Published in final edited form as:

J Pediatr Health Care. 2014 ; 28(3): 251–261. doi:10.1016/j.pedhc.2013.05.006.

The Importance of Self-Perceptions to Psychosocial Adjustment in Adolescents with Heart Disease

Kathleen A. Mussatto, PhD, RN¹, Kathleen J. Sawin, PhD, RN, CPNP-PC, FAAN^{1,2}, Rachel Schiffman, PhD, RN, FAAN², Jane Leske, PhD, RN, CNS-BC², Pippa Simpson, PhD³, and Bradley S. Marino, MD, MPP, MSCE⁴

¹Children's Hospital of Wisconsin, Milwaukee, WI

²University of Wisconsin – Milwaukee, Milwaukee, WI

³Medical College of Wisconsin, Milwaukee, WI

⁴Cincinnati Children's Hospital Medical Center

Abstract

Introduction—This study examined the importance of self-perceptions as determinants of psychosocial adjustment reported by adolescents with heart disease and compared adolescents with heart disease to healthy norms.

Methods—Ninety-two adolescents with heart disease from a single Midwestern institution provided reports of self-perceptions (health, self-worth, competence, and importance), internalizing behavior problems (IP) (e.g. anxiety, depression) and externalizing behavior problems (EP) (e.g. attention problems, aggression), and health-related quality of life (HRQOL). Hierarchical linear regression was used to assess the impact of self-perceptions, as well as clinical factors (illness severity, time since last hospitalization, medications) and demographic characteristics on outcomes.

Results—Self-perceptions explained the most variance in behavioral and HRQOL outcomes ($R^2_{adj}=0.34$ for IP, 0.24 for EP, and 0.33 for HRQOL, $p<0.001$). Male gender and lower household income were associated with more behavior problems. Clinical variables were only related to HRQOL. Compared to healthy norms, IP were significantly more common in males and HRQOL was lower ($p<0.001$).

Discussion—Adolescents with heart disease are at risk for internalizing behavior problems and reduced HRQOL; however, positive self-perceptions appear protective. Self-perceptions are critical and should be addressed by clinicians.

Corresponding author: Kathleen A. Mussatto, PhD, RN, Children's Hospital of Wisconsin, 9000 Wisconsin Avenue, PO Box 1997, MS B550A, Milwaukee, WI 53201, kmussatto@chw.org, Phone: 414-266-2073, Fax: 414-266-6248.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Keywords

Adolescent; Self-perception; Adjustment; Congenital heart disease

Over 1.3 million children and adults in the United States are living with some form of congenital or acquired pediatric heart disease (American Heart Association, 2010). As survival for these conditions has increased, so too has the recognition that psychosocial problems are a common comorbidity. Little is known about the determinants of these complex psychosocial problems. Demographic characteristics and disease severity have not proven to be reliable predictors of psychosocial outcomes (Moons, VanDeyk, DeGeest, Gewillig, & Budts, 2005; Mussatto & Tweddell, 2005). Individual perceptions of well-being, which reflect adaptation over time, may provide added insight into understanding these outcomes.

Adolescents with pediatric heart disease may be at high risk for psychosocial adjustment problems as they face not only the normative transitions of adolescence but also the additional stressors imposed by their heart disease such as medication use, altered physical appearance, or activity restrictions (Sawin, Cox, & Metzger, 2010; Vessey & Sullivan, 2010). Much of what is known about psychosocial adjustment in adolescents with pediatric heart disease has been obtained from parent proxy reports. Reports from parents have demonstrated limited correlation with adolescent self-report of psychosocial adjustment, particularly on measures of internal characteristics and emotions (Drotar, 2004). Parents, teachers, and health professionals tend to report more problems than do the adolescents themselves (Latal, Helfricht, Fischer, Bauersfeld, & Landolt, 2009; Spijkerboer, Utens, Bogers, Verhulst, & Helbing, 2008). It is unclear whether the differences reflect a lack of insight on the part of the adolescents or a healthy sense of coherence and adjustment to the challenges of their condition (Bellinger et al., 2011; Lambert et al., 2009; Moons et al., 2005). Detailed assessment of the direct perspective of the adolescent is needed to provide greater insight into this phenomenon.

Previous research has demonstrated that adolescents with pediatric heart disease are at risk for behavioral problems (Hovels-Gurich et al., 2007; Karsdorp, Everaerd, Kindt, & Mulder, 2007; Shillingford & Wernovsky, 2004), reduced social skills (Bellinger, 2008; McCrindle et al., 2006), altered self-perception (Chen, Li, & Wang, 2005; Karsdorp, Kindt, Rietveld, Everaerd, & Mulder, 2007; Rietveld et al., 2002; Salzer-Muhar et al., 2002), and reduced quality of life (Mussatto & Tweddell, 2005; Rose et al., 2005; Uzark et al., 2008). In one of the few studies focusing on adolescent self-report, subjects with severe heart disease reported lower self-esteem, more depression, and reduced HRQOL compared to healthy adolescents and participants with mild or moderate pediatric heart disease. Self-esteem, depressed mood, and the adolescent's perception of their disease severity accounted for 44% of the variation in HRQOL outcomes (Cohen, Mansoor, Langut, & Lorber, 2007).

The purpose of this study was to examine the importance of self-perceptions as determinants of psychosocial adjustment reported by adolescents with heart disease and to compare adolescents with heart disease to healthy norms. Understanding the relationships of these factors could identify targets amenable to interventions to improve adjustment.

