

# The Role of Psychology in a Pediatric Outpatient Cardiology Setting: Preliminary Results from a New Clinical Program

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Published online: 14 September 2014  
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**Abstract** The aim of this study was to provide a descriptive analysis of a new clinical program integrating psychology services within a pediatric outpatient cardiology clinic. Patients with congenital heart disease (CHD) ( $n = 79$ ) were referred for psychological services by their pediatric cardiologist. Parents completed the child behavior checklist, and the pediatric quality of life inventory generic core scales (PedsQL parent report). Teachers completed the teacher report form. Reasons for referral included: emotional problems (29 %); attention problems (25 %); learning problems (22 %); behavior problems (16 %); and developmental delay (8 %). Parents and teachers reported higher rates of behavior problems and lower quality of life scores than the general population. Psychological evaluation suggested that incorporating a psychologist within a pediatric cardiology clinic may be beneficial for children with CHD in order to optimize their psychosocial functioning. Practice implications for implementing psychology services within a pediatric outpatient cardiology program are discussed.

**Keywords** Congenital heart disease · Quality of life · Outcomes · Program development

## Introduction

Congenital heart disease (CHD) is the most common birth defect, occurring in approximately 8 out of 1,000 live births, affecting nearly 40,000 infants annually in the United States (Hoffman & Kaplan, 2002). Due to advances in diagnostic/surgical techniques and postoperative management strategies, a dramatic decline in mortality rates for young children with even the most complex cardiac defects has occurred (Tweddell et al., 2002; Wetter et al., 2001), and most children with CHD are now surviving to adulthood (Warnes, 2005). However, with improved survival has come the recognition that these children are at increased risk for neurodevelopmental and psychosocial problems, thought to be related to a variety of preoperative, intraoperative, and postoperative factors (Wernovsky, 2006). Children with CHD have lower cognitive functioning and higher rates of attentional, behavioral and emotional problems when compared to the normal population (Karsdorp, Everaerd, Kindt, & Mulder, 2007; Sananes et al., 2012; Shillingford, Glanzman, Ittenbach, Clancy, Gaynor, & Wernovsky, 2008; Snookes, Gunn, Eldridge, Donath, Hunt, Galea, & Shekerdemian, 2009). In addition, increased parental stress, as well as impaired quality of life (QOL) for both children with CHD and their parents has been reported (Brosig, Mussatto, Kuhn, & Tweddell, 2007; Garcia Guerra et al., 2013; Latal, Helfricht, Fischer, Bauersfeld, & Landolt, 2009; Lawoko & Soares, 2003; Rempel, Ravindran, Rogers, & Magill-Evans, 2013; Sarajuuri, Lonquist, Schmitt, Almquist, & Jokinen, 2011; Uzark & Jones, 2003).

It is important to identify and address these psychosocial issues, as failure to do so can result in adverse consequences. Adult cardiac patients with anxiety and depression have been found to have more cardiac complications

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and worse mortality rates than psychologically well-adjusted cardiac patients (Barth, Schumacher, & Hermann-Lingen, 2004; Roest, Martens, Denollet, & deJonge, 2010). Patients with implantable cardioverter-defibrillators with untreated emotional distress reported poorer health status (Hoogwegt et al., 2012). Several studies on children with CHD have shown that family variables such as parenting style, parenting stress and parental anxiety were more significant predictors of child behavioral outcomes than disease or surgical factors (Goldberg et al., 1997; McCusker et al., 2007). Finally, in pediatric heart transplant recipients, children whose parents were identified to be “at risk from a psychosocial perspective” prior to transplant were found to be at increased risk for rejection episodes, hospitalization, and subtherapeutic medication levels post-transplant (Stone et al., 2006).

Despite increased awareness of the links between behavioral health issues and the management of chronic health conditions, many patients with psychosocial risk factors are not identified by their primary or specialty care physician. Physicians are under increased pressure to see more patients, and therefore, they may not be able to fully explore psychosocial issues with their patients in the context of a brief clinic visit. In one study of adult cardiac patients following invasive cardiac procedures, most encounters with the cardiologist lasted less than 5 min, with the majority of utterances made by the physician (Gordon, Street, Kelly, Soucek, & Wray, 2005). To address both the medical and behavioral/mental health needs of the patient and family, there has been interest in moving to more comprehensive models of care (Sullivan, 2003). Models range from referral only (i.e. the physician refers the patient to a psychologist off-site), to co-located (i.e. the psychologist is housed in the same space as the medical provider, but appointments with the physician and psychologist are separate), to fully integrated (i.e. the physician and psychologist see the patient at the same time during the same visit; Collins, Hewson, Munger, & Wade, 2010).

