

# A cohort study on psychosocial adjustment and psychopathology in adolescents and young adults with congenital heart disease

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## ABSTRACT

**Objectives:** Our purpose was to study psychosocial adjustment and psychiatric morbidity of adolescents and young adults with congenital heart disease (CHD).

**Design:** All assessment measures were obtained on a single occasion. Clinical data was obtained through the patient's clinical records.

**Setting:** A teaching and tertiary care facility in Porto, Portugal.

**Participants:** We evaluated 110 CHD patients (62 male) aged from 12 to 26 years (mean=18.00±3.617), 58 cyanotic. All assessment measures were obtained on a single occasion in a tertiary hospital. Demographic information and clinical history were collected.

## Primary and secondary outcome measures:

Questionnaires regarded topics such as social support, family educational style, self-image and physical limitations, a standardised psychiatric interview Schedule for Affective Disorders and Schizophrenia—Lifetime version (SADS-L), and a self-report questionnaire on psychosocial adjustment, youth self-report or adult self-report. One of the relatives completed an observational version of the same questionnaire (child behaviour checklist (CBCL) or ABCL (adult behaviour checklist)).

**Results:** We found a 21.8% lifetime prevalence of psychopathology, 31.3% in females, 14.5% in males, showing a somewhat increased proneness in CHD patients. Females also showed worse psychosocial adjustment, with more somatic complaints ( $u=260\ 000$ ;  $p=0.011$ ), anxiety/depression ( $u=984\ 000$ ;  $p=0.002$ ), aggressive behaviour ( $u=920\ 500$ ;  $p=0.001$ ), attention problems ( $u=1123\ 500$ ;  $p=0.027$ ), thought problems ( $u=1069\ 500$ ;  $p=0.010$ ), internalisation ( $u=869\ 000$ ;  $p=0.0$ ) and externalisation ( $u=1163\ 000$ ;  $p=0.05$ ). Patients with severe CHD ( $u=939\ 000$ ;  $p=0.03$ ) and surgical repair ( $u=719\ 000$ ;  $p=0.037$ ) showed worse psychosocial adjustment. Those with poor social support showed more withdrawal ( $u=557\ 500$ ;  $p=0.0$ ) and social problems ( $u=748\ 500$ ;  $p=0.023$ ), and patients with unsatisfactory school performance revealed more anxiety/depression ( $u=916\ 000$ ;  $p=0.02$ ) and attention problems ( $u=861\ 500$ ;  $p=0.007$ ).

**Conclusions:** CHD males with good social support and good academic performance have a better psychosocial adjustment.

## ARTICLE SUMMARY

### Article focus

- This study systematically tested the effects of different demographic, clinical and psychosocial variables in psychosocial adjustment and psychiatric morbidity.
- Do female patients have higher predisposition for psychiatric morbidity than males?
- Do female patients have worst psychosocial adjustment than males?

### Key messages

- This study systematically tested the effects of different demographic, clinical and psychosocial variables in psychosocial adjustment and psychiatric morbidity.
- When prevalence of psychiatric disorder in our patients was compared with the reference value of the WHO, 10% of the world population, it seems that adolescents and young adults with CHD have an increased proneness for psychiatric diagnosis.

### Strength and limitations of the study

- In a growing population of adults with CHD, this information is rather important in unveiling strategies that can be used to assist and care for patients, leading to better emotional adjustment and better outcome in different life challenges.
- The interviews were held in the waiting room, which could have an influence on the patients attention, leading to answers that may not be entirely true.

