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Education as important predictor for successful employment in adults with congenital heart disease worldwide

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Abstract

Background: Conflicting results have been reported regarding employment status and work ability in adults with congenital heart disease (CHD). Since this is an important determinant for quality of life, we assessed this in a large international adult CHD cohort.

Methods: Data from 4028 adults with CHD (53% women) from 15 different countries were collected by a uniform survey in the cross-sectional APPROACH International Study. Predictors for employment and work limitations were studied using general linear mixed models.

Results: Median age was 32 years (IQR 25-42) and 94% of patients had at least a high school degree. Overall employment rate was 69%, but varied substantially among countries. Higher education (OR 1.99-3.69) and having a partner (OR 1.72) were associated with more employment; female sex (OR 0.66, worse NYHA functional class (OR 0.67-0.13), and a history of congestive heart failure (OR 0.74) were associated with less employment. Limitations at work were reported in 34% and were associated with female sex (OR 1.36), increasing age (OR 1.03 per year), more severe CHD (OR 1.31-2.10), and a history of congestive heart failure (OR 1.57) or mental disorders (OR 2.26). Only a university degree was associated with fewer limitations at work (OR 0.62).

Conclusions: There are genuine differences in the impact of CHD on employment status in different countries. Although the majority of adult CHD patients are employed, limitations at work are common. Education appears to be the main predictor for successful employment and should therefore be encouraged in patients with CHD.

KEYWORDS
adult, congenital heart defects, disability, education, employment, work ability

1 | INTRODUCTION

With survival rates to adulthood over 90%, most children with congenital heart disease (CHD) go to school and subsequently obtain employment.[1,2] Employment and work ability contribute to well-being and are nowadays crucial in daily life for most adults with CHD.[3] Employment has been reported as one of the most important aspects of quality of life (QOL) and, inversely, lack of employment with lower QOL.[4,5] Aspects influencing work such as concentration and fatigue, are important patient-reported outcomes that receive increasing attention. However, in contrast to previous guidelines,[6] education and employment are no longer mentioned in the latest European guidelines for the management of grown-up CHD.[7]

Higher rates of unemployment, disease-related work absences, and limitations at work have been reported in adults with CHD compared to the general population in The Netherlands, Germany, Denmark, the United Kingdom, and the United States.[8-13] In contrast, studies from Finland, Sweden, and Malta, have reported employment rates similar or even above those of the general population.[14-16] Research in other chronic diseases (eg, rheumatoid arthritis, asthma, chronic obstructive pulmonary disease, diabetes mellitus, and ischemic heart disease) has consistently shown that employment and work ability are negatively influenced by these conditions. Patients with other chronic diseases are less often employed, work fewer hours when they work and report limitations at work.[17] These findings were associated with older age, female sex, perceived health complaints, and limitations in daily physical activities caused by the disease.[18] It remains unknown whether these contributing factors for work disability are applicable to adults with CHD.

The conflicting findings on employment and limitations at work and contributing factors in adults with CHD, suggest that they might be influenced by other factors than solely the CHD itself. Therefore, the aim of this study was to explore employment, work ability, and the presence of limitations at work in a large international adult CHD cohort in a uniform way, to investigate differences between countries and to identify predictors for employment and work limitations.

2 | METHODS

2.1 | Study design and setting

Data were collected from April 2013 to March 2015 in the "Assessment of Patterns of Patient-Reported Outcomes in Adults with Congenital Heart disease—International Study" (APPROACH-IS). APPROACH-IS is an international cross-sectional multicenter study conducted in partnership with the International Society for Adult Congenital Heart Disease (ISACHD). The rationale and methodology of this study have been previously described.[19] In summary, inclusion criteria were age 18 years or above, known CHD with continuing follow-up and the ability to complete self-report questionnaires. The study was approved by the institutional review board of the coordinating center (University Hospitals Leuven/KU Leuven, Belgium) and local institutional review boards when required. All participating patients provided written informed consent. Data from 5 different continents were collected in 15 participating countries: Belgium, France, Italy, Malta, Norway, Sweden, Switzerland, and The Netherlands (Europe); Canada and the United States (North America); India, Japan, and Taiwan (Asia); Argentina (South America); and Australia.

