

Original Article

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Implementation and analysis of clinic administered behavioural health screen in an outpatient paediatric cardiology clinic

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Abstract

Previous studies investigating behavioural health screening processes have focused on selected diagnoses within paediatric cardiology and focused on a smaller number of potential concerns. We developed and administered a brief survey in our paediatric heart centre to assess the presence of a wider variety of behavioural health concerns and to connect patients with resources. A cohort of 305 patients aged 2–29 years ($M = 11.97$ years; $SD = 6.00$ years; 50.49% female), representing a variety of indications for a cardiology clinic visit, or a parent, completed a survey of 14 common behavioural health concerns. Behavioural health concerns were included based on practice patterns within paediatric psychology. Respondents indicated if they were currently receiving behavioural health services and if they were interested in behavioural health follow-up. Surveys were administered during check in and collected by clinic staff. A behavioural health provider attempted to reach all those who indicated interest by phone. Approximately 45% of the sample endorsed one or more behavioural health concerns and 30.16% of the sample endorsed at least one concern but were not already connected to services. Only 27.17% of this group requested follow-up. Most commonly endorsed concerns were anxiety, sleep problems, depressed/irritable mood, and somatic complaints. Survey results converge with existing literature to indicate that behavioural health concerns are common among youth seen in a paediatric cardiology clinic but most patients are not connected to appropriate services. Screening programmes can help meet this need but challenges remain. Clinical implications and future directions are discussed.

Introduction

Over the past two decades, there has been a continual increase in literature demonstrating that behavioural health concerns are common among paediatric cardiology patients. Behavioural health concerns are problems with mood, coping, or behaviour that impact an individual's quality of life and functioning in home, school, medical, or social settings. Specific behavioural concerns may include adherence difficulties, disruptive behaviour, inattention, and other symptoms of attention-deficit/hyperactivity disorder, depressive symptoms, anxiety, social difficulties, sleep problems, and academic challenges.

Much of the research on behavioural health in paediatric cardiology has been conducted within the CHD population. For example, children with transposition of the great arteries^{1,2} and hypoplastic left heart syndrome² were found to have elevated externalising symptoms and other problems with disruptive behaviour relative to population norms. More broadly, DeMaso et al.³ found that adolescents with single ventricle conditions had an elevated risk for meeting criteria for at least one psychiatric diagnosis relative to healthy controls. The most common diagnoses in the study were attention-deficit/hyperactivity disorder and anxiety disorders. This elevated risk has not been exclusive to those with complex or severe CHD. In a large-scale study of patients 4–17 years of age presenting to the emergency department or hospital floor, Gonzalez and colleagues⁴ found that those with either simple or complex CHD were 5–7 times more likely to be diagnosed with depression or anxiety conditions or to be prescribed an antidepressant relative to a general population of hospitalised patients without CHD. Those with CHD were also 1.6–2.7 times more likely to be diagnosed with attention-deficit/hyperactivity disorder or to be prescribed medication for attention-deficit/hyperactivity disorder. Due to the increased acknowledgement of this problem, a scientific statement was recently released from the American Heart Association calling for increased mental and behavioural health assessment and intervention services to be integrated into CHD programmes across the lifespan.⁵

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Although much of the literature to date has focused on CHD, elevated risk for behavioural and emotional difficulties has also been documented in other paediatric cardiology populations, such as those undergoing heart surgery^{6,7} and those with implantable cardioverter-defibrillator implantation.⁸ For example, Koopman et al.⁹ found that adolescents with implantable cardioverter-defibrillator placement had higher rates of depressive and anxiety symptoms and sleeping problems than healthy controls. Paediatric heart transplant recipients have also been demonstrated to have increased rates of anxiety, posttraumatic stress symptoms, and overall poor adjustment and health-related quality of life.^{10–15} Results from another study revealed high rates of psychiatric disorders, especially anxiety disorders, among youth referred for cardiac evaluation for symptoms of chest pain, palpitations, or syncope.¹⁶ Although anxiety disorders, generalised anxiety disorder in particular, were more common among youth with specific cardiac diagnoses, elevated rates of disorders were also observed in patients without cardiac conditions presenting for cardiology consultation.

