

# Correlates of posttraumatic stress disorder in adults with congenital heart disease

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## Abstract

**Objective:** The aims of this study were to compare the level of posttraumatic stress disorder between adults with and without congenital heart disease, and to examine the correlates of posttraumatic stress disorder (e.g., sociodemographics).

**Design:** Cross-sectional.

**Setting:** Two university-affiliated heart hospitals in Tehran, Iran.

**Patients:** A sample of 347 adults with congenital heart disease aged 18–64 years (52% women), and 353 adults without congenital heart disease matched by sex and age ( $\pm 2$  years) was recruited.

**Outcome Measures:** The PTSD Scale: Self-report version was used to assess the diagnosis and severity of posttraumatic stress disorder. Hierarchical multivariate logistic regression analyses were performed to explore correlates of likely posttraumatic stress disorder diagnosis among each group of participants.

**Results:** The posttraumatic stress disorder in the patients was comparable to those of the control group, except for increased arousal ( $P = .027$ ) which was scored higher among the patients. Over 52% of adults with congenital heart disease met the criteria for a likely posttraumatic stress disorder diagnosis compared with 48% of adults without congenital heart disease. The regression analyses among patients revealed that elevated depressive symptoms ( $OR = 1.27$ ) and a positive history of cardiac surgery ( $OR = 2.02$ ) were significantly associated with posttraumatic stress disorder. The model could explain 29% of the variance in posttraumatic stress disorder.

**Conclusions:** The high and comparable prevalence of posttraumatic stress disorder among patients and nonpatients highlight the significance of the context in which adults with congenital heart disease may face other/additional stressors than disease-related ones, an issue that clinicians need also take into account. Furthermore, the association of posttraumatic stress disorder with elevated depressive symptoms warrant a comprehensive psychological assessment and management of adults with congenital heart disease, in particular among those with a history of invasive procedures.

## KEYWORDS

cardiac surgery, depression, developing country, grown up with CHD, mental health

## 1 | INTRODUCTION

Adults with congenital heart disease (CHD) are a growing group of patients with an estimated prevalence of 4–6.12 per 1000.<sup>1,2</sup> Today, adults with CHD outnumber the children with the disease, owing this

to the dramatic advances in medical care over the past decades.<sup>1,3</sup> Congenital heart disease is a lifelong comorbidity since a treated heart is not a “cured” one. Thus, adults with CHD may need repeated hospitalizations, and to undergo invasive interventions (e.g., surgery) and regular medical investigations even after the completion of active

treatments. Moreover, they may need to adhere to medication regimens for lifetime.<sup>4,5</sup>

Anxiety, depression, and negative thoughts about future are among reported emotional distresses in adults with CHD,<sup>6-9</sup> but very little is known about posttraumatic stress disorder (PTSD) in this group of patients. PTSD is a stress-response condition in which a suffering person often reexperience the trauma, avoid reminders, and present some symptoms that are related to high autonomic arousal.<sup>10</sup> Life-threatening disease can entail PTSD and being treated for life-threatening illness has been suggested as repeated trauma.<sup>10,11</sup> Aside from the societal costs of PTSD in terms of vocational and familial dysfunction, the negative health consequences of PTSD are increased risk of suicidality<sup>12</sup>; mood, anxiety and substance disorders<sup>13</sup>; risky health behavior<sup>14,15</sup>; and cardio-vascular events.<sup>16,17</sup> Medically induced PTSD, with prevalence estimates of 12%-25%, has a unique characteristic insofar as the stressful event/threat is within the body and ongoing.<sup>18</sup> Additionally, it has been shown to be associated with limitations in physical functioning, poor quality of life, and increased mortality.<sup>18-20</sup> Ginzburg and Ein-Dor reported that PTSD symptoms developed due to acute coronary events could screen positive after several years.<sup>20</sup> Accordingly, the objectives of the present study were to compare the level of PTSD between adults with and without CHD and to examine the correlates of PTSD (e.g., depressive symptoms) among each group of participants.

