp, in conjunction with a decrease in solitary play activities. The increase in social activity and the decrease in solitary play were still apparent at follow-up one month after camp.

Punnett and Thurber (1993) investigated a camp for children with asthma in order to identify factors that contribute to the overall improvement in the children who attend camp. Over a period of 3 years, 125 campers, ages 10-13 years old, participated in the overnight camp. Parents completed the Child Behavior Checklist (CBCL; Achenbach & Edelbrock, 1983) and the Four Factor Index of Social Status (Hollingshead, 1975) before camp. Campers completed the Self-Perception Profile (Harter, 1985) and an asthma health education test pre- and post-camp. An observational measure developed by the authors, the Punnett Adjustment to Camp Scale, was completed on each child each day of camp. The instrument measured the child's participation and contributions during structured activities and reflected complaints that would suggest maladjustment, e.g., psychosomatic complaints, homesickness.

Punnett and Thurber (1993) conducted intercorrelations among the above measures and then summarized them by means of principal component analysis in order to differentiate children in terms of their reactions to camp experiences. Analyses revealed gender differences; boys who arrived at camp more self-competent tended to show better overall adjustment and girls with higher levels of disease knowledge were found to be more adequately adjusted to camp experiences. The authors reported that informal feedback from parents also suggested improvements in their children after the camp experience; children seemed more self-sufficient, better adjusted with a more positive attitude about their disease, and more knowledgeable about their condition. Specific statistical analyses, including correlation coefficients, were not presented in this study, thus the conclusions that were drawn by the authors may be limited.

In an observational study, Thomas and Gaslin (2001) reported the positive effects the camp experience had on children with hemophilia and their subsequent enhancement of self-esteem. The camp environment used Bandura's Social Learning theory by planning the camp

activities and staff orientations with the focus on increasing each child's self-esteem. The primary focus of staff orientation was role modeling: with the thought that the campers will mimic the words, actions, and activities of the counselors. The authors report the more engaged campers became in activities, the more likely self-esteem enhancement would occur, which was reinforced by positive feedback from counselors. Camp outcomes were reported through anecdotal evaluations from the children including, "I can't wait until next year," "I wish camp lasted three weeks," and "Someday I want to be a counselor and help other people with hemophilia" (Thomas & Gaslin, 2001, p. 261).

Briery and Rabian (1999) explored the effects of the camp experience on the psychological functioning of children with asthma, diabetes, and spina bifida. The study attempted to examine the impact of a summer camping program on children's attitudes towards their illness and their overall levels of trait anxiety. Ninety participants, between the ages of 6 and 16 years, attended a one-week camp for children with asthma ($n = 37$), diabetes ($n = 32$), or spina bifida ($n = 21$). Children lived in cabins with five to eight other campers and two to six counselors. Activities at camp included, swimming, canoeing, arts and crafts, nature hikes, archery, and spending one night cooking and camping out. In addition, campers at the asthma and diabetes camp attended daily education sessions regarding care and maintenance of medications, equipment, and lifestyles.

Briery and Rabian (1999) administered the Child Attitude Towards Illness Scale (CATIS; Austin & Huberty, 1993) and the State-Trait Anxiety Inventory for Children, A-Trait Form (STAIC; Spielberger, 1973) to campers following registration for camp and again at the end of camp. Only the A-Trait Form, which measures internal trait anxiety, of the State-Trait Anxiety Inventory was used for this study. Analyses of variance were conducted and statistically

significant results indicated that children had a more positive attitude towards their illness and lower levels of trait anxiety at the end of camp, although these constructs were not specifically targeted in the camp programming. These changes were evident across diagnoses; all three groups showed significant changes on the CATIS (Austin and Huberty, 1993) and the STAIC (Speilberger, 1973) in the desired direction. Thus, the results were not specific to any one group or condition; demonstrating that the benefits of camping programs are not illness specific and can improve children's attitudes towards their illness and levels of trait anxiety across conditions (Briery & Rabian, 1999).

This examination of the research indicates that camps for children with chronic illness seem to have a positive impact on their psychosocial development. To review, camps for children with chronic illness provided normalcy to these children outside the parameters of their illness (ACA, 1998), and exposed children to peers that can relate to the emotional, physical, and psychological issues surrounding their illness (Rosenbloom, 2001). Parents reported that children who attended pediatric camps participated in more physical and social activities, while engaging in fewer solitary activities (Smith et al., 1987), were more self-sufficient, better adjusted, had more positive attitudes and increased knowledge about their illness (Punnett & Thurber, 1993). Children who attended camp also experienced enhanced self-esteem (Thomas & Gaslin, 2001), lower levels of trait anxiety, and more positive attitudes towards their illness (Briery & Rabian, 1999).

When considering the benefits that camp can offer children with cardiac conditions, it is important to also consider how these benefits can be measured. As previously mentioned, past research has relied heavily on anecdotal reports and observations in reporting the benefits of camp (Briery & Rabian, 1999). Quantitative evaluations of the camp experience, including

studies using measures developed specifically for assessing the psychosocial benefits of camp, seem to be relatively absent in the literature. Next, the few known existing quantitative instruments that have been used to measure children's camp experience will be reviewed.

Camp Evaluation Measures

There is little literature on quantitative evaluation methods to assess the benefits of pediatric camps for children with chronic illnesses. Punnett and Thurber (1994) stated that no standardized measure of the child's impression of camp had been developed. In an attempt to address this deficit, Punnett and Thurber (1994) adapted the Child Evaluation Inventory (CEI; Kazdin, Esveldt-Dawson, French, & Unis, 1987) for use at a camp for children with asthma. The CEI was an instrument originally constructed for the evaluation of individual psychotherapy by children. The CEI was designed based upon the Therapist Evaluation Inventory (Kazdin, Esveldt-Dawson, French, & Unis, 1987) and appeared to measure progress in therapy and acceptability of treatment (see Thurber, Snow, & Thurber, 1990).

The CEI consists of 19 items rated by the child using a 5-point response format, ranging from *unfavorable* to *favorable*. In adapting the instrument for use at a camp for children with asthma, Punnett and Thurber (1994) retained the original CEI items with the substitution of the word *camp* for *psychotherapy* (8 items) and the word *asthma* for *behavior* (4 items). The term *psychotherapist* (4 items) was replaced by the names of the most significant adults to the camper: nurse and cabin counselor. Inserting the names of both significant adults added two additional questions to the instrument, resulting in a total of 21 items (Punnett & Thurber, 1994).

Forty-six children (30 boys; 16 girls) between the ages of 10-13 years completed the CEI after a one-week residential camp for children with asthma. During the week, the children participated in camp and recreational activities, including education, crafts, and self-esteem

classes as part of the daily curriculum. The classes focused on education regarding asthma in these areas, as well as having fun.

Results indicated that campers generally had positive reactions to the camp experience. The scale indicated suitable scale homogeneity with the mean item-total correlation of .57 ($p < .01$). Three items, which asked the child to rate the nurse and camp counselor, had the lowest item-total correlations in the scale. The alpha reliability coefficient was .909 for total items and .912 with the three items related to nurse and counselor ratings deleted (Punnett & Thurber, 1994).

While the adaptation of the CEI for a camp for children with asthma seems to be a reliable, homogeneous scale (Punnett & Thurber, 1994), this adaptation of the instrument appears to measure the same components of the original CEI, progress in therapy and acceptability of treatment. It seems this instrument determines an overall satisfaction at camp and does not indicate specific benefits or changes in psychosocial functioning in children who attend camp. Although general progress and acceptability are important concepts to assess, the literature indicates that pediatric camps address more explicit areas of functioning (e.g. anxiety, activity level, self-esteem) (Briery & Rabian, 1999, Punnett & Thurber, 1993, Smith et al., 1987, Thomas & Gaslin, 2001).

In a study examining homesickness, Thurber and Sigman, (1998) developed a questionnaire, My Time at Camp, to assess well children's general, social, and environmental satisfaction of camp. The sample consisted of 293 boys, ages 8-16 years, who spent 2 weeks at an overnight summer camp. The campers were asked to rate their overall quality of their stay on an 11 point Likert scale from *terrible* to *excellent* to determine a general satisfaction score. Social and environmental satisfaction were measured with multi-item subscales. Examples from

the social satisfaction subscale include, “In general, the kids in my cabin were...” and “In general, my cabin leader was....” Questions from the environmental satisfaction subscale include, “How much did you like living in a cabin in the woods?” and “How much did bugs and poison ivy bother you?” Good internal consistency was found for both multi-item subscales with a reliability coefficient alpha of .84 for Social Satisfaction (8 items) and an alpha of .73 for Environmental Satisfaction (7 items) (Thurber & Sigman, 1998).

Since the My Time at Camp scale (Thurber & Sigman, 1998) was not designed for children with chronic illnesses, its contents do not seem to reflect the psychosocial benefits outlined in the literature on pediatric camps (e.g., self-esteem, better attitude towards illness, lower levels of anxiety). Furthermore, the questions from this measure were directed more towards general camping issues and do not seem to capture and adequately measure the specific benefits offered by pediatric camps to children with chronic illnesses.

In summary, this examination of the research indicates that quantitative measures designed to assess the benefits of camp for children with chronic illnesses are lacking. The Child Evaluation Inventory (Punnett & Thurber, 1994), while successfully adapted for a camp for children with asthma, appeared to measure general progress and acceptability of treatment. The CEI did not indicate specific benefits or changes in psychosocial functioning in children who attend camp. My Time at Camp (Thurber & Sigman, 1998) was an instrument designed to measure overall satisfaction with the camp experience for children without chronic illnesses. While this instrument is used to assess satisfaction, My Time at Camp did not measure the psychosocial benefits of camp for children with chronic illness. The paucity of quantitative instruments to measure the benefits of pediatric camps provided a foundation and rationale for this study.