Conceptual Model

This research was guided by the transactional stress and coping model of adjustment (Thompson & Gustafson, 1996). The model was modified to examine the relationships between contextual factors (demographic and clinical characteristics), adaptational processes (self-perceptions), and psychosocial adjustment (behavior problems and HRQOL) as reported by adolescents with pediatric heart disease (Figure 1). Contextual factors delineate the conditions under which the adolescent is experiencing life with pediatric heart disease. Adaptational processes are an early response to stress and are defined as active processes that may include biological, psychological, and/or social-ecological changes. The goal of these processes is to decrease discrepancies between actual and desired states in order to reduce stress (Thompson & Gustafson, 1996). Self-perceptions are an example of an adaptational process. Self-perceptions can be global (e.g., self-worth) or domain-specific (e.g., athletic skill, physical appearance). The latter are influenced by both the individual's perception of competence and the degree of importance assigned to that domain (Harter, 1987; Harter, Whitesell, & Junkin, 1998; Harter, 1999). Psychosocial adjustment, the primary outcome of interest in this study, is a later response to the stress of chronic illness. Adjustment cannot be directly observed; rather, it is inferred from other variables that can be directly measured or are observable. Behavior problems and HRQOL are two measurable constructs that have been used to represent psychosocial adjustment in subjects with chronic health conditions.

Methods

This study employed a descriptive secondary analysis of preexisting data. The data source was a multicenter study designed to establish the psychometric properties of the Pediatric Cardiac Quality of Life Inventory (PCQLI), a new disease-specific HRQOL measure for children and adolescents with pediatric heart disease (Marino et al., 2008; Marino et al., 2010). Participants were eligible for the study if they were between the ages of 8-18 years and had some form of congenital or acquired pediatric heart disease. Subjects were excluded if they did not speak English or if they had developmental delay (trisomy 21) or other conditions believed to exert an independent effect on HRQOL (e.g., sickle cell disease, cystic fibrosis). Measures of self-perceptions, behavior problems, and HRQOL were obtained in order to establish the validity of the new disease-specific instrument (Marino et al., 2010). All adolescents independently completed self-report questionnaires under the supervision of a study team member before a scheduled pediatric cardiology clinic visit. All participants provided written informed consent/assent to participate in the study. Institutional review board approval to access existing research data was obtained from Children's Hospital of Wisconsin for this secondary analysis.

Study Participants

The sample consisted of 92 adolescents between 11 and 18 years of age. Participants were patients at a pediatric heart center based in a free-standing children's hospital. Given the exploratory nature of this study the convention of a minimum of 5 subjects per parameter being investigated was used to determine a minimum sample size (Polit & Beck, 2007). The

conceptual model (Figure 1) identifies 13 possible predictor variables and 3 outcome variables; therefore, a minimum sample size of 80 subjects was needed to effectively evaluate the relationships proposed.

Measures

The data sources and measures used in the study are organized according to the theoretical framework (Figure 1). The primary outcome was psychosocial adjustment measured by adolescent self-report of internalizing and externalizing behavior problems and HRQOL. Predictor variables included the demographic and clinical contextual factors and adaptational processes measured as self-perceptions.

Contextual factors—All demographic and clinical contextual data were obtained from the subject's parent or abstracted from the medical record. Individual demographic variables included gender, age, and race. Family characteristics included birth order, family structure (one versus two biological parent families), maternal education, and household income. Clinical variables included the severity of the subject's heart condition, time since last hospitalization, and need for medications. Severity of disease was categorized using the Cardiologist's Perception of Medical Severity (CSEV) (DeMaso, Campis, Wypij, Bertram, Lipshitz, & Freed, 1991) which accounts for diagnosis, type of repair, and prognosis using the following 5-level ordinal scale:

1. insignificant disorder – disorder has no impact on adolescent's health;
2. mild disorder – lesion requires no operative intervention, only long-term follow-up (e.g. small ventricular septal defect);
3. moderate disorder – adolescent is asymptomatic, but has had or will require operation, simple repair (e.g. atrial septal defect);
4. marked disorder – adolescent is quite symptomatic; has had or will require major difficult repair but lesion is anatomically correctable (e.g. tetralogy of Fallot, transposition of the great arteries);
5. severe disorder –cardiac lesions that are not anatomically correctable or for which only complex palliative repair is possible (e.g. pulmonary vascular obstruction, Fontan palliation, valve replacement, heart transplant).

A pediatric cardiologist independently ranked the disease severity of 30 subjects (32% of the sample). The author ranked these same 30 subjects. The interclass correlation coefficient for these rankings was 0.92 indicating high inter-rater agreement. Given this level of agreement, the author proceeded with ranking the disease severity of the remaining subjects. The time since last hospitalization to survey completion served as a measure of how recently the adolescent had experienced significant manifestations of their condition. The need for medications was included as a measure of the daily burden associated with the presence of the chronic heart disease.

Adaptational processes—Adolescent participants reported self-perception of competence and importance in domains considered relevant to adolescents using the Self-

Perception Profile for Children (age 8-12 years) (SPPC) (Harter, 1985) and the Self-Perception Profile for Adolescents (age 13-18 years) (SPPA) (Harter, 1988). The instruments have 36 items and six subscales in common that address the general domain of global self-worth as well as competence and importance in five specific domains: 1) behavioral conduct; 2) scholastic competence; 3) athletic competence; 4) physical appearance; and 5) social acceptance. Each subscale is measured with six items. The questionnaires required the adolescent to choose one of two opposing statements describing a behavior or feeling. They are then asked to rate whether the idea is “Really true for me” or “Sort of true for me.” Items are scored on a scale of 1-4. Higher scores indicate higher self-concept or importance in each domain. The SPPC and SPPA have been widely used in studies of self-concept and have well-established psychometric properties with Cronbach’s α for internal reliability ranging from 0.71 – 0.92 (Christian & D’Auria, 2006; Harter et al., 1998; Sawin, Buran, Brei, & Fastenau, 2003) and a stable factor structure (Shevlin, Adamson, & Collins, 2003).

The Self-Perception Profile (SPP) discrepancy score is calculated by subtracting the importance rating from the competence score on those domains assigned high importance scores by the participants (importance scale rating of 3). All of the discrepancy scores are summed (taking sign into account) and divided by the number of domains deemed important, resulting in a mean discrepancy score. A negative value for the SPP discrepancy score indicates that the participant perceived his or her competence to be lower than the importance they assigned to the domain.

