

Original Article

Cite this article: Gleason LP, Deng LX, Khan AM, Drajpuch D, Fuller S, Ludmir J, Mascio CE, Partington SL, Tobin L, Kim YY, Kovacs AH. (2019) Psychological Distress in Adults with Congenital Heart Disease: Focus beyond Depression. *Cardiology in the Young* 29: 185–189. doi: 10.1017/S1047951118002068

Received: 5 July 2018

Revised: 23 October 2018

Accepted: 1 November 2018

Key words:

Adult Congenital Heart Disease; Anxiety; Depression; Quality of Life

Author for correspondence:

Adrienne H. Kovacs, PhD, Division of Cardiology, Department of Medicine, Oregon Health & Science University, 3181 Sam Jackson Park Rd, UHN-62, Portland, OR, 97239, USA. Tel: 503-494-7400; E-mail: kovacs@ohsu.edu

Psychological distress in adults with congenital heart disease: focus beyond depression

Lacey P. Gleason¹, Lisa X. Deng¹, Abigail M. Khan², David Drajpuch¹, Stephanie Fuller³, Jonathan Ludmir⁴, Christopher E. Mascio³, Sara L. Partington^{1,5}, Lynda Tobin⁵, Yuli Y. Kim^{1,5} and Adrienne H. Kovacs²

¹Division of Cardiology, The Children's Hospital of Philadelphia, Philadelphia, PA, USA ²Knight Cardiovascular Institute, Oregon Health & Science University, Portland, OR, USA ³Division of Cardiothoracic Surgery, The Children's Hospital of Philadelphia, Philadelphia, PA, USA ⁴Division of Pulmonary and Critical Care Medicine, Stanford University School of Medicine, Stanford, CA, USA and ⁵Division of Cardiovascular Medicine, Hospital of the University of Pennsylvania, Philadelphia, PA, USA

Abstract

Background: Adults with congenital heart disease face psychological challenges although an understanding of depression vs. anxiety symptoms is unclear. We analyzed the prevalence of elevated symptoms of anxiety and depression and explored associations with demographic and medical factors as well as quality of life. **Methods:** Adults with congenital heart disease enrolled from an outpatient clinic completed the Hospital Anxiety and Depression Scale and two measures of quality of life: the Linear Analogue Scale and the Satisfaction with Life Scale. Medical data were obtained by chart review. **Results:** Of 130 patients (median age = 32 years; 55% female), 55 (42%) had elevated anxiety symptoms and 16 (12%) had elevated depression symptoms on subscales of the Hospital Anxiety and Depression Scale. Most patients with elevated depression symptoms also had elevated anxiety symptoms (15/16; 94%). Of 56 patients with at least one elevated subscale, 37 (66%) were not receiving mental health treatment. Compared to patients with 0 or 1 elevated subscales, patients with elevations in both ($n = 15$) were less likely to be studying or working (47% vs. 81%; $p = 0.016$) and reported lower scores on the Linear Analogue Scale (60 vs. 81, $p < 0.001$) and the Satisfaction with Life Scale (14 vs. 28, $p < 0.001$). **Conclusions:** Among adults with congenital heart disease, elevated anxiety symptoms are common and typically accompany elevated depressive symptoms. The combination is associated with unemployment and lower quality of life. Improved strategies to provide psychosocial care and support appropriate engagement in employment are required.

Introduction

As the population of adults with congenital heart disease (CHD) continues to increase,¹ it is important to address the full impact of living with this lifelong medical condition. Previous studies indicate that up to one-third of these patients experience difficulties with anxiety or depression.^{2–4} Elevated rates of anxiety and mood disorders have in turn been associated with poorer clinical outcomes.^{4,5} Guidelines for the management of adults with CHD recommend screening for depression symptoms during clinical encounters.⁶ This is consistent with an American Heart Association Science Advisory recommending routine screening for depression symptoms in adults with coronary artery disease.⁷ This likely reflects the known link between depression and poorer prognosis among adults with acquired heart disease.⁸ However, as the connections between stress and anxiety with cardiovascular disease are further elucidated,^{9,10} a broader definition of psychological distress among adults with CHD becomes necessary.

Study aims were to: (1) investigate the prevalence of elevated symptoms of depression vs. anxiety in adults with CHD, and (2) explore whether demographic factors, medical variables, and/or quality of life differ between patients with elevated depression vs. anxiety symptoms.

Materials and methods

Study population

Consecutive adults (≥ 18 years old) with CHD who presented for outpatient care were approached to participate. Patients who lacked cognitive or language abilities to provide informed consent and complete surveys in English were excluded. Study participation included completion of questionnaires, including a background information survey, as well as medical record

review. This study was approved by the institutional review board, and verbal and written informed consent were obtained from all participants.

