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Health Related Quality of Life and Social Support in Pediatric Patients with Pacemakers

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Abstract Prior research evaluating health-related quality of life (HRQOL) among pediatric patients with internal cardiac devices has primarily focused on children with cardiac defibrillators, with scant attention devoted to pacemaker recipients. Social support has been conceptualized as a protective factor that partially accounts for differences in HRQOL. This study compares the HRQOL of children with pacemakers with that of healthy children, and examines associations between HRQOL and social support. Twenty-seven pediatric pacemaker recipients completed measures of HRQOL and social support. Their parents also completed measures of child HRQOL. High concordance was found for child and parent-proxy reports of child HRQOL. Children with pacemakers and their parents both reported relatively low child HRQOL when compared to published normative data for healthy children and parents of healthy children. Family and friends emerged as the sources of support positively associated with the greatest number of HRQOL domains. In conclusion, these findings suggest that pediatric pacemaker recipients experience lower levels of HRQOL compared to healthy peers, and that social support from those closest to the child is associated with their perceived HRQOL.

Keywords Pacemaker · Internal cardiac device · Quality of life · Social support · Pediatrics

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Introduction

Disorders of cardiac rhythm affect thousands of children worldwide, with approximately 30,000 newly diagnosed with arrhythmias or cardiac conduction abnormalities in the US every year (Moller et al., 1993). Arrhythmias may occur as congenital idiopathic disorders or as acquired conditions directly caused by a medical procedure or existing illness (Fish & Benson, 2001). Common symptoms include fatigue, dizziness, nausea, cardiac chest pain, palpitations, and in extreme cases, cardiac arrest (Fish & Benson, 2001; Martin & Kugler, 1999). Internal cardiac devices, which include both pacemakers and internal cardiac defibrillators (ICD), are used to treat these abnormal or potentially life threatening heart rhythm disturbances. They are often used to prevent sudden cardiac death or when non-invasive pharmacological approaches have failed to resolve abnormalities in electrical heart activity. Advancements in cardiac device technology, coupled with parallel medical progress, have dramatically increased the life expectancy of children and adolescents with arrhythmias (Taylor, Zeigler, & Clark, 2001). Although both devices are commonly used as treatment modalities, the medical and psychosocial literature has focused more on outcomes of children and adults with ICDs compared to those with pacemakers. Greater research focus on pediatric

patients with ICDs may be due to the unpredictable and painful shocks that defibrillators deliver, which may be accompanied by significant shock-related anticipatory anxiety (Sola & Bostwick, 2005; Vitale & Funk, 1995). In contrast, pacemakers operate less noticeably than ICDs, and there have been few investigations of the adjustment of children with pacemakers.

Although many children with artificial cardiac devices are able to lead healthy lives after implantation, others remain affected by their underlying cardiac condition, and/or factors associated with having an implanted device (Yerra & Reddy, 2007). Children implanted with a cardiac device are frequently asked to refrain from participating in sports or activities that might damage the device, and are often advised to avoid using electromagnetic equipment that could impair its functioning (Yerra & Reddy, 2007). Consistent with these medical recommendations, children report avoiding activities or locations as a result of device implantation (Sears et al., 2011). Children with ICDs in particular may also experience psychosocial difficulties related to their health condition. Anxiety disorders, for instance, have been found in young patients diagnosed with arrhythmia who have received an ICD, including those who have received shocks from their ICD (Stefanelli et al., 2002). Other studies, however, have reported subclinical levels of anxiety in this population (DeMaso et al., 2004). In studies using qualitative methodology, children with pacemakers report concerns regarding social isolation from their peers, future hospitalizations, and parental over-involvement (Zeigler & Corbett, 1995). Further, the majority of children with an implanted cardiac device will face periodic and potentially life-threatening medical procedures to replace expended or faulty implanted cardiac devices and leads (Moak, Mercader, & Berul, 2010), as well as surgery to reposition leads that become displaced due to growth (Antretter et al., 2003). Related, recipients of cardiac devices also report concerns surrounding body image due to the visible bulge caused the by placement of the device under the skin, and scarring caused by surgical procedures (LeRoy & Dick, 2001). Thus, even though medical advances have lowered morbidity and increased life expectancy in children with cardiac rhythm disturbances, these children's health and psychosocial well-being, often referred to as their health-related quality of life (HRQOL), warrants further investigation.