Given the elevated risk, there have been several efforts to implement screening programmes for behavioural health problems in specific populations so as to connect them to behavioural health services. In one such programme at Nemour's DuPont, the Pediatric Symptom Checklist-17¹⁷ was utilised to identify internalising symptoms (depression, anxiety), externalising symptoms (disruptive behaviour, hyperactivity), or inattention problems in paediatric CHD, cardiomyopathy, and arrhythmia patients under 18 years of age.¹⁸ Results indicated that similar proportions of parents of children with CHD identified externalising and inattention problems for their children compared to those seen in primary care settings, and fewer parents of children with CHD identified internalising problems compared to primary care settings. Parents did, however, more frequently endorse items related to school functioning and development. Still, the authors noted that this is inconsistent with the literature indicating higher prevalence of such problems in patients with CHD. The authors suggested that the Pediatric Symptom Checklist-17 has low sensitivity to the needs of paediatric cardiology patients and may not be the most appropriate tool for this population. They also found that only a minority of those expressing concerns were interested in follow-up and even fewer were ultimately connected with services.

In another study, Butz et al.¹⁹ administered the Patient Health Questionnaire-4²⁰ to adolescents and adults with CHD and found 27% of the sample to report at least moderate symptoms of anxiety or depressed mood, with young adults and those over 40 years of age reporting more symptoms than adolescents or middle-aged adults.

These studies have been important developments with regard to screening for behavioural health concerns in paediatric cardiology. However, they have been limited in scope to anxiety, depressive symptoms, and externalising behaviours without a wider inclusion of additional behavioural health domains. Moreover, the target population has been limited to patients with CHD and excluded patients with other indications for cardiac evaluation. Access to care remains an issue as well, and it is imperative to determine processes that may facilitate connection to services with qualified clinicians. To address these gaps, our group administered a brief survey in our centre to assess the presence of a variety of behavioural health concerns commonly reported in this population and which typically trigger a referral for paediatric psychology services. Our goals for the programme were to identify the presence

of behavioural health concerns in our clinic and to connect patients with behavioural health services and resources. This programme was piloted over 10 months. The aims of this article are to (1) describe the programme, (2) report on results of behavioural health concerns, (3) analyse demographic and clinical correlates of behavioural health concerns, (4) report on results of clinical outcomes (i.e., connecting to behavioural health care), and (5) discuss future directions.

Method

Participants

The target population included all patients, ages 2–30 years old, who attended a clinic appointment with the Blalock–Taussig–Thomas Pediatric and Congenital Heart Center. Patients with a variety of cardiac diagnoses or reasons for referral to a cardiologist were included. Those who were non-English speaking or whose visit was for prenatal counselling were excluded. Patients who were part of the heart centre's transplant program and therefore already followed by the transplant psychologist were also excluded.

Materials and procedures

We developed a brief survey to screen for the presence of behavioural health problems and assess interest in follow-up with a behavioural health clinician. The decision was made to develop a new survey for several reasons. First, existing brief screening measures focus on a limited set of behavioural health domains, and one of the goals of this programme was to expand to include additional behavioural health problems. Second, as noted above, previous studies have not identified a broad measure that has adequate sensitivity that would justify its use in this population. Third, utilising multiple instruments to capture responses for multiple behavioural health domains was deemed to be not feasible for busy clinic flow. The current survey was developed based on commonly endorsed issues and common presenting and referral concerns for paediatric psychology services in general and within the paediatric cardiology population in particular.^{1,3,21–27} Domains included medication adherence, medical coping, feeding problems, sleep concerns, depressed mood, anxiety symptoms, externalising behaviours, school functioning, social functioning, medical/procedural anxiety, medical traumatic stress, pain and physical symptoms, and parental coping. Each domain included a single item in order to balance programme goals of querying a wide scope of behavioural problems while maintaining brevity. See Figure 1 for an overview of each item. Both self- ($\alpha = 0.84$) and parent-report ($\alpha = 0.82$) versions demonstrated good internal consistency.

With regard to the process, individuals aged 11 years and older completed the survey as self-report, while parents responded for children aged 2–10 years. The paper survey was administered to families or patients as they entered clinic during registration and handed off to the clinic triage nurse during patient intake. Respondents rated each concern for the previous month on a 4-point scale (0 = not concerned, 1 = a little concerned, 2 = somewhat concerned, and 3 = very concerned). Respondents also indicated if the patient currently or previously received mental/behavioural health services, as well as if they were interested in follow-up contact with a paediatric psychologist. Completed surveys were collected by two of the study authors and entered into a clinical database. The paediatric psychologist working with the