Pediatric Camp From a Systems Theory Perspective

In order to gain a comprehensive understanding of a child's experience at camp, the experience must be examined in the context of the system or systems in which the child is embedded. Examples of such systems include the child's family, the camp environment, and the social network that exists at camp (Whitchurch & Constantine, 1994).

Systems Theory researchers (e.g., Klein & White, 1996) attempt to examine people and social phenomena using a holistic approach. This approach is defined by two major concepts. The first concept is the idea that all parts of a system are interconnected (Klein & White, 1996). Consequently, the action of one individual within a system affects the other members of that system. For example, the praise of a kind counselor will affect the campers to whom the acknowledgement is directed.

The second defining concept in Systems Theory is based upon hierarchy, or the interrelation among smaller and larger systems (Whitchurch & Constantine, 1994). Thus, a system is comprised of smaller systems, often called subsystems, and is embedded within larger systems called suprasystems (Whitchurch & Constantine, 1994). For example, a child with CHD is embedded within a population of children that experience specific physical and psychosocial challenges because of their medical condition. At a pediatric camp, the child exists within the subsystem of children with CHD, which exists within the suprasystem of the camp as a whole. The child who is a participant in a pediatric camp is connected to the other campers with CHD. All of these children collectively comprise the larger camp environment or suprasystem. Thus, the factors that affect each child individually may affect the camp as a whole and vice versa.

Building upon the psychosocial difficulties of children with CHD and the benefits that a pediatric camp can offer them, the present study on the development of the Hubbard Camp

Outcome Scale will be explored from a Systems Theory perspective. The specific medical condition of the children, CHD, and the systems operating in the camp environment were considered when developing the Hubbard Camp Outcome Scale.

Summary of Literature Review

Children with congenital heart defects experienced difficulties in their psychosocial development. One intervention that had been explored in addressing these concerns was pediatric camps for children with chronic illnesses. Research has examined the benefits children with chronic illness gain from participating in these camps, yet no known formal research has been conducted on camps for children with CHD. Additionally, little empirical research has studied quantitative instruments designed to measure the benefits children with any chronic illness gain from attending these camps. Further research would help give insight into the experiences of children with CHD who attend pediatric camps.

Hypotheses

The Hubbard Camp Outcome Scale (H-COS) is a quantitative measure designed to assess the benefits children with congenital heart defects gain from the camp experience. Based on the literature and research discussed, this study will examine the reliability and validity of the Hubbard Camp Outcome Scale. The following hypotheses will be examined:

1. Exploratory factor analysis of the Hubbard Camp Outcome Scale will result in a total scale and five subscales: Normalization, self-esteem/self-efficacy, anxiety/depression, social functioning, and physical activity.
2. The Hubbard Camp Outcome Scale total scale and subscales will demonstrate convergent validity with the following measures given concurrently at camp.

- a. The H-COS total scale score will have a significant positive relation with attitude towards illness, as measured by the Child Attitude Towards Illness Scale.
 - b. The H-COS total scale score will have a significant negative relation with anxiety, as measured by the Revised Child Manifest Anxiety Scale.
 - c. The H-COS total scale score will have a significant negative relation with depression, as measured by the Child Depression Inventory.
 - d. The H-COS total scale score will have a significant positive relation with pediatric quality of life, as measured by the Pediatric Quality of Life Inventory.
 - e. The H-COS total scale score will have a significant positive relation with cardiac quality of life, as measured by the Pediatric Quality of Life Cardiac Module.
3. The Hubbard Camp Outcome subscales, once determined by exploratory factor analysis, will be significantly related to the measures, listed in Hypothesis 2, that were given concurrently at camp. Specific hypotheses for the subscales will be presented in the Results section.
 4. The Hubbard Camp Outcome Scale will be reliable, as demonstrated by an adequate Cronbach's alpha for internal consistency and test-retest reliability, for the total scale and each subscale.
 5. The Hubbard Camp Outcome Scale will not be significantly different based upon gender, as measured by males and females responding similarly on the total scale and each subscale.

6. The Hubbard Camp Outcome Scale will not be significantly different based upon age, with children ages 8-12 years responding similarly to children ages 13-18 years on the total scale and each subscale.

CHAPTER 3

METHODS

This chapter will describe the methods used for this study, including the participants, procedure, and measures. The development of the Hubbard Camp Outcome Scale will also be described.

Participants

Camp Braveheart takes place annually in Rutledge, Georgia at a facility built specifically for children with special medical needs. A twenty-four hour medical facility, staffed by volunteer Children's Healthcare of Atlanta (CHOA) nurses and doctors, is located on the grounds to provide medical treatments and emergency care to campers during their stay. The children participate in typical camping activities such as paddle boating, swimming, mountain biking, arts and crafts, scavenger hunts, and horseback riding. Campers reside in cabins, designated by gender and age group, with a volunteer counselor living in each cabin. Camp Braveheart's mission is "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 (CHOA, 2001, p. 2)."

Children were invited to participate in the one week camp, by Camp Braveheart's sponsoring organization, Children's Healthcare of Atlanta, if they met the following qualifications: a) the child must have a congenital heart defect, and b) be regularly followed by CHOA because of their heart condition. Each year, Camp Braveheart invites children to attend the camp free of charge with no expense to the patient or their families.

For this study, only children 8 years and older were eligible to participate. Of the 63 campers who attended camp, 57 children were eligible for this study ($n = 6$ were under 8 years old). The present sample consisted of 29 campers, ages 8 to 17 years, resulting in a completion rate of 51%. Fifteen of the campers were male and 14 were female. The sample was predominantly Caucasian (72.4%), with a small proportion of African American (6.9%), Asian (6.9%), and those who did not endorse any ethnicity (13.8%). The majority of the families in the sample, 72.3%, reported earning salaries of \$30,000 or above annually.

Hubbard Camp Outcome Scale

The Hubbard Camp Outcome Scale (H-COS, developed in this study) was designed to be a summed rating scale that measures children's perceptions of the camp experience (See Appendix A). The idea for the scale was first developed by conducting a focus group of pediatric researchers that had piloted previous research at Camp Braveheart. The participants in the focus group suggested developing a quantitative measure to capture the benefits children reported after attending Camp Braveheart. A thorough literature review was conducted to identify potential psychosocial issues for children with cardiac conditions and the benefits that camp may offer these children. The items for the H-COS were developed to assess the psychosocial issues children might be experiencing at camp. Thirty-seven items were developed at a reading level appropriate for an instrument that could be completed independently by children 8-18 years (i.e. approximately third grade level). The scale was then reviewed by the same group of pediatric researchers, and several faculty members in the Child and Family Development and Psychology departments for face and content validity. Their considerations and suggestions were incorporated into the scale, which underwent nine revisions before being piloted.

The scale was first piloted with a group of three healthy children, two females, and one male whose age ranged from 8-14 years, who had never attended a camp. Each child independently completed the measure before the author reviewed each item with the child individually, for clarity, content comprehension, and readability. Their comments were incorporated and the measure underwent another revision before the second pilot. A second pilot was conducted with one male child, age 10, who had attended a camp for children with asthma. He completed the measure independently, and then the author reviewed each question with him for content and reading comprehension.

The scale underwent a final revision after the second pilot, which resulted in a 33-item measure. Four additional questions, of the same Likert format, assessing general camp experiences were included at the end of the scale. These questions were not to be included in computing the total scale score or in the subscale scores. The general camp questions were incorporated to provide additional information or explanation for outlier scores, if necessary.

The H-COS was designed to be a multidimensional instrument with a total scale score along with five subscale scores. Children were asked to respond to questions on a 5-point Likert response format (e.g., almost never, not often, sometimes, often, almost always) regarding their feelings while at camp. The item scores were totaled to produce a total scale score, which measures the overall camp experience, and five hypothesized subscale scores: normalization, social functioning, anxiety/depression, physical activity, and self-esteem/self-efficacy.

A total scale score is computed by summing scores on the scale items and dividing the total score by the number of items completed. This result is a score ranging between 1 and 5, with higher scores indicating greater benefit or a better time at camp while lower scores are thought to indicate less benefit or a worse time at camp. Twelve items are negatively worded, so

when scoring these items, a lower score determines a greater benefit or better time at camp while greater scores indicate less benefit or a worse time at camp. These 12 items are reverse coded to align all responses in the positive directions for ease of interpretation. Thus, higher numbers indicate a greater benefit or a better time at camp while lower numbers indicate a worse time at camp. Subscale scores are computed by adding the items within the subscale and dividing by the total number of items completed within that subscale. Final scoring information, including the exploratory factor analysis, is presented in the Results section.

Procedure

Approval for this study was obtained from the Internal Review Board at both the University of Georgia and Emory University School of Medicine. Participants in the current study were part of a larger study examining the effects of a cardiac camp experience on the attitudes, emotions, and social functioning of children with cardiac abnormalities conducted by Laura Simons, Ronald Blount, and Robert Campbell through the University of Georgia, Children's Healthcare of Atlanta's Sibley Heart Center, and Emory University School of Medicine. Funding for the study was obtained through Sibley Heart Center's Cardiac Research Department at Children's Healthcare of Atlanta.

