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Original Article

Educational achievement among long-term survivors of congenital heart defects: a Danish population-based follow-up study

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Abstract *Background:* Congenital heart defect patients may experience neurodevelopmental impairment. We investigated their educational attainments from basic schooling to higher education. *Patients and methods:* Using administrative databases, we identified all Danish patients with a cardiac defect diagnosis born from 1 January, 1977 to 1 January, 1991 and alive at age 13 years. As a comparison cohort, we randomly sampled 10 persons per patient. We obtained information on educational attainment from Denmark's Database for Labour Market Research. The study population was followed until achievement of educational levels, death, emigration, or 1 January, 2006. We estimated the hazard ratio of attaining given educational levels, conditional on completing preceding levels, using discrete-time Cox regression and adjusting for socio-economic factors. Analyses were repeated for a sub-cohort of patients and controls born at term and without extracardiac defects or chromosomal anomalies. *Results:* We identified 2986 patients. Their probability of completing compulsory basic schooling was approximately 10% lower than that of control individuals (adjusted hazard ratio = 0.79, ranged from 0.75 to 0.82 0.79; 95% confidence interval: 0.75–0.82). Their subsequent probability of completing secondary school was lower than that of the controls, both for all patients (adjusted hazard ratio = 0.74; 95% confidence interval: 0.69–0.80) and for the sub-cohort (adjusted hazard ratio = 0.80; 95% confidence interval: 0.73–0.86). The probability of attaining a higher degree, conditional on completion of youth education, was affected both for all patients (adjusted hazard ratio = 0.88; 95% confidence interval: 0.76–1.01) and for the sub-cohort (adjusted hazard ratio = 0.92; 95% confidence interval: 0.79–1.07). *Conclusion:* The probability of educational attainment was reduced among long-term congenital heart defect survivors.

Keywords: Congenital heart defects; educational status; population based; prognosis

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The prevalence of congenital heart defects is more than 6 per 1000 live births and is one of the most frequent congenital defects.[1] Most congenital heart defects are diagnosed during the first year of life, but age at diagnosis varies according to defect type and severity.[2] Survival of congenital heart defect patients has improved markedly during recent decades,[3] and the prevalence of adults living with severe congenital heart defects is increasing.[4] The current goal is to ensure these patients' broad well-being, including prevention of comorbidity and promotion of educational attainment.

Several factors affect the educational level of the congenital heart defect patients. Hospital stays may interfere with school attendance, or motivation may

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Table 1. Diagnostic categories with corresponding ICD-8 and ICD-10 codes.

Diagnostic category	ICD-8 codes	ICD-10 codes
Common arterial trunk	7460	Q200
Transposition of great vessels	7461	Q203, Q205
Tetralogy of Fallot	7462	Q213
Ventricular septal defect	7463	Q210
Atrial septal defect	7464	Q211
Atrioventricular septal defect	7465, 74641	Q212, Q218B
Anomalies of heart valve	7466	Q220–Q229, Q230–Q239
Other		
Other specified anomalies of heart	7468	Q201, Q202, Q204, Q206, Q208, Q209, Q214, Q218, Q219, Q240–Q248
Unspecified anomalies of heart	7469	Q249
Patent ductus arteriosus	7470	Q250
Coarctation of aorta	7471	Q251
Other anomalies of great arteries		
Other anomalies of aorta	7472	Q252–Q254
Stenosis or atresia of pulmonary artery	7473	Q255–Q256 Q257–Q259
Malformations of great veins	7474	Q260–Q264, Q268–Q269

ICD = International Classification of Diseases

be lacking as a result of emotional difficulties, social isolation, and restricted physical activity.[5–7] Perhaps most importantly, neurodevelopmental impairment may affect these patients' ability to pursue education, owing to, for example chromosomal abnormalities, preterm birth, or treatment-related factors.[8,9]

More information on long-term educational outcomes among the growing population of adults with congenital heart defects is needed to counsel patients and their parents, to provide appropriate care and follow-up, and to better understand the effect of congenital heart defects on the brain.[10] Interpretation of existing studies is hampered by the use of self-reported educational data, low participation rates,[11,12] failure to include all types of congenital heart defect,[13–15] follow-up ending after basic schooling,[16] and failure to control for socio-economic factors related to educational attainment.