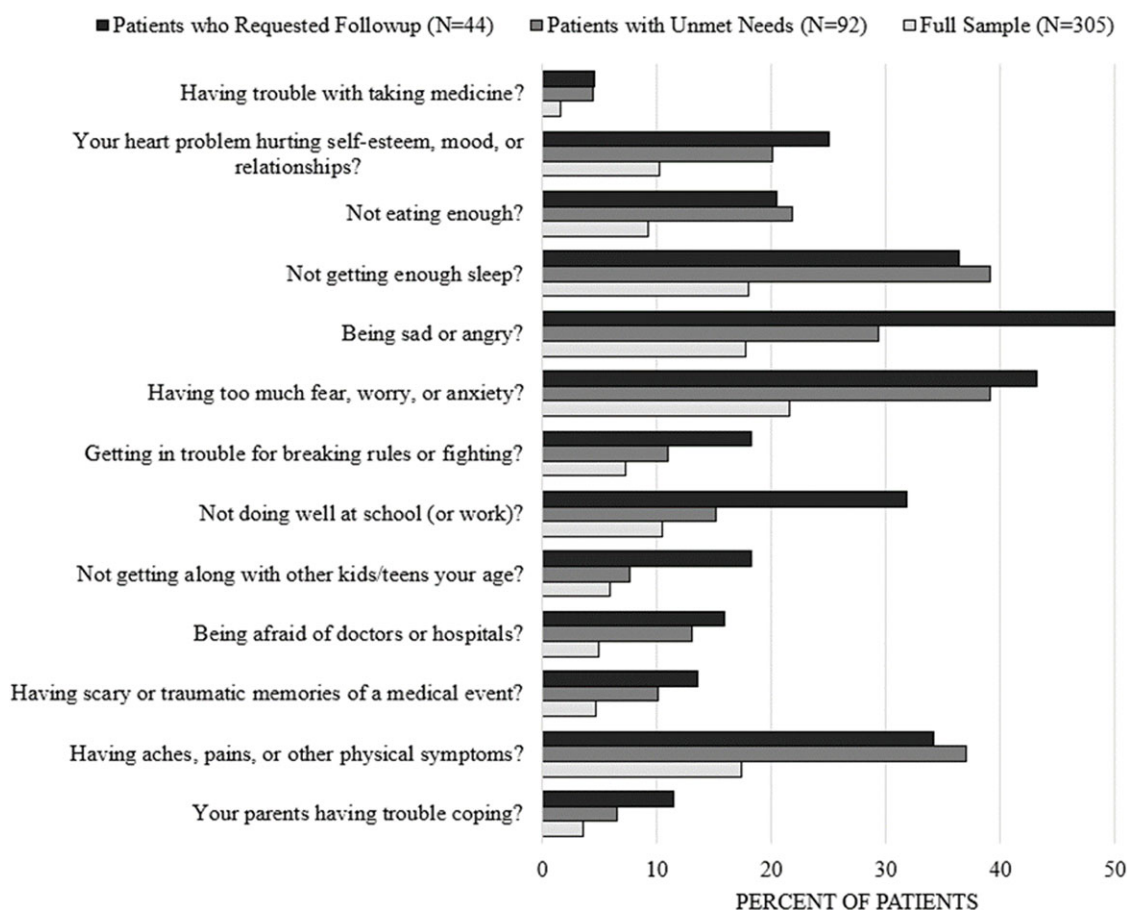


Figure 1. Percent of all patients, patients with unmet needs, and patients who requested behavioural health follow-up who endorsed each behavioural health concern.

heart centre contacted each of the families who endorsed interest in follow-up.

Each concern was coded as endorsed if it was rated as 2 or 3 and coded as not endorsed if rated as 0 or 1. Skipped or missing items were also considered not endorsed. An additional variable of “unmet needs” was coded as present if the respondent endorsed any behavioural health concern and indicated that they are not currently meeting with a mental or behavioural health provider.

Cardiac diagnosis was coded into categories through chart review. Diagnostic categories included CHD, electrophysiological conditions (arrhythmias), postural orthostatic tachycardia syndrome, those with other medical conditions that require monitoring from a cardiologist (e.g., risk of cardiomyopathy from chemotherapy, obstructive sleep apnoea), and new patients without specific cardiac diagnosis (e.g., chest pain, benign palpitations, and syncope).

Data collection occurred between January and October of 2018. Following data entry, the clinical database was de-identified for research purposes. All analyses were approved by the Institutional Review Board at Johns Hopkins University School of Medicine.