The integration of behavioral health into subspecialty care has previously been described for patients with a variety of medical conditions, including HIV (Farber et al., 2012) and inflammatory bowel disease (Maddux, Bass, Geraghty-Sirridge, Carpenter, & Christenson, 2013). Because psychological interventions have been shown to reduce mortality and morbidity in adult patients with cardiovascular disease (Linden, Phillips, & Leclerc, 2007), integrated care models have been successfully implemented in some adult cardiology settings, resulting in a subspecialty referred to as “psychocardiology” (Herrmann-Lingen, 2011). While it has been suggested that there is a role for psychology in working with adults with CHD (Kovacs, Silversides, Saidi, & Sears, 2006), little has been

written about the role that psychologists could play in working with children with CHD, and an integrated care model has not been previously described in the pediatric outpatient cardiology setting.

In order to address the neurodevelopmental and psychosocial concerns of children and families with CHD, beginning in July 2007, a cardiology division at a tertiary pediatric hospital in the Midwest employed a pediatric psychologist (.6 clinical FTE) to provide psychological services within the pediatric outpatient cardiology setting, in an attempt to provide more integrated care. The purpose of this study is to describe the clinical program and the behavioral/emotional functioning and QOL of children with CHD who were referred for outpatient psychological services by their respective cardiologists. Practice implications for implementing psychology services within a pediatric outpatient cardiology program are discussed.

## Methods

### Description of Clinical Program

Prior to the psychologist being hired in the cardiology division, patients who needed behavioral services were referred to psychologists located in other divisions within the hospital (Child Development or Child Psychiatry), or to providers in the community. Because of the growing need for behavioral health services for pediatric cardiology patients, the Section Chief of Cardiology requested that a psychologist position be included in the Division of Cardiology budget. A rationale for why the position was needed, summarizing the literature on neurodevelopmental and psychosocial problems in the CHD population, was presented to the Chair of Pediatrics and the department administrator, and the position was approved. Of note, this did not require adding a position to the department budget, as the psychologist for the cardiology program moved from another division within Pediatrics.

After the position was approved, a number of integrated care models were reviewed. It was determined that a co-located model of care would be most appropriate and feasible in the pediatric outpatient cardiology setting. An office was designated within the cardiology clinic, specifically for use by the psychologist, with furniture and equipment suitable for conducting psychological testing and/or therapy. The office was located in a quiet area near the back of the clinic and was in a separate space from the cardiology medical exam rooms. However, patients checked in and waited for the psychologist at the same location that they used for their appointments with their cardiologist.

Prior to the implementation of psychology services within the outpatient cardiology clinic setting, the psychologist gave formal presentations to the cardiologists and nurses at faculty and nursing staff meetings about the types of neurodevelopmental and psychosocial issues commonly seen in children with CHD. Cardiologists and nurses were educated about the types of services that the psychologist would provide, including short-term psychotherapy and psychological assessment. It was clarified that it was not the role of the psychologist to provide psychiatric crisis management services, and that usual protocols for those situations (i.e. paging the medical social worker or psychiatrist on-call) should still be followed.

Children with CHD were seen at regular intervals by their cardiologists for routine cardiac follow-up care. During outpatient cardiac follow-up clinic visits, cardiologists and/or nurses asked families about the child's emotional, behavioral, and academic functioning as part of their social history evaluation. No standardized set of questions or screening tool was used to elicit this information, and providers varied with regard to how much of the clinic visit was spent asking about these issues. Cardiologists and nurses were not asked to make any changes to their normal clinic practices, other than to inform families that there was a psychologist available within the cardiology clinic if behavioral health concerns were identified. If there were concerns in these areas, and a referral to the pediatric psychologist was recommended, this was discussed with the family. After the cardiology visit, the cardiologist or nurse contacted the psychologist about the child they were referring with the nature of their concerns, and also completed a referral form with the patient's demographic information. The family was contacted by the psychologist's administrative assistant to schedule the appointment after insurance authorization was obtained. Patients were scheduled separately with the psychologist at the family's convenience. If requested, the appointment was scheduled on the same day as the patient's next visit with the cardiologist. Behavioral rating scales were mailed to the family, to be completed and returned by mail prior to their psychology appointment. The psychologist billed for services.