Self-perception of health was derived from the adolescent’s response to a single item. Participants were asked to rank their health on a 5-point scale from “Excellent” to “Poor.” Responses were scored on a scale of 1-5 with lower scores indicating better health. This is the same single item that is used in the National Longitudinal Study of Adolescent Health (Boardman, 2006).

Psychosocial adjustment—Adolescents completed the Youth Self-Report (YSR) (Achenbach & Rescorla, 2001). The YSR has 105 items that load onto two scales, internalizing and externalizing behavior problems. Internalizing problems are overcontrolled behaviors directed inward and include anxiety, depression, social withdrawal, and somatic complaints. Externalizing problems are undercontrolled behaviors directed outward and include aggressiveness, rule breaking, and acting out. Reports are scored using software that converts raw scores to T-scores (normative mean = 50, SD = 10) and percentiles. Problem scale T-scores of 60-63 are considered borderline and 64 or greater are considered clinically significant. Psychometric characteristics of the instrument have been well established across hundreds of studies in both healthy and clinical populations. Cronbach’s α for both the internalizing and externalizing problem scales of the YSR is reported as 0.90 (Achenbach & Rescorla, 2001).

Adolescents completed the Pediatric Quality of Life Inventory (PedsQL™) (Varni, Seid, & Rode, 1999), a 23-item self-report form for children, ages 8-12 years, and adolescents, ages 13-18 years, to assess HRQOL. Participants responded by reporting how much of a problem an activity or issue had been in the past month. The responses are transformed to a 0-100

scale where higher scores indicate better quality of life. Norms were developed in large samples of children. Discriminant, construct, and convergent validity, reliability, sensitivity, and responsiveness have been established in healthy and chronically ill populations (Varni et al., 1999; Varni, Seid, & Kurtin, 2001; Varni, Seid, Knight, Uzark, & Szer, 2002) as well as in samples of subjects with pediatric heart disease (Mussatto & Tweddell, 2005; Uzark, Jones, Burwinkle, & Varni, 2003). Internal reliability for the total score is $\alpha = 0.88$ in children 5–18 years of age from healthy and chronic condition populations (Varni et al., 2001) and $\alpha = 0.89$ for adolescents with pediatric heart disease (Uzark et al., 2003).

Statistical Methods

Descriptive statistics were used to examine the characteristics of the sample. Means and standard deviations and/or medians and ranges were determined for all continuous variables and percentages for all dichotomous and categorical variables. Pearson correlations between all predictor and outcome variables were examined. Where there were high correlations noted between predictor variables, e.g., maternal level of education and income group, only the variable with the highest correlation with the outcome variables was retained. Only those predictors with significant correlations ($p < 0.05$) to the psychosocial adjustment outcomes of interest, internalizing problems, externalizing problems, or HRQOL were considered in evaluating the conceptual model.

Three separate multivariable, hierarchical linear regression equations were used to evaluate the model proposed; one each for the ability to explain internalizing problems, externalizing problems, and HRQOL. The analytical approach described by Thompson was employed (Thompson, Gil, Burbach, & Keith, 1993). This involved entering the contextual factors in two blocks, with clinical factors entering the hierarchical regression model first, the demographic factors as a second block, and the self-perception variables as a third and final block.

Results

Contextual factors

The demographic and clinical characteristics of the sample expressed as count and percent are displayed in Table 1. The mean age of the participants was 14.2 ± 2.1 years. The sample was predominantly white, non-Hispanic (86%) and the household income suggested an upper middle class sample.

The majority of the subjects had congenital heart disease ($n = 78$, 85%). The remaining 14 (15%) had acquired heart conditions including arrhythmias, cardiomyopathies, or infection-related cardiac conditions. Severity of the adolescent's primary cardiac diagnosis was rated as "marked" or "severe" for 61% of the participants, and 65% were taking medications on a daily basis either for their heart condition or for another chronic condition, e.g., asthma, attention deficit. The time since the subject's last hospitalization ranged from 40 days to 18.9 years with a median duration of 7.6 years. Seven subjects were never hospitalized for cardiac or other reasons. Health care utilization was common with 70% of the sample reporting 3 or more health care visits in the past year.

Adaptational processes

The median for all scales of the Self-Perception Profile was near three, which is not significantly different from healthy reference samples (Harter 1985, 1988). In this sample, Cronbach's α for global self-worth was 0.78 on the SPPC and 0.79 on the SPPA. The median SPP Discrepancy Score was -0.30 indicating that participants reported somewhat lower competence on the domain specific scales than what they ranked as important. Overall, 71 subjects (77.2%) reported negative SPP Discrepancy Scores. Median importance ratings for behavioral conduct and scholastic competence were greater than 3; indicating that these were the most important domains identified for this sample. Importance ratings for social acceptance, athletic competence, and physical appearance had a median of less than 3; identifying these domains as less important overall (Table 2). Self-perception of health had a median value of 2, equivalent to "very good" health. Sixty (65.2%) of the subjects reported their health to be "very good" or "excellent." No subjects reported their health to be "poor."

Psychosocial adjustment

The median T-score for internalizing behavior problems was 56 for the entire sample, which is within one standard deviation of the normative mean of 50. Higher scores are indicative of more problems. However, 35% of the sample reported internalizing problems in the borderline or clinical range. This is significantly higher than the normative reference of 17% with borderline or clinical problems ($p < 0.05$) (Achenbach & Rescorla, 2001). For externalizing behavior problems the sample median was 50, equal to the population norm. Externalizing problems in the borderline or clinical range were reported by 15% of the sample which is not different from the normative sample. In this sample, Cronbach's α was 0.89 for both internalizing and externalizing problem scales. For overall HRQOL, Cronbach's $\alpha = 0.93$ in both 11-12 and 13-18 year olds. Subjects reported a median score of 75 for HRQOL with a range of 22-100. For healthy children the mean is 84.4 ± 13 for children age 8-12 years and 85.5 ± 12 for teens 13-18 years (Varni et al., 2001; Varni, Burwinkle, Seid, & Skarr, 2003). Thirty-three adolescents in this sample (36%) reported HRQOL that was > 1 SD below the mean from a healthy reference sample. This represents a significantly impaired HRQOL (Uzark et al., 2008; Varni et al., 2003). In summary, the adolescents in this study reported a higher than expected rate of internalizing problems and a lower HRQOL than population norms.

