ASSOCIATIONS BETWEEN SOCIAL SUPPORT AND QUALITY OF LIFE FOR 
CHILDREN AND ADOLESCENTS WITH INTERNAL CARDIAC DEVICES 

by 

PATRICIA SINPEI CHENG 

(Under the Direction of Ronald L. Blount) 

ABSTRACT 

There is considerable evidence that cardiac devices such as pacemakers and internal cardiac defibrillators (ICDs) are important treatments which have led to increased life expectancy and decreased mortality rates for individuals with chronic cardiac arrhythmias (Taylor et al., 2001). Despite the impact of these devices on their physical condition, children and adolescents with internal cardiac devices also face a variety of psychosocial challenges. However, very little research is available regarding the impact of these treatments on the quality of life (QOL) of children and adolescents with arrhythmias. Research has supported the role of social support as an important protective factor against the effects of chronic stressors. However, this relationship has not been adequately examined for a population of pediatric patients with internal cardiac devices. The current study examined associations between three types (Esteem-enhancing, Informational, Tangible) and five sources (Family, Friends, Classmates, Teachers, Doctors/Nurses) of social support and the psychosocial functioning of children and adolescents with cardiac pacemakers and ICDs. Thirty-one children and adolescent with a cardiac pacemaker or ICD and their parents completed questionnaires assessing the child’s health-related quality of life, self-competency, psychological adjustment, and social functioning. Results of bi-variate correlational analyses indicated that, as hypothesized, each of the three types of support
were positively associated with positive outcomes, while family members and friends were the
two sources of support most consistently associated with positive outcomes. Support from
classmates and teachers was positively associated with fewer social problems and better self-
competency. There were no significant associations when support from doctors or nurses was
considered. Between group differences using ANOVA procedures indicated that the interaction
of low Informational and high Esteem support was consistently associated with positive QOL
outcomes. These findings have important implications for the development of future social
support interventions for children adolescents with internal cardiac devices. Several important
implications for future research in this area are also discussed.

INDEX WORDS: Social support, Quality of life, Children, Adolescents, Cardiac,
Pacemaker, Internal cardiac defibrillator, Self-competency, Social
problems, Adjustment, Chronic illness
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by

PATRICIA SINPEI CHENG

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M.S., University of Georgia, 2002

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by

PATRICIA SINPEI CHENG

Major Professor: Ronald Blount

Committee: Kimberly Shipman
Lily McNair
Stacey Neuharth-Pritchett

Electronic Version Approved:

Maureen Grasso
Dean of the Graduate School
The University of Georgia
December 2004
DEDICATION

To my grandmother, Gladys Cheng, whose love, energy, and generosity was an inspiration that will always live on.
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CHAPTER 1
INTRODUCTION

*Pediatric Cardiac Arrhythmias and Pacemakers*

For most of us, whether our heart is going to keep pace with us when we walk up a flight of stairs or go jogging is not something that we ever pause to consider; the regular and rhythmic beating of our heart is something that we take for granted. However, for children who have heart rhythm disturbances, also known as cardiac arrhythmias, the seemingly basic assumption that their heart will keep pace can be an uncertainty and a source of concern on a daily basis. Although cardiac arrhythmias are often treatable, having an arrhythmia can significantly impact a child’s life and there can be a risk for sudden death.

Recent medical advances in pediatric cardiology have significantly increased our knowledge about the etiology and characteristics of arrhythmias. Disorders of cardiac rhythm may present as a primary disorder in otherwise healthy children or may occur as a secondary consequence of other cardiac or systemic diseases (Fish & Benson, 2001). Children can experience a variety of different types of cardiac arrhythmias which can also have a variety of etiological mechanisms (LeRoy & Dick, 2001). Arrhythmias may be present in the absence of other overt heart disease, associated with congenital or acquired heart disease, or associated with other diseases, such as muscular dystrophy or thyroid abnormalities.

Arrhythmias can be caused by a variety of factors that result in abnormalities in cardiac impulse formation or propagation. The symptoms created by arrhythmias also vary greatly depending on the underlying etiology. Symptoms may be generalized, such as lethargy, nausea,
chest pain, decreased appetite, and lightheadedness. Other symptoms may be more specific, such as palpitations, syncope (fainting), and cardiac arrest or failure (Fish & Benson, 2001). While children with arrhythmias may present with a variety of symptoms, an untreated arrhythmia can cause discomfort and limit activity, as well as have serious implications such as long-term deficits in cardiac performance or the risk of sudden death.

Previously, disturbances in heart rhythm and conduction were considered untreatable, and severe arrhythmias in children were often fatal (O’Connor, 1995). Recently, however, major advances have been made in treating children who experience arrhythmias. Over the past several decades, a growing number of children have received cardiac pacemakers to treat their arrhythmia. Although pacemaker technology was first introduced almost 80 years ago, the original models were bulky and very difficult to use (O’Connor, 1995). However, as our understanding of the mechanisms and etiologies of arrhythmias has improved and pacemaker technology has advanced, pacemakers have become an important treatment for adults and children with cardiac arrhythmias. Advances in medicine and the advent of the permanent cardiac pacemaker have significantly increased the chances for individuals with arrhythmias to lead normal lives. Approximately two million people have implanted cardiac pacemakers, with 40,000 of those individuals being children and adolescents (American Heart Association, 2003).

According to data from the Midwest Pediatric Pacemaker Registry (2002), surgical heart block is the most common reason for pacemaker implantation. Surgical heart block refers to blocks or delays in the conduction of electrical impulses in the heart circuitry which result from a surgical procedure (Fish & Benson, 2001). Surgical procedures for certain congenital heart defects, such as septal defects, tetralogy of Fallot, and transposition of the great arteries, are more commonly associated with increased rates of surgically induced heart block. Due to recent
medical advances, more children with simple and complex congenital heart disease (CHD) are surviving cardiac surgical procedures. Therefore, there is a related increase in the population of patients with cardiac arrhythmias who receive pacemakers as a secondary consequence of surgery. Approximately 60% of all initial pacemaker implants in children are for arrhythmias that develop as a consequence of cardiac surgical procedures (Taylor, Zeigler, & Clark, 2001).

The majority of the remaining 40% of initial implants are a consequence of congenital heart block, or blocks in heart impulse conduction that the individual is born with and are naturally occurring rather than acquired. The age at which a pacemaker is needed is variable from 1 day to young adulthood; however, the average age of implantation is around age 7. The presence of structural cardiac disease often necessitates earlier pacemaker implantation. However, the need for a pacemaker must be determined individually for each child based on the presence of symptoms.

Pacemakers function by delivering an electrical stimulus to the heart to maintain, or “pace”, a stable heart rhythm. Pacemakers typically consist of a pulse generator, which is usually about the size of a silver dollar, and wire leads which extend to the heart. Depending on the type of pacemaker and its particular function, the generator is usually implanted under one of the collarbones or under the skin of the right or left abdomen. Pacemaker implantation typically occurs while the child is under general anesthesia and in the cardiac catheterization laboratory or the operating room. Once a pacemaker is placed, children typically have regular follow-up visits in a pacemaker clinic. Pacemakers typically last about ten years. When the pacemaker battery becomes low on energy, children must undergo a procedure to have the pacemaker replaced. Often, the original incision is reopened, the old pacemaker is removed, and a new one is put in its place (Taylor et al., 2001).
There is considerable evidence that pacemaker technology has been an extremely significant advancement that has led to increased life expectancy and decreased mortality rates for children with arrhythmias (Taylor et al., 2001). However, very little research is available about the impact of pacemakers on the quality of life for these children. Although many children with pacemakers can participate in the usual daily activities of their peers, others continue to experience limitations on physical activity. Children with pacemakers who have anatomically normal hearts are usually allowed to participate in athletics, but are typically not allowed to participate in contact sports, such as football or hockey. Other children often experience limitations in daily activities due to their underlying heart condition. In particular, individuals with recurrent arrhythmias or complex heart disease may experience a greater degree of limitation and often experience unanticipated interruptions in activities of daily living (LeRoy & Dick, 2001).

In addition to possible physical limitations, children with pacemakers face a variety of unique psychosocial challenges. Children and adolescents must cope with lifelong dependency for an implanted mechanical device, and must also face the possibility of future periodic procedures for generator and/or lead replacements. They must also cope with issues surrounding body image due to having an implanted device, as well as from scars resulting from surgical procedures (LeRoy & Dick, 2001). The impact of having an implanted mechanical device, the effects of prior and future medical procedures, and lingering difficulties due to the underlying heart condition are important factors which may influence the patient’s psychosocial development.
Cardiac Disorders and Psychosocial Adjustment

Findings regarding the psychosocial adjustment of children with chronic illness are somewhat mixed. Many studies have found that children with a variety of chronic illnesses appear to have poorer psychological and behavioral functioning than their healthy peers (e.g., Lavigne & Faier-Routman, 1993; Wallander, VARNI, Babni, Banis & Thompson, 1988). However, other studies have found that children with chronic illness do not differ significantly from healthy children on measures of psychosocial functioning (e.g., Lemanek, Moore, Gresham, Williamson, & Kelly, 1986; Spirito, DeLawyer, & Stark, 1991). There appears to be, however, a general consensus in the literature that these children are more at risk for psychosocial difficulties (Wallander & Varni, 1992).

Research has also been conducted which examines psychosocial adjustment in relation to particular illness factors and disorders. Although few studies have specifically examined children with cardiac arrhythmias and pacemakers, a relatively large amount of research has focused on the psychosocial adjustment of children with heart disorders. In general, the findings indicate that children with heart disease can be considered to be at particular risk for social and emotional difficulties when compared to pediatric patients with many other chronic conditions. Results from a meta-analysis of psychosocial functioning for a variety of pediatric chronic illnesses indicated that a diagnosis of heart disease was associated with a “large” level of risk for psychosocial problems, while illnesses such as asthma and cancer were found to be associated with “moderate” risk levels (Lavigne & Faier-Routman, 1993). Generally, results have indicated that illness factors such as the type of cardiac defect and severity of cardiac illness do not appear to be related to adjustment (e.g., Branhagen, Feldt, & Williams, 1991; DeMaso, Beardslee,
Silbert, & Fyler, 1990). Additionally, gender and age differences in adjustment have not been systematically found (Utens et al., 1993).

Casey, Sykes, Craig, Power, & Mulholland (1996) examined adjustment in 26 children with complex CHD that was treated surgically. These children were compared to a control group of 26 children diagnosed with a benign heart murmur. Parents and teachers completed measures rating the children’s behavioral, academic, and social adjustment. Results indicated that the children with complex CHD were not rated by parents or teachers as being more inattentive, and although their academic functioning was below that of the control group, the difference was not statistically significant. While findings regarding behavioral and academic adjustment were not significant, findings regarding the social and emotional functioning of these children were more striking. Parents and teachers rated the children with complex CHD as being more withdrawn, having more social difficulties, and engaging in fewer activities than the healthy control group.

DeMaso et al. (1990) compared the psychological and cognitive functioning of young children with CHD to that of a control group of children originally diagnosed with CHD, but who required no medical intervention and experienced spontaneous recovery. The children with CHD were reported to have significantly poorer global psychological functioning. They also had significantly lower scores on standardized measures of intelligence than the children who spontaneously recovered from their heart disease. Several other studies have reported findings suggesting that children with CHD are at risk for problems in cognitive development and below average IQ scores (e.g., Aram, Ekelman, Ben-Schachar, & Levinsohn, 1985; Bloom, Wright, Campbell, & Krawiecki, 1997). The negative impact on cognitive development appears to be primarily caused by experiencing cardiac arrest and heart defects that lead to cyanosis, or inadequate oxygenation to the brain (Delamater, 2003).
In studies examining the long-term outcome of children with CHD, findings have generally reflected lasting deficiencies in psychosocial functioning. A long-term follow-up study of adjustment was conducted with individuals who were diagnosed during childhood as having CHD (Brandhagen, Feldt, & Williams, 1991). One hundred and sixty-eight individuals completed measures of psychological functioning and health status 25 years after they were originally treated for their heart condition. Based on standardized measures of psychological functioning, the respondents reported significant levels of psychological distress on subscales measuring symptoms of obsessive-compulsive behaviors, interpersonal sensitivity, depression, paranoid ideation, anxiety, hostility, phobic anxiety and psychosis, as well as on a general severity index and symptom total. Qualitative data also indicated that 27% of these individuals reported that they felt their parents overprotected them when they were young.

Another study examined the long-term behavioral and emotional functioning of children and adolescents with CHD (Utens et al., 1993). All participants had undergone surgical correction for their CHD as children and were contacted nine years after their surgery. Self-report and parent-report measures indicated that a significant proportion of the participants experienced clinically significant levels of difficulty in areas of emotional and behavioral functioning. Participants also reported experiencing significant levels of social problems.

Very few studies have focused specifically on children with pacemakers. Only three published studies were located that examine the impact of having a pacemaker on psychosocial functioning for a pediatric population. Galdston and Gamble (1969) conducted a longitudinal study examining the impact of pacemaker implantation on 16 children and 2 adults. Participants were interviewed while hospitalized for their initial pacemaker implantation and then were followed for seven years and interviewed annually during subsequent follow-up clinic visits.
This study was initiated during the early 1960s when pacemaker and battery technology was in its infancy; the pacemakers were large and produced visible bulges when placed under the skin, the batteries depleted quickly requiring frequent surgical procedures, and post-operative complications were more problematic. Despite the many obstacles pacemaker recipients faced, 17 of the 18 participants were found to be functioning normally. Only one participant was found to have developed what the authors term “cardiac neuroses,” described as symptoms of hyperactivity, antisocial behavior, and eating and sleeping disturbances.

More recently, Alpern, Uzark, & Dick (1989) examined levels of reported psychosocial functioning, locus of control, and knowledge about heart and pacemaker systems in children with pacemakers. The study compared 30 children and adolescents aged 7 to 19 with cardiac pacemakers with two sex- and age-matched comparison groups, including one group of children and adolescents with heart disease but without pacemakers and one group of physically healthy children and adolescents. Results indicated that there were no significant differences on standardized self-report measures of trait anxiety, self-competence, or self-esteem among the three groups. However, the pacemaker group reported a significantly greater external locus-of-control orientation when in comparison to the physically healthy group. All three groups reported that there would be potential negative peer reactions to an individual with a pacemaker.

Additionally, although the pacemaker group did not identify themselves as being different from peers, the heart disease but no pacemaker group and the physically healthy group rated individuals with pacemakers as differing significantly from peers in social and emotional functioning. The authors also presented informative qualitative data based on structured interviews conducted as part of the study that provide further insight into the nature of social interactions for these individuals. For instance, participants in the heart disease non-pacemaker
and physically healthy groups reported that a peer with a pacemaker might be teased due to his or her limitations in sports and play activities. They also reported that a peer with a pacemaker would be considered “weird” or might be avoided by others who were fearful of “catching” their disease or having the patient die in front of them.

Finally, Zeigler and Corbett (1995) conducted a qualitative examination of 20 adolescents with pacemakers. Their study utilized an open-ended interview format which asked the adolescents to describe the impact and meaning that having a pacemaker had on their lives. Based on the interview responses, the study authors used analytic induction to identify several key themes regarding the impact of living with a pacemaker for these adolescents. Several of the themes and responses were consistent with other descriptions in the literature of the psychosocial development of children with chronic illness. Specifically, adolescents in this study identified concerns with peer integration and a strong desire to be “normal” and similar to their peers. Adolescents reported struggling with having peers and teachers treat them differently or as if they were “fragile.” For instance, the authors report one adolescent as stating:

My mother made sure all my teachers knew it. You know, my teachers would tell my friends not to be rough or anything—you know, watch out because I was sick or whatever. But I tried to get my friends not to do that because I wanted to be treated equally and not like I was something with the plague. (p.193)

Participants also reported concerns about body image due to scars from procedures and surgeries. Almost all of the participants reported feeling fear related to hospitalization, having procedures, and experiencing pain. They also reported being fearful of not knowing exactly what will happen with their illness and described fearing the possibility of upcoming procedures for pacemaker replacement. Adolescents described having to go through a period of adjustment
to learn to cope with having a pacemaker. Many indicated initially wondering “Why me?” and coping with related aspects such as feeling a loss of control, body image changes, and potential peer rejection. One participant in the study reported:

Well, I mean I’m glad I have it because without it I wouldn’t be here. But its not...sometimes it’s scary because if you’re small, you don’t know anything about it. You don’t know exactly what you can do, what you can’t do. Sometimes you have limitations on what you can do…Once you get older and realize what it’s for and exactly what it does--it gets better. (p. 197)

Adolescents also reported that having a pacemaker had a significant impact on their relationship with their parents. In particular, participants identified parental overprotectiveness as another major theme which greatly impacted their lives. Adolescents reported that their parents often restricted their activities, even if their physicians did not place restrictions on them. They reported feeling as if their parents worried more about them than their healthy siblings. Finally, participants indicated that having an ongoing relationship with consistent caregivers was an important part of their care. They reported valuing a trusting relationship with their healthcare team and that having an honest, open relationship with their physician was important.

