DOES QUALITY OF LIFE DIFFER BY GENDER IN PEDIATRIC IMPLANTABLE CARDIOVERTER DEFIBRILLATOR PATIENTS? A MULTI-SITE PILOT STUDY

By

JAY B. ST. AMANT

A THESIS PRESENTED TO THE GRADUATE SCHOOL
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To my late father, Percy “Jay” St. Amant, Jr., for inspiring me to never give up.

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The implantable cardioverter defibrillator (ICD) has continually outperformed medications in numerous clinical trials for the treatment of lethal ventricular arrhythmias. Psychosocial research on ICD patients has shown that quality of life is strongly associated with measures of anxiety, depression, and family functioning. Young patients, women, and patients receiving an ICD shock have been identified as risk groups for increased adjustment difficulties. Extant research has indicated that younger patients have a greater probability of receiving ICD shock but possible gender differences have not been examined. Recent literature has highlighted psychological consequences of an ICD that are unique to adult women, specifically focusing on factors such as sexuality, femininity, caretaking abilities, and body image satisfaction.

The purpose of this project was to examine possible differences between male and female pediatric ICD patients across cognitive, social, physical and psychosocial domains. The participants were 20 patients (13 male - Mean age = 13.08, *SD* = 4.13, and 7 female - Mean age = 12.86, *SD* = 2.73) who had been implanted with an ICD prior to participation. Patients were recruited at the Baylor University Medical Center and the University of Florida Health Science Center. Participants completed psychosocial batteries during a routine office visit.

The patient packets included measures in the domains of quality of life, social and cognitive functioning. ANOVAs were completed to test for differences and results indicated that girls reported significantly lower scores on the PedsQL total scale quality of life measure, $F(1,19) = 5.70$, $p = .028$, the PedsQL physical health scale, $F(1,19) = 7.57$, $p = .013$, and the PedsQL cardiac health scale, $F(1,19) = 7.63$, $p = .013$, than their male counterparts. Comparisons across social and cognitive domains were not significant.

The current study indicates that the gender differences in QOL that have been demonstrated in the adult ICD literature were extended in the pediatric ICD sample. The clinical implication of these findings suggests that clinicians may want to consider gender differences in their treatment of not only adult, but pediatric ICD patients. Further research should focus on identifying efficacious gender-specific psychosocial interventions for female ICD patients of all ages.

CHAPTER 1
INTRODUCTION

Background

According to the American Heart Association (2007), cardiovascular disease is the number one cause of death in the United States. Sudden cardiac death due to ventricular arrhythmias kills approximately 300,000 to 350,000 people every year (Myerburg & Castellanos, 2006). The implantable cardioverter defibrillator (ICD) has continually outperformed medications in clinical trials (DiMarco, 2003; Buxton et al., 1999; Bardy et al., 2005; Moss et al., 1996), and remains the treatment of choice for these potentially life-threatening ventricular arrhythmias.

While the majority of ICD recipients are adults, children are frequently indicated for ICD implantation due to some form of congenital heart disease. In 2000, over 25,000 operations were performed for congenital heart disease on patients under age 20 (American Heart Association, 2006). Some of those surgeries likely involved implantation of an ICD. The ICD has shown success in decreasing mortality rates in pediatric cases of ICD recipients (Chatrath et al., 2002; Stefanelli et al., 2002). These pediatric ICD recipients are at a greater risk for device complications due to patient growth and increased physical activity (Cooper et al., 2003). Further, the pediatric patient will typically be a long-term healthcare consumer, given their younger age at problem onset. Increased attention to individual needs of pediatric patients is largely warranted to improve health outcomes of young ICD recipients.

The biopsychosocial model proposes that physical and psychological factors combine to produce health outcomes (Engel, 1977). With this in mind, physicians are increasingly encouraged to treat the "whole" patient, using a holistic approach to treatment. The application of this multi-dimensional approach to health outcomes is frequently referred to as "Quality of Life" (Sears et al., 2002). Research on health-related quality of life (QOL) has increased over

the past two decades. Going beyond mortality and morbidity, QOL measures typically focus on broad domains of functioning, such as social, physical, academic, and psychological well-being.

While quality of life (QOL) research exists in adult ICD patients that shows a superior outcome when compared to anti-arrhythmic medications (Burke et al., 2003) (Herbst et al., 1999), extensive research regarding pediatric ICD patients does not exist. In fact, there is a paucity of research to date on psychosocial functioning of pediatric ICD patients. Thus, turning to pediatric chronic illness literature can provide some insight into potential relationships that might exist in pediatric ICD populations. Epidemiological studies suggest that approximately one-third of children with chronic illness experience some degree of psychosocial maladjustment (Cadman et al., 1987; Pless & Roghmann, 1971). More specifically, research by Varni and colleagues (2007) indicated that children with heart disease, which may have included some patients with ICDs, report significantly lower health-related QOL than healthy normative samples. This study also compared children with several other chronic diseases, such as asthma, obesity, and end-stage renal disease, all of which reported similarly lower levels of QOL when compared to healthy normative data. Based on these findings, it could be assumed that a pediatric ICD sample would perform at a comparable level to these other chronic illness populations, although no such research has yet been accomplished.

