Employment in Adults With Congenital Heart Disease

Mascha Kamphuis, MD; Ton Vogels, MA; Jaap Ottenkamp, MD, PhD; Ernst E. van der Wall, MD, PhD; S. Pauline Verloove-Vanhorick, MD, PhD; Hubert W. Vliegen, MD, PhD

Objective: To evaluate job participation, career-related problems, and actual job problems in adults with complex congenital heart disease (CHD) compared with adults with mild CHD and reference groups.

Design: Cross-sectional study.

Setting: Patients were randomly selected from the archives of the Department of Pediatric Cardiology, Leiden University Medical Center, Leiden, the Netherlands.

Patients and Main Outcome Measures: In total, 76 patients with complex CHD and 80 with mild CHD (age range, 17-32 years) completed a self-reported questionnaire on employment and handicaps, with reference data available (response rate, 70%).

Results: In the study groups, 45 (59%) of 76 patients with complex CHD had a paid job compared with 61 (76%) of 80 patients with mild CHD. Patients older than 25 years with complex CHD had significantly lower job participation (64%) than the general population (83%). Multiple logistic regression showed that type of CHD and level of education were significantly and independently related to job participation (odds ratio, 4.8; 99% confidence interval, 1.2-19.6; and odds ratio, 4.7; 99% confidence interval, 1.3-17.2, respectively). Of the 76 patients with complex CHD, 42 (55%) experienced disease-related career problems, in contrast to only 1 patient with mild CHD. Both CHD groups had more job-related mobility handicaps than did the reference group. However, in the mild CHD group, handicaps could be attributed to additional noncardiac diseases.

Conclusions: Patients with complex CHD have reduced job participation compared with patients with mild CHD and the general population. Many receive disability benefits or experience career problems or job handicaps. Career counseling focusing on physical abilities and level of education may help prevent or reduce these job-related problems.

Arch Pediatr Adolesc Med. 2002;156:1143-1148

ADVANCES IN medical and surgical treatment of congenital heart disease (CHD) have led to the survival of increasing numbers of young adults with a range of residual cardiovascular abnormalities. Employment prospects are a major concern for patients and their parents. Paid employment is important in daily life, not only in terms of earnings and social status, but also for its social support and social distraction.1 Moreover, a recent report has revealed an association between unemployment and depression in cyanotic patients with CHD.2 Although various studies have shown that most patients with CHD are able to work,3-7 it is unclear whether patients experience handicaps and, if so, which adaptations would be helpful. Such information could help improve vocational counseling and employment prospects of patients with CHD.

Therefore, the aim of this study was to evaluate job participation, career-related problems, and job handicaps in adults who had previously undergone operations for complex CHD. These data were compared with those of patients with mild CHD. For job participation and job handicaps, data were also compared with a reference group from the general population.

METHODS

The study was approved by the local medical ethics committee, and informed consent was obtained from each participant.

The study was cross-sectional. Information on cardiac diagnosis was searched for retrospectively; however, if the information was more than 1 year old, patients were re-examined.

PATIENT SELECTION

In total, 80 patients who had undergone operations for CHD (complex) and 80 with mild CHD were needed for the study to reach sufficient power. We selected patients from a representative sample of patients with CHD from the Dutch population and not just those who currently visited the Leiden University Medical Center, Leiden, the Netherlands. There-
fore, patients were selected from the archives of the Department of Pediatric Cardiology, Leiden University Medical Center, which has complete information on patients seen from 1950 onward; 4383 of these patients were born between 1968 and 1982. All patient files were numbered, and the files were studied using a random numbering list. Patients were categorized in a certain CHD group, and then excluded, owing to death or mental retardation, for example, or included for further study. After 30 patients were included, their latest medical information and home addresses were obtained from the most recent medical file, either the general practitioners' or the local authorities' because the archives contained only information from childhood. It was important to find out if the patient was still alive and still met the criteria for mild or complex CHD. If the patient could indeed be included according to our criteria, the patient was invited to participate. This process continued until 80 patients in each group had agreed to participate. In all, 2280 files from the archives were studied, including 500 patients with complex or mild CHD; 128 patients had died, and others were excluded for mental retardation (n = 51), not speaking Dutch/not living in the Netherlands (n = 46), or having participated in a previous study (n = 44). Seven patients were lost to follow-up. The remaining 224 patients (86 with complex and 138 with mild CHD) were invited to participate in the study. Of these, 160 agreed to participate, and 136 returned the questionnaire.