Zeigler and Corbett’s (1995) study highlights several important challenges adolescents with pacemakers experience. This data indicates that having a pacemaker has a significant impact on the psychosocial functioning for these individuals. Additionally, their findings regarding adolescents’ concerns about their peer relationships, as well as the importance of their relationship with their parents and their healthcare workers emphasizes the impact and value of their social environment.
Health-Related Quality of Life

Health-related quality of life has been an area of growing research interest for some time. However, the assessment of quality of life in children and adolescents with chronic illness has only recently received greater attention. This shift in attention appears to be at least partly due to advances in treatment and related decreases in mortality rates (Spieth & Harris, 1996). As survival rates increase, various pediatric illnesses that previously were considered to be terminal are treated as chronic conditions with greater frequency.

The World Health Organization (WHO) describes quality of life as a concept that represents “the state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO, 1947). Health-related quality of life generally refers to both the subjective and objective impact of illness, injury, and associated medical treatment and health care policies (Spieth & Harris, 1996). Although the WHO definition has provided a general framework from which to conceptualize quality of life, there continues to be a lack of consensus on a specific theoretical definition of this construct. Therefore, while there is growing interest and research in this area, the lack of agreement on underlying theoretical and operational definitions creates a barrier to progress.

Although debate exists around the specific areas of functioning that should be encompassed in the definition of quality of life, there appears to be a consensus that quality of life is a multidimensional construct. The WHO definition has been commonly expanded to include four general dimensions of health-related quality of life: disease state and physical symptoms, functional status, psychological functioning, and social functioning (Aaronson, 1998).
Much of the medical literature examining health-related quality of life has focused on disease state. Disease state is generally defined by the physical symptomatology or physical dysfunction associated with illness. Although the relationship between severity of physical symptoms and overall health is clear, assessing disease state alone is not an indicator of quality of life (Spieth & Harris, 1996). Research has indicated that physical symptomatology does not necessarily negatively impact childhood adjustment (Perrin, Stein, & Drotar, 1991). Additionally, a clear correlation has not always been established between physiological indicators of health and other domains of quality of life (Bradlyn, Harris, Warner, Ritchey, & Zaboy, 1993).

The dimension of functional status looks beyond physical symptomatology and disease state to consider the impact of the disease on daily functioning. Functional status is characterized by the individual’s ability to perform age-appropriate, daily activities such as self-care, leisure activities, and job/school activities (Aaronson, 1988). Although functional status has been used interchangeably with quality of life, functional status typically represents an objective measure of impairment, and does not account for the individual’s subjective evaluation of his or her level of functioning.

Psychological functioning typically includes assessing symptoms of psychopathology and psychological adjustment. Although a relationship between health and psychological well-being has been well-established, the nature of this relationship is not always clear. The difficulty in measuring psychological states independent of illness states has been noted, as affective and somatic symptoms often co-occur and may influence one another (Perrin et al., 1991). Social functioning can be defined as the child’s ability to maintain social relations and may assess relationships with peers, family members, teachers, and health care professionals. Psychological
and social functioning are important indicators of health and well-being. Although previous studies have considered the relationship between illness and psychosocial functioning, some have focused exclusively on psychological functioning as an indicator of adjustment and quality of life (e.g., Alpern, Uzark, & Dick, 1989; Brandhagen, Feldt, & Williams, 1991). However, assessing psychosocial functioning does not fully describe the potential impact of illness on global functioning.

The combination of disease state, functional status, and psychological and social functioning is necessary in order to adequately capture the concept of health-related quality of life. This multidimensional definition is consistent with biopsychosocial models of functioning which illustrate interdependent relationships among biological, psychological, and individual, family, and community systems (Levi & Drotar, 1998). The construct of health-related quality of life can thus be best considered as a method of translating the individual’s experience of illness into quantifiable outcomes consistent with a biopsychosocial model of functioning.

As the concept of quality of life has been difficult to define, the operationalization and assessment of this complex and multidimensional factor has been equally difficult. Although substantial advances have been made, debate continues to surround the measurement of quality of life. With the growing interest in this area, various operational definitions and measures have proliferated. However, there continues to be a lack of consensus and often measures are created in an absence of a structured theoretical basis (Weinman, 1994).

Recent research proposes that the lack of empirical findings that children with chronic illness are not at greater risk for experiencing psychosocial problems than healthy children may be due to failure to consider these children’s overall health-related quality of life rather than their psychological adjustment and pathology. One key problem with considering only the absence of
psychological and behavioral pathology is that it does not take into account levels of functioning that were previously above average and therefore can lead to underestimates of changes in quality of life (Mulhern, Horowitz, Ochs, Friedman, Armstrong, & Copeland, 1989). Additionally, attempting to define normal quality of life as the absence of pathology does not account for individuals’ perceptions of changes in their level of functioning regardless of whether it falls within a deviant range. A suggested improvement to previous measurement methods involves assessing the child and adolescents’ perception of their quality of life, rather than comparison to healthy peers or standardized norms based on healthy children (Mulhern, 1989).

Perrin et al. (1991) emphasize this point, indicating that using measures of psychological adaptation alone are not adequate measures of adjustment in children with chronic illness. In particular, they point out that children with chronic illness are more likely to have biased scores as indicated by greater levels of behavioral or psychological problems than healthy children due to items which assess physical symptoms on measures such as the Child Behavior Checklist (CBCL; Achenbach & Edelbrock, 1983). Perrin et al. (1991) also point out the importance of examining variations in functioning within the normal range. Because measures such as the CBCL were created to identify psychopathology, they may not be sufficiently sensitive to variations in functioning for children with chronic illness, who although they may not demonstrated significant psychopathology, may have had changes in quality of life or significant impact on their lives due to their illness.

Although survival rates for many pediatric populations have increased and the health status of children with a variety of illnesses has generally improved, children with chronic illnesses continue to experience significant stressors. There is considerable evidence that factors
such as frequent hospitalizations and invasive medical procedures have a negative impact on
development and psychosocial adjustment (Spieth & Harris, 1996). Therefore, the assessment of
health-related quality of life has been recognized as an increasingly important outcome measure.
Health-related quality of life contributes several unique and important aspects of information.
Levi and Drotar (1998) identify three primary areas in which health-related quality of life
assessment can have important implications for research and practical care. Assessment of
quality of life can provide useful descriptive information about the health status of children with
chronic illness. This descriptive information can then allow for comparison of the efficacy of
various treatment protocols, assessment of a child’s progress over time, and comparison of
children at different disease stages. Information from quality of life assessment can also help
identify children who are at-risk for developing psychological difficulties and identify
dysfunction following illness or treatment.

Finally, quality of life information is essential in informing and improving the clinical
decision-making process. Clinical decisions have traditionally been based on diagnostic tests
measuring physical symptomatology and outcome measures such as mortality, morbidity, re-
admission or relapse rates (Bowling, 1995). However, research with adults has indicated that
patients’ subjective reports and perceptions of their health and the effectiveness of treatment
procedures do not necessarily correlate with these traditional outcome measures (Evans et al.,
1985). Therefore, assessing the impact on quality of life, which provides information about the
individual’s subjective experience of health, illness, and treatment outcome, appears to be an
essential factor for health-care professionals to consider. Assessment of health-related quality of
life expands the scope of evaluating the quality of medical care to assessing the impact of the
condition and treatment on the child’s daily functioning and lifestyle.
**Social Support and Chronic Illness**

Children with chronic illnesses can encounter a variety of ongoing stressors such as chronic pain, visible physical side effects, and painful procedures, which can have a negative impact on psychosocial adjustment and quality of life. Wallender and Varni (1992) have proposed a theoretical model of stress and coping that conceptualizes stress as the primary factor related to increased risk for poor psychosocial adjustment. For children with chronic physical illness, the illness is seen as an ongoing strain on the ill child as well as his or her parents. The model identifies sources of stress such as illness characteristics, functional limitations, and psychosocial stressors. Chronic strain involves repeated interference with the performance of daily role-related activities and requires that the individual continually readjust to the stressor (Pearlin, Lieberman, Menaghan, & Mullan, 1981).

However, not all children react to chronic stressors in the same manner and with the same outcome. Within Wallander and Varni’s (1992) disability-stress-coping model, social support has been conceptualized as moderating the process of coping with the chronic stressors associated with pediatric chronic physical disorders. Social support has been postulated to be a protective factor which may account for some of the variability noted in children and adolescents’ adaptation and quality of life when living with a chronic illness; Social support appears to act as a buffer against the negative effects of stressors. However, there is also evidence for the direct contribution of social support to well-being by enhancing self-esteem, positive mood, and a favorable view of life, and diminishing feelings of distress (Procidano & Smith, 1997).

The construct of social support has generally been conceptualized as a multidimensional factor. Three primary dimensions of social support that are frequently identified include social
embeddedness, enacted support, and perceived social support (Barrera, 1986). Social embeddedness typically refers to the size of the individual’s social support network, while enacted social support indicates the frequency of actual helping behavior from others. Perceived social support is defined as the individual’s satisfaction with their perception of the availability and adequacy of their social support. Research has generally supported the individual’s perception and cognitive appraisal of the adequacy and availability of support as the most salient and influential factor in psychological adjustment (Barrera, 1986). Therefore, it seems that it is not just the actual number of helping behaviors provided by others or the size of the social network, but rather the individual’s appraisal that they are cared for and that significant others are available if they need them that acts as a protective factor against stressors (Varni, Katz, Colegrove, & Dolgin, 1994).

**Associations Between Social Support and Quality of Life**

There has been a significant amount of research conducted which highlights the importance of social support for adults with chronic disease. Findings have generally supported the positive role of social support for adults coping with illness stressors. For instance, Baker, Zabora, Jodrey, Polland, & Marcellus (1995) examined the relationship between quality of life and social support in 437 adults undergoing evaluation for bone marrow transplantation. Results indicated that the availability and adequacy of social support was positively related to quality of life for these individuals.

Unfortunately, there is a paucity of research focused on the role of social support in the quality of life and adjustment of children and adolescents who are chronically ill. Evidence from the relatively few studies that have investigated this relationship indicates that social support plays an important, positive role in psychosocial adaptation for children and adolescents with
chronic illnesses. In their examination of a peer support group intervention for older children and adolescents with Type 1 Diabetes, Greco, Pendley, McDonnell, & Reeves (2001), found that participants reported improved levels of support, increased knowledge about diabetes, and decreased conflict with their parents.

Children with chronic illness have often also been described as being socially isolated. Factors such as limitations in activities, frequent school absences, and periods of extended hospitalization can negatively impact these children’s opportunities to relate with peers (Eiser, 1994). Research has provided evidence that children with chronic illness are at risk for social isolation that can also result in a decrease in available social support. Melzer, Leadbetter, Reisman, Jaffe, & Lieberman (1989) compared the peer social networks of adolescents with end-stage renal disease to a control group of healthy adolescents. They reported that although the adolescents with end-stage renal disease indicate a greater family support network, they had a smaller peer social network than healthy adolescents.

Kazak and Meadows (1989) examined changes in perceived social support over a 6-month period for adolescent survivors of cancer and a healthy comparison group. The survivor group in this study was reported to be free of disease for at least 5 years. Results indicated that the survivor group reported somewhat lower levels of support from family, friends, and teachers/other adults than the control group, although the differences between groups were not statistically significant. The adolescent survivors of cancer also reported experiencing a significant decrease in perceived social support over the 6-month period of time. The adolescent survivors of cancer also reported significantly lower levels of school-related competency than the control group. These findings indicate that experiencing illness may have lingering negative effects social functioning.
Sources and Types of Social Support

Recently, there has been an emphasis on more in-depth examinations of the role of perceived social support. Although social support has been examined as a global construct, there has been conceptual and empirical support for the importance of distinguishing among different sources as well as among different types of social support (House & Khan, 1985). Cauce and Srebnik (1989) identified three primary categories of support sources available through an individual’s social network. These sources include family support, peer support, and formal support sources, such as school personnel. The relative importance of these three primary sources of support is dependent upon developmental changes and progression. Family supports appear to play a larger role when children are in elementary school. As children enter adolescence, peer supports appear to take on a larger role (Cotterell, 1994). The importance of other formal support individuals, such as teachers or doctors, appears to be variable based on the type of difficulty and type of support provided.

There is evidence that children and adolescents differentially perceive and appraise social support from various individuals in their social network. Varni, Katz, Colegrove, & Dolgin (1994) examined the relationship between sources of social support and psychological functioning for 30 children with newly diagnosed cancer. Participants’ report of increased perceived social support from classmates, parents, and teacher was negatively correlated with symptoms of depression, state and trait anxiety, social anxiety, and positively correlated with self-esteem. Results also indicated that support from classmates was the most consistent predictor of positive adaptation.

Wallander and Varni (1989) examined the impact of social support on adjustment to chronic illness. The study sample included children with a range of chronic illnesses, including
diabetes, spina bifida, obesity, cerebral palsy and juvenile rheumatoid arthritis. Findings based on parent report indicated that children who were rated as having high social support from both family and friends were rated as having better adjustment than children rated as having high levels of social support from only one of those sources. A lack of family and peer support was associated with having increased levels of externalizing behavior problems, while a lack of only peer support was associated with internalizing problems.

Haluska, Jessee, and Nagy (2002) examined the relationship between sources of social support reported by adolescents with newly diagnosed cancer. Sixty-four adolescents with newly diagnosed cancer were compared to a control group of healthy, age-matched adolescents. Both groups reported similar levels of perceived support from friends and family, as well as satisfaction with the amount of support available. However, those adolescents with cancer reported greater perceived support from parents than healthy controls. Varni, Setognchi, Rappaport, & Talbot (1992) examined perceptions of social support and the effects of support on adjustment to disease for children with congenital or acquired limb deficiencies. Results indicated that perceived social support by peers was a more powerful predictor of positive self-esteem and lower levels of depression and anxiety than parent or teacher support. Although the findings regarding differential impact of various sources of social support are somewhat mixed, evidence supports the notion that sources of support can have a differential impact.

Varni, Rubenfeld, Talbot, & Setoguchi (1989) examined the relationship between social support and depressive symptomatology in 27 children with congenital or acquired limb deficiencies. Results of their investigation indicated that higher levels of support from parents, teachers, and classmates significantly predicted lower levels of depressive symptomatology. Based on these findings, Varni et al. propose that there are likely to be differential associations
between various perceived sources of social support and adjustment and assert the importance of measuring multiple sources of perceived social support. The authors also warn against assessing the relationship between psychological adjustment and social support as a global index, which may obscure relationships that are specific to the particular source of support or to different age groups of children.

Considerable attention has also focused on identifying and organizing various types of behaviors into categories of support. These approaches typically seek to delineate behaviors on the basis of the function that the supportive behaviors serve. Although a variety of typologies have been presented, most suggest a distinction between several functions of support including emotional support, informational support, affirmation or appraisal support, and instrumental support (e.g., Cohen & Willis, 1985; House & Khan, 1985; Pierce, Sarason, Sarason, Joseph, & Henderson, 1996). Emotional support communicates that the individual is cared for and loved. Often emotional support is expressed as concern for the individual, listening to the individual, and support for the individual’s expressions of affect. Informational support involves the provision of information about a particular issue, and is often provided in the form of advice and guidance. Affirmation or appraisal support is characterized by providing social companionship, or “being there” for the individual, and providing positive feedback. Instrumental support is defined as providing assistance in efforts that are directed on a particular coping task, and often involves the provision of material aid, such as transportation or money.

Generally, there has not been as much clear support for the impact of the type of support as an individual factor or for one type of support consistently being more effective than another (Cauce, Mason, Gonzales, Hiraga, Liu, 1994). Rather, there appears to be an interaction between the source of support and the type of support provided. Research in the normal development of
social support also suggests that various individuals provide different types of support, and that
the sources and types of support are perceived by the recipient of the support differently and can
have a differential impact. For instance, parents typically provide nurturing, emotional support,
which establishes a child’s sense of security and protection, as well as tangible, or instrumental,
forms of support (Hartup, 1989). However, peer support is more broadly provided as affirmation
and acceptance and has a positive impact when in the form of social companionship and
acceptance (Parker & Asher, 1993).