## INTRODUCTION

The survival rate in the 1950s for children born with moderate CHD was about 20% whereas, today, about 90% of these children achieve adulthood.<sup>1</sup>

There has been a decrease in child mortality thanks to advances over the last four decades in diagnostic, surgical and catheter interventional techniques.<sup>2</sup> As these children

survive, the interest in issues such as psychosocial outcomes has increased also.<sup>3</sup>

Most children with CHD are diagnosed in uterus or in infancy, and are expected to undergo surgical procedures either to correct or palliate their defect.<sup>4 5</sup> These children need to be seen regularly by a cardiologist.<sup>4</sup>

Many studies have been conducted assessing the impact of CHD on children's or adolescents' psychosocial and cognitive functioning. Although a consensus among these studies has not yet been reached, some report higher rates of behaviour problems in children and adolescents with CHD, while others have not found any differences between patients with CHD and norms.<sup>4</sup>

It is believed that children with CHD have a higher risk of developing behavioural and emotional problems, when compared with healthy children. Several studies have reported that these children have increased feelings of anxiety and inferiority, higher degrees of impulsiveness and higher levels of emotional and behavioural problems.<sup>6</sup> On the other hand, some European studies have showed a good psychological functioning in adults with CHD.<sup>7</sup>

Not much is known about this topic, as some studies say that, in a 25-year follow-up, more psychosocial distress was found in adults with CHD in comparison with a normative group. The differences found were limited to somatic complaints and thought problems and behaviours.<sup>6</sup>

As for psychopathology studies have also disagreed in some aspects, many authors believe that CHD patients have a higher probability of having psychopathological symptoms while others have found similar numbers between these patients and healthy children and adolescents.<sup>8</sup>

Several characteristics can be described as facilitators of positive perspectives of stressful life situations and reduced psychological distress such as self-esteem and similar conduct like self-concept and self-perception. Some studies found that usually CHD patients have lower self-esteem, although, after surgery, patients reported better self-esteem or self-concept.<sup>9</sup>

Cognitive perceptions are believed to have an influence on a CHD patient's life. The more negative these perceptions were, the higher psychological distress was found. The negative perception can be associated, more than the severity of the disease itself, with higher distress and worse psychological adjustment.<sup>9</sup>

Some studies have shown that patients with cyanotic heart disease have a higher risk of presenting behavioural problems compared with patients with non-cyanotic heart defects, but other studies did not show this association.<sup>5 10</sup>

Patients with CHD who underwent surgical procedures, had more behavioural problems when compared with those who did not require surgery, and were more likely to develop psychiatric problems.<sup>5</sup>

As far as the physical condition is concerned, most patients with CHD have limitations, which can lead to more behavioural and emotional problems.<sup>5 8</sup>

In this study, we aimed to evaluate psychosocial adjustment and prevalence of psychopathology in adolescents and young adults with CHD. The importance of our investigation is that it systematically addressed the question of how several demographic and clinical variables relate to psychiatric morbidity and to psychosocial adjustment, using very strict methods of psychiatric diagnosis.

## METHODS

### Participants

The study enrolled 110 CHD patients, 62 male and 48 female, with a mean age of  $8\pm3.62$  years (range 12–26 years old). The participants who had not achieved an educational level that enabled them to understand and complete the written questionnaires were excluded from the study.

At the time of the interview, two participants were married; one was divorced; two were living in a marital union. All the others (105) were single. A total of 53 patients had completed their secondary education (12th grade), 40 the third cycle (9th grade), 11 the second cycle (6th grade) and 6 had graduated from college. Of these patients, 55 had at least repeated 1 year at school (mean= $1.49\pm0.50$  year). Of the 110 participants, 20 were employed full-time or part-time; 7 were unemployed and all the others, 83, were students.

Complete medical records were available for all the patients, who had been followed in the paediatric cardiology or cardiology departments of a tertiary hospital. For 58 individuals, the CHD was cyanotic, and for 52, it was acyanotic; 34 of these patients had a severe form of CHD, 18 a moderate and 58 a mild one; 41 patients had some physical limitations while 69 did not; these limitations were given by their doctors, stating that the most severe cases could not have any kind of physical activity while the moderate or mild cases were allowed controlled physical activity. Four patients had severe residual lesions, 21 moderate and 85 mild lesions. In total, 23 patients were never submitted to any kind of surgical procedure, while 42 had one surgery, 25 had two, 11 had three, 5 had four, 3 had five and 1 had nine surgeries. Forty-seven patients were on pharmacological therapy while 63 were not.