## 2 | METHODS

### 2.1 | Design and sample

In this cross-sectional study, 853 consecutive patients hospitalized due to CHD-related issues (e.g., cardiac surgery) between April 2002 and March 2010 in two heart hospitals in Tehran were selected. Patients aged between 18 and 64 years at the time of data collection, not suffering from Marfan's syndrome or cognitive impairments, resident in the Tehran Province, and fluent in Persian were eligible to participate. It was possible to locate and approach 373 adults with CHD. After the first phone contact with patients, those willing to participate were given the survey package (i.e., questionnaire and the informed consent form) to complete at their homes. Based on a mutual agreed appointment, study personnel returned between 4 and 7 days later to collect completed surveys at patients' homes. Of 373 adults with CHD, 11 declined to participate and 15 did not return the questionnaire which resulted in a participation rate of 93%.

A group of adults without CHD, matched by sex and age ( $\pm 2$  years), were recruited through a systematic randomization procedure from the same residency area as the CHD patients to serve as a comparison group if they had intact cognitive function and were fluent in Persian. The process of data collection was the same as the patient group except for the first contact which was made at their homes.

The study was approved by the institutional research ethics committee. Further details of this process have been published elsewhere.<sup>7</sup>

### 2.2 | Measures

*Posttraumatic stress disorder* (PTSD) was measured with The PTSD Symptom Scale: Self-Report Version (PSS-SR), comprising 17 questions with total scores ranging from 0 to 51.<sup>21,22</sup> The PSS-SR scores are categorized into three groups of items: re-experiencing (5 items), avoidance (7 items), and increased arousal (5 items). High scores correspond to high severity of posttraumatic symptoms. For a diagnosis of PTSD, a score of 1 or higher in 1 of re-experiencing items, 3 in avoidance, and 2 in arousal are required. Cronbach's  $\alpha$  for the total sample, CHD and non-CHD, was 0.92 in this study. Previous research<sup>21,23</sup> have shown that the PSS-SR has high sensitivity and specificity to screen PTSD.

Symptoms of *depression* were assessed with The Hospital Anxiety and Depression Scale (HADS-D), containing 7 items with total scores ranging from 0 to 21. Higher scores indicate worse depressive symptoms.<sup>24,25</sup> Cronbach's  $\alpha$  for the HADS-D was 0.80 for adults with CHD and 0.78 for non-CHD participants.

*Social support* was assessed with the Multidimensional Scale of Perceived Social Support (MSPSS), which is a 12 items tool with high scores indicating high perceived social support.<sup>26</sup> Cronbach's  $\alpha$  for the MSPSS was 0.88 for the CHD group and 0.89 for the non-CHD group.

*Sociodemographic* variables were age, sex, marital status (married, never married, widowed/divorced), experiencing parenthood (yes/no), educational level (low = informal/primary/similar, middle = high school/similar, high = university/similar), employed (yes/no), and perceived financial strain (yes/no).

*Lifestyle* variables encompassed physical activity (e.g., at least 30 minutes walking 3 times a week), body mass index based on self-reported height and weight, daily cigarette smoking (yes/no), and alcohol consumption (yes/no).

*CHD parameters* were disease severity inspired by Marelli et al.<sup>27</sup> (see Table 1), age at the CHD diagnosis (before or after turning 18 years), and history of cardiac surgery (yes/no) and interventions (yes/no). Further details have been published elsewhere.<sup>7,28</sup>

### 2.3 | Statistical analyses

The continuous variables are described as means and standard deviation (SD), while the categorical variables as frequencies and percentages. The adults with CHD were compared with the non-CHD participants in terms of PTSD, sociodemographics, lifestyle, depressive symptoms, and social support by means of chi-square tests for the categorical variables and the independent samples *t* test for the continuous variables. Bivariate and hierarchical multivariate logistic regression analyses for each group of participants were performed. The dependent variable was the diagnosis of PTSD (1 = yes, 0 = no). The independent variables were sociodemographics, lifestyle, depressive symptoms, and social support for both groups. Moreover, CHD parameters were included into the models as independent variables for the CHD group. Simple bootstrapping with a sample number of 1000 was used. The data are expressed in the form of Odds Ratios (ORs), 95% Confidence Intervals, and *P* values. The *P* values were corrected by the