We, therefore, undertook a nationwide study to compare the educational attainments of congenital heart defect patients, from basic schooling to higher education, with that of a population-based comparison cohort.

Patients and methods

Data on congenital heart defects

We conducted this population-based follow-up study using electronic data from the Danish National Registry of Patients to identify all Danish patients born between 1 January, 1977 and 1 January, 1991 who received a primary discharge diagnosis of congenital heart defect before the age of 13 years. These patients were followed until 1 January, 2006. The Danish National Registry of Patients contains information on all hospital admissions in Denmark, including patients' civil registration number, dates of admission and discharge, surgical procedures, and up to 20 discharge diagnoses coded exclusively by physicians according to the International Classification of Diseases. The 8th edition of the International Classification of Diseases was used until the end of 1993 and the 10th edition thereafter. International Classification of Diseases' eighth revision codes used to identify congenital heart defect patients were 746–747 – except for 746.7 and 747.5–747.9, which were not specific to congenital heart defects – and International Classification of Diseases' tenth revision codes Q20–Q26 – except for Q26.5–Q26.6, which were not specific to congenital heart defects. Diagnoses of patent ductus arteriosus were only considered for infants with gestational age of 37 weeks or more.

For study purposes, each patient was assigned one congenital heart defect diagnostic code, based on the first primary discharge diagnosis of congenital heart defect. We subsequently grouped International Classification of Diseases' tenth revision codes according to the corresponding International Classification of Diseases' eighth revision codes, to uniformly categorise the study cohort during the study period (Table 1).

We used Denmark's Civil Registration System to sample a comparison cohort of 10 persons per congenital heart defect patient, frequency matched on sex and year of birth.[17] The Civil Registration System also allowed us to identify the parents of all the patients in the study. The 10-digit unique civil registration number assigned to every Danish

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resident since 1968 allows for valid linkage among Danish national registries. In Denmark, all persons with congenital heart defects receive public health care free of charge.[18]

Data on educational attainment

We used Denmark's Integrated Database for Labour Market Research to obtain annually updated information on the educational level of each patient in the study and his/her parents, family structure, and parental income. Completion of the following educational levels was ascertained, with the corresponding International Standard Classification of Education level[19]: Basic schooling (9 or 10 years of compulsory education; International Standard Classification of Education level 2); Youth education (International Standard Classification of Education level 3), including upper secondary school and vocational education – the latter leading to jobs such as skilled craftsman or assistant nurse; Higher education, designated as short cycle (International Standard Classification of Education level 4), leading to jobs such as programmer or laboratory technician, medium cycle (International Standard Classification of Education level 5), leading to jobs such as primary school teacher or nurse, and long cycle (International Standard Classification of Education level 5), leading to jobs such as attorney or physician.

Data on extracardiac defects, chromosomal abnormalities, and preterm birth

We used the following codes to identify diagnoses of extracardiac defects and chromosomal abnormalities in the Danish National Registry of Patients: International Classification of Diseases' eighth revision: 310.40–310.41, 310.5, 311.40–311.41, 311.5, 312.40–312.41, 312.5, 313.40–313.41, 313.5, 314.40–314.41, 314.5, 315.40–315.41, 315.5, and 740.99–759.99 and International Classification of Diseases' tenth revision: DQ00.0–DQ99.9. We considered diagnoses given at all ages. According to a guideline from the European Surveillance of Congenital Anomalies (EUROCAT), we disregarded isolated minor defects such as torticollis (Q68.0) or protuberant ears (Q17.3).[20] We obtained data on gestational age from the National Medical Birth Registry and defined preterm birth as gestational age <37 weeks.

Data on mortality

We obtained data on vital status for the entire cohort through linkage with the Civil Registration System, which has kept electronic records on date of birth, date of emigration, and exact date of death for all Danish residents since 1968.[17]

Data analyses

Person-years at risk was calculated based on a prespecified age preceding the earliest age at which each educational level could be completed: 13 years of age for basic schooling; 16 years of age for youth education; 18 years of age for short-, medium-, and long-cycle higher education. Persons were followed until the level of education under investigation was attained or until death, emigration, or the end of the study period, whichever came first. We estimated the hazard ratio of attaining each educational level using discrete-time Cox regression analysis, with calendar time as the underlying time scale, conditional on attainment of the foregoing level. This method was adapted from Koch et al.[21] We report estimates adjusted for current age, sex, parental income, number of siblings, presence of only a single parent, and parents' highest educational level. The adjusted and unadjusted estimates were not substantially different. We repeated the analysis after excluding individuals in both cohorts who were born preterm or with extracardiac defects or chromosomal abnormalities.