Studies have shown that children with ICDs experience lower levels of HRQOL than was found in normative samples of healthy children (DeMaso et al., 2004; Sears et al., 2011; Vitale & Funk, 1995). Of the published studies investigating HRQOL among pediatric ICD recipients, only one (Sears et al., 2011) examined parent and child concordance of HRQOL. In this study, children reported significantly higher HRQOL scores on the psychosocial and physical health domains than was reported by their parents. However, comparison of child and parent-proxy report of HRQOL among pediatric patients with various cardiac conditions has revealed agreement rather than differences between reporters across several domains of HRQOL (Uzark, Jones, Burwinkle, & Varni, 2003). HRQOL in children with pacemakers has not yet been investigated. Further, generalizing from studies of children with ICDs to those with pacemakers is not appropriate because the two devices operate via different mechanisms as ICDs deliver shocks while pacemakers do not.

Wallander and Varni's disability-stress-coping model (Wallander & Varni, 1992) suggests that social support is one of the factors that is associated with levels of HRQOL in pediatric populations. Past research with chronically ill children supports the positive role of social support on health and well-being (Kyngas et al., 2001; O'Dell McCollum, 1997; Varni, Katz, Colegrove, & Dolgin, 1994; von Weiss et al., 2002). Although no investigations of the association between social support and HRQOL have been conducted with pediatric patients with cardiac devices, Wallace et al. (2002) found that social support was positively associated with HRQOL in a study of 58 adult ICD recipients. Similar associations may exist for children with implanted cardiac devices. In a study investigating the relationship between types of social support and HRQOL in patients with sickle cell disease, for example, only two of the four aspects of social support assessed were identified as being significantly associated with overall HRQOL (Jenerette, 2008). Thus, identifying specific sources of social support that are associated with HRQOL may serve to direct further assessment and intervention research.

The present study adds to the existing literature on the psychological adjustment of pediatric recipients of internal cardiac devices in several ways. First, no other studies have evaluated HRQOL in children and adolescents with pacemakers. Consistent with methodologies used in prior studies of HRQOL in children with ICDs, participants' self-reported and parent-reported HRQOL were compared to normative data for the PedsQL previously published by Varni, Seid, and Kurtin (2001). Second, child and parent-proxy report of child HRQOL were compared. There are inconsistent reports in the literature on children with cardiac conditions about the concordance of children and parent-proxy reports about children's HRQOL. Third, this investigation evaluated the association between different sources of social support and HRQOL. Peers, family and teachers have been the sources of support most typically assessed in past research with pediatric populations. In addition, given that children with pacemakers have expressed that physician-patient relationships are important (Zeigler & Corbett, 1995), this study assessed the degree to which children with pacemakers perceive social support

Table 1 Sample demographic and medical characteristics

Basic demographics	
Female % (*n*)	59.3 % (16)
Caucasian % (*n*)	70.4 % (19)
Age (mean)	13.6 years (*SD* = 3.3, range 8–18)
SES: $60,000 or above % (*n*)	40.7 % (11)
Mother % (*n*)	88.9 % (24)
Mother education level (mean)	12.8 years (*SD* = 1.6, range 9–16)
Father education level (mean)	13.2 years (*SD* = 1.9, range 9–17)
Classification of cardiac illness	
Primary electrical disease % (*n*)	59.3 % (16)
Acquired electrical disease % (*n*)	40.7 % (10)
On antiarrhythmic medication % (*n*)	29.6 % (8)
Number of lifetime surgeries (mean)	3.7 (*SD* = 3.9, range 1–7)
Hospitalizations in last year (mean)	0.6 (*SD* = 1, range 0–3)
Age at diagnosis (years)	3.1 years (*SD* = 4.9, range 0–15)
Age at last surgery (years)	10.3 years (*SD* = 3.8, range 3–17)
Age at device implantation (mean)	6.5 years (*SD* = 5.3, range 0–17)
Years since device implantation (mean)	6.5 years (*SD* = 4.9, range 0–18)

from healthcare providers. It was hypothesized that pacemaker recipients would experience lower levels of HRQOL when compared to norms for healthy children, and that there would be agreement between child and parent report of the child's HRQOL. Further it was hypothesized that there would be positive and significant associations between different sources of social support and HRQOL. Specifically, support from those closest to the child, namely family and friends, was hypothesized to be positively and significantly correlated with more domains of parent- and child-reported HRQOL. Support from classmates, teachers and medical providers was hypothesized to be significantly associated with fewer domains of HRQOL.

Method

Participants

Twenty-seven children and adolescents with implanted pacemakers were enrolled in this study. Table 1 shows the sample demographic and medical characteristics. There were 16 females and 11 males who ranged in age from 8 to 18 years ($M = 13.59$ and $SD = 3.30$). Participants were primarily Caucasian ($n = 19$; 70 %), followed by African American ($n = 3$; 11 %), Hispanic ($n = 3$; 11 %), Asian ($n = 1$; 4 %) and bi-racial ($n = 1$; 4 %). A total of eleven families (40.7 %) of the sample reported their annual income as $60,000 or above. Participants represent a wide range of medical diagnoses, length of time since device implantation, and number of surgeries (see Table 1). The participant sample size of this study is comparable to previous studies in children with ICDs (DeMaso et al., 2004).