Data analytic plan

Descriptive statistics were used to analyse the number of endorsed items in the entire sample, as well as for the sub-sample of patients with unmet needs and those requesting follow-up with a paediatric psychologist. The percentage of patients in each of these groups who endorsed each individual item was also calculated. Analyses of

variance and Pearson correlations were performed to determine associations between demographic and clinical variables with total number of behavioural health concerns endorsed. Pearson correlations and chi-square analyses were performed to determine associations between demographic and clinical variables and endorsement of specific behavioural health concerns.

Results

Participants

A total of 305 surveys were collected from unique patients among 2,282 (13.37%) eligible patients who completed a visit to the heart centre during the study period. Clinical and demographic data for those who did not complete the survey were not available for comparison to those who completed it, and patient-specific reasons for not completing (e.g., patients/families declining, no opportunity in-clinic visit, and inconsistent administration) were likewise not available. A small number of patients (<20) completed the survey more than once. For these patients, only the first administration was included in analyses. Patients in the study sample ranged in age from 2 to 29 years ($M=11.97$ years; $SD=6.00$ years). Half of the patients were female ($n=154$, 50.49%). The majority of the sample was white ($n=164$; 53.8%) followed by Black ($n=95$; 31.1%), Latinx ($n=16$; 5.2%), and patients who do not identify in any of these categories ($n=30$; 9.8%). Of the 305 patients, 113 (37.05%) families lived within Baltimore City limits and 101 (33.11%) had public insurance while

the remainder had private insurance. New patients without a prior cardiac diagnosis accounted for 20.66% of the sample ($n = 63$) and an additional 10.49% ($n = 32$) of the sample were patients without cardiac conditions who were being monitored by a cardiologist. Of the patients with cardiac diagnoses, CHD was the most common ($n = 112$; 36.72%), followed by electrophysiological conditions ($n = 43$; 14.10%), and postural orthostatic tachycardia syndrome ($n = 20$, 6.56%). Patients with CHD who may also have a device for an electrophysiological condition (e.g., pacemaker and implantable cardioverter defibrillator) were classified in the CHD group. Additionally, 35 patients (11.48%) had cardiovascular diagnoses that did not fall into the aforementioned categories (e.g., cardiomyopathy, hypertension, familial hyperlipidaemia, and Kawasaki disease).

Behavioural health

Of all respondents, 166 patients/parents (54.42%) endorsed no behavioural health concerns, 45 (14.75%) endorsed one concern, 32 (10.49%) endorsed two concerns, 19 (6.23%) endorsed three concerns, and 43 (14.10%) endorsed four or more problem areas. The most commonly endorsed concerns were anxiety, sleep problems, depressed/irritable mood, and somatic complaints (see Figure 1). Although approximately 45% of the sample endorsed one or more behavioural health concerns, only 50 (16.39%) respondents reported that they were already connected to mental health services (Figure 1).

Correlates of behavioural health

Associations between specific behavioural health concerns and demographic and clinical characteristics are presented in Table 1. The correlation between the number of behavioural health concerns endorsed and patient age was small but statistically significant, $r(303) = 0.11$, $p = .048$. The number of behavioural health concerns reported did not differ based on patient sex, $t(303) = 0.58$, $p = 0.282$, ethnicity, $F(3, 301) = 0.90$, $p = 0.441$, or cardiac diagnosis, $F(5, 299) = 1.66$, $p = 0.145$. Endorsement of concerns did differ based on insurance type (i.e., private vs. public; $t(303) = 1.88$, $p = .031$), with higher numbers of concerns reported by patients with medical assistance.

When exploring differences in the specific concerns endorsed, patient age significantly and positively correlated with the items capturing medical coping, $r(303) = 0.13$, $p = 0.027$, anxiety, $r(303) = 0.16$, $p = 0.006$, and physical symptoms, $r(303) = 0.22$, $p < .001$. Anxiety, $X^2(1, N = 305) = 5.82$, $p = 0.016$, was also endorsed at higher rates by females than males. Problems with depressed mood, $X^2(1, N = 305) = 6.70$, $p = 0.010$, anxiety, $X^2(1, N = 305) = 10.84$, $p < 0.001$, rule-breaking behaviours, *Of all respondents, 166 patients/parents*² $(1, N = 305) = 7.22$, $p = 0.007$, and social problems, $X^2(1, N = 305) = 4.35$, $p = 0.037$, were all endorsed at higher rates by patients with public insurance. Sleep difficulties, $X^2(3, N = 305) = 8.57$, $p = 0.036$, and medical trauma, $X^2(3, N = 305) = 8.54$, $p = 0.036$, were endorsed at significantly different rates depending on patient ethnicity and post-hoc analyses demonstrated that they were endorsed at higher rates by Latinx patients. Lastly, results indicated that there were significant differences in the number of patients endorsing difficulties with sleep, $X^2(5, N = 305) = 19.71$, $p = 0.001$, and physical symptoms, $X^2(5, N = 305) = 52.40$, $p < 0.001$, across diagnostic groups. Post-hoc analyses indicated that both problems were endorsed at higher rates in patients with postural orthostatic tachycardia syndrome (Table 1).