2.2 | Variables and measurements

A uniform survey developed by the research team consisting of questions on demographic, medical and QOL items was sent to either a random or consecutively approached selection of patients at each participating center. The first question of the Work Ability Index, inquiring about current work ability compared to lifetime best, was used to assess work ability. This question is considered a valid and reliable predictor of work disability and is frequently used to measure work ability.[20,21] Patients were asked to rate their current work ability on a scale from 0 (not being able to work at all) to 10 (equivalent of lifetime best work ability). A Work Ability Score (WAS) of 8 or higher was considered good to excellent, a score of 6 or 7 was considered moderate, and any score of 5 or below was considered poor. Limitations at work were collected through several questions on experiencing limitations at work attributed to the CHD, eg, having symptoms at work, having to slow down due to the symptoms, or having to work part-time because of the disease. Country-specific data on employment and unemployment were drawn from the International Monetary Fund (IMF) and the Organisation for Economic Co-operation and Development (OECD) and used as reference data.[22,23]

2.3 | Definitions

CHD was diagnosed according to the European Paediatric Cardiac Code Short List coding scheme.[24] To categorize complexity of CHD, a prespecified hierarchical scheme was used, classifying type of CHD as either mild, moderate, or severe.[25] Employment status was classified by the patient as either full- or part-time, unemployed (including job seeking), disabled/government financial assistance, homemaker, student, retired, or other. From all patients that had chosen "other," additional free text was individually verified. For all analyses regarding work ability, only patients with working experiences were analyzed. Therefore, since most of the participating countries have a retirement age of 65 years and older, patients were censored from that age and homemakers, early retired participants, and students were all excluded from work ability analyses. Unemployed or disabled patients who considered themselves entirely unable to work were also excluded from all analyses on working experiences. Limitations at work were considered when "yes" was answered on one or more questions regarding work limitations. Only employed patients were included for the analyses on work limitations.

2.4 | Statistical methods

Categorical data were presented as numbers and percentages and continuous data as medians with interquartile ranges (IQR) since they were not normally distributed. Clinical characteristics were compared using chi-square statistics for dichotomous and categorical variables and Mann-Whitney *U* tests for continuous variables. The differences in parameters for employment and work limitations were first tested by univariate analyses. The association of patient-specific characteristics of employment and work limitations was estimated with the use of general linear mixed models. By this multilevel structure, patients were nested within countries, to account for as much influence from cultural differences as possible. Odds

TABLE 1 Characteristics of the study population

Variable	Respondents	APPROACH-IS (*N* = 4028)			*P* value
		Men (*N* = 1897 (47))	Women (*N* = 2115 (53))	Total (*N* = 4012[a])	
Age, y (IQR)	4013	31 (24-43)	32 (25-41)	32 (25-42)	.649
Origin, *N* (%)[b]	4028				
Europe		869 (46)	866 (41)	1 735 (43)	.003
North America		560 (29)	700 (33)	1 260 (32)	.016
Asia		330 (17)	377 (18)	707 (18)	.761
South America		68 (4)	110 (5)	178 (4)	.018
Australia		70 (4)	62 (3)	132 (3)	.177
Marital status	4008				
Never married		911 (48)	839 (40)	1750 (44)	<.001
Married/living with partner		901 (48)	1134 (54)	2035 (51)	<.001
Divorced/widowed		73 (4)	129 (6)	202 (5)	.001
Having children	4004	696 (37)	881 (42)	1577 (40)	.002
Educational level	3989				
Less than high school		109 (6)	114 (5)	223 (6)	.623
High school		834 (44)	873 (42)	1707 (43)	.086
College degree		390 (21)	455 (22)	845 (21)	.459
University degree		542 (29)	657 (31)	1199 (30)	.085
CHD severity	4028				
Mild		420 (22)	618 (29)	1038 (26)	<.001
Moderate		924 (49)	1021 (48)	1945 (49)	.783
Severe		553 (29)	476 (23)	1029 (25)	<.001
NYHA I and II	3927	1665 (90)	1778 (88)	3443 (89)	<.001
NYHA III and IV		186 (10)	251 (12)	437 (11)	.037
Comorbidity					
Congestive heart failure	3959	193 (10)	240 (12)	435 (11)	.471
Cognitive impairment	3998	29 (2)	19 (1)	48 (1)	.066
History of mental disorder	4012	149 (8)	265 (13)	418 (10)	<.001
Employment status	3993				
Employed		1381 (74)	1364 (65)	2745 (69)	<.001
Full-time		1151 (83)	893 (65)	2044 (74)	<.001
Part-time		230 (17)	471 (35)	701 (26)	<.001
Homemaker or retired		79 (4)	255 (12)	334 (8)	<.001
Unemployed[c]		192 (10)	201 (10)	393 (10)	.511
Disabled		127 (7)	173 (8)	300 (8)	.074
Student or other		101 (5)	105 (5)	206 (5)	.606
Good WAS (≥8)[d]	3227	1248 (78)	1247 (77)	2495 (77)	.596
Poor WAS (≤5)		135 (8)	148 (9)	283 (9)	.467
Any work limitations[e]	2745	441 (32)	499 (37)	940 (34)	.010