In a study conducted with adult women with chronic illness, differences in adjustment
appeared to be related to the types of support available and the source of the support (Primomo,
Yates, & Woods, 1990). The authors differentiated among several types of support including
affective support, affirmation, reciprocity, and tangible aid. They also considered several
sources of support including partner, family, friends, and others. Results indicated that, overall,
partners provided the greatest amount of support. Beyond partners, family members provided
more affective support while friends provided more affirmation. Also, women confided about
their illness more with professional sources of support such as counselors, religious personnel,
and healthcare providers than they did with friends and family. In general, support from partners
and family was associated with better adjustment to illness as indicated by lower levels of
depression, higher marital quality, and better family functioning. Tangible aid was not related to
adjustment.

In a study examining perceptions of support types for adults diagnosed with either breast
cancer or colorectal cancer, respondents reported that emotional support was most helpful and
instrumental support was the least helpful types of support (Dunkel-Schetter, 1984). When the
source of support was also considered, informational support was reported as helpful only when
the source was a healthcare professional. Emotional and instrumental support were reported to be helpful from any source. Similar results were found in a study examining social support with 55 adults with cancer (Dakof & Taylor, 1990). When the source was a spouse, family member, or friend, participants indicated that emotional support was the most helpful when present and the most harmful if absent. When the source was a physician, informational support was reported as most helpful. Instrumental support was also reported to be more helpful for individuals who had poor-prognosis.

Findings, therefore, appear to generally support the positive impact of emotional support, regardless of the source of support. Informational support appears to be more effective when provided by healthcare workers, while there is little support for the efficacy of instrumental support in these chronic illness populations. Results from these studies lend support for the importance of differentiating among various sources and types of support and their differential impact on adjustment to chronic illness. Therefore, looking at global social support is likely not an adequate approach. Rather, assessment should include gathering information sources as well as types of available perceived support. Additionally, although research on the relationship between types of social support and adjustment has been examined with adult populations, further research in this area must be conducted with child and adolescent populations.

*The Current Study*

The purpose of the current study is to examine the associations between types and sources of social support and the health-related quality of life of children and adolescents with pacemakers. Although research has generally supported the theory that social support is positively related to improved quality of life for children with chronic illness, this relationship has not been adequately examined with a population of pediatric pacemaker recipients.
Additionally, it remains unclear which aspects of social support have the greatest impact for children. Previous studies have failed to focus on child populations or have relied only on parent-proxy report of child social support (Dubow & Ullman, 1989). The differential associations between children’s perceptions of various sources and types of available support and quality of life have not been carefully considered. Although there is some research which has considered the role of parents and peers as providers of support, medically ill children interact with a range of individuals who have the potential to provide support. Previous studies have not considered the impact and support that individuals such as doctors, nurses, or teachers may play in the overall quality of life of pediatric transplant recipients. This study will expand upon previous research by looking beyond social support as a global construct to an in-depth examination of the relationship between various types and sources of social support on quality of life for children with pacemakers. It will also expand the current literature by examining the role of healthcare workers and teachers as sources of social support and their impact on children’s quality of life.

There has been significant interest in examining the psychosocial adjustment of children with chronic illness. However, the majority of research has focused primarily on the assessment of psychosocial adjustment based on measures of psychopathology. Recently, the limitations of using such measures have been highlighted (i.e., Perrin, Stein & Drotar, 1991) and there has been an increased emphasis in looking at the health-related quality of life for children with chronic illness. The construct of quality of life looks beyond the presence or absence of pathology to consider the child’s perception of the impact of illness on their functioning in a variety of life areas. Therefore, measures of quality of life provide a more accurate depiction of functioning and adaptation as related to health. This study proposes to add to the development and growth of more specific knowledge about the health-related quality of life of children and adolescents with
pacemakers by including measures of both global and disease specific quality of life. As noted by Quittner, Davis, & Modi (2003), including both global and disease specific measures allows for broader cross-condition comparisons as well as information that provides greater sensitivity. Previous studies have failed to consider quality of life with measures that allow for this. This study will provide information that examines quality of life as it applies to more general health as well as illness variables that are specific to having a cardiac condition.

Research has noted that children with chronic illness appear to be at particular risk for poor social competence due to the impact of illness on peer relations and social adaptation (Brem, Brem, McGrath, & Spirito, 1988; Hurtig & White, 1986). Recently, there has been a recognition for the need to move away from comparing pediatric populations with “normal” populations. Rather, there is emphasis on focusing on within-group analyses of factors associated with positive or negative disease adaptation (La Greca, 1990). Previous research has failed to provide a specific focus on social functioning and social competency. Perrin, Stein, and Drotar (1991) also caution against using general measures of child psychopathology to examine social competency in children because these measures cannot distinguish social difficulties due to the child’s illness (i.e., limitations in participating in sports activities) from difficulties due to poor global social competence. This study proposes to clarify the picture of social functioning for children with pacemakers by examining social competency. Additionally, social competence will be assessed with a measure that separates social difficulties due to the child’s illness from social difficulties that are unrelated to the child’s illness.

Children with pacemakers face a variety of psychosocial challenges. Although their quality of life has been considered from a functional or physical perspective, further examination of social, emotional, and behavioral aspects of their functioning has not been carefully examined.
Based on the relatively little research that has been conducted with this population, as well as on research with children and adolescents with cardiac disorders in general, it is likely that these children are at greater risk for psychosocial difficulties than their healthy peers. Developing a better understanding of the relationship between types and sources of social support and quality of life for children with pacemakers will inform future research and may advance the ability to develop treatments and interventions to improve the quality of life for these at-risk children as well as for children with chronic illness in general.

**Hypotheses**

1. It is predicted that there will be no significant associations between the demographic variables of age, gender, socioeconomic status, and race/ethnicity and measures of quality of life, psychopathology, social functioning, and self-competency.

2. There will be no significant associations between variables measuring illness severity or length of illness and measures of overall quality of life, psychopathology, social functioning, and self-competency. However, there will be a negative correlation between illness severity and cardiac quality of life.

3. Higher levels of overall perceived social support based on the available types of support behaviors (Esteem-enhancing, Informational, and Tangible support) will be positively correlated with higher levels of child overall and cardiac quality of life, self-competency, and social functioning and will be negatively correlated with symptoms of psychopathology.

4. Higher levels of overall perceived social support from various members of the child’s support network (Family, Friends, Classmates, Teachers, and Doctors/Nurses) will be positively correlated with higher levels of child overall and cardiac quality of life, self-
competency, and social functioning and will be negatively correlated with symptoms of psychopathology.

5. The social support sources will be differentially related to overall child quality of life and psychosocial adjustment. In particular, children and adolescents who report high levels of support from family members will have higher levels of general and cardiac quality of life and fewer symptoms of psychopathology than those who report low levels of family support. Also, children and adolescents who report high levels of support from friends and classmates will have fewer social problems than those who report low levels of support from friends and classmates.

6. The social support types will be differentially related to overall child quality of life and psychosocial adjustment. In particular, children and adolescents who report high levels of Esteem-enhancing support will have higher levels of overall and cardiac quality of life and fewer symptoms of psychopathology than those who report low levels of Esteem-enhancing support. Also, children and adolescents who report high levels of Informational support will have higher levels of self-competency than those who report low levels of Informational support.
CHAPTER 2

METHOD

Participants

Thirty-one children and adolescents with implanted cardiac devices and their parents participated in this study. Twenty-seven of the children had a cardiac pacemaker, while four of the children had an internal cardiac defibrillator (ICD). Participants ranged in age from 8 to 18 years (M = 13.53, SD = 3.10), with 16 females and 15 males. Twenty-eight mothers and 3 fathers completed measures for the study. The majority of participants were Caucasian (74%), while 10% were African American, 10% were Hispanic, 3% were American Indian, and 3% were bi-racial. The mean yearly gross family income of the sample was in the above $60,000 range.

Measures (See Appendix A)

Demographic and Health Information Questionnaire. This measure was created specifically for the purposes of this study. Parents were asked to provide basic demographic information including their child’s gender, age, ethnicity, and income. Parents were also asked to answer several questions gathering information about their child’s current and past medical and pacemaker history. Items assessed aspects of the child’s health such as medical diagnoses, length of time since pacemaker implantation, and frequency of hospitalizations and doctors visits, and number of previous surgeries in order to gather information about the severity and length of the child’s illness.

Pediatric Quality of Life Inventory, Version 4.0 (PedsQL). The PedsQL (Varni, Seid, & Kurtin, 2001) is a standardized measure that assesses the health-related quality of life in pediatric
patients with chronic health conditions. There is a 23-item scale which assesses general health-related quality of life. The general scale consists of four subscales measuring physical, emotional, social, and school functioning. There is also a 27-item cardiac-specific module that assesses aspects of quality of life for specific to children with cardiac conditions. The cardiac module consists of 6 subscales that assess problems with cardiac health, taking medications, physical appearance, treatment anxiety, cognitive functioning, and communication. There are different self-report forms for children ages 8 to 12 years and adolescents ages 13 to 18 years. There are also separate, parallel parent proxy-report forms which assess parents’ perceptions of their children’s quality of life. The items for the forms are essentially identical, differing only such that questions are phrased in developmentally appropriate language or in first- or third-person tense. Children and parents are asked to rate how much of a problem each item has been in the past one month on a five-point scale ranging from Never a Problem (0) to Almost Always a Problem (4). Scores for each of the subscales are computed by summing the item scores and dividing by the number of items answered. The subscale scores from the general scale are summed to form a Total General Quality of Life scale score. The subscale scores from the cardiac module are summed to form a Total Cardiac Quality of Life scale score. Higher scores indicate better health-related quality of life.

The PedsQL has been widely used to assess quality of life in a variety of pediatric populations. The measure has demonstrated good internal consistency reliability for the Total scale scores with Chronbach’s alphas of .88 for the child report and .90 for the parent report (Varni, Seid, & Kurtin, 2001). The subscale scores have also demonstrated adequate internal consistency reliability with alphas above .70 for each of the subscales for the parent-proxy and child/adolescent self-report forms. Construct validity has been empirically demonstrated as the
PedsQL was able to distinguish between healthy children and children with acute or chronic health conditions. Construct validity was further demonstrated as the PedsQL scores were correlated with indicators of morbidity and illness burden.

Survey of Children’s Social Support (SOCSS). The SOCSS (Dubow & Ullman, 1989) is a child self-report measure assessing children’s perceptions of the degree of social support they receive. The measure was created for use with children age 8 years and older. The measure consists of three independent subscales, and only the Available Behaviors (SAB) subscale and the Appraisals of Support (APP) subscale will be used in this investigation. The SAB measures the frequency with which children feel they receive three types of social support: emotional/esteem-enhancing support, emotional/informational support, and tangible support. The subscale consists of 38-items and asks children to rate how frequently they receive each of the supportive behaviors on a scale of Never (1) to Always (5). Scores for each of the three categories of support are computed by summing over the child’s item responses, with higher scores indicating greater perceived support. A total subscale score is then computed by summing over the three support category scores. This subscale has demonstrated good internal consistency with Chronbach’s alpha = .91 and adequate test-retest reliability (.74) (Dubow & Ullman, 1989).

The APP assesses sources of social support by measuring the degree to which children feel they receive support from various individuals. In its original form, the subscale consists of 31-items assessing support from family, peers, and teacher. This subscale will be slightly modified in order to assess perceptions of support by healthcare professionals. Doctors and nurses potentially play an important role in the degree of support that children and adolescents feel in coping with their illness. However, their role has not been carefully examined and few formal methods of assessing their role are available (Dunkel-Schetter, 1984). Therefore, five
items assessing support from healthcare providers were added by modifying the items assessing teacher support by replacing the word “teacher” with the phrase “doctor or nurse”.

Items are presented in a “structured alternative format” (e.g., “Some kids feel left out by their friends, but others don’t. Do you feel left out by your friends?”) in order to limit social desirability in responding. Children respond to each item on a scale ranging from Never (1) to Always (5). Scores for each of the sources of support are computed by summing over the child’s item responses, with higher scores indicating greater perceived support. A total subscale score is then computed by summing over the support source scores. Internal consistency reliability for the APP in its original form is strong, with a Chronbach’s alpha of .88 for the total 31-items and alphas ranging from .78 to.83 for each of the three sources of support. Test-retest reliability is acceptable at .75

The Perceived Competence Scale for Children (PCS). The PCS (Harter, 1982) is a 28-item child self-report inventory assessing children’s sense of mastery across four domains of competency: cognitive, social, physical, and general self-worth. The PCS has been used with children ages 8 and above. In order to avoid children providing socially desirable responses, items are presented in a “structured alternative” response format. Respondents are first asked to chose which statement best describes them, and they are then asked to indicate whether the statement is “really true for me” or “sort of true for me”. Each item is then scored on a scale of 1 to 4, with “1” representing low perceived competency and “4” representing high perceived competency. Item scores are summed and averaged for each subscale to result in four separate subscale means. This measure has been widely used and has demonstrated good reliability and validity (Harter, 1982). The four subscales have adequate internal consistency with alpha’s of .76, .78, .83, and .73 for the cognitive, social, physical, and general subscales respectively.
Three-month test-retest data indicated correlations ranging from .70 to .87 for the four subscales, while nine-month test-retest data indicated correlations ranging from .69 to .80. The measure has also been shown to demonstrate good convergent and discriminant validity.

*Living with Chronic Illness (LCI).* The LCI (Adams, Streisand, Zawacki, & Joseph, 2002) is a 29-item measure assessing social functioning in children and adolescents with chronic illness. It is designed to distinguish between social difficulties related to the individual’s illness and social difficulties due to other factors. There are two forms of the LCI. The youth form (LCI-Y) is a self-report measure for children and adolescents ages 9 to 18. There is also an accompanying parent report form (LCI-P) with identical items, but appropriately formatted for parents to respond about their children’s social functioning. The LCI requires participants to respond in a dichotomous, true/false format to each item. If respondents endorse false to an item, they move on to the next item. If they endorse true to an item, respondents are then asked to indicate whether this is related to the illness or treatment and the degree to which it upsets the child. Degree of upset is indicated on a four-point Likert scale ranging from Not At All (0) to Very Much (3). The Likert ratings of all items that were endorsed as being true and related to the child’s illness are then summed to yield an Illness Difficulties (ID) score. Those items endorsed as true but not related to the child’s illness are summed to create a Non-illness Difficulties (NID) score. The LCI has adequate internal consistency with Chronbach’s alphas of .86 for the parent version and .82 for the youth version. It has also demonstrated convergent validity with other parent- and self-report measures of child and adolescent psychosocial functioning.

*Behavior Assessment System for Children- Parent Report (BASC-PRS) and Youth Self-Report Forms (BASC-YSR).* The BASC (Reynolds & Kamphaus, 1992) is a multidimensional
measure of child and adolescent psychosocial functioning. There are separate parent-proxy report (BASC-PRS) and child/adolescent self-report (BASC-YSR) forms. There are also two age-appropriate versions of the BASC, with a form for children ages 6 to 11 and a form for adolescents ages 12 to 18. The BASC-PRS version for children consists of 138 items while the BASC-PRS version for adolescents has 126 items. The BASC-PRS assesses parents’ perceptions of their children’s problematic behaviors in the following domains: externalizing problems (aggression, hyperactivity, conduct problems subscales), internalizing problems (anxiety, depression, somatization subscales), and school problems (attentional problems, learning problems subscales). The BASC-PRS also assesses positive behaviors which are represented by an Adaptive Skills dimension (leadership, social skills, study skills, adaptability—not included on the adolescent version, subscales). Parents indicate the frequency of each behavior on a four-point scale of Never (1) to Almost Always (4).

The BASC-YSR child and adolescent self-report forms assess similar domains as that of the BASC-PRS forms. Due to length of the questionnaire, children and adolescents will only complete the 12 items on the social skills subscale of the BASC-YSR. Children and adolescents respond by indicating if each item is either True (1) or False (0) for them. The number of true statements is then summed to obtain a social skills subscale score.

The BASC-PRS and BASC-YSR have been shown to have internal consistency with alpha levels ranging from .80 to .90 for both the child and adolescent versions. Strong test-retest reliability has been demonstrated with median values of .91 for the child form and .82 for the adolescent form. Interrater reliability ranges from .63 to .71 for the scaled scores and .70 to .90 for the composite scores. The BASC-PRS and BASC-YSR have also exhibited concurrent validity with other assessment measures of adaptive and behavior problems including the Child
Behavior Checklist, Behavior Rating Profile, and Burks’ Behavior Rating Scale (Reynolds and Kamphaus, 1992). They have also been shown to demonstrate convergent validity with the Child Behavior Checklist and criterion-related validity based on ability to predict membership into DSM-based diagnostic groupings (Doyle, Ostrander, Skare, Crosby, & August, 1997).

