Psychosocial Screening in Children with Congenital Heart Disease

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Author Note

This project was funded, in part, by a DNP Project Grant from the National Association of Pediatric Nurse Practitioners Foundation.

Abstract

Children with congenital heart disease (CHD) are at increased risk for psychosocial issues (PSI), decreased quality of life (QOL), and decreased resilience. The purpose of this project was to implement a screening protocol for PSI, QOL, and resilience, with appropriate psychosocial referral for children with CHD.

A pilot protocol was implemented to screen children with CHD, aged 8-17 years, and parents, for resilience, QOL, and PSI. Referrals for psychosocial services were made for 84.2% of children screened (n = 16) based on scoring outcomes. Statistically significant differences in the parents and children's resilience mean scores were noted. Higher parental scores may indicate that parents believe their children are more resilient than the children perceive themselves to be. Early identification of concerns regarding QOL, resilience, and PSI in children with CHD can provide ongoing surveillance, while affording opportunities for improved communication between providers, parents, and children. Routine screening and longitudinal follow-up is recommended.

Keywords: Congenital heart disease, resilience, quality of life, psychosocial issues, children, screening, depression, anxiety, referral

Psychosocial Screening in Children with Congenital Heart Disease

Congenital heart disease (CHD) is one of the most common birth defects found in children, with an incidence of approximately nine in every 1000 live births worldwide (van der Linde et al., 2011). Children with complex CHD are living longer due to dramatic advances in medical procedures and surgical techniques (Berger et al., 2017). Costs related to the care of children with CHD are greater than $5.6 billion dollars per year, with an average hospitalization costing more than $25,000 (Simeone et al., 2014). The natural history of CHD as a chronic health condition, often requires multiple hospitalizations or surgical interventions, which places these children at higher risk for PSI. The severity of the underlying disease does not correlate with psychosocial outcomes in a predictable manner (Marino et al., 2012).

Children with CHD have increased rates of mental health comorbidities, which include depression and anxiety. Depression and mood disorders are positively correlated with lower physical and psychosocial quality of life (QOL) in this population (Drakouli et al., 2015). Children with CHD may have significantly impaired QOL, requiring psychological and/or psychosocial interventions to help reduce depressive symptoms and improve QOL (Lane, Millane, & Lip, 2013).

Quality of life in the child with CHD has been examined extensively by comparing age, socioeconomic factors, parental versus child perspective, neurocognitive and psychosocial factors, severity of illness and frequency of treatment interventions, and the role that resilience plays in influencing QOL. Resilience and coping ability are positively correlated with increased QOL in children with CHD (Lee et al., 2014).

Background and Significance

Psychosocial Issues in Children with CHD

There is an increased risk for behavioral and psychosocial issues (PSI), with the prevalence of anxiety, depression, or attention and aggression problems affecting up to 15% to 25% of children and adolescents with CHD (Marino et al., 2012). Decreased QOL and resilience also has been noted in this population and is associated with a greater risk for depression and anxiety that can negatively impact QOL and resilience (Drakouli et al., 2015). The strongest predictor of QOL in perceived and clinical health status is emotional stability (Rassart et al., 2013).

This population may require psychological and/or psychosocial interventions to help reduce depressive symptoms and improve QOL (Lane, Millane, & Lip, 2013). Furthermore, depression is a risk factor for medical nonadherence in children with chronic, life-threatening illnesses (Apter, Farbstein, & Yaniv, 2003), and is associated with increased morbidity and mortality in children (Olivia et al., 2013).

Older children with CHD have an increase in overall behavioral problems, including internalizing (i.e., anxiety, depression), and externalizing (i.e., hyperactivity, aggression) when compared to a normalized control group, but exhibit more internalizing than externalizing problems overall. In an earlier study, it noted that the severity of the child's CHD was not significantly related to psychosocial problems (Karsdorp et al., 2007).

In a systematic literature review examining the determinants of QOL in children with CHD, loneliness and depression in adolescents with CHD was negatively correlated with QOL, while health related quality of life (HRQoL) was positively correlated with lower levels of anxiety and depression (Drakouli et al., 2015). Assessment of health and well-being in children

and adolescents with CHD should include evaluations for psychosocial impairments in the child and their family. This includes personalized and focused assessment on the family unit, as well as the individual child (Drakouli et al., 2015).

Psychosocial Screening and Referral

The recognition and treatment of PSI in children with CHD may improve QOL and resilience. In a study examining the importance of self-perceptions and psychosocial adjustment in adolescents with CHD, a child's perception of self-worth, competence, and health were more important than the clinical indices of their condition (Mussatto et al., 2013). Collaborative care for adolescents with PSI, which includes the provision of evidence-based treatments and active follow up, is cost effective (Wright et al., 2016a). The screening of adolescents for PSI and appropriate referral and intervention may decrease healthcare costs (Wright, et al., 2016b).

When examining the role of psychology in a pediatric outpatient clinic setting, Brosig et al. (2014) assessed QOL in children referred by their pediatric cardiologist to psychology compared to a healthy sample. Parents of children who were referred to the cardiology psychologist reported lower QOL scores for their children. Following this referral and psychological evaluation, 92% of patients had services recommended, whether for mental health, special education services or both (Brosig et al., 2014). This study did not utilize a formal screening tool for referral to psychology, and a formal screening tool is recommended by the authors to optimize referrals (Brosig et al., 2014).

Struemph et al. (2016) examined the systematic utilization of the Pediatric Symptom Checklist 17 in an outpatient cardiology clinic. In a sample of 561 pediatric patients, 20% (n = 112) scored above the clinical cutoff score and were identified as having PSI. Parents of children with history of cardiac surgery had increased concerns about learning and development than

those that did not ($p = 0.005$). Older age in children was positively associated with internalizing symptoms ($r = 0.18$, $p < 0.001$) and negatively associated with externalizing symptoms ($r = -0.16$, $p < 0.001$). Male children scored higher on attentive symptoms ($p = 0.001$), externalizing symptoms ($p = 0.006$), and total PSI ($p = 0.005$). Children with public insurance scored higher on attention symptoms ($p < 0.001$), externalizing symptoms ($p < 0.001$), and total PSI ($p < 0.001$). A total of 37% of parents indicated an interest in speaking to behavioral healthcare provider (HCP), and 26% of families attended a psychology consult as a result of PSC-17 screening (Struemph et al., 2016).

In a study examining the need for psychosocial care reported by parents and children the week before an invasive cardiac procedure or cardiac surgery, Levert et al. (2016) reported that 45% of parents studied reported a need for psychosocial care, with the highest need for individual psychotherapy was reported by parents of children aged 8 -12 years. On self-reports, greater than 50% of children indicated a need for psychosocial care, with the highest need in the emotional domain in children aged 8-12 years (Levert et al., 2016).

Due to the nature and frequency of follow-up visits for the child with CHD, the cardiology HCP has many opportunities to screen for PSI, QOL, and resilience, and when the child is at increased risk for PSI, make the appropriate referral. Early identification and appropriate referral for intervention for PSI may improve the child's QOL, even when their CHD is less severe, and so the cardiology HCP assumes a pivotal role in the identification of these at-risk children and their referral to appropriate services (Wang et al., 2014).