Contributing Factors to QOL in Pediatric ICD Patients

Psychosocial Adjustment

The extant literature regarding psychological functioning of pediatric ICD patients remains particularly limited with only four available studies. Hamilton and colleagues (1996) conducted a 5-year follow-up of 11 children with ICDs. All children returned to school following implantation, although additional psychosocial variables were not examined. Wilson and colleagues (1998) examined the psychological and medical outcomes of 5 children with ICDs

between the ages of 7 and 18 years. Although all children returned to school following implantation, two children developed transient neurological symptoms and experienced depressive symptoms including suicidal ideation. In their clinical review of 27 pediatric and young adult ICD patients, Stefanelli and colleagues (2002) reported that 22% of their sample experienced various forms of anxiety disorders (i.e., prolonged shock anxiety, school phobia, posttraumatic stress disorder) that seem directly related to the ICD.

Young ICD patients are hypothesized to be at risk for psychosocial difficulties because of increased lifestyle disruption and distressing social comparisons (Sears et al., 2001). In addition to adjusting to the risk of potentially life-threatening arrhythmias, young patients must deal with the appearance of the ICD device, the likely experience of life-saving shock, and the social and lifestyle ramifications of the ICD. Not surprisingly, the ICD can present significant psychological difficulties for some young patients. DeMaso and colleagues (2004) studied 20 ICD recipients between the ages of 9 and 19 years, using both child and parent reports of patient functioning. These young patients did not report increased rates of depression or anxiety, but they had lower physical functioning and quality of life (QOL) as reported by their parents. The development of symptoms of anxiety has been established as the most significant and common psychological consequence for the adult ICD recipient (Sears et al., 1999). It is assumed that anxiety symptoms and related behaviors of hypervigilance and avoidance would also exist in children and adolescents with ICDs, although this has yet to be explored by researchers.

Investigation of the social adjustment of children with ICDs in terms of both peer and family functioning is also warranted. Children with ICDs may be labeled by parents, teachers, and peers as having special needs or "being different." Such negative feedback may be internalized by the children, thereby resulting in greater levels of distress and lower levels of

social involvement. Children may also be hesitant or unable to participate in school interactions due to real or perceived physical limitations and/or fears of rejection, resulting in a smaller network of friends. It has been suggested that the presence of severe medical conditions may make youth vulnerable for being teased (Storch et al., 2004), a peer experience that has been uniquely related to negative psychosocial adjustment. Alpern and colleagues (1989) discussed concerns of social rejection by children with pacemakers although this has not been explored in the context of ICDs. Clearly, the ICD and potentially life threatening arrhythmias could produce similar if not greater effects.

Device Acceptance

In addition to psychological and social adjustment, it is noteworthy to investigate the health-related QOL of these young patients. Burke (2003) described patient acceptance among adult ICD patients as, "a process characterized by choosing to live with technology, integrating technology into life, and living through technology." To assess device acceptance, Burns and colleagues (2005) developed the Florida Patient Acceptance Survey (FPAS), a measure of cognitive appraisal of the ICD.

A similar process is reflected in device-specific adjustment among pediatric ICD patients. Among children with congenital heart disease, those with cardiac pacemakers were likely to report fears of pacemaker failure (Alpern et al., 1989). Similarly, it is necessary to investigate device acceptance among the pediatric ICD population. It seems likely that some children with ICDs will experience similar, if not greater fear of their device.

Lead Fractures, Frequency and Appropriateness of Shocks

While studies have shown that survival rates in children with ICDs are comparable to adults (Gradaus et al., 2003), children with ICDs frequently encounter entirely different experiences with their device. These differences are particularly related to exposure to shocks.

Recent research by Kaski and colleagues (2007) observed ICD outcomes in pediatric patients with hypertrophic cardiomyopathy (one of many congenital heart diseases that are commonly treated with ICDs) and showed that 71.4% of their secondary prevention population (N=22) received an appropriate (occurred as a result of a sustained ventricular arrhythmia) shock during the observation period (range 1-2.3 years) compared to a mere 11% of adult comparisons over the same time period. This suggests that children with ICDs are more likely to experience a higher frequency of ventricular arrhythmias than adult ICD patients.

In addition to the higher frequency of appropriate shocks, research suggests that children with ICDs are also more susceptible to inappropriate shocks, which are not necessary to sustain life. Korte and colleagues (2004) showed that approximately one half of pediatric ICD patients in their sample received inappropriate shocks over a four year period. The higher proportion of inappropriate shocks in children is mainly attributed to lead failure/fracture that occurs as a result of normal physical growth. Data from Cecchin and colleagues (2003) suggests that nearly 25% of all pediatric patients will encounter lead fracture. These lead fractures can result in device failure, or in a rapid series of inappropriate shocks, referred to as an ICD storm. Collectively, pediatric ICD patients appear more likely to be exposed to ICD shocks, both appropriate and inappropriate, than their adult counterparts.