Factors Associated with Psychosocial Adjustment

Factors associated with more internalizing behavior problems included male gender, lower global self-worth, a larger negative SPP discrepancy score, and self-perception of poorer health ($R^2 = 0.39$, $p < 0.001$). Factors associated with more externalizing behavior problems included male gender, lower household income, lower global self-worth, a larger negative SPP discrepancy score, and self-perception of poorer health ($R^2 = 0.36$, $p < 0.001$). Lower HRQOL was associated with a shorter time since last hospitalization, need for medications, lower household income, lower global self-worth, a larger negative SPP discrepancy score, and self-perception of poorer health ($R^2 = 0.54$, $p < 0.001$). The results of the hierarchical linear regression analyses are shown in Table 3.

As a group, the self-perception variables (global self-worth, SPP discrepancy score, and perception of health) accounted for the largest portion of variability in the outcomes: internalizing problems, 34%; externalizing problems, 23.7%; and HRQOL, 33.2%. Global self-worth and the SPP discrepancy score emerged as significant predictors in the regression models for each outcome. Self-perception of health was a significant predictor of internalizing problems and HRQOL but not externalizing problems.

Discussion

This study examined the importance of self-perceptions as determinants of psychosocial adjustment reported by adolescents with heart disease and compared adolescents with heart disease to healthy norms. The main findings are summarized in Table 4. Adolescents in this sample reported a higher incidence of internalizing behavior problems, such as anxiety and depression, and reduced HRQOL than the normative population. These findings are consistent with previous research in pediatric heart disease (Cohen et al., 2007; Hovels-Gurich et al., 2007; Karsdorp et al., 2007; McCrindle et al., 2006; Uzark et al., 2008). Demographic and clinical contextual factors explained only a small portion of the variance in outcomes. On the other hand, self-perceptions of health, self-worth, and the discrepancy between self-perceived competence and importance in specific domains accounted for a large portion of the variance in behavior problems and HRQOL. The detailed examination of self-perceptions provides new data in this population. These findings suggest that for adolescents with pediatric heart disease the *perception* of self-worth, competence, importance, and health are more important determinants of psychosocial adjustment than objective indicators of the clinical condition. This fits the theoretical logic of the transactional stress and coping model of adjustment which proposes that self-perceptions are adaptational processes that influence the link between clinical factors and adjustment outcomes (Thompson & Gustafson, 1996).

The results for global self-worth and the domain-specific competence scales of the Self-Perception Profile for this sample of adolescents with heart disease were found to be similar to a healthy reference sample. These findings are consistent with those of Chen et al. (2005) in children with heart disease. The finding that perceptions of global self-worth were preserved despite more internalizing behavior problems and a lower HRQOL suggests that these adolescents were able to distinguish between their overall satisfaction with themselves and other aspects of adjustment. A strong sense of self may be a significant protective factor in the management of stress associated with chronic illness.

Over half of this sample reported discrepancies between importance and competence on two or more domains of the Self-Perception Profile, meaning that they ranked their competence low in an area they considered important. A larger negative SPP discrepancy score was significantly associated with poorer global self-worth. Sixty-seven percent of the participants had a negative SPP discrepancy score for behavioral conduct and 83% for scholastic competence. Both global self-worth and the SPP discrepancy score were significant determinants of internalizing problems, externalizing problems, and HRQOL, suggesting that lack of congruence between perceived competence and importance is a risk factor for maladjustment.

Among the demographic factors, gender and household income were associated with adjustment. The fact that the current study did not find a relationship with age might be due to the relatively narrow age range included, whereas other studies have included subjects from 2-18 years of age (Krol et al., 2003; Mussatto & Tweddell, 2005; Spijkerboer et al., 2006). Male gender was associated with a higher prevalence of behavior problems but did not influence HRQOL, which is consistent with previous studies of adolescents with heart disease (Cohen et al., 2007; Culbert et al., 2003; Krol et al., 2003; Salzer-Muhar et al., 2002; Spijkerboer et al., 2006). In this sample, boys reported a significantly higher incidence of internalizing problems such as anxiety and depression. These findings suggest this population could benefit from thorough assessment of psychosocial issues. Higher household income had a protective effect demonstrated by its inverse relationship with externalizing problems and its association with better HRQOL. Previous work has found that social disadvantage is a risk factor for poorer psychosocial outcomes in this population (Goldbeck & Melches, 2006; McCrindle et al., 2006).

Among the clinical variables, time since last hospitalization and need for medications, were not associated with behavioral outcomes but did account for nearly 15% of the variance in HRQOL. In contrast to the current research, previous studies have found disease severity to be more associated with behavioral outcomes than with HRQOL (Hovels-Gurich et al., 2007; Spurkland, Bjornstad, Lindberg, & Seem, 1993; Utens et al., 1998). However, Cohen and colleagues (2007) found that adolescents with severe pediatric heart disease reported both a higher incidence of depressed mood (an internalizing problem) and lower HRQOL. Both Cohen et al.'s study and the current study used instruments that were specifically designed to measure "health-related" quality of life as opposed to global quality of life or, more generically, health status. This may account for the higher association between the clinical variables and HRQOL. The need for medications presents a daily reminder to the adolescent that he or she has a health condition requiring treatment and was associated with poorer HRQOL. Some of the medications common to pediatric heart disease, for instance, diuretics and anticoagulants, have an effect on an adolescent's daily routine or ability to participate in age-appropriate activities such as sports, which may negatively impact HRQOL.

Although the regression models explained a significant portion of the variance in each of the outcomes assessed, approximately two-thirds of the variance in internalizing problems and externalizing problems and half of the variance in HRQOL was left unexplained. This suggests that other factors not accounted for in this model are making significant contributions to these outcomes. Family function and parent stress have been shown to contribute to child adjustment in pediatric heart disease (Majnemer et al., 2006; McCusker et al., 2007; Wray & Maynard, 2005). DeMaso and colleagues (1991) found that maternal perceptions contributed much more to variance in child adjustment than disease severity. A limitation of this study is the lack of a formal assessment of family functioning or parent perceptions.