Quality of Life in Children with CHD

Neal et al. (2015) examined the predictors of QOL in children with Tetralogy of Fallot TOF) and compared these children to a normative sample of healthy children. The authors utilized several standardized measurement tools. Comorbid conditions, such as poor executive function (EF) and ADHD, were strongly correlated with poorer psychosocial health in the study participants, suggesting that early identification and intervention of these PSI may improve QOL in this population.

When assessing HRQoL in children, the utilization of the appropriate standardized tool that can measure QOL across the important domains (i.e., physical, emotional, social, school) is essential. The 23-item PedsQL 4.0 Generic Core Scales (PedsQL) includes these important domains and consists of a parallel child self-report and a proxy parental report. Uzark et al. (2013) utilized the PedsQL in a pediatric cardiology clinical setting and noted that 38% of participants reported significant problems in at least one of these domains. Cardiologists initiated referrals to psychology or behavioral therapy based on the PedsQL scores for 30% of patients. Mean PedsQL scores for the patients referred were significantly lower than the mean scores of patients not referred (Uzark et al., 2013).

Resilience in Children with CHD

When examining resilience in the context of children and families living with health and developmental issues, the achievement of a positive outcome, such as high QOL, is an essential aspect of resilience (Hilliard et al., 2015). Greater positive outcomes in children with CHD were correlated with active connectedness to family and friends (Sharp et al., 2015).

In the assessment of coping and resilience of adolescents with CHD, Lee, Kim, and Choi (2014) applied standardized tools to measure coping and resilience in adolescents who had

undergone corrective cardiac surgery or intervention for CHD. Resilience was positively correlated with task-oriented coping, which encompasses task-oriented strategies aimed at problem solving. Adolescents with CHD had low levels of resilience, while task-oriented coping was positively associated with increasing resilience (Lee et al., 2014).

Resilience and positive coping ability have been positively correlated with increased QOL in children with CHD (Lee et al., 2014). There is a need for psychometric measures that can specifically assess a child and family's strengths and protective processes in relation to resilient outcomes in this population (Hilliard et al., 2015).

Internal Evidence

A large children's hospital in the southwestern United States was the site for this Doctor of Nursing Practice (DNP) project. This hospital performs over 450 open heart surgical procedures on a yearly basis, with survival rates greater than 97% (Phoenix Children's Heart Center, 2017). This hospital was the second busiest heart transplant center in 2016 in the United States, with 19 heart transplants performed between June 2016 and July 2017 (Scientific Registry of Transplant Recipients, 2018). The outpatient cardiology clinic associated with this children's hospital offers many support services, including social work, child life, and nutritional specialists. However, only children who are being evaluated for a heart transplant undergo extensive psychological screening as part of their pre-transplant work-up. These children are not routinely screened post-transplant for PSI, unless there were concerns noted during the initial work-up.

Individual and family psychosocial screening, incorporated into routine care and health evaluation is recommended by the American College of Cardiology (ACC) and the American Heart Association (AHA) (Warnes et al., 2008). However, many pediatric cardiology centers that

care for children with CHD, including this one, do not routinely utilize psychosocial screening tools as part of their follow up care (Lane, Millane, & Lip, 2013). It is recommended that all children with CHD receive screening for PSI, regardless of the severity of their underlying defect (Marino et al., 2012). Due to this gap, providers are not able to accurately identify those children with PSI in this at-risk population. Therefore, there is a lack of appropriate referral and psychosocial care currently at this center.

Problem Statement

Given that children with CHD are at greater risk for PSI, and the risk for medical non-adherence, increased mortality, and medical resource utilization is increased with PSI, the implementation of a protocol aimed at the identification of decreased resilience, decreased QOL and PSI in this high-risk population and appropriate referral may have a positive effect on QOL and resilience. This has led to the clinically relevant PICO question "In children with congenital heart disease (P), how does the implementation of a protocol for routine screening for psychosocial and/or behavioral issues in a pediatric cardiology clinic, and appropriate referral (I) versus no routine screening (C), impact resilience and quality of life scores (O)?"

Search Strategy

Guided by the PICO question, a thorough review of the literature was conducted. The databases searched included the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Public/Publisher MEDLINE (PubMed), and the Psychology Information Database (PsycINFO). Keyword searches included: *congenital heart disease*, *quality* of *life*, *resilience*, *depression, anxiety*, *psychosocial factors*, *pediatric*, *child*, *adolescent*, *interventions for depression, depression screening, psychosocial issues, behavioral issues,* and *referral*. Current literature within the past five years, and literature with the highest evidence-based information

relevant to the population of interest was preferred Exclusion criteria included non-English studies, studies focused on adults with CHD only, studies focused on parental depression, dissertations, or unpublished studies. Inclusion criteria included studies of children zero to 18 years of age with CHD, studies from scholarly journals (preferably peer reviewed) from various countries examining any combination of the PICO components. Ancestral and hand searches of articles from reference lists of identified studies and meta-analysis yielded an additional four cohort studies.

The initial CINAHL search used keywords *congenital heart disease,* and *depression* or *anxiety,* and *pediatric* or *adolescent* and *quality of life* or *resilience*, and yielded 12 articles, 11 of which were relevant to the PICO question. A subsequent search using the keywords *depression* or *anxiety,* and *screening* or *referral,* and *congenital heart disease,* and *pediatric* or *adolescent* yielding two studies which were relevant to the PICO question.

The initial PubMed search using keywords *congenital heart disease,* and *anxiety* or *depression,* and *quality of life* or *resilience,* and *pediatric* or *adolescent* or *child* yielded 35 articles, 17 of which were relevant to the PICO question. A follow-up PubMed search using the keywords *screening* or *referral*, and *depression* and *psychosocial issues* or *behavioral issues,* and *pediatric* or *adolescent* and *congenital heart disease* yielded 18 studies, eight of which were relevant to the PICO question.

The initial PsycINFO search using keywords *congenital heart disease,* and *anxiety* or *depression,* and *quality of life* or *resilience* yielded 13 studies, six of which were relevant to the PICO question. A subsequent search using keywords *screening* or *referral* and *depression* and *chronic illness* or *congenital heart disease,* and *pediatric* or *adolescent* or *child* yielded six studies, two of which were relevant to the PICO question.

A final yield of 11 studies was retained for critical appraisal, including one meta-analysis (Karsdorp et al., 2007) and 10 cohort studies (Lee, Kim, & Choi, 2014; Levert et al., 2016; Luyckx, K. et al.,2012; Moon et al., 2009; Neal et al., 2015; Schaefer et al., 2013; Struemph et al., 2016; Uzark et al., 2012; & Wang et al., 2013) These studies were critically appraised and placed in evaluation tables. Using Melnyk and Fineout-Overhold (2015) recommendations, all studies were evaluated for level of evidence. Excluding the meta-analysis, all other studies were levels IV to V. There was a lack of randomized controlled trials (RCTs) and systematic reviews (SRs) possibly due to the vulnerability and age of this population. Therefore, a lower level of evidence accepted to guide the development of this project. Included were two studies outside of the preferred five-year window, due to their wealth of information relative to all components of the PICO question (Karsdorp et al., 2007; & Moon et al., 2009). The studies selected had the most relevant and complete data that addressed all or most of the components of the PICO question and examined the relationships between QOL, resilience, PSI, and screening and referral for PSI in children and adolescents with CHD.