SUBJECT GROUPS

Complex CHD

Patients who had undergone operations for complex CHD were approached, excluding those who underwent anatomic or surgical corrective surgery according to sequential segmental analysis (a proven practical system for the classification of CHD based on the anatomical construction of the heart). All included patients had undergone a nonanatomical correction, such as venous switch for transposition of the great arteries, a correction with the use of autologous tissue (eg, Rastelli correction or insertion of a mechanical valve), or partial or complete cavopulmonary connection. The main common characteristic of this group was that, postoperatively, none of the participants had an anatomically normal heart as described by segmental analysis, in contrast to patients who underwent anatomical corrective surgery (to treat, for example, ventricular or atrial septal defects, coarctation of the aorta, patent ductus arteriosus, pulmonary or aortic stenosis, uncomplicated tetralogy of Fallot, and total anomalous pulmonary venous connection).

Mild CHD

Patients with mild CHD and patients with a spontaneously resolved congenital heart lesion were included in the study. None needed an operation or intervention because the malformation was diagnosed as hemodynamically insignificant. The hypothesis was that this group would not experience heart-related problems in daily life. Therefore, for comparison with patients with complex CHD, this group was considered to be a control group.

Reference

In addition, reference groups were available for comparison with patient data on job participation and job handicaps. For job participation, patients were compared with the general population concerning the overall percentage employed and the percentage employed divided into different age groups, available from the central database of Statistics Netherlands for 1999. For job handicaps, patient data were compared with data from a nonimpaired healthy reference group of 185 subjects selected in a study by Andries et al.10

QUESTIONNAIRE

The self-completed questionnaire covered the following subjects. Job participation and demographic data, including age, sex, and education, were evaluated. Primary education included education and vocational training for 12- to 16-year-olds, whereas higher education included secondary education and university.

Career-related problems were evaluated with 5 questions as part of the “difficulties in daily life” module that covered life and health insurance, education, employment, sports, and other daily activities. For employment, the questions concerned feeling restricted in the choice of a job, being excluded from a job, having given up on a job, being excluded from a job after a medical examination, and not being promoted. If a problem was noted, it was determined whether it was caused by the cardiac disorder.

Job handicaps were evaluated with a questionnaire that was developed and validated in other research projects within the TNO (Netherlands Organization for Applied Scientific Research) Vocational Handicap Research Program.10,12,13 This questionnaire comprised 3 different parts: daily life activities (for all respondents), work activities and adaptations (for those presently working), and reasons for stopping work and adaptations (for those with previous work experience). Job handicaps were measured by comparing job demands and patient or worker abilities, as well as adjustment at work. Therefore, daily living difficulties were evaluated for 18 different activities divided into 5 domains: mobility (7 activities), communication (3 activities), mental abilities (3 activities), hand/arm movements (3 activities), and physical power (2 activities). Then, it was assessed whether these activities were performed at work, and if so, whether they caused difficulties. By comparing daily life activities with the same activities performed at work, the following classifications were determined for job handicaps:

1. No difficulty: the activity caused no difficulty at all or was not applicable at work.
2. Adaptation: the activity caused difficulty in daily life but not at work because certain adaptations had been made.
3. Job handicap: the activity caused difficulty both in daily life and at work, adaptations not withstanding.

STATISTICAL ANALYSIS

To examine the effects of CHD (complex or mild), age, sex, and level of education on job participation, multiple logistic regression analyses were performed. These analyses included all patients except students because their reason for not having a job (still attending school) was not related to CHD. Patients were categorized as working if they had a paid job for more than 12 hours a week.

For job handicaps, chi² analyses were used for comparison between patients with complex or mild CHD and the nonimpaired healthy reference group with regard to overall and domain-specific percentages. Therefore, the percentages for no difficulty, adaptation, and handicap were dichotomized as follows: no difficulty vs other, adaptation vs other, and handicap vs other.

Nonresponse analyses concerning age, sex, disease group, and distance to the hospital were also performed using χ² tests. P ≤ .01 was considered significant.

©2002 American Medical Association. All rights reserved.
RESULTS

PATIENTS

Of the 224 patients selected, 160 agreed to participate. Four patients did not return their questionnaires, so analyses were based on a sample of 156 patients. This resulted in an overall response rate of 70%, with an 88% response rate in the group of patients with complex CHD vs 58% for the group of patients with mild CHD. Table 1 lists the diagnoses and presents the number of patients per diagnosis or operation. All 156 participants, 73 men and 83 women, were aged between 17 and 32 years, with a mean age of 24.5 years (Table 2).