Characteristics of the sample included in this study also pose limitations to the generalizability of the findings. This study included subjects recruited from a single Midwestern heart center. The demographic background of the sample demonstrates that they

were largely white, non-Hispanic (86%), and from an upper middle-class income group with relatively high maternal education. Further evaluation of the relationships identified in this study in a larger, more diverse sample is warranted. While the sample was limited to adolescents age 11-18 years, this age range represents a wide span of physical and psychological changes that occur during normal development. There was no method of accounting for differences in actual psychosocial or neurocognitive maturity in the participants.

It is also important to note that adolescent self-perceptions of behavior or function may be inaccurate. Previous research has suggested that adolescents with pediatric heart disease may demonstrate poor social cognition or lack insight into problems that are perceived as significant by parents or teachers (Bellinger, 2008; Bellinger et al., 2011; Calderon et al., 2010). Nevertheless, the adolescent's self-perceptions may drive care-seeking behavior; therefore, they are critically important to assess. This also suggests that the incidence of problems with behavior and reduced HRQOL detected in this study, with reliance on self-report, may underestimate the actual incidence.

Implications for practice and research

It is important that health care providers in all settings address these psychosocial issues with children and families. Formal assessment using well-established instruments like those included in this study may be warranted in some cases but informal assessment through questions exploring self-perceptions, behavioral problems, and HRQOL should be included as a routine part of every adolescent's care. A useful finding from this study is that severity of cardiac condition does not appear to be related to psychosocial outcomes, so screening is important for all, even those with mild conditions. In primary health care, especially well child care, health care providers need to carefully assess strengths and challenges early in life for children and their families experiencing chronic cardiac conditions and other chronic conditions. Resilience skills can be taught and children with cardiac conditions may need targeted interventions. Families should be supported in providing interventions that may strengthen the child's perception of self such as helping the child develop expertise in an activity such as debate, drama, or music. Children with cardiac conditions have more cognitive or learning disabilities than others. Early neuropsychological screening, testing, and development of an individualized education plan (IEP) can provide the child with important academic supports. It is of interest to note that the highest discrepancy score reported by participants in this study was scholastic competence.

It is important to screen all adolescents for psychosocial health. A well established framework used by many primary health care providers is the HEADSS assessment for adolescents (home and environment; education and employment; activities; drugs; sexuality and depression/suicide) (Cohen, MacKenzie, & Yates, 1991). In working with adolescents who have chronic health conditions it would be important to integrate screening for discrepancies between importance and perception of competence into this assessment. Especially important are discrepancies in scholastic, physical appearance, behavioral and athletic domains. Data from this study show that it is the discrepancy—not the perception itself—that is critical. Over half of the participants in this study reported discrepancies, yet

we rarely ask adolescents about them. If the adolescent has an IEP due to learning issues, the primary care provider needs to make sure that any psychosocial issues are also identified and addressed in the IEP.

Health care providers in acute care conditions often see adolescents in their most vulnerable state and are able to identify psychosocial issues that otherwise may not be apparent. Sometimes these can be addressed when the adolescent is in an acute setting where referral might be convenient and the adolescent available due to an inpatient stay. However, if targeted interventions are not possible at that time, referral to primary care or specialty care providers with knowledge of resources to address the specific issues would be critical.

Finally, findings from this study can also be used to counsel families of younger children with pediatric heart disease on setting appropriate goals and expectations, to prepare parents for adolescent issues, and to emphasize that the development of a healthy sense of self may be a protective factor for psychosocial adjustment. This anticipatory guidance has the potential to avert later problems.

Further research is needed that assesses psychosocial adjustment using longitudinal designs. This may identify developmental periods when the child with pediatric heart disease is at particular risk or when key concepts like self-perception of global self-worth or health are beginning to be formed. Interventions that target parenting strategies to promote self-worth such as being a positive role model, identifying and redirecting inaccurate beliefs, and promoting activities in areas where children are more likely to feel competent could benefit early childhood development. For older children, strategies to promote the development of healthy coping skills, realistic expectations, and self-management behaviors could improve adjustment. Research using behavioral interventions that target strategies to improve self-perceptions, reduce internalizing behavior problems, and improve HRQOL, should be a focus of ongoing study.

Summary

Adolescents with pediatric heart disease are surviving in increasing numbers. In addition to physical issues imposed by their condition, psychosocial problems are a common comorbidity. In this study, adolescents reported a higher incidence of internalizing behavior problems and lower health-related quality of life than normative samples. Positive self-perceptions regarding global self-worth, competence, and health were associated with better psychosocial adjustment. Improved understanding of the factors that contribute to an adolescent's self-perceptions will be an important addition to guide future clinical practice, counseling, and intervention research.

Acknowledgments

The authors would like to extend their gratitude to the adolescents and parents who participated in this study. We also are thankful for the integral contributions of the PCQLI Validation Study staff in the Heart Institute Research Core at Cincinnati Children's Hospital Medical Center and the vital contributions of Mara Koffarnus at Children's Hospital of Wisconsin for her support of this study and preparation of this manuscript.