QOL of Female ICD Patients

In addition to pediatric ICD patients, women have also been identified by researchers as an at-risk population for psychological distress secondary to cardiac disease (Con et al., 1999; Vaccarino et al., 2003). Research in adult heart failure patients, who commonly required ICDs for treatment, revealed that female patients consistently exhibit lower QOL than their male counterparts, as well as higher levels of depression (Gottleib et al., 2004). Epidemiological studies suggest that women report clinically significant levels of depression and anxiety at

almost twice the rate of males (Regier et al., 1994; Kessler et al., 1994). Walker and colleagues (2004) identified the existence of distinctly negative impacts of the ICD on women, including effects on social role maintenance, femininity, sexuality, body image satisfaction, and caretaking abilities.

Body image satisfaction remains a relevant issue in women's health research (Vazquez Sowell et al., 2006). Socially visible physical scars, such as those typical after an ICD implantation, have been related to poor ratings of overall appearance, as well as appearance satisfaction and appearance related anxiety (Lawrence et al., 2004). Further research has suggested that alternative implantation techniques in women, such as submammary implantation, could potentially negate some of this impact (Giudici, 2001). However, no research has examined if this gender difference exists between boys and girls with ICDs in the same manner.

Current Study

The present study expands on the current literature by examining possible differences between male and female pediatric ICD patients across social and cognitive functioning, as well as physical, psychosocial, and cardiac domains of QOL. The study included two aims: (1) to identify any differences in QOL between male and female pediatric ICD patients, and (2) to compare patient self reports and parent observed reports on the measures of QOL and cognitive appraisal of their ICD. Consistent with the adult female literature, it is hypothesized that female pediatric ICD patients will exhibit worse QOL than their male counterparts. Given that parents of chronically ill children tend to rate their child's physical and psychosocial functioning as lower than the child's report (Guyatt et al., 1997), it is expected that parent-observed reports on their child's psychosocial functioning will rate poorer than the child's self-report.

CHAPTER 2
METHODS

Participants

Participants were 20 pediatric ICD patients and their respective parent/guardian who were on routine electrophysiology visits at one of two major southeastern medical centers. Patients' ages ranged from 8-18 years. Sixty-five percent (n=13) of the study sample was male. There was no significant difference in age between males and females, $t(18) = .126$, $p = .901$. Of the male patients (n=13), 46% (n=6) identified themselves as Caucasian, 46% (n=6) identified themselves as Hispanic/Latino, and 8% (n=1) self-identified as African-American. The female patient population (n=7) was self-identified as 57% (n=4) Caucasian and 43% (n=3) Hispanic/Latino. Participating legal guardians were primarily mothers (70%), with fathers (15%), grandparents (5%), other legal guardian (5%), and no response (5%) comprising a smaller percentage of the population. 60% of the adults in the sample reported being married or remarried, and the median annual family income ranged between $30,000 and $59,999.

Procedure

Potential participants and their parents/guardians were approached by medical staff while attending routine cardiology/electrophysiology appointments at Shands Hospital at the University of Florida in Gainesville or at Baylor University Medical Center in Houston Texas. For study eligibility, patients were required to meet the following criteria: (1) past ICD implantation, (2) age between 8 and 18 years, (3) ability to read and complete questionnaires, (4) ability to read and write English, and (5) accompanied by a consenting parent or guardian who is at least 18 years old. Patients were excluded from consideration in this study if they had ever been diagnosed with mental retardation or a psychotic disorder, and/or if they were unable to read and write in English. None of the potential participants approached for this multi-center

IRB approved study met the criteria for exclusion. After obtaining informed consent and assent, the pediatric ICD patient and the parent/guardian were each given separate self-report psychosocial assessment packet. The packets were completed in the clinic waiting rooms and took approximately 20 minutes to complete. Staff members were available to help the patient and parent/guardian for clarification.

Measures

Demographics

Each parent/guardian completed a demographic questionnaire to obtain the following information about the patient and parent/guardian: (1) age, (2) gender, (3) race/ethnicity, and (4) highest grade completed. Parent/guardian marital status and average annual household income were also obtained.

Medical Severity

The *Defibrillator Severity Index* (DeMaso et al., 2004) is a cardiologist-designed rating scale that allows physicians and medical staff to classify ICD patients in a standardized format based on the severity of their underlying disease. The following domains are covered in the 8-item index: (1) cardiovascular disease, (2) surgical treatment, (3) ICD indications, (4) ventricular arrhythmias, (5) current arrhythmia medications, (6) appropriate ICD discharges, (7) comorbid medical conditions, and (8) activity limitations. Each item is rated by degree of severity, with higher ratings indicating increased severity. An example item assessing ventricular arrhythmia diagnoses asks the medical provider to rate on the following scale, "0) None, 1) Nonsustained ventricular tachycardia, 2) Sustained monomorphic or polymorphic ventricular tachycardia, or 3) Ventricular fibrillation." Scoring is accomplished by determining the total of items 1 through 8, with a scoring range of 2 to 18. This measure has shown acceptable cardiologist inter-rater reliability, Pearson's $r = 0.90$, κ 0.51, $p < 0.01$.