Abbreviations: CHD, congenital heart disease; NYHA, New York Heart Association (functional class).
[a]Sex unknown in 16 patients.
[b]Percentages within columns.
[c]Unemployed also includes job seeking.
[d]WAS = work ability score = only from patients aged below 65 years who were currently employed or had experiences with employment (*N* = 3283, from 56 patients WAS unknown).
[e]Work limitations among employed patients (*N* = 2756, from 11 patients sex unknown).

ratios (ORs) and 95% confidence intervals (CIs) were calculated using multivariable logistic regression. The level of statistical significance was set at $P \leq .05$ and all reported P values were two-tailed. All statistical analyses were performed using SPSS statistical software for Windows (version 23; IBM, Armonk, New York).

3 | RESULTS

A total of 4028 adults with CHD were enrolled in APPROACH-IS. Characteristics of the study population are described in Table 1. Median age was 32 years (IQR 25-42). Slightly more women than men (53% vs 47%, $P = .002$) were included and CHD distribution was more severe in men. The majority of patients originated from Europe or North America, had at least a high school degree, were married or living with a partner, had no children and had NYHA functional class I symptoms. Fifty-one percent of all patients had a college or university degree.

Data on employment status were missing from 35 (<1%) participants. In addition, 135 (3%) patients 65 years or older, 334 (8%) homemaker or retired, 157 (4%) students, and 180 (5%) unemployed or disabled patients who considered themselves entirely unable to work, were excluded. Exclusion criteria were partly overlapping. Factors influencing employment status and work ability were assessed on the remaining 3283 (82%) patients.

3.1 | Employment status

As shown in Table 1, 69% of all patients were employed, varying from 43% in India to 80% in Belgium. Employment status per country is depicted in Figures 1 and 2 (see Tables S1, S2, and S3, and, Table 1, for exact numbers). Women were generally less often employed than men (65% vs 74%, $P < .001$), varying from 23% in India to 77% in Belgium. Disability rates increased by age and CHD severity (from 4% in mild to 11% in severe CHD, $P < .001$). Additional data on employment status, WAS and work limitations according to CHD complexity can be found online in Table 2. As shown in Figure 1, employment rates were lower than expected in 8 of 12 countries, particularly in India and Switzerland, and higher than expected in the remaining 4 countries. There was notable variation between countries, ranging from an employment rate of 18% above the general population in Belgium to 18% below the general population in India. Overall, unemployment (including job seeking) was observed in 10% of patients, equally in men and women. In all countries except for Belgium and The Netherlands, unemployment rates were higher in CHD patients than in the general population (Table 1).The proportion of patients