Synthesis of the Evidence

All studies, except one (Lee et al., 2014), included tools that examined PSI in children with CHD. Six of the 11 studies included tools that measured QOL in children with CHD (Brosig et al., 2014; Levert et al., 2016; Luyckx et al., 2012; Schaefer et al., 2013; Uzark et al., 2012; & Wang et al., 2013) , and five of the 11 studies included measurement of the severity of CHD (Luyckx et al., 2012; Moon et al., 2009; Neal et al., 2015; Schaefer et al., 2013; & Wang et al., 2013). Eight of the 11 studies examined the effect of PSI on QOL in children with CHD as a dependent variable (DV) (Brosig et al., 2014; Karsdorp et al., 2007; Levert et al., 2016; Neal et al., 2015; Schaefer et al., 2013; Uzark et al., 2012; & Wang et al., 2013). There was homogeneity

in the findings of increased PSI being associated with decreased QOL across all the studies that measured these variables, while the correlations between the severity of CHD and QOL were not homogeneous in the populations studied. Independent variables (IV) included age, cognitive function, executive function, academic performance, parental support, resilience, and sense of coherence (SOC). Other DVs included: the effect of the severity of CHD on PSI and/or QOL; the effect of the severity of CHD on cognitive function and/or physical health, and resilience; the effect of age on psychosocial health; the identification of PSI; and referral to psychology.

There was homogeneity in the recommendation for screening for PSI in children with CHD and appropriate referral across all studies. Lower socioeconomic status, decreased physical health, and decreased SOC were associated with decreased QOL in those studies examining these variables (Karsdorp et al., 2007; Luyckx et al., 2012; & Schaefer et al.,2013). There was homogeneity in findings of negative correlations between PSI, parental support and/or behavior, the type of coping strategies that child used, and resilience (Lee et al., 2014; & Moon et al., 2009).

While there was a high homogeneity in the measurement of QOL scores as a DV across studies, QOL was measured with several different tools, due to the heterogeneity of the countries of origin. Three of the 11 studies used The PedsQL (Brosig et al., 2014; Uzark et al., 2012; & Wang et al., 2013). Various tools measured resilience, none of which were repeated across those studies that included its measurement. There was a homogeneity in the use and results of the Child Behavior Checklist (CBCL), included in all 36 studies included in the meta-analysis by Karsdorp et al. (2007), as well as the study by Brosig et al. (2014). The New York Heart Association (NYHA) classification measured the severity of CHD in five of the 11 studies (Lee et al., 2014; Luyckx et al., 2012; Moon et al., 2009; Neal et al., 2015; & Wang et al., 2013).

Despite the heterogeneity of the tools utilized to measure QOL, resilience, and PSI, all the tools were reported as valid and reliable. Therefore, the results found translated across the culturally diverse populations of children with CHD that were studied. There was a high degree of demographic homogeneity with the mean age of subjects being greater than eight years of age. This was due in part to the desire to view the variables from the child's point of view and the ability of the children to respond to the questionnaires presented.

Conclusions from the Evidence

The prevalence of PSI in children with CHD is significant and is negatively correlated with QOL and resilience in this population. The age and gender of the child with CHD impact not only the presence of PSI, but also the type (internalizing versus externalizing), with children of older age being affected more frequently than their younger counterparts, and girls having more internalizing symptoms than boys. All studies recommended the screening of children with CHD for PSI on a routine basis in the outpatient cardiology clinic setting with appropriate referral.

Purpose Statement

The purpose of this DNP project was to implement a screening protocol for PSI, QOL, and resilience, and to develop appropriate psychosocial referral for children with CHD. The DNP student, the transplant social worker (TSW), the transplant nurse practitioners, the cardiology psychologist, and medical director of the Heart Transplant/Heart Failure clinic performed this screening as a collaborative, interdisciplinary effort, as collaborative care for children and adolescents with PSI includes the provision of evidence-based treatments and active follow up.

Evidence-Based Practice Model

The model for evidence-based practice change by Rosswurm and Larrabee (1999) is a six-step model used to guide, support, and provide a solid foundation for evidence-based practice changes. The revised model includes six steps: 1) Assess the need for change in practice; 2) Locate the best evidence; 3) Critically analyze the evidence; 4) Design practice change; 5) Implement and evaluate change in practice; and 6) Integrate and maintain change in practice (Melnyk & Fineout-Overholt, 2015). The reflection of discipline-specific and interdisciplinary accountabilities must be included in patient outcomes, and practitioners and researchers must collaborate to enhance practice innovations (Rosswurm & Larrabee, 1999).

Evidence related to PSI in children with CHD suggests that this is a significant problem requiring early intervention to improve QOL and resilience and decrease comorbidities related to PSI. This model guided: 1) the implementation of an evidence-based protocol for the routine screening for PSI in children with CHD in the outpatient cardiology clinic setting; 2) the evaluation of the goodness of fit for this protocol in this population and practice; and 3) the feasibility of the maintenance of this protocol in this setting.

Conceptual Model

The biopsychosocial model of disease (Engel, 1977), which examines the interrelationship between the biological, psychological, and social domains related to the cause and manifestation of health outcomes and overall well-being, underpins a great deal of the evidence examined. It states that all biological, psychological, and social aspects of the individual are interrelated and influence one another, and therefore, must be addressed in their care (Engel, 1977). The evidence examining the underlying disease severity of CHD in children, along with psychosocial health, and parental or peer support, while correlating the

interrelatedness and causal relationships between these variables, is supported by this model and was highly relevant to this project and population.

Methods

Setting and Sample

This single-center, prospective, pilot, quality improvement project was implemented in an outpatient cardiology and heart transplant clinic located in a children's hospital in a major southwest urban area. After institutional review board approval was obtained from the children's hospital and Arizona State University, a convenience sample of 24 children and 24 parents/legal guardians were recruited from the heart failure/heart transplant clinic. Eligible children being treated for heart failure or having received a heart transplant and their parents/legal guardians were invited to participate in the project during their regularly scheduled clinic appointment (see project protocol, Appendix 1).

The DNP student and/or the TSW assessed eligibility in person at the clinic. Inclusion criteria included: (1) children aged eight to 17 years, (2) diagnosed with CHD or received a heart transplant, (3) fluent in reading, writing, and speaking English or Spanish at the appropriate age level, and (4) developmentally able to fill out the required screening tools with the assistance of the screener. One or both parents/legal guardians of children were required to be fluent in reading, writing, and speaking English or Spanish at the 6th grade reading level. Exclusion criteria included: (1) children with severe neurodevelopmental deficits, or (2) children with identified neurodevelopmental syndromes.

Procedures

Upon confirmation of eligibility, parental consent and child assent were obtained. Participants completed the screening survey and demographic information during their regularly scheduled appointment. Rescreening occurred 3-4 months later using the same screening survey.

Measurements

Demographic information including age, gender, race/ethnicity, household income, and relationship to child was obtained utilizing a standardized data collection form. Survey scores were totaled, and results were discussed with the attending cardiologist, and, if indicated, the cardiology psychologist. The DNP student and the TSW then met with the child and parents/legal guardians to discuss the survey scores, areas of concern, preform brief interventions and discuss any recommendations for psychosocial referrals, if necessary.