Measures

Demographic and Health Information

A questionnaire was used to collect (I) basic demographic information including children's age, sex, race and annual family income, and (II) information regarding participants' current and past medical history. Parents provided all demographic and health-related information. Based on their report and review of the patient's medical history, cardiologists later categorized the patients' cardiac condition into a primary or acquired electrical disease group (Table 1). Electrical cardiac disorders can be divided into primary electrical disease and acquired electrical disorders. The most common form of primary electrical disease is congenital complete heart block, most commonly associated with maternal lupus. Other forms of primary electrical disorders would include the channelopathies, such as long QT syndrome, Brugada syndrome, or sick sinus syndrome. The most common cause of acquired electrical disease is in the post operative congenital heart disease patient. After repair of a structural problem, the conduction system is damaged necessitating the need for a pacemaker. Other causes of acquired electrical disorders include post infectious damage to the electrical system as seen infrequently in myocarditis, endocarditis, or rheumatic heart disease.

Pediatric Quality of Life Inventory, Generic Core Scales, Version 4.0 (PedsQL)

The PedsQL (Varni et al., 2001) is a widely used measure of HRQOL in healthy children and pediatric populations with chronic medical conditions. Developmentally appropriate versions of the PedsQL exist for children aged 8–12 years and adolescents aged 13–18 years. Given that past research with pediatric ICD recipients has shown that children and parents' ratings of HRQOL can differ significantly (DeMaso et al., 2004) both child and parent proxy-report forms were included. These forms are parallel and have identically worded items except for the word "you" which is substituted with the phrase "your child" or "your teen" in the parent-proxy form.

The PedsQL has 23 items and four subscales, including physical, emotional, social, and school functioning. Participants use a 5-point Likert scale ranging from Never (0) to Almost Always (4) to rate how relevant each problem-item had been in the past month (e.g., physical subscale:

"walking more than one block," emotional subscale: "feeling afraid or scared," social subscale: "getting along with other children," school functioning subscale: "keeping up with school work"). The Psychosocial HRQOL composite score is calculated by averaging the emotional, social, and school functioning subscale scores. To determine the Total HRQOL score, individual subscale scores are added. Higher scores reflect better HRQOL. Internal consistency and construct validity for PedsQL has been empirically demonstrated (Varni et al., 2001). In this study, Cronbach's alphas were 0.89 for the child-reported Total scale. Child-reported subscale alphas ranged from 0.57 to 0.78. Cronbach's alpha was 0.92 for the parent-reported Total score, with subscale alphas ranging from 0.75 to 0.86. To evaluate the level of HRQOL as reported by children and parents participating in the current study, we drew on normative data for the PedsQL (Version 4.0) previously published by Varni et al. (2001).

Survey of Children's Social Support (SOCSS)

The SOCSS (Dubow & Ullman, 1989) is a child self-report measure that assesses different sources and aspects of children's social support. This measure consists of three independent subscales that were developed for children age 8 and above. Only the Social Support Appraisals Scale (APP), which assesses children's own perception of support from various sources, was used in this study. The APP consists of 31 items assessing perceived support from family, peers and teachers. In addition to the standard scale format, the APP scale was slightly modified in two ways. First, items were added to assess the degree to which children with pacemakers perceive healthcare professionals (doctors and nurses) as a source of social support. We reasoned that because healthcare providers play a critical role in the medical management of pacemaker recipients, and these children have expressed that the physician-patient relationship is important (Zeigler & Corbett, 1995), support from these professionals may play a significant role in the HRQOL of these patients. As a result, five new items were created and added to this scale by modifying the original teacher support items, such that the word "teacher" was replaced with the phrase "doctor or nurse." Second, the existing peer subscale items were divided for purposes of reporting results into two groups: one comprised of items that specifically mention support derived from friends, and another consisting of identical items that explicitly measure support from classmates. Although patients interact with both groups of peers, we speculated that support from friends would be more important than support from classmates, who may or may not be friends.