In many of our participants, the main CHD was combined with other heart diseases (box 1). Patients with associated extracardiac malformations or genetic disorders were excluded from the study. The participants had the following distribution of pathologies.

The diagnosis was determined during the neonatal period for 61, before the first birthday for 28; 5 were diagnosed between the ages of 1 and 3 years, 6 were diagnosed between the ages of 3 and 6 years and between the ages of 6 and 12 for 12 participants.

The first surgery was performed for 5 of the participants during the neonatal period, before the first birthday for 30, between the ages of 1 and 3 for 19, and between the ages 3 and 6 for 20 participants, between the ages 6 to 12 for 8 and between the ages of 12 to 18 for 28.

**Box 1** Patients and cardiac diseases

Nine TGA: from those, two also had VSD and AS, and one also had VSD and PS

30 TF

11 CA: from those, 1 also had VSD and 1 also had AS

24 VSD: from those, 1 also had IAA and 1 also had MI

6 ASD: from those, 1 also had MA and PH, and 1 also had E

4 AVSD

6 AS

2 SV: from those, 1 also had PA and 1 also had PS

2 PDA

1 DORV

3 PA

3 ED

1 MVP

1 BAV

1 TVR

AS, aortic stenosis; ASD, atrial septal defect; AVSD, atrioventricular septal defect; BAV, bicuspid aortic valve; CA, coarctation of the aorta; DORV, double outlet right ventricle; ED, Ebstein disease; IAA, interruption of the aortic arch; MA, mitral atresia; MI, mitral insufficiency; MVP, mitral valve prolapse; PA, pulmonary atresia; PDA, patent ductus arteriosus; PH, pulmonary hypertension; PS, pulmonary stenosis; SV, single ventricle; TF, tetralogy of Fallot; TGA, transposition of the great arteries; TVR, tricuspid valve regurgitation; VSD, ventricular septal defect.

We also invited one relative of each patient to participate in this study and 100 accepted to take part in it.

**Assessment instruments**

In this study, we used different surveys to collect the necessary information: an identification form, a semi-structured interview, a standardised psychiatric interview Schedule for Affective Disorders and Schizophrenia—Lifetime version (SADS-L), the self-report and observational questionnaires of the ASEBA system for psychosocial adjustment, adult self-report (ASR), youth self-report (YSR), adult behaviour checklist (ABCL) and child behaviour checklist (CBCL) (for patients  $\geq 18$  and  $<18$  years). Additional questionnaires used in this research are described in detail in another report.<sup>11</sup>

We used an identification form to collect personal and demographic data from each patient (eg, marital status, educational level and occupation), as well as all relevant aspects from their medical history (diagnosis, severity and category of heart disease, surgical interventions, pharmacological therapy and presence of residual lesions, among others).

The semistructured interview included 38 multiple-choice or short-answer questions that focused on different topics such as social support, family upbringing, self-image, functional limitations and emotional adjustment.

A standardised psychiatric interview, SADS-L,<sup>12</sup> was administered to obtain a clinical diagnosis of any psychopathological disorders that may have existed before the interview in these patients.

The YSR and ASR are self-report questionnaires, designed to collect a description of a child or adult's functioning; they assess individuals in scales of withdrawn behaviour, somatic complaints, anxiety/depression, thought problems, social problems, attention problems, delinquent behaviour, aggressive behaviour, internalisation and externalisation.<sup>12</sup> The CBCL and ABCL are observational versions of the same questionnaires, to be completed by the patients' parents or caregivers, having as a requirement being knowledgeable about the patient, as they report their perception on the behaviour and possible problems occurring in the patient. For their similarities, and to have a better representative sample, the results of the YSR and ASR were pooled, along with the results of the CBCL and the ABCL, and for statistical purposes, the overall results were counted for each scale.<sup>13</sup>

**Procedure**

Prospective participants were contacted while waiting for their appointment in the cardiology or paediatric cardiology department. Our first concern was to get their or their parents' consent (when they were under 18 years old). At this time, they were informed about all aspects of the research, and when they accepted to participate, they completed an informed consent form approved by the hospital's ethical committee, which followed international conventions guaranteeing the rights of the patients. The interview happened on the spot. The parents or caregivers accompanying the patient were asked to fill out a questionnaire, and 10 caregivers refused to participate or were not present for the application of the protocol, and subsequently expressed their intention not to participate. The whole investigation (plan, assessment instruments used and procedures) was previously submitted to appreciation of the hospital's ethical committee and was approved.