## Measures

As part of the initial psychology visit, parents completed a demographic form, that included questions about the child's medical history, past and current intervention services, parental age, education and occupation, and family constellation. Socioeconomic status (Four Factor Index of Social Status, Hollingshead, 1975) was calculated based on parent education, occupation, sex, and marital status. Hollingshead scores are classified into 5 categories,

ranging from I "major business and professional" to V "unskilled laborers".

Because it is recommended that clinical evaluations utilize data gathered from multiple sources (Pinquart & Shen, 2011), additional rating scales were distributed to parents and teachers in order to obtain further information about the child's functioning in the home and school environment. Information from rating scales was used in conjunction with the clinical information obtained during the psychology visit to determine recommendations.

**Behavior** The Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2000), is a measure of behavioral and emotional functioning. Parents indicate whether the listed behaviors are "not true", "somewhat true" or "very true" of their child. Three summary scores are calculated (Mean = 50, SD = 10) for Internalizing Problems, Externalizing Problems, and Total Problems (which includes both internalizing and externalizing behaviors). Sample items for the Internalizing Problems scale include "cries a lot" and "feels too guilty". Sample items for the Externalizing Problems scale include "argues a lot" and "disobedient at home". Higher scores represent more problems. Although additional subscale scores are also reported, these were not utilized for purposes of the current study. Reliability and validity for the measure has been well-established, with test-retest reliability reported as .85. Criterion-related validity has been demonstrated by all items discriminating significantly between children who were referred and not referred to a mental health clinic for behavioral problems (Achenbach & Rescorla, 2000). Teachers or daycare providers completed a similar measure, the Teacher Report Form (TRF; Achenbach & Rescorla, 2000), which includes the same summary scores as the CBCL. These scales have been the most extensively and commonly used measures to assess behavioral outcomes in children with chronic health conditions (Pinquart & Shen, 2011).

**Quality of Life** The Pediatric Quality of Life Inventory Generic Core Scales—Parent Report (PedsQL™; Varni, Seid, & Murtin, 2001) is a measure of the parent's perception of the child's QOL. Parents indicate whether the items listed are "never a problem" to "almost always a problem" for their child. Sample items include "low energy level", "feeling afraid or scared", "getting teased by other children", and "keeping up with schoolwork". A Total score, Physical Health Summary score and Psychosocial Health Summary score are computed, as well scores for the following subscales: Physical Health, Emotional Functioning, Social Functioning, and School Functioning (if age appropriate). Scores range from 0 to 100; higher scores represent better QOL. The reliability and validity of the measure has been established in healthy and patient populations (Varni, Seid, & Murtin, 2001). Internal

consistency reliability for the Parent Report Total score, Physical Health Summary Score, and Psychosocial Health Summary score were reported as  $\alpha = .90$ ,  $\alpha = .88$ , and  $\alpha = .86$ , respectively. Validity was demonstrated using factor analysis and correlation with indicators of illness severity and burden (Varni, Seid, & Murtin, 2001).

Of note, self-report measures of behavior and QOL were completed by patients who were at least 11 years of age at the time of the visit ( $n = 18$ , 23 %). Due to the limited sample size for this age group, patient self-report data are not presented.

Parents provided consent and children (ages 7 years and older) gave assent to have results from the questionnaires be utilized for research purposes. The study was approved by the hospital institutional review board.

### Statistical Analyses

Comparative analyses were performed to determine sample characteristics and frequency of behavioral problems compared to a reference population (based on scale norms). McNemar's test was conducted to compare paired percentages of patients falling within normal or clinical range on parent and teacher rating scales. Correlational analyses were performed to determine the relationship between behavioral functioning and QOL. One sample t-tests were used to compare scores of the clinic patients to reference samples of healthy and CHD patients; QOL scores for comparison samples were obtained from previous studies (Varni, Burwinkle, Seid, & Skarr, 2003; Varni, Seid, & Murtin, 2001; Uzark et al., 2008). Two sample t-tests were used to compare healthy subjects and CHD patients. The healthy sample was comprised of children ages 2–18 years without a chronic health condition. The CHD comparison sample was comprised of children ages 2–18 years who were recruited from a general pediatric cardiology clinic at a Midwest children's hospital; this clinic did not have a co-located psychologist, and the comparison sample of patients with CHD were not specifically referred for psychological evaluation.

