

Depression and anxiety in adult congenital heart disease: Predictors and prevalence

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Received 29 March 2008; received in revised form 20 June 2008; accepted 28 June 2008

Available online 15 August 2008

Abstract

Background: Adult congenital heart disease (ACHD) patients face unique medical and social challenges that may contribute to psychological difficulties. The goals of this study were to identify predictors of symptoms of depression and anxiety and evaluate the prevalence of mood and anxiety disorders among North American ACHD patients.

Methods: In this cross-sectional study, consecutive patients were recruited from two ACHD outpatient clinics. All patients completed self-report psychosocial measures and a subset was randomly selected to participate in structured clinical interviews. Linear regression models were used to predict symptoms of depression and anxiety.

Results: A total of 280 patients (mean age=32 years; 52% female) completed self-report measures. Sixty percent had defects of moderate complexity and 31% had defects of great complexity. Significant predictors of depressive symptoms were loneliness ($p<0.001$), perceived health status ($p<0.001$), and fear of negative evaluation ($p=0.02$). Predictors of anxiety symptoms were loneliness ($p<0.001$) and fear of negative evaluation ($p<0.001$). Disease severity and functional class did not predict mood or anxiety symptoms. Fifty percent of interviewed patients (29/58) met diagnostic criteria for at least one lifetime mood or anxiety disorder, of whom 39% had never received any mental health treatment.

Conclusions: The results confirm an increased risk and under-treatment of mood and anxiety disorders in ACHD patients. Social adjustment and patient-perceived health status were more predictive of depression and anxiety than medical variables. These factors are modifiable and therefore a potential focus of intervention.

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Keywords: Adult congenital heart disease; Depression; Anxiety; Social functioning

1. Introduction

As a reflection of advances in the diagnosis and treatment of congenital heart disease, over 90% of infants born with congenital heart defects now reach adulthood [1]. Today, there are more adults than children and adolescents living with congenital heart disease [2]. Adult congenital heart disease (ACHD) patients face a number of potential medical

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complications in adulthood and have a reduced life expectancy [3]. Along with medical residua that might present in adulthood, ACHD patients have an increased risk of psychosocial difficulties. Potential challenges include heart-focused anxiety, concerns about mortality, treatment decision-making, surgical preparation, adjustment to implanted cardiac devices, difficult pediatric-adult transitions, and adherence concerns [4]. Previous research suggests poorer emotional functioning among North American ACHD patients compared to healthy peers [5–7]. Guidelines for the care of ACHD patients, therefore, advocate for the treatment of psychosocial difficulties including depression, anxiety, and social limitations [8]. However, a comprehensive understanding of the medical and social predictors of psychological difficulties does not exist.

The objective of this study was to evaluate the psychosocial adjustment of ACHD patients recruited from outpatient hospital clinics by examining (a) the prevalence of mood and anxiety disorders among ACHD patients and (b) predictors of symptoms of depression and anxiety.

2. Methods

2.1. Participants

Patients were recruited from hospital outpatient ACHD clinics at the University of Toronto (Toronto, Ontario, Canada) and the University of Florida (Gainesville, Florida, USA). The inclusion criteria were as follows: (1) structural congenital heart disease, as confirmed by echocardiogram or cardiac catheterization or surgery, (2) ability to read and complete the consent form and questionnaires in English, and (3) age of 18 years or older.

2.2. Design and procedure

This cross-sectional study received the approval of the Institutional Review Boards at both institutions. After providing written consent, patients completed study packets that included a demographics and background information survey and psychosocial measures. Prior to each outpatient clinic, one or two participants were randomly selected with an online randomization program to participate in a semi-structured clinical interview. Patients who met diagnostic criteria for a psychiatric disorder were provided with mental health referral information and/or the coordination of subsequent mental health treatment.

Medical records of all participants were reviewed. Consistent with published classification schema, cardiac defects were categorized as simple, of moderate complexity, or of great complexity [8]. The functional status classification system of the Canadian Cardiovascular Society (CCS) was slightly modified in order to evaluate the impact of shortness of breath and chest pain with the following four grades: (1) no limitation of ordinary physical activity, (2) slight limitation of ordinary activity (e.g., chest pain/shortness of breath might

occur with walking or climbing stairs rapidly), (3) marked limitation of ordinary physical activity (e.g., chest pain/shortness of breath occurs walking one or two blocks on the level), and (4) inability to carry on any physical activity without chest pain or shortness of breath.