Item presentation in the APP occurs in a "structured alternative format" fashion (e.g., friends subscale: "Some kids feel left out by their friends, but others don't. Do you feel left out by your friends?," classmates subscale: "Some kids feel left out by their class, but other kids don't. Do you feel left out by your class?" family subscale: "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?," teacher subscale: Some kids feel very close to their teachers, but other kids don't. Do you feel very close to your teachers?," doctor/nurse subscale: "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?"). Children respond using a 5-point scale ranging from Always (1) to Never (5). Higher scores signify greater perceived support. No parent-proxy version of this measure has been developed, and thus, only child report of sources of social support was used. Internal consistency reliability, for the original APP subscales used in this study was adequate to good, with Cronbach's alphas of 0.88 for Family, 0.88 for Peers, and 0.64 for Teachers. These alphas are similar or slightly lower than those originally reported by the developers of the measure, which ranged from 0.78 to 0.83 (Dubow et al., Dubow & Ullman, 1989). As previously discussed, the APP Peers subscale was broken down into a Friends and a Classmates subscale for this study. Cronbach's alphas for these subscales were 0.87 and 0.63 respectively. Similarly, the Doctor/Nurse subscale created for this study had a comparable alpha of 0.75.

Procedure

This study was approved by the Institutional Review Boards from participating institutions. Recruitment was conducted at the Pacemaker Clinic of a major pediatric medical center in the Southeastern United States. Patients were eligible for the study if they were between 8 and 18 years of age, had no significant intellectual impairments, were primarily English-speaking and were receiving follow-up care for an implanted pacemaker. Patients were excluded from participation if they were not accompanied by a caregiver to the clinic appointment. Thirty two parent–child dyads were approached for participation in the study. Three of the families approached were excluded based on the exclusion criteria (2 exclusions based on intellectual impairment, and 1 exclusion based on the non-English speaking criteria), and two families eligible to participate declined to do so due to shyness and health stressors.

Potential participants were identified by review of the clinic appointment roster. Parents of eligible children were contacted by phone prior to their appointment to explain the study. Informed consent, assent, and Health Insurance Portability and Accountability Act (HIPAA) release were obtained from the children and their parents during their

clinic visit. Participants completed the measures before and/or after their medical appointment. Parents provided demographic and family medical information and completed the parent-proxy version of the PedsQL. Children completed the PedsQL and the social support measure. Upon study completion, parents were given a hospital parking voucher and children received a small prize.

Data Analysis

Mean differences in HRQOL between the participants in this investigation and those in the normative sample were evaluated using one-sample *t*-tests, with Cohen's *d* values used to indicate effect size (Cohen, 1998). In preliminary analyses, point biserial or Pearson correlations were used to examine associations between PedsQL Total and subscale scores and demographic and medical factors. Based on these results, partial or bivariate Pearson correlations were used to explore the relationship between sources of social support and HRQOL. In other words, if significant associations were found between demographic or medical variables and any of the HRQOL domains, partial correlations were used to control for the effects of those variables on HRQOL. This analytical approach allowed us to examine the degree of association between HRQOL and social support removing the influence that confounding variables may have had on participants' level of HRQOL. Therefore, the partial correlation coefficient is adjusted for the influence of covariates and allows for drawing conclusions about the unique variance between HRQOL and social support while eliminating the variance from confounding demographic and medical variables. Alternatively, if no significant associations were found between demographic or medical variables and HRQOL, bivariate Pearson correlations were employed. Based on a priori hypotheses, all differences at $p \leq .05$ will be described. Additionally, Bonferroni correction for multiple comparisons indicates that those p values $\leq .0083$ remain significant when controlling for the possibility of Type I error.

Results

Between Group Analyses

Participants' PedsQL scores were compared to the scores from a healthy comparison group of 10,241 families (Varni, Burwinckle, Seid, & Skarr, 2003). Table 2 presents the means and standard deviations for both groups for child and parent-proxy report. One-sample *t*-test comparisons indicated that based on child self-report, participants scored significantly lower than the healthy comparison group on all domains of the PedsQL, including Physical, Emotional, Social, School, Psychosocial and Total HRQOL. These differences yielded Cohen's *d* effect sizes (Cohen, 1998) that ranged from 0.44 to 0.90. Parent reported scores on the PedsQL were also compared to Varni et al.'s (2003) normative sample. Parents of children with pacemakers reported significantly lower HRQOL scores on all domains of PedsQL relative to norms, except for Physical HRQOL. The significant differences demonstrated Cohen's *d* effect sizes that ranged from 0.47 to 0.71.

Child and parent report of the child's HRQOL were compared using paired samples *t*-tests and Intraclass Correlation Coefficients (ICC). Intraclass correlation is used to assess the agreement of two raters on the same construct or measure. In the current study, ICCs were calculated to assess agreement between parent and child report about the child's HRQOL. The ICC is derived by using a ratio between participant variability and total variability, which allows for consideration of both covariation and agreement between raters (McGraw & Wong, 1996). The use of ICCs in addition to paired samples *t*-tests has been recommended in the literature as a more rigorous approach for examining agreement between raters (De Civita, Regier, Alamgir, Anis, FitzGerald, & Marra, De Civita et al. 2005). There were significant ICCs found between child and parent report for the Total score, Psychosocial health, School functioning, and Physical health (see Table 3). The ICCs for these domains were large (0.689–0.720). There was no significant agreement found between child and parent report of Social functioning or Emotional functioning. Child and parent report were also compared using paired samples *t*-tests. Based on these analyses, there were no significant mean differences on any domain of HRQOL suggesting that parents and children reported similar scores.