The Simons, Blount, and Campbell study examined children with cardiac abnormalities who attended Camp Braveheart at three different sampling points: one month prior to camp, the last day of camp, and two months post camp. At the three sampling times, campers and their parents completed the following measures as part of the larger study: Demographic and Medical Survey, Maternal Separation Anxiety Scale adapted (MSAS; Hock, McBride, Gnezda, 1989), Self-Reported Attachment Style Prototypes (SRASP; Bartholmew & Horowitz, 1991), Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997), Living with Chronic Illness (LCI;

Adams, Streisand, Zawacki, Joseph, 2002), Revised Children's Manifest Anxiety Scale (RCMAS; Reynolds & Richmond, 1985), Child Attitude Towards Illness Scale (CATIS; Austin & Huberty, 1993), Child Depression Inventory (CDI; Kovacs, 1992), Pediatric Quality of Life Inventory (PedsQL; Varni, 1998), and the Hubbard Camp Outcome Scale (H-COS).

The current study utilized only the camper population from the larger study that was sampled at the end of camp and the two-month follow-up period, although information from the Demographic and Medical Survey, that was gathered from the camper's parents prior to camp, was used to determine the sample demographics. The measures that were used for this study include only those administered to children at the end of camp: Revised Children's Manifest Anxiety Scale (RCMAS; Reynolds & Richmond, 1985), Child Attitude Towards Illness Scale (CATIS; Austin & Huberty, 1993), Child Depression Inventory (CDI; Kovacs, 1992), Pediatric Quality of Life Inventory and Cardiac Module (PedsQL; Varni, 1998), and the Hubbard Camp Outcome Scale (H-COS). The data from these measures were used to conduct correlation analyses in order to determine the factor structuring, factor analysis, and reliability analysis of the H-COS. In addition, this study utilized the two-month follow-up data from the H-COS. This follow-up data was used for test-retest reliability purposes only. No other data gathered at follow-up was used in this study (See Appendix B for complete instrument information).

To recruit participants for the proposed study, investigators mailed informed consent/assent forms for the parents and children, measures used in the study, and self-addressed stamped envelopes to each 8-18 year old who was invited to attend camp (See Appendix C for consent/assent forms). 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. Each of the measures included specific instructions to assist parents in administering the measures to younger children.

On the evening of the last day of camp, campers completed the RCMAS, CATIS, CDI, PedsQL, PedsQL-cardiac, and the H-COS. Camp staff members were present to monitor administration in order to maintain validity and clarify any questions for the campers.

Approximately one month following camp, PedsQL parent and child versions, PedsQL-cardiac parent and child versions, RCMAS, CATIS, CDI, and H-COS were mailed to participating families with a self-addressed envelope and instructions to complete the forms and return them within one month. The researchers conducted reminder calls to increase the percentage of completed measures. The data gathered from this follow-up administration was used only to determine test-retest reliability for the H-COS. The sample size at follow-up administration was 18 campers, resulting in a completion rate of 62% of the original 29 campers who first completed the study.

Measures

Demographic and Medical Survey

Selected information from the Demographic and Medical Survey was used and included: a) ethnicity, b) gender, c) gross family income, and d) previous camp experience.

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 coefficients for internal consistency range from $\alpha = .72$ to $\alpha = .85$. Test-retest reliability is fairly stable with reported $\alpha = .98$ at a 3-week interval and $\alpha = .68$ at a 9-month interval (Reynolds & Paget, 1983). The convergent validity of the instrument is supported by a significant correlation between the RCMAS and the A-trait scale ($r = .85$) of the State-Trait Anxiety Inventory for Children (STAIC; Spielberger, 1973).

The Child Attitude Toward Illness Scale

The Child Attitude Toward Illness Scale (CATIS; Austin & Huberty, 1993) is a 13-item scale designed to assess children's attitudes toward their specific illnesses or disabilities. Children answer each question on a 5-point Likert-type scale. A total scale score, representing their attitude towards illness, is generated by averaging the score across items (Austin & Huberty, 1993). Scale scores range from 1 to 5; with a score of 1 indicating a more negative attitude toward illness and a score of 5 indicating a more positive attitude toward illness. The scale was reliable, as indicated by an overall alpha for internal consistency across illnesses of .8, with an alpha of .74 for children 8-10 years of age and an alpha of .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 years (Heimlich, Westbrook, Austin, Cramer, & Devinsky, 2000).

Children's Depression Inventory

The Children's Depression Inventory (CDI; Kovacs, 1992) is a 27-item scale assessing self-reported symptoms of depression resulting in a total score and five subscale scores: negative mood, interpersonal problems, ineffectiveness, anhedonia, and negative self-esteem. Designed for school age children ages 7 to 17 years old, the scale presents three alternatives for each described symptom, and children select the response that most represents their feelings. The CDI measures symptom severity, by quantifying the magnitude of the depressive complaints, and can be used to measure change in depressive symptoms following treatment. The CDI has good internal consistency, extensive normative data, and correlates positively with self-reported depressive cognitions and negatively with self-esteem (Kovacs, 1992).

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 four areas of functioning: physical, emotional, social, and school. Respondents answered each question on a 5-point Likert-type scale, and it derives scale scores for each of the four areas of functioning, a psychosocial health summary score, and a total scale score. This inventory is a relatively new measure with preliminary reliability and validity data. In one investigation with 291 pediatric cancer patients at various stages of treatment, the Cronbach's alpha coefficient for the core measure ($\alpha = .83$) was acceptable for group comparisons. Reliability coefficient alphas for the patient self-report modules ranged from .70 to .89. Discriminant validity was demonstrated for patients who were receiving treatments versus those patients who were off-treatments (Varni,

Seid, & Rode, 1999). In another investigation, the PedsQL was administered to 963 children recruited from pediatric health care settings. Internal consistency reliability for the Total Scale Score ($\alpha = 0.88$), Physical Health Summary Score ($\alpha = 0.80$), and Psychosocial Health Summary Score ($\alpha = 0.83$) were acceptable for group comparisons. 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; Varni, 1998) is a 27-item instrument that measures 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, medication related treatment, perceived physical appearance, treatment anxiety, cognitive problems, and communication. Respondents answer each question on a 5-point Likert-type scale. A total scale score is derived, as well as scale scores for each area of functioning. Preliminary reliability and validity data comparing the PedsQL-core module with the PedsQL-cardiac module demonstrate adequate internal consistency, with alpha reliability coefficients ranging from .72 to .96 and validity, with statistically significant correlations ranging from .36 to .78. (Uzark, Jones, Burwinkle, & Varni, 2003).

Analysis of Data

Data was analyzed by examining differences in scores on the Hubbard Camp Outcome Scale. Exploratory factor analysis was conducted on the H-COS to determine the factor structure of the measure. Although the recommended ratio for factor analysis is 3 cases for every 1 item (Guadagnoli & Velicer, 1988) and the current study did not meet those recommendations,

exploratory factor analysis was conducted on the Hubbard Camp Outcome Scale since this study was a preliminary investigation of the measure. Intercorrelations between the H-COS and validated measures (i.e. RCMAS, CATIS, CDI, PedsQL, PedsQL Cardiac module) were performed to determine the construct validity of the Hubbard Camp Outcome Scale.

Intercorrelations and reliability analyses using Cronbach's alpha were conducted to determine the reliability of the H-COS total scores and subscale scores. In order to determine group differences in reporting between both gender and age of the child, independent t-tests were performed.

CHAPTER 4

RESULTS

The major purpose of this study was to describe the development and validation of a quantitative measure, the H-COS, to assess children's perceptions of Camp Braveheart. This section will present the analysis of data, including the factor analysis, validity, and reliability of the H-COS. Results will be presented in sequential order and addressed by hypotheses.

Missing Data

There were six instances of missing data on the H-COS. Four subjects failed to complete one item and one subject failed to complete two items on the scale. However, none of the subjects failed to complete the same question. In the instances where there was missing data for an item, the average score of the remaining participants for that item was inserted for analyses. The percentage of missing data was less than .01 percent of the total completed items.

Item Analyses

Item analyses were conducted on the 33 items hypothesized to assess an overall camp score and five subscales areas including: normalization, social functioning, anxiety/depression, physical activity, and self-esteem. Initially each item was correlated with the total scale score by conducting an item-total correlation. In six cases, the items had a correlation below $r < .25$ with the total scale score. These six items were "How often did you feel like the other kids at camp were the same or similar to you?," "How often did you think about your heart condition at camp?," "How did you feel about your ability to do activities while you were at camp?," "How often did you play with someone you did not know very well at camp?," "How often did you do

sports activities at camp?,” “How often did you get tired and have to sit down at camp?” Based upon these results, these items were eliminated from future analyses.

Furthermore, two additional questions that were included to assess general camp experiences at the end of the scale were included in the analyses. Although initially the questions were not to be included in the analyses, it was thought that they may relate to the hypothesized subscales and that these additional questions contained information that would increase the validity of the instrument. These questions, “How often did you feel homesick at camp?” and “How much did you like or dislike camp?” were included in all future analyses.

Exploratory Factor Analysis

Hypothesis (1)

Exploratory factor analysis of the Hubbard Camp Outcome Scale will result in a total scale and five subscales: normalization, self-esteem/self-efficacy, anxiety/depression, social functioning, and physical activity.