Connection to mental health services and unmet needs

Of the 305 respondents, 92 (30.16%) endorsed at least one concern and reported that they were not connected to behavioural health services and therefore were categorised as having unmet needs. Within this sub-sample, high rates of behavioural health problems were endorsed: 38 (41.30%) endorsed one problem area, 20 (21.74%) endorsed two problem areas, 13 (14.13%) endorsed three problem areas, and 21 (22.83%) endorsed four or more problem areas. Somatic complaints, anxiety, and sleep problems were the most commonly endorsed concerns within this sub-sample (see Figure 1). When considering the number of patients in each diagnostic subgroup with unmet needs, patients without a cardiac diagnosis presenting for initial visits ($n = 23$; 36.5%) were most likely to have unmet needs, followed by patients with postural orthostatic tachycardia syndrome ($n = 7$; 35.0%), patients with electrophysiological diagnoses ($n = 14$; 32.6%), patients with CHD ($n = 31$; 27.7%), patients whose cardiac condition did not fall under another diagnosis (e.g., cardiomyopathy, hypertension; $n = 9$; 25.7%), and patients with other medical concerns requiring follow-up with cardiology ($n = 8$; 25.0%). Over half (57.50%) of those with unmet needs endorsed multiple problem areas (see Figure 2).

All study participants were invited to indicate if they were interested in follow-up with a paediatric psychologist. A total of 44 patients (14.43%) indicated that they were interested in follow-up. Of these, 21 had been classified as having unmet needs and 23 had been classified as being without unmet needs and nevertheless requested follow-up services. In other words, 22.83% of those with unmet needs and 10.80% of those who did not endorse behavioural health concerns and/or were already meeting with a provider requested follow-up with a paediatric psychologist.

Nearly two-thirds of those 44 patients who requested follow-up endorsed multiple problem areas (Figure 2). Only 25 (56.82%) of those patients ended up speaking with a provider, whereas the other 19 (43.18%) were lost to follow-up (e.g., did not return calls to attempt to schedule). White patients were less likely than those from ethnic minorities to request follow-up ($X^2(3, N = 305) = 18.87$, $p < .001$). When considering the number of patients in each diagnostic subgroup who requested follow-up, patients with postural orthostatic tachycardia syndrome were most likely to request follow-up ($n = 5$; 25.0%), followed by patients with CHD ($n = 18$; 17.5%), patients whose cardiac condition did not fall under another diagnosis (e.g., cardiomyopathy, hypertension; $n = 5$; 14.7%), patients without a cardiac diagnosis presenting for initial visits ($n = 8$; 14.0%), patients with other medical concerns requiring follow-up with cardiology ($n = 4$; 13.3%), and patients with electrophysiological diagnoses ($n = 4$; 10.5%). For patients and families requesting follow-up services, depressed mood/irritability, anxiety, sleep problems, somatic complaints, and impaired school functioning were the most commonly endorsed concerns (see Figures 1 and 2).

Discussion

Our survey results converge with existing literature to indicate that behavioural health concerns are common among youth seen in a paediatric cardiology clinic. Concerningly, though perhaps not surprisingly, most patients who endorsed behavioural health concerns were not connected to appropriate services. Indeed, over a quarter of all patients in our sample had unmet behavioural health needs. Many of these families requested follow-up contact with a behavioural health provider but the majority did not. Many