**Design**

All the assessment measures were obtained on a single occasion. Clinical data were collected retrospectively by using each patient's clinical record, with assistance from hospital medical staff.

**Data analysis**

Statistical analysis of the data was processed using the software IBM SPSS (Statistical Package for Social Sciences, Chicago, Illinois, USA), V.19. The distribution of all the variables was tested. Differences for parametric variables were established using Student's *t* tests, whereas differences for non-parametric variables (the majority) were established using Mann-Whitney *U* test and  $\chi^2$  tests of association.

**RESULTS**

We found that 21.8% of our participants had a psychiatric disorder and that there was a statistical difference between the two genders, with females almost doubling males' rate

## Psychosocial adjustment and psychopathology

(31.3% in females and 14.5% in males;  $p=0.035$ ). One or more of the following psychiatric disorders had been diagnosed for our participants in all their lifetime prior to interview: minor or major depressive syndrome (13), panic disorder (3), anxiety disorder (4), manic syndrome (3) and cyclothymic personality (1).

For the sake of data analysis, we grouped the results on psychosocial adjustment in either self-reported or observational.

In [table 1](#), we summarise the main results of this study regarding self-report measures.

When analysing patients according to gender, females show worse psychosocial adjustment, when compared with males. As for patients with a severe form of CHD, these had worse psychosocial adjustment than the ones with moderate-to-mild CHD.

Patients who were submitted to surgical procedures showed worse psychosocial adjustment than patients that were not submitted to any surgical procedures.

When it comes to social support, patients with poor social support reported worse psychosocial adjustment when compared with patients with good social support.

As for the patient's physical competence, the ones with limitations presented worse psychosocial adjustment. Patients with worse academic performance had worse psychosocial adjustment. When it comes to residual lesions, the ones with severe-to-moderate residual lesions showed worse psychosocial adjustment than those with mild residual lesions.

No differences were found when analysing the impact of CHD and the need for pharmacological therapy in psychosocial adjustment.

According to the assessment of patient's caregivers, as seen on [table 2](#), no differences were found between patients who underwent surgical procedures and the ones who did not have surgical procedures carried out.

In the caregivers' assessment ([table 2](#)), male patients were perceived as having worse psychosocial adjustment than females. The cyanotic patients showed worse psychosocial adjustment, also according to the caregivers.

When compared with patients with good social support ([table 3](#)), those with poor support showed worse psychosocial adjustment, again in the caregivers' perspective. When it comes to residual lesions, patients with a severe-to-moderate form of residual lesions showed worse psychosocial adjustment.

## DISCUSSION

This study systematically tested the effects of different demographic, clinical and psychosocial variables in psychosocial adjustment and psychiatric morbidity. In a growing population of adults with CHD, this information is rather important in unveiling strategies that can be used to assist and care for patients, leading to better emotional adjustment and better outcomes in different life challenges.

The assessment instruments used for psychosocial adjustment enabled us to compare subgroups of patients, regarding demographic, clinical and psychosocial variables. One main finding of our study was that females with CHD reported higher levels of somatic complaints, anxiety/depression, thought problems, attention problems, aggressive behaviour, internalisation and externalisation, than males, thus showing a worse psychosocial adjustment. Conversely, relatives find male patients more withdrawn than girls.