Resilience. Resilience is defined as a dynamic process incorporating adaptation when faced with significant adversity, while maintaining adaptive function, growth and development (Lee et al., 2014). The Child and Youth Resilience Measure (CYRM-12) was used to measure resilience. The CYRM-12 consists of 12 statements examining personal skills, peer support, social skills, psychological caregiver, education, and cultural protective factors. These categories are further grouped into individual, caregiving, and context (sense of belonging) aspects of resilience. Responses were scored on a 3-point Likert scale from 1 (no), 2 (sometimes), and 3 (Yes). Scores were calculated for subgroups, categorically, and total, with a maximum total score of 36. The CYRM-12 measures positive resources regarding the individual capacities or resources, the child's relationship with the caregiver, and contextual aspects related to a sense of belonging. Higher scores indicate the presence of greater resilience factors in the child (The

Resilience Research Center, 2013). This tool is valid and reliable with a Cronbach's α of 0.84 (Liebenberg, Ungar, & LeBlanc, 2013). In the current project, the Cronbach's α was α =0.85.

Quality of life. Quality of life is defined as the overall satisfaction with life, either positively or negatively influenced by psychosocial and/or physical variables, which the individual perceives to be important, including health status, psychological functioning, and matters related and unrelated to health (Ferguson, & Kovacs, 2013). The Pediatric Quality of Life Inventory (PedsQL) Transplant and Cardiac versions were used to measure QOL, utilizing parallel child self-report and parent proxy-report. The PedsQL Transplant version consists of 46 questions related to medicines, transplant and others, pain, worry, treatment anxiety, physical appearance and communication. Responses were scored on a 5-point Likert scale, ranging from 0 (never) to 4 (almost always). Items are then reverse scored and converted into a 0-100 scale. Overall higher scores indicating greater QOL.

To account for missing data, the sum of the items was divided by the number of items answered. At-risk status indicating impaired QOL was determined by approximating one standard deviation below the mean of the total population sample (Varni & Limbers, 2009).This tool is valid and reliable in children from healthy and chronic illness populations, α = 0.88 (Varni, Seid, & Kurtin, 2001), and adolescents with CHD, α = 0.89 (Uzark et al., 2003). In the current project, the Cronbach's α was α = 0.93.

The PedsQL Cardiac version consists of 27 questions related to heart problems and treatment, physical appearance, treatment anxiety, cognitive problems, and communication. Responses were scored in the same manner as the PedsQL Transplant version.

Psychosocial functioning. The Pediatric Symptom Checklist (PSC-35) measured psychosocial functioning and is designed to enable the identification of cognitive, emotional, and

behavioral problems so that a timely, appropriate referral is initiated (Jellinek et al., 1999). The PSC-35 consisted of 35 statements reflecting the child's psychosocial functioning, with subcategories of attention, internalization, and externalization examined. Responses were scored on a 3-point Likert scale ranging from 0 (never), 1 (sometimes), and 2 (often). This tool includes three subscales; (1) Attention, which measures difficulties with concentration or attention where a score of greater than 7 can indicate significant concern; (2) Internalizing, which screens for symptoms of depression or anxiety, where a score of 5 or higher can indicate significant concern; and (3) Externalizing, which screens for conduct difficulties, where a score of 7 or greater may indicate significant concern (Struemph et al., 2016). A total score of 28 or higher in children aged 6 to 16 years may indicate psychological impairment and further testing be undertaken (Jellinek et al., 1999). This tool is valid and reliable. In the current project, the Cronbach's α was $\alpha = 0.80$.

Post-screening questionnaire. After the second screening, parents filled out a 7-item questionnaire. This survey was used to assess whether any referrals had been made at the initial screening, if the child had received any of the referred (if any) services and how many times, if there were any barriers to the child receiving services (if any), if the screening survey added any value to their child's care, and what changes, if any, they would want to see in the survey.

Data Analysis

Data was analyzed using SPSS for Windows (version 24.0, SPSS Inc, Chicago, IL). Descriptive statistics were used to report demographic data. Independent t-tests were used to compare the mean scores by age, gender, and parent to child. Pearson and Spearman's correlations were used to measure the strength and direction of the relationships between the variables. Paired t-tests were used to compare pre- and post-mean scores. Cohen's *d* was utilized

to determine the effect size of the results. One-sample t-tests were used to compare mean scores of cardiac and transplant participants. Finally, Cronbach's alpha was used to measure scale reliability in this population. A critical value of $p \leq .05$ was used for all data analyses.

Results

Sample Characteristics

A total of 24 children and 24 parents were recruited. Of those, 19 children and 20 parents consented to participate (80%), most (84%) had received a heart transplant, while the others were being followed for heart failure. All completed the initial set of screening surveys. Ten children and 11 parents completed the second set of screening surveys. Demographic characteristics of the project participants are listed in Table 1. The mean and standard deviation (SD) ages of the children and parents were 11.8 (3.2) and 40.2 (5.8) years, respectively. Most parents were female (85%) and most of the children were male (63.2%). Race/ethnicity was comparable to the surrounding demographics with a sizable portion of our participants identified as White/Non-Hispanic (36%) or Hispanic (46%). Reported household income was evenly divided between < $49,999 (46%) and ≥ $50,000 (66%).

Referrals

Referrals for psychosocial and/or behavioral services were made for 16 of the children during the initial screening (84.2%) based on scoring outcomes. The breakdown of the types of referrals made after the initial screening is listed in Figure 1. Most of the children screened were referred for mental health counseling/therapy (32%), although a small percentage required referrals for community (support groups), mental health counseling/therapy and neurocognitive or neuropsychological testing (16%). Following the second screening, five of the children (50%), who had not previously required a mental health counseling/therapy referral, now did based on

positive screening results that had not previously been noted and five (50%) required reinforcement and assistance in following through with a previous referral.

Brief Interventions

Brief interventions were utilized to provide psychosocial interventions following administration of the screening survey when scores indicated issues such as anxiety or depressive symptoms. The TSW and the DNP student engaged patients and caregivers in brief interventions, including motivational interviewing, diaphragmatic breathing, behavioral activation and psychoeducation to address symptoms of depression, anxiety, and to improve interpersonal communication skills. Of the children screened, most required some form of intervention (68%), whether it was instructions on diaphragmatic breathing (37%) or psychoeducation and diaphragmatic breathing instruction (32%).

Resilience

Children's pre- and post-CYRM mean scores are presented in Table 2. Parent's pre- and post-CYRM mean scores are presented in Table 3. An independent-samples t-test comparing parent and child scores found:

- Pre-CYRM context scores were significantly higher for parents (M = 9.85 [1.84]) than for children, (M = 8.74 [1.59]), (t = -2.01, p = .05, d = 0.65).
- Post-CYRM context scores were significantly higher for parents (M = 10.91 [0.94]) than for children (M = 9.0 [2.36]) (t = - 2.48, p = .023, d = 1.06).
- Pre-CYRM total scores were significantly higher for parents (M =31.35 [2.89]) than for children (M = 28.79 [4.26]) (t = -2.21), p = .034, d = .070).
- Post-CYRM total scores were significantly higher for parents (M = 33.47 [2.24]) than for children (M = 31 [2.75]) (t = -2.09, p = .05, d = 0.91)

A Pearson correlation was run to determine the relationship between the child's age and CYRM, PSC, and PedsQL scores and found a moderate, positive correlation between age and Pre-CYRM individual scores ($r = .476$, $n = 19$, $p = .04$). A Spearman's correlation was run to determine the relationship between the child's annual household income and CYRM scores and found a strong, negative monotonic correlation between the child's annual household income and Pre-CYRM caregiver subcategory scores ($r_s = -.565$, $n = 19$, $p = .012$) and Post-CRYM individual subcategory scores ($r_s = -.767$, $n = 10$, $p = .01$).