Table 1. Differences in behavioural health concerns endorsed across patient age, sex, insurance type, ethnicity, and cardiac diagnosis

| | Age | Sex | Insurance type | Ethnicity | Cardiac diagnosis |
|---|----------------|--------------|-----------------|--------------|-------------------|
| | (<i>r</i>) | (<i>t</i>) | | (<i>F</i>) | |
| Total number of behavioural health concerns | 0.11* | 0.58 | 1.88* | 0.90 | 1.66 |
| | (<i>r</i>) | (χ^2) | | | |
| Having trouble with taking medicine? | 0.06 | 1.89 | 0.11 | 1.11 | 5.18 |
| Your heart problem hurting self-esteem, mood, or relationships? | 0.13* | 0.02 | 2.26 | 5.02 | 4.62 |
| Not eating enough? | 0.07 | 0.00 | 1.90 | 0.48 | 7.63 |
| Not getting enough sleep? | 0.09 | 0.28 | 1.03 | 8.57* | 19.71** |
| Being sad or angry? | 0.05 | 0.14 | 6.70* | 0.55 | 6.08 |
| Having too much fear, worry, or anxiety? | 0.16** | 5.82* | 10.84*** | 2.52 | 4.89 |
| Getting in trouble for breaking rules or fighting? | −0.11 | 0.24 | 7.22** | 1.07 | 3.69 |
| Not doing well at school (or work)? | 0.07 | 0.65 | 0.03 | 3.05 | 7.60 |
| Not getting along with other kids/teens your age? | 0.04 | 0.00 | 4.35* | 1.91 | 3.92 |
| Being afraid of doctors or hospitals? | −0.06 | 0.05 | 2.91 | 4.57 | 3.56 |
| Having scary or traumatic memories of a medical event? | −0.06 | 0.26 | 1.89 | 8.54* | 4.41 |
| Having aches, pains, or other physical symptoms? | 0.22*** | 3.56 | 0.25 | 5.77 | 52.40*** |
| Your parents having trouble coping? | −0.02 | 0.08 | 0.18 | 1.55 | 5.17 |

All significant *p*-values are bolded. * *p* < 0.05, ** *p* < 0.01, *** *p* < 0.001.

of these patients endorsed multiple behavioural health concerns, suggesting that the acuity of the need may be significant. It is important to note that the scope of this problem in our data, which reflect the behavioural health needs from prior to the COVID-19 pandemic, may underestimate the current, post-pandemic needs. Studies, as well as clinical experience, have suggested a dramatic increase in behavioural health needs due to the impact of the COVID-19 pandemic on youth mental health in general³² as well as specifically for those with heart disease.³³

The most commonly endorsed behavioural health concerns in our study included anxiety, somatic concerns, sleep issues, and depressed/irritable mood. This is consistent with previous studies using structured clinical interviews to determine psychiatric diagnosis.^{3,16} In our study, these were the most commonly endorsed concerns across demographics, age groups, and cardiac conditions. Though it is still important to assess concerns broadly, it may be beneficial to specifically screen for these issues in a more targeted fashion. For example, the Patient Health Questionnaire-4 is a very brief and widely used screening tool for anxiety and depressive symptoms and may be appropriate for this population.¹⁹ Moreover, in our study, adolescents endorsed concerns at higher rates than other age groups, followed by school-age, young adults, and young children. This is important to consider, as the Patient Health Questionnaire-4 and similar screening tools are validated for adolescents and adults.

With regard to demographic and clinical correlates of behavioural health concerns, we found the number of reported concerns increased with age, and this may be due to the most commonly endorsed concerns in our study (e.g., anxiety symptoms and depressed mood) being more common in adolescents than younger children. Interestingly, patients who are ethnic minorities and those who have postural orthostatic tachycardia syndrome did not specifically endorse more behavioural health concerns but were more likely to request follow-up. The finding concerning ethnicity

may be an artefact from proximity to the hospital; those who lived in Baltimore City were more likely to be from an ethnic minority group as well as more likely to request follow-up. It is reasonable that families who live closer to the hospital would be more inclined to pursue services than those who live further away. With regard to postural orthostatic tachycardia syndrome diagnosis, this may indicate that the specific problems more often reported by patients with postural orthostatic tachycardia syndrome (e.g., depressive or anxiety symptoms, sleeping problems, and somatic complaints) are perceived to be more urgent in this population. It will be important for future research with larger sample sizes to further explore the behavioural health needs of patients with postural orthostatic tachycardia syndrome.

Interestingly, concerns that typically appear more commonly among younger school-age children such as behaviour problems and school issues were not highly endorsed among our sample. This contrasts with existing literature, which consistently finds higher externalising problems and diagnoses of attention-deficit/hyperactivity disorder within CHD populations.^{12,3,4} It is likely that our survey lacks adequate sensitivity to externalising issues. The reliance on patient, rather than parent report, for youth 11 and older could also have contributed to an underreporting of concerns in this age group. Following this reasoning, the rates of behavioural health problems endorsed in our survey, though high enough to be of concern, may still represent an underestimate of the true rate of behavioural health concerns.