The dimensionality of the remaining 29 items from H-COS was analyzed using exploratory factor analysis. In order to clarify the extracted factors and force the factors into categories that were not correlated, the factors were rotated using an orthogonal varimax-rotated procedure. Using a minimum eigenvalue of one, the first rotated solution yielded seven factors. Preliminary hypothesis predicted that this scale had five dimensions; so another exploratory factor analysis was conducted in an effort to increase the interpretation of the scale. The second analysis, setting a criterion of a minimum eigenvalue of two, resulted in three interpretable factors: Enjoyment/Socialization, Difficulty/Homesickness, and Self-Esteem/Normalization. Items yielding a factor loading below .5 on any of the three factors were eliminated. This resulted in one item, “How often did you feel like you had to tell the other kids at camp what it

was like to have a heart condition?,” being eliminated from future analyses. Theoretically, one additional item, “How often did you feel like yourself at camp?,” did not fit within the factor construct of Difficulty/Homesickness and was therefore eliminated. This resulted in a final 27-item three factor measure. The factor loadings of the final version of the H-COS are presented in Table 1.

The total scale score of the H-COS accounts for a cumulative variance of 61%. The first factor, Enjoyment/Socialization, was the strongest factor with 13 items and accounted for 37.87% of the item variance. Difficulty/Homesickness was the second strongest factor, containing nine items and accounting for 13.55% of the item variance. Finally, the third factor, Self-Esteem/Normalization, consisted of five items and explained 9.57% of the item variance (Table 2).

Construct Validity

Construct validity was determined by computing Pearson correlation coefficients between the H-COS total scale score and the three subscale scores. Correlations were conducted to assess evidence of validity for the H-COS constructs. Examination of the results indicated that the total scale score was significantly correlated with each of the three subscales:

Enjoyment/Socialization ($r = .88, p < .01$), Difficulty/Homesickness ($r = -.78, p < .01$), and Self-Esteem/Normalization ($r = .56, p < .01$). These correlations are presented in Table 3.

Pearson correlation coefficients were also conducted between each of the H-COS scores, (i.e., total scale score and each subscales) and theoretically related constructs (assessed with valid and reliable instruments) administered at the same time to determine evidence for concurrent construct validity. Hypotheses 2a, 2b, 3b, 3e, and 3f were not significant as shown in Table 3. Significant results are presented by hypothesis as follows and displayed in Table 3.

Hypothesis (2c)

The H-COS total scale score was hypothesized to have a significant negative relation with depression as measured by the Child Depression Inventory.

An expected significant negative correlation was found between the H-COS total scale score and depression, as measured by the Child Depression Inventory ($r = -.44, p < .05$). In addition, significant negative correlations were noted between the H-COS total scale score and the Child Depression Inventory Ineffectiveness subscale ($r = -.42, p < .05$) and the Child Depression Inventory Anhedonia subscale ($r = -.44, p < .05$) as shown in Table 3.

Hypothesis (2d)

The H-COS total scale score was hypothesized to have a significant positive relation with pediatric quality of life as measured by the Pediatric Quality of Life Scale.

While there was no significant relation between the H-COS total scale score and the Pediatric Quality of Life total score, a modestly significant positive correlation existed between the H-COS total scale score and the Pediatric Quality of Life Physical Functioning subscale ($r = .35, p < .10$). Results are shown in Table 3.

Hypothesis (2e)

The H-COS total scale score was hypothesized to have a significant positive relation with cardiac quality of life, as measured by the Pediatric Quality of Life Cardiac Module.

There was a significant positive relation between the H-COS total scale score and the cardiac quality of life ($r = .46, p < .05$) as shown in Table 3.

Hypothesis (3a)

The H-COS Enjoyment/Socialization subscale was hypothesized to have a significant negative relation with depression as measured by the Child Depression Inventory.

As expected, a significant negative correlation existed between the Enjoyment/Socialization subscale and depression ($r = -.39, p < .05$). In addition, significant negative correlations were found between the Enjoyment/Socialization subscale score and the Child Depression Inventory Ineffectiveness subscale ($r = -.48, p < .01$) and the Child Depression Inventory Anhedonia subscale ($r = -.38, p < .05$) as shown in Table 3.

Hypothesis (3c)

The H-COS Enjoyment/Socialization subscale was hypothesized to have a significant positive relation with cardiac quality of life as measured by the Pediatric Quality of Life Cardiac Module.

A significant positive correlation was found between the Enjoyment/Socialization subscale and cardiac quality of life ($r = .40, p < .05$) as shown in Table 3.

Hypothesis (3d)

The H-COS Difficulty/Homesickness subscale was hypothesized to have a significant positive relation with depression as measured by the Child Depression Inventory.

There was not a significant relationship between the Difficulty/Homesickness subscale and the Child Depression Inventory total score. However, a modest positive correlation was found between the Difficulty/Homesickness subscale and the Anhedonia subscale of the Child Depression Inventory ($r = .32, p < .10$) as shown in Table 3.

Hypothesis (3g)

The H-COS Self-Esteem/Normalization subscale was hypothesized to have a significant positive correlation with cardiac quality of life as measured by the Pediatric Quality of Life Cardiac Module.

A significantly positive correlation existed between the Self-Esteem/Normalization subscale and cardiac quality of life ($r = .40, p < .05$) as shown in Table 3.

Hypothesis (3h)

The H-COS Self-Esteem/Normalization subscale was hypothesized to have a significant negative relation with depression as measured by the Child Depression Inventory.

Although there was not a significant relation between the Self-Esteem/Normalization subscale and the Child Depression Inventory total score, a significant negative correlation indicated a relation between the Self-Esteem/Normalization subscale and the Negative Self-Esteem subscale of the Child Depression Inventory subscale ($r = -.51, p < .01$) (Table 3).

Reliability

Hypothesis (4)

The Hubbard Camp Outcome Scale was hypothesized to be reliable, as demonstrated by an adequate Cronbach's alpha for internal consistency and test-retest reliability, for the total scale and each subscale.

After the final scale was determined through factor analysis, a reliability analysis (i.e., item total correlations, squared multiple correlations, and Chronbach's alpha reliability coefficients) was conducted on the 27-item H-COS. See Table 4. The 12 items with negative valences (Items #1, 8, 9, 10, 11, 12, 13, 20, 24, and 26) were recoded to align all responses in the positive direction for ease of interpretation. The internal consistency estimate of reliability demonstrated acceptable internal consistency with a Chronbach's alpha of .93. See Table 5.

Item analyses were also conducted on the three subscales. Item number one was recoded when running this analyses, since it was the only negatively worded item on the Self-Esteem/Normalization subscale. All items on the Difficulty/Homesickness subscale were

negatively worded, so the items were not reverse coded. The subscales also suggest reasonable reliability based on the coefficient alpha of .7 or higher; a value of .93 for the subscale Enjoyment/Socialization, a value of .91 for the subscale Difficulty/Homesickness, and a value of .78 for Self-Esteem/Normalization. The coefficient alpha values are presented in Table 5.

Correlations were conducted to determine test-retest reliability for the total scale score and the three subscales. Of the initial 29 participants, 18 participants completed the H-COS at the follow-up administration two months after camp. This resulted in a retention rate of 62% of the initial sample. The test-retest reliability for the Enjoyment/Socialization subscale and the Difficulty/Homesickness subscale was not acceptable, displaying correlation coefficient values of .31 and .31 respectively. The Self-Esteem/Normalization subscale was significant at $p < .01$ level, with an correlation coefficient of .66. See Table 6. The test-retest reliability for the total scale was moderately significant ($r = .42, p < .10$) as shown in Table 6. A significance level of $p < .10$ was used in order to determine small effects due to the small sample size.

Hypothesis (5)

It was hypothesized that the Hubbard Camp Outcome Scale scores would not be significantly different based upon gender, as measured by males and females responding similarly on the total scale and each subscale.

Independent t-tests showed male ($n = 15$) and female ($n = 14$) participants were not significantly different in their responses on the Enjoyment/Socialization subscale scores ($t = -.39, p > .05$), Difficulty/Homesickness subscale scores ($t = .58, p > .05$), Self-Esteem/Normalization subscale scores ($t = .22, p > .05$) and Hubbard Camp Outcome Scale total scores ($t = -.45, p > .05$). See Table 7.

Hypothesis (6)

It was hypothesized that the Hubbard Camp Outcome Scale would not be significantly different based upon age, with children ages 8-12 years responding similarly to children ages 13-18 years on the total scale and each subscale.

Independent t-tests were calculated, and examination of the results indicated that younger children, ages 8-12 years old ($n = 16$), and older children, ages 13-18 years old ($n = 13$), were not significantly different in their responses on the Enjoyment/Socialization subscale scores ($t = -.99$, $p > .05$), the Difficulty/Homesickness subscale scores ($t = .82$, $p > .05$) and the Hubbard Camp Outcome Scale total scores ($t = -1.34$, $p > .05$). The Self-Esteem/Normalization subscale scores were approaching significance ($t = -1.74$, $p \leq .10$) at the $p \leq .10$ level which was used to determine small effect due to the small sample size (Table 8).