2.3. Assessment of psychosocial functioning

Participants completed a demographic survey that included the following items: marital, parenting, and employment status; household income; and current and past mental health treatment. Participants completed the following validated psychosocial measures: the Beck Depression Inventory-II (BDI-II), the State-Trait Anxiety Inventory—Trait Version (STAI-T), the Brief Fear of Negative Evaluation (BFNE), the UCLA Loneliness Scale (UCLA-L), and the Short Form Health Survey (SF-36) [9–13]. The SF-36 produces two summary scales: physical component summary (PCS) and mental component summary (MCS).

The BDI-II and STAI were included to assess current symptoms of depression and anxiety. Elevated symptoms of depression or anxiety, however, are not sufficient to diagnose a mood or anxiety disorder. To evaluate diagnostic criteria for psychiatric disorders in the subset of randomly selected patients, the Structured Clinical Interview for DSM-IV Axis I Disorders (SCID) was administered [14]. The SCID is a semi-structured clinical interview that assesses disorders according to the Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition (DSM-IV) [15]. The following SCID modules were administered: Mood Episodes, Psychotic Symptoms Screener, Mood Disorders, Anxiety Disorders, and Adjustment Disorders. Interviews were conducted by a registered psychologist (AK) or one of two doctoral-level clinical psychology students (EK and LO).

2.4. Statistical analyses

All data analyses were performed using SPSS (Version 12.0.1, Chicago, Illinois, 2003). Six scales underwent transformation of scores to address distribution skewness. These transformed scores were used in statistical analyses, although raw scores are presented for ease of interpretation. To reduce the impact of three univariate outliers, scores were changed to be one unit greater than the next case that was not considered to be an outlier. Two cases were eliminated because they were multivariate outliers (as detected by Mahalanobis distance scores).

Group differences (Toronto vs. Gainesville patients) were examined with *t*-tests and chi-square analyses. Linear regression analyses were performed to (1) predict BDI-II depressive symptoms and (2) predict STAI-T anxiety symptoms. In both analyses, a forced entry block model was used to reduce the risk of model over-fitting. Variables were selected for model inclusion based on theoretical rationale drawn from the extant research literature as well as the recommendation that

psychological, macro (e.g., socioeconomic status), biological, and social variables should be considered within the biopsychosocial model [16]. Psychological variables (depressive and anxiety symptoms) were dependent variables and each regression analysis included three blocks (clusters) of variables.

3. Results

3.1. Participant characteristics

Of 335 patients approached for study participation from the two sites, 282 (84%) consented to participate and returned study questionnaires, 26 (8%) declined study participation, and 27 (8%) consented to participate but did not return study questionnaires. Two patients were excluded from analyses because their scores were multivariate outliers. The final sample consisted of 280 ACHD patients (190 from Toronto and 90 from Gainesville) who provided informed consent and completed study questionnaires. Table 1 presents the demographic and medical characteristics of the sample. The socioeconomic status of Gainesville patients was significantly lower than that of Toronto patients, as indicated by lower educational attainment (43% vs 70% with education beyond high school, $p < 0.001$) and an increased likelihood of receiving a disability allowance or other government assistance (19% vs. 10%; $p = 0.03$). With regard to cardiac defect complexity, 10% of the total sample had simple defects, 60% had defects of moderate complexity, and 31% had defects of great complexity. Sixty-five percent of the total sample had no impairment in CCS functional status, 24% had Class II symptoms, 10% had Class III

Table 1
Participant characteristics.

	Total sample (N=280)	Toronto, Canada (n=190)	Gainesville, USA (n=90)	P value
Age (mean±SD)	31.9±11.3	32.3±11.9	31.2±10.2	0.45
Female	52%	49%	59%	0.12
Have child(ren)	32%	31%	34%	0.58
Partnered	43%	44%	40%	0.60
>High school education	61%	70%	43%	<0.001
Employment				
Full or part time work	69%	72%	62%	0.09
Government assistance	13%	10%	19%	0.03
Functional class*				
I	65%	68%	58%	0.08
II–IV	35%	32%	42%	
Defect complexity				
Simple	10%	11%	7%	0.05
Moderate	60%	63%	53%	
Great	31%	26%	40%	

*Canadian Cardiovascular Society.

Table 2
Congenital cardiac diagnoses.