Preliminary Analyses Prior to Correlational Analyses

Point biserial correlations were used to examine associations between PedsQL Total and subscale scores and sex, race (Caucasian vs. Non-Caucasian), and income ($\geq$ or $<$ \$60,000/year). Non-Caucasian groups were combined, given the small percentages of each of the different minority racial groups. To examine for the effects of income, which was collected as a categorical variable, participants were divided into a lower income group whose gross family income was below \$60,000 ($n = 16$) and a higher income group whose gross family income was \$60,000 or above ($n = 11$). All non-Caucasian participants were in the lower income group ($n = 8$), whereas only 42 % of the Caucasian participants were also in this group ($n = 8$). Pearson correlations were used to examine the associations between PedsQL scores and the continuous variables of current age, number of lifetime surgeries,

Table 2 HRQOL in children with pacemakers compared to a normative sample

PedsQL domain	Sample mean	Sample *SD*	Normative mean	Normative *SD*	Mean difference (95 % CI)	*t* Score	*p* Value	Cohen's *d*[a]
Child report total score	72.13	15.09	83.91	12.47	−11.78 (−17.75 to −5.81)	−4.06	.000[§]	0.85
Psychosocial health	70.86	14.78	81.83	13.97	−10.97 (−16.81 to −5.12)	−3.86	.001[§]	0.76
School functioning	66.11	17.72	81.31	16.09	−15.20 (−22.21 to −8.19)	−4.46	.000[§]	0.90
Social functioning	75.00	17.88	84.97	16.71	−9.97 (−17.04 to −2.90)	−2.90	.008[§]	0.58
Emotional functioning	71.48	17.19	79.21	18.02	−7.73 (−14.53 to −0.92)	−2.33	.028	0.44
Physical health	75.93	19.80	87.77	13.12	−11.84 (−19.68 to −4.01)	−3.11	.005[§]	0.70
Parent report total score	70.89	18.68	82.29	15.55	−11.50 (−18.89 to −4.11)	−3.20	.004[§]	0.66
Psychosocial health	69.51	18.15	81.24	15.34	−11.73 (−18.91 to −4.55)	−3.36	.002[§]	0.70
School functioning	67.78	24.43	78.27	19.64	−10.49 (−20.16 to −0.83)	−2.23	.034	0.47
Social functioning	72.36	23.50	83.05	19.66	−10.69 (−19.99 to −1.39)	−2.36	.026	0.49
Emotional functioning	68.33	19.81	81.20	16.40	−12.87 (−20.70 to −5.03)	−3.38	.002[§]	0.71
Physical health	75.38	22.89	84.08	19.70	−8.70 (−17.75 to 0.35)	−1.98	.059	0.41

PedsQL Pediatric Quality of Life Inventory

[a] Small effect size: $d = 0.20$, medium effect size: $d = 0.50$, large effect size: $d = 0.80$

[§] $p \leq .0083$ (significant following Bonferroni correction). Normative data for healthy children and their parents were drawn from research published by Varni et al. (2001)

Table 3 Comparison of child and parent report of HRQOL

PedsQL domain	Child mean	Child *SD*	Parent mean	Parent *SD*	Mean difference (95 % CI)	*t* Score	*p* Value	ICC
Total score	71.72	14.91	70.71	18.79	1.01 (−5.38 to 7.41)	0.326	.747	0.706***,[§]
Psychosocial health	70.43	14.52	69.51	18.15	0.93 (−5.40 to 7.26)	0.301	.766	0.689**,[§]
School functioning	66.11	17.72	67.78	24.43	−1.67 (−9.56 to 6.23)	−0.434	.668	0.720***,[§]
Social functioning	73.70	17.52	72.41	23.55	1.30 (−9.16 to 11.76)	0.255	.801	0.317
Emotional functioning	71.48	17.20	68.33	19.81	3.15 (−6.08 to 12.38)	0.701	.490	0.345
Physical health	75.58	19.90	74.21	23.53	1.27 (−5.38 to 7.41)	0.314	.756	0.696**,[§]

PedsQL Pediatric Quality of Life Inventory, *ICC* Intraclass Correlation Coefficient

* $p \leq .05$; ** $p \leq .01$; *** $p \leq .001$; [§] $p \leq .0083$ (significant following Bonferroni correction)

number of hospitalizations in the last year, age at device implantation, and age at last surgery.