Measures

Participants completed the Hospital Anxiety and Depression Scale, which is comprised of a 7-item anxiety subscale and a 7-item depression subscale.¹¹ Scores ≥ 8 on a subscale indicate clinically elevated symptoms within that domain. The Hospital Anxiety and Depression Scale was developed and psychometrically validated for use in individuals with medical conditions,^{12,13} and has previously been administered to adults with CHD.^{14,15}

We adopted the definition from Moons et al. that quality of life is most appropriately defined as overall life satisfaction, both related and unrelated to health,¹⁶ and the following two surveys which have previously been used in CHD were selected.¹⁷ The Linear Analogue Scale ranges from 0 (worst imaginable quality of life) to 100 (best imaginable quality of life).¹⁷ The Satisfaction with Life Scale is a 5-item measure for which total scores range from 5 to 35, with higher scores reflective of greater life satisfaction.¹⁸

Patients also completed a background demographics survey. Medical data abstraction included CHD complexity,⁶ history of cardiac surgeries or catheter interventions, and medical comorbidities.

Statistical analysis

Descriptive statistics were performed with normally distributed continuous variables summarized as means and standard deviations and skewed continuous variables summarized as medians and interquartile ranges. Counts and percentages are reported for categorical variables. We focused on Hospital Anxiety and Depression Scale cut-off scores ≥ 8 because we wished to explore factors that differentiated patients with vs. without elevated psychological distress. Chi-Square tests were performed to explore the distribution of categorical variables across groups. Mann-Whitney U Tests and Kruskal-Wallis Tests were performed to determine differences in continuous dependent variables. All statistical tests were two-tailed, and p values of < 0.05 were considered statistically significant in this exploratory study. Data were analyzed using SPSS version 22 software (IBM Corp., Armonk, NY, USA).

Results

Patient characteristics

Of 222 patients approached, 138 (62%) consented and were enrolled. Time and scheduling concerns were the most frequently cited reasons for declining study participation. Eight participants were excluded from analysis due to incomplete or uninterpretable surveys, resulting in a final sample size of 130. The most common CHD diagnoses were tetralogy of Fallot (21%), transposition of the great arteries (10%), and bicuspid aortic valve/congenital aortic stenosis (9%). The median number of previous surgical or interventional procedures was 2 and ranged from 0 to 9. Table 1 presents the demographic and medical characteristics of the sample.

Prevalence of elevated psychological distress and mental health treatment

The mean anxiety subscale score was 7.0 ± 3.8 and the mean depression subscale score was 4.0 ± 3.1 . Overall, 56 participants

Table 1. Participant demographic and clinical characteristics (n = 130).

Characteristic	Count (%)
Female	72 (55%)
Race	
White	105 (81%)
Black/African American	17 (13%)
Asian	6 (5%)
Other	2 (2%)
Married/remarried/living with a partner	63 (48%)
Education Level	
High school or less	53 (41%)
College/university degree	42 (32%)
Graduate/professional degree	35 (27%)
Employment	
Full-time paid work	75 (58%)
Part-time paid work	20 (15%)
Receiving disability/government financial assistance	12 (9%)
Unemployed	8 (6%)
Homemaker	7 (5%)
Student	5 (4%)
Retired	2 (2%)
Congenital heart disease complexity	
Simple	18 (14%)
Moderate	76 (58%)
Great	36 (28%)
Comorbidities	
Arrhythmia	57 (44%)
Pacemaker or defibrillator	28 (22%)
Heart failure	25 (19%)
Obesity	21 (16%)
Hypertension	20 (15%)
Lung disease	15 (12%)
Genetic syndrome	12 (9%)
Stroke/transient ischemic attack	12 (9%)
Myocardial infarction	7 (5%)
Diabetes	6 (5%)
Cirrhosis or chronic liver disease	6 (5%)
Median (range) number of surgical or interventional procedures	2 (0-9)

(43%) reported elevated symptoms (scores ≥ 8) on at least one subscale; 15 patients (12%) reported elevations on both subscales, 40 patients (31%) reported elevations on the anxiety subscale

only, and 1 patient reported elevated symptoms on the depression subscale only. Thus, most patients with elevated depression symptoms (15/16; 94%) also had elevated anxiety symptoms.

Fifty-one participants (39%) reported having engaged in psychotherapy and/or pharmacotherapy for a psychological concern. Patients with a self-reported history of mental health treatment were more likely to have elevated anxiety scores (59% vs. 32%; $p = 0.003$) but not more likely to have elevated depression scores (16% vs. 10%; $p = 0.360$). Thirty-four percent (19/56) of participants with elevated anxiety and/or depression symptoms reported mental health treatment at the time of study participation.