## Results

### Patient Population

New patients/families seen by the psychologist in the outpatient pediatric cardiology clinic, who completed behavioral questionnaires, were eligible for inclusion in the study. Follow-up patients, patients seen by the psychologist in the cardiac intensive care unit, or patients seen in the multidisciplinary transplant clinic were excluded, as they

did not complete questionnaires, and the focus of the study was to report results from the general outpatient setting.

From July 2007–June 2011, there were 9193 new patients (ages 3–17) seen in the general outpatient cardiology clinic. Of these, 144 (2 %) were referred to the cardiology psychologist. Seven of these patients could not be seen due to denial by insurance; these families were assisted in finding a behavioral health provider in their insurance network. Two families indicated they already had other mental health services in place, and did not need additional services. Six families indicated that they were not interested in services, and an additional 10 families did not return calls when they were contacted to set up an appointment.

There were 119 new patients seen by the psychologist within the outpatient cardiology clinic. Only English-speaking parents of cardiac patients less than 18 years of age were asked to complete forms as part of their psychology visit, resulting in 107 eligible patients for this study. Nine families who met eligibility criteria did not complete forms because they were seen on an urgent basis. Of the 98 families with completed forms, 81 % ( $n = 79$ ) consented to participate in the present study. The most common reason that consent was not able to be obtained was that the family was in a hurry to leave so consent forms could not be completed ( $n = 16$ , 84 %). These patients were excluded from data analyses. Patients who did not consent did not differ from patients who did consent on gender (69 % male vs. 75 % male) or age (mean age = 9.8 years vs. 8.3 years). This study reports results from the 79 patients/families with completed forms that consented to participate.

Demographic characteristics are presented in Table 1. Sixty-three percent of parents were married. Median age of the sample was 8.3 years (range 2.7–17 years). A majority of children who were enrolled were male (75 %,  $n = 69$ ) and  $\leq 10$  years of age (76 %,  $n = 60$ ). In contrast, 53 % ( $n = 4,908$ ) of the new patients seen in the general cardiology clinic during the same time period were male, and 54 % ( $n = 4,978$ ) were  $\leq 10$  years of age. Thus, there appears to be a bias toward referral of young males as evidenced by the difference between the clinic population and the referred sample. Patients were referred by 16 different cardiologists; referral patterns varied largely based on the nature of the cardiologist's specialty and location (e.g. cardiologists specializing in cardiac interventions, fetal echocardiography, adult CHD, or those located in outreach settings away from the main campus referred fewer patients). Reasons for referral included emotional problems (29 %,  $n = 23$ ), attention problems (25 %,  $n = 20$ ), learning problems (22 %,  $n = 17$ ), behavioral problems (16 %,  $n = 13$ ), and developmental delay (8 %,  $n = 6$ ). Reason for referral did not differ based on type of

**Table 1** Demographic characteristics

Variable	N	Percentage
Gender	Female = 20	25.32
	Male = 59	74.68
Time of diagnosis	Prenatal = 23	30.67
	Postnatal = 52	69.33
	Missing data = 4	
Ventricular anatomy	Single = 35	44.38
	Two = 44	55.70
Other medical condition	No = 43	54.43
	Yes = 36	45.57
Socioeconomic status (Hollingshead, 1975) <sup>a</sup>	I = 12	16.00
	II = 24	32.00
	III = 19	25.33
	IV = 17	22.67
	V = 3	4.00
	Missing data = 4	

<sup>a</sup> Hollingshead scores are classified into 5 categories, ranging from I “major business and professional” to V “unskilled laborers”

**Table 2** Child behavior checklist (CBCL) and teacher report form (TRF) T-scores compared to test norms

	CBCL (parent; n = 78)	TRF (teacher; n = 62)	Test norms
Internalizing problems	58.09*	53.19*	50.00
Externalizing problems	57.01*	54.32*	50.00
Total problems	59.55*	56.69*	50.00

\* Indicates significantly different than test norms,  $p \leq .001$

cardiac diagnosis. More girls than boys were referred for emotional problems (50 vs. 22 %,  $\chi^2(1) = 4.39, p = .036$ ). Older children ( $\geq$ age 11) were more likely than younger children ( $\leq$ age 10) to be referred for emotional problems (70 vs. 15.3 %,  $\chi^2(1) = 19.12, p < .0001$ ).