For child- and parent-reported PedsQL Total and subscale scores, no significant associations were found for the sex of the child. In contrast, as shown in Table 4, income was significantly associated with Total HRQOL scores and all domains of child- and parent-reported HRQOL, except Emotional functioning. Significant correlations ranged from .40 to .58, with the higher income group reporting significantly higher perceived HRQOL than the lower income group. Similarly, race was significantly associated with child-reported PedsQL Total scores and all domains of HRQOL except School functioning. Significant correlations ranged from -.45 to -.56, with participants in the non-Caucasian group reporting significantly lower HRQOL than participants in the Caucasian group. Race was not significantly associated with parent-reported PedsQL scores. In contrast, age was significantly associated with parent-reported, but not child-reported, PedsQL scores. Significant correlations ranged from .46 to .51, with parents of older children reporting higher HRQOL. Two medical variables were significantly associated with parent-reported PedsQL scores, but none were associated with child-reported HRQOL. Specifically, number of lifetime surgeries and number of hospitalizations in the previous year were both significantly associated with parent-reports of lower Physical, Social, Psychosocial and Total PedsQL scores. Significant correlations ranged from −.41 to −.50 for number of lifetime surgeries, and from −.46 to −.50 for number of hospitalizations over the last year. Based on these results, partial correlations were used in subsequent correlational analyses between social support and the PedsQL Total, Psychosocial health composite, and other subscale scores to control for the confounding effects of

Table 4 Correlation between HRQOL and demographic and medical variables

	Race	Income	Age	Lifetime surgeries	Hospitalizations last year
PedsQL domain					
Child report					
Total QOL score	−.56**	.52**	.09	.02	−.12
Psychosocial health	−.51**	.44*	.13	.01	−.08
School functioning	−.35	.40*	.15	−.03	.00
Social functioning	−.45*	.41*	−.01	.00	−.11
Emotional functioning	−.49**	.29	.16	.04	−.11
Physical health	−.56**	.58**	−.01	.04	−.19
Parent report					
Total QOL score	−.34	.52**	−.50**	−.45*	−.48*
Psychosocial health	−.31	.47*	−.46*	−.44*	−.46*
School functioning	−.33	.44*	−.29	−.28	−.18
Social functioning	−.19	.48*	−.37	−.50**	−.50**
Emotional functioning	−.22	.19	−.48*	−.27	−.45
Physical health	−.38	.58**	−.51**	−.41*	−.48*

Non-Caucasians were assigned a value of 1 and Caucasians a value of 0. Race and income are highly correlated and should not be viewed as independent factors

PedsQL Pediatric Quality of Life Inventory

* $p \leq .05$; ** $p \leq .01$; *** $p \leq .001$

income, race, age, and/or medical variables, dependent upon whether significant associations were found for those variables. Partial correlation coefficients are adjusted for the influence of confounding effects and thus, allowed us to examine the unique variance between social support and the PedsQL Total and composite scores while eliminating the variance from confounding demographic and medical variables.

Associations Between Sources of Social Support and HRQOL

Partial or bivariate Pearson correlations as determined by preliminary analysis were used to explore the relationship between sources of social support and HRQOL. As shown in Table 5, results for sources of support and child-reported HRQOL indicate that family and friends emerged as the two sources of support most highly and positively correlated with the domains of the PedsQL. Specifically, perceived social support from Family was positively correlated with Physical, Social, Psychosocial and Total HRQOL ($r = .45$–$.64$). Support from Friends showed a similar pattern plus there were also significant associations found for School functioning ($r = .40$–$.63$). Support from Classmates ($r = .53$) and Teachers ($r = .48$) were significantly associated with Social functioning. Additionally, Teacher support was positively associated with Physical health ($r = .42$). No significant associations were found between perceived support from Doctors/Nurses and the child-reported PedsQL dimensions assessed. Also, no significant associations were found between parent-reported PedsQL scores and any of the sources of social support reported by the child.