TABLE 1 Categorization of CHD among 346 adults with CHD

Hierarchical groups	Categories	n	%
Group 1	Atrio-ventricular canal defect	83	24.0
	Tetralogy of Fallot		
	Univentricular heart		
	Transposition of the great vessels		
	Truncus arteriosus		
Group 2	Hypoplastic left heart syndrome	185	53.5
	Atrial septal defect		
	Ventricular septal defect		
	Patent ductus arteriosus		
	Aortic coarctation		
Group 3	Ebstein's anomaly	78	22.5
	Anomalies of the pulmonary artery		
	Anomalies of the pulmonary valve		
	Congenital tricuspid valve disease		
	Congenital aortic stenosis		
	Congenital aortic insufficiency		
Congenital mitral stenosis			
	Congenital mitral insufficiency		

CHD, congenital heart disease; n, number.

false discovery rate, if needed. The significance level for all analyses was set at a  $P < .05$ .

### 3 | RESULTS

The final sample consisted of 353 non-CHD and 347 CHD participants at a mean age of  $33 \pm 12$  year (52% women) in both groups. One patient was not included in the analyses due to missing data on PSS-SR scale.

#### 3.1 | Adults with CHD versus non-CHD adults

As is shown in Table 2, the adults with CHD were more often unemployed ( $\chi^2(1) = 9.28, P = .012$ ) and had lower educational level ( $\chi^2(2) = 40.56, P < .001$ ) and body mass index ( $t(697) = 3.89, P = .009$ ) than the non-CHD adults.

As is depicted in Table 3, 52% of the adults with CHD and 48% of the non-CHD adults met criteria for a likely PTSD diagnosis. There were no significant differences between the two groups as regards depressive symptoms, perceived social support, and diagnosis and severity of PTSD except for increased arousal ( $t(697) = -2.62, P = .027$ ), which was scored higher among the adults with CHD.

#### 3.2 | Factors associated with PTSD among adults with CHD

The multivariate logistic regression analyses (see Table 4) revealed that the likelihood of PTSD diagnosis was higher among the CHD survivors who suffered from depressive symptoms (OR = 1.27,  $P = .001$ ) and

had a positive history of cardiac surgery (OR = 2.02,  $P = .031$ ). The final model explained 29% of the variance in PTSD. Although being unemployed and perceiving financial strain were associated with higher odds and perceived social support with lower odds of PTSD diagnosis in the crude logistic regression, these factors were not independently associated with PTSD after introducing other variables into the model.

#### 3.3 | Factors associated with PTSD among non-CHD adults

As is demonstrated in Table 4, a low level of education was associated with lower odds of PTSD by approximately 60%, while alcohol consumption (OR = 2.72,  $P = .25$ ) and depressive symptoms (OR = 1.21,  $P = .001$ ) were associated with higher odds of PTSD diagnosis among the non-CHD adults. The final model accounted for 23% of the variance of PTSD.

## 4 | DISCUSSION

This is the first study to examine PTSD among adults with CHD in comparison with non-CHD participants. The results showed that over 50% of adults with CHD met the criteria for a likely PTSD diagnosis and that the adults with CHD scored higher in increased arousal than the adults without CHD, although the severity of PTSD was not

TABLE 2 Independent samples *t* test and chi-square tests comparing adults with ( $n = 346$ ) and without ( $n = 353$ ) CHD on socio-demographic and lifestyle variables