**Rating Scales**

Mean CBCL (parent report) and TRF (teacher report) summary scores are reported in Table 2. All CBCL and TRF scores were significantly higher than test norms; however, group means still fell within the normal range. From a clinical perspective, the number of individual patients who fell within the clinical range on these measures is of interest. For purposes of analysis, patients falling in the borderline or clinical range were combined into one group. These results are presented in Table 3. Overall, parents reported more problems than teachers.

**Table 3** Percent of patients in the borderline/clinical range on the child behavior checklist (CBCL) and teacher report form (TRF)

	CBCL (parent)	TRF (teacher)	p value
Internalizing problems	50.00	21.67	.002
Externalizing problems	39.34	19.67	.02
Total problems	42.62	29.51	.17

Of note, only 18 % of a healthy sample scored in the borderline/clinical range on these scales (Achenbach & Rescorla, 2000)

PedsQL scores (parent report) are presented in Table 4. As shown in Table 4, when compared to a healthy sample (Varni, Burwinkle, Seid, & Skarr, 2003; Varni, Seid, & Murtin, 2001), and when compared to another sample of children with CHD presenting to a general cardiology clinic that were not specifically referred for psychological evaluation (Uzark et al., 2008), parents of the children seen by the psychologist in the cardiology clinic reported significantly lower QOL scores for their children in all domains. The relationship between child emotional/behavioral functioning and QOL is presented in Table 5. As shown in Table 5, in general, patients with more behavioral problems had lower QOL scores.

**Prior Services and Treatment Recommendations**

Parents were asked whether their children had received any prior services to address developmental, learning or behavioral concerns. Forty-two percent of children had previously been enrolled in Birth to Three services, an early intervention program that provides speech, occupational and/or physical therapy for children under the age of 3 years. Eighteen percent of children had been enrolled in Early Childhood services, which provides interventions for preschool aged children. Eight percent of children had previously been enrolled in special education, and 9 % had previously had mental health treatment. Parents were also asked about services the child was currently receiving; this information is provided in Fig. 1. Seventy-four percent of patients were not enrolled in any special education or mental health services. Only 17 % were receiving special education, 5 % were receiving mental health services, and 4 % were receiving both. Following the psychological evaluation, services were recommended for 92 % of patients: special education—15 %, mental health—39 %, and both—38 % (see Fig. 1). Recommendations for special education and/or mental health services were based on all sources of information gathered during the evaluation (including measures completed by parents and teachers), as well as clinical judgment. Specific cutoff scores on measures were not used to determine recommendations.

**Table 4** PedsQL parent report scores: CHD study sample vs. healthy and other CHD sample

PedsQL generic (parent)	Healthy sample (Varni et al., 2001; 2003)			CHD study sample			<i>t</i> statistics value	<i>p</i> value (healthy Varni vs. CHD study sample) <sup>b</sup>	CHD (Uzark et al., 2008)			<i>t</i> statistics value	<i>p</i> value (CHD Uzark vs. CHD study sample) <sup>b</sup>
	<i>N</i> <sup>a</sup>	Mean	SD	<i>N</i>	Mean	SD			<i>N</i> <sup>a</sup>	Mean	SD		
Total	9,430	82.70	15.72	75	65.62	19.71	-7.50	<.0001	473	80.57	14.81	-6.57	<.0001
Physical health	9,413	84.48	19.82	76	68.84	23.63	-5.77	<.0001	473	83.88	17.05	-5.55	<.0001
Psychosocial	9,431	81.65	15.51	74	64.07	20.13	-7.51	<.0001	472	78.70	15.64	-6.25	<.0001
Emotional	9,410	81.31	16.56	76	65.77	24.28	-5.58	<.0001	472	76.20	19.13	-3.75	.0004
Social	9,406	83.70	19.68	76	67.27	23.16	-6.19	<.0001	471	84.17	17.70	-6.36	<.0001
School	6,455	76.83	19.64	73	58.42	23.11	-6.81	<.0001	353	72.68	19.24	-5.27	<.0001