References

- Achenbach, TM.; Rescorla, LA. Manual for ASEBA school-age forms & profiles. Burlington, VT: University of Vermont, Research Center for Children, Youth, & Families; 2001.
- American Heart Association. Understand your risk for congenital heart defects. 2010. Retrieved January 5, 2011, 2011, from http://216.185.112.30/HEARTORG/Conditions/CongenitalHeartDefects/UnderstandYourRiskforCongenitalHeartDefects/Understand-Your-Risk-for-Congenital-Heart-Defects_UCM_001219_Article.jsp
- Bellinger DC. Are children with congenital cardiac malformations at increased risk of deficits in social cognition? *Cardiology in the Young*. 2008; 18(1):3–9.10.1017/S104795110700176X [PubMed: 18093362]
- Bellinger DC, Wypij D, Rivkin MJ, DeMaso DR, Robertson RL Jr, Dunbar-Masterson C, Newburger JW, et al. Adolescents with d-transposition of the great arteries corrected with the arterial switch procedure: Neuropsychological assessment and structural brain imaging. *Circulation*. 2011; 124(12):1361–1369. [PubMed: 21875911]
- Boardman JD. Self-rated health among U.S. adolescents. *Journal of Adolescent Health*. 2006; 38(4): 401–408.10.1016/j.jadohealth.2005.01.006 [PubMed: 16549301]
- Calderon J, Bonnet D, Courtin C, Concordet S, Plumet MH, Angeard N. Executive function and theory of mind in school-aged children after neonatal corrective cardiac surgery for transposition of the great arteries. *Developmental Medicine & Child Neurology*. 2010; 52(12):1139–1144. [PubMed: 20804511]
- Chen CW, Li CY, Wang JK. Self-concept: Comparison between school-aged children with congenital heart disease and normal school-aged children. *Journal of Clinical Nursing*. 2005; 14(3):394–402.10.1111/j.1365-2702.2004.01068.x [PubMed: 15707450]
- Christian BJ, D'Auria JP. Building life skills for children with cystic fibrosis: Effectiveness of an intervention. *Nursing Research*. 2006; 55(5):300–307. [PubMed: 16980830]
- Cohen E, MacKenzie RG, Yates GL. HEADSS, a psychosocial risk assessment instrument: Implications for designing effective intervention programs for runaway youth. *Journal of Adolescent Health*. 2001; 12(7):539–544. [PubMed: 1772892]
- Cohen M, Mansoor D, Langut H, Lorber A. Quality of life, depressed mood, and self-esteem in adolescents with heart disease. *Psychosomatic Medicine*. 2007; 69(4):313–318.10.1097/PSY.0b013e318051542c [PubMed: 17510294]
- Culbert EL, Ashburn DA, Cullen-Dean G, Joseph JA, Williams WG, Blackstone EH, et al. CongenitalHeartSurgeons, S. Quality of life of children after repair of transposition of the great arteries. *Circulation*. 2003; 108(7):857–862.10.1161/01.CIR.0000084547.93252.9A [PubMed: 12900343]
- DeMaso DR, Campis LK, Wypij D, Bertram S, Lipshitz M, Freed M. The impact of maternal perceptions and medical severity on the adjustment of children with congenital heart disease. *Journal of Pediatric Psychology*. 1991; 16(2):137–149.10.1093/jpepsy/16.2.137 [PubMed: 2061786]
- Drotar, D. Health status and quality of life. In: Naar-King, S.; Ellis, DA.; Frey, MA., editors. *Assessing children's well-being : A handbook of measures*. Mahwah, N.J: Lawrence Erlbaum Associates; 2004. p. 1-1-4.
- Goldbeck L, Melches J. The impact of the severity of disease and social disadvantage on quality of life in families with congenital cardiac disease. *Cardiology in the Young*. 2006; 16(1):67–75.10.1017/S1047951105002118 [PubMed: 16454880]
- Harter, S. The determinants and mediational role of global self-worth in children. In: Eisenberg, N., editor. *Contemporary topics in developmental psychology*. New York: John Wiley & Sons; 1987. p. 219-242.
- Harter, S. *The construction of the self: A developmental perspective*. The Guilford Press; 1999.
- Harter S, Whitesell NR, Junkin LJ. Similarities and differences in domain-specific and global self-evaluations of learning-disabled, behaviorally disordered, and normally achieving adolescents. *American Educational Research Journal*. 1998; 35(4):653–680.10.3102/00028312035004653