Many of those who endorsed high rates of behavioural health problems have CHD or electrophysiological conditions, but also many represent new patient visits with no established cardiac diagnoses. This is consistent with the findings of Gumus and Senturk¹⁶ who found high rates of psychiatric disorders among youth referred to a cardiology clinic for evaluation of somatic complaints with or without a specific diagnosis. In fact, in our sample, those without specific cardiac diagnoses endorsed

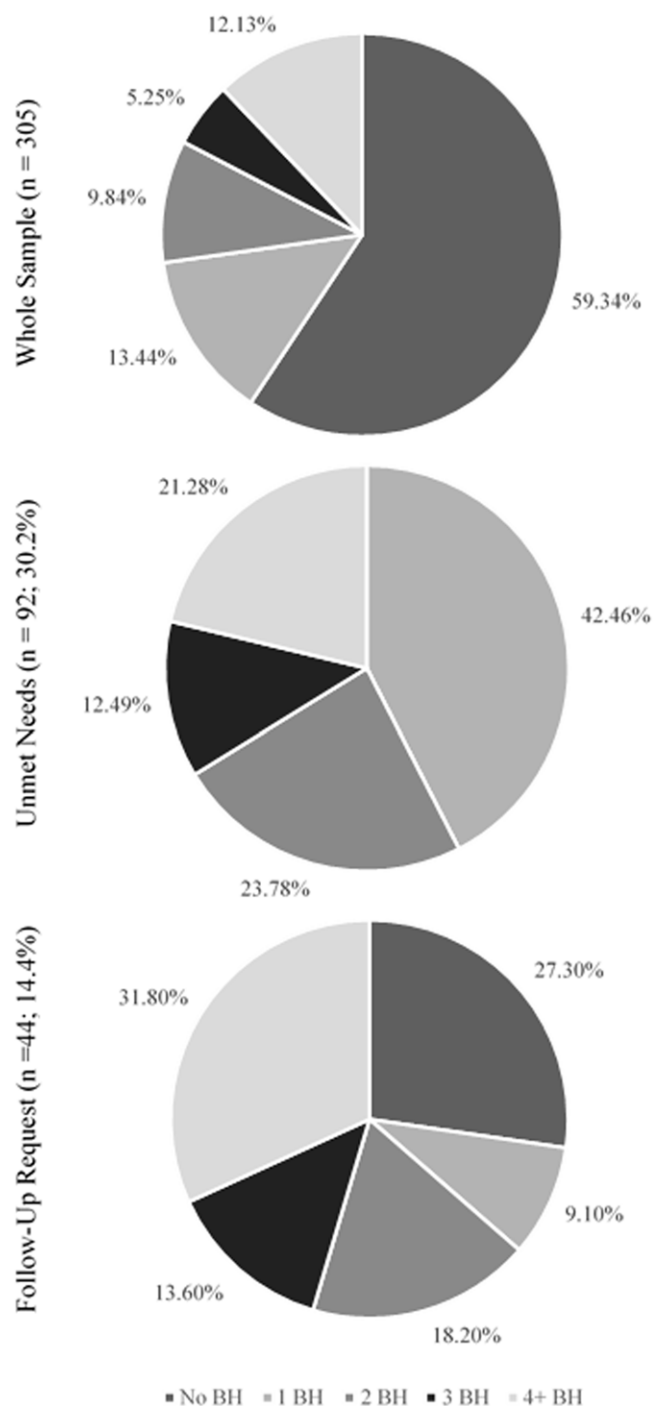


Figure 2. Proportion of all patients, patients with unmet needs, and patients who requested behavioural health follow-up who endorsed 0, 1, 2, 3, or 4+ behavioural health concerns.

behavioural health concerns at higher rates than those with CHD or electrophysiological conditions. This is important to consider, as many paediatric heart centres have embedded paediatric psychology services within specific programmes or specialty clinics such as heart transplant programmes, single ventricle clinics, or electrophysiology clinics.³⁴ Although this is often necessary with limited resources, broader screening may be necessary to ensure that patients with unmet needs are not inadvertently left unidentified.