Quality of Life

Children's pre- and post-PedsQL Transplant and Cardiac version mean scores with critical cutoff percentages are presented in Table 2. Parent's pre- and post-PedsQL Transplant and Cardiac version mean scores with critical cutoff percentages are presented in Table 3. An independent-samples t-test indicated that there was no significant difference between children's and parent's scores on either the Pre- or Post-PedsQL Transplant or Cardiac version. Pearson correlation was run to determine the relationship between age and PedsQL Transplant scores and found a strong, negative correlation between the child's age and Post-PedsQL transplant medicine scores ($r = -.760$, $n = 10$, $p = .011$). A Spearman's correlation was run to determine the relationship between the child's race/ethnicity and the PedsQL Transplant scores. The results include a strong, negative monotonic correlation between the child's race/ethnicity and Pre-PedsQL Transplant scores related to:

- medicine ($r_s = -.714$, $n = 16$, $p = .002$);
- worry ($r_s = -.756$, $n = 16$, $p = .001$);
- physical appearance ($r_s = -.611$, $n = 16$, $p = .012$);
- communication ($r_s = -.622$, $n = 16$, $p = .012$); and

- total mean scores (r_s = -.676, n = 16, p = .004).

There was a strong, negative monotonic correlation between the child's race/ethnicity and Post-PedsQL Transplant communication scores (r_s = -.691, n = 10, p = .027). A Spearman's correlation was run to determine the relationship between the child's annual household income and PedsQL Transplant scores. The results include strong, positive monotonic correlations between the child's annual household income and PedsQL scores related to:

- Post-PedsQL transplant and others subcategory (r_s = .622, n = 10, p = .037);
- Post-PedsQL worry (r_s = .832, n = 10, p = .003);
- Post-PedsQL total mean scores (r_s = .756, n = 10, p = .011); and
- Pre-PedsQL Transplant communication (r_s = .500, n = 16, p = .049).

Psychosocial Functioning

Children's pre- and post-PSC mean scores with critical cutoff percentages are presented in Table 2. Parent's pre- and post-PSC mean scores with critical cutoff percentages are presented in Table 3. An independent-samples t-test indicated that there was no significant difference between children's and parent's scores on either the Pre- or Post-PSC; however, male Pre-PSC attention scores (M = 5.13 [2.3]) were marginally higher than female Pre-PSC attention scores (M = 3.29 [1.98]) (t = 1.77, p = .10, d = 0.86). A one-sample t-test indicated that there was a significant difference in the mean Pre-PSC total scores in cardiac children (M = 20.33 [0.58]) and children who had received a heart transplant (M = 23.72 [10.6]) (t = -10.16, p = .010, d= 0.45). Pearson correlation was run to determine the relationships between CYRM, PSC, and PedsQL scores. Results indicated:

- A strong, negative correlation between Pre-PSC internalizing scores and Pre-PedsQL Transplant version total scores (r = -.572, n = 19, p = .01);

- A moderate, positive correlation between the Pre-PSC internalizing scores and Pre-PSC attention scores ($r = .401$, $n = 19$, $p = .04$), and
- A strong positive correlation between Pre-PSC internalizing scores and Pre-PSC total scores ($r = .692$, $n = 19$, $p = .001$).

A Spearman's correlation was run to determine the relationship between the child's gender and PSC subcategory and total scores. There was moderate, negative monotonic correlation between gender and Pre-PSC attention scores ($r_s = -.455$, $n = 19$, $p = .05$).

When evaluating the percentage of children whose mean scores were above the critical cutoff scores for the subcategories of Attention, Internalizing, and Externalizing, a small percentage had critical scores on both the Pre- and Post-PSC screening tools (see Table 2). While mean total Pre-PSC scores in our sample (M = 23.18 [9.77]) were below the critical cutoff value of 27% of the sample (n=5) had a score ≥ 28. Post-PSC total mean scores in our sample (M = 22.35 [9.62]) were also below the critical cutoff value of ≥28, 30% (n =3) of our sample had total scores ≥ 28 (see Table 2). Parent proxy mean scores had comparable results (see Table 3).

Comparison of Pre- and Post-Screening Results

A paired-samples t-test compared pre- and post-screening scores. No significant differences were noted between the scores for the CYRM, PedsQL Transplant version, or the PSC. Paired samples t-tests correlations indicated moderate to strong correlations for all the PedsQL Transplant categories and total scores, as well as, for PSC categories and total scores. The CYRM subcategories and total scores were not significantly correlated between tests, except CYRM cultural, and individual categories, which were strongly correlated, and CYRM total scores which were moderately correlated.

Post-Screening Questionnaire

Of the parents who filled out the post-screening questionnaire 82% (n = 9) stated that the screening survey added value to their child's care. Regarding the survey's length, 73% stated that they would not make any changes. When asked about barriers to child receiving recommended services, 29% (n =2) responded that they could not get a referral related appointment and 29% (n = 2) cited problems with distance to appointment or insurance coverage.

Discussion

Referral

When examining the findings regarding the high rate of referral for the participants in this project (84%), these referral rates are comparable to the findings reported by Brosig et al., 2014, where, of the children (n = 79) who had been referred to the cardiology psychologist by the cardiology HCP, 92% of patients had services recommended, whether for mental health, special education or both. This study did not utilize a formal screening tool to inform the referral to psychology (Brosig et al., 2014). Parents cited logistics, insurance, and financial barriers to mental health services in the post-survey questionnaire, which is consistent with previously reported research (Reardon et al., 2016). Many participating families travel from far-outreaching rural areas in Arizona, where access to mental/behavioral health services is severely limited. Some parents, who lived in small rural towns, stated that they did not want their child to receive mental health services in the town that they lived in, citing the stigma of others knowing that their child was seeing a psychologist or therapist. This is consistent with previous research that found an increased frequency of social stigma being cited as a barrier to receiving mental health services in rural communities (Polaha et al., 2015).

Brief Intervention

In response to positive screening results the TSW administered some form of brief intervention to many of our participants (68%) during their clinic appointment. Brief interventions are effective in the primary care setting, addressing a multitude of disorders, including depression (Roy-Byrne et al., 2009). The dynamic of the social worker's relationship when providing brief interventions involves establishing an empathetic relationship with the goal of patients self-activating, thereby improving QOL, self-efficacy and medical adherence. (Roy-Byrne et al., 2009). Providing psychoeducation to patients, who are engaging and advocating in their own medical care, can increase health literacy in prescribed regimens and in theory, increase medical adherence. (Erickson et. al., 2005).