Variables	CHD adults		Non-CHD adults		$p^*$
	n/mean	%/SD	n/mean	%/SD	
Women	181	52.3	182	51.6	.842
Age (mean, SD)	33.25	12.13	33.49	12.18	.842
Marital status					.286
Married	184	53.2	214	60.6	
Never married	148	42.8	125	35.4	
Widowed/divorced	14	4.0	14	4.0	
No children	197	56.9	172	48.7	.108
Educational level <sup>a</sup>					<.001
Low	109	31.5	63	17.8	
Middle	153	44.2	126	35.7	
High	84	24.3	164	46.5	
Unemployed	215	62.1	179	50.7	.012
Financial strain	276	79.8	291	82.4	.518
BMI (mean, SD)	23.98	4.62	25.27	4.11	.009
Smoking	43	12.4	52	14.7	.518
Alcohol use	37	10.7	35	9.9	.816
Physical activity	132	38.2	159	45.0	.183

<sup>a</sup>Low = informal/primary/similar, middle = high school/similar, high = university/similar.

BMI, body mass index; CHD, congenital heart disease; n, number; SD, standard deviation.

\*Corrected  $P$  value (=  $q$ -value obtained by false discovery rate).

**TABLE 3** Independent samples *t* test and chi-square tests comparing adults with (*n* = 346) and without (*n* = 353) CHD on PTSD, depressive symptoms and social support

Variables	CHD adults		Non-CHD adults		P*
	Mean (SD)	<i>n</i> (%)	Mean (SD)	<i>n</i> (%)	
PTSD (total)	14.21 (11.07)		12.76 (10.39)		.183
Reexperiencing	4.10 (3.78)		3.84 (3.60)		.518
Avoidance	5.70 (4.96)		5.22 (4.58)		.398
Increased arousal	4.42 (3.84)		3.70 (3.45)		.027
PTSD case					.518
Yes		181 (52.3)		171 (48.4)	
No		165 (47.7)		182 (51.6)	
Depressive symptoms	6.51 (4.30)		6.36 (3.98)		.807
Perceived social support	58.27 (15.04)		57.80 (14.80)		.816

CHD, congenital heart disease; *n*, number; PTSD, posttraumatic stress disorder; SD, standard deviation.

\*Corrected *P* value (= *q*-value obtained by false discovery rate).

considerable. PTSD diagnosis was significantly associated with a positive history of cardiac surgery and elevated depressive symptoms among our patients. These findings highlight the fact that health care providers need to take into account that adults with CHD might suffer PTSD; consequently, screening, diagnosis, and effective treatment should be included in their care schedule— in particular for patients undergoing more invasive treatments. Furthermore, these findings emphasize the importance of other factors than objective CHD contributing to well-being of this group of patients.

The prevalence of PTSD in this sample was higher than that in CHD adults in a study from North America, which reported a prevalence rate of likely PTSD of between 11% and 21%,<sup>29</sup> and higher than in another group with medically induced PTSD.<sup>18</sup> Although, the American study<sup>29</sup> had a smaller sample with no control group, it used self-report measures similar to current study. This considerable difference in prevalence could be ascribed to the contextual parameters and maybe supportive of the suggestion that PTSD is a “culture-bound” syndrome.<sup>30,31</sup> Previous studies have shown that the level of trauma exposure differs across nations and the prevalence and presentation of PTSD are influenced by societal and cultural values.<sup>32,33</sup> Cultural and social factors could influence the susceptibility to the disorder.<sup>33</sup>

These results also revealed that the adults with CHD did not differ from the non-CHD adults in terms of the total PTSD score, re-experiencing and avoidance subscales, and PTSD diagnosis— indicating that 48% of the non-CHD adults met the criteria suggestive of PTSD. Generally, the exposure to trauma is prevalent even in general population,<sup>13</sup> and it has been shown that daily living hardship could result in PTSD.<sup>34</sup> Iran–Iraq war (about 30 years ago), high rate of natural crisis, social violence and political unrest could somehow explain the high prevalence of likely PTSD diagnosis among the patients and non-patients in this sample. Some other studies from Middle-East show similar results. In a community sample in Cairo, Abdelmonem et al.<sup>35</sup> have observed that 60% of the participants met the criteria for likely diagnosis of PTSD at aftermath of 2011 Uprisings. These researchers have also used the PSS-SR to assess the PTSD. Moreover, Gardozo et al.<sup>36</sup> have reported that 42% of Afghan general population have the