Nonresponse analyses between participants and nonparticipants within the group of patients with mild CHD showed the following significant differences. Participants in this group lived closer to the hospital than nonparticipants, and the response rate for participating women (50% [66%] of 76) was significantly higher than that for men (30% [48%] of 62). In addition, the response rate in the group of patients whose mild cardiac lesion had resolved (36% [73%] of 49) differed significantly from responses in the group with current mild disease (44% [49%] of 89).

JOB PARTICIPATION

A total of 45 (59%) of 76 patients with complex CHD had a paid job, compared with 61 (76%) of 80 patients in the mild group, which is significantly different. These rates of job participation were similar to the reference group from the general population (66%). However, in the 25- to 29-year-old group, job participation among patients with complex CHD 18 (64%) of 28 was significantly lower (P = .008) than that in the general population (83%).

Twenty patients, 17 with complex CHD, received full or partial disability benefits. Among patients with complex CHD who received disability benefits, 3 (8%) of 38 had a systemic right ventricle, 6 (27%) of 22 had conduit of mechanical protheses, 4 (36%) of 11 had univentricular atroioventricular connection, and 4 (80%) of 5 underwent a palliative operation.

Multiple logistic regression on the sample excluding students showed that having complex CHD (P = .004) and only a primary education (P = .002) increased the risk for unemployment significantly and independently (Table 3). Female sex and age had no significant influence.

Patients with complex CHD worked in a wide range of sometimes physically demanding occupations, such as welder, driver, electrician, waiter, cook, construction worker, nurse, or computer worker.

CAREER-RELATED PROBLEMS

Patients with complex CHD reported the following problems: feeling restricted in the choice of a job (39% [51%] of 76), being excluded from a job (13% [17%]), having given up on a job (12% [16%]), being excluded from a job after a medical examination (7% [9%]), and not being promoted (2% [3%]). Considering all these problems together, 42 patients (55%) reported having at least 1 problem in their career as a result of their heart disease. The main reasons patients stopped working were physical disabilities, tiredness, and emotional problems.

Only 1 patient with a mild aortic stenosis had to choose another job. He wanted to join the army, which was not possible with this defect. No other cardiac-related problem was mentioned in the mild CHD group.

Table 1. Diagnoses and Operations in Patients With Congenital Heart Disease (CHD)*

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Operation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systemic right ventricle (n = 38)</td>
<td>Senning (n = 11) or Mustard (n = 10)</td>
</tr>
<tr>
<td>TGA (n = 21)</td>
<td>Senning (n = 3) or Mustard (n = 2) with PS repair</td>
</tr>
<tr>
<td>TGA and PS (n = 5)</td>
<td>Senning (n = 5) or Mustard (n = 1) with ventricular SD closure and PS repair</td>
</tr>
<tr>
<td>TGA, ventricular SD, and PS (n = 6)</td>
<td>Ventricular SD closure with PS repair (n = 2)</td>
</tr>
<tr>
<td>Congenitally corrected TGA, ventricular SD, and PS (n = 2)</td>
<td>Conduit or mechanical prosthesis (n = 22)</td>
</tr>
<tr>
<td>Palliative operation (n = 5)</td>
<td>Glenn shunt (n = 1)</td>
</tr>
<tr>
<td>Atrioventricular SD (n = 1)</td>
<td>Modified Blalock-Taussig shunt (n = 1)</td>
</tr>
<tr>
<td>Double inlet LV (n = 1)</td>
<td>After Glenn shunt, atrioventricular shunt axillary (n = 1)</td>
</tr>
<tr>
<td>Univentricular heart (n = 1)</td>
<td>After banding pulmonary artery, pulmonary hypertension (n = 1)</td>
</tr>
<tr>
<td>TA (n = 8)</td>
<td>Fontan (n = 1)</td>
</tr>
<tr>
<td>TA and TGA (n = 1)</td>
<td>Fontan (n = 1)</td>
</tr>
</tbody>
</table>

*MGA indicates simple transposition of the great arteries; PS, pulmonary stenosis; PA, pulmonary atresia; SD, septal defect; AS, aortic stenosis; TA, tricuspid atresia; LV, left ventricle; and ellipses, not applicable.
For job handicaps, no significant differences were found between the complex and mild CHD groups. However, the reference group had a significantly lower rate of mobility handicaps (7 [4%] of 185 patients) than did patients with complex (5 [14%] of 36; \( \text{P} = .001 \)) or mild (7 [12%] of 61; \( \text{P} = .002 \)) CHD. No significant differences were found for the other domains at work. In contrast to the patients with complex CHD, all 7 patients with mild CHD who experienced a handicap suffered from a noncardiac disease, such as knee or shoulder problems or asthma. Of the 5 patients with complex CHD who experienced handicaps, 3 had a systemic right ventricle, and 2 had a conduit or mechanical prosthesis.