Resilience

The CYRM-12 is better suited for omnibus surveys, such as the one used in this screening project (Liebenberg, Ungar, & LeBlanc, 2013). Parents may have over-estimated their child's resilience related to their contextual sense of belonging and overall resilience. Context, which is related to the child's sense of belonging, is an important construct where positive factors may compensate for decreased positive caregiving experiences. Context resilience factors may impact both the child and the caregiver and are important to individual and caregiving subscales (Liebenberg, Ungar, & LeBlanc, 2013). This under identification of decreased resilience in children by their caregivers may impact QOL and PSI. A positive correlation between the child's age and CYRM individual resilience scores may indicate, that as children get older, individual resilience factor scores increase, indicating that older children may have more individual resilience protective factors than younger children.

Identification of the child's individual strengths, promoting a sense of self-control, and positive social relationships are factors that positively impact resilience in children (Horner, 2016). Allowing children opportunities to participate in activities that they are passionate about, which can allow them to excel, may increase their level of self-confidence, and provide opportunities for the development of peer relationships, thereby promoting resilience (Horner, 2016).

A transplant support group is available at the hospital affiliated with the heart clinic. There also are opportunities to connect with other children who have CHD and their families, including special outings at the zoo and a summer sleep away camp is available for children with CHD. This can allow the children to form peer relationships with children/adolescents who have an intimate understanding of living with CHD.

Quality of Life

When examining the results, gender was not significantly correlated with other scores and did not appear to influence QOL, which is consistent with previous studies of children with CHD (Cohen et al., 2007). A positive correlation was noted between annual household income and PedsQL Transplant version worry, communication, and total scores in this sample. This may indicate that as the child's annual income increases, so do these scores and QOL improves. These results align with previous studies that found that low socioeconomic status was correlated with decreased QOL (Mussatto et al., 2013). In our sample, race and ethnicity were negatively correlated to most PedsQL category scores and the total scores.

PSC internalizing scores, which measure depression and anxiety symptoms, and the PedsQL Transplant version total scores, which measure QOL, were negatively correlated. This indicates that as the children's anxiety and depression symptoms increase, QOL decreases. These

findings are consistent with previous research findings that increased PSI is associated decreased QOL (Drakouli et al., 2015). The possible impact of psychosocial issues on QOL aligns with the biopsychosocial model of disease underpinning this project (Engel, 1977).

Psychosocial Functioning

While previous studies have found an increase in the probability of higher psychosocial dysfunction among children with low socioeconomic status (Jellinek et al, 1999), this project's outcomes found no significant correlation between socioeconomic status or race/ethnicity and PSC scores. Male participants scored marginally higher than female participants on the PSC attention subcategory and there was a negative correlation between the child's gender and PSC attention scores. This is consistent with previous studies, where male children were found to have an increase in PSC attention scores, which are associated with an inability to pay attention, difficulty concentrating, and being fidgety (Mussatto et al., 2013). Previous research regarding PSC total scores in children with CHD found that 20% of their sample had scores ≥ 28 (Struemph et al., 2016). However, 28% of children in our initial screening and 30% of children in our second screening had a total PSC score ≥ 28. This would indicate that the participant children may be at increased risk for psychosocial concerns.

In the literature, psychosocial issues, that have not been addressed through screening or treatment, have been associated with increased medical nonadherence. One barrier to medication nonadherence appears to be related to the effect that transplant and cardiac medications may have on the child and adolescent's appearance (Steuer & McCauley, 2017). During adolescence, the teen is trying to fit in and seek acceptance, while struggling with body image and the changes associated with puberty. This may cause children and adolescents to become nonadherent with

their medications and there may be a lack of understanding on their part as to the consequences of medication nonadherence (Steuer & McCauley, 2017).

Limitations

There was a limited amount of time between screenings due to the nature of this DNP project, which may account for the lack of change between pre- and post-screening scores. The sample size was somewhat smaller than previous studies (Brosig et al., 2014; Pike et al., 2012; Struemph et al., 2016) and consisted primarily of children who had received a heart transplant. Future projects should either focus solely on pediatric heart transplant patients or increase the number of children with CHD who have not received a heart transplant as participants.

Conclusion and Practice Implications

Many of the children receiving care in this Heart Transplant/Heart Failure clinic had positive screening results for PSI that may be impacting their QOL or resilience. Early identification, utilizing a standardize protocol and screening tools examining PSI, QOL, and resilience, on a routine basis, can provide valuable information to the HCPs, parents and children. while addressing their potential to increase risk factors for morbidity and mortality, related to medical nonadherence. A collaborative approach by the cardiology team will help ensure that children and adolescents, identified by positive screening results, receive timely referrals psychosocial or behavioral services as needed. The ongoing assessment of the family's ability to receive the recommended services, as well as, addressing any barriers to treatment, needs to be completed on a scheduled periodic basis to ensure that any potential barriers can be mitigated. Integration of a screening reminder system within the patient's electronic medical record (EMR) may decrease the number of missed screening opportunities. Significant differences in child and parent proxy screening results confirm previous research

recommendations for the use of multiple informants in the screening process. Therefore, both children and their parents/legal guardians should continue to be screened together.

Routine psychosocial screening will provide an ongoing surveillance for PSI, and decreased QOL or decreased resilience, along with opportunities for improved communication between providers, parents and children regarding their CHD and its impact on their lives. Longitudinal follow-up and rescreening of children and families who were referred is recommended. The evidence supported by the data in this project suggests that the adoption of this screening protocol into the standard of care is highly beneficial.

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Tables

Table 1

Demographic Characteristics of Child and Parent Participants

Variable	Sample size	Frequency	Percent	Mean ± SD	Range
Child characteristics	N = 19				
Age (years)				11.84 ± 3.22	8-17
Gender					
Male		12	63.2		
Female		7	36.8		
Race/Ethnicity					
White/ Non-Hispanic		7	36.8		
Hispanic		9	47.4		
Black or African American		1	5.3		
American Indian or Alaska Native		1	5.3		
Asian		1	5.3		
Parent characteristics	N = 20				
Age (years)				40.2 ± 5.83	28-54
Gender					
Male		3	15		
Female		17	85		
Race/Ethnicity					
White/ Non-Hispanic		7	35		
Hispanic		9	45		
Black or African American		2	10		
American Indian or Alaska Native		1	5		
Asian		1	5		
Annual Household Income					
Less than $20,000		4	20		
$20,000 to $34,999		4	20		
$35,000 to $49,999		1	5		
$50,000 to $74,999		4	20		
$75,000 to $99,999		3	15		
Over $100,000		4	20		