	Frequency
Simple defects (n=27)	
Isolated restrictive ventricular septal defect	11
Repaired atrial septal defect/ventricular septal defect/patent ductus arteriosus	9
Bicuspid aortic valve disease (no significant stenosis or regurgitation)	5
Other simple defects	2
Defects of moderate complexity (n=167)	
Repaired tetralogy of Fallot	53
Coarctation of the aorta	26
Bicuspid aortic valve disease (with stenosis, regurgitation, or valve replacement)	26
Pulmonary valve disease (with stenosis, regurgitation, or valve replacement)	12
Subvalvar or supravalvar aortic stenosis	11
Anomalous pulmonary venous drainage and/or sinus venous atrial septal defect	9
Atrioventricular canal defects	8
Marfan Syndrome	5
Other defects of moderate complexity	17
Defects of great complexity (n=86)	
Repaired transposition of the great arteries (atrial or arterial switch procedure)	30
Univentricular anatomy (Fontan circulation)	29
Pulmonary atresia (all forms)	13
Cyanotic heart disease or Eisenmenger syndrome	5
Congenitally-corrected transposition of the great arteries	4
Other defects of great complexity	5

Classification system guided by the report of the 32nd Bethesda Conference.[8].

symptoms, and less than 1% had Class IV symptoms. Table 2 presents a distribution of the most common cardiac defects classified as simple, of moderate complexity, or of great complexity according to previously-published classification schema [8].

3.2. Symptoms of depression and anxiety

The mean BDI-II depression symptom score was 8.4 + 9.4 (range: 0 to 46). Seventy-eight percent of the sample received scores indicative of minimal symptoms (scores between 0 and 13), 10% received scores suggesting mild symptoms (scores between 14 and 19), and 12% received scores indicative of moderate to severe depressive symptomatology (scores of 20 and above). The mean STAI-T anxiety symptom score was 36.5 + 11.4 (range: 20 to 70). Thirty-four percent (89/260) of the patients received STAI-T scores of 40 or higher, and a cut-off score of 40 has been used to suggest elevated anxiety in cardiac populations [17].

Two forced entry linear regression analyses were performed to predict BDI-II depressive symptoms and STAI-T anxiety symptoms. Excluding patients whose questionnaires contained missing items, 225 patients fully completed all questionnaires relevant to the prediction of BDI-II scores and 226 patients fully completed all questionnaires relevant to the prediction of STAI-T scores. The

final model predicted 44.5% of the variance in BDI-II scores. As presented in Table 3, the following emerged as significant variables within this model: greater loneliness (partial correlation=0.444, $p<0.001$), poorer patient-perceived physical health status (partial correlation=-0.285, $p<0.001$), and greater fear of negative evaluation (partial correlation=0.160, $p=0.02$). Neither cardiac defect complexity nor functional status emerged as significant predictors of BDI-II scores, even prior to the entry of social variables in the regression model.

The final regression model explained 67.4% of the variance in STAI-T scores. As shown in Table 3, two factors, greater loneliness (partial correlation=0.630, $p<0.001$) and greater fear of negative evaluation (partial correlation=0.392, $p<0.001$), emerged as significant variables within this final model. Cardiac defect complexity was not a significant predictor of STAI-T scores, even prior to the inclusion of social variables in the regression model.

3.3. Prevalence of mood and anxiety disorders

Of the 280 participants, 58 participated in SCID interviews. There were no significant differences between interviewed and non-interviewed patients in terms of age, gender, defect severity, or functional impairment. Fifty percent (29/58) of the interviewed sample met diagnostic criteria for a lifetime mood or anxiety disorder; 19 (33%) met criteria for a mood disorder (Major Depressive Disorder, Bipolar Disorder, or Dysthymic Disorder) and 15 (26%) met criteria for an anxiety disorder (Generalized Anxiety Disorder, Panic Disorder, Social Phobia, Specific Phobia, or Obsessive–Compulsive Disorder). All but one of these patients who received diagnoses responded to questions

about mental health treatment. Thirty-nine percent (11/28) of patients who currently or previously met diagnostic criteria for a mood or anxiety disorder denied ever participating in psychotherapy or taking psychotropic medications.

Seventeen patients (29%) met diagnostic criteria at the time of their interviews; 9 (16%) were diagnosed with a mood disorder and 10 (17%) were diagnosed with an anxiety disorder. Sixteen of these 17 patients answered questions regarding current or past mental health treatment. Of these 16 patients who met diagnostic criteria at the time of study participation, 11 (69%) were not currently participating in psychological treatment or taking psychotropic medications.

4. Discussion

There is an increasing focus on the unique psychosocial challenges faced by adults living with congenital heart disease. This study, strengthened with the inclusion of ACHD patients from two countries, highlights the high prevalence of mood and anxiety disorders. Empirical data regarding determinants of depression and anxiety are necessary in order to target psychosocial interventions specifically toward this unique patient population. The results of this study indicate that social adjustment and patient-perceived health status are more predictive of depression and anxiety than medical variables.