Discussion

This study adds to the literature by comparing HRQOL in children and adolescents with implanted pacemakers and a normative sample, as well as assessing the relationship between sources of social support and HRQOL. To our knowledge, this is the first study to examine these factors in this patient population. Consistent with our hypothesis, results indicated that compared to healthy peers (Varni et al., 2003), perceived HRQOL among pediatric patients with pacemakers is significantly lower across all HRQOL domains. This pattern of results was corroborated by parental report of child HRQOL, with significant differences found for all but one domain. Overall, these results indicate that either something about having a pacemaker, the patients' medical regimens, or their underlying cardiac condition may negatively impact HRQOL relative to healthy peers. These results are consistent with a number of prior investigations conducted with children with ICDs, which show that the HRQOL of pediatric patients with ICDs is also lower than that of healthy peers (DeMaso

Table 5 Correlation of children's perception of sources of social support with HRQOL reports

	Child's view of various sources of social support				
	Family	Friends	Class	Teachers	Doctor/Nurse
PedsQL domain					
Child report					
Total score	.59**,§	.57**,§	.34	.39	.19
Psychosocial health	.58**,§	.54**,§	.29	.32	.17
School functioning	.36	.40*	.12	.21	.24
Social functioning	.64***,§	.63***,§	.53**,§	.48*	.23
Emotional functioning	.39	.24	.10	.06	−.04
Physical health	.45*	.46*	.35	.42*	.18
Parent report					
Total score	.38	.22	.09	.16	−.15
Psychosocial health	.42	.14	.15	.12	−.10
School functioning	.34	.12	.08	.19	−.17
Social functioning	.30	.08	−.07	−.09	−.05
Emotional functioning	.20	−.02	.27	.04	.10
Physical health	.19	.39	−.08	.21	−.26

[a] PedsQL = Pediatric Quality of Life Inventory

* $p \leq .05$; ** $p \leq .01$; *** $p \leq .001$; § $p \leq .0083$ (significant following Bonferroni correction)

et al., 2004; Sears et al., 2011), and comparable to children with other chronic medical conditions (Sears et al., 2011). Thus, based on the results of this investigation, the HRQOL of children who receive pacemakers should be monitored in clinical contexts, as well as receive additional research attention.

The agreement between child and parent-proxy reports of their child's HRQOL was also compared, with results generally supporting our hypothesis of child-parent concordance. There were no significant mean differences in parent and child report across HRQOL domains. Additionally, intraclass correlations, which are used to assess covariation and agreement between multiple raters on the same construct, between parent and child reports revealed that there was a high level of agreement between parent and child reports of child HRQOL, with four of six correlations showing large effect sizes. However, the correlations between reporters' scores on Social and Emotional functioning were not significant. Thus, although the overall pattern of these results indicates agreement between reporters, some discrepancies in reporting were found, suggesting that it will be important to obtain both parent and child perspective in future studies.

The third objective of this study was to examine the relationship between HRQOL and social support from different sources among children with pacemakers. Past research with children with a chronic illness supports the positive role of social support on health and well-being (Kyngas et al., 2001; O'Dell McCollum, 1997; Varni et al., 1994; von Weiss et al., 2002). Few studies, however, have considered the role of specific sources of social support on the HRQOL of pediatric populations, and none with pediatric patients with implanted cardiac devices. Findings from the present study showed that support from family and friends was positively associated with higher child-reported HRQOL across most HRQOL domains. Interestingly, friends, but not classmates, teachers or family, was the only source of support significantly associated with school functioning HRQOL. This suggests that friends may play a unique role in the well-being of children with pacemakers in school settings. Classmates and teachers emerged as sources of social support associated with higher levels of social functioning HRQOL, and teacher support was also associated with higher Physical health HRQOL. Even though these results show that support from classmates and teachers may be beneficial, it was not significantly associated with other HRQOL domains.

Contrary to our hypothesis, there were no significant associations between Doctor/Nurse support and child HRQOL. This finding is in contrast to the scant anecdotal and research evidence found in the adult literature indicating that the physician-patient relationship has a significant connection with quality of life (Dakof & Taylor, 1990; Shanafelt et al., 2009). It is possible that medical professionals are indeed providing some type of support that is beneficial but different from that provided by other sources. Since the measure we utilized was not specifically

developed to measure support from healthcare professionals, it may not be a sensitive tool to detect ways in which medical professionals provide support. In addition, the benefits of support from medical staff may not be assessed by inventories such as the PedsQL. More context-specific and medically-based scales may be needed to capture the positive impact that healthcare professionals have on children with pacemakers. This potential relationship between support from healthcare professionals and HRQOL warrants a more in depth, focused examination in future studies with this population.

In terms of the association between social support and parent reported HRQOL, there were no significant associations between any sources of social support and domains of HRQOL. These unexpected results suggest that even though parents seem to be attuned to their children's HRQOL, as indicated by both parent and child reported deficits in HRQOL relative to the normative sample, there is enough variability across reporters that significant associations between child-perceived social support and parent-reported HRQOL were not detected.