It is also important to highlight that many patients are still missed, even when screened and offered follow-up. This is similar to the results reported by Strumpe and colleagues¹⁸ who found that only 41.4% of patients who expressed interest in speaking with a behavioural health provider ultimately scheduled and attended an appointment. As noted above, families who do not live in close proximity to the hospital are easily missed, and developing a more robust network of services available in underserved areas is imperative. Some families may be uninterested in pursuing services due to persistent stigma associated with mental health problems. Many of these families may also be experiencing a complex network of other burdens, including medical, economic, and academic difficulties. While it is clearly important to respect patient autonomy and incorporate any individual patient's or family's readiness and availability into decision-making, it is incumbent on the field to increase access to care, which warrants further analysis and quality improvement efforts. Important initiatives exist within the CHD community, notably the American Heart Association scientific statements that stress the urgent need for increased access to mental health and neurodevelopmental services.^{5,35} Kovacs et al.⁵ present a model of reciprocal impact among behavioural health problems, quality of life, and cardiac morbidity in CHD across the lifespan. In addition to screening programmes, models of integrated psychosocial services have been developed to help meet this need.²² However, implementation of these care models often faces institutional barriers. Advocacy efforts for increasing resources will likewise be essential; since the goals of such programmes are to both identify those in need as well as connect them to appropriate services, such services need to be available. It is imperative to continue to build on these efforts and expand to other areas within paediatric cardiology.

The findings reported in this study build on existing literature in a few important ways. The current survey includes a focus on a wider variety of potential behavioural health concerns. Moreover, the broader paediatric cardiology population was included, and the study was not restricted to a specific subpopulation (e.g., CHD). The focus on identifying behavioural health concerns among youth who do not currently have access to care (i.e., unmet needs) fills an important gap that can inform future screening efforts. Despite these strengths, there are several important limitations. Data from this study come from a survey that has not yet been established or validated. As this was intended primarily as a clinical initiative, no data from other instruments to validate this survey are available. In addition, single items were used to identify behavioural health concerns. While this is a limitation of the current survey, previous literature has supported use of single-item measures in behavioural health settings.^{28–31} Future research is needed to further assess the validity of the measure and explore whether single items are sensitive to patients' presenting concerns. The fact that a number of patients did not endorse concerns on our survey but nevertheless requested follow-up suggests the possibility that, despite the attempt at breadth, there may have been additional domains that were not included in our survey. Moreover, we did not include non-English speaking patients or families in our programme. This is a notable limitation, as excluding these families exacerbates already unacceptable healthcare disparities in our field with regard to access to care. Future iterations of this programme will include surveys that have been translated into other languages so as to address this issue. Relatedly, the proportion of patients in our sample who are part of a racial/ethnic minority group was similar to or higher than those reported in similar studies with paediatric cardiology populations, including CHD^{1,2,3,18}, electrophysiological

conditions³⁶, and postural orthostatic tachycardia syndrome.³⁷ This may reflect the sociodemographic differences of the geographic catchment areas across institutions. Still, given that over 50% of our sample was White, our results may be less representative of patients from racial or ethnic minority groups, particularly Latinx patients and those of Asian or Middle Eastern descent.

Additional limitations include inconsistent return of surveys and incomplete information on severity of cardiac conditions. Only a minority of eligible patients completed the survey. As noted above, while data on reasons for not completing the survey are not available, it can be speculated to be a combination of factors that may include inconsistent administration of surveys by staff, not having the opportunity to complete the survey due to busy clinic flow, and/or families declining. Addressing this may require more active engagement from clinicians involved with the programme to explain the rationale for the screening and address questions or concerns. As a further matter, paediatric psychology services are available at our heart centre and can therefore handle the increase in volume that would be expected of a screening programme. This is a limitation because other paediatric cardiology programmes, particularly those outside of academic institutions, may not have this access. The question of appropriateness of screening patients for behavioural health problems without adequate resources to address issues that may be identified is important to consider before implementing such a programme.

Future work to expand on these findings and address limitations noted above will be important. The screening programme is currently under revision to focus on more commonly endorsed concerns and include surveys in additional languages, particularly Spanish. Revision and validation of the survey instrument used in this study will also be planned. Finally, quality improvement initiatives to address access to care will be crucial, including the possibility of embedding additional psychology support in targeted clinic programmes. Issues with dissemination and broader implementation will also need to be addressed by our field to support the behavioural health needs of patients with heart disease, improve quality of life, and erase healthcare disparities.

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Competing interests. None.

Ethical standards. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national guidelines on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008, and have been approved by the Institutional Review Board at Johns Hopkins University School of Medicine.

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