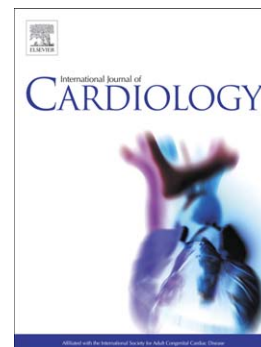# Accepted Manuscript

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Please cite this article as: Eslami Bahareh, Kovacs Adrienne H., Moons Philip, Abbasi Kyomars, Jackson Jamie L., Hopelessness among adults with congenital heart disease: Cause for despair or hope?, *International Journal of Cardiology* (2016), doi:10.1016/j.ijcard.2016.12.090

Hopelessness among adults with congenital heart disease: Cause for despair or hope?

Bahareh Eslami[a,b], Adrienne H. Kovacs[c], Philip Moons[d,e], Kyomars Abbasi[b], Jamie L. Jackson[f,g]

[a] Department of Health Sciences, Mid Sweden University, Sundsvall, Sweden. This author takes responsibility for all aspects of the reliability and freedom from bias of the data presented and their discussed interpretation.

[b] Department of Research, Tehran Heart Center, Tehran University of Medical Sciences, Tehran, Iran. This author takes responsibility for all aspects of the reliability and freedom from bias of the data presented and their discussed interpretation. kyomarsabbasi@yahoo.com

[c] Knight Cardiovascular Institute, Oregon Health & Science University, Oregon, USA. This author takes responsibility for all aspects of the reliability and freedom from bias of the data presented and their discussed interpretation. kovacs@ohsu.edu

[d] Department of Public Health and Primary Care, KU Leuven- University of Leuven, Leuven, Belgium. This author takes responsibility for all aspects of the reliability and freedom from bias of the data presented and their discussed interpretation. philip.moons@kuleuven.be

[e] Institute of Health and Care Sciences, University of Gothenburg, Gothenburg, Sweden.

[f] Center for Biobehavioral Health, Nationwide Children's Hospital, Ohio, USA. This author takes responsibility for all aspects of the reliability and freedom from bias of the data presented and their discussed interpretation. Jamie.Jackson2@nationwidechildrens.org

[g] College of Medicine, The Ohio State University, Ohio, USA.

Corresponding author:

Bahareh Eslami, MD, PhD

Division of Public Health Sciences, Department of Health Sciences

Mid Sweden University, Holmgatan 10, SE-851 70 Sundsvall, Sweden

Phone number: 0046 (0) 760850667, Email: bahareh.eslami@miun.se

Conflict of interest: The authors report no relationships that could be construed as a conflict of interest.

Abstract

Background: Adults with congenital heart disease (CHD) face unique life courses and challenges that may negatively influence their psychological functioning. The aims of this study were to (1) examine the level of hopelessness among adults with CHD in comparison with non-CHD participants and (2) identify correlates of elevated hopelessness among adults with CHD.

Methods: We enrolled 347 patients with CHD (18-64 years, 52.2% female) and 353 matched (by sex/age) non-CHD persons in this cross-sectional study. Hopelessness was assessed by Beck Hopelessness Scale. Hierarchical multiple logistic regression analyses were performed to explore correlates of elevated hopelessness.

Results: The mean total hopelessness score did not significantly differ between the CHD and non-CHD groups. Twenty-eight percent of CHD patients had elevated hopelessness scores. Within the CHD patient sample, regression analyses revealed that being male (odds ratio=2.62), not having children (odds ratio=3.57), being unemployed (odds ratio=2.27), and elevated depressive symptoms (odds ratio=1.21) were significantly associated with hopelessness. Regular physical activity (odds ratio=0.36) emerged as a protective factor and all CHD disease parameters were unrelated to hopelessness. The final model explained 43% of the variance in hopelessness.

Conclusions: Adult CHD teams are encouraged to continue to explore strategies to support patients to live as rich and full as lives as possible by pursuing relationships, employment and physical activity, as well as managing depression and hopelessness.