PedsQL scores for the healthy comparison sample were obtained from the PedsQL healthy children database (Varni, Burwinkle, Seid, & Skarr, 2003; Varni, Seid, & Murtin, 2001). PedsQL scores for the CHD comparison sample were obtained from a previous study (Uzark et al., 2008)

<sup>a</sup> Over all ages ≤18 years

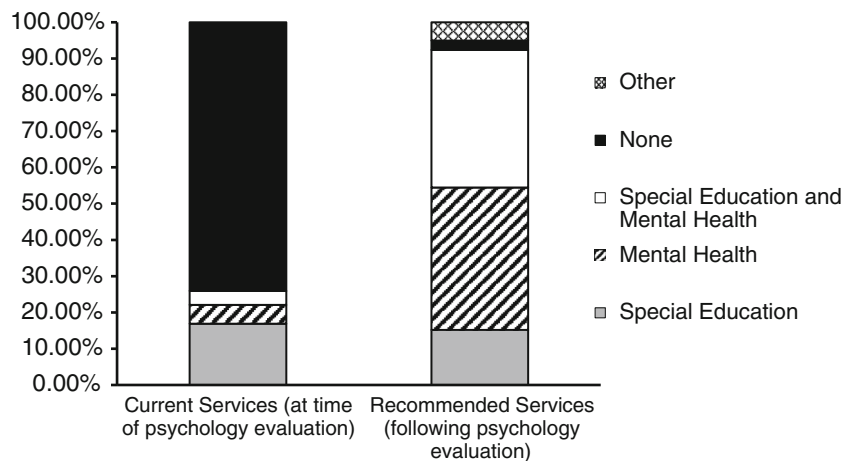
<sup>b</sup> One-sample *t* test

**Table 5** Relationship between behavioral functioning and quality of life (spearman correlations)

	PedsQL physical health summary	PedsQL psychosocial health summary	PedsQL total score
CBCL internalizing problems	<b>-.39</b> <b>p = .0006</b> <b>N = 76</b>	<b>-.66</b> <b>p &lt; .0001</b> <b>N = 74</b>	<b>-.62</b> <b>p &lt; .0001</b> <b>N = 75</b>
CBCL externalizing problems	-.19 p = .1077 N = 76	<b>-.44</b> <b>p &lt; .0001</b> <b>N = 74</b>	<b>-.37</b> <b>p = .0012</b> <b>N = 75</b>
CBCL total problems	<b>-.34</b> <b>p = .0029</b> <b>N = 76</b>	<b>-.65</b> <b>p &lt; .0001</b> <b>N = 74</b>	<b>-.58</b> <b>p &lt; .0001</b> <b>N = 75</b>

Bolded numbers indicate correlations that were statistically significant

**Fig. 1** Services being received at the time of psychology evaluation vs. services recommended following the evaluation



**Discussion**

This study provides a descriptive analysis of a new clinical program that integrates psychological services in an

outpatient pediatric cardiology clinic. Results of this study indicate that it is possible to provide co-located psychological services in this type of medical setting. However, implementing such a program does present some challenges.

What follows is a summary of “lessons learned” which may be helpful to other institutions who are considering moving toward more integrated models of care.

### Lessons Learned and Future Directions

Previous studies have suggested that 5–40 % of patients with CHD have psychological problems (Latal, Helfricht, Fischer, Bauersfeld, & Landolt, 2009); however, over the four years reviewed in the present study, only 2 % of general cardiology patients were referred to the psychologist in clinic, and the rate of referral remained stable over time. Because cardiology providers were not instructed to ask specific questions about emotional, behavioral and academic functioning, and a formal screening tool was not utilized, it is possible that some providers did not ask about these issues in detail, and some patients with such concerns may have been missed. To optimize appropriate referrals for psychological evaluation, it is recommended that cardiology providers be instructed to use specific questions in their social history and/or a formal screening tool to assess for psychological problems, to ensure that these questions are asked of every patient. Having such questions or tools embedded into templates used as part of the electronic medical record may prompt providers to ask about these issues on a routine basis. Relying solely on a clinical cutoff score from a screening tool to determine which patients are referred to psychology may not be sufficient, as previous studies have found that few patients scored in the clinically significant range of problems on such measures (Struempf, Sood, Barhight, Thacker, & Gidding, 2013; Maddux, et al., 2013). Reviewing responses to a psychosocial screening tool in addition to asking specific questions during the social history may be the most accurate way to identify which patients should be referred for psychology services. In addition, the psychologist may need to continually educate both providers and families about potential psychological issues in these patients, and market the program so that everyone is aware of what the program offers.