Factors associated with elevated psychological distress

Table 2 presents sociodemographic and clinical variables across 3 categories of patients: those with no psychological distress ($n = 74$), those with elevated anxiety scores only ($n = 40$), and those with elevations in both anxiety and depression scores ($n = 15$). The one patient with an elevated depression score without an elevated anxiety score was not included in this set of analyses. There were no significant differences in age, sex, race, education level, or defect complexity between the 3 categories. However, compared to a collapsed group of patients with no elevated symptoms or elevated anxiety subscales alone ($n = 114$), patients with both elevated depression and anxiety symptoms ($n = 15$) were approximately half as likely to be employed or a student (47% vs. 81%, $p = 0.016$).

In the entire sample, the median Linear Analogue Scale quality of life score was 80 (interquartile range: 65-90). Compared to patients with 0 or 1 elevated subscales, patients with elevations in both reported lower scores on the Linear Analogue Scale (60 vs. 81, $p < 0.001$). The median score of the Satisfaction with Life Scale was 27 (interquartile range: 19-30). Compared to patients with 0 or 1 elevated subscales, patients with elevations in both also reported lower scores on the Satisfaction with Life Scale (14 vs. 28, $p < 0.001$). Figure 1 displays scores on the 2 quality of life measures across 3 categories: no psychological distress, elevated anxiety scores only, and elevated anxiety plus depression scores.

Discussion

There are two important findings from this study. First, elevated symptoms of anxiety ($n = 55$) were over three times more common than elevated symptoms of depression ($n = 16$). The majority of participants (73%) with elevated anxiety symptoms did not demonstrate simultaneous elevated depression symptoms. This suggests that routine clinical screening for depression, as advocated by published guidelines,^{6,7} would likely miss a sizable proportion of the psychological distress among adults with CHD. A recent study also observed that approximately 1 in 5 adults with CHD endorsed symptoms consistent with post-traumatic stress disorder.¹⁹ Thus, attempts to identify and manage psychological distress in adults with CHD must extend beyond a singular focus on depression symptoms. Given the unique challenges faced by individuals with CHD throughout their lives, often including multiple surgeries and interventions, it is not unexpected that psychological symptoms are common. Thus, adult CHD programs and providers are urged to develop strategies to identify clinically-significant psychological distress and facilitate mental health treatment with professionals experienced in providing care to individuals with chronic health conditions.

Second, 15 of 16 patients with elevated depression symptoms also had elevated anxiety symptoms and it was this combination that was most strongly associated with poorer outcomes (less likely to be employed/studying and lower quality of life). Although we anticipated being able to compare participants with elevated depression symptoms vs. those with elevated anxiety symptoms, this was not possible because there was only one patient with an elevation on the depression subscale without an elevation on the anxiety subscale. However, given that elevated depression symptoms most often co-occurred with elevated anxiety symptoms, and that the combination had strong quality of life implications, this may be considered a higher-needs group to which to target psychological intervention. When conducting future research and also when providing mental health treatment, it is important to be mindful of the relationship between psychological and social functioning (e.g., family, friendships, and romantic relationships). For example, a prior study identified

Table 2. Sociodemographic and clinical variables by symptom categories ($n = 129$).

Patient Characteristic	No Elevated Symptoms ($n = 74$)	Elevated Anxiety ($n = 40$)	Elevated Anxiety + Depression ($n = 15$)	p-value
Sociodemographic Variables				
Female	35 (47%)	23 (58%)	9 (60%)	0.867
White	57 (77%)	36 (90%)	11 (73%)	0.193
College Education	46 (62%)	25 (63%)	6 (40%)	0.134
Employed/Student	60 (81%)	32 (80%)	7 (47%)	0.043
Medical History				
Complex congenital heart disease	16 (22%)	14 (35%)	6 (40%)	0.731
Mental health history				
Documented anxiety or depression	5 (7%)	15 (38%)	4 (27%)	< 0.001
Self-report history of psychotherapy	19 (26%)	23 (58%)	7 (47%)	0.472
Self-report history of pharmacotherapy	11 (15%)	20 (50%)	7 (47%)	0.826

* $p < 0.05$

Note: We excluded one patient with an elevated HADS-D score without an elevated HADS-A score