Questionnaires

Child questionnaires

The *PedsQL Pediatric Quality of Life Inventory – Child Versions* (Uzark et al., 2003; Varni, 1999) was used to assess pediatric QOL. The PedsQL versions that were used in this study include the *core module*, measuring generic QOL in the last month, with separate versions for children 8-12 years of age and teens 13-18 years of age. This 23-item module assesses four scales (Physical – 8 items, Emotional – 5 items, Social – 5 items, and School – 5 items) which generate three summary scores: (1) Total Scale Score – 23 items, (2) Physical Health Summary Score – 8 items, and (3) Psychosocial Health Summary Score – 15 items. All items are statements to which the child is asked to rate their agreement on a 5-item Likert scale ranging from "Never" to "Almost Always," and include statements such as "It is hard to pay attention in class," and "I worry about what will happen to me." Cronbach's α values for reliability for the Total Scale Score (α = 0.88), Physical Health Summary Score (α = 0.80), and Psychosocial Health Summary Scale (α = 0.83) are all within acceptable limits for group comparisons. In terms of validity, the PedsQL differentiates not only between healthy children and acutely or chronically ill children, but also between levels of disease severity within a given medical condition.

In addition, the *PedsQL 3.0 Cardiac Module* (Uzark et al., 2003) was used to measure cardiac-specific QOL with versions for children 8-12 years of age and teens 13-18 years of age. Statements from this disease-specific 27-item module include statements such as, "My lips turn blue when I run," and "I don't like other people to see my scars." This module has 5 scales assessing: 1) symptoms – 7 items, 2) perceived physical appearance – 3 items, 3) treatment anxiety – 4 items, 4) cognitive problems – 5 items, and 5) communication – 3 items. Additionally, a treatment barriers scale (5 items) was included to assess cardiac medication

adherence. Similar to the other PedsQL modules, patients rate their agreement on a 5-point Likert scale ranging from "Never" to "Almost Always." This module has exhibited satisfactory internal consistency, with reliability values across scales ranging from $r = 0.72$ to $r = 0.85$.

The *Children's Loneliness and Social Dissatisfaction Scale* (LSDS; Asher & Wheeler, 1985) was used to assess loneliness as an indicator of social adjustment. This 24-item questionnaire is comprised of statements to which the child rates their agreement on a 5-point scale ranging from "That's not true at all about me" to "That's always true about me." Of the 24 items, 16 have been factor analyzed to be loaded on the factor of loneliness and social dissatisfaction. Those items focus on: (1) children's feelings of loneliness, (2) feelings of social adequacy versus inadequacy, and (3) subjective estimations of peer status. Statements from this measure include, "I have nobody to talk to in class," and "It's easy for me to make new friends at school." The collective 16 items have been found to be internally consistent (Cronbach's $\alpha = 0.90$). The remaining eight items are filler items, focusing on hobbies and preferred activities, and are not loaded on the loneliness and social dissatisfaction factor.

The *Florida Patient Acceptance Survey – Child Version* (FPAS; Burns et al., 2005) was used to assess patient cognitive appraisal and acceptance of the ICD. This scale was developed for an adult population and was modified to be reader-friendly for children under 18 years of age. This 17-item measure consists of statements related to the ICD to which the patient rates their agreement on a 5-point scale ranging from "Strongly Disagree" to "Strongly Agree." Of the 17 items, two are filler items, with the remaining 15 loading on one of four factors. Each factor has exhibited acceptable reliability using Cronbach's α. The first factor, Return to Function ($\alpha = 0.89$), includes four statements such as, "I know I will be able to return to school if I want to." The second factor, Device-Related Distress ($\alpha = 0.79$), contains five statements such

as, “It is hard for me to do things without thinking about my device.” The third factor, Positive Appraisal (α = 0.82), consists of four statements including, “I am safer because of my device.” The fourth factor, Body Image Concerns (α = 0.74), includes two statements such as, “I feel ugly because of my device.” Overall, the FPAS has exhibited good internal consistency (α = 0.83).

Parent questionnaires

The *PedsQL Pediatric Quality of Life Inventory – Parent Versions* (Uzark et al., 2003; Varni, 1999) was used to assess pediatric QOL, as answered by the parent about their child. The PedsQL parent versions used in this study include the *core module*, measuring generic QOL, with separate versions for parents to answer for their 8-12 year old child or for their 13-18 year old teen. Like the child version, this version is a 23-item measure of four core scales (Physical Functioning, Emotional Functioning, Social Functioning, and School Functioning) that generate three summary scores (Total Scale Score, Physical Health Summary Score, and Psychosocial Health Summary Scale). The parent versions of this measure have shown similar reliability to the child versions (Total Scale Score α = 0.90, Physical Health Summary Score α = 0.88, and Psychosocial Health Summary Scale α = 0.88). The statements are slightly modified from the child version, and ask the parent/guardian to rate how much of a problem their child has had in each of the measured domains in the past month.

Similarly, the parent proxy version of the *PedsQL 3.0 Cardiac Module* (Uzark et al., 2003) was used to measure parent-perceived cardiac-specific QOL with parent versions for children 8-12 years of age and teens 13-18 years of age. This 27-item measure asks the parent to rate their agreement to statements about their child’s heart-related functioning on a 5-point Likert scale ranging from “Never” to “Almost Always.” Like the child version, the parent proxy version of this module has 5 scales assessing: 1) symptoms – 7 items, 2) perceived physical appearance – 3 items, 3) treatment anxiety – 4 items, 4) cognitive problems – 5 items, and 5) communication – 3

items. Additionally, a treatment barriers scale (5 items) was once again included to assess cardiac medication adherence. Psychometric testing of the parent proxy version of this module has demonstrated satisfactory internal consistency reliability across all scales, ranging from r = 0.81 to r = 0.95.