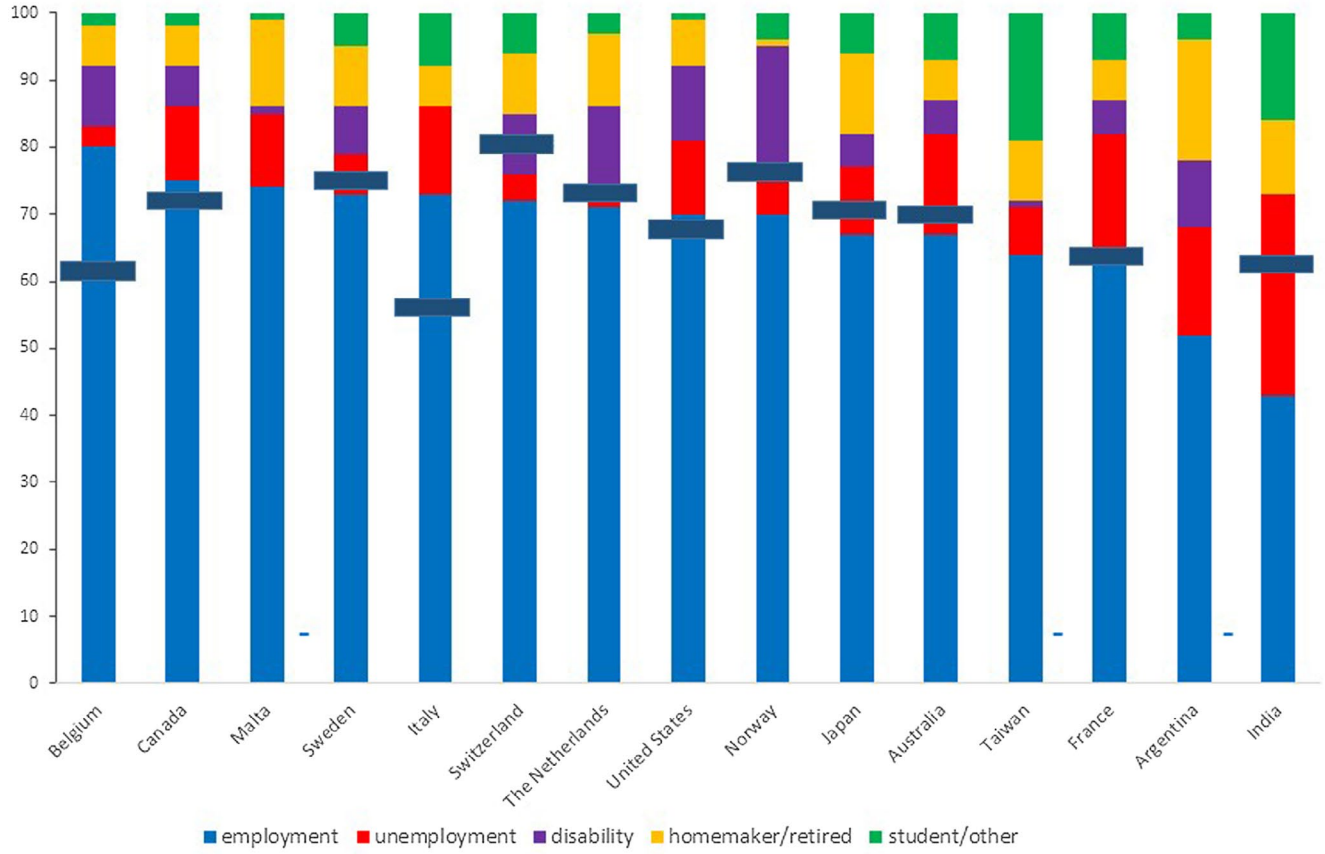
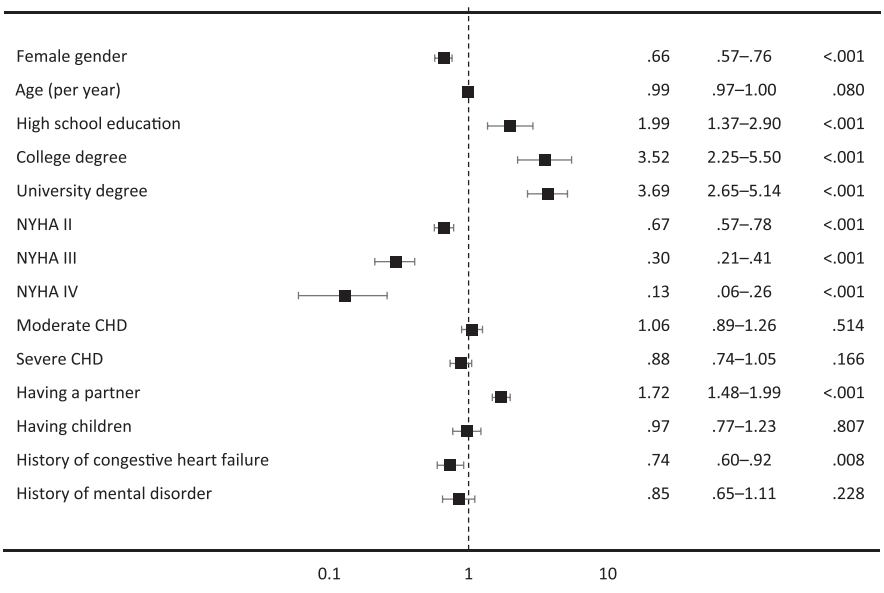