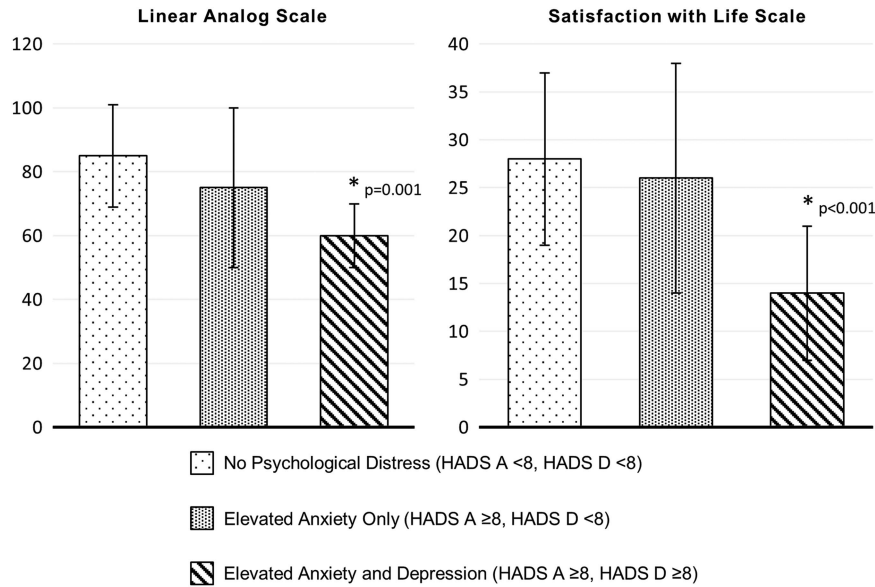


Figure 1. Scores on two quality of life measures according to psychological symptom profiles. Patients with elevated symptoms of anxiety and depression have significantly lower scores on quality of life metrics compared to those with no psychological distress or elevated anxiety alone.

social adjustment (loneliness and social anxiety) as the strongest correlates of depression and anxiety symptoms.²

There is emerging evidence supporting the importance of employment for quality of life of adults with CHD.²⁰ It is reasonable to hypothesize a bidirectional relationship between employment status and psychological distress. Some patients will be unable to work due to physical limitations, possibly contributing to psychological distress. Some patients with significant psychological distress may have difficulty facing the challenges of obtaining and retaining employment. It is thus reasonable to speculate that better outcomes may be associated with combined interventions that target psychological distress and employment readiness in adults with CHD who are medically able to work. We strongly encourage future research to better understand and address employment challenges faced by adults with CHD, including those who are job-seeking as well as those who have jobs and might be struggling to maintain them.

Participation was limited to patients who had health insurance, attended scheduled appointments at a tertiary center, and consented to participate. Thus, findings may not be generalizable to all adults with CHD, particularly those without access to specialized care. We also do not know whether patients who opted not to participate (most often reportedly due to time and scheduling concerns) differed from those who chose to participate; it is unknown whether they would have equivalent, worse, or better psychological well-being. Another limitation is the use of self-report instruments (rather than clinical interviews) to assess anxiety and depression. We do not know the percentage of patients with elevated symptoms who would meet diagnostic criteria for a mood or anxiety disorder and be directed toward mental health treatment. However, our observation that 43% of study participants had elevations on at least one subscale is only slightly higher than North American clinical interview studies in which 29–36% met diagnostic criteria.^{2,3} Finally, given the significant overlap between elevated depression and anxiety symptoms in our sample, as stated we were unable to explore differences between patients with elevated depression vs. anxiety symptoms.

Conclusions

The responsibility to adults with CHD extends beyond medical treatment and outcomes. Over 40% of adults with CHD in our study reported elevated symptoms of anxiety and/or depression. Routine screening limited to depression would overlook a large proportion of patients with other forms of psychological distress, including anxiety and post-traumatic stress disorder. Further strategies to identify clinically-significant anxiety and depression in the clinical setting, facilitate mental health treatment, and support appropriate engagement in employment are needed to enhance the lives of adults with CHD.

Acknowledgements. The authors wish to acknowledge Katherine Awh for editing assistance.

Financial Support. This study was supported with a grant from Big Hearts to Little Hearts and the Bronchick Family Foundation.

Conflicts of Interest. None.

Ethical Standards. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant American guidelines on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008, and has been approved by the Hospital of the University of Pennsylvania Institutional Review Board.