Table 2

Children's Pre- and Post-Screening Scores

Variable	1st Screen N	1st Screen Mean ± SD	1st Screen Range	1st Screen Scores > or < critical cutoff n (%)	2nd Screen N	2nd Screen Mean ± SD	2nd Screen Range	2nd Screen Percent > or < critical cutoff n (%)
CYRM-12	N = 19				N = 10			
Individual		12.3 ± 2.4	6-15			13.5 ± 1.1	12-15	
Caregiver		7.8 ± 1.6	3-9			8.5 ± 0.8	7-9	
Context		8.7 ± 1.6	6-11			9 ± 2.4	5-12	
Total Score		28.8 ± 4.3	16-34			31 ± 2.7	26-36	
PedsQL Transplant	N = 16				N = 10			
Medicine		76 ±20	25-100	3 (19)		85 ±12	64-100	2 (20)
Medicine II		91 ± 9	75-100	3 (19)		96 ± 4	91-100	4 (40)
Transplant & Others		65 ± 24	13-100	3 (19)		76 ± 16	56-100	3 (30)
Pain		74 ±19	42-100	3 (19)		78 ± 20	42-100	2 (20)
Worry		70 ± 25	25-100	3 (19)		76 ± 16	50-100	2 (20)
Anxiety		67 ± 36	0-100	3 (19)		59 ± 35	0-100	2 (20)
Appearance		76 ± 27	17-100	2 (13)		83 ± 25	25-100	2 (20)
Communication		68 ± 31	0-100	2 (13)		68 ± 21	38-100	1 (10)
Total Score		74 ± 17	34-100	3 (19)		79 ± 11	56-94	2 (20)
PedsQL Cardiac	N = 3				N = 0			
Heart Problems		61 ± 7	14-54	1 (33)				
Treatment		90 ± 5	85-95	0				
Appearance		83 ± 29	50-100	1 (33)				
Anxiety		85 ± 13	75-100	0				
Cognitive Problems		52 ± 20	30-70	1 (33)				
Communication		61 ± 42	17-100	1 (33)				
Total Score		71 ± 4	66-75	1 (33)				
PSC	N = 19				N = 10			
Attention		4.4 ± 2.3	0-10	3 (16)		3.3 ± 1.8	1-7	1 (10)
Internalizing		2.8 ± 2.3	0-9	3 (16)		3.3 ± 1.5	1-6	2 (20)
Externalizing		2.7 ± 1.7	0-5	0		3.5 ± 3.1	0-9	2 (20)
Total Score		23.2 ± 9.8	11-52	5 (27)		22.3 ± 9.6	8-38	3 (30)

Table 3

Parent's Pre- and Post-Screening Scores with Critical Cutoffs

Variable	1st Screen N	1st Screen Mean ± SD	1st Screen Range	1st Screen Scores above critical cutoff n (%)	2nd Screen N	2nd Screen Mean ± SD	2nd Screen Range	2nd Screen Percent above critical cutoff n (%)
CYRM-12	N = 20				N = 11			
Individual		13 ± 1.5	9-15			13.3 ± 1.6	9-15	
Caregiver		8.5 ± 0.9	6-9			9 ± 0	9	
Context		9.9 ± 1.8	5-12			10.9 ± 0.9	9-12	
Total Score		31.4 ± 2.9	25-36			33.3 ± 2.2	28-36	
PedsQL Transplant	N = 17				N = 11			
Medicine		85 ± 12	64-100	4 (24)		84 ±7	75-94	1 (9)
Medicine II		92 ± 13	56-100	3 (18)		88 ± 13	69-100	2 (18)
Transplant & Others		68 ± 18	38-100	2 (12)		71 ± 11	53-88	3 (28)
Pain		77 ±16	50-100	3 (18)		74 ± 21	33-100	2 (18)
Worry		76 ± 24	14-100	2 (12)		64 ± 28	7-100	2 (18)
Anxiety		56 ± 32	0-100	3 (18)		54 ± 30	0-100	2 (18)
Appearance		73 ± 23	17-100	2 (12)		68 ± 29	17-100	2 (18)
Communication		72 ± 23	13-100	2 (12)		68 ± 21	38-100	2 (18)
Total Score		77 ± 15	48-98	3 (18)		72 ± 28	13-100	0
PedsQL Cardiac	N = 3				N = 0			
Heart Problems		68 ± 27	39-93	1 (33)				
Treatment		95 ± 5	90-100	0				
Appearance		81 ± 27	50-100	1 (33)				
Anxiety		79 ± 26	50-100	1 (33)				
Cognitive Problems		55 ± 9	50-65	0				
Communication		47 ± 21	25-67	1 (33)				
Total Score		71 ± 9	63-81	0				
PSC	N = 20				N = 11			
Attention		4.1 ± 2.5	1-9	4 (20)		3.3 ± 2.3	0-7	2 (18)
Internalizing		2.5 ± 1.7	0-5	3 (15)		2.6 ± 2.2	0-6	1 (9)
Externalizing		3.0 ± 2.8	0-0	2 (10)		2.8 ± 2.6	0-7	1 (9)
Total Score		19.4 ± 9.6	4-35	4 (20)		18.5 ± 10.5	4-39	2 (18)