The *FPAS – Child by Parent Proxy Version* (FPAS; Burns et al., 2005) was used to assess perceived patient device acceptance, as answered by the parent(s). The FPAS scale was modified to be appropriate for the parent to answer each item as they believe their child with an ICD would answer for themselves. Beyond the phrasing modifications, the measure is identical to the child version. Sample statements include, "It is hard for my child to function without thinking about his/her device," and "My child feels less attractive because of the device."

Statistical Analyses

All data processing and statistical analyses were conducted using the statistical software package, SPSS for Windows Version 15.0.

To investigate any differences in QOL between male and female pediatric ICD patients, a one-way analysis of variance test was utilized, with gender used as the fixed variable, and the *PedsQL* Summary Scales (Total Summary Scale, Physical Health Summary Scale, and Psychosocial Summary Scale) as dependent variables.

To examine the relationship between patient self-report and their respective parent-observed reports, paired samples t-tests were conducted on the *PedsQL* Child vs. Parent versions, as well as the Child and Child by Parent Proxy versions of the FPAS. Since multiple statistical analyses were conducted on the same data, a Bonferroni correction factor was implemented to control for any family-wise error and the resulting criterion level of significance was set to p = .01.

To examine any gender differences in social functioning, independent sample t-tests were conducted comparing mean scores on the *Children's Loneliness and Social Dissatisfaction Scale* (LSDS) between genders.

In order to identify any differences in medical severity between male and female patients as a potential factor influencing QOL, independent sample t-tests were conducted comparing mean scores on the *Defibrillator Severity Index* between males and females.

CHAPTER 3
RESULTS

Demographics of Participants

The participants in this study were predominantly male (65%), with 50% identifying as Caucasian and 45% identifying as Hispanic/Latino. Only one participant (5%) identified as African-American. Detailed descriptive statistics are shown in Table 1.

Effect of Gender on QOL

An omnibus one-way analysis of variance (ANOVA) was conducted to examine differences in QOL between genders in our sample. Based on the extant adult ICD literature, it was expected that female pediatric ICD patients would report lower levels of QOL than their male counterparts. Means and standard deviations for QOL by gender are reported in Table 2. Statistical analyses indicated that females reported significantly lower scores on the PedsQL Total Scale Score, $F(1,19) = 5.70$, $p = .028$, Physical Health Summary Score, $F(1,19) = 7.57$, $p = .013$, and Cardiac Health Summary Score, $F(1,19) = 7.63$, $p = .013$, than their male counterparts (Table 3). The effect of gender also showed a trend toward significance for the Psychosocial Health Summary Score, $F(1,19) = 4.34$, $p = .052$, with females reporting lower scores in this domain as well. Additional analyses comparing males and females across cognitive appraisal (Florida Patient Acceptance Survey) and social (Loneliness and Social Dissatisfaction) domains were not significant. Further exploratory analysis showed that neither the FPAS, $p = .377$, nor the LSDS, $p = .167$, were significantly correlated with the PedsQL Total Scale Score in this sample. Additional analysis showed that the PedsQL Total Scale score and age of the patient were not significantly correlated, $p = .438$.

Relationship between Patient Self-Reports and Parent-Observed Reports on QOL and Cognitive Appraisal of the ICD

Paired-sample t-tests were conducted to examine the relationship between patient self-report and their respective parent-observed reports on the *PedsQL* and FPAS measures. Parent-reports were predicted to be worse than patient self-reports. Multiple comparisons were conducted on the same data, necessitating a Bonferroni correction to avoid family-wise error. This was accomplished by dividing the previous level for significance, .05, by the number of comparisons, which was five. Therefore, for these analyses values for significance were set at $p = .01$. Means and standard deviations for QOL Summary Scale Scores and FPAS scores by parents and patients are shown in Table 4. Statistical analyses, shown in Table 5, indicated that parents rated their child's functioning significantly lower than the patient self-report on the *PedsQL* Total Scale Score ($t(19) = 3.42$, $p = .003$) and the Psychosocial Health Summary Scale, $t(19) = 3.21$, $p = .005$ (Table 4). Further, results indicated a trend toward significantly lower parent-observed scores on both the Physical Health Summary Scale, $t(19) = 2.45$, $p = .024$, and the FPAS, $t(13) = 2.94$, $p = .012$. No significant differences were found in the Cardiac Health Summary Scale. Additionally, no significant differences existed between reports of parents of female children versus parents of male children.