Procedure

Participants were recruited from the Children’s Healthcare of Atlanta (CHOA) at Egelston pacemaker clinic. Permission was obtained by the Emory University IRB to conduct the study and to review the clinic appointment roster to identify potential participants. All children who received regular follow-up care at the clinic and had a confirmed appointment on a day during which data was being collected, who were between the ages of 18 to 18 years, who were known by the clinic staff to be of average intellectual functioning, and who were primarily English-speaking were eligible to participate. The parents of potential participants were contacted by telephone prior to their scheduled clinic appointment by a research assistant.

Those who agreed to participate completed the study either before or after their regularly scheduled clinic visit. The primary investigator or a research assistant obtained consent and assent from the children and their parents. The research assistant explained the instructions for each questionnaire to the parent who then independently completed the questionnaires. The research assistant then led the child to a private area and assisted him or her by reading the questions to them. Children were also given a sheet which listed the likert scale ratings in words and corresponding numbers (e.g., Never (1), Sometimes (2), Often (3), Always (4)) for each measure to provide a visual cue to assist their responding. Children completed the age-appropriate forms of the following measures: Pediatric Quality of Life Inventory, Version 4.0 General and Cardiac modules, Survey of Children’s Social Support, Perceived Competency
Scale, Living with a Chronic Illness, and the Behavioral Assessment System for Children Social Skills subscale items. Parents completed the parent-report versions of the following measures: Demographic and Health Information Questionnaire, Pediatric Quality of Life Inventory, Version 4.0 General and Cardiac modules, Living with a Chronic Illness, and the Behavioral Assessment System for Children. Parents and children were given an opportunity to ask questions or get clarification on questionnaires as needed as well as at the end of the study. Children and parents complete the questionnaires in approximately 25 to 40 minutes. Parents were given a pass for free parking in the hospital parking deck and children were given a small token, such as a piece of candy or a pencil, for participating in the study. Due to time restrictions, one family completed consent and assent forms in the clinic and returned the questionnaires by mail.
CHAPTER 3
RESULTS

Preliminary Analyses

Reliability of the SOCSS

Because the Doctor/Nurse subscale of the SOCSS was created for use in this study, the internal consistency reliability for the subscales of the SOCSS-APP and SOCSS-SAB based on participants’ responses in the current study were computed. Internal consistency reliability of the sources of support, as measured by Chronbach’s alphas, appeared strong with alphas of .88 for the Friends subscale, .76 for the Class subscale, .85 for the Family subscale, .70 for the Teachers subscale, and .78 for the Doctor/Nurse subscale. Internal consistency reliability for the types of support were also adequate, with alphas of .86 for the Esteem subscale, .76 for the Informational subscale, and .61 for the Tangible subscale.

Demographic Variables

In order to explore the relationship between the demographic variables and the variables measuring child QOL, social functioning, self-competency, and psychosocial adaptation, one-way analyses of variance (ANOVA) were conducted for gender, age, race, and income groups and the composite scores of the variables of interest. No significant gender differences were found. Contrary to hypotheses, several group differences were found based on age, race, and income. In order to examine income, a median split was used to divide participants into two income groups; the lower income group consisted of those with a gross family income below $60,000 ($N = 17) and the higher income group consisted of those with gross yearly family income of $60,001 ($N = 14) or more. For child self-report on the Psychosocial QOL composite
score \((F [1, 29] = 4.51, p \leq .05)\) and the General QOL total score \((F [1, 29] = 7.88, p \leq .01)\), the higher income group \((M = 75.48, SD = 13.77; M = 78.48, SD = 11.88, \text{respectively})\) had significantly higher QOL scores than participants in the lower income group \((M = 64.22, SD = 15.40; M = 64.52, SD = 15.22, \text{respectively})\). A similar pattern was also found with parent report of child functioning on the General QOL composite \((F [1, 29] = 4.03, p \leq .05)\), as the higher income group \((M = 75.67, SD = 18.10)\) reported significantly higher mean scores than those in the lower income group \((M = 62.16, SD = 19.03)\). Child-report of self-competency also indicated that on the Social self-competency \((F [1, 29] = 4.03, p \leq .05)\) and General self-competency scales \((F [1, 29] = 4.03, p \leq .05)\) those participants in the higher income group \((M = 2.28, SD = .58; M = 2.21, SD = .48, \text{respectively})\) reported higher competency scores than the lower income group \((M = 1.82, SD = .50; M = 1.80, SD = .50, \text{respectively})\).

A median split was also used in order to form two relatively balanced groups based on age, with participants ages 8 to 13 (\(N = 13\)) forming the younger group and participants ages 14 to 18 (\(N = 18\)) forming the older group. On child self-report of Social self-competency \((F [1, 29] = 8.28, p \leq .01)\), younger participants \((M = 1.71, SD = .53)\) had significantly lower means than older participants \((M = 2.25, SD = .50)\). However, for Social Problems Not Due to Illness \((F [1, 29] = 5.13, p \leq .05)\) older participants \((M = 8.71, SD = 10.05)\) reported having greater levels of difficulty than younger participants \((M = 5.00, SD = 9.73)\). There were no significant group differences for age based on any of the parent-report measures.

Due to a low number of participants from each of the various ethnic groups, participants were combined to form two groups consisting of Caucasian (\(N = 23\)) and non-Caucasian participants (\(N = 8\)). Groups differed on child self-report of the Psychosocial QOL composite \((F [1, 29] = 5.24, p \leq .05)\) and the General QOL total score \((F [1, 29] = 7.92, p \leq .05)\), with
participants in the non-Caucasian group reporting significantly lower QOL means \( (M = 59.17, SD = 19.40; M = 59.02, SD = 18.75, \text{respectively}) \) than the Caucasian group \( (M = 72.83, SD = 12.60; M = 74.93, SD = 11.76, \text{respectively}) \). Non-Caucasian participants \( (M = 1.51, SD = .36) \) also reported lower levels of General self-competency \( (F [1, 29] = 11.69, p < .01) \) than Caucasian participants \( (M = 2.15, SD = .48) \). There was also a group difference for Social Problems Due to Illness \( (F [1, 29] = 5.58, p < .05) \) as the Non-Caucasian participants \( (M = 7.63, SD = 8.33) \) reported a greater number of social problems than the Caucasian participants \( (M = 2.96, SD = 2.92) \).

**Illness Variables**

ANOVA s were also conducted to examine the relationship between the dependent variables and variables measuring child illness, including age at cardiac diagnosis, the number of pacemaker clinic visits, emergency room visits, cardiac procedures, and hospitalizations in the past one year, and the number of missed school days and missed play days in the past two months. Groups were formed for each of the illness variables with the negative occurrence group (NEG) consisting of children who did not have any occurrences of the variable (e.g., no ER visits within the past 2 years), while those with 1 or more occurrences were placed in the positive occurrence group (POS) for each of the following illness variables: number of hospitalizations \( (\text{NEG} N = 19, \text{POS} N = 12) \), emergency room visits \( (\text{NEG} N = 16, \text{POS} N = 15) \), invasive cardiac procedures \( (\text{NEG} N = 23, \text{POS} N = 8) \), missed days of school \( (\text{NEG} N = 15, \text{POS} N = 16) \), missed days of play \( (\text{NEG} N = 17, \text{POS} N = 14) \). For the variable measuring number of pacemaker clinic visits, groups were formed based on the median number of two visits per year, with the low group representing participants who had 2 or fewer visits \( (N = 21) \) and the high group representing those with 3 or more visits \( (N = 10) \). Two groups were formed
for age at diagnosis, with participants diagnosed at birth representing the younger group ($N = 17$) and those diagnosed at age 1 or later representing the older group ($N = 14$).

Results of the ANOVA comparisons indicated that there were no significant group differences based on age at diagnosis, number of clinic visits or cardiac procedures in the past one year, or the number of missed play days in the past two months. There were group differences based on other illness variables, although as hypothesized, the differences were primarily on those outcome variables related to physical functioning. Specifically, child-report of Physical QOL indicated significant group differences ($F [1, 29] = 4.42, p \leq .05$), as those in the no hospitalization group ($M = 80.92, SD = 19.43$) had higher Physical QOL scores than those in the hospitalization group ($M = 66.66, SD = 16.55$). Group differences were also found for parent-report of child Physical QOL ($F [1, 29] = 5.51, p \leq .05$) and Cardiac QOL ($F [1, 29] = 5.45, p \leq .05$), as participants in the no hospitalization group ($M = 79.61, SD = 22.76; M = 83.08, SD = 17.65$, respectively) had significantly better functioning than those in the hospitalization group ($M = 59.64, SD = 23.55; M = 64.58, SD = 26.62$, respectively). Those in the no hospitalization group ($M = 48.84, SD = 10.27$) had fewer Somatization symptoms based on parent report ($F [1, 29] = 7.99, p \leq .01$) than those in the hospitalization group ($M = 60.42, SD = 12.34$). This was also found for parent report of child Internalizing symptoms ($F [1, 29] = 4.32, p \leq .05$), with the no hospitalization group ($M = 48.26, SD = 8.84$) having fewer Internalizing symptoms than those who had experienced hospitalization ($M = 57.08, SD = 14.87$).

Group differences were also found based on emergency room visits. Participants differed on scores of parent reported Physical QOL ($F [1, 29] = 6.94, p \leq .01$) and parent reported Cardiac QOL scores ($F [1, 29] = 4.18, p \leq .05$), with the no ER visit group ($M = 82.22, SD = 23.01; M = 83.71, SD = 19.65$, respectively) having higher QOL scores than those who had
required ER visits ($M = 60.83, SD = 22.16; M = 67.62, SD = 24.09$, respectively). Significant group differences were found based on number of missed school days ($F [1, 29] = 4.03, p \leq .05$), as participants in the no missed school days group ($M = 82.29, SD = 18.09$) had significantly higher self-reported Physical QOL than those who had missed school ($M = 68.95, SD = 18.87$). Those in the no missed school days group ($M = 48.00, SD = 11.19$) also had significantly fewer parent reported child Somatization symptoms ($F [1, 29] = 6.39, p \leq .05$) than those who had missed school ($M = 58.31, SD = 11.49$).

Cardiac Device. Group differences on the illness and demographic variables were explored for the participants who had pacemakers in comparison to those who had an internal cardiac defibrillator (ICD). Because there were only four participants with an ICD, compared to 27 participants with a pacemaker, the groups were unbalanced and results should be interpreted with caution. There was a significant gender difference ($F [1, 29] = 5.44, p \leq .05$) as all four participants with an ICD were male. There was also a significant difference for age at diagnosis ($F [1, 29] = 8.19, p \leq .01$), as the ICD participants were older at the time of diagnosis with a mean age of 10.25 years in comparison to the pacemaker participants who had a mean age of 3.09 years at time of diagnosis. There were no other differences between the two groups on any other demographic or illness variables.

Groups were also compared on the composite scores of the dependent variables. There was a group difference based on parent-report of child Externalizing symptoms ($F [1, 29] = 4.91, p \leq .05$), with the pacemaker participants ($M = 47.85, SD = 10.42$) reporting significantly fewer problems than the ICD group ($M = 60.25, SD = 10.69$). Although the pacemaker and ICD participants differed on gender and age of diagnosis, because these variables do not appear to play an influential role in the dependent variables, these group differences are not considered in
future analyses. Additionally, because there was only a group difference on one dependent variable of interest, the two groups are considered to be similar enough in key characteristics and will be considered in combination for all further analyses.

**Associations Between Social Support and QOL**

**Overview of Analyses**

In order to examine differences in QOL, self-competency, social functioning, and psychosocial adjustment for the pacemaker sample in comparison to healthy peers, the data were compared to mean scores for healthy children and adolescents on the same dependent measures. The comparisons were based on published scores for healthy peer groups either from previous studies or to standardized norms when available. The data were then considered using correlational methods in order to examine the associations between social support and the variables measuring QOL, self-competency, social functioning, and psychosocial adjustment. Results of the correlations for each of the three types of support and support type composite score and each of the variables of interest will be presented first. Correlations between each of the five sources of social support and support source composite score and each of the variables of interest will then be presented.

To examine group differences in the dependent variables for individuals with differing levels of perceived social support, the data were then examined using between-groups analyses. The between-groups analyses were used in addition to the correlational analyses because the ANOVA procedures allow for the examination of 2-way interactions for the various types of support as well as various sources of support. For each type and source of support, a median split was used to form a high perceived support group and a low perceived support group. ANOVAs
were then used to compare high and low support groups for the composite scores of each of the dependent variables.

**Comparisons with Healthy Peers**

Participants’ general QOL as measured by their scores on the General PedsQL were compared to the scores of a healthy comparison group as collected in a study by Varni, Seid, and Kurtin (2001). Table 1 presents the means and standard deviations for both groups on the General PedsQL scales. One-sample t-test comparisons indicated that based on child self-report, participants scored significantly below the healthy comparison group on each of the subscales of Physical ($t_{[30]} = -2.58, p \leq .05$), Emotional ($t_{[30]} = -3.47, p \leq .01$), Social ($t_{[30]} = -4.11, p \leq .001$), and School QOL ($t_{[30]} = -4.16, p \leq .001$). Participants also had a significantly lower Psychosocial QOL composite score ($t_{[30]} = -4.69, p \leq .001$) and General QOL composite score ($t_{[30]} = -4.44, p \leq .001$). Comparisons of parent-report on the General PedsQL scales also indicated that participants were significantly lower than the healthy comparison group on Physical ($t_{[30]} = -3.93, p \leq .001$), Emotional ($t_{[30]} = -4.56, p \leq .001$), Social ($t_{[30]} = -5.04, p \leq .001$), and School QOL ($t_{[30]} = -4.56, p \leq .001$) subscales. Parent-report also indicated that participants were significantly lower on the Psychosocial QOL composite score ($t_{[30]} = -5.68, p \leq .001$) and General QOL composite score ($t_{[30]} = -5.52, p \leq .001$).

Comparisons were also made between participants’ self-competency scores and the published means from a healthy comparison group on the PCS (Harter, 1982). Table 2 presents the means and standard deviations for both groups. Participants scored significantly below the healthy comparison group on each of the Cognitive ($t_{[30]} = -5.94, p \leq .001$), Social ($t_{[30]} = -8.17, p \leq .001$), Physical ($t_{[30]} = -12.07, p \leq .001$), and General self-competency subscales ($t_{[30]} = -9.46, p \leq .001$).
On the BASC, participants’ mean scores on all subscales and composite scores measuring both positive and negative psychosocial adjustment were within the Average range. Published means from healthy comparison groups were not available for the child or parent versions of the Cardiac PedsQL or LCI.

Correlational Analyses

The data were examined using bivariate correlational analyses in order to determine the relationship between the three types of social support and measures of QOL, psychological adjustment, social functioning, and self-competence. Correlational analyses were then conducted for these variables of interest with the five sources of social support. In order to determine possible effects of demographic variables, correlations between age and income and the variables measuring QOL, psychosocial adjustment, social functioning, and self-competency were conducted as a preliminary step. As displayed in Table 3, age was significantly associated with parent-report of child Cardiac QOL composite, Social Problems due to Illness, and Internalizing symptoms, income was associated with child self-report of General QOL composite and Social Problems due to Illness, and both age and income were significantly correlated with parent-report of child General QOL composite and Psychosocial QOL composite. Therefore, partial correlations were conducted in the subsequent correlational analyses to control for age and/or income for the composite scores of the dependent variables when appropriate.

Types of support. Table 4 presents results of the correlations for child self-report of General and Cardiac QOL subscales and composite scores and the social support types. As was hypothesized, there was a strong pattern of positive associations among the variables measuring General QOL and each of the three types of support, as well as the composite for type of support. The social support type composite score was significantly and positively associated with each of
the General QOL subscale scores measuring Physical, Emotional, Social, and School QOL, and the Psychosocial QOL composite. Individually, each of the three support types of Informational, Esteem, and Tangible support was significantly associated with each of the General QOL variables and Psychosocial composites, except for Physical QOL. Partial correlations controlling for income indicated that each of the three types of support and the support type composite score was positively associated with the General QOL composite score.