References

- Mareljuli AJ, Ionescu-Ittu R, Mackie AS, Guo L, Dendukuri N, Kaouache M. Lifetime prevalence of congenital heart disease in the general population from 2000 to 2010. *Circulation* 2014; 130 (9): 749–756.
- Kovacs AH, Saidi AS, Kuhl EA, et al. Depression and anxiety in adult congenital heart disease: predictors and prevalence. *Int J Cardiol* 2009; 137 (2): 158–164.
- Bromberg JI, Beasley PJ, D'Angelo EJ, Landzberg M, DeMaso DR. Depression and anxiety in adults with congenital heart disease: a pilot study. *Heart Lung* 2003; 32 (2): 105–110.
- Kourkovi P, Rammos S, Parissis J, Maillis A, Kremastinos D, Paraskevaids I. Depressive Symptoms in Patients with Congenital Heart

- Disease: Incidence and Prognostic Value of Self-Rating Depression Scales. *Congenit Heart Dis* 2015; 10 (3): 240–247.
5. Kim YY, Gauvreau K, Bacha EA, Landzberg MJ, Benavidez OJ. Resource use among adult congenital heart surgery admissions in pediatric hospitals: risk factors for high resource utilization and association with inpatient death. *Circ Cardiovasc Qual Outcomes* 2011; 4 (6): 634–639.
 6. Warnes CA, Williams RG, Bashore TM, et al. ACC/AHA 2008 guidelines for the management of adults with congenital heart disease: a report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines (Writing Committee to Develop Guidelines on the Management of Adults With Congenital Heart Disease). Developed in Collaboration With the American Society of Echocardiography, Heart Rhythm Society, International Society for Adult Congenital Heart Disease, Society for Cardiovascular Angiography and Interventions, and Society of Thoracic Surgeons. *J Am Coll Cardiol* 2008; 52 (23): e143–263.
 7. Lichtman JH, Bigger JT Jr., Blumenthal JA, et al. Depression and coronary heart disease: recommendations for screening, referral, and treatment: a science advisory from the American Heart Association Prevention Committee of the Council on Cardiovascular Nursing, Council on Clinical Cardiology, Council on Epidemiology and Prevention, and Interdisciplinary Council on Quality of Care and Outcomes Research: endorsed by the American Psychiatric Association. *Circulation* 2008; 118 (17): 1768–1775.
 8. Lichtman JH, Froelicher ES, Blumenthal JA, et al. Depression as a risk factor for poor prognosis among patients with acute coronary syndrome: systematic review and recommendations: a scientific statement from the American Heart Association. *Circulation* 2014; 129 (12): 1350–1369.
 9. Steptoe A, Kivimaki M. Stress and cardiovascular disease. *Nat Rev Cardiol* 2012; 9 (6): 360–370.
 10. Tully PJ, Cosh SM, Baune BT. A review of the affects of worry and generalized anxiety disorder upon cardiovascular health and coronary heart disease. *Psychol Health Med* 2013; 18 (6): 627–644.
 11. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983; 67 (6): 361–370.
 12. Bjelland I, Dahl AA, Haug TT, Neckelmann D. The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *J Psychosom Res* 2002; 52 (2): 69–77.
 13. Bambauer KZ, Locke SE, Aupont O, Mullan MG, McLaughlin TJ. Using the Hospital Anxiety and Depression Scale to screen for depression in cardiac patients. *Gen Hosp Psychiatry* 2005; 27 (4): 275–284.
 14. Enomoto J, Nakazawa M. Negative effect of aging on psychosocial functioning of adults with congenital heart disease. *Circ J* 2015; 79 (1): 185–192.
 15. Westhoff-Bleck M, et al. Mental disorders in adults with congenital heart disease: Unmet needs and impact on quality of life. *Journal of Affective Disorders* 2016; 204: 180–186.
 16. Moons P, Marquet K, Budts W, De Geest S. Validity, reliability and responsiveness of the “Schedule for the Evaluation of Individual Quality of Life-Direct Weighting” (SEIQoL-DW) in congenital heart disease. *Health Qual Life Outcomes* 2004; 2: 27.
 17. Apers S, Kovacs AH, Luyckx K, et al. Assessment of Patterns of Patient-Reported Outcomes in Adults with Congenital Heart disease - International Study (APPROACH-IS): rationale, design, and methods. *Int J Cardiol* 2015; 179: 334–342.
 18. Diener E, Emmons RA, Larsen RJ, Griffin S. The Satisfaction With Life Scale. *J Pers Assess* 1985; 49 (1): 71–75.
 19. Deng LX, Khan AM, Drajpuch D, et al. Prevalence and Correlates of Post-traumatic Stress Disorder in Adults With Congenital Heart Disease. *Am J Cardiol* 2016; 117 (5): 853–857.
 20. Apers S, Kovacs AH, Luyckx K, et al. Quality of Life of Adults With Congenital Heart Disease in 15 Countries: Evaluating Country-Specific Characteristics. *J Am Coll Cardiol* 2016; 67 (19): 2237–2245.