1. Introduction

The mental health of adults with congenital heart disease (CHD) has attracted significant attention during recent years, corresponding to the recognition that this growing population of patients typically faces unique life courses and challenges. Most adults with CHD require long-term medical care that may include several hospitalizations and/or additional invasive procedures due to the disease course or complications from previous interventions [1-3]. CHD survivors may also face difficulties in their daily lives, including finding appropriate jobs given physical limitations and insurance needs [4] as well as building their own families. These disease-related and life stressors may place survivors at elevated risk of emotional distress.

Several studies have demonstrated that adults with CHD, as compared to healthy controls, experience higher levels of emotional distress (e.g. anxiety and depressive symptoms, negative thoughts) and have lower self-esteem [5-8], although a meta-analysis revealed the inability to draw definitive conclusions regarding mental health outcomes [9]. Surprisingly, hopelessness, namely negative expectations about oneself and the future [10], has not been directly examined in this population. Hopelessness is a known predictor of depression [11,12], an independent risk factor for suicidal ideation [13-15], and a predictor of suicidal behavior even in the absence of clinically confirmed depression [16]. Hopelessness can be experienced in the absence of depression [17,18] and is associated with poor health, as well as cardiovascular morbidity and all-cause mortality [13,19-23].

The aims of the current study were (1) to examine the level of hopelessness among adults with CHD in comparison with non-CHD participants, and (2) among adults with CHD, to determine the association of hopelessness with socio-demographic factors (e.g. sex, education), health behaviors (e.g. physical activity), depressive and somatic symptoms, social support, and medical variables (e.g., CHD disease severity).

2. Methods

2.1. Study design

This was a cross-sectional case-control study conducted in Iran. The study was approved by the Research Ethics Committee of the Tehran Heart Center. Study participation consisted of completing a survey packet and medical record review. Recruitment and the informed consent process occurred in participants' homes; study personnel returned 4-7 days after this initial meeting to retrieve completed surveys. Further details of this process have been published [6].

2.2. Participants

Patients were consecutively recruited from two heart hospitals in the Tehran Province. Patients were eligible to participate if they (1) had been hospitalized due to CHD from April 2002 to March 2010, (2) were 18-64 years at the time of data collection, and (3) were fluent in Persian. Patients with a diagnosis of a Marfan's syndrome or cognitive impairment that would prevent completion of study surveys were excluded from participation.

To serve as a comparison group, adults without CHD, matched by sex and age (±2 years), were invited to participate through a systematic randomization procedure from the same residency area as the CHD patients. Inclusion criteria for this non-CHD comparison group included (1) fluency in Persian and (2) the absence of cognitive impairment that would preclude study participation.

2.3. Survey measures

Hopelessness was assessed with The Hopelessness Scale [10], which includes 20 true-false items that are scored 0 or 1. Total scores range from 0-20 and are categorized according to symptom severity as follows: 0–3 = none/minimal; 4–8 = mild; 9–14 = moderate; 15– 20 =

severe [24, 25]. For the purposes of this study, a score ≥9 was categorized as elevated

hopelessness. Cronbach's α was 0.81 for the CHD group and 0.79 for the non-CHD

comparison group.

Depressive symptoms were assessed with the depression subscale of The Hospital

Anxiety and Depression Scale (HADS-D), [26,27]. The measure is comprised of 7 items

scored 0-3. The total HADS-D score ranges from 0-21; higher scores correspond to worse

depressive symptoms. Cronbach's α for the HADS-D was 0.80 for adults with CHD and 0.78

for non-CHD participants.

Somatic symptoms were measured with the short 24-item version of the Giessen

Complaint List (GBB), [28], which has four domains of physical symptoms: exhaustion,

gastrointestinal, musculoskeletal, and cardiac. Items are scored 1-5 and summed to produce a

total somatic symptom score ranging from 0 to 96; higher scores suggest greater somatic

complaints. Cronbach's α for the total GBB-24 was 0.92 for both groups.