FIGURE 1 Distribution of employment status in ACHD patients per country. Since reference data are not available, employment rates for the general population per country (available for 12 countries) were derived from the Organisation for Economic Co-operation and Development (OECD). They are highlighted with a dark blue bar

FIGURE 2 Distribution of employment and work limitations (work limitations among employed patients) among participating countries. This map shows the amount of employment and work limitations per country, with darker colors reflecting less unemployment and more limitations. Participating countries with total number of participants and percentage employed: Argentina (*N* = 174, 52% employed), Australia (*N* = 132, 67%), Belgium (*N* = 275, 80%), Canada (*N* = 517, 75%), France (*N* = 95, 63%), India (*N* = 199, 43%), Italy (*N* = 64, 74%), Japan (*N* = 257, 67%), Malta (*N* = 116, 74%), Norway (*N* = 172, 70%), Sweden (*N* = 468, 73%), Switzerland (*N* = 276, 72%), Taiwan (*N* = 250, 64%), The Netherlands (*N* = 254, 70%), and United States (*N* = 744, 70%)

TABLE 2 Factors associated with employment in adult CHD patients (*N* = 3283 with *N* = 2756 employed patients)

Variable	OR	95% CI	*P* value
Female gender	.66	.57–.76	<.001
Age (per year)	.99	.97–1.00	.080
High school education	1.99	1.37–2.90	<.001
College degree	3.52	2.25–5.50	<.001
University degree	3.69	2.65–5.14	<.001
NYHA II	.67	.57–.78	<.001
NYHA III	.30	.21–.41	<.001
NYHA IV	.13	.06–.26	<.001
Moderate CHD	1.06	.89–1.26	.514
Severe CHD	.88	.74–1.05	.166
Having a partner	1.72	1.48–1.99	<.001
Having children	.97	.77–1.23	.807
History of congestive heart failure	.74	.60–.92	.008
History of mental disorder	.85	.65–1.11	.228



Abbreviations: NYHA = New York Heart Association (functional class); CHD = congenital heart disease.

working part-time varied between countries from 8% in India to 51% in Australia. Women were more likely to work part-time than men (35% vs 17%, *P* < .001, Table 1). Overall, part-time employment did not differ according to CHD severity (Table 2), but patterns in part-time workers varied strongly between countries. For example, in Australia, part-time workers were mostly patients with more severe CHD, whereas in The Netherlands, mainly women worked part-time.

Factors associated with less employment in multivariate logistic regression analyses by generalized linear models were female sex, worse NYHA functional class, and a history of congestive heart

failure (but not CHD severity) (Table 2). Higher education (ORs ranging from 1.99, 95% CI 1.37-2.90 for only high school to 3.69, 95% CI 2.65-5.14, for university degree) and having a partner (OR 1.72, 95% CI 1.48-1.99) were positively associated with being employed.

3.2 | Work ability

Most employed patients (77%) found themselves well capable of working, expressed in a WAS of 8 or higher. This varied from 57% in Taiwan to 94% in Malta (data per country shown online in Table 1). In total, only 283 patients (9%) with working experiences scored a WAS of 5 or below (ranging from 0% in Malta to 19% in India). Among all employed patients, 5% considered themselves not at all capable of working, varying from 0% in Argentina, Malta, and The Netherlands to 11% of employed patients in India and Taiwan.

3.3 | Work limitations

Among currently employed patients, 34% experienced some degree of limitations (varying from 16% in Malta to 50% in India and Taiwan, Table 1). Figure 2 reflects the employment situation including limitations per country. Patients that experienced working limitations were slightly older (35 ± 11 vs 34 ± 11 years, $P < .001$) and more likely to be female: limitations were reported by 37% of working women vs 32% of working men ($P = .010$). Part-time workers reported more limitations than patients who worked full-time (43% vs 31% limitations among full-time workers, $P < .001$). Table 3 shows that female sex (OR 1.36, 95% CI 1.17-1.58), increasing age (OR 1.03, 95% CI 1.02-1.04; for each increasing year of age, 3% more limitations were seen), more severe CHD (OR 1.31, 95% CI 1.09-1.58 for moderate to 2.10, 95% CI 1.68-2.62 severe CHD), history of congestive heart failure (OR 1.57, 95% CI 1.19-2.08), and mental illness (OR 2.26, 95% CI 1.67-3.06) were all associated with limitations at work. Only 4% of patients with work limitations had none of these associated factors. A university degree was the only factor associated with fewer limitations (OR 0.62, 95% CI 0.41-0.93). Patients with more severe CHD reported more work limitations (presented in Table 2, together with the reported symptoms). The impact of severe CHD (compared to nonsevere CHD) on work limitations varied greatly by country, but was strongly predictive in Japan, India, Sweden, Switzerland, Canada, and the United States (ORs ranging from 1.9 to 5.2, see Table 3).