Effect of Medical Severity on QOL

To examine any effect that medical severity may have on QOL in this sample, an independent-samples t-test was conducted comparing male and female total scores on the *Defibrillator Severity Index* (DSI). The males in our sample were rated with a mean score of 8.20 and a standard deviation of 2.394. The females were rated with a mean score of 8.40 and a standard deviation of 3.578. Statistical analyses indicated no significant difference, $p = .899$, in medical severity between genders in this sample. Because there was no difference in medical

severity between males and females in this sample, there was no need to control for this variable when examining differences in QOL. Additional exploratory analysis indicated that medical severity was not significantly correlated, $p = .311$, with the PedsQL Total Scale Score in this sample.

Comparison of Social Functioning

In order to examine any differences between genders in the domain of social functioning, an independent-samples t-test was conducted comparing male and female total scores on the *Children's Loneliness and Social Dissatisfaction Scale* (LSDS). In this sample, the males scored a mean of 52.08 and a standard deviation of 12.89. The females scored a mean of 60.67 and a standard deviation of 14.17. Upon completion of statistical analyses, no significant differences in social functioning were noted between males and females in this study, although this may be attributed to the relatively small sample size rather than the effect of gender on this domain. Further exploratory analysis of effect size produced a Cohen's *d* value that suggests that there exists a medium to large effect of gender on ratings of the LSDS in this sample, $d = .63$.

Table 1. Participant Demographic Data

	N	%	M	SD	Range
Child					
Age	20		13.00	3.63	8-18
Gender					
Male	13	65.0			
Female	7	35.0			
Race/Ethnicity					
Caucasian	10	50.0			
African-American	1	5.0			
Hispanic	9	45.0			
Parent/Guardian					
Relationship to child					
Mother	14	70.0			
Father	3	15.0			
Grandparent	1	5.0			
Other legal guardian	1	5.0			
No response	1	5.0			
Marital Status					
Single/Never Married	4	20.0			
Married/Remarried	12	60.0			
Separated/Divorced	1	5.0			
No response	3	15.0			
Annual family income					
Below 14,999	1	5.0			
15,000-29,999	3	15.0			
30,000-44,999	4	20.0			
45,000-59,999	2	10.0			
60,000-74,999	0	0.0			
75,000-89,999	1	5.0			
90,000 and above	2	10.0			
No response	7	35.0			

Table 2. Quality of Life Means and Standard Deviations by Gender

	Boys (n=13)		Girls (n=7)	
PedsQL Scale	M	SD	M	SD
Total Scale Score	79.48	11.78	62.56	20.19
Psychosocial Health Summary Score	79.62	14.11	63.09	21.46
Physical Health Summary Score	79.17	10.52	61.61	18.29
Cardiac Health Summary Score	85.97	6.95	66.93	23.49

Table 3. One-way ANOVA of Gender on Quality of Life

PedsQL Scale	$F(1,19)$	p-value
Total Scale Score	5.701	.028*
Psychosocial Health Summary Score	4.344	.052
Physical Health Summary Score	7.574	.013*
Cardiac Health Summary Score	7.631	.013*

* - Significant at $p < .05$

Table 4. QOL and FPAS Means and Standard Deviations by Patient Report and Parent Report

	Child Report		Parent Report	
	M	SD	M	SD
PedsQL Total Scale Score	73.56	16.88	64.58	13.01
PedsQL Psychosocial Health Summary Score	75.26	16.90	64.91	15.92
PedsQL Physical Health Summary Score	73.02	15.79	65.89	14.03
PedsQL Cardiac Health Summary Score	79.31	17.07	76.38	15.36
Florida Patient Acceptance Survey (FPAS) Score	73.81	15.06	66.07	16.07

Table 5. Paired-Sample t-tests of PedsQL and FPAS Scores between Patient Report and Parent Report

	t	Degrees of Freedom (df)	*p*-value
PedsQL Total Scale Score	3.420	19	.003*
PedsQL Psychosocial Health Summary Score	2.445	19	.024
PedsQL Physical Health Summary Score	3.210	19	.005*
PedsQL Cardiac Health Summary Score	1.025	19	.318
Florida Patient Acceptance Survey (FPAS) Score	2.935	13	.012

CHAPTER 4
DISCUSSION

The current study is unique in that it is one of the first to examine gender differences in quality of life of pediatric ICD patients. By formally investigating these gender differences, this study was able to add to the limited information that exists in the extant research literature in this area. Few studies have examined the psychosocial impact that ICD implantation presents to pediatric populations. Generalizations from adult literature cannot always be assumed to be accurate due to numerous developmental differences (DeMaso et al., 2004). Previously, research had not focused on different treatments or outcomes for male versus female pediatric ICD patients, giving clinicians few options other than utilizing a uniform approach to implantation, treatment and maintenance. This study identified some apparent differences in quality of life between genders, necessitating further research tailored to gender-specific approaches to treatment of the pediatric ICD patient.

This study found that female pediatric ICD patients, like adult female ICD patients, exhibited poorer quality of life than their male counterparts. Specifically, gender differences in quality of life of pediatric ICD patients in this study were consistent across all of the subscales of the *PedsQL*, with the exception of the Psychosocial Health Summary Score, which also showed a trend towards significance. Since there were no significant differences in medical severity or age between genders in our study, it seems likely that this difference in quality of life could be related to the ICD, although further research is needed for clarification. Given the similarly poor quality of life presented in adult female ICD patients, it is possible that pediatric female ICD patients experience some of the same negative factors outlined by Walker and colleagues (2004), including social role maintenance, femininity, sexuality, body image satisfaction, and caretaking

abilities. However, until more specific research can be conducted, no precise attributions can be made.