Social support was assessed with the Multidimensional Scale of Perceived Social

Support (MSPSS), [29]. Twelve items are scored from 1-7, thus producing a total score

ranging from 12-84. Higher scores correspond to greater perceived social support. Cronbach's

α for the total MSPSS was 0.88 for the CHD group and 0.89 for the non-CHD group.

Sociodemographic variables collected by participant survey included age, sex,

relationship status (i.e. married/being in partnership, never married/widowed/divorced),

having children (yes/no), educational attainment (i.e. low = informal/primary/similar; middle

= high school/equivalent; high = university/similar), employment status (i.e. employed,

unemployed) and perceived financial strain (i.e. never, quite often/often, always).

Health behaviors included self-reported body mass index (BMI) based on height and

weight, physical activity (i.e., yes/no response to walking at least 30 minutes three times a

week), daily cigarette smoking (yes/no), regular tobacco smoking by water-pipe (yes/no), and daily alcohol use (yes/no).

2.4. Medical record review

Patients with CHD were categorized into one of three diagnostic groups [30]: Group 1 (atrioventricular canal defect, tetralogy of Fallot, univentricular heart, transposition of the great vessels, truncus arteriosus, and hypoplastic left heart syndrome), Group 2 (atrial/ventricular septal defect, patent ductus arteriosus, aortic coarctation, and Ebstein's anomaly), and Group 3 (anomaly of pulmonary artery/valve, tricuspid valve disease, and aortic/mitral valve stenosis/insufficiency). The following were also documented for each patient: age at diagnosis (younger or older than 18 years of age), history of CHD surgeries (yes/no) and intervention, and cardiac medications use (yes/no). Further details have been published elsewhere [6, 31].

2.5. Statistical analyses

Data were analyzed with the PASW statistic package 22.0 (IBM/SPSS Inc., Chicago, IL). Categorical variables were described as absolute frequencies and percentages, and continuous variables were reported as means and standard deviations. In bivariate analyses, categorical variables were compared using chi-square test, while the Student's t-test was used for the continuous variables.

First, we compared CHD and non-CHD participants on hopelessness, psychosomatic constructs and social support. Thereafter, we performed multiple logistic regression analyses selecting an elevated hopelessness (score of ≥9 vs. score < 9) as the dependent variable. To determine whether there was an association between the presence of CHD and hopelessness, our first model included both CHD and non-CHD participants and CHD was included as an independent variable. Our next models were limited to adults with CHD. We performed

bivariate and hierarchical multiple logistic regression analyses to examine the association of psychosocial functioning, socio-demographic factors, health behaviors, and medical factors with the presence of elevated hopelessness. We introduced each variable block into the models in steps to build the final model and used simple bootstrapping with a sample number of 1000. The data were expressed in the form of Odds Ratios (ORs), 95% Confidence Intervals, and p-values. P-values were corrected by false discovery rate, as required. The significance level for all bivariate and multivariate analyses was set at p<0.05.

3. Results

3.1. Participants

Of 373 adults with CHD who were approached for study participation, 11 declined participation and 15 consented to participate but did not return questionnaires, thus resulting in a total patient sample of 347 (93% participation rate). Three-hundred and fifty-three individuals without CHD consented and completed study surveys.

As shown in Table 1, the mean age across both groups was 33 (SD=12) years and 52% were females. Compared to CHD survivors, non-CHD participants were more likely to obtain a higher educational level (χ^2 (2)=41.14, *p<0.001*) and be employed (χ^2 (1)=9.48, *p=0.008*). As a group, non-CHD participants had a higher BMI (t (698)=3.90, *p=0.008*), but the average BMI for both groups was within the normal range.

Among the 347 adults with CHD in the study, the diagnoses of 83 were categorized in Group 1, 186 in Group 2, and 78 in Group 3. A total of 189 (54%) were diagnosed with CHD before the age of 18 years and 268 (77%) had undergone at least one CHD surgery.