In our study, female patients had almost double of life-time prevalence of psychopathology than males. These findings on psychiatric morbidity and on different scales of psychosocial adjustment are consistent with other studies on the general population that report differences between genders, with females showing higher rates of emotional problems. Studies show also that females have greater likelihood of displaying higher levels of anxiety/depression and somatic complaints when facing negative obstacles that interfere with the interpersonal level, resulting in higher levels of internalisation.<sup>6 8 14</sup>

This may be due to the presence of a scar, situated on the chest, being a source of uncertainties or discomfort. In addition to affecting sexual relationships, CHD can also interfere with pregnancy and delivery, leading to a sense of anxiety about their physical condition.<sup>6 8</sup>

Some studies show that females are more likely to develop depressive symptoms when facing negative life events than males.<sup>6 10</sup>

In this study, adolescents or young adults with severe type of CHD reported having higher levels of social problems and, thus, worse psychosocial adjustment, compared with those with moderate or mild form of CHD.

These results may be related to the fact that they need further medical care throughout their life, while patients with mild or moderate CHD may have a daily life similar to healthy adolescents and young adults.<sup>8</sup> Patients with severe forms of CHD show higher level of internalisation and somatic complaints and that may be associated with the fact that these patients are more vigilant about their health, being more anxious about any complications. This may explain the results, since anxiety is a component of internalisation scale.<sup>15</sup>

The type of CHD did not show any impact with statistical relevance in patients' self-report measures of psychosocial adjustment. However, the caregivers' standpoint seems to be more sensitive regarding this feature, as they perceive the cyanotic patients as having more attention problems and worse psychosocial adjustment.

Other published studies also showed that cyanosis is not a stable indicator that patients will have behavioural and emotional problems.<sup>8 10 16</sup>

Patients who underwent surgical procedures revealed higher levels of withdrawn behaviour. This may be related with the fact that admissions as well as recovery are long, thus providing a prolonged absence from education and from contact with peer groups, which could



**Table 1** Comparing psychosocial adjustment measures (self-report) in male versus female participants, in severe versus moderate-to-mild CHD, in participants with versus without surgical intervention and with severe/moderate versus mild residual lesions

| ASR/YSR (self-report) | Male (N=62) |         | Female (N=48) |         | Severe CHD (N=34) |         | Moderate/mild CHD (N=76) |         | With surgical intervention (N=87) |         | No Surgical intervention (N=23) |        | Severe/moderate residual lesions (N=25) |        | Mild Residual lesions (N=85) |         |
|-----------------------|-------------|---------|---------------|---------|-------------------|---------|--------------------------|---------|-----------------------------------|---------|---------------------------------|--------|---|--------|------------------------------|---------|
|                       | Mean        | U       | Mean          | U       | Mean              | U       | Mean                     | U       | Mean                              | U       | Mean                            | U      | Mean                                    | U      | Mean                         | U       |
|                       | Mean        | p       | Mean          | p       | Mean              | p       | Mean                     | p       | Mean                              | p       | Mean                            | p      | Mean                                    | p      | Mean                         | p       |
| Withdrawn             | 54.02       | 1396000 | 57.42         | 1049000 | 62.63             | 1049000 | 52.31                    | 1049000 | 58.74                             | 1049000 | 43.26                           | 719000 | 65.14                                   | 719000 | 52.56                        | 821500  |
| Somatic complaints    | 26.03       | 260000  | 37.70         | 260000  | 37.43             | 260000  | 26.77                    | 264000  | 32.80                             | 264000  | 23.60                           | 234000 | 37.7                                    | 234000 | 28.14                        | 231500  |
| Anxiety/depression    | 47.37       | 984000  | 66.00         | 984000  | 56.53             | 984000  | 55.04                    | 1257000 | 58.09                             | 1257000 | 45.70                           | 775000 | 59.46                                   | 775000 | 54.34                        | 963500  |
| Social problems       | 51.85       | 1261500 | 60.22         | 1261500 | 62.63             | 1261500 | 52.31                    | 1049500 | 56.82                             | 1049500 | 50.50                           | 885500 | 64.96                                   | 885500 | 52.72                        | 826000  |
| Thought problems      | 48.75       | 1069500 | 64.22         | 1069500 | 63.06             | 1069500 | 52.12                    | 1035000 | 56.47                             | 1035000 | 51.83                           | 916000 | 57.52                                   | 916000 | 54.91                        | 1012000 |
| Attention problems    | 49.62       | 1123500 | 63.09         | 1123500 | 54.40             | 1123500 | 55.99                    | 1254500 | 58.48                             | 1254500 | 44.24                           | 741500 | 67.62                                   | 741500 | 54.88                        | 1009500 |
| Aggressive behaviour  | 55.71       | 920500  | 55.23         | 920500  | 61.87             | 920500  | 52.65                    | 1120000 | 55.23                             | 1120000 | 56.52                           | 890500 | 63.38                                   | 890500 | 53.18                        | 968000  |
| Internalisation       | 46.35       | 869000  | 67.32         | 869000  | 60.56             | 869000  | 53.24                    | 917000  | 56.76                             | 917000  | 50.72                           | 880500 | 59.28                                   | 880500 | 54.39                        | 782500  |
| Externalisation       | 45.52       | 1163000 | 68.40         | 1163000 | 66.53             | 1163000 | 50.57                    | 1214500 | 56.88                             | 1214500 | 50.28                           | 817500 | 66.70                                   | 817500 | 52.21                        | 1045500 |