- Hovels-Gurich HH, Konrad K, Skorzinski D, Herpertz-Dahlmann B, Messmer BJ, Seghaye MC. Attentional dysfunction in children after corrective cardiac surgery in infancy. *Annals of Thoracic Surgery*. 2007; 83(4):1425–1430.10.1016/j.athoracsur.2006.10.069 [PubMed: 17383351]
- Karsdorp PA, Everaerd W, Kindt M, Mulder BJ. Psychological and cognitive functioning in children and adolescents with congenital heart disease: A meta-analysis. *Journal of Pediatric Psychology*. 2007; 32(5):527–541.10.1093/jpepsy/jsl047 [PubMed: 17182669]
- Karsdorp PA, Kindt M, Rietveld S, Everaerd W, Mulder BJ. Stress-induced heart symptoms and perceptual biases in patients with congenital heart disease. *International Journal of Cardiology*. 2007; 114(3):352–357. [PubMed: 16891004]
- Krol Y, Grootenhuis MA, DestrEeVonk A, Lubbers LJ, Koopman HM, Last BF. Health related quality of life in children with congenital heart disease. *Psychology & Health*. 2003; 18(2):251–260.10.1080/0887044021000058076
- Lambert LM, Minich LL, Newburger JW, Lu M, Pemberton VL, McGrath EA, et al. Pediatric Heart Network, I. Parent- versus child-reported functional health status after the fontan procedure. *Pediatrics*. 2009; 124(5):e942–9. [PubMed: 19841109]
- Latal B, Helfricht S, Fischer JE, Bauersfeld U, Landolt MA. Psychological adjustment and quality of life in children and adolescents following open-heart surgery for congenital heart disease: A systematic review. *BMC Pediatrics*. 2009; 9:6.10.1186/1471-2431-9-6 [PubMed: 19161602]
- Majnemer A, Limperopoulos C, Shevell M, Rohlicek C, Rosenblatt B, Tchervenkov C. Health and well-being of children with congenital cardiac malformations, and their families, following open-heart surgery. *Cardiology in the Young*. 2006; 16(2):157–164.10.1017/S1047951106000096 [PubMed: 16553978]
- Marino BS, Shera D, Wernovsky G, Tomlinson RS, Aguirre A, Gallagher M, Shea JA, et al. The development of the pediatric cardiac quality of life inventory: A quality of life measure for children and adolescents with heart disease. *Quality of Life Research*. 2008; 17(4):613–626.10.1007/s11136-008-9323-8 [PubMed: 18347927]
- Marino BS, Tomlinson RS, Wernovsky G, Drotar D, Newburger JW, Mahony L, et al. Pediatric Cardiac Quality of Life Inventory Testing Study Consortium. Validation of the pediatric cardiac quality of life inventory. *Pediatrics*. 2010; 126(3):498–508.10.1542/peds.2009-2973 [PubMed: 20805147]
- McCordle BW, Williams RV, Mitchell PD, Hsu DT, Paridon SM, Atz AM, et al. Pediatric Heart Network Investigators. Relationship of patient and medical characteristics to health status in children and adolescents after the fontan procedure. *Circulation*. 2006; 113(8):1123–1129.10.1161/CIRCULATIONAHA.105.576660 [PubMed: 16490823]
- McCusker CG, Doherty NN, Molloy B, Casey F, Rooney N, Mulholland C, Stewart M, et al. Determinants of neuropsychological and behavioural outcomes in early childhood survivors of congenital heart disease. *Archives of Disease in Childhood*. 2007; 92(2):137–141.10.1136/adc.2005.092320 [PubMed: 17030557]
- Moons P, VanDeyk K, DeGeest S, Gewillig M, Budts W. Is the severity of congenital heart disease associated with the quality of life and perceived health of adult patients? *Heart*. 2005; 91(9):1193–1198.10.1136/hrt.2004.042234 [PubMed: 16103557]
- Mussatto K, Tweddell J. Quality of life following surgery for congenital cardiac malformations in neonates and infants. *Cardiology in the Young*. 2005; 15(Suppl 1):174–178. [PubMed: 15934713]
- Polit, DF.; Beck, CT. *Nursing research: Generating and assessing evidence for nursing practice*. 8. Lippincott Williams & Wilkins; 2007.
- Rietveld S, Mulder BJ, van Beest I, Lubbers W, Prins PJ, Vioen S, Karsdorp P, et al. Negative thoughts in adults with congenital heart disease. *International Journal of Cardiology*. 2002; 86(1):19–26. [PubMed: 12243847]
- Rose M, Kohler K, Kohler F, Sawitzky B, Fliege H, Klapp BF. Determinants of the quality of life of patients with congenital heart disease. *Quality of Life Research*. 2005; 14(1):35–43.10.1007/s11136-004-0611-7 [PubMed: 15789939]
- Salzer-Muhar U, Herle M, Floquet P, Freilinger M, Greber-Platzer S, Haller A, Schlemmer M, et al. Self-concept in male and female adolescents with congenital heart disease. *Clinical Pediatrics*. 2002; 41(1):17–24.10.1007/s11136-004-0611-7 [PubMed: 11866361]

- Sawin, KJ.; Cox, AW.; Metzger, SG. Transitions to adulthood. In: Allen, PJ.; Vessey, JA., editors. Primary care of a child with a chronic condition. Fifth Edition. St. Louis, MO: Mosby Elsevier; 2010. p. 60-73.
- Sawin KJ, Buran CF, Brei TJ, Fastenau PS. Correlates of functional status, self-management, and developmental competence outcomes in adolescents with spina bifida. *Sci Nursing*. 2003; 20(2): 72–85. [PubMed: 14626030]
- Shevlin M, Adamson G, Collins K. The self-perception profile for children (SPPC): A multiple-indicator multiple-wave analysis using LISREL. *Personality and Individual Differences*. 2003; 35(8):1993–2005.10.1016/S0191-8869(03)00046-1
- Shillingford AJ, Wernovsky G. Academic performance and behavioral difficulties after neonatal and infant heart surgery. *Pediatric Clinics of North America*. 2004; 51(6):1625–1639.10.1016/j.pcl.2004.07.007 [PubMed: 15561177]
- Spijkerboer AW, Utens EM, Bogers AJ, Verhulst FC, Helbing WA. Long-term behavioural and emotional problems in four cardiac diagnostic groups of children and adolescents after invasive treatment for congenital heart disease. *International Journal of Cardiology*. 2008; 125(1):66–73.10.1016/j.ijcard.2007.02.025 [PubMed: 17433472]
- Spijkerboer AW, Utens EM, De Koning WB, Bogers AJ, Helbing WA, Verhulst FC. Health-related quality of life in children and adolescents after invasive treatment for congenital heart disease. *Quality of Life Research*. 2006; 15(4):663–673.10.1007/s11136-005-3692-z [PubMed: 16688499]
- Spurkland I, Bjornstad PG, Lindberg H, Seem E. Mental health and psychosocial functioning in adolescents with congenital heart disease. A comparison between adolescents born with severe heart defect and atrial septal defect. *Acta Paediatrica*. 1993; 82(1):71–76. [PubMed: 8453226]
- Thompson RJ, Gil KM, Burbach DJ, Keith BR. Psychological adjustment of mothers of children and adolescents with sickle cell disease: The role of stress, coping methods, and family functioning. *Journal of Pediatric Psychology*. 1993; 18(5):549–559. [PubMed: 8295079]
- Thompson, RJ.; Gustafson, KE. Adaptation to chronic childhood illness. 1. Washington, DC: American Psychological Association; 1996.
- Utens EM, Verhulst FC, Duivenvoorden HJ, Meijboom FJ, Erdman RA, Hess J. Prediction of behavioural and emotional problems in children and adolescents with operated congenital heart disease. *European Heart Journal*. 1998; 19(5):801–807.10.1053/euhj.1997.0855 [PubMed: 9717016]
- Uzark K, Jones K, Slusher J, Limbers CA, Burwinkle TM, Varni JW. Quality of life in children with heart disease as perceived by children and parents. *Pediatrics*. 2008; 121(5):e1060–7.10.1542/peds.2006-3778 [PubMed: 18450848]
- Uzark K, Jones K, Burwinkle T, Varni J. The pediatric quality of life inventory(TM) in children with heart disease. *Progress in Pediatric Cardiology*. 2003; 18(2):141–149.
- Varni JW, Burwinkle TM, Seid M, Skarr D. The PedsQL 4.0 as a pediatric population health measure: Feasibility, reliability, and validity. *Ambulatory Pediatrics*. 2003; 3(6):329–341. [PubMed: 14616041]
- Varni JW, Seid M, Knight TS, Uzark K, Szer IS. The PedsQL 4.0 generic core scales: Sensitivity, responsiveness, and impact on clinical decision-making. *Journal of Behavioral Medicine*. 2002; 25(2):175–193.10.1023/A:1014836921812 [PubMed: 11977437]
- Varni JW, Seid M, Kurtin PS. PedsQL 4.0: Reliability and validity of the pediatric quality of life inventory version 4.0 generic core scales in healthy and patient populations. *Medical Care*. 2001; 39(8):800–812. [PubMed: 11468499]
- Varni JW, Seid M, Rode CA. The PedsQL: Measurement model for the pediatric quality of life inventory. *Medical Care*. 1999; 37(2):126–139. [PubMed: 10024117]
- Vessey, JA.; Sullivan, BJ. Chronic conditions and child development. In: Allen, PJ.; Vessey, JA., editors. Primary care of the child with a chronic condition. Fifth Edition. St. Louis, MO: Mosby Elsevier; 2010. p. 22-41.
- Wray J, Maynard L. Living with congenital or acquired cardiac disease in childhood: Maternal perceptions of the impact on the child and family. *Cardiology in the Young*. 2005; 15(2):133–140. [PubMed: 15845155]