**SPECIFIC ADAPTATIONS**

Patients with complex CHD mostly stopped working or wanted another job because the work was physically too strenuous, they had emotional problems, or there were problems with transportation. Only 2 patients mentioned specific adjustments for disease-related handicaps at work, but 10 patients would have appreciated adaptations (12 [27%] of 44 who answered the questionnaire).

The most important adaptations were more flexibility in working hours, reduced time-pressure demands, adapted working hours, and increased freedom to organize one’s work. In the reference group, 13% wanted at least 1 of these adaptations. Patients with mild CHD did not mention any specific adaptation related to their heart defect.

**COMMENT**

This study evaluated job participation, career-related problems, and job handicaps for adults with complex CHD compared with adults with mild CHD and reference groups.

**JOB PARTICIPATION**

Most patients with complex CHD were employed. However, the percentage of working patients with complex CHD is significantly lower than in the mild CHD group (59% vs 76%, respectively) or the 25- to 29-year-old general population group (64% vs 83%, respectively). Excluding 2 studies that presented extreme percentages,2,14 in studies of patients with complex CHD,5,6,15-17 the rates of job participation ranged from 71% to 84%; this is somewhat higher than in the present study. The percentage of patients with complex CHD who received disability benefits (26%) is higher than the 10% to 15% reported in other studies.5,6,15 This is probably owing to the high level of social security in the Netherlands compared with other countries. Multivariate analyses showed a relationship between the CHD group and education and job participation, in accordance with a previous study.12 Although cause and consequence cannot be predicted from this cross-sectional study, it seems plausible to assume that having complex CHD increases the risk for unemployment and that stimulating patients to complete the highest possible educational level will improve their job prospects.

**CAREER-RELATED PROBLEMS**

More than half the patients with complex CHD experienced problems in their careers. Previous studies have reported similar problems;3,15,18,19 however, because of differences in diagnoses studied and questions asked, specific comparison is difficult. In our study, patients with complex CHD reported significantly more career-related problems than did patients with mild CHD.

---

**Table 2. Patient Characteristics**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Complex</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean, median (range), y</td>
<td>24.3, 24.5 (18-32)</td>
</tr>
<tr>
<td>Male sex</td>
<td>43 (57)</td>
</tr>
<tr>
<td>Medical care &gt;1 y ago</td>
<td>6 (8)</td>
</tr>
<tr>
<td>Education level</td>
<td>32 (42)</td>
</tr>
<tr>
<td>Daily life</td>
<td>44 (58)</td>
</tr>
<tr>
<td>Employed &gt;12 h/wk</td>
<td>43 (57)</td>
</tr>
<tr>
<td>Employed + disability, partial</td>
<td>2 (3)</td>
</tr>
<tr>
<td>Student</td>
<td>11 (15)</td>
</tr>
<tr>
<td>Student + disability benefits, full</td>
<td>4 (5)</td>
</tr>
<tr>
<td>Disability benefits, no activities</td>
<td>10 (13)</td>
</tr>
<tr>
<td>Other (housewife, unemployed, or sick leave)</td>
<td>5 (7)</td>
</tr>
<tr>
<td>Other + disability benefits, full</td>
<td>1 (1)</td>
</tr>
<tr>
<td>Other + disability benefits, partial</td>
<td>...</td>
</tr>
</tbody>
</table>

*Data are presented as the number (percentage) of patients unless otherwise indicated. Ellipses indicate not applicable.*

**Table 3. Effects of Variables on Employment Status Based on Multiple Regression Analysis**

<table>
<thead>
<tr>
<th>Variable</th>
<th>% of Patients</th>
<th>Odds Ratio (99% Confidence Interval)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Congenital heart disease</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild†</td>
<td>9</td>
<td>4.8 (1.2-19.6)</td>
</tr>
<tr>
<td>Complex</td>
<td>31</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Higher†</td>
<td>12</td>
<td>4.7 (1.3-17.2)</td>
</tr>
<tr>
<td>Primary</td>
<td>36</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male†</td>
<td>14</td>
<td>3.5 (0.9-13.4)</td>
</tr>
<tr>
<td>Female</td>
<td>25</td>
<td></td>
</tr>
<tr>
<td>Age, y</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17-24†</td>
<td>29</td>
<td>1.0 (0.3-3.7)</td>
</tr>
<tr>
<td>25-32†</td>
<td>29</td>
<td></td>
</tr>
</tbody>
</table>

*Sample (n = 131) does not include students.*

©2002 American Medical Association. All rights reserved.
JOB HANDICAPS

For job handicaps, significant differences between both patient groups and the reference group were found for mobility. None of the patients with complex CHD who reported handicaps had another chronic disease, in contrast to the group with mild CHD in which all patients with handicaps had a noncardiac chronic disease. Therefore, it is assumed that for patients with complex CHD, handicaps were related to the cardiac defect. Physical problems were frequently reported as a specific reason for quitting a job. The most important specific adaptations mentioned concerned working time and workload.