ASR, adult self-report; CHD, congenital heart disease; YSR, youth self-report.

lead to difficulties of reintegration and therefore to isolation of patients.<sup>5 7 17</sup>

Patients with worse social support had higher levels of withdrawn behaviour and social problems, and thus, a worse psychosocial adjustment. The assessment of the caregivers also reported higher levels of withdrawn behaviour and internalisation in patients with poor social support, showing worse psychosocial adjustment.

According to several studies, parents and siblings of adolescents or young adults with CHD are more prone to face a different number of psychosocial stresses putting the whole family in need of psychosocial support. Many studies reveal a higher need for intervention on family problems in families with children with chronic medical diseases. When the complexity of the disease is low, parents seem to be more fitted to provide support.<sup>18</sup> These families are reported to experience more stress, that can have an impact on the child's adjustment.<sup>16</sup>

Parents of children with CHD can be overprotective and hypervigilant about their child's health, making it hard for their children to be more independent. Many studies show that these patients are more unlikely to have 'independent lifestyles' than healthy adolescents or young adults.<sup>7</sup> Participation in leisure time activities can be a contributor to a better social outcome.<sup>14</sup>

Limited physical competence translated into more withdrawn, feeling more isolated, when compared with patients with satisfactory physical competence. Self-report showed that patients with physical limitations have worse psychosocial adjustment. A low exercise capacity can be translated into more internalising problems. For older heart patients, limited physical competence led to concerns and anxiety about their health.

According to some authors, patients submitted to physical training intervention showed a decrease in internalising problems.<sup>8</sup>

Physical limitations and school absences prevent full participation in different activities, leading to isolation and social awkwardness. This can be translated into restricted employment opportunities.<sup>7</sup>

In our study, an unsatisfactory academic performance led to worse psychosocial adjustment, as patients report having higher levels of anxiety/depression, attention problems and externalisation than those with good academic performance. Several previous published studies show that CHD has an impact on school careers, for many hospitalisations and restrictions, being the main reason for the attendance of special education by these patients. When compared with healthy adolescents or young adults, the CHD patients are more unlikely to complete a lower educational level.<sup>14</sup>

Sometimes, children with CHD have neurodevelopment deficits. These often will not show until school age, when the academic demands start having an impact on their lives. Many families rationalise their child's developmental delay to the disease and several hospitalisations.<sup>19</sup>