symptoms of PTSD due to hardships caused by political conflicts. Current findings call for research and appropriate interventions regarding the existing stressors and traumas in that context. Appropriate social and political efforts could diminish the level of stressful events and relieve the distress in the aftermath of the traumas.<sup>33</sup> Furthermore, interventions to increase social cohesion and to augment resilience could be helpful. For healing in country level, “to construct a viable social structure” has been suggested.<sup>13</sup> It is worthy of note that clinicians take into account that adults with CHD may experience other/ additional stressors than disease-related ones. Moreover, these findings seem to suggest that the differences between countries in terms of politics and culture may play a role in psychosocial outcomes of the citizens, which warrant caution in generalizing the findings.

Current results showed that a positive history of cardiac surgery was associated with double odds of PTSD among the adults with CHD, which chimes in with some studies<sup>37,38</sup> reporting the increased risk of PTSD among children undergoing cardiac surgery and is at odds with an American study,<sup>29</sup> which did not find such association.

Similar to previous research,<sup>29,39</sup> elevated depressive symptoms were associated with higher odds of PTSD diagnosis among the adults with and without CHD. It has been suggested that a prior history of mental disorders (e.g., depression) may increase the probability of exposure to trauma as well as increase vulnerability to PTSD in the aftermath of trauma.<sup>13,39</sup> Herein, this finding emphasizes the importance of prevention, diagnosis and adequate treatment of depression as well as PTSD among adults with CHD as the negative health consequences of both are well documented.<sup>12,13,16,17</sup>

Furthermore, alcohol consumption was associated with higher odds of PTSD among the non-CHD adults (OR = 2.72). Given the cross-sectional design of this study, the temporality of alcohol consumption and PTSD could not be determined, but it has been shown that PTSD is associated with risky health behaviors.<sup>14,15</sup> On the other hand, alcohol problems may affect vulnerability to psychiatric disorders.<sup>40,41</sup> The author has no explanation why this association did not exist among the adults with CHD as there was no difference between groups regarding alcohol consumption. Moreover, the amount of

TABLE 4 Factors associated with posttraumatic stress disorder among adults with ( $n = 346$ ) and without ( $n = 353$ ) CHD

Variables	CHD adults		Non-CHD adults	
	Crude OR (95% CI)	Adjusted OR (95%CI)	Crude OR (95%CI)	Adjusted OR (95% CI)
<b>Sociodemographics</b>				
Sex <sup>a</sup>				
Men	.78 (.51–1.19)	.67 (.36–1.26)	.84 (.55–1.28)	.64 (.36–1.15)
Age	1.00 (.99–1.2)	1.00 (.96–1.03)	1.00 (.98–1.01)	1.00 (.98–1.03)
Marital status <sup>b</sup>				
Married	.42 (.13–1.38)	.34 (.08–1.44)	.45 (.15–1.39)	.64 (.19–2.14)
Never married	.43 (.13–1.44)	.29 (.06–1.50)	.62 (.20–1.96)	1.19 (.30–4.70)
Parenting <sup>c</sup>	1.05 (.68–1.60)	1.34 (.56–3.18)	1.08 (.71–1.64)	.57 (.24–1.36)
Educational level <sup>d</sup>				
Low	1.20 (.68–2.13)	.83 (.39–1.76)	.92 (.58–1.46)	.43 (.20–.92)*
Middle	.87 (.51–1.49)	.69 (.36–1.31)	.73 (.41–1.31)	.87 (.51–1.49)
Unemployed <sup>c</sup>	1.60 (1.03–2.48)*	1.41 (.77–2.58)	.88 (.58–1.34)	.79 (.45–1.38)
Financial strain <sup>c</sup>	2.00 (1.35–2.95)**	1.41 (.73–2.70)	2.26 (1.27–4.04)**	1.83 (.94–3.55)
<b>R<sup>2</sup></b>		<b>.069</b>		<b>.068</b>
<b>Lifestyle</b>				
BMI	.99 (.95–1.04)	.94 (.89–1.00)	.98 (.93–1.03)	.97 (.91–1.04)
Cigarette smoking <sup>c</sup>	1.31 (.69–2.50)	1.54 (.64–3.70)	1.29 (.71–2.33)	.72 (.34–1.54)
Alcohol use <sup>c</sup>	1.39 (.70–2.78)	1.35 (.54–3.38)	1.92 (.93–3.94)	2.72 (1.10–6.70)*
Physical activity <sup>c</sup>	.78 (.50–1.20)	.95 (.57–1.58)	.76 (.50–1.15)	.91 (.56–1.46)
<b>R<sup>2</sup></b>		<b>.086</b>		<b>.086</b>
<b>Psychosocial</b>				
Depressive symptoms	1.25 (1.18–1.33)**	1.27 (1.18–1.37)**	1.22 (1.15–1.30)**	1.21 (1.13–1.29)**
Social support	.97 (.96–.99)**	.99 (.98–1.01)	.98 (.96–.99)**	.99 (.97–1.01)
<b>R<sup>2</sup></b>		<b>0.273</b>		<b>.229</b>
<b>CHD</b>				
Severity <sup>e</sup>			–	–
Group I	.88 (.47–1.63)	.84 (.40–1.76)		
Group II	.94 (.56–1.61)	1.06 (.54–2.07)		
Time of diagnosis <sup>f</sup>			–	–
age <18 years	1.10 (.72–1.69)	1.17 (.60–2.28)		
Cardiac surgery <sup>c</sup>	1.62 (.98–2.69)	2.02 (1.10–3.73)*	–	–
Cardiac intervention <sup>c</sup>	1.54 (.80–2.56)	1.59 (.73–3.46)	–	–
<b>R<sup>2</sup></b>		<b>0.294</b>		