3.2. CHD vs. non-CHD participants: Hopelessness and psychosocial variables

As shown in Table 1, the mean total hopelessness score for both groups (CHD and non-CHD) was within the mild range and the mean scores did not significantly differ between groups. There were also no differences in depressive symptoms or social support between the two groups, however somatic symptoms were significantly higher among CHD participants (t (691)=-5.369, *p=0.008*).

3.3. Factors associated with hopelessness

3.3.1. Bivariate analyses

Of 347 adults with CHD, 98 (28%) had elevated hopelessness scores (as defined by a total score ≥9). More specifically, 80 (23%) had scores within the moderate range and 18 (5%) had scores indicative of severe hopelessness.

As depicted in Table 2, elevated hopelessness was associated with elevated depressive symptoms (t (345)=-9.69, *p=0.005*) and somatic symptoms (t (345)=-4.99, *p=0.005*) as well as less social support (t (344)=4.60, *p=0.005*). Physical inactivity was also associated with elevated hopelessness (χ^2 (1)=10.64, *p=0.005*). Hopelessness did not vary as a function of any medical variables.

3.3.2. Multivariate analyses

Analyses among all participants (n=700) revealed that the male sex (OR=2.07, 95% CI=1.24-3.30, *p=0.005*), not having children (OR= 2.69, 95% CI=1.32-5.48, *p=0.006*), being unemployed (OR=1.71, 95% CI=1.07-2.72, *p=0.025*), and having depressive symptoms (OR=1.28, 95% CI=1.20-1.36, *p<0.001*) were associated with higher odds of elevated hopelessness. The presence of CHD was not associated with hopelessness. The model accounted for 32% of the variance of hopelessness.

As shown in Table 3, analyses limited to adults with CHD (n=347) showed that socio-demographic determinants (Model 1) explained 10% of the variance in hopelessness, while health behavior determinants (Model 2) and psychosomatic and social support determinants (Model 3) added 6% and 26% to the explained variance of the model, respectively. The final model that included CHD disease parameters (Model 4) accounted for 43% of the variance of hopelessness, such that CHD parameters only explained an additional 0.5% of the variance.

Within the final model, the likelihood of having elevated hopelessness was higher among men (OR=2.62, *p=0.016*), those who were unemployed (OR=2.27, *p=0.026*), and those without children (OR=3.57, *p=0.029*). Regular physical activity reduced the odds of elevated hopelessness by approximately 64%, while depressive symptoms were associated with higher odds of elevated hopelessness (OR=1.21, *p=0.001*).

Despite the fact that not being in a relationship, perceiving financial strain, and using tobacco through a water-pipe increased the odds of elevated hopelessness in the crude logistic regression, these factors were not independently associated with hopelessness after other variables were included in the model.

4. Discussion

This is the first study to investigate hopelessness and its determinants among adults with CHD. Our results indicated that neither the presence of CHD (in the combined sample analyses) nor CHD parameters (in the CHD-only analyses) were associated with elevated hopelessness, highlighting that factors other than objective CHD status contribute significantly to the well-being of adults with CHD. Nonetheless, among those with CHD, 28% reported moderate to severe hopelessness which must be considered while providing care to this group of patients, a percentage that is similar to patients with acute coronary syndrome [32].

Contrary to previous research suggesting that people more frequently experience hopelessness as they grow older, age was not associated with hopelessness in our sample [18, 33]. Interestingly, male sex increased the odds of elevated hopelessness, while parenting (i.e. having own children) was a protective factor among adults with CHD. Those who did not experience parenthood had approximately a 3-fold increase in risk of experiencing elevated hopelessness. One could argue that having children may have been interpreted as a sign of being "normal" and living full adult life [34] by adults with CHD. On the other hand, parenting may have been protective for females rather than for males in this sample, as women were more likely to be parents [6]. Otherwise, females in general are more prone to emotional distress (e.g., depression) than men [35,36]. Conformed to patriarchal cultural norms, Iranian women are expected to bear children and take care of them, while men are expected to work and support the family economically [37]. However, some previous research has shown that experiencing parenthood may increase emotional distress among men [38]. As 33% of men and 24% of women with CHD in current study reported elevated hopelessness, one could recommend that health care providers should be comprehensive in their psychological assessments and not only focus on symptoms of depression as this might not capture hopelessness which is higher among male patients. Sex differences in hopelessness among adults with CHD was an unexpected and interesting finding in this sample which should be explored in more depth in future studies.