The decision to utilize a co-located model of care in the program described was a strategic one, designed to make it easier for cardiologists to refer patients and easier for families to access behavioral health services. By housing the psychologist within the cardiology clinic, it was hoped that any possible stigma families perceived about seeing a psychologist might be reduced. It is not clear that this goal was achieved, as approximately 11 % of families who were referred to the psychologist in cardiology did not schedule an appointment. Simply co-locating a psychologist within the cardiology clinic may not be enough to reduce stigma. Previous research has suggested that many parents of children with CHD who endorsed psychosocial concerns

on a screening tool were not interested in meeting with a behavioral health specialist (Struempf, et al., 2013). In addition, negative attitudes toward behavioral health services were a significant barrier to parents attending behavioral health appointments provided in a pediatric primary care setting (Wildman & Langkamp, 2012). Additional research is needed on how to make behavioral health services more acceptable to parents. In the case of the program presented, it may have been helpful to have the cardiologist provide more education to the family about the role of the psychologist in the cardiology clinic, including ways that the psychologist may be able to assist the family. In addition, having the cardiologist introduce the psychologist to the family while they are in clinic may further decrease stigma. Finally, exploring more fully integrated models of care, in which the psychologist sees the patient with the cardiologist as part of a multidisciplinary clinic, at least for the initial visit, may also normalize the role of psychology for families.

The importance of obtaining administrative support when developing a new clinical program cannot be underemphasized. In the current example, it was helpful to present literature documenting the neurodevelopmental and psychosocial problems of the CHD population, as justification for why the program was needed. Because this program did not require additional personnel, and the psychology position already existed within the Department of Pediatrics, it was not difficult to get administrative support for the program. It should be noted that the program was proposed during a time in the Department when clinical revenues were high, and there were sufficient funds available to support new program development. In the current fiscal climate of healthcare, in which clinical revenues are declining, it may be more difficult to generate administrative support, particularly if the program cannot sustain itself based on clinical revenue generated. For others proposing similar programs, a sound business plan will be needed, outlining projected revenue/losses, as well as needs for space, equipment, and personnel. Presenting data on how integrating behavioral health services in other medical settings has resulted in reduced health care costs (Blount et al., 2007) may result in a greater likelihood of administration funding the program. Medical cost offset data was not collected for the program described, and is an area for further investigation.

The program presented was not designed in response to any significant problem or major clinical incident; thus, the formal quality improvement/performance improvement (QI/PI) system of the institution was not involved in the development of the program. The intent of the described program was to make it easier for families to access behavioral health services with a provider who was familiar with the neurodevelopmental and psychological

problems commonly seen in children with CHD. Co-locating the psychologist within the cardiology clinic was also designed to make it easier for cardiologists to refer patients, and to improve communication between the medical and behavioral health providers. However, a formal “plan-do-study-act” (Lerner, Cheung, & Klaber, 2013) process, done as part of QI/PI studies, was not implemented. As a result, whether the program resulted in reduced time for families to get a psychology appointment was not measured. In addition, although anecdotal evidence from providers and families suggests that they like the program, formal measures of patient and provider satisfaction were not implemented. Enlisting the help of the QI/PI system of the institution at the outset, particularly when deciding how to measure the impact of the change that is being proposed, would be useful for others considering starting similar programs. Finally, seeking input from families on how to improve the current system of care is recommended (Armstrong et al., 2013).

Review of the clinical data gathered during the psychological evaluation identified needs for mental health services and/or special education that were not being addressed, thus confirming the value of integrating psychological services for these children and families into their overall medical care. The children who were referred for psychological evaluation presented with a wide variety of behavioral, learning and emotional problems; these problems are similar to what is reported in the CHD neurodevelopmental and psychosocial outcomes literature (Karsdorp, et al., 2007; Wernovsky, 2006). Parents and teachers reported higher rates of emotional and behavior problems compared to a healthy population; this is not surprising, given that many of the children were referred for these reasons. Children with CHD who were referred for psychological services had lower QOL scores when compared to healthy peers and a general pediatric cardiology sample. In addition, children with CHD who had higher levels of behavioral/emotional problems had lower QOL scores; this is consistent with previous research that has identified emotional problems as a risk factor for impaired QOL in children with CHD (Ferguson & Kovacs, 2013).