**Table 2** Comparing psychosocial adjustment measures (caregivers' report) in male versus female participants, in cyanotic versus acyanotic CHD, in participants with good versus poor social support and with severe/moderate versus mild residual lesions

| ABCL/CBCL (report from caregivers) | Male (N=58) |       | Female (N=43) |      | Cyanotic (N=51) |       | Acyanotic (N=50) |      | Good Social support (N=76) |       | Poor social support (N=25) |      | Severe or moderate residual lesions (N=24) |       | Mild residual lesions (N=77) |      |
|------------------------------------|-------------|-------|---------------|------|-----------------|-------|------------------|------|----------------------------|-------|----------------------------|------|--|-------|------------------------------|------|
|                                    | Mean        | Mean  | U             | p    | Mean            | Mean  | U                | p    | Mean                       | Mean  | U                          | p    | Mean                                       | Mean  | U                            | p    |
| Withdrawn                          | 56.78       | 43.20 | 911500        | 0.02 | 54.15           | 47.79 | 1114500          | 0.27 | 45.30                      | 68.32 | 517000                     | 0.00 | 56.46                                      | 49.30 | 793000                       | 0.29 |
| Somatic complaints                 | 47.19       | 56.14 | 1026000       | 0.12 | 54.44           | 47.49 | 1099500          | 0.23 | 49.92                      | 54.28 | 868000                     | 0.51 | 55.73                                      | 49.53 | 810500                       | 0.36 |
| Anxiety/depression                 | 49.66       | 52.81 | 1169000       | 0.59 | 55.19           | 46.73 | 1061500          | 0.15 | 48.65                      | 58.14 | 771500                     | 0.16 | 57.29                                      | 49.04 | 773000                       | 0.23 |
| Social problems                    | 31.08       | 29.57 | 404000        | 0.74 | 33.88           | 27.34 | 351500           | 0.14 | 29.01                      | 34.59 | 286500                     | 0.27 | 39.91                                      | 26.78 | 205500                       | 0.01 |
| Thought problems                   | 48.64       | 54.19 | 1110000       | 0.32 | 54.27           | 47.66 | 1108000          | 0.23 | 50.91                      | 51.26 | 943500                     | 0.96 | 57.58                                      | 48.95 | 766000                       | 0.18 |
| Attention problems                 | 52.34       | 49.20 | 1169500       | 0.59 | 56.75           | 45.13 | 981500           | 0.05 | 48.82                      | 57.62 | 784500                     | 0.19 | 62.44                                      | 47.44 | 649500                       | 0.03 |
| Aggressive behaviour               | 50.77       | 51.31 | 1233500       | 0.92 | 51.21           | 50.79 | 1264500          | 0.94 | 50.52                      | 52.46 | 913500                     | 0.77 | 53.92                                      | 50.09 | 854000                       | 0.57 |
| Internalisation                    | 45.80       | 58.01 | 945500        | 0.04 | 54.07           | 47.87 | 1118500          | 0.29 | 49.79                      | 54.68 | 858000                     | 0.47 | 59.15                                      | 48.46 | 728500                       | 0.12 |
| Externalisation                    | 49.55       | 52.95 | 1063000       | 0.56 | 55.86           | 46.04 | 1027000          | 0.09 | 46.50                      | 64.68 | 608000                     | 0.01 | 65.85                                      | 46.37 | 567500                       | 0.00 |

ABCL, adult behaviour checklist; CBCL, child behaviour checklist.

**Table 3** Comparing psychosocial adjustment measures (self-report) in participants with good versus poor social support, in those with versus without physical limitations, in those with poor versus good academic performance