Table 1
Summary of Factor Loadings for Varimax Orthogonal Three-Factor Solution for the H-COS
 (N = 29)

Items (Responses)	Factor Loading			Communality
	1	2	3	
Factor 1: Enjoyment/Socialization				
6. How often did you feel like you could do the activities the other kids at camp were doing?	.63	.30	.51	.74
7. How happy or sad were you at camp?	.51	.34	.48	.60
14. How often did you spend time with your friends at camp?	.81	.26	.19	.76
15. How often did you have someone to talk to at camp?	.70	.24	.22	.60
16. What was it like to make friends at camp?	.72	.24	.05	.58
17. What was it like to play with kids you did not know very well?	.75	.15	.09	.60
18. How often did you play with the other kids at camp?	.78	.25	-.16	.69
19. How often did you feel like you were part of the group at camp?	.80	.29	.24	.77
21. How often did you get along with the other kids at camp?	.79	.28	.26	.77
22. How often were you active at camp?	.59	-.13	.05	.36
23. How often did you feel like you had energy at camp?	.62	.08	.26	.46
25. How often did you exercise at camp?	.64	-.05	.14	.43
27. How much did you like or dislike camp?	.81	.13	-.18	.70
Factor 2: Difficulty Homesickness				
8. How often were you nervous at camp?*	.08	.81	.02	.66
9. How often did you worry at camp?*	.08	.79	.14	.64
10. How often did you worry <u>about your heart condition</u> at camp?*	.27	.74	.18	.66
11. How often were you lonely at camp?*	.25	.75	-.25	.69
12. How often did you worry about what the other kids at camp thought about you?*	.28	.73	.05	.61
13. How often did you feel sad or blue at camp?*	.30	.77	-.05	.68
20. How often did you feel left out at camp?*	.23	.80	.27	.77
24. How often did you feel like you couldn't keep up when you were playing with the other kids at camp?*	-.05	.68	.23	.51
26. How often did you feel homesick at camp?*	.06	.61	.29	.46
Factor 3: Self-Esteem/Normalization				
1. How often did you feel different from the other kids at camp?***	.25	-.02	.74	.61
2. How often did you feel like you fit in with the other kids at camp?	-.23	.44	.57	.57
3. How did you feel about yourself at camp?	.05	.08	.69	.48
4. How often were you proud of yourself at camp?	.10	.15	.77	.63
5. How often did you like yourself at camp?	.36	.06	.58	.46

Note. *Reversed for coding for computing full scale score. **Reversed for coding for full scale score and subscale score. Boldface indicate highest factor loadings.

Table 2
Eigenvalues, Percentages of Variance, and Cumulative Percentages for the Three Subscales of the H-COS (N = 29)

Subscale	Eigenvalue	% of variance	Cumulative %
Enjoyment/Socialization	10.22	37.87	37.87
Difficulty/Homesickness	3.66	13.55	51.42
Self-Esteem/Normalization	2.58	9.57	61.00

Table 3

Intercorrelations, Means, and Standard Deviations for H-COS and Psychological Measures given at camp (N = 29)

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	M	SD
1. Overall camp outcome	---	.88**	-.78**	.56**	-.08	-.15	-.44*	-.25	-.42*	-.44*	.28	.35 ⁺	.20	.46*	3.95	0.66
2. Enjoyment/Socialization		---	-.44*	.33 ⁺	-.15	-.07	-.39*	-.07	-.48**	-.38*	.26	.27	.20	.40*	3.93	0.83
3. Difficulty/Homesickness			---	-.34	-.03	.26	.29	.22	.20	.32 ⁺	-.23	-.32	-.17	-.31	2.06	0.89
4. Self-Esteem/Normalization				---	.00	.02	-.35	-.51**	-.16	-.31	.11	.18	.00	.40*	4.01	0.77
5. CATIS total score					---	-.18	-.11	-.18	-.01	-.21	.07	.07	-.02	.06	40.60	3.19
6. RCMAS total score						---	.39*	.10	.22	.38*	-.71**	-.71**	-.66**	-.48**	10.28	6.17
7. CDI total score							---	.59**	.78**	.90**	-.40*	-.40*	-.36	-.48**	7.83	5.70
8. CDI ss: Negative self-esteem								---	.16	.46*	-.17	-.18	-.14	-.31	.97	1.24
9. CDI ss: Ineffectiveness									---	.64**	-.17	-.22	-.18	-.27	1.90	1.95
10. CDI ss: Anhedonia										---	-.35	-.35	-.33	-.40*	2.86	2.07
11. PedsQL total score											---	.93**	.94**	.83**	72.73	18.88
12. PedsQL ss: Physical function												---	.84**	.85**	73.60	21.47
13. PedsQL ss: Social function													---	.71**	69.82	19.65
14. PedsQL Cardiac total score														---	72.29	16.61

Note. ⁺ $p < .10$, * $p < .05$, ** $p < .01$, two tailed

Table 4
Final 27-item Hubbard Camp Outcome Scale (H-COS)(N = 29)

Items (Responses)	<i>M</i>	<i>SD</i>	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?	3.79	1.35	.77	.92
7. How happy or sad were you at camp?	4.14	.79	.70	.93
14. How often did you spend time with your friends at camp?	4.22	1.15	.76	.92
15. How often did you have someone to talk to at camp?	4.00	1.22	.67	.93
16. What was it like to make friends at camp?	3.90	.98	.61	.93
17. What was it like to play with kids you did not know very well?	3.45	1.02	.61	.93
18. How often did you play with the other kids at camp?	4.17	1.31	.58	.93
19. How often did you feel like you were part of the group at camp?	4.03	1.09	.78	.92
21. How often did you get along with the other kids at camp?	4.00	1.28	.79	.92
22. How often were you active at camp?	4.00	1.13	.33	.93
23. How often did you feel like you had energy at camp?	3.76	1.12	.55	.93
25. How often did you exercise at camp?	3.59	1.38	.43	.93
27. How much did you like or dislike camp?	4.17	1.04	.54	.93
Difficulty/Homesickness				
8. How often were you nervous at camp?*	2.24	1.12	.51	.93
9. How often did you worry at camp?*	2.17	1.07	.55	.93
10. How often did you worry about your heart condition at camp?*	1.97	1.27	.67	.93
11. How often were you lonely at camp?*	1.90	1.05	.49	.93
12. How often did you worry about what the other kids at camp thought about you?*	2.17	1.34	.61	.93
13. How often did you feel sad or blue at camp?*	1.83	1.10	.63	.93
20. How often did you feel left out at camp?*	1.86	1.09	.72	.93
24. How often did you feel like you couldn't keep up when you were playing with the other kids at camp?*	2.17	1.31	.42	.93
26. How often did you feel homesick at camp?*	2.21	1.11	.49	.93
Self-Esteem/Normalization				
1. How often did you feel different from the other kids at camp?***	1.93	.92	.40	.93
2. How often did you feel like you fit in with the other kids at camp?	3.81	1.14	.28	.93
3. How did you feel about yourself at camp?	4.14	1.13	.30	.93
4. How often were you proud of yourself at camp?	3.86	1.03	.41	.93
5. How often did you like yourself at camp?	4.17	1.10	.45	.93

Note. * Reversed for coding for computing full scale score. **Reversed for coding for full scale score and subscale score.

Table 5
Means, Standard Deviations, and Alpha Internal Consistency Values for the H-COS (N = 29)

Scale	<i>M</i>	<i>SD</i>	Alpha
Enjoyment/Socialization	3.93	.83	.93
Difficulty/Homesickness	2.06	.89	.91
Self-Esteem/Normalization	4.01	.77	.78
Total Scale	3.95	.66	.93

Table 6
Means, Standard Deviations, and Test-Retest Correlation Coefficients for At Camp and Follow-up Administrations of the H-COS (n = 18)

Scale	Time 1		Time 2		Correlation Coefficient
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
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. * $p < .01$, ⁺ $p \leq .10$

Table 7
Means, Standard Deviations, and Group Differences for Males and Females on the H-COS
 (N = 29)

Scale	Females		Males		<i>t</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Enjoyment/Socialization	3.87	.77	3.99	.90	-.39
Difficulty/Homesickness	2.16	1.04	1.96	.75	.58
Self-Esteem/Normalization	4.04	.79	3.98	.67	.22
Total Scale	3.89	.67	4.00	.68	-.45

Table 8
Means, Standard Deviations, and Group Differences for Younger and Older Children on the H-COS (N =29)

Scale	Younger Children		Older Children		<i>t</i>
	<i>Mean</i>	<i>SD</i>	<i>Mean</i>	<i>SD</i>	
Enjoyment/Socialization	3.80	.77	4.10	.90	-.99
Difficulty/Homesickness	2.18	.71	1.91	1.10	.82
Self-Esteem/Normalization	3.79	.90	4.28	.49	-1.74 ⁺
Total Scale	3.80	.69	4.13	.61	-1.34

Note. ⁺ $p \leq .10$

CHAPTER 5

DISCUSSION

The major purpose of this study was to describe the development and validation of a quantitative measure, the Hubbard Camp Outcome Scale, which was developed to assess children's perceptions of Camp Braveheart. This final section will present a discussion of the results by hypotheses and will address limitations, recommendations for future research, and implications of this study.

Hypothesis One: Exploratory Factor Analysis of the H-COS

As indicated by the results, exploratory factor analysis revealed three factors on the Hubbard Camp Outcome Scale instead of the hypothesized five factors. This resulted in a H-COS total scale score and three subscale scores: Enjoyment/Socialization, Difficulty/Homesickness, and Self-Esteem/Normalization. While these three subscales combine the hypothesized five factors, the issues specific to children with CHD are still apparent in the resulting subscales.