Adults with CHD who were unemployed were at greater risk for elevated symptoms of hopelessness, consistent with previous studies showing that hopelessness is associated with lower socio-economic status [17, 18, 39]. Unemployment can result in significant financial strain [40,41], thus decreasing one's autonomy. This is in addition to the nonfinancial benefits that often accompany employment, such as increased self-esteem and self-efficacy, and decreased social isolation [42]. Moreover, employment may be a buffer against hopelessness,

especially for Iranian men given that work is seen as a prerequisite for maturity and adult life, as well as necessary for building a family. Future studies should examine this relationship more closely with different cultural contexts.

Our results also revealed that physical activity remained a protective factor after considering socio-demographic, psychological and CHD-related factors. This finding is in line with previous research [43] linking a sedentary life-style with the development of hopelessness. Physical activity decreases emotional distress and increases life-satisfaction by reducing sensitivity to stress [44] and increasing self-esteem and self-confidence [45]. Thus, encouraging adults with CHD to engage in regular physical activity may have both physical and mental benefits. This finding supports the idea of adopting a salutogenic approach that focuses on well-being above and beyond disease in the care of adults with CHD [46].

Although adults with CHD with moderate/severe hopelessness had higher scores in depressive and somatic symptoms, only depressive symptoms were associated with a greater likelihood of elevated hopelessness, which is in line with previous research in medical and general settings [13, 33, 39]. Although high levels of depressive symptoms did not emerge as the strongest correlate of elevated hopelessness, the amount of variance captured by the model peaked dramatically when depressive symptoms were added (from 16.3% to 42.5%). This finding emphasizes the need to increase awareness of health care providers, to develop interventions, and to allocate resources to prevent, diagnose and provide appropriate treatment of depression among adults with CHD.

This study has provided new insights into the experience of hopelessness among adults with CHD. The strengths of this study were a relatively large sample size and having a non-CHD comparison group matched for age and gender. However, study limitations must be acknowledged. Patient participants were recruited from two urban hospitals, and we thus caution against overgeneralization of the findings to those living in more rural areas or those

who do not present for treatment in a hospital setting. The cross-sectional design prevents proposing causal links between hopelessness and its covariates. For example, there are likely bidirectional relationships between hopelessness and unemployment. Although subjective measures of psychosocial well-being are appropriate, we have no way to confirm reported health behaviors, such as physical activity. While a large number of factors that could be relevant to CHD and the experience of hopelessness were included in this study, we acknowledge that there may be other factors (e.g. functional class) that have been shown as important to emotional functioning [47] were not considered here. Future studies with a longitudinal design considering more precise and broader CHD-related variables are warranted.

In conclusion, this study demonstrated that neither the presence of CHD nor CHD parameters were independently associated with hopelessness. However, we observed that adults with CHD and elevated hopelessness are more likely to be male, to not have children, to be unemployed, and to have greater depressive symptoms. Physical activity emerged as a correlate of reduced hopelessness. These findings emphasize that the focus of CHD health care teams ought not to be limited to cardiac functioning; another important aim is to support patients to live as rich and full as lives as possible by pursuing relationships, employment and physical activity, as well as managing depression.

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Table 1. Students' t-test and chi-square tests examining differences between those with CHD (n=347) and a non-CHD comparison group (n=353) on socio-demographic, health behavior, psychosomatic and social support variables.