Surprisingly, there were fewer significant associations when child self-report of Cardiac QOL and the three types of support were examined. The support type composite score was significantly positively correlated with Cognitive QOL. Tangible support was positively correlated with Appearance QOL and Cognitive QOL. There were no significant associations between Informational or Esteem support and any of the variables measuring Cardiac QOL. In contrast to child self-report, there were no significant associations between parent report of child General and Cardiac QOL and types of social support.

In terms of social functioning, Child self-report on the BASC Social Problems subscale was negatively correlated with Esteem support \( (r = -0.48, p \leq .01) \), Tangible support \( (r = -0.51, p \leq .01) \), and Support Type composite \( (r = -0.51, p \leq .01) \) indicating that these types of support are associated with having fewer social problems for these participants. There were no significant associations, however, between support types and parent-report of either Social Problems Due to Illness or Social Problems Not Due to Illness on the LCI scale. Child self-report of Social Problems Due to Illness was also not significantly associated with support type. However, child self-report of Social Problems Not Due to Illness was negatively correlated with Esteem support \( (r = -0.41, p \leq .05) \), Tangible support \( (r = -0.42, p \leq .05) \), and the support type composite score \( (r = -0.43, p \leq .05) \), indicating fewer social difficulties not due to illness.
Variables measuring child self-reported self-competency, as measured by the PCS, were significantly associated with support types, as was hypothesized. Children’s Social self-competency was positively associated with Informational ($r = .46, p \leq .01$), Esteem ($r = .63, p \leq .001$), and Tangible support ($r = .69, p \leq .001$), and the support type composite ($r = .69, p \leq .001$). General self-competency was related to Informational, Esteem, and Tangible support ($r = .54, p \leq .01; r = .52, p \leq .01; r = .51, p \leq .01$, respectively) and the support type composite ($r = .61, p \leq .001$). Physical self-competency was positively correlated with Esteem ($r = .35, p \leq .05$), and Tangible support ($r = .40, p \leq .05$) as well as the support type composite ($r = .39, p \leq .05$). Cognitive self-competency was not correlated with any of the three support types or the support type composite score.

Correlations between parent-report of child psychological adjustment as measured by the BASC and the three types of support were also considered. A significant positive association was found between Informational support and greater symptoms of Atypicality ($r = .42, p \leq .05$). Contrary to hypothesis, no other significant associations were found between the three types or the support type composite score and any of the other BASC subscale or composite scores.

Sources of support. The relationships between the possible sources of social support and measures of quality of life, social functioning, psychological adaptation and self-competency were then examined. Table 5 presents the results of bivariate correlations between the sources of support and child self-report of General and Cardiac QOL. The social support source composite score was positively associated to the Physical and Social QOL subscale scores and the Psychosocial QOL composite and General QOL total scores of the child self-report of General QOL. It appears that Family and Friends were the two sources of support that yielded mostly significant positive associations with each of the domains of General QOL, as was hypothesized.
Perceived support from family members was positively correlated with each of the General QOL subscale and composite scores, while perceived support from friends was positively correlated with all of the General QOL variables except Emotional QOL. Support from classmates was positively associated with the Social QOL subscale and the Psychosocial composite and General QOL total scores. Teacher support was positively correlated only with Social QOL and the General QOL total score. There were no significant correlations between support from Doctors/Nurses and any of the General QOL variables.

As was true for types of support, there were relatively fewer associations between sources of support and child self-report of Cardiac QOL in comparison to results for General QOL. The support source composite score was positively correlated with Cognitive QOL. Additionally, Family support was positively associated with Appearance and Cognitive QOL, while Friend support was positively associated with Cardiac and Cognitive QOL subscales. However, there were no significant associations between Classmate, Teacher, or Doctor/Nurse support and any of the Cardiac QOL subscale or composite scores.

When correlations between parent-report of child General and Cardiac QOL and the various sources of support were examined, only Family support was significantly associated with School QOL \( (r = .47, p < .01) \). There were no other significant associations for Family support, and Friend, Class, Teacher, Doctor/Nurse, and the support source composite score were not significantly correlated with any of the parent-reported General or Cardiac QOL subscale or composite scores.

Children’s self-report of Social Problems as measured by the BASC was negatively correlated with Class \( (r = -.36, p < .05) \) and Family \( (r = -.40, p < .05) \) support, indicating that these sources of support were correlated with fewer social problems. Support from Friends,
Teachers, and Doctors/Nurses and the support source composite score were not significantly related to children’s BASC Social Problems scores. There were also no significant associations between child- or parent-report of Social Problems Not Due to Illness or child-report of Social Problems due to Illness and any of the support types of support composite. There was a significant negative association between Family support and parent-report of child Social Problems Due to Illness ($r = -.38$, $p < .05$). There were no significant associations between any of the social support sources and child self-competency or child psychological adjustment.

**Between Group Analyses**

ANOVA procedures were conducted in order to further explore between-group differences for the various types or sources of social support and the dependent variables. ANOVA procedures allow for the examination of possible interactions between sources of support or between types of support for each dependent variable of interest. In order to form balanced groups, a median split was performed on participants’ subscale scores for each of the three types of support and the five sources of support. For each type and source, participants were categorized into either a low support or high support group. In order to eliminate redundant results and streamline the presentation of data, only results of group comparisons for the composite scores of the dependent measures are presented.

**Types of support.** In order to examine the relationships between the three types of social support (Esteem-enhancing, Informational, and Tangible) and the dependent variables, 3-way ANOVAs were conducted for each of the composite scores of interest. The main effects of each of the three types of support and the three possible 2-way interactions of Informational x Esteem, Informational x Tangible, and Esteem x Tangible were examined. Due to problems with empty cells, higher-order interactions were not considered. Based on the preliminary analyses,
demographic variables in which significant group differences were present for the composite scores of the dependent variable were included as a covariate in these ANOVA procedures.

Child self-report on the General QOL composite was examined. Group comparisons for the General QOL composite indicated a significant main effect for Esteem support and a significant interaction effect of Informational support by Esteem support. Table 6 presents the results of the 3-way ANOVA for the General QOL composite. Because the interaction between Information and Esteem support was significant, the main effect of Esteem support will not be discussed in further detail. The interaction was further examined with simple main effects analyses indicating that the high and low Esteem groups were significantly different when at a low level of Informational support ($F [1, 27] = 13.89, p ≤ .001$). As Figure 1 displays, at a low level of Informational support, the high Esteem support group had a General QOL composite mean of 87.58 ($SD = 12.21$) while the low Esteem group had a mean of 59.93 ($SD = 13.99$).

There were no significant main effects for the Psychosocial QOL composite, but there was a significant interaction effect for Informational support and Esteem support (Table 7). Simple main effects analyses revealed that at the low Informational support level, the high and low Esteem support groups differed significantly ($F [1, 27] = 10.32, p ≤ .01$). As displayed in Figure 2, at the low Informational support level, the high Esteem support group ($M = 82.92, SD = 15.54$) had a significantly higher Psychosocial composite score than the low Esteem group ($M = 58.03, SD = 14.39$). There was no significant difference between the low and high Esteem groups at a high level of Informational support.

Child self-report of the Cardiac QOL composite score was then examined, with the results of the 3-way ANOVA presented in Table 8. There was a significant main effect for Tangible support level ($F [1, 24] = 4.90, p ≤ .05$). The low Tangible support group had a
significantly lower Cardiac QOL composite score ($M = 67.09, SD = 13.59$) than the high Tangible support group ($M = 79.64, SD = 11.72$). There was also a significant interaction effect for Informational support with Esteem support. Due to the significant interaction effect, the main effect of Tangible support was not considered further. Examination of the interaction effect with simple main effect analyses indicated that there were no significant group differences in Esteem support at the high Informational support level. However, there was a significant group difference at the low Informational level ($F [1, 27] = 6.31, p \leq .05$), with the high Esteem support group with a mean Cardiac QOL composite score of 88.90 ($SD = 6.92$) and the low Esteem support group with a mean of 68.88 ($SD = 10.80$) (Figure 3).

Group differences for the types of support and child-report on each of the four self-competency subscales were then considered. For the Social self-competency subscale, there was a significant main effect for the covariates of age ($F [1, 22] = 8.32, p \leq .01$), and income ($F [1, 22] = 5.83, p \leq .05$). Individuals who were younger ($M = 1.71, SD = .53$) had lower Social self-competency means than older participants ($M = 2.25, SD = .50$), while those who were in the lower income group ($M = 1.82, SD = .50$) had lower Social self-competency means than those in the higher income group ($M = 2.03, SD = .58$). There was also a significant main effect for Tangible support ($F [1, 29] = 4.11, p \leq .05$), with the low Tangible support group ($M = 1.67, SD = .44$) reporting a significantly lower Social self-competency mean than the high Tangible support group ($M = 2.35, SD = .49$).

Cognitive self-competency was then examined. While there were no significant main effects, both the Informational by Tangible support and the Esteem by Tangible support interaction terms were significant (Table 9). Examination of the simple main effects for the interaction of Information and Tangible support indicated that there were no differences between
the two Tangible support groups at the low Informational support level. There were significant differences at the high Informational support level \( (F[1, 27] = 8.06, p \leq .01) \), however. As Figure 4 portrays, when at the high Informational support level, the high Tangible group \((M = 2.49, SD = .50)\) had a significantly higher Cognitive self-competency mean than those in the low Tangible group \((M = 1.60, SD = .88)\). Simple main effects analyses for the interaction of Esteem support and Tangible support, indicated there were significant group differences for the high and low Esteem groups when at a low level of Tangible support \((F[1, 27] = 7.61, p < .01)\). The high Esteem group had a significantly lower Cognitive self-competency mean \((M = 1.25, SD = .59)\) than the low Esteem group \((M = 2.17, SD = .46)\) when at the low Tangible support group level (Figure 5).

Group differences in the relationship between types of support and social functioning as measured by child and parent report on the LCI and Social Problems subscale of the BASC were then considered. There were no significant main effects or interaction effects for the child-report on the LCI subscales or child or parent report on the BASC Social Problems subscale. When parent report on the LCI subscale measuring Social Problems Not Due to Illness was examined, however, there was a significant interaction of Informational and Tangible support. Table 10 presents the results of the 3-way ANOVA. Examination of the simple main effects indicated that at the low level of Tangible support, there were no group differences for Informational support. However, there were significant group differences when Tangible support was high \((F[1, 27] = 5.42, p \leq .05)\), with the high Tangible, high Information support group \((M = .64, SD = 1.03)\) reporting a significantly lower mean, and therefore a lower level of social problems, than the high Tangible, low Information support group \((M = 4.20, SD = 5.02)\) (Figure 6).
Group differences for parent report of child General and Cardiac QOL composite scores were examined and there were no significant group differences. There were also no significant group differences for parent-report of child psychosocial adjustment as measured by composite scores on the BASC.

Sources of social support. ANOVAs were also conducted to examine group differences for the five sources of social support and the dependent variables. In order to examine the relationships between the five sources of social support and the dependent variables, 5-way ANOVAs were conducted for each of the composite scores of interest. The main effects of each of the five sources of support (Friends, Family, Class, Teacher, Doctor/Nurse) and the ten possible 2-way interactions (Friend x Family, Friend X Class, Friend x Teacher, Friend x Doctor/Nurse, Family x Class, Family x Teacher, Family x Doctor/Nurse, Class x Teacher, Class x Doctor/Nurse, Teacher x Doctor/Nurse) were examined. Due to problems with empty cells, higher-order interactions were not considered. Based on the preliminary analyses, demographic variables that were significantly related to the composite scores of the dependent variables of interest were included as a covariate in these ANOVA procedures.

Contrary to expectation, there were no significant group differences for the support sources when parent- or child-report of General QOL or Cardiac QOL composites were examined. There were also no significant group differences when parent-report of child psychosocial adjustment based on the BASC composite scores were examined. Group differences for the sources of support and child social functioning as measured by the BASC Social Problems subscale and the LCI were then considered. Significant group differences were found only for parent-reported child Social Problems Not Due to Illness. There was a significant main effect (F [1, 14] = 5.92, p < .05) for Teacher support, with the low Teacher support group
having a significantly greater level of non-illness related social problems ($M = 2.53, SD = 3.37$) than the high Teacher support group ($M = 1.21, SD = 2.36$). No significant interaction effects were found. Child self-report of self-competency was also examined with sources of support. Group differences were found for General self-competency, as there was a main effect of Class support ($F [1, 14] = 4.44, p < .05$). The low Class support group ($M = 1.69, SD = .41$) had significantly lower General self-competency than those who were high in Class support ($M = 2.35, SD = .42$). No significant interaction effects were present.
CHAPTER 4
DISCUSSION

The purpose of this study was to examine associations between social support and various aspects of QOL and psychosocial functioning for children and adolescents with cardiac pacemakers and ICDs. Children’s perceptions of the amount of support they received from three different types of support and from five different sources of support was assessed. These measures of support were considered in relation to the children’s own and to their parents’ reports of their general and cardiac QOL, self-competency, social problems that were both related and unrelated to their illness, and their psychological adjustment. While several studies have examined the role of social support in the psychological and social functioning of medically ill adults (e.g., Baker, Zabora, Jodrey, Polland, & Marcellus, 1995; Dakof & Taylor, 1990; Dunkel-Schetter, 1984), few studies have considered the role of specific types and sources of social support for pediatric populations (e.g., Greco, Pendley, McDonnell, & Reeves, 2001), and no studies have considered the role of social support for children and adolescents with internal cardiac devices. Additionally, this study addresses the current dearth of research which looks beyond measures of the usual outcomes of psychological and social adjustment to consider the relationship between social support and QOL for children and adolescents with chronic illness.

Overall, results supported the hypotheses that perceived social support would be positively associated with higher levels of general and cardiac quality of life and self-competency and lower levels of social problems. This association was most consistently found for both the types and sources of social support and children’s self-report of General QOL. When specific types of support are considered, each of the three types were generally positively
associated with higher levels of General QOL and self-competency and fewer social problems. Also, as expected Family and Friend support were the sources of support that were most consistently associated with higher levels of child General and Cardiac QOL. Between-groups analyses revealed several significant interaction effects for types of support and the dependent variables. For both the correlational and between-group analyses, even though social support was generally associated with higher QOL, better self-competency, and fewer social problems, it was not associated with fewer psychological difficulties in this sample. Also, there were few significant associations for either the correlational or between-group analyses when parent-report measures and child self-report of social support were considered.

The finding that children’s self-report of General QOL was positively correlated with each of the three types of support is consistent with previous findings that, although they may vary in the degree of helpfulness, each of the three types of support is generally associated with positive outcomes (Cauce, Mason, Gonzales, Hiraga, & Liu, 1994). Support for the positive role of each of the types of support was also found when child self-competency was examined, as a pattern of positive associations was found for each type of support with child Social, Physical, and General self-competency. Esteem, Informational, and Tangible support each appear to play a positive role in children’s perceptions of their overall daily life functioning as well as their perceptions of their overall, social, and physical abilities.

Although unexpected, the relative lack of significant associations between the types of support and the Cardiac QOL factors is possibly due to the physically-oriented nature of the scale. The Cardiac QOL scale measures factors such as problems with cardiac health and treatment (e.g., “My lips turn blue when I run”), which are directly related to the child’s physical condition and possibly less easily influenced by psychosocial factors, such as social support.
Similarly, there were no significant associations between support types and Cognitive self-competency. Children with pacemakers or ICDs are susceptible to experiencing cognitive difficulties related to their underlying cardiac condition. Therefore, their perceptions of their cognitive abilities may be realistically lower than their peers and are not likely to be as easily impacted by factors such as social support. The finding that Emotional, Social, and School QOL were positively associated with each of the three types of support and the support type composite, while Physical QOL was significantly associated only with the support type composite score also fits with this pattern of results.

Support was also found for the positive role of social support types in children’s social difficulties. Both Esteem support and Tangible support were positively associated with fewer social problems as measured by the BASC Social Problems subscale. However, when social problems were delineated into problems attributed to the child’s illness and problems not attributed to the child’s illness, as measured by parent- and child-report on the LCI, Esteem and Tangible support were related only to children’s self-reports of social problems that were not illness-related. These two support types appear to have a beneficial association with social problems that children do not attribute to their illness (e.g., “I am not invited to parties”). However, there appears to be fewer associations between social support and social problems when children place an illness-oriented attribution on the problem (e.g., “I am not invited to parties because of my heart condition”). Similar to the findings for the Cardiac QOL scales, these differential associations may reflect the greater physical orientation of social problems due to illness, which may not be as influenced by social support. While social support may not have a significant direct impact on a child’s physical condition, there does appear to be an important
relationship between social support and other key aspects of the child’s social, emotional, and psychological functioning, all of which are important factors in a child’s overall sense of QOL.