4.1. The importance of social functioning

Two measures of social functioning (loneliness and fear of negative evaluation) and perceived physical health status emerged as significant correlates of depressive symptoms. Loneliness and fear of negative evaluation emerged as significant correlates of anxiety symptoms. Adults with congenital heart disease may be at greater risk of social difficulties due to several factors including impaired peer relationships, family overprotection, and delayed progression into independent adulthood. Many ACHD patients describe school absences and physical limitations that restricted participation with siblings and peers and contributed to perceptions of social awkwardness or isolation [6]. Many adult patients recall some degree of parental overprotection during childhood and adolescence [5]. Some adolescents and young adults struggle as they attempt to assume greater independence and control over their health care and other lifestyle matters. Social functioning appears to be particularly salient for the quality of life (QOL) of this patient population, as four of the five strongest determinants of their QOL are family, job/education, friends, and leisure time [18].

Although there is likely circular causality between social maladjustment and psychological distress, it was unexpected that other demographic or medical factors did not emerge as significant variables in the multivariate models predicting symptoms of depression and anxiety. Age and being female have been associated with increased psychological symptoms in patients with congenital and acquired cardiac diseases [19–

Table 3
Determinants of symptoms of depression ($n=225$) and anxiety ($n=226$).

Predictors of depression symptoms			
Significant variables	Standardized coefficient (β)	Partial correlation	p -value
Loneliness	0.448	0.444	<0.001
Perceived health status	-0.269	-0.285	<0.001
Fear of negative evaluation	0.147	0.160	0.02
Predictors of anxiety symptoms			
Significant variables	Standardized coefficient (β)	Partial correlation	p -value
Loneliness	0.577	0.630	<0.001
Fear of negative evaluation	0.304	0.392	<0.001

Note: The following variables were entered into the first block: age, gender, clinic site (Toronto vs. Gainesville), and educational attainment (\leq high school vs. $>$ high school). The following health variables were entered into the second block: cardiac defect complexity (mild, moderate or great), CCS functional status (no functional impairment vs. any degree of functional impairment), and perceived health status (SF-36 PCS). The following measures of social functioning were entered into the third block: loneliness (UCLA-L) and fear of negative evaluation (BFNE).

23], but these variables were not significant individual predictors in the final regression models. Surprisingly, gender did not emerge as a significant predictor of depressive symptoms, even before health and social variables were entered into the models. Similarly, although socioeconomic status (of which educational attainment is considered a strong proxy) is considered a strong determinant of both cardiovascular health and psychosocial adjustment [24], education was not a significant predictor of depressive or anxiety symptoms. These are two examples demonstrating that the psychological experiences of ACHD patients do not mimic those of patients with acquired cardiac disease and studies in the field of acquired heart disease cannot necessarily be extrapolated to the ACHD population.

The observed relationship between social functioning and psychological functioning was not unexpected. It is noteworthy, however, that cardiac defect severity and functional status did not emerge as significant individual predictors of depression and anxiety symptoms. In fact, cardiac defect complexity was not a significant predictor of BDI-II or STAI-T scores even prior to the entry of social variables in the multivariate regression models. This finding supports the results of prior studies that did not observe a significant relationship between cardiac defect classification and psychosocial adjustment and/or QOL [5,25]. The results, however, do contradict those of other studies that have observed a link between cardiac diagnoses and psychosocial outcomes [7,22,23]. Although these other studies have compared subgroups of ACHD patients with respect to psychosocial variables, this study utilized a broader classification schema which might not allow for comparison between individual lesions. The absence of functional status as a significant predictor in the final model was unexpected, as other researchers have observed a link between ACHD patient functional and psychosocial well-being and QOL [21,23,26,27].

4.2. High prevalence of mood and anxiety disorders

Fifty percent of interviewed patients met diagnostic criteria for a current or past mood or anxiety disorder (33% met criteria for a lifetime mood disorder; 26% met criteria for a lifetime anxiety disorder). Approximately one-third met diagnostic criteria at the time of their interviews (16% met criteria for a current mood disorder and 17% met diagnostic criteria for a current anxiety disorder). These results are consistent with those of two American studies of ACHD patients that employed a clinical interview methodology in which the observed point prevalence of psychiatric disorders was 28% (8/29 patients) and 35% (8/22 “well-adjusted” patients) [6,7]. The advantages of the current study include a larger sample size, the utilization of a validated clinical interview to improve diagnostic accuracy [28], and the inclusion of patients from two centres in two different countries. It must also be noted that in contrast to North American studies, published European data suggest that the psychological functioning of ACHD

patients is equal or superior to that of the general population [25,29]. Thus, the unique patient characteristics within a specific geographic region or ACHD clinic catchment area must not be overlooked.