The majority of the patients who were referred were male. Although prevalence rates for some forms of CHD are somewhat higher in males than females (Kornosky & Salihu, 2008), this does not explain why three times as many boys as girls were referred for evaluation. Other studies on behavior problems in children with other chronic illnesses have found that girls are more likely to present with emotional problems of an internalizing nature, such as anxiety or depression, whereas boys are more likely to present with externalizing behavior problems (Pinquart & Shen, 2011); this is consistent with findings from the present study. Internalizing problems may not be as apparent as externalizing problems, which may

explain why fewer girls were referred in the present study. This underscores the need to include patient self-report measures as part of the evaluation, particularly to gather additional information about emotional symptoms that may not be visible to the outside observer. While self-report measures were utilized for older patients in the clinical program described, due to the small sample size for this age group, there was not sufficient data to analyze. This is an area for future investigation in the CHD population, as studies from children with other chronic illnesses have found significant differences between patient self-report data and information provided by parents and teachers (Pinquart & Shen, 2011).

It is interesting to note that the majority of patients who were referred were 10 years of age or younger, yet previous literature on children with CHD has found elevated levels of behavior problems in older patients, suggesting that children may “grow into” problems that are not present earlier in life (Karsdorp, et al., 2007). It is not clear why more adolescents were not referred. It is possible that while the developmental delays of infants and toddlers with CHD may be addressed by routine referral to early intervention services and/or systematic developmental follow-up programs (Brosig Soto, et al., Brosig Soto et al. 2011), the psychological needs of older patients with CHD may receive less attention. Thus, incorporating psychological services within a pediatric cardiology program may be beneficial for children with CHD in order to improve their behavioral/emotional functioning and overall QOL across their lifespan, and ensure continuity of supports from infancy through adolescence.

Although research has shown that children with CHD are at higher risk for neurodevelopmental and psychosocial problems, little has been written about the role that pediatric psychologists could play with this population. Discussions with psychologists who are members of the Society of Pediatric Psychology Cardiology Special Interest group indicate that many leading cardiac centers are planning to expand psychology involvement in a variety of areas (personal communication, September 13, 2013). The recent guideline paper from the American Heart Association and American Academy of Pediatrics (Marino, et al., 2012) has called attention to the neurodevelopmental and psychosocial needs of the CHD population, and is recommending routine neurodevelopmental follow-up of these children. This guideline paper will likely increase the demand for psychologists working with this population. However, given the challenges with reimbursement for psychology services in a cardiology setting (Brosig, 2012), these services may require philanthropic support and/or the financial support of the institution. Program evaluation to investigate whether incorporating these services results in improved psychosocial outcomes is needed.

There are a number of limitations to the current study. Because patients were specifically referred for psychology



services, they would be expected to have higher rates of behavioral/emotional problems than a general CHD population; thus, results from the behavioral/emotional and QOL measures would not be expected to generalize to the CHD population as a whole. Information about how many parents followed up on the recommendations made by the psychologist was not obtained, which is a direction for future investigation. Finally, it is possible that data regarding the socioeconomic status of the families may not accurately reflect their actual functioning, as the Hollingshead Four Factor Index of Social Status (1975), while widely used, is based on census data from the 1970s.

## Conclusion

Incorporating psychological services within a pediatric outpatient cardiology clinic may be beneficial for children with CHD in order to optimize their psychosocial functioning and overall QOL across their lifespan. As leading cardiac centers around the world increase their attention to the neurodevelopmental and psychosocial needs of this patient population, there will be enhanced opportunities for psychologists to be involved in clinical care, education, and research. Psychology training programs should offer additional experience with this population, as there is a growing demand. Cardiologists may benefit from additional education and tools on how to identify which patients are in need of psychology services. Finally, various models of integrated care should be explored to determine which models result in greater family and provider satisfaction with services, better health outcomes, and reduced health care costs.

**Acknowledgement** This research was supported by the Pediatrics Department of the Medical College of Wisconsin and the Herma Heart Center at Children's Hospital of Wisconsin. The authors would like to acknowledge Angie Klemm for her assistance with database management.

**Conflict of Interest** Authors Brosig, Yang, Hoffmann, Dasgupta and Mussatto declare that they have no conflict of interest.

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

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