The first factor, Enjoyment/Socialization, seems to be a common theme in the literature. Children with CHD tend to have more difficulty with socialization than healthy children (Bowen, 1985; Casey et al., 1996; Gantt, 1992; Kramer et al., 1989; Sparacino et al., 1997; Thomason, 1997). The questions that compose the first factor, Enjoyment/Socialization, consisted of related socialization themes such as playing with other children, making/socializing with friends, participating in activities, being happy at camp, and liking camp. Camp creates a social environment for children with CHD in which they are one of many campers with a similar

medical condition and this may be what signifies enjoyment of the experience for them. Thus, they associate socialization with enjoyment of camp. The three questions that were hypothesized to fall into the physical activity subscale were also included in this factor, suggesting that being able to participate in the physical activities at camp encouraged socialization and an increased enjoyment of camp. In addition, since the Enjoyment/Socialization factor had the strongest factor loadings this may indicate that camp is most importantly an enjoyable social experience for children with CHD. This conclusion is consistent with previous research findings stating that children with chronic illness have generally positive reactions to the camp experience (Punnett & Thurber, 1994).

The second factor, Difficulty/Homesickness, seems to be supported by the literature as well. Children with CHD often experience severe anxiety (Bowen, 1985), medical fears, and depressive symptoms (Gupta et al., 2001). Children with CHD report feeling different from others (Gantt, 1992; Sparacino et al., 1997), have difficulty relating and being accepted by their peers, (Bowen, 1985; Sparacino et al., 1997; Thomason, 1997) and experience feelings of inferiority (Kramer et al., 1989). The questions in the second factor, Difficulty/Homesickness, were related to these reports in the above studies by including themes such as depression, worry, loneliness, being left out, being unable to participate in physical activities, and homesickness. This subscale seemed to combine the hypothesized subscales of 1) internalizing issues such as anxiety and depression, 2) social functioning, and 3) physical activity related to group inclusion. When campers reported being able to participate in physical activities and feeling like part of a group, they experienced fewer difficulties at camp. It seems children who experienced difficulty/homesickness at camp were less likely to enjoy camp and less likely to feel a strong connection with friends in this setting.

The third factor, Self-Esteem/Normalization, also appears to be supported by similar themes in the literature. Research indicates that children with CHD tend to have poor self-esteem, poor self-concept, (Bowen, 1985; Gantt, 1992) and a poor body image (Bowen, 1985; Gantt, 1992; Thomason, 1997). Furthermore, children with CHD reported having difficulty relating and being accepted by their peers (Bowen, 1985; Sparacino et al., 1997; Thomason, 1997) and feeling normal or different from others (Gantt, 1992; Sparacino et al., 1997). The third factor of the H-COS scale, Self-Esteem-Normalization, reflected similar issues with questions surrounding feeling different from other kids at camp, fitting in with other kids, self-pride, and self-acceptance. These results imply that children associate self-acceptance and self-esteem with normality and fitting in with their peers at camp. This association follows closely with the underlying principle of camps for children with chronic illnesses whose overarching goals are to provide normalcy to these children, outside the parameters of their illness (ACA, 1998).

Hypotheses Two and Three: Construct Validity of the H-COS

The correlation coefficients of the H-COS total scale score and the three subscale scores were acceptable, indicating that the total scale was indeed measuring interrelated components that composed three separate yet related factors. Additional significant correlations between the H-COS, Child Depression Inventory, Pediatric Quality of Life Scale, and Pediatric Quality of Life Cardiac Module revealed concurrent validity of both the total scale score and subscale scores. These results indicate that the H-COS is a valid instrument for measuring the benefits of camp for children with CHD. The correlations between the H-COS total scale score, three subscale scores, and the other measures given concurrently at camp will now be discussed.

As hypothesized, children who report enjoying camp and socializing with peers experience fewer difficulties in this environment. The H-COS total scale scores and the

Enjoyment/Socialization subscale scores both had a negative correlation with depression, ineffectiveness, and anhedonia which suggests that children with higher scores on the H-COS experience less depressive symptoms at camp than children with lower scores on these scales. The negative correlation between the H-COS total scale score and the Difficulty/Homesickness subscale also seems to suggest these implications that children who enjoy camp more and view it as a positive social environment experience fewer depressive symptoms at camp. Since children with CHD report having increased psychosocial difficulties such as anxiety (Bowen, 1985), depression (Gupta et al., 2001), and trouble relating and being accepted by their peers (Bowen, 1985; Sparacino et al., 1997; Thomason, 1997), it is encouraging that most of the children reported enjoying camp and not experiencing these psychosocial difficulties while at camp.

Past research has shown that children with chronic illnesses that attend camp participate in more activities during and following camp (Smith et al., 1987). The negative correlation between the Anhedonia subscale of the Child Depression Inventory and the H-COS total scale score supports the idea that children who participate in more activities at camp get greater enjoyment from the experience. Additionally, the moderately significant correlation between H-COS Difficulty/Homesickness subscale and the Anhedonia subscale of the Child Depression Inventory further implicates that children who have difficulty at camp and are homesick are less likely to participate in camp activities. The positive correlation between the H-COS total scale score and the PedsQL physical subscale also suggests that children with CHD who enjoyed camp participated in more activities.

The results also indicate that children who enjoy the camp experience and feel like they “fit in” have a higher cardiac quality of life. The third factor of the H-COS, Self-Esteem/Normalization, had a significant negative correlation with negative self-esteem which

seems to signify that children who feel “normal” or “fit in” at camp have high self-esteem in this environment. The self-esteem or normalization they feel may be related to their increased cardiac quality of life as indicated by a positive correlation between the Self-Esteem/Normalization subscale and the PedsQL Cardiac Module. In addition, the positive correlation between the Enjoyment/Socialization subscale and the PedsQL Cardiac Module, as well as the positive correlation between H-COS total scale score and the PedsQL Cardiac Module, may indicate that campers who enjoyed camp experienced a higher quality of life in relation to their heart condition. The increase of self-esteem due to “normalization” is similar to past research that indicates that children with chronic illnesses report having increased self-esteem after participating in a camp program (Thomas & Gaslin, 2001).

Although hypotheses 2b, 3b, 3e, and 3f were not significant, all of these hypotheses were in the expected direction. The limitation of a small sample size may have prevented the discovery of the hypothesized significant correlations between the Hubbard Camp Outcome Scale and these measures (i.e RCMAS, PedsQL). Further investigation of the H-COS with a larger sample size may reveal significant differences between these instruments.

A significant positive correlation was expected between the H-COS total scale score and the CATIS, as noted in Hypothesis 2a, but a slightly negative correlation was found between these two instruments. Although Briery and Rabian (1999) found that children with diabetes, asthma, and spina bifida had a better attitude towards illness following camp, children with CHD may have different issues surrounding their attitude towards illness and thus not show significant improvements in this area. Children with CHD may also gain different benefits from the camp experience that exist outside of the constructs the CATIS is designed to measure. Furthermore, there is no known existing literature on use of the CATIS with children who have CHD and since

the CATIS was not significantly correlated with any measure used in the current study, it may not be an ineffective instrument for this population in this setting.

Whereas past camp evaluation measures addressed only general satisfaction with camp (i.e. Punnett & Thurber, 1994, Thurber & Sigman, 1998), the H-COS appears to measure the psychosocial benefits that children with CHD gain from attending camp (i.e. enjoyment, increased socialization with peers, fewer depressive symptoms, increased activities, increased self-esteem, normalization). The significance of correlations between the H-COS total scale scores, subscale scores, and the Child Depression Inventory, Pediatric Quality of Life Scale, and Pediatric Quality of Life Cardiac Module reinforces the validity of the H-COS as a quantitative instrument for this population.

Hypothesis Four: Reliability of the H-COS

As hypothesized, the internal consistency of the H-COS is adequate demonstrating that all items within the H-COS are interrelated and compose a reliable total scale score. Also, all subscale scores had adequate reliability in measuring specific constructs or factors.

When examining test-retest reliability over 8 weeks, the H-COS had moderately significant reliability for the total scale score. However, the Enjoyment/Socialization and the Difficulty/Homesickness subscale scores did not reach significance. In fact, the mean scores for the Enjoyment/Socialization subscale increased and the Difficulty/Homesickness subscale scores decreased at the two month follow-up. This could be attributed to campers remembering camp more fondly and reporting higher scores on Enjoyment/Socialization and lower scores on Difficulty/Homesickness. The scores on the Self-Esteem/Normalization factor were significantly reliable for a two-month interval, which could possibly indicate that children with CHD accurately remembered their level of self-esteem and “fitting in” within the camp environment.

Previous research on camps for children with chronic illnesses have noted the limitations of their study because of their lack of a follow-up administration (Briery & Rabian, 1999) and those that had included a follow-up used a two week time frame for readministration (Smith et al. 1987). Although the current study did administer the measure at a two-month interval to determine test-retest reliability, perhaps the interval was too long and affected the reliability. The return rate for the two-month follow up was limited with only 62% ($n = 18$) of the initial sample participating, which may have also affected the test-retest reliability of the H-COS.

Hypothesis Five: Gender Differences in Reporting on the H-COS

There were no significant differences in gender reporting on the H-COS total scale scores or subscale scores. Males and females reported similarly on all three factors, which indicates that both sexes enjoy camp equally, experience similar difficulties, and gain similar benefits in relation to self-esteem. Since camp is designed to include activities for both sexes, and includes several non-gendered activities, it is not surprising that boys and girls report similar benefits from the camp environment. Although they did not measure the psychosocial benefits of camp, Briery and Rabian (1999) found similar results to the present study on gender reporting following camp. The authors found no differences between males and females reporting at camp on the Revised Child Manifest Anxiety Scale (RCMAS) and the Child Attitude Toward Illness Scale (CATIS) (Briery & Rabian, 1999) indicating that males and females enjoy and benefit from camp equally.