Variables	CHD		Non-CHD		P^{*}
	n (%)	Mean (SD)	n (%)	Mean (SD)	
Women	181(52.2)		182 (51.6)		*0.880*
Age		33.24 (12.11)		33.49 (12.18)	*0.857*
Married/being in partnership	185 (53.3)		214 (60.6)		*0.099*
Having children	150 (43.2)		181 (51.3)		*0.096*
Higher educational level	84 (24.2)		164 (46.5)		***<0.001***
Employed	131 (37.8)		174 (49.3)		***0.008***
Experiencing financial strain	277 (79.8)		291 (82.4)		*0.561*
BMI		23.98 (4.61)		24.27 (4.11)	***0.008***
Smoking cigarette	43 (12.4)		52 (14.7)		*0.561*
Water-pipe use	69 (19.9)		105 (29.7)		*0.096*
Alcohol use	37 (10.7)		35 (9.9)		*0.857*
Physically active	132 (38.0)		159 (45.0)		*0.099*
Hopelessness (total)		6.69 (3.97)		6.10 (3.71)	*0.096*
Depressive symptoms		6.51 (4.33)		6.36 (3.99)	*0.803*
Somatic symptoms		17.28 (14.52)		11.76 (12.52)	***0.008***
Social support		58.29 (15.02)		57.80 (14.87)	*0.803*

CHD, congenital heart disease; SD, standard deviation; n, number.

[*] q-value or corrected *p*-value

Table 2. Factors associated with hopelessness among adults with CHD (n=347).

Variables	Hopelessness n (%)	Hopelessness Mean (SD)	Non-Hopelessness n (%)	Non-Hopelessness Mean (SD)	P^*
Sex					*0.197*
Women	44 (24.3)		137 (75.7)		
Men	54 (32.5)		112 (67.5)		
Age		32.14 (12.29)		33.67 (12.04)	*0.408*
Married/being in partnership	43 (23.2)		142 (76.8)		*0.077*
Having children	32 (21.3)		118 (78.7)		*0.052*
Higher educational level	23 (27.4)		61 (72.6)		*0.620*
Being employed	31 (23.7)		100 (76.3)		*0.254*
Experiencing financial strain	86 (31.0)		191 (69.0)		*0.070*
BMI		23.45 (4.90)		24.15 (4.50)	*0.408*
Smoking cigarette	16 (37.2)		27 (62.8)		*0.202*
Alcohol use	11 (29.7)		26 (70.3)		*0.620*
Water-pipe use	26 (37.3)		43 (62.3)		*0.515*
Physically active	24 (18.2)		108 (81.8)		***0.005***
Depressive symptoms		9.68 (3.79)		5.27 (3.82)	***0.005***
Somatic symptoms		23.65 (14.92)		14.75 (13.58)	***0.005***
Social support		52.50 (14.93)		60.58 (14.58)	***0.005***
CHD severity					*0.320*
Group 1	28 (33.7)		55 (66.3)		
Group 2	45 (24.2)		141 (75.8)		
Group 3	25 (32.1)		53 (67.9)		
CHD diagnosis <18 years old	61 (32.3)		128 (67.7)		*0.170*
Experience of surgical correction	75 (28.0)		193 (72.0)		*0.845*
Experience of angiography	24 (29.6)		57 (70.4)		*0.515*
Using cardiac medication	61 (30.3)		140 (69.7)		*0.409*

CHD, congenital heart disease; n, number; SD, standard deviation.

[*] q-value or corrected *p*-value

Table 3. Factors associated with hopelessness among CHD patients (n=347) in multiple logistic regression analyses.