Results

Descriptive data

Of the congenital heart defect patients born between 1977 and 1991, 2986 were alive at the age of 13 years. The proportion of patients born with extracardiac defects or chromosomal abnormalities (19%) or born preterm (8%) was higher in the congenital heart defect cohort than in the comparison cohort (4% and 4%, respectively; Table 2).

Educational attainment

The proportion of all congenital heart defect patients who completed basic schooling (85.0%) was lower than the corresponding proportion in the comparison cohort (87.5%; adjusted hazard ratio = 0.79; 95% confidence interval: 0.75–0.82). In addition, in the sub-cohort, after excluding persons born with extracardiac defects or chromosomal abnormalities or born preterm, the probability of attaining basic school education among congenital heart defect patients was lower than that for the comparison cohort (hazard ratio = 0.87; 95% confidence interval: 0.83–0.92). We repeated this analysis after grouping some of the patients as those with severe congenital heart defects, including common arterial trunk, transposition of great vessels, tetralogy of Fallot, atrioventricular septal

Table 2. Characteristics of CHD patients more than 13 years of age and the comparison cohort.

	Patients with CHD (frequency) n (%)	Comparison cohort (frequency) n (%)
All	2986	29,246
Preterm birth	232 (8)	1234 (4)
ECD or chromosomal abnormality	558 (19)	1177 (4)
Diagnostic categories		
Common arterial trunk	6	–
Transposition of great vessels*	72	–
Tetralogy of Fallot	89	–
Ventricular septal defect	727	–
Atrial septal defect	312	–
Atrioventricular septal defect	111	–
Anomalies of heart valve	151	–
Other anomalies of heart	1069	
Patent ductus arteriosus	231	–
Coarctation of aorta	140	–
Other malformations of great arteries	76	–
Malformation of great veins	2	–

ECD = extra cardiac defect; CHD = congenital heart defect
*Complete and congenitally corrected transposition

defect, anomalies of heart valve, other malformations of great arteries, and malformations of great veins, and as minor-to-moderate severity congenital heart defects, such as ventricular septal defect, atrial septal defect, patent ductus arteriosus, and coarctation of aorta. Congenital heart defect patients in both sub-groups had a lower probability of attaining basic schooling than controls and the estimates did not differ according to severity (severe congenital heart defects: hazard ratio = 0.87; 95% confidence interval: 0.76–1.00), moderate severity congenital heart defects: hazard ratio = 0.92; 95% confidence interval: 0.85–1.00.

Among patients who completed basic schooling, the proportion then completing youth education was lower among congenital heart defect patients (57.8%) than in the comparison cohort (67.4%; hazard ratio = 0.76; 95% confidence interval: 0.72–0.81). The lower probability of attaining youth education held in the sub-cohort analysis is due to differences in the attainment of upper secondary school education (hazard ratio: 0.80; 95% CI: 0.73–0.86), but not vocational education (hazard ratio: 1.03; 95% confidence interval: 0.87–1.25). Among sub-cohort patients completing youth education, the probability of then attaining a higher education was lower overall than that for the comparison sub-cohort (hazard ratio = 0.92; 95% confidence interval: 0.79–1.07) (Table 3).

Discussion

In this population-based follow-up study, we found a lower probability of completing basic and upper secondary school among congenital heart defect patients compared with a population-based control cohort. For all congenital heart defect patients who had completed youth education, the likelihood of completing a medium- or long-cycle higher education was also lower than that for population controls.

Our study findings extend previous research on this topic.[11–16] In line with our results, van Rijen et al[12] found lower-than-expected educational achievement in a study among adult Dutch patients with a wide range of congenital heart defect diagnostic categories, after exclusion of mentally retarded patients. In contrast to our findings, Nieminen et al[11] found that the educational level among congenital heart defect patients was comparable to that of the general population in a Finnish nationwide study encompassing all congenital heart defect diagnostic categories. However, this study was based on self