Hypothesis Six: Age Differences in Reporting on the H-COS

There were no significant differences in reporting on the H-COS total scale scores or subscale scores for young children, ages 8-12, and older children, ages 13-18. Younger children and older children reported enjoying camp equally, experience similar difficulties, and gain

similar benefits in relation to self-esteem at camp. In addition to camp being designed to include activities for both younger and older children, the schedules for younger and older campers are tailored to include age-appropriate activities, which may explain why there are no differences in scores on the H-COS based upon age. These reports that younger and older children enjoy camp equally are congruent with previous research that has also reported no significant differences on the benefits of camp based upon the age of the child (Briery & Rabian, 1999).

Limitations

A major limitation of the current study is the small sample size. Although attempts were made to recruit more participants, only 51% ($N = 29$) of the eligible campers participated. This participation rate may be attributed to the sensitive and chronic nature of the children's medical condition and the lack of enthusiasm of the families to complete further paperwork on their child's medical condition. Since camp is based upon enjoyable activities, and camp may be the only chance children with CHD get to participate in these unique activities, families may be hesitant to involve their children in research, which they might view as not enjoyable.

Another limitation is the follow-up administration of the H-COS at a two-month interval. While previous research mentioned the lack of follow-up as a limitation (Briery & Rabian, 1999), those who have administered a follow-up measure used a two-week interval (Smith et al. 1987). As previously mentioned, the follow-up interval may have been too long and affected reliability because the content of the scale is camp specific. Since the follow-up was also administered by mail, the exact interval of the readministration cannot be determined. As long as the measures were returned within the two-month post camp time period, the data was included in the analysis. Thus, it cannot be determined if some children completed the measure after five weeks, six weeks, or seven weeks.

There are also issues surrounding the generalizability of the H-COS for use with other populations of children with chronic illness who attend camp. The H-COS was designed to assess the benefits that children with CHD gain from the camp experience based upon the specific psychosocial issues of this population that are outlined in the literature. Since the psychosocial effects of each individual illness may differ from population to population, the measure may need to be revised for additional populations. Furthermore, since all camps for children with chronic illnesses are designed differently, the measure may need to be revised for the particular goals or benefits of individual camps.

Recommendations for Future Research

More research is needed to further confirm the validity and reliability of the Hubbard Camp Outcome Scale. Additional research may also focus on repeating the current study at Camp Braveheart with a larger population of children with CHD. Research could also expand to test the H-COS at other camps for children with CHD to see if similar benefits are reported at camps across the country and not just in the state of Georgia.

In addition, further examination of the instrument with other populations of chronically ill children, i.e. cancer, diabetes, are needed to confirm the effectiveness of the H-COS in measuring the psychosocial benefits children with chronic illness gain from the camp experience. Although it appears from the literature that children with various forms of illness experience similar psychosocial developmental issues, the H-COS should be tested with other populations before generalizing the results to all chronically ill children who attend camp.

Further research could also focus on qualitative components such as interviewing campers and conducting qualitative analyses to enrich the existing research on children with CHD. The H-COS could be administered to campers in addition to personal or group interviews,

focus groups, or conversation analyses with campers. Qualitative components could also be expanded to include pre-camp and post-camp collections to further examine the benefits children with CHD gain from participation in camp.

Implications

The findings from the present study provide empirical information on the benefits of camp for children with CHD based upon results of the H-COS. This information can be applied to professionals interested in camp research for children with CHD, or for those interested in designing camp programs for children with chronic illnesses, including CHD, and for parents whose children with CHD attend a camp program. Based upon the results of the current study, the H-COS seems to be a valid and reliable instrument for measuring the benefits children with CHD gain from attending camp. The results also imply that the psychosocial benefits that have often been anecdotally reported in the literature can be quantified and captured through a self-report measure. The H-COS is the first known instrument that indicates valid factors that measure quantifiable psychosocial benefits of camp for children with CHD. Previous measures have only described general satisfaction with camp.

Information obtained from the H-COS could also assist professionals who design and operate camps for children with chronic illnesses, including camps for children with CHD. Camp directors can use the H-COS to evaluate the programming of their camps, and then use results to reassess their programming components to maximize the psychosocial benefits children gain from the experience. The H-COS would also be useful for evaluating the individual goals of the camps to determine if the benefits children are reporting from the camp experience are aligned with the camp's goals and missions. The H-COS may prove to a valuable source of information

because it is based on the psychosocial difficulties outlined in the literature on children with CHD.

The implications from the current study could also affect parents whose children attend these camps. If parents gain information about the benefits their child is receiving from camp it may complement their child's anecdotal reports and obvious changes parents may observe in their child following the camp experience. This information could lead to increased satisfaction with the camp experience from parents, further involvement of the family with the camp program, and positive word of mouth recruitment of other families who have children with CHD that may benefit from the experience.

Overall, this study broadens the existing quantitative research on the benefits of camp for children with CHD. The findings of this study combined with future research can effectively enhance the camp experience for children with CHD and their families.

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APPENDIX A
HUBBARD CAMP OUTCOME SCALE

Hubbard Camp Outcome Scale: Master Copy

The Hubbard Camp Outcome Scale consists of 37 questions that are intended to measure the benefits children with congenital heart defects gain from participating in a weeklong summer camping program. Respondents answer each question on a 5-point Likert type scale with self-reported benefits determined by a total scale score and scores on each of the following 5 subscales: Normalization, Self, Internalizing Behaviors, Social, and Physical. Scores on the Hubbard Camp Survey range between 1 and 5, with a score 1 indicating no gain or benefit from the camping experience and a score of 5 indicating a greater gain of benefits from the camping experience.

The survey consists of five subscales that are labeled accordingly:

Five Subscales of the Hubbard Camp Outcome Scale

- N: Normalization
(Items # 1-6)
- S:SE: Self: Self-esteem and Self-efficacy
(Items # 7-11)
- I:AD: Internalizing Behaviors: Anxiety and Depression
(Items # 12-18)
- SA: Social: Social Activity and Social Efficacy
(Items # 19-27)
- PA: Physical Activity
(Items #28-33)

An additional set of questions assessing general camp experiences (Items # 34-37) is included at the end of the survey. These questions will not be included in the total scale score or in tabulating the survey's subscales. The general camp questions are included to provide additional information or explanation for outlier scores, if necessary.

- Indicates items that are reversed coded for scoring purposes.
(Items # 2, 4, 5, 13, 14, 15, 16, 17, 18, 26, 31, and 33)

Name _____

Age _____

Answer each of the questions below by picking the *best one for you*. There are no right or wrong answers. Make sure to circle the one that describes how you felt while you were at Camp Braveheart.

1. How often did you feel like the other kids at camp were the same or similar to you?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
2. How often did you feel different from the other kids at camp?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
3. How often did you feel like you fit in with the other kids at camp?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
4. How often did you think about your heart condition at camp?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
5. How often did you feel like you had to tell the other kids at camp what it was like to have a heart condition?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
6. How often did you feel like yourself at camp?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
7. How did you feel about your ability to do activities while you were at camp?				
1 very bad	2 bad	3 OK	4 good	5 very good

8. How did you feel about yourself at camp?				
1 very bad	2 bad	3 OK	4 good	5 very good
9. How often were you proud of yourself at camp?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
10. How often did you like yourself at camp?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
11. How often did you feel like you could do the activities the other kids at camp were doing?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
12. How happy or sad were you at camp?				
1 very sad	2 sad	3 OK	4 happy	5 very happy
13. How often were you nervous at camp?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
14. How often did you worry at camp?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
15. How often did you worry <u>about your heart condition</u> at camp?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always

16. How often were you lonely at camp?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
17. How often did you worry about what the other kids at camp thought about you?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
18. How often did you feel sad or blue at camp?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
19. How often did you spend time with your friends at camp?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
20. How often did you have someone to talk to at camp?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
21. What was it like to make friends at camp?				
1 very hard	2 hard	3 OK	4 easy	5 very easy
22. What was it like to play with kids you did not know very well?				
1 very hard	2 hard	3 OK	4 easy	5 very easy
23. How often did you play with the other kids at camp?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always

24. How often did you play with someone you did not know very well at camp?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
25. How often did you feel like you were part of the group at camp?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
26. How often did you feel left out at camp?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
27. How often did you get along with the other kids at camp?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
28. How often were you active at camp?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
29. How often did you feel like you had energy at camp?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
30. How often did you do sports activities at camp?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
31. How often did you feel like you couldn't keep up when you were playing with the other kids at camp?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always

32. How often did you exercise at camp?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
33. How often did you get tired and have to sit down at camp?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
34. How often did you feel homesick at camp?				
1 almost never	2 not often	3 sometimes	4 often	5 almost always
35. How much did you like or dislike camp?				
1 I hated it	2 I didn't like it	3 It was OK	4 I liked it	5 I really liked it
36. What would you tell other kids about Camp Braveheart?				
1 It was very bad	2 It was bad	3 It was OK	4 It was good	5 It was very good
37. Would you want to come back to Camp Braveheart next year?				
Yes		No		

APPENDIX B
MEASURES USED IN THE CURRENT STUDY

Administration Schedule for Simons, Blount, and Campbell Camp Study

Campers	SRASP RCMAS CATIS CDI PEDSQL PEDSQL-Cardiac LCI-Y	RCMAS* CATIS* CDI* PEDSQL* (w/o school domain) PEDSQL-Cardiac* H-COS*	RCMAS CATIS CDI PEDSQL LCI-Y PEDSQL-Cardiac H-COS*
Parents of Campers	DEMO/INFO* MSAS PEDSQL LCI-P SDQ		LCI-P PEDSQL SDQ

Note: **Parent Forms:** DEMO/INFO = Demographic and Medical Survey; MSAS = Maternal Separation Anxiety Survey, adapted; PEDSQL = Pediatric Quality of Life Inventory, 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 Towards Illness Scale; CDI = Child Depression Inventory; PEDSQL = Pediatric Quality of Life Inventory, LCI-Y = Living with Chronic Illness, Youth form; H-COS = Hubbard Camp Outcome Scale.