Figure 1.
Modified Transactional Stress and Coping Model of Adjustment

Table 1

Contextual Factors – Demographic and Clinical

DEMOGRAPHIC VARIABLES		
Total N=92	N	%
Male Gender	55	60
Early in Adolescence (11-12 years)	28	30
Later in Adolescence (13-18 years)	64	70
Birth Order		
- Oldest	32	35
- Middle	20	21
- Youngest	33	36
- Only	7	8
Family Structure - Child lives with:		
- Both biological parents	71	77
Race of Adolescent		
- White (non –Hispanic)	79	86
- Other	13	14
Adolescent Level of Education		
- K-5 th	14	15
- 6 th -8 th	45	49
- 9 th -12 th	33	36
Type of Education		
- School Full Time	85	92
- School Part Time	3	3
- Home Schooled	4	4
Educational Programs		
- Mainstream	49	53
- Gifted Program	12	13
- Special Ed or Learning Support	31	34
Maternal Level of Education		
- 10 th -11 th Grade	1	1
- High School Graduate	18	20
- Partial College or Trade School	29	31
- College Graduate	31	34
- Post-Graduate Degree	13	14
Household Income Group		
- < \$25,000	5	5
- \$25,000-50,000	13	14
- \$51,000-75,000	29	31
- \$76,000-100,000	21	23
- \$101,000-150,000	12	13
- > \$150,000	12	13

DEMOGRAPHIC VARIABLES		
Total N=92	N	%
CLINICAL VARIABLES		
Diagnostic Group		
- Congenital Heart Disease	78	85
- Acquired Heart Disease	14	15
Disease Severity of Original Cardiac Diagnosis		
- Insignificant	5	5
- Mild	6	7
- Moderate	25	27
- Marked	23	25
- Severe	33	36
Need for Daily Medication(s)	60	65
Number of Cardiac Surgeries		
- 0	1	1
- 1-3	43	47
- > 3	48	52
Number of Health Care Visits in the Past Year		
- 0	1	1
- 1-2	27	29
- 3-4	28	30
- >4	36	40

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 2
Importance and Discrepancy Scores for Self-Perception Profile Competence Scales

	Behavioral Conduct	Scholastic Competence	Athletic Competence	Physical Appearance	Social Acceptance
% Reported as Important	86.8	85.9	42.9	39.1	33.7
% With a Negative Discrepancy Score	67.1	82.9	48.7	51.4	35.5

Table 3

Regression Coefficients for Predictor Variables

	B	SE	β	R²	R²
Internalizing Behavior Problems					
Block 1		10.1		.05	.05*
Gender	-4.7		-0.23*		
Block 2		8.2		.39	.34***
Gender	-4.5		-0.22*		
Global Self-Worth	-3.5		-0.20*		
Discrepancy Score	-6.5		-0.29**		
Self-Perception of Health	3.6		0.29**		
Externalizing Behavior Problems					
Block 1		8.7		.12	.12**
Gender	-4.4		-0.24*		
Income Group	-1.5		-0.23*		
Block 2		7.5		.36	.24***
Gender	-4.1		-0.22*		
Income Group	-1.2		-0.18*		
Global Self-Worth	-3.2		-0.21*		
Discrepancy Score	-6.7		-0.31**		
Self-Perception of Health	1.0		0.09		
Health-Related Quality of Life					
Block 1		15.6		.17	.17***
Time Since Last Hospitalization	0.89		0.27**		
Medications	-9.1		-0.26*		
Block 2		15.3		.21	.04*
Time Since Last Hospitalization	0.89		0.27**		

	B	SE	β	R^2	R^2
Medications	-7.8		-0.22*		
Income Group	2.6		0.21*		
Block 3		11.8		.54	.33***
Time Since Last Hospitalization	0.46		0.14		
Medications	-7.4		-0.21**		
Income Group	1.2		0.10		
Global Self-Worth	5.4		0.19*		
Discrepancy Score	9.4		0.24**		
Self-Perception of Health	-7.2		-0.35***		

* $p < .05$,
** $p < .01$,
*** $p < .001$

Table 4**Summary of Main Findings**

Adolescents with heart disease reported:

- a higher than expected incidence of internalizing problems, e.g. anxiety, depression;
- lower health-related quality of life than healthy norms;
- global self-worth, competence, and the presence of externalizing problems were not different from healthy norms;
- self-perceptions of health, self-worth, and the discrepancy between competence and importance in specific domains explained the most variance in behavior and HRQOL.