Although no hypotheses were offered regarding the effects of race, income, age, or medical variables on HRQOL, preliminary analyses revealed that younger, non-Caucasian participants, participants with lower family incomes, and those with more hospitalizations and surgeries over the last year appear to have lower levels of HRQOL. All of the non-Caucasian participants were in the lower income group compared to only 42 % of the Caucasian participants. Thus, it is possible that racial differences in HRQOL were due primarily to the effects of low income. In prior research on HRQOL in patients with defibrillators, racial and income composition of the samples were described, but no explicit results describing their association with HRQOL were reported (DeMaso et al., 2004; Sears et al., 2011). Age, number of lifetime surgeries, and hospitalizations in the last year were inversely related to HROQL as indicated by parents' report, but not for child report. It is not surprising that those pacemaker recipients who had more hospitalizations and surgeries had lower quality of life. These medical treatments may reflect poorer physical health, as well as some measure of exposure of the patients to unpleasant medical interventions, both of which could decrease HRQOL. Also, parents reported that their younger children had lower HRQOL. It is possible that parents view their adolescents as behaving more independently and therefore seeming to have adjusted to their condition, whereas younger children are monitored and supervised more closely and receive more care from their parents. It is curious that medical events and age were not associated with child report of HRQOL. Parents may base their impression of their children's HRQOL more on the medical events the children experience than the children themselves do. The effects of these demographic and medical variables and their association with HRQOL should be examined in future investigations.

Limitations of this study should be noted. First, the relatively small sample size limits the power of the statistical analyses to find significant associations. Second, all patients in our study were recruited from a single institution, and thus, may not be fully representative of children with pacemakers. Multicenter studies are needed to more accurately represent the host of patients' characteristics. Third, limited information on the characteristics of participating parents was collected. Fourth, no direct measures of illness severity were available for this study other than the number of surgeries and hospitalizations. Fifth, the findings of this study are correlational in nature, and therefore, the directionality of the relationship between social support and HRQOL cannot be clearly determined. Social support may be the initiating factor that results in a certain level of HRQOL. Alternatively, HRQOL may also influence the child's ability to adequately solicit and receive different levels of support. Also, although all significant correlations between social support and HRQOL are in the predicted direction, it is possible that some were significant by chance. For this reasons, those which remained significant following Bonferroni correction were indicated. Finally, although the internal consistency for the Total score on the child-report version of the PedsQL was high, alphas for some of the subscales were low. However, all subscales were retained to facilitate comparisons to prior research investigating HRQOL with children who have implanted ICDs (DeMaso et al., 2004; Sears et al., 2011).

Additional research on the HRQOL and psychosocial functioning of patients with pacemakers is needed. First, research with young ICD recipients has shown that some of these patients experience psychological difficulties, including symptoms of depression and anxiety (Eicken et al., 2006; Stefanelli et al., 2002; Wojcicka, Lewandowski, Smolis-Bak, & Szwed, 2008). Additional domains of psychological functioning should also be assessed in children with pacemakers. Second, future research should also examine additional possible correlates of HRQOL after device implantation, such as age, medical variables such as objective measures of health status, time since diagnosis, and additional aspects of family functioning. Third, this study supports the potential benefit of including family members and friends in interventions to increase social support, as well as possible improvements in patients' HRQOL. Fourth, the role of support from health care professionals on the HRQOL of young pacemaker recipients needs to be explored in more detail in future studies. Finally, because the patients of this study were not followed longitudinally from before device implantation, we are unable to determine whether the lower HRQOL

observed in this sample relative to healthy peers is reflective of lower pre-pacemaker functioning or the result of device implantation. These questions await future investigation.

In conclusion, pediatric pacemaker recipients experience lower overall levels of HRQOL compared to healthy norms, as indicated by both child self-report and parent-proxy report of their children's HRQOL. Deficits in these patients' HRQOL when compared to healthy peers are comparable to those found for pediatric patients with ICDs. Child and parent-proxy reports of HRQOL were largely in agreement with each other, though different patterns of correlations were found for parent and child report and measures of social support and demographic and medical factors. Inclusion of both parent and child report of child HRQOL in future research is indicated. Child-perceived HRQOL was related to the amount of support received from certain sources, with higher support from family and friends being associated with higher levels of HRQOL in most domains of child-reported, but not parent-reported HRQOL. In contrast, parents' perceptions of their children's HRQOL were not significantly associated with any of the various aspects of social support included in this study. These findings indicate the need for further research and clinical focus on the HRQOL of pediatric patients with pacemakers, as well as inclusion of additional psychological and social factors that may be associated with patients' HRQOL.

Conflict of interest Patricia Cheng, Ana M. Gutierrez-Colina, Kristin A. Loiselle, Margaret Strieper, Patrick Frias, Kevin Gooden, and Ronald L. Blount declare that they have no conflict of interest.

Ethical Standards All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients for being included in the study.

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