The results of this study allow us to make recommendations specifically for the group of patients with complex CHD. Career counseling and use of job adjustments, taking into account physical abilities, are important in this patient group to prevent unemployment and dependency on disability benefits and to reduce work-related problems. Using existing guidelines for counseling might be helpful.20 The patients mentioned specific adaptations mainly concerning working time and workload. Creating opportunities to work at home could also reduce or prevent job-related problems. Another important issue is encouraging patients to complete higher education because this is associated with higher levels of job participation.

Patients should also be made aware that questions about medical health are prohibited during job interviews, according to the Dutch Medical Examinations Act of 1997. In addition, in the Netherlands, specific financial advantages are available for employers who hire persons with a handicap. In the United States, the National Rehabilitation Act of 1973 prohibits discrimination because of a preexisting condition.21,22 Celemajer and Deanfield23 found inconsistencies in job policy that might be due to a lack of appropriate guidelines for the outcome of adults with CHD. This could also cause unnecessary problems and even unemployment. Therefore, informing employers and company physicians about this outcome is recommended. Advising patients about these issues is an important task for pediatric or congenital cardiologists who deal with adult patients.

STUDY LIMITATIONS AND REMARKS

The results of this study might have been affected by selection bias. The difference in response percentages between patients with complex and mild CHD (88% vs 58%) can be explained. Most patients with mild CHD had their latest medical examination more than 1 year previously and had to visit the hospital for an updated cardiac examination, which involved more effort than just answering the questionnaire. This could also explain why participants in the mild CHD group lived closer to the hospital than nonparticipants. In addition, more patients who could make this visit might have been unemployed. This could then explain the difference in the response rate of participating women (66%) and men (49%), assuming that more men than women have jobs. Therefore, job participation in the mild CHD group might still be underestimated. The response rate in the group of patients whose mild cardiac lesion had resolved (74%) differed from that in the group with actual mild CHD (50%). During cardiac reexamination, it was observed that most patients asked questions or expressed worries that they had lived with for several years. Possibly, patients with relatively more difficulties or questions might have joined the study, influencing results toward more difficulties in this participating group of patients with mild disease than in the entire group. As with the mild CHD group, there might also have been a negative selection of patients with complex CHD with relatively more unemployment and more difficulties or questions than in the total group. However, the influence on employment would only be minor because few participants had to visit the hospital for reexamination, and therefore arguments about time efforts are not relevant.

Studying only surviving patients implies a positive selection bias. This applies only to the group of patients with complex CHD because no cardiac death was reported in the group of patients with mild CHD.

The present study focused on relatively young patients. Because studies of medical outcomes have shown that physical condition decreases in patients with complex CHD after age 30 years, the number of reported problems would most likely increase with age. Furthermore, medical developments allow treating more patients with more complicated CHD than in the past. It is expected that a new generation of patients will experience even more career-related problems and more unemployment than the current study shows.

CONCLUSIONS

Paid employment is important in daily life, not only in terms of earnings and social status but also for social support and social distraction. Although various studies have shown that most patients with CHD are able to work, it is unclear whether patients experience handicaps and which factors are related to reduced job participation. Such information could contribute to improvements in vocational counseling and employment prospects for patients with CHD.

The present study shows that patients with complex CHD have reduced job participation compared with patients with mild CHD and the general population. Many receive disability benefits or experience career problems or job handicaps because of mobility. Career counseling focusing on physical abilities and level of education may help to prevent or reduce these job-related problems.

Patients with complex CHD have reduced job participation compared with patients with mild CHD and the general population. Many of them receive disability benefits or experience career problems or job handicaps (mainly concerning mobility). Career counseling focusing on physical abilities and level of education may help prevent unemployment and dependency on disability benefits and reduce job-related problems.
Accepted for publication August 5, 2002.

We thank Frank Andries, TNO Work and Employment, Amsterdam, the Netherlands, for advice on the use of the TNO Vocational Handicap Research Program questionnaire and for providing data on the reference group.

Corresponding author: Mascha Kamphuis, MD, TNO Prevention and Health, Wassenaarseweg 56, PO Box 2215, 2301 CE Leiden, the Netherlands (e-mail: kamphuis.m@freeler.nl).

REFERENCES