It is helpful to compare the prevalence of psychiatric disorders among ACHD patients with the prevalence observed in general population, although methodological variation prevents a direct comparison. The results of a study of 9282 American adults revealed the following lifetime prevalence of DSM-IV disorders: mood disorder (21%), anxiety disorder (29%), impulse control disorder (25%), substance use disorder (15%), and any disorder (46%) [30]. Within this same sample, the 12-month prevalence of mood disorders was 10% and the 12-month prevalence of anxiety disorders was 18% [31]. The results of a study of 9953 Canadians living in the province of Ontario indicated that the 12-month prevalence of mood disorders was 5% and the 12-month prevalence of anxiety disorders was 12% [32]. Results from the 2003 Joint Canada/United States Survey of Health revealed that the 12-month prevalence of major depression was similar between Canadians (8%) and Americans (9%) [33]. Therefore, it appears that the 12-month prevalence of anxiety disorders is similar among ACHD patients in this study (17%) and the general population (12–18%). The 12-month prevalence of mood disorders, however, appears higher among ACHD patients (16%) than has been reported in the general population (5–10%).

Approximately 40% of the patients with lifetime diagnoses of mood and/or anxiety disorders denied any history of psychotherapy or psychotropic medications. Further, approximately 70% of the patients who met diagnostic criteria at the time of study participation were not engaged in mental health treatment. Therefore, a large proportion of ACHD patients with clinically significant depression and anxiety do not receive appropriate mental health treatment. There are several possible reasons for this. First, patients might be unaware that their symptoms are of clinical significance and that mental health treatment would be recommended. Second, health professionals working with ACHD patients might be unaware that patients are experiencing significant anxiety or depression. This was clearly illustrated by the results of a previous study in which 8 of 22 ACHD patients who were considered “well-adjusted” by their medical team met psychiatric diagnostic criteria [7]. Third, patients might not be interested in mental health treatment or have the necessary resources, including time, financial abilities, and the availability of suitable mental health professionals.

4.3. Study limitations

Potential sample biases regarding the psychosocial assessment of ACHD patients have previously been noted [4]. Patients who did not possess the language or cognitive abilities to complete written study questionnaires were excluded from participation. In addition, the sample was drawn from ACHD patients receiving follow-up care for

congenital heart defects at hospital-based facilities with programs of research. The majority of individuals born with heart defects do not receive specialized ACHD care, and thus study results are not generalizable to the entire population of ACHD patients. It is unknown whether patients not receiving specialized care have superior or poorer psychosocial functioning. Study results are best generalized to patients who receive treatment at tertiary ACHD centers. Further, conclusions based on the prevalence of mood and anxiety disorders are drawn from a subset (58 patients) of the sample.

It is also improper to draw conclusions regarding international differences from a study of ACHD patients from only two clinics. Although there were differences in socioeconomic factors between the two samples, clinic site did not emerge as a significant predictor of either depressive or anxiety symptoms. Further multi-site studies are encouraged.

Finally, patient functional status was quantified by subjective, rather than objective assessment. This study categorized the functional status of ACHD patients using the CCS classification schema, whereas other researchers have utilized objective measures of cardiopulmonary functioning (e.g., maximum oxygen uptake) [26,27]. The objective assessment of functional status is encouraged in future studies.

5. Conclusions

These results, particularly the high incidence and under-treatment of psychiatric disorders, prompt increased attention to the psychosocial needs of this patient population. In addition to potential medical residua that might present in adulthood, ACHD patients have a notable risk of psychosocial difficulties. Although this study focused on depression, anxiety, and social functioning, the broader spectrum of potential psychosocial challenges of ACHD patients must not be ignored. In order to understand the psychological experiences of ACHD patients, greater attention should be given to patient-perceived health status and social functioning, as these variables were more predictive of depression and anxiety than demographic variables or physician-rated health.

Despite increasing awareness of the psychological impact of congenital heart disease, clinical care guidelines are likely under-utilized due to limitations of time, cost, and mental health personnel. The results of this study, however, underscore the inclusion of mental health professionals in ACHD programs. There is also a need for the development and evaluation of psychosocial interventions targeted specifically toward this unique patient population. Although there are currently no published intervention studies focused on psychological distress in adolescents or adults with congenital heart disease, the identification of loneliness and social anxiety as the strongest correlates of symptoms of depression and anxiety should prompt inclusion of social interaction strategies in the content of future psychological interventions.

Acknowledgement

The authors of this manuscript have certified that they comply with the Principles of Ethical Publishing in the International Journal of Cardiology [34].

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