Strong support was also found for the positive association between perceived social support from the various support sources and child self-report of General QOL. However, in comparison to results for the support types in which each of the three types was positively associated with child QOL, certain support sources appeared to play a more important role than others. As anticipated, support from family and friends had the most consistent pattern of positive associations with the General QOL scales. These two sources of support were also positively associated with several Cardiac QOL scales. Family support was associated with fewer social problems as measured by child-report on the BASC Social Problems subscale, as well as parent-report of child illness-related social problems as assessed by the LCI. These findings are consistent with previous findings with chronically ill adults (Parker & Asher, 1993; Primomo, Yates, & Woods, 1990). Support from friends has only recently been considered in relation to the psychosocial functioning of adolescents with chronic illness (e.g., Greco, Pendley, McDonnell, & Reeves, 2001), and results have generally indicated the positive impact of peer support. Results from this study, therefore, lend further support for the positive role of support from friends for adolescents with chronic illness, while also expanding upon previous findings by demonstrating the positive associations of friend support for younger children.

Classmates and teachers are two support sources which have received considerably less attention in previous studies examining support sources for children with chronic illness. Although the pattern of significant positive associations was not as strong as for Family and Friend support, support from Classmates and Teachers was positively associated with children’s report of Social QOL and the General QOL and Psychosocial QOL composites. Classmate
support was also associated with fewer social problems based on child self-report. Children spend copious amounts of time at school with their classmates and teachers on a daily basis, and these individuals appear to play a unique and important role for children with chronic illness. Children who have pacemakers and ICDs often experience physical limitations or difficulties secondary to their cardiac condition, and the support and understanding of their classmates and teachers can have a tremendous impact on the social functioning of these children.

The associations between social support provided by healthcare professionals and pediatric patients’ QOL and adjustment has not been examined. In the current study, contrary to hypothesis, there were no significant associations for Doctor/Nurse support and any of the variables measuring child QOL, self-competency, or social problems. This finding is in contrast to the scant anecdotal and research evidence found in the adult literature (e.g., Dakof & Taylor, 1990). It is possible that the type of support provided by healthcare practitioners is indeed beneficial, but that it differs from that provided by other sources due to factors such as the limited amount of contact with the patients, as well as the medical staffs’ emphasis on the children’s physical condition and treatment. For these reasons, it would appear that both the type of medical staffs’ support, as well as the effects of that support, should be measured in different and more medically-based, context-specific ways. The relationship between social support from doctors, nurses, and other healthcare professionals and child functioning on measures of QOL and psychosocial adaptation warrants a more in depth, focused examination in future studies.

Examination of the between-group analyses revealed several interaction effects for types of support with the composite scores of the dependent variables. In particular, there appeared to be a distinct pattern of significant interaction effects for Informational and Esteem support with measures of General and Cardiac QOL. Participants in the low and high Esteem support groups
differed primarily when at a low level of Informational support. Therefore, Esteem support, which typically communicates caring for the individual’s expression of affect, was associated with higher levels of QOL, but only when accompanied by a low level of Informational support. This finding is somewhat inconsistent with previous studies indicating that both Esteem and Informational support are generally consistently associated with positive outcomes for individuals with chronic illness (Dakof & Taylor, 1990; Primomo, Yates, & Woods, 1990). However, previous studies have not considered the interaction of the two types of support. It is possible that Informational support, which typically involves providing guidance or information, is not as effective in circumstances in which emotional support and validation are what the child is seeking. Additionally, it may be that a high level of both types of support is perceived as overwhelming or confusing to the child.

Tangible support appeared to play an important, positive role in several aspects of children’s QOL, self-competency, and social functioning. Tangible support typically involves providing the individual with things they need, such as money, material goods, or hands-on assistance. While typically associated with positive outcomes, tangible support generally has not been found to be as helpful as other support types (Dakof & Taylor, 1990; Dunkel-Schetter, 1984). However, for Cardiac QOL, there was a significant main effect of Tangible support for the Cardiac QOL composite score in which higher levels of Tangible support were related to higher Cardiac QOL means. In addition, higher Social self-competency was found for those who were higher in Tangible support. These positive effects may be to some degree related to the direct, “hands-on” nature of tangible support. Tangible support often involves providing concrete assistance with problems and thus can have a direct and immediate impact. For instance, Tangible support may be expressed in the form of providing transportation or money so
that the child can engage in social activities with peers which may have an impact on the child’s sense of social self-competency.

Consistent with other findings, the combination of high levels of Informational support and high levels of Tangible support was related to better Cognitive self-competency scores. A similar pattern was found for parent-report of child Social Problems Due to Illness, as at the high Tangible support level, the high Informational support group reported having a significantly lower number of illness-related social problems than the low Informational group. In contrast, however, the significant interaction of Esteem support and Tangible support revealed that the low Esteem, high Tangible group had a significantly higher Cognitive self-competency score than high Esteem, high Tangible support group.

Generally, these findings appear to indicate the positive benefits of high levels of Tangible support. In particular, the combination of high Informational and high Tangible support appears to be associated with better outcomes. However, the relationship between Tangible support and other types of support appears somewhat complicated. Tangible support may differ somewhat from Esteem and Informational support because it is more likely to be concrete in comparison to the more affect-oriented nature of the other types of support. It is possible that the combination of Tangible and Information support is more beneficial in certain circumstances because they target different needs in the child, in comparison to the combination of Esteem and Information support which are more similar to each other. It may also be that children who have higher self-competency or fewer illness-related social problems, elicit higher levels of Tangible support. Clearly, however, the role of Tangible support is more important than previously considered and warrants further examination.
When sources of support were considered, the between group analyses indicated a main effect of Teacher support for parent-reported Social Problems Not Due to Illness, with greater levels of support from teachers associated with fewer social problems, as would be anticipated. The significant main effect of Class support for child General self-competency was also in the expected direction with higher levels of support related to higher levels of General self-competency. Taken with the results of the correlational analyses, these findings lend further support for the role of Teachers and Classmates as important sources of social support for children and adolescents with chronic illness. Although not typically considered a primary source of social support, teachers can have a tremendous impact as they often have the ability to shape the social atmosphere of the classroom as well as to intervene when children are experiencing social problems in the classroom. Also, positive support from classmates can have a positive impact on a child’s overall sense of self and self-competency. Obviously these are two sources of support which deserve further examination and may prove to be important in the development of future school-based social support interventions for children and adolescents with chronic illness.

Interestingly, there was a general lack of significant associations between social support types and sources and the parent-report measures. This was true for both the correlational and the between-group analyses. The lack of associations for parent-report on the QOL measures is especially notable in comparison to the strong pattern of associations found for types and sources of support and child-report on the QOL scales. This disparity between parent and child report has frequently been noted in other research studies (Martin, Ford, Dyer-Friedman, Tang, & Lynne, 2004) and there have been a number arguments regarding which source is the most appropriate reporter of children’s internal states. While the findings have been mixed, there is some support
for the position that parents are not always accurate reporters of their children’s emotions and perceptions which may account for the differences across reporters to some degree.

Results also indicated that the children and adolescents with pacemakers or ICDs examined in this study had significantly lower general QOL and self-competency in comparison to a healthy peer group. This is similar to previous findings indicating diminished functioning for pediatric populations in comparison to healthy peer groups (Delamater, 2003; Lavigne & Faier-Routman, 1993; Wallander & Varni, 1992). Although participants were significantly lower than healthy peers on all areas of QOL, their scores on the parent-report on the BASC, a standardized measure of child psychosocial functioning, indicated that they were within the average range on all subscale and composite scores and did not differ significantly from the normative population. The disparity between scores on measures of QOL and psychosocial functioning is consistent with arguments indicating the need to conduct assessments with children with chronic illness using measures of QOL in conjunction with or instead of measures of psychopathology (Perrin, Stein, & Drotar, 1991). Measures of psychopathology or psychosocial functioning may not be sufficiently sensitive to variations in functioning for children with chronic illness. Although these children may not demonstrate significant psychopathology, they may still have experienced decrements in quality of life or had a significant impact on their lives due to their illness.

Even though children with pacemakers and ICDs reported lower QOL than healthy peers, the results of analyses conducted within this cardiac sample indicates aspects of the children’s physical condition were associated only with those outcome variables measuring physical functioning. Within this sample, the overall QOL of children and adolescents with chronic illness is influenced much more by social factors than by their general physical condition or the degree of their illness severity (also see Spieth & Harris, 1996). QOL is comprised of a multitude of
factors, all of which need to be assessed in order to capture a comprehensive picture of a child’s ability to cope and function with his or her illness on a daily basis.

There were several significant associations between the demographic variables of age, race, and income, and the outcome measures. Results from this study seem to indicate that children and adolescents who had poorer QOL, self-competency, and social functioning tended to be those who were younger, of lower income, and who belonged to a minority racial group. These findings are consistent with research indicating that children and adolescents who are demographically at-risk have poorer adjustment in a variety of areas of life functioning (Taylor, Seaton, & Rodriguez, 2002). Therefore, it can be expected that in some circumstances these vulnerable individuals could have generally poorer QOL and psychosocial functioning. These findings also suggest that patients who display some or all of these demographic characteristics may be in greater need of psychosocial intervention to increase support and provide other services.

There are several limitations to this study that should be considered. First, the relatively small sample size limits the power of the statistical analyses to find significant associations. Additionally, because these participants were children and adolescents with implanted cardiac devices, the generalizability of these results to pediatric patients with other physical conditions should be considered with caution. Also, due to time constraint and concerns about requiring the participants to complete extensive inventories, the amount and type of data collected from the participants was somewhat restricted and child self-report of psychosocial functioning was not obtained. This study approached types and sources of social support separately. In reality, however, social support is a complex and multifaceted construct, and each source of social support provides varying amounts of each of the different types of support. Finally, the findings
of this study are correlational in nature. Therefore, the directionality of the relationship between social support and the dependent measures cannot be clearly determined. The support source may be the initiating factor that results in a certain level of QOL. In contrast, QOL may also influence the child’s ability to adequately solicit different levels of support.

The results of this study highlight several important directions for future research in this area. Due to the correlational nature of this study, the ability to draw causal conclusions from the results is restricted. Future research should focus on employing other methods of design, such as longitudinal studies, which would allow a prospective examination of the development of the relationship between social support and child QOL and psychosocial functioning. A prospective, longitudinal design would also allow for the examination of developmental changes in the associations between social support and child QOL or psychosocial functioning as children mature. Also, other methods of data collection, such as using interviews, observational methods, and reports from multiple informants would provide a more detailed picture of children’s and adolescents’ perceptions of their social relationships and the associations with QOL and psychosocial functioning.

Based on the significant associations for Teacher and Classmate support and child social functioning found in this study, these sources of support, which previously have received very little attention, should be explored further. The results also suggest that Tangible support, which in previous studies has not been associated with positive outcomes to the degree found in this study, deserves greater attention. Additionally, it would be important for future investigations to further consider the role that demographic variables such as socioeconomic status or racial group differences may have in the relationship between social support and child QOL and psychosocial functioning. Finally, the overall lack of findings for the between group analyses for sources of
support is likely due to the large number of interaction terms examined. However, because these relationships have not been considered in previous research studies, a priori hypotheses were not generated. Future research would benefit from conducting a more focused between-group analysis of the interactions of various support sources of interest.

This study brings to light many important factors regarding QOL and social support in children with pacemakers and ICDs. Although previous research has examined the relationship between social support and psychosocial adjustment for adults with chronic illness, few studies have been conducted which examine this relationship for children and adolescents. In addition, no studies have been conducted in which a more detailed examination of the specific types and sources of perceived support and QOL were examined for children.

The findings from this study may have several important implications for developing coping interventions for children. In particular, it can be instructive for counselors and parents to be aware that not all social support is equal; particular types of support or combinations of types of support are more beneficial to children’s ability to function with their illness on a daily basis. Additionally, the findings provide further evidence for the importance of including family members as well as friends in the support process for these children. Intervention programs for children with chronic illness which include elements of social support and involve family members as well as friends have potential to have more beneficial effects than working with the child or adolescent alone. Findings also speak to the important role that individuals who are not typically seen as sources of social support, such as teachers and classmates, can have for children and adolescents who are coping with an illness. This may be informative for the development of future school-based interventions for children with chronic illness in which their teachers, classmates, and friends can participate.
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APPENDIX A

MEASURES

Demographic and Health Information Questionnaire

Child’s Date of Birth:___________  Child’s Age: ______  Gender:________

Child’s Race/Ethnicity (check all that apply):
☐ Caucasian
☐ African American
☐ Latino or Hispanic
☐ Asian or Pacific Islander
☐ South Asian (Indian)
☐ Native American
☐ Middle Eastern
☐ Bi-racial or mixed heritage:_______________________________
☐ Other:______________________________________________

Father’s highest level of education:
☐ 6  ☐ Some college or associates degree
☐ 7  ☐ College degree
☐ 8  ☐ Some graduate work
☐ 9  ☐ MA or MS
☐ 10 ☐ Ph.D., MD or other similar level degree
☐ 11
☐ 12

Father’s occupation (please list type of job):________________________

Mother’s highest level of education:
☐ 6  ☐ Some college or associates degree
☐ 7  ☐ College degree
☐ 8  ☐ Some graduate work
☐ 9  ☐ MA or MS
☐ 10 ☐ Ph.D., MD or other similar level degree
☐ 11
☐ 12

Mother’s occupation (please list type of job):__________________________________

Approximate yearly gross family income (before taxes):
☐ less than $15,000
☐ $15,000 to $30,000
☐ $30,000 to $45,000
$45,000 to $60,000
☐ Above $60,000

1. What is your child’s primary cardiac diagnosis? _____________________________

2. Does your child currently have any other medical or psychiatric problems? If yes, please list: __________________________________________________________

3. What medications is your child currently taking (please list all)? _________________
   _____________________________________________________________________

4. How old was your child when he/she was first diagnosed with his/her cardiac disorder? __________________________________________________________

5. How old was your child when he/she received his/her first pacemaker? _________________________________________________________________

6. What type of pacemaker does your child currently have? ______________________

7. How many surgeries has your child had in his/her lifetime? _________________

8. When was your child’s most recent surgery? _______________________________

9. How many times has your child been hospitalized in the past year? __________

10. How many total days has your child spent in the hospital in the past year? ______

11. How many times has your child had to go to the emergency room or had emergency clinic visits in the past year? _________________________________

11. How many invasive procedures has your child undergone related to his/her pacemaker in the past year (i.e., catheterizations, surgeries)? _________________

12. How many outpatient visits has your child had related to his/her pacemaker in the past year? _________________________________

13. How many days did your child miss from school due to physical illness in the past two months? _________________________________

14. How many days was your child sick in bed or too sick to play in the past two months? _______________________________
Survey of Children’s Social Support- Scale of Available Behaviors (SAB- Types of support)

1. How often does somebody help you when you need help making up your mind about something?
   - always (1)
   - most of the time (2)
   - sometimes (3)
   - hardly ever (4)
   - never (5)

2. How often does someone help you when you want to settle an argument or fight that you had?
   - always (1)
   - most of the time (2)
   - sometimes (3)
   - hardly ever (4)
   - never (5)

3. How often can you find someone to talk to when you are mad about something?
   - always (1)
   - most of the time (2)
   - sometimes (3)
   - hardly ever (4)
   - never (5)

4. When you are happy, how often can you find someone who will be happy with you?
   - always (1)
   - most of the time (2)
   - sometimes (3)
   - hardly ever (4)
   - never (5)

5. How often does somebody help you calm down when you are nervous about something?
   - always (1)
   - most of the time (2)
   - sometimes (3)
   - hardly ever (4)
   - never (5)

6. When you want to go somewhere, how often does somebody take you?
   - always (1)
   - most of the time (2)
   - sometimes (3)
   - hardly ever (4)
   - never (5)

7. When you want to learn how to do something new, how often does somebody teach you how to do it?
   - always (1)
   - most of the time (2)
   - sometimes (3)
   - hardly ever (4)
   - never (5)

8. When you want to know all about a new movie or TV show, can you find someone to tell you about it?
   - always (1)
   - most of the time (2)
   - sometimes (3)
   - hardly ever (4)
   - never (5)
9. When you have to do a special project for school (like a book report or a science project), can you find someone to give you advice about what to do?
always  most of the time  sometimes  hardly ever  never
(1)  (2)  (3)  (4)  (5)

10. How often does someone give you ideas about how to spend your time when you have nothing to do?
always  most of the time  sometimes  hardly ever  never
(1)  (2)  (3)  (4)  (5)

11. When you want to play with somebody’s new toy or game, how often do they share it with you?
always  most of the time  sometimes  hardly ever  never
(1)  (2)  (3)  (4)  (5)

12. How often does someone give you money when you want to buy candy or something else?
always  most of the time  sometimes  hardly ever  never
(1)  (2)  (3)  (4)  (5)

13. How often can you find someone to talk to who will help make you feel better when you had a fight?
always  most of the time  sometimes  hardly ever  never
(1)  (2)  (3)  (4)  (5)

14. How often does somebody notice when you are upset about something?
always  most of the time  sometimes  hardly ever  never
(1)  (2)  (3)  (4)  (5)

15. How often can you find someone to be with when you are lonely?
always  most of the time  sometimes  hardly ever  never
(1)  (2)  (3)  (4)  (5)

16. How often do you get a special reward or treat?
always  most of the time  sometimes  hardly ever  never
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<td>17. How often do people give you something that they don’t need anymore?</td>
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<td>18. How often do you go on vacations or trips with your family?</td>
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<td>19. How often does somebody make you feel better when you mess up at something?</td>
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<td>20. How often does somebody make you feel better when you hurt yourself?</td>
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<td>21. How often does someone help you when you want to learn how to do better at something?</td>
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<td>22. When you don’t understand a question, how often does somebody help answer it for you?</td>
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<td>23. How often does somebody cheer you up when you lose a game?</td>
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<td>24. When you have a secret you want to share, how often can you find someone to tell it to?</td>
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<td>25. When you want to trade things with other people, how often do they trade with you?</td>
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26. When you try and sell something to people you know (like Girl Scout cookies, or a candy or magazine sale), how often do they buy it from you?