Reference variables: <sup>a</sup>Women, <sup>b</sup>Widowed/divorced, <sup>c</sup>No, <sup>d</sup>High educational level, <sup>e</sup>Block III, <sup>f</sup>Diagnosis at age  $\geq 18$  years.

Educational level: low = informal/primary/similar; middle = high school/similar; high = university/similar.

CHD, congenital heart disease; CI, confidence interval; OR, odds ratio.

\* $P < .05$ , \*\* $P < .01$ , \*\*\* $P < .001$ .

variance captured by the model for lifestyle variables in multiple logistic regression was equal across groups. One could speculate that alcohol was not a stressor for the CHD adults compared with the non-CHD adults. Further research into the issue is warranted.

Although this study had a relatively large sample size and a comparison group of non-CHD adults matched by age and sex, there are some limitations that should be considered. The cross-sectional design of the study precluded us from establishing causal links: this warrants

future longitudinal studies. The data relied on self-report and were not confirmed with other sources; however, the subjective measures of psychosocial well-being are appropriate. Only adults with CHD from two heart hospitals in urban areas were recruited; thus, the author cautions against the overgeneralization of the findings. Although the PSS-SR is a suitable screening test for PTSD, in particular in settings where mental health professionals are lacking, it is a traditional PTSD screening measure. Medically induced stress, for instance in adults with CHD,

is not a discrete external life-threatening event that has passed but it is within the body and ongoing. Hence, administration of a disease-related measure could be more relevant.

In conclusion, the current study showed that half of the adults with CHD met the criteria for a likely PTSD diagnosis, which was significantly associated with elevated depressive symptoms and previous cardiac surgery. These findings highlight the importance of comprehensive psychological assessments and care for adults with CHD. Furthermore, it is acknowledged that contextual factors need to be taken into account in assessing even medically induced PTSD. However, further studies with a longitudinal design assessing CHD-related variables more precisely and considering coping strategies are warranted to be able to determine the factors that predict the vulnerability and resilience toward PTSD among this unique group of patients.

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## CONFLICT OF INTEREST

The author declares no conflicts of interest.

## AUTHOR CONTRIBUTION

BE: design, data collection, data analysis/interpretation, drafting of manuscript, revising, and final approval.

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