Variables	Crude OR (95% CI)	Model 1 OR (95% CI)	Model 2 OR (95% CI)	Model 3 OR (95% CI)	Model 4 OR (95% CI)
Socio-demographic block					
Age	0.99 (0.97-1.01)	1.01 (0.98-1.04)	1.02 (0.99-1.05)	1.01 (0.97-1.05)	1.02 (0.97-1.06)
Sex					
Women [a]	1	1	1	1	1
Men	1.50 (0.94-2.40)	1.72 (0.98-3.02)	1.91 (1.05-3.49)[*]	2.09 (1.03-4.21)	2.62 (1.24-5.52)[*]
Relationship status					
Married/being in partnership [a]	1	1	1	1	1
Never married/widowed/divorced	1.70 (1.06-2.72)[*]	1.17 (0.61-2.24)	1.11 (0.56-2.19)	1.02 (0.46-2.24)	1.15 (0.50-2.64)
Parenting					
Yes [a]	1	1	1	1	1
No	1.86 (1.14-3.03)[*]	2.21 (0.93-5.23)	2.54 (1.02-6.29)[*]	3.56 (1.23-10.33)[*]	3.57 (1.15-11.04)[*]
Educational level					
High [a]	1	1	1	1	1
Intermediate	0.94 (0.52-1.71)	0.93 (0.49-1.75)	0.81 (0.41-1.57)	0.80 (0.37-1.77)	0.80 (0.36-1.80)
Low	1.24 (0.66-2.31)	1.42 (0.70-2.89)	1.15 (0.54-2.44)	0.91 (0.37-2.24)	0.90 (0.36-2.25)
Employment					
Yes [a]	1	1	1	1	1
No	1.45 (0.88-2.38)	1.99 (1.11-3.57)[*]	2.34 (1.26-4.35)[**]	1.98 (0.98-3.98)	2.27 (1.09-4.74)[*]
Financial strain					
No [a]	1	1	1	1	1
Yes	2.18 (1.11-4.26)[*]	2.37 (1.71-4.81)[*]	2.28 (1.11-4.69)[*]	1.04 (0.44-2.46)	1.05 (0.43-2.52)
Health behavior block					
BMI	0.97 (0.92-1.02)		0.98 (0.92-1.04)	0.97 (0.90-1.04)	0.97 (0.90-1.04)
Cigarette use					
No [a]	1		1	1	1
Yes	1.60 (0.82-3.13)		1.18 (0.48-2.92)	1.46 (0.46-4.58)	1.46 (0.47-4.56)
Water-pipe use					
No [a]	1		1	1	1
Yes	1.73 (0.00-1.09)*		2.04 (0.97-4.27)	1.45 (0.60-3.49)	1.76 (0.72-4.30)
Alcohol use					
No [a]	1		1	1	1
Yes	1.08 (0.51-2.28)		0.79 (0.31-2.03)	0.49 (0.16-1.49)	0.40 (0.13-1.26)
Physical activity					
Yes [a]	1		1	1	1
No	0.42 (0.25-0.72)[**]		0.38 (0.21-0.68)[**]	0.40 (0.21-0.78)[**]	0.36 (0.18-0.70)[**]
Psychosomatic and social support block					
Depressive symptoms				1.34 (1.22-1.48)[**]	1.21 (1.14-1.28)[***]
Somatic symptoms	1.04 (1.02-1.06)			1.01 (0.99-1.04)	1.00 (0.97-1.02)
Social support	0.97 (0.95-0.98)			0.98 (0.96-1.00)	0.98 (0.96-1.00)
CHD parameters block					
Disease severity					
Block III [a]	1				1
Block II	0.68 (0.38-1.21)				0.67 (0.28-1.58)
Block I	1.08 (0.56-2.08)				1.16 (0.48-2.82)
Time of diagnosis					
≥18 years old [a]	1				1
<18 years old	1.56 (0.97-2.51)				0.78 (0.34-1.79)
History of surgical intervention					
No [a]	1				1
Yes	0.95 (0.54-1.65)				0.80 (0.39-1.67)
History of angiography					
No [a]					1
Yes	1.34 (0.63-2.84)				0.78 (0.30-2.03)
History of cardiac medication use					
No [a]	1				1
Yes	1.28 (0.80-2.07)				0.95 (0.50-1.80)
R[2]		0.096	0.163	0.425	0.430

[a]reference

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

[*]$p<0.05$, [**]$p<0.01$, [***]$p<0.001$