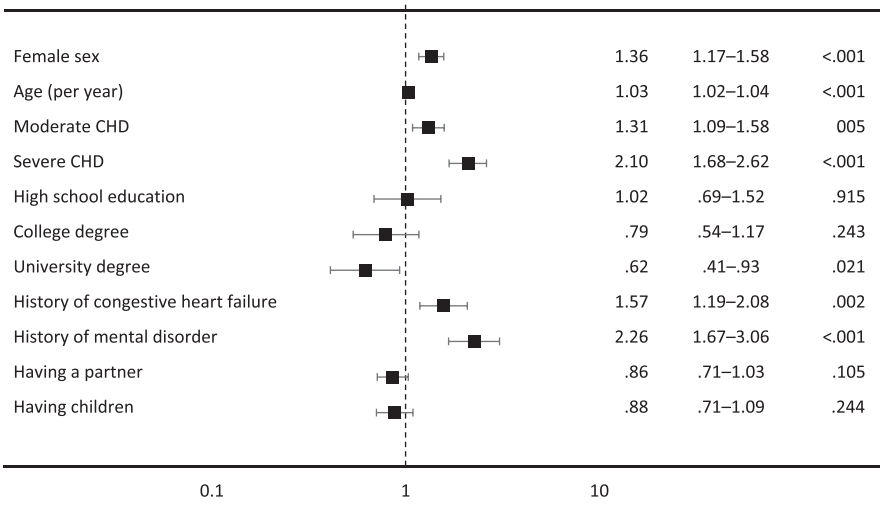
4 | DISCUSSION

In the present study, employment was studied in a large international cohort using a uniform methodology. The majority of CHD patients were employed, despite experiencing severe limitations. The most significant factors positively associated with employment were education and male gender.

To date, there are only a few prior studies investigating employment in adults with CHD and—despite increasing focus on patient-reported outcomes—they are mostly limited to the assessment of employment status. Previous studies indicated that adults with CHD from Western Europe and the United States were less likely to be employed than healthy controls, particularly in cyanotic but even in mild CHD.[8-10,12,26] However, two Scandinavian studies reported employment levels higher than observed in the general population.[14,15] In our study, employment rates were lower than in the general population in most countries, but there was substantial variation between countries. Since the same questionnaires and

TABLE 3 Risk factors associated with work limitations among employed patients ($N = 941$ in $N = 2756$ employed patients)

Variable	OR	95% CI	*P* value
Female sex	1.36	1.17–1.58	<.001
Age (per year)	1.03	1.02–1.04	<.001
Moderate CHD	1.31	1.09–1.58	005
Severe CHD	2.10	1.68–2.62	<.001
High school education	1.02	.69–1.52	.915
College degree	.79	.54–1.17	.243
University degree	.62	.41–.93	.021
History of congestive heart failure	1.57	1.19–2.08	.002
History of mental disorder	2.26	1.67–3.06	<.001
Having a partner	.86	.71–1.03	.105
Having children	.88	.71–1.09	.244



Abbreviation: CHD = congenital heart disease.

reference data were used for all participating countries, we assume that there are indeed genuine differences in the impact of CHD on employment status in different continents and countries.

Although the majority of patients were employed and self-reported as well capable of working, one third experienced limitations at work. More work limitations and a poor self-declared work ability were observed in economically disadvantaged countries. This may be explained by insufficient social security with less financial support for disabled patients. For example in India, a considerable number of employed patients still considered themselves not capable of working and 50% reported limitations. However, even in a wealthy country like Australia, patients with cardiovascular disease have been reported to be at risk of living in poverty when unemployed due to their condition.[27]