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27. When you have a problem that you want to talk about, how often can you find someone to tell it to?

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28. How often does somebody cheer you up when you are sad?

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29. How often does somebody say nice things to you when you do something well?

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<th></th>
<th>always</th>
<th>most of the time</th>
<th>sometimes</th>
<th>hardly ever</th>
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30. How often does somebody stand up for you when you get picked on?

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<th>always</th>
<th>most of the time</th>
<th>sometimes</th>
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31. How often do people say things that make you feel good, or happy, or important?

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<th></th>
<th>always</th>
<th>most of the time</th>
<th>sometimes</th>
<th>hardly ever</th>
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32. How often can you find someone to help you when you get in trouble?

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<tr>
<th></th>
<th>always</th>
<th>most of the time</th>
<th>sometimes</th>
<th>hardly ever</th>
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<td>(1)</td>
<td>(2)</td>
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</table>

33. How often are people happy for you when you do something well?

<table>
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<tr>
<th></th>
<th>always</th>
<th>most of the time</th>
<th>sometimes</th>
<th>hardly ever</th>
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34. When you do work (like drawings or other papers), how much are people interested in it (by hanging it up, or sending it to your grandparents)?

<table>
<thead>
<tr>
<th>always</th>
<th>most of the time</th>
<th>sometimes</th>
<th>hardly ever</th>
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35. How often do people listen to you when you have ideas?

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<thead>
<tr>
<th>always</th>
<th>most of the time</th>
<th>sometimes</th>
<th>hardly ever</th>
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36. When something is bothering you, how often does somebody help you forget about it?

<table>
<thead>
<tr>
<th>always</th>
<th>most of the time</th>
<th>sometimes</th>
<th>hardly ever</th>
<th>never</th>
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<td>(1)</td>
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37. How often can you find somebody to be with when you don’t feel good?

<table>
<thead>
<tr>
<th>always</th>
<th>most of the time</th>
<th>sometimes</th>
<th>hardly ever</th>
<th>never</th>
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<td>(1)</td>
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38. How often are you one of the first to be chosen for a team?

<table>
<thead>
<tr>
<th>always</th>
<th>most of the time</th>
<th>sometimes</th>
<th>hardly ever</th>
<th>never</th>
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</table>
Survey of Children’s Social Support - Appraisals of Support (APP - Sources of support)

1. Some kids feel left out by their friends, but other kids don't. Do you feel left out by your friends?
   always most of the time sometimes hardly ever never
   (1) (2) (3) (4) (5)

2. Some kids are well-liked by their friends, but other kids aren't. Are you well-liked by your friends?
   always most of the time sometimes hardly ever never
   (1) (2) (3) (4) (5)

3. Some kids get picked on and teased by their friends, but other kids don't. Do you get picked on and teased by your friends?
   always most of the time sometimes hardly ever never
   (1) (2) (3) (4) (5)

4. Some kids' friends make fun of them, but other kids' friends don't. Do your friends make fun of you?
   always most of the time sometimes hardly ever never
   (1) (2) (3) (4) (5)

5. Some kids' friends like to hear their ideas, but other kids' friends don't. Do your friends like to hear your ideas?
   always most of the time sometimes hardly ever never
   (1) (2) (3) (4) (5)

6. Some kids and their friends do a lot of things for each other, but other kids and their friends don't. Do you and your friends do a lot of things for each other?
   always most of the time sometimes hardly ever never
   (1) (2) (3) (4) (5)

7. Some kids feel very close to their friends, but other kids don't. Do you feel very close to your friends?
   always most of the time sometimes hardly ever never
   (1) (2) (3) (4) (5)

8. Some kids can count on their friends for help or advice when they have problems, but other kids can't. Can you count on your friends for help or advice when you have problems?
9. Some kids think their friends really care about them, but other kids don't. Do you think your friends care about you?

always  most of the time  sometimes  hardly ever  never
(1)     (2)                   (3)               (4)          (5)

10. Some kids' friends make them feel bad, but other kids' friends don't. Do your friends make you feel bad?

always  most of the time  sometimes  hardly ever  never
(1)     (2)                   (3)               (4)          (5)

11. Some kids feel like they belong in their class, but other kids feel like they don't belong. Do you feel like you belong in your class?

always  most of the time  sometimes  hardly ever  never
(1)     (2)                   (3)               (4)          (5)

12. Some kids feel left out by their class, but other kids don't. Do you feel left out by your class?

always  most of the time  sometimes  hardly ever  never
(1)     (2)                   (3)               (4)          (5)

13. Some kids feel like nobody in their class cares about them, but others don't feel this way. Do you feel like nobody in your class cares about you?

always  most of the time  sometimes  hardly ever  never
(1)     (2)                   (3)               (4)          (5)

14. Some kids are well-liked by their classmates, but others are not. Are you well-liked by your classmates?

always  most of the time  sometimes  hardly ever  never
(1)     (2)                   (3)               (4)          (5)

15. In some classes, kids do a lot of things for each other, but in other classes they don't. In your class, do kids do a lot of things for each other?

always  most of the time  sometimes  hardly ever  never
(1)     (2)                   (3)               (4)          (5)
16. Some kids can count on their family for help or advice when they have problems, but other kids cannot. Can you count on your **family** for help or advice when you have problems?
   always  most of the time  sometimes  hardly ever  never
   (1)    (2)       (3)         (4)       (5)

17. Some kids and their families do a lot of things for each other, but other kids and their families don't. Do you and your **family** do a lot of things for each other?
   always  most of the time  sometimes  hardly ever  never
   (1)    (2)       (3)         (4)       (5)

18. Some kids' families make them feel bad, but other kids' families don't. Does your **family** make you feel bad?
   always  most of the time  sometimes  hardly ever  never
   (1)    (2)       (3)         (4)       (5)

19. Some kids share a lot with their family, but other kids don't. Do you share a lot with your **family**?
   always  most of the time  sometimes  hardly ever  never
   (1)    (2)       (3)         (4)       (5)

20. Some kids have a hard time talking to their family, but other kids don't. Do you have a hard time talking to your **family**?
   always  most of the time  sometimes  hardly ever  never
   (1)    (2)       (3)         (4)       (5)

21. Some kids feel like their family is there when they need them, but other kids don't feel this way. Do you feel like your **family** is there when you need them?
   always  most of the time  sometimes  hardly ever  never
   (1)    (2)       (3)         (4)       (5)

22. Some kids feel left out by their family, but other kids don't. Do you feel left out by your **family**?
   always  most of the time  sometimes  hardly ever  never
   (1)    (2)       (3)         (4)       (5)

23. Some kids' families ignore their ideas, but other kids' families don't. Does your **family** ignore your ideas?
24. Some kids are an important member of their family, but other kids are not. Are you an important member of your family?

always  most of the time  sometimes  hardly ever  never
(1)      (2)          (3)          (4)          (5)

25. Some kids think their families really care about them, but other kids think their families don't. Do you think your family cares about you?

always  most of the time  sometimes  hardly ever  never
(1)      (2)          (3)          (4)          (5)

26. Some kids feel like they belong in their family, but other kids feel like they don't belong. Do you feel like you belong in your family?

always  most of the time  sometimes  hardly ever  never
(1)      (2)          (3)          (4)          (5)

27. Some kids feel very close to their teachers, but other kids don't. Do you feel very close to your teachers?

always  most of the time  sometimes  hardly ever  never
(1)      (2)          (3)          (4)          (5)

28. Some kids' teachers make them feel like they are not good enough, but other kids' teachers don't make them feel this way. Do your teachers make you feel like you are not good enough?

always  most of the time  sometimes  hardly ever  never
(1)      (2)          (3)          (4)          (5)

29. Some kids have a hard time talking to their teachers, but other kids don't. Do you have a hard time talking to your teachers?

always  most of the time  sometimes  hardly ever  never
(1)      (2)          (3)          (4)          (5)

30. Some kids think their teachers care about them, but other kids don't. Do you think your teachers care about you?

always  most of the time  sometimes  hardly ever  never
31. Some teachers are good to ask for help or advice about problems, but other teachers are not. Are your teachers good to ask for help or advice about your problems?

always  most of the time  sometimes  hardly ever  never
1  2  3  4  5

32. Some kids feel very close to their doctors or nurses, but other kids don't. Do you feel very close to your doctors or nurses?

always  most of the time  sometimes  hardly ever  never
1  2  3  4  5

33. Some kids' doctors or nurses make them feel like they are not good enough, but other kids' doctors or nurses don't make them feel this way. Do your doctors or nurses make you feel like you are not good enough?

always  most of the time  sometimes  hardly ever  never
1  2  3  4  5

34. Some kids have a hard time talking to their doctors or nurses, but other kids don't. Do you have a hard time talking to your doctors or nurses?

always  most of the time  sometimes  hardly ever  never
1  2  3  4  5

35. Some kids think their doctors or nurses care about them, but other kids don't. Do you think your doctors or nurses care about you?

always  most of the time  sometimes  hardly ever  never
1  2  3  4  5

36. Some doctors or nurses are good to ask for help or advice about problems, but other doctors or nurses are not. Are your doctors or nurses good to ask for help or advice about your problems?

always  most of the time  sometimes  hardly ever  never
1  2  3  4  5
Behavioral Assessment Scale For Children (BASC) - Social Stress Subscale Child Version (ages 8-11)

Circle True or False :

1. Other people always find things wrong with me  T  F
2. Other children are happier than I am  T  F
3. I wish I were invited to more parties  T  F
4. People say bad things about me  T  F
5. People act as if they don't hear me  T  F
6. I feel out of place around people  T  F
7. Sometimes I feel lonely, even when there are people with me  T  F
8. I want to be more independence, but it scares me  T  F
9. I am lonely  T  F
10. I am bothered by rumors about me or my friends  T  F
11. I feel someone will tell me I do things the wrong way  T  F
12. I am bothered by teasing from others  T  F
Behavioral Assessment Scale For Children (BASC)- Social Stress Subscale
Adolescent Version (ages 12-18)

Circle True or False:

1. Other people always find things wrong with me    T  F
2. Other children are happier than I am            T  F
3. Sometimes I feel as if I am invisible           T  F
4. People say bad things to me                     T  F
5. People act as if they don't hear me             T  F
6. I feel out of place around people               T  F
7. Sometimes I feel lonely, even when there are people with me T  F
8. I feel that others do not like the way I do things T  F
9. I am lonely                                     T  F
10. I am left out of things                        T  F
11. I feel really "stressed out"                   T  F
12. My friends have more fun than I do             T  F
Harter- Perceived Competency Scale (PCS)

What I am Like

Decide how well each of the sentences describes you and put a circle the one answer that fits best. Of course there are no right or wrong answers, so please answer as honestly as possible.

1 = Not at all like you
2 = A little bit like you
3 = A lot like you
4 = A whole lot like you

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little bit</th>
<th>A lot</th>
<th>A whole lot</th>
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<tbody>
<tr>
<td>1.</td>
<td>I am very good at my schoolwork</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>2.</td>
<td>I find it hard to make friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
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<tr>
<td>3.</td>
<td>I would be better if I changed a lot of things about myself</td>
<td>0</td>
<td>1</td>
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<tr>
<td>4.</td>
<td>I am just as smart as other kids my age</td>
<td>0</td>
<td>1</td>
<td>2</td>
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<tr>
<td>5.</td>
<td>I have a lot of friends</td>
<td>0</td>
<td>1</td>
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<tr>
<td>6.</td>
<td>I am pretty sure of myself</td>
<td>0</td>
<td>1</td>
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<tr>
<td>7.</td>
<td>I am pretty slow at finishing my schoolwork</td>
<td>0</td>
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<tr>
<td>8.</td>
<td>I am a pretty important member of my class</td>
<td>0</td>
<td>1</td>
<td>2</td>
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<tr>
<td>9.</td>
<td>I feel good about the way I act</td>
<td>0</td>
<td>1</td>
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<tr>
<td>10.</td>
<td>I can usually do things alone instead of with other kids</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>11.</td>
<td>I usually do things alone instead of with other kids</td>
<td>0</td>
<td>1</td>
<td>2</td>
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<tr>
<td>12.</td>
<td>I am not a very good person</td>
<td>0</td>
<td>1</td>
<td>2</td>
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<tr>
<td>13.</td>
<td>I do well in class</td>
<td>0</td>
<td>1</td>
<td>2</td>
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<tr>
<td>14.</td>
<td>Kids seem to really like me</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Not at all like you</td>
<td>A little bit like you</td>
<td>A lot like you</td>
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<tr>
<td>15.</td>
<td>I am happy with the way I am</td>
<td>0</td>
<td>1</td>
<td>2</td>
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<tr>
<td>16.</td>
<td>I have a hard time understanding what I read</td>
<td>0</td>
<td>1</td>
<td>2</td>
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<tr>
<td>17.</td>
<td>I am popular with other kids my age</td>
<td>0</td>
<td>1</td>
<td>2</td>
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<tr>
<td>18.</td>
<td>I really wish I could do a lot of things better</td>
<td>0</td>
<td>1</td>
<td>2</td>
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<tr>
<td>19.</td>
<td>I have trouble figuring out the answers in school</td>
<td>0</td>
<td>1</td>
<td>2</td>
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<tr>
<td>20.</td>
<td>I am really easy to like</td>
<td>0</td>
<td>1</td>
<td>2</td>
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<tr>
<td>21.</td>
<td>Most of the time I am not so sure whether I am doing the right thing</td>
<td>0</td>
<td>1</td>
<td>2</td>
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**Living with Chronic Illness (LCI) - Child Report**

**Instructions:** For each question, indicate whether you have had this problem in the **past 6 months**. If **False**, circle “False” and go to the next question. If **True**, circle “True” and then circle “Yes” or “No” to show whether this problem is caused by your illness or treatment. Then circle an answer to indicate how much this problem upsets you.

1. I miss school.
   
   **Circle one:** True or False
   
   If **False**, go on to question # 2.
   
   If **True**, is it because of illness?  **Circle one:** Yes No
   
   How upset are you by this?  **Circle one:** Not at all A little Pretty much Very much

2. I do not take part in school activities (Example: school clubs, pep rallies).

   **Circle one:** True or False
   
   If **False**, go on to question # 3.
   
   If **True**, is it because of illness?  **Circle one:** Yes No
   
   How upset are you by this?  **Circle one:** Not at all A little Pretty much Very much

3. I am left out from activities or games with other kids.

   **Circle one:** True or False
   
   If **False**, go on to question # 4.
   
   If **True**, is it because of illness?  **Circle one:** Yes No
   
   How upset are you by this?  **Circle one:** Not at all A little Pretty much Very much

4. I do not play team sports (Example: soccer, football, softball).

   **Circle one:** True or False
   
   If **False**, go on to question # 5.
   