| ASR/YSR (self-report) | Good social support (N=85) |       | Poor social support (N=25) |      | With physical limitations (N=41) |       | No physical limitations (N=69) |      | Poor academic performance (N=77) |       | Good academic performance (N=33) |      |
|-----------------------|----------------------------|-------|----------------------------|------|----------------------------------|-------|--------------------------------|------|----------------------------------|-------|----------------------------------|------|
|                       | Mean                       | Mean  | U                          | p    | Mean                             | Mean  | U                              | p    | Mean                             | Mean  | U                                | p    |
| Withdrawn             | 49.56                      | 75.70 | 557500                     | 0.00 | 65.05                            | 49.83 | 1023000                        | 0.02 | 53.71                            | 59.68 | 1132500                          | 0.36 |
| Somatic complaints    | 31.02                      | 29.06 | 329000                     | 0.70 | 34.41                            | 28.24 | 332000                         | 0.18 | 31.20                            | 28.40 | 306000                           | 0.59 |
| Anxiety/depression    | 54.98                      | 57.28 | 1018000                    | 0.75 | 61.93                            | 51.68 | 1151000                        | 0.10 | 50.90                            | 66.24 | 916000                           | 0.02 |
| Social problems       | 51.81                      | 68.06 | 748500                     | 0.02 | 57.80                            | 54.13 | 1320000                        | 0.55 | 53.32                            | 60.59 | 1102500                          | 0.27 |
| Thought problems      | 56.11                      | 53.42 | 1010500                    | 0.71 | 59.78                            | 52.96 | 1239000                        | 0.27 | 53.44                            | 60.32 | 1011500                          | 0.29 |
| Attention problems    | 53.96                      | 60.74 | 931500                     | 0.35 | 61.12                            | 52.75 | 1225000                        | 0.24 | 50.19                            | 67.89 | 861500                           | 0.01 |
| Aggressive behaviour  | 53.49                      | 62.32 | 911000                     | 0.28 | 62.99                            | 51.05 | 1254500                        | 0.32 | 54.44                            | 57.97 | 1116000                          | 0.31 |
| Internalisation       | 53.72                      | 61.56 | 892500                     | 0.23 | 59.40                            | 53.08 | 1121500                        | 0.07 | 53.49                            | 60.18 | 1056500                          | 0.16 |
| Externalisation       | 53.50                      | 62.30 | 1032500                    | 0.83 | 62.65                            | 51.25 | 1353500                        | 0.71 | 52.72                            | 61.98 | 973500                           | 0.05 |

**Table 4** Comparing the prevalence of psychiatric disorders in our participants with data from studies in other countries

| Author/year /country                              | Number of participants | Kind of population    | Lifetime prevalence of psychiatric disorders (%) | Comments  |
|---|------------------------|-----------------------|--|---|
| Portugal  | 110                    | CHD patients          | 21.8   | These numbers were obtained between 2010 and 2012   |
| Kessler <i>et al.</i> /2007/Spain <sup>22</sup>   | 842                    | Population in general | 19.4   | These results were found in the WMH data using discrete-time survival analysis to predict onset of disorders across age groups 18–34, 35–49, 50–64, and 65+ (between 2002 and 2005). No meaningful difference exists between less developed and developed countries |
| Kessler <i>et al.</i> /2007/Italy <sup>22</sup>   | 612                    | Population in general | 37.9   |   |
| Kessler <i>et al.</i> /2007/France <sup>22</sup>  | 847                    | Population in general | 18.1   |   |
| Kessler <i>et al.</i> /2007/Germany <sup>22</sup> | 573                    | Population in general | 25.2   |   |
| Kessler <i>et al.</i> /2007/USA <sup>22</sup>     | 3929                   | Population in general | 47.4   |   |

CHD, congenital heart disease; WMH, World Mental Health survey initiative.

Some studies show that an unsatisfactory educational background can be translated into lower educational and occupational achievement.<sup>7</sup>

This study showed a 21.8% prevalence of psychiatric disorder in our patients. Females showed a higher percentage of psychiatric disorder with 31%, and males only had 14%.

When compared with the reference value of the WHO, 10% of the world population, it seems that adolescents and young adults with CHD have an increased proneness for psychiatric diagnosis.<sup>20</sup> However, a study of six different European countries showed a prevalence of 25% in the general population, which is closer but higher than the results for CHD patients in our study (table 4).<sup>21</sup> Another study estimated that the lifetime prevalence of psychopathology is 19.4% in Spain, 18.1% in Italy (countries that can be considered culturally close to Portugal), and 25.2% in Germany, but in striking contrast, 37.9% in France and 47.4% in the USA.<sup>22</sup>

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