4.1 | Predictors for employment and limitations at work

Factors associated with employment in adults with CHD were in great part similar to factors associated with employment in the general population and in other chronic diseases.[17] Higher educational levels and male gender were associated with more employment. Our previous qualitative study on barriers and limitations at work showed that less physical work was beneficial for our patients.[11] Higher education generally leads to jobs with less physical work, more internal and external recovery possibilities, and, often, better job conditions. However, patients with CHD are at increased risk for neurodevelopmental disorders.[28] On the whole, patients with CHD attain lower educational levels than the general population.[10,29-32] Since this study demonstrates a positive effect on employment and limitations at work from higher education, efforts should be undertaken to maximize academic attainment in this population. In a scientific statement, Marino et al. called for vocational planning early in adolescence to maximize appropriate educational options.[28] Previous studies have indicated that patients with CHD lack advice on education and career.[8,11] Although they were less likely to consider offered advice helpful than healthy controls, the chance to return to work in patients on sick leave can be influenced by the treating physician.[33] Since most patients with CHD are in lifelong cardiac care, the potential impact of advice from health care providers should not be taken lightly.

As in the general population, female gender was found to be a risk factor for less employment.[23] This factor might therefore be more of a cultural reflection of specific gender roles or social stereotyping than a specific risk factor for patients with CHD. However, in prior studies comparing adult CHD patients to the general population, the effect of CHD on employment was larger for men, meaning that employment patterns in male CHD patients differed more from the patterns in the male general population than female patterns did.[9,10,34] It would be interesting, but beyond the scope of this study, to compare male and female working patterns per country.

What could promote successful employment in CHD patients besides good education? Besides early developmental interventions and governmental disability support, hypothetically, working part-time could be seen as a way to stay employed despite limitations. In our study, patients working part-time reported more limitations than those working full-time. However, in countries where a large proportion of patients worked part-time, disability, or unemployment rates were not specifically lower than countries with fewer part-time workers. Working part-time requires flexibility from the employer to accommodate part-time employment and requires alternative sources for the patient for the remaining income. The lack of the latter may explain that for some patients in certain countries, working part-time was not an option.

4.2 | Strengths and limitations

The relatively large sample size is a major strength of this study. However, the number of participants (as well as countries per continent) varied between countries, which did not allow for detailed analyses on a national or continental level. Furthermore, the most important limitation, is the lack of reference data on employment on a national level. Therefore, the influence of socioeconomic and cultural factors is unknown. The study was based on uniform questionnaires assessing patient-reported outcomes. In hindsight, definitions—favorably country-specific—could have been made more explicit, since some descriptions such as "disability" may have different meanings or regulations between countries. Similarly, the Work Ability Score consists of a "ladder" scale system and the way in which patients interpret this scale and are likely to choose extreme values, could be influenced by country or culture. Furthermore, data on work limitations were only studied in employed patients. This selected sample is likely healthier than the larger CHD population (known as the "healthy worker effect"), thereby limiting generalizability of our findings.[35] However, we prioritized internal validity by including only employed patients. Any bias from a "healthy worker effect" is likely in the direction of underestimation of work-related limitations.

5 | CONCLUSIONS

A history of CHD has consequences beyond the medical field. Although most adults with CHD are employed, CHD continues to have a negative impact on employment. Further, in this global study with uniform questionnaires, employment status and difficulties varied widely between countries. Differences could only be partly explained by economic status. Education is the main predictor for successful employment with higher education appearing to even protect against limitations at work. Since the Work Ability Score (WAS) has proven to be a useful tool to predict future disability in other chronic diseases, a longitudinal follow-up study is required to determine whether it can also predict disability in CHD patients. In the meantime, a poor WAS in an employed patient should be considered a poor prognostic sign that needs to be addressed and may indicate consultation of an occupational physician or therapist. In general, our results support advocating for patients with CHD to reach their full educational potential.

REGISTRATION

ClinicalTrials.gov: NCT02150603.

AUTHOR CONTRIBUTIONS

On behalf of the APPROACH-IS consortium and the International Society for Adult Congenital Heart Disease (ISACHD)

Maayke A. Sluman: Concept/Design; Data collection; Data analysis/interpretation; Statistics; Drafting article; Critical revision of article; Approval of article.

Silke Apers: Data collection; Critical revision of article; Approval of article.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

TABLE S1 Employment status, work ability and work limitations per country, N=3993

TABLE S2 Employment status, WAS and work limitations per CHD severity

TABLE S3 Impact of severe CHD as risk factor for work limitations (N=941 among N=2756 employed participants), adjusted for age and sex

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