Figures

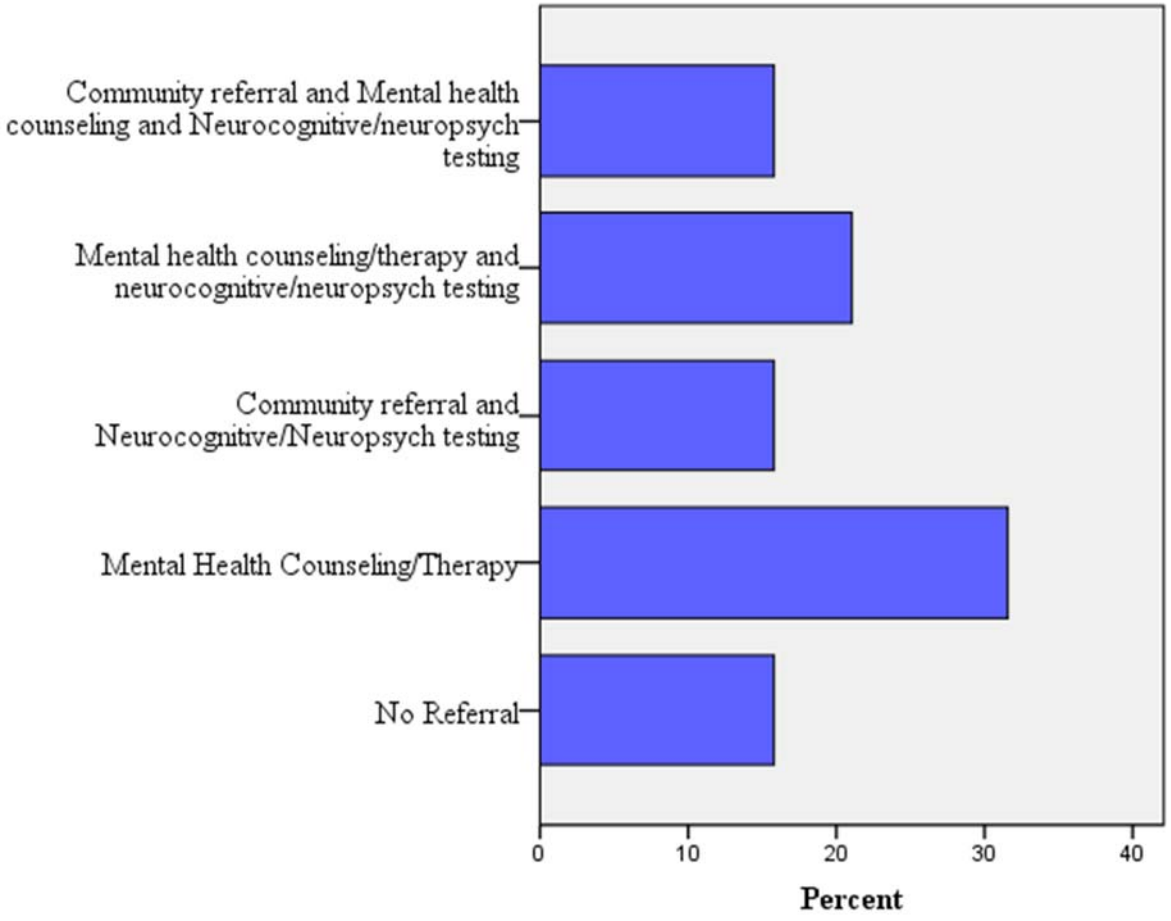

Figure 1. Types of Referrals Made After Initial Screening

APPENDIX A

Pilot Psychosocial Screening Protocol in Children with Congenital Heart Disease

1. Eligible children will be determined by Kelley Bonowski, RN, BSN, DNP student and Jenifer Espinoza, LMSW/MPA, Solid Organ Social Worker by examining the upcoming clinic schedule a day previous to the scheduled clinic day (e.g., Friday for Monday clinic, Wednesday for Thursday clinic).
2. Kelley Bonowski, RN, BSN, DNP student or Jenifer Espinoza, LMSW/MPA, Solid Organ Transplant Social Worker, will meet with eligible children and their parents/legal guardians at the beginning of their clinic appointment to ask if they would like to participate in the Doctor of Nursing Practice (DNP) project.
3. If the child and parents/legal guardians agree, then parents/legal guardians will be given the PCH consent form for the DNP project and the child will be assented using the PCH assent form for the DNP project.
4. Once the child has been assented and the parent/legal guardian has consented, the child will be given survey packets that will include three tools: The Pediatric Symptom Checklist (PSC), the Pediatric Quality of Life Inventory (PedsQL) 3.0 Transplant or Cardiac Module and the Child and Youth Resilience Measure Scale (CYRM). The PedsQL 3.0 Transplant or Cardiac Module survey content will vary depending on if the child is being cared for heart failure or has received a heart transplant.
5. Kelley Bonowski, RN, BSN, DNP student, and/or Jenifer Espinoza, LMSW/MPA, Solid Organ Transplant Social Worker will be available to assist the child and answer any questions that might arise during the completion of the surveys.

6. The surveys will be scored by Kelley Bonowski, RN, BSN, DNP student, and Jenifer Espinoza, LMSW/MPA, Solid Organ Transplant Social Worker.
7. The scores will then be evaluated per the scoring criteria for each tool:
    - Pediatric Symptom Checklist (PSC) Scoring:
        - For children and adolescents age 6-16 years: a cutoff score of 28 or higher indicates psychological impairment.
        - The cutoff score for the Youth report is 30 or higher to indicate psychological impairment.
        - Items left blank are ignored; If 4 or more items are left blank, the questionnaire is considered invalid.
    - Pediatric Quality of Life Inventory (PedsQL) 3.0 Cardiac and Transplant Module Scoring:
        - 5-point Likert scale from 0 (Never) to 4 (Almost Always)
        - 3-point Likert scale from 0 (Not at all), 2 (Sometimes), 4 (A lot)
        - Items are reversed scored
            - 0 = 100
            - 1 = 75
            - 2= 50
            - 3 = 25
            - 4 = 0
        - Higher scores indicate lower problems
        - If more than 50% of items in scale are missing, the scale scores should not be computed.

        - Mean score = sum of items over the number of items answered
        - Mean scores < 70% of predicted indicate potential concern
        - If 50% or more items are completed: input the mean of the completed items in a scale.
    - Child and Youth Resilience Measure Scale (CYRM) Scoring:
        - 28 questions on a 3-point Likert Scale
            - No = 1
            - Sometimes = 3
            - Yes = 5
        - Higher scores = Higher levels of characteristics associated with resilience
        - Range 12-60
        - Scores < 70% of predicted indicate potential concern

8. Kelley Bonowski, RN, BSN, DNP student, and/or Jenifer Espinoza, LMSW/MPA, Solid Organ Transplant Social Worker, will then consult with cardiology healthcare providers regarding the results of the surveys if there are acute issues, and determine if a referral needs to be initiated. If a child indicates a desire to self-harm or express suicidal thoughts will be transported to the ED at Phoenix Children's Hospital accompanied by a healthcare provider.

9. If it is determined that a referral is necessary, the following referrals can potentially be made, as the below conditions present:
    - Referral Codes:
        - 1. Transplant Psychology
        - 2. Psychiatry

- 3. Neuropsychology
- 4. Social Work (SW)

Note: When more than one referral code is listed, consult all practitioners in the order listed (4, 1) = (Social Work, Psychology); if there is an arrow ($\rightarrow$) shown, the first practitioner listed will decide whether to call the next practitioner.

Transplant Phase:	**Pre-Eval**	**Output**	**Input**
Presenting Symptoms:	**Referral Codes:**		
Depressive/Anxiety Disorder with severe unresolved symptoms	1,2	1,2	4, 1, 2
History of bipolar disorder diagnosis	1	No need to refer if stable	No need to refer if stable
Questions about pharmacology for any psychiatric diagnosis	2	2	2
Suicide attempt or psychiatric hospitalization in the past	4, 1	4, 1	4, 1
Recent suicide attempt or voiced suicidal ideation	$\rightarrow$ 4 2	$\rightarrow$ 4 2	2, 1, 4
Substance Use Concerns	SW refer to CD Evaluation	4, 1	4, 1
Noncompliance with medication regimen	4, 1	4, 1	4, 1
Lack of social support (or concerns with support system)	4	4	4
Altered mental status (ex. Delirium)	2	Coordinator send to emergency room	2
Questionable decision-making capacity	4, 1, 3	4, 1	4, 1
Behavioral Concerns (ex. Aggression)	4, 1	4, 1	4, 1
Concerns for Illness acceptance	4, 1	4, 1	4, 1

Crisis Interventions	4, 1	4, 1	4, 1
Financial stress/ resource needs	4	4	4
Family Behavioral Health concerns	4	4	4
Concerns for Neglect/ Abuse4	4	4	4
Familial Discord	4	4	4

10. The child and parents/legal guardians will receive the scored results of the surveys and any referral information the same day the child is seen in the Heart Transplant/Heart Failure clinic.
11. The child will then be rescreened utilizing the same tools at their 4-month or 6-month regularly scheduled follow up appointment, depending on what interval their appointments are scheduled at (1, 2, or 3-month intervals).
12. At this rescreening, the parents/legal guardians will also be asked to complete the Psychosocial Screening Follow-up Survey. This survey consists of 5 short questions regarding follow through with referral recommendations or identifying what barriers the child and parents/legal guardians may have faced when trying to follow through with behavioral or mental health referrals.
13. Scores from the rescreening surveys will be examined in the same fashion as they were during the first screening and the results and possible need for referral will be handled in the same manner as during the first screening.
14. If the child and/or family speak only Spanish, the cardiology Spanish interpreter will be available to translate during each clinic visit. If the cardiology Spanish interpreter is not available, then a Cyracom interpreter will be used. All screening tools are available in Spanish.
15. If the child misses their regularly scheduled clinic appointment, Kelley Bonowski, RN, BSN, DNP student or Jenifer Espinoza, LMSW/MPA, Solid Organ Transplant Social Worker, will call the parents/legal guardians to determine when the next clinic

appointment will be or will notify Renee Cordova, Transplant clinic coordinator, who is responsible for the rescheduling of appointments.