   If **True**, is it because of illness?  **Circle one:** Yes No
   
   How upset are you by this?  **Circle one:** Not at all A little Pretty much Very much
5. I have trouble making or keeping friends.

Circle one: True or False

If False, go on to question # 6.
If True, is it because of illness? Circle one: Yes No
How upset are you by this? Circle one: Not at all A little Pretty much Very much

6. Other children tease me about the way I look.

Circle one: True or False

If False, go on to question # 7.
If True, is it because of illness? Circle one: Yes No
How upset are you by this? Circle one: Not at all A little Pretty much Very much

7. I do not take part in outdoor exercise sports (Example: swimming, bike riding).

Circle one: True or False

If False, go on to question # 8.
If True, is it because of illness? Circle one: Yes No
How upset are you by this? Circle one: Not at all A little Pretty much Very much

8. Teachers treat me different from my classmates.

Circle one: True or False

If False, go on to question # 9.
If True, is it because of illness? Circle one: Yes No
How upset are you by this? Circle one: Not at all A little Pretty much Very much
9. I am not as independent (doing things on his/her own) as other kids my age.

Circle one: True or False

If False, go on to question # 10.
If True, is it because of illness? Circle one: Yes No

How upset are you by this? Circle one: Not at all A little Pretty much Very much

10. I do not take part in social activities after school hours (Example: overnight stays, dances).

Circle one: True or False

If False, go on to question # 11.
If True, is it because of illness? Circle one: Yes No

How upset are you by this? Circle one: Not at all A little Pretty much Very much

11. I do not take part in social clubs or organizations (Example: scouts, youth groups).

Circle one: True or False

If False, go on to question # 12.
If True, is it because of illness? Circle one: Yes No

How upset are you by this? Circle one: Not at all A little Pretty much Very much

12. My school grades are below average (D's and F's).

Circle one: True or False

If False, go on to question # 13.
If True, is it because of illness? Circle one: Yes No

How upset are you by this? Circle one: Not at all A little Pretty much Very much
13. I have problems getting along with people in my family.

*Circle one:* True or False

If **False**, go on to question # 14.

If **True**, is it because of illness? *Circle one:* Yes No

How upset are you by this? *Circle one:* Not at all A little Pretty much Very much

14. I feel different from other children my age.

*Circle one:* True or False

If **False**, go on to question # 15.

If **True**, is it because of illness? *Circle one:* Yes No

How upset are you by this? *Circle one:* Not at all A little Pretty much Very much

15. I feel uncomfortable or uneasy in social events (Example: parties, get togethers with family friends).

*Circle one:* True or False

If **False**, go on to question # 16.

If **True**, is it because of illness? *Circle one:* Yes No

How upset are you by this? *Circle one:* Not at all A little Pretty much Very much

16. I do not like others to know the things I have to do to take care of my illness (diet, medication, etc.).

*Circle one:* True or False

If **False**, go on to question # 17.

If **True**, is it because of illness? *Circle one:* Yes No

How upset are you by this? *Circle one:* Not at all A little Pretty much Very much
17. I do not get along with people outside my family (adults and children).

Circle one: True or False

If False, go on to question # 18.

If True, is it because of illness? Circle one: Yes No

How upset are you by this? Circle one: Not at all A little Pretty much Very much

18. I do not do many activities that my brother(s) &/or sister(s) do.

Circle one: True or False

If False, go on to question # 19.

If True, is it because of illness? Circle one: Yes No

How upset are you by this? Circle one: Not at all A little Pretty much Very much

19. I do not play outside often.

Circle one: True or False

If False, go on to question # 20.

If True, is it because of illness? Circle one: Yes No

How upset are you by this? Circle one: Not at all A little Pretty much Very much

20. Other kids tease me.

Circle one: True or False

If False, go on to question # 21.

If True, is it because of illness? Circle one: Yes No

How upset are you by this? Circle one: Not at all A little Pretty much Very much
21. I do not get along with other kids my age.

Circle one: True or False

If False, go on to question # 22.

If True, is it because of illness? Circle one: Yes No

How upset are you by this? Circle one: Not at all A little Pretty much Very much

22. I do not take part in many family activities (Example shopping, eating out, going to the park).

Circle one: True or False

If False, go on to question # 23.

If True, is it because of illness? Circle one: Yes No

How upset are you by this? Circle one: Not at all A little Pretty much Very much

23. I am not able to travel.

Circle one: True or False

If False, go on to question # 24.

If True, is it because of illness? Circle one: Yes No

How upset are you by this? Circle one: Not at all A little Pretty much Very much

24. I do not start new projects at school or at home (Example: hobbies, papers).

Circle one: True or False

If False, go on to question # 25.

If True, is it because of illness? Circle one: Yes No

How upset are you by this? Circle one: Not at all A little Pretty much Very much
25. I do not do my chores at home.

Circle one: True or False

If False, go on to question # 26.

If True, is it because of illness? Circle one: Yes No

How upset are you by this? Circle one: Not at all A little Pretty much Very much

26. Other kids ignore or do not pay attention to me.

Circle one: True or False

If False, go on to question # 27.

If True, is it because of illness? Circle one: Yes No

How upset are you by this? Circle one: Not at all A little Pretty much Very much

27. I have fewer friends than my classmates do.

Circle one: True or False

If False, go on to question # 28.

If True, is it because of illness? Circle one: Yes No

How upset are you by this? Circle one: Not at all A little Pretty much Very much

28. I do not regularly take part in Gym/PE (Physical Education) class at school.

Circle one: True or False

If False, go on to question # 29.

If True, is it because of illness? Circle one: Yes No

How upset are you by this? Circle one: Not at all A little Pretty much Very much

How upset are you by this? Circle one: Not at all A little Pretty much Very much

Circle one: True or False

If False, stop here.

If True, is it because of illness? Circle one: Yes No

29. Other kids do not invite me to play or take part in fun activities.
Living with Chronic Illness (LCI) - Parent Report

Instructions: For each question, indicate whether your child has had this problem in the past 6 months. If False, circle “False” and go to the next question. If True, circle “True” and then circle “Yes” or “No” to show whether this problem is caused by your child’s illness or treatment. Then circle an answer to indicate how much this problem upsets your child.

1. My child misses school.
   Circle one: True or False
   If False, go on to question # 2.
   If True, is it because of illness? Circle one: Yes No
   How upset is your child by this? Circle one: Not at all A little Pretty much Very much

2. My child does not take part in school activities (Example: school clubs, pep rallies).
   Circle one: True or False
   If False, go on to question # 3.
   If True, is it because of illness? Circle one: Yes No
   How upset is your child by this? Circle one: Not at all A little Pretty much Very much

3. My child is left out from activities or games with other children.
   Circle one: True or False
   If False, go on to question # 4.
   If True, is it because of illness? Circle one: Yes No
   How upset is your child by this? Circle one: Not at all A little Pretty much Very much

4. My child does not play team sports (Example: soccer, football, softball).
   Circle one: True or False
   If False, go on to question # 5.
   If True, is it because of illness? Circle one: Yes No
   How upset is your child by this? Circle one: Not at all A little Pretty much Very much
5. My child has trouble making or keeping friends.

*Circle one:* True or False

If **False**, go on to question # 6.

If **True**, is it because of illness? *Circle one:* Yes No

How upset is your child by this? *Circle one:* Not at all A little Pretty much Very much

6. Other children tease my child about the way he/she looks.

*Circle one:* True or False

If **False**, go on to question # 7.

If **True**, is it because of illness? *Circle one:* Yes No

How upset is your child by this? *Circle one:* Not at all A little Pretty much Very much

7. My child does not take part in outdoor exercise sports (Example: swimming, bike riding).

*Circle one:* True or False

If **False**, go on to question # 8.

If **True**, is it because of illness? *Circle one:* Yes No

How upset is your child by this? *Circle one:* Not at all A little Pretty much Very much

8. Teachers treat my child different from his/her classmates.

*Circle one:* True or False

If **False**, go on to question # 9.

If **True**, is it because of illness? *Circle one:* Yes No

How upset is your child by this? *Circle one:* Not at all A little Pretty much Very much
9. My child is not as independent (doing things on his/her own) as other children his/her age.  
*Circle one:* True or False  
If **False**, go on to question # 10.  
If **True**, is it because of illness?  
*Circle one:* Yes No  
How upset is your child by this?  
*Circle one:* Not at all A little Pretty much Very much

10. My child does not take part in social activities after school hours (Example: overnight stays, dances).  
*Circle one:* True or False  
If **False**, go on to question # 11.  
If **True**, is it because of illness?  
*Circle one:* Yes No  
How upset is your child by this?  
*Circle one:* Not at all A little Pretty much Very much

11. My child does not take part in social clubs or organizations (Example: scouts, youth groups).  
*Circle one:* True or False  
If **False**, go on to question # 12.  
If **True**, is it because of illness?  
*Circle one:* Yes No  
How upset is your child by this?  
*Circle one:* Not at all A little Pretty much Very much

12. My child’s school grades are below average (D’s and F’s).  
*Circle one:* True or False  
If **False**, go on to question # 13.  
If **True**, is it because of illness?  
*Circle one:* Yes No  
How upset is your child by this?  
*Circle one:* Not at all A little Pretty much Very much
13. My child has problems getting along with people in our family.

*Circle one:* True or False

If **False**, go on to question # 14.

If **True**, is it because of illness?  
*Circle one:* Yes No

   How upset is your child by this?  
*Circle one:* Not at all A little Pretty much Very much

14. My child feels different from other children his/her age.

*Circle one:* True or False

If **False**, go on to question # 15.

If **True**, is it because of illness?  
*Circle one:* Yes No

   How upset is your child by this?  
*Circle one:* Not at all A little Pretty much Very much

15. My child feels uncomfortable or uneasy in social events (Example: parties, get togethers with family friends).

*Circle one:* True or False

If **False**, go on to question # 16.

If **True**, is it because of illness?  
*Circle one:* Yes No

   How upset is your child by this?  
*Circle one:* Not at all A little Pretty much Very much

16. My child does not like others to know the things he/she has to do to take care of his/her illness (diet, medication, etc.).

*Circle one:* True or False

If **False**, go on to question # 17.

If **True**, is it because of illness?  
*Circle one:* Yes No

   How upset is your child by this?  
*Circle one:* Not at all A little Pretty much Very much
17. My child does not get along with people outside the family (adults and children).

*Circle one:* True or False

If False, go on to question # 18.

If True, is it because of illness? *Circle one:* Yes No

How upset is your child by this? *Circle one:* Not at all A little Pretty much Very much

18. My child does not do many activities that his/her brother(s) &/or sister(s) do.

*Circle one:* True or False

If False, go on to question # 19.

If True, is it because of illness? *Circle one:* Yes No

How upset is your child by this? *Circle one:* Not at all A little Pretty much Very much

19. My child does not play outside often.

*Circle one:* True or False

If False, go on to question # 20.

If True, is it because of illness? *Circle one:* Yes No

How upset is your child by this? *Circle one:* Not at all A little Pretty much Very much

20. Other children tease my child.

*Circle one:* True or False

If False, go on to question # 21.

If True, is it because of illness? *Circle one:* Yes No

How upset is your child by this? *Circle one:* Not at all A little Pretty much Very much
21. My child does not get along with other kids his/her age.

Circle one:  True  or  False

If False, go on to question # 22.

If True, is it because of illness?  Circle one:  Yes  No

How upset are you by this?  Circle one:  Not at all  A little  Pretty much  Very much

22. My child does not take part in many family activities (Example: eating out, going to

Circle one:  True  or  False

If False, go on to question # 23.

If True, is it because of illness?  Circle one:  Yes  No

How upset are you by this?  Circle one:  Not at all  A little  Pretty much  Very much park).

23. My child is not able to travel.

Circle one:  True  or  False

If False, go on to question # 24.

If True, is it because of illness?  Circle one:  Yes  No

How upset are you by this?  Circle one:  Not at all  A little  Pretty much  Very much

24. My child does not start new projects at school or at home (Example: hobbies, papers).

Circle one:  True  or  False

If False, go on to question # 25.

If True, is it because of illness?  Circle one:  Yes  No

How upset are you by this?  Circle one:  Not at all  A little  Pretty much  Very much
25. My child does not do his/her chores at home.

Circle one: True or False

If False, go on to question # 26.

If True, is it because of illness? Circle one: Yes No

How upset are you by this? Circle one: Not at all A little Pretty much Very much

26. Other children ignore or do not pay attention to my child.

Circle one: True or False

If False, go on to question # 27.

If True, is it because of illness? Circle one: Yes No

How upset are you by this? Circle one: Not at all A little Pretty much Very much

27. My child has fewer friends than his/her classmates.

Circle one: True or False

If False, go on to question # 28.

If True, is it because of illness? Circle one: Yes No

How upset are you by this? Circle one: Not at all A little Pretty much Very much

28. My child does not regularly take part in Gym/ PE (Physical Education) class at school.

Circle one: True or False

If False, go on to question # 29.

If True, is it because of illness? Circle one: Yes No

How upset are you by this? Circle one: Not at all A little Pretty much Very much
29. Other children do not invite my child to play or take part in fun activities.

*Circle one:* True or False

If **False**, stop here.

If **True**, is it because of illness? *Circle one:* Yes No

How upset are you by this? *Circle one:* Not at all A little Pretty much Very much
Table 1

*Means and Standard Deviations for the Current Pacemaker/ICD Sample and Healthy Peer Comparison Group on the General PedsQL Scale*

<table>
<thead>
<tr>
<th>QOL Category</th>
<th>Pacemaker/ICD</th>
<th>Healthy Peers</th>
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<td>School QOL</td>
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Table 2

Means and Standard Deviations for the Current Pacemaker/ICD Sample and Healthy Peer Comparison Group on the Perceived Competence Scale

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<td>Healthy Peers</td>
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Table 3

Correlations for Age, Income, and Child- and Parent-report on QOL, Self-competency, Social Functioning, and Psychosocial Adjustment Composite Scores

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<td>Social Problems Due to Illness</td>
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<td><strong>Parent Report</strong></td>
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*p < .05

**p < .01
Table 4

*Correlations for Social Support Types and Child Self-Report of General and Cardiac QOL*

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<th>Support Type Composite</th>
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<td>.59***</td>
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*Note. Superscript a indicates a partial correlation was conducted controlling for income*

*p < .05

**p < .01

***p < .001
Table 5

Correlations for Social Support Sources and Child Self-Report of General and Cardiac QOL

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<th>Class</th>
<th>Teachers</th>
<th>Doctors/Nurses</th>
<th>Support Source Composite</th>
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*Note. Superscript a indicates a partial correlation was conducted controlling for income
*p < .05
**p < .01
***p < .001
Table 6

*Three-way ANOVA for Child Self-Report General QOL Composite and Social Support Types*

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<th>MS</th>
<th>F</th>
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</tbody>
</table>

* p ≤ .05
Table 7

*Three-way ANOVA for Child Self-report Psychosocial QOL Composite and Social Support Types*

<table>
<thead>
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<th>Source</th>
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</tbody>
</table>

* p ≤ .05
Table 8

*Three-way ANOVA for Child Self-Report Cardiac QOL Composite and Social Support Types*

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</table>

* p ≤ .05
Table 9

Three-way ANOVA for Child Self-report Cognitive Self-competency and Social Support Types

<table>
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</tbody>
</table>

* p ≤ .05
Table 10

*Three-way ANOVA for parent-report Social Problems Not Due to Illness and Social Support Types*

<table>
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* p ≤ .05
Figure 1. Two-way Interaction of Informational and Esteem Support for Child-reported General QOL Composite
Figure 2. Two-way Interaction of Informational and Esteem Support for Child-reported Psychosocial QOL Composite

- Low Informational Support and Low Esteem Support: 58.03
- Low Informational Support and High Esteem Support: 72.78
- High Informational Support and Low Esteem Support: 82.92
- High Informational Support and High Esteem Support: 76.25

Legend:
- Solid line: low Esteem Support
- Dashed line: high Esteem Support
Figure 3. Two-way Interaction of Informational and Esteem Support for Child-reported Cardiac QOL Composite

Esteem Support

- low
- high

Informational Support

- low
- high

- 88.9
- 75.96
- 68.88
- 71.95
Figure 4. Two-way Interaction of Informational and Tangible Support for Child-reported Cognitive Self-competency
Figure 5. Two-way Interaction of Esteem and Tangible Support for Child-reported Cognitive Self-competency
Figure 6. Two-way Interaction of Informational and Tangible Support for Parent-report of Child Social Problems Not Due to Illness