* denotes measures used for this study

Contact Information for the Measures used in the Current Study

The measures used in the current study can be obtained from the following sources:

The Revised Child Manifest Anxiety Scale (RCMAS; Reynolds & Richmond, 1985) can be obtained through Western Psychological Services, 12031 Wilshire Blvd., Los Angeles, CA 90025.

The Child Attitude Toward Illness Scale (CATIS; Austin & Huberty, 1993) may be obtained by contacting Joan K. Austin at Indiana University School of Nursing, 1111 Middle Drive, NU403, Indianapolis, Indiana 46202-5107.

The Children's Depression Inventory (CDI; Kovacs, 1992) can be acquired through Multi-Health Systems, Inc. at 908 Niagara Falls Blvd, North Tonawanda, New York 14120-2060.

The Pediatric Quality of Life Inventory and the Pediatric Quality of Life Inventory - Cardiac Module (PedsQL; Varni, 1998) child and teen versions may be obtained through www.pedsql.org.

APPENDIX C
CONSENT/ASSENT FORMS

Heart Camp Experience
Version 3: 2/20/2003

Campbell/Simons

Emory University School of Medicine, Children's Healthcare of Atlanta, &
University of Georgia

Consent to be a Research Subject

Title: A cardiac camp experience: examining attitudes, emotional, and social functioning in children with cardiac abnormalities.

Principal Investigator: Robert Campbell, MD, Department of Pediatric Cardiology, Emory University

Co-Investigators: Laura E. Simons, Department of Psychology, University of Georgia; Ronald L. Blount, PhD, Department of Psychology, University of Georgia

Introduction/Purpose:

You and your child are being asked to volunteer for a research project. The purpose of the study is to better assess children with heart conditions. This study will examine your child's attitude towards his/her illness, social functioning, and emotions.

The participants will consist of children who choose to attend or not to attend a cardiac summer camp. More specifically, this project will assess how a one-week summer camping program can affect your child's attitude toward illness.

Many camps exist across the country dedicated to children with chronic illness. Currently, research has been conducted examining camps for many other chronic illnesses, but children with heart conditions have not received proper attention. The adjustment needs of these children are extremely important, as are issues surrounding their quality of life. Participation in this study will inform medical staff and newly diagnosed families of important issues related to caring for a child with a congenital heart defect.

Each year, over 100 children with heart conditions are invited to attend Camp Braveheart. We wish to ask questions of both the children that attend this camp and also those that chose not to attend as well as their parents/legal guardian(s).

Procedures:

All forms will be administered by one of the listed investigators, a research assistant under the supervision of one of the investigators, or sent by mail.

FOR THOSE CHILDREN ATTENDING CAMP AND THEIR PARENTS

1. Fill out parent questionnaires and assist your child with the self-report forms asking how your child feels about his/her heart problem, going to school, and general medical information.
2. The completed forms will be turned in at routine appointments, through the mail, or on the first day of camp registration.
3. The night before the last day of camp, your child will complete questionnaires assessing emotions, attitudes, relationship styles, and their reactions to camp.
4. One month following camp, you and your child will receive the same questionnaires completed before camp to complete again based on your child's feelings after attending camp. A self-addressed envelope will be included for you to return the forms to us.

FOR THOSE CHILDREN NOT ATTENDING CAMP AND THEIR PARENTS

1. Fill out parent questionnaires and assist your child with the self-report forms asking how your child feels about his/her heart problem, going to school, and general medical information.
2. Return the completed forms by mail in the self-addressed envelope sent from our institution or during a routine medical visit.
3. You and your child will receive these questionnaires again approximately one month following camp to be filled out again to see if your child's feelings have changed. A self-addressed envelope will be included for you to return the forms to us.

It will take approximately 30-55 minutes for you and 35-60 minutes for your child to fill out the initial questionnaires. For those attending camp, on the evening before the last day of camp, your child will be asked to fill out another set of questionnaires. This will take approximately 40 minutes. One month later, questionnaires will be sent to all participants. It will take about 30-55 minutes for you and 35-55 minutes for your child to fill out these forms. If necessary, the investigators will call to remind you to return forms and clarify any confusing/missed responses.

As a component of this research study, your child's medical records will be reviewed to obtain information concerning your child's diagnosis, date of diagnosis, previous treatments, current medications, and the current severity of your child's condition.

Risks:

No discomforts or stresses are expected. However, it is possible that the questions asked could be emotionally upsetting to your child. If this occurs, and your child would like to speak to a medical or psychological professional, please contact Ronald Blount, Ph.D., Clinical Psychologist at 706-542-3012 or Robert Campbell, MD at 404-256-2593.

Benefits:

There may be no direct benefit to your child for participating in this study, but we doctors and psychologists may learn new things that will help others living with heart problems. Additionally, your child's participation may lead to information that could shape the programming of Camp Braveheart and other similar camps across the country with the intent to better address the challenges and difficulties faced by children who live with a heart condition.

Confidentiality:

People other than those doing the study may look at both medical charts and study records. Agencies that make rules and policy about how research is done have the right to review these records. Those with the right to look at your study records include Emory Institutional Review Board, Children's Healthcare of Atlanta Ethics Board, the Food and Drug Administration, and other regulating bodies. Records can also be opened by court order. We will keep your records private to the extent allowed by law. We will do this even if outside review occurs. We will use a study number and initials rather than your name on study records where we can. Your name and other facts that might point to you will not appear when we present this study or publish its results.

Compensation:

The cost for you is the time and effort needed to complete these forms. Movie ticket gift certificates will be provided for completing the forms that are mailed to your house prior to the scheduled camp. Also, for those of you who complete the forms that are mailed to your home following camp, you will receive additional movie ticket gift certificates.

Heart Camp Experience
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We will arrange for emergency care if your child is injured by this research. However, Emory University and Children's Healthcare of Atlanta have not set aside funds to pay for this care if a mishap occurs. If you believe you have been injured by this research, you should contact Robert Campbell, MD at 404-256-2593.

Contact Persons:

Robert Campbell, MD (404-315-2098) or Laura Simons (706-542-1173) will answer any inquiries that you may have concerning the procedures. If you have any questions about your rights or your child's rights as a participant in this research study, you may contact Dr. Karen Hegtvedt, Chair, Social, Humanist, and Behavioral Institutional Review Board, which oversees the protection of human research participants. She can be reached at 404-727-7517 or khegtv@emory.edu.

New Findings:

Any information that is developed during the course of this study which may influence your willingness to continue participation in this study will be made available to you and your child.

Voluntary Participation and Withdrawal:

Your child's participation is completely voluntary and you have the right to refuse to allow your child to be in this study. You and your child are free to skip any questions. You can withdraw your child at any time after giving your consent. This decision will not affect in any way your child's current or future medical care or any other benefits to which your child is otherwise entitled. The study doctor/investigator may stop your child from taking part in this study at any time if they decide it is in your child's best interest, or if your child does not follow study instructions. You will be provided a copy of this informed consent.

If you are willing to allow your child to participate in this research, please sign below.

Printed Name of Subject

Signature of Parent/Legal Guardian

Date of Signature

Assent for ages 16 and 17:

Signature of Participant

Date of Signature

Investigator Obtaining Consent

Date of Signature

IRB#: 035-2003

Consent Form Approval Period
FROM: 3/2/03 TO: 3/2/04

AUTHORIZATION: mc

Heart Camp Experience
Version 3: 2/20/2003

Campbell/Simons

Emory University, Children's Healthcare of Atlanta, &
University of Georgia

ASSENT FORM
For ages 8-15

A cardiac camp experience: examining attitudes, emotional, and social functioning in children
with cardiac abnormalities

Principal Investigator: Robert Campbell, MD/Laura Simons

We are asking you to be a part of a special study about summer camps. If you agree to be in it, you will answer questions about your heart and your feelings. If you go to Camp Braveheart, we'll ask you about camp too. Your parents will answer questions about your heart, your feelings, and camp.

You will answer these questions now, at camp (if you go), and after camp. It will take almost an hour to answer them each time. The stuff that you tell us may help other kids with heart problems in the future. For taking time to answer these questions, you and your family will get movie tickets for these first questions and for ones that come in the mail later.

Talk to your parents about doing this before you choose. We will also ask your parents what they think. But, even if your parents say "yes", you can still say "no."

If you don't want to do this, you don't have to. You don't have to answer all the questions if you don't want to. No one will be upset if you don't want to do it or if you change your mind later and want to stop. Your doctors will still treat you.

You can ask questions anytime, and your parents can call anytime at 404.315.2098. Writing your name on this paper means you want to be in the study.

Remember, your doctors will still treat you either way. Your parents will get a copy of this sheet to keep for you. Thanks!

No, I do not want to be in the study

Yes, I want to be in the study.

IRB#: 035-2003

Consent Form Approval Period
FROM: 03/03/03 TO: 03/02/04

AUTHORIZATION: [Signature]

Printed Name of Subject

Signature of Subject

Date Age Time

This statement has been read to the above child, and he or she appears to understand.

Signature of Witness

Date Time

Investigator Obtaining Consent

Date Time