Findings from this study suggest that the impact of the ICD on pediatric quality of life is potentially remarkable. Given the higher likelihood of physical restrictions than healthy children, it seems logical that children with ICDs would rate lower levels of quality of life. While female ICD patients exhibited significantly lower physical quality of life ratings than males, both genders rated distinctly lower levels of physical quality of life (Males – M = 79.17, SD = 14.11; Females – M = 61.61, SD = 18.29) when compared to published norms (M = 84.41, SD = 17.26) (Varni et al., 2001). This drop in physical health-related quality of life, a phenomenon shared by many childhood medical conditions, highlights the impact of the ICD as comparable to other chronic conditions in overall functioning.

Comparing the self-reported quality of life of children in the current sample to previously published reports of quality of life in children with a variety of chronic health conditions (Varni et al., 2007), illustrates that point and emphasizes the potential negative impact of an ICD on health-related quality of life. Specifically, children with ICDs in our sample reported a mean total quality of life score of 73.53 (SD = 16.88), which is commensurate with mean scores reported in other chronic illness conditions, including obesity (74.00, SD = 14.20), end-stage renal disease (73.97, SD = 15.22), psychiatric disorders (72.20, SD = 12.70), and cancer (71.97, SD = 16.12). This further illustrates the gravity of this condition on overall functioning, necessitating further research.

Regarding the social domain of quality of life, Alpern and colleagues (1999) focused on concerns about social rejection in pediatric pacemaker populations. It seems logical that an ICD could have a similar, if not more intense impact on social functioning in children. The present

study shed some light on this issue in the participants' ratings on the Children's Loneliness and Social Dissatisfaction Scale (LSDS). Although there were no significant gender differences on this measure, both male (M = 52.08, SD = 12.90) and female (M = 60.67, SD = 14.17) participants' mean scores were markedly higher than published norms (M = 29.88, SD = 8.01) (Asher & Wheeler, 1985), indicating elevated feelings of loneliness, social inadequacy, and negative views of peer status. Additional exploratory analysis indicated that there is a medium to large effect of gender on social functioning in this study as measured by the LSDS, such that females feel lonelier and more rejected than their male counterparts. Thus, the non-significant findings of the present study are likely a consequence of the small sample size rather than a true representation of no gender difference in this domain. Since it is already hypothesized that young ICD patients are at risk for psychosocial difficulties because of increased lifestyle disruption and distressing social comparisons (Sears et al., 2001), this study suggests that further research focusing on improving social functioning of all pediatric ICD patients, with additional emphasis on females, is largely warranted.

Previous research on children with pacemakers suggested that these children were likely to report fears of pacemaker failure (Alpern et al., 1989). Similarly, it was hypothesized that children and adolescents with ICDs could potentially exhibit fear and an overall negative appraisal of the device due to the invasive nature of the device and the shocks that it generates. Results from the current study indicate that pediatric ICD patients exhibit cognitive appraisal of their ICD on a level similar to adults, although no normative data is currently available. No differences were noted between males and females in this domain. Additional exploratory analyses, although not part of this study's hypothesis, indicated no significant correlation between the FPAS and PedsQL Total Scale Score. This could suggest that cognitive appraisal of

the ICD is not associated with quality of life; although the small sample size in the present study limits any related assumptions.

Previous research using parent-reported quality of life in pediatric ICD patients indicated that this population exhibits poor quality of life (DeMaso et al., 2004). Chronically ill child literature suggests that parent reports of patient functioning are variable in their accuracy (Guyatt et al., 1997). It was hypothesized that parent reports of pediatric ICD patient functioning would differ from patient reports. Parents of pediatric ICD patients in the current study reported significantly lower levels of functioning than patient self-reports on the Total Scale Score and the Psychosocial Health Summary Scale of the PedsQL, with trends toward significance on the Physical Health Summary Scale and the FPAS. This reporting gap across various domains is noteworthy for clinicians when inquiring about a patient's functioning. This difference in observed functioning extends knowledge of similar parent/patient gaps in other chronically ill child populations to the pediatric ICD population. Interestingly, no significant differences were noted between patient and parent on the Cardiac Health Summary Scale of the PedsQL, indicating a much higher level of congruency in the cardiac-specific domain than appears in broader domains of functioning. This could potentially be attributed to the amount of focus spent on the condition itself, rather than the ramifications of the condition on other areas of functioning.

Limitations

The current study has some limitations that must be taken into consideration when interpreting its data and analyses. First, this pilot study used a small sample size, which limited the number and types of analyses that could be conducted. The size of this sample also restricted the variability of patient attributes, such as race/ethnicity, family income, and locality. Adding more participants to the sample may further exemplify the apparent "gender gap" in the quality

of life of these patients. Second, while this study has illuminated an apparent gender difference in quality of life, no causality can be assessed from this information. Third, participants were recruited from only two medical centers in Florida and Texas, respectively. The sample used in this is study is not necessarily representative of pediatric ICD populations in other areas of the country. Fourth, the FPAS, a valid and reliable measure of cognitive appraisal and acceptance of the ICD, does not currently have normative data available for comparisons to pediatric patients.

Despite these limitations, the current study adds vital information to the limited knowledge of psychosocial functioning in pediatric ICD populations. Given that this is one of the first studies to examine gender differences in psychosocial functioning of this population, the information gained is valuable in our effort to provide more comprehensive and individually-tailored treatment to these children with a goal of improved quality of life.

Implications and Future Research

The current study identified an apparent gender difference in quality of life of pediatric ICD patients. Future research should expand our understanding of this difference by identifying specific factors responsible for this "gender gap." Specifically, research should focus on identifying whether this apparent gender difference is in fact a result of factors associated with the ICD, or if what we are seeing is a result of intrinsic differences in quality of life between males and females in youth and adolescence. By identifying the specific predictors of quality of life in this population, researchers will be better equipped to develop and implement gender-specific and pediatric-specific psychosocial interventions in order to improve overall functioning. These studies should include larger and more culturally and socioeconomically diverse populations in order to make more accurate generalizations from findings.

The findings from the current study also illustrated a difference in patient self-report and parent-observed report of overall functioning. These findings could be used in future research

investigating factors that may influence this difference (i.e., financial problems, family problems, etc.), as well as developing interventions to reduce this gap. Once again, a larger and more diverse sample would aide in identifying these contributing factors. Clinicians should also take this information into consideration when receiving conflicting information from parent and patient regarding psychosocial functioning.

APPENDIX
CHILD MEASURES

FPAS - Child

We want to understand what it is like for you to live with a medical device. Below are some statements that describe living with a medical device. Please rate the extent to which you agree or disagree with each of the following statements by circling the most appropriate numbered response.

	Strongly Disagree	Mostly Disagree	Neither Agree or Disagree	Mostly Agree	Strongly Agree
1. Thinking about the device makes me sad.	1	2	3	4	5
2. When I think about the device I don't do things I like.	1	2	3	4	5
3. I don't do my usual activities because I feel ugly by my device.	1	2	3	4	5
4. It is hard for me to do things without thinking about my device.	1	2	3	4	5
5. My device was my best treatment option.	1	2	3	4	5
6. I know I will be able to return to school if I want to.	1	2	3	4	5
7. I am safer because of my device.	1	2	3	4	5
8. The positive benefits of this device out-weigh the negatives.	1	2	3	4	5
9. I would receive this device again.	1	2	3	4	5
10. I know enough about my device.	1	2	3	4	5
11. I am careful when hugging or kissing people I love.	1	2	3	4	5
12. I have returned to a full life.	1	2	3	4	5
13. I feel that others see me as ugly by my device.	1	2	3	4	5
14. I feel ugly because of my device.	1	2	3	4	5
15. I know how my device works and what it does for me.	1	2	3	4	5
16. I am not able to do things with my family the way I used to.	1	2	3	4	5
17. I am concerned about resuming my daily physical activities.	1	2	3	4	5

LSDS

Below are some statements about how you may feel about people, places, or activities. Please rate how true each of the following statements is for you.

	Always True	Mostly True	Sometimes True	Hardly Ever True	Not At A True
1. It's easy for me to make new friends at school.	θ	θ	θ	θ	θ
2. I like to read	θ	θ	θ	θ	θ
3. I have nobody to talk to in class	θ	θ	θ	θ	θ
4. I'm good at working with other children in my class	θ	θ	θ	θ	θ
5. I watch TV a lot	θ	θ	θ	θ	θ
6. It's hard for me to make friends at school	θ	θ	θ	θ	θ
7. I like school	θ	θ	θ	θ	θ
8. I have lots of friends in my class	θ	θ	θ	θ	θ
9. I feel alone at school	θ	θ	θ	θ	θ
10. I can find a friend in my class when I need one	θ	θ	θ	θ	θ
11. I play sports a lot	θ	θ	θ	θ	θ
12. It's hard to get kids in school to like me	θ	θ	θ	θ	θ
13. I like science	θ	θ	θ	θ	θ
14. I don't have anyone to play with at school	θ	θ	θ	θ	θ
15. I like music	θ	θ	θ	θ	θ
16. I get along with my classmates	θ	θ	θ	θ	θ
17. I feel left out of things at school	θ	θ	θ	θ	θ
18. There's no other kid I can go to when I need help at school	θ	θ	θ	θ	θ

19.	I like to paint and draw	θ	θ	θ	θ	θ
20.	I don't get along with other children in school	θ	θ	θ	θ	θ
21.	I'm lonely at school.	θ	θ	θ	θ	θ
22.	I am well liked by the kids in my class	θ	θ	θ	θ	θ
23.	I like playing board games a lot	θ	θ	θ	θ	θ
24.	I don't have any friends in class	θ	θ	θ	θ	θ

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BIOGRAPHICAL SKETCH

Jay St. Amant received a bachelor's degree in psychology from Mount Olive College in 2006. He is currently a master's degree candidate in the Department of Clinical and Health Psychology at the University of Florida. Upon receipt of his master's degree in May 2008, he will continue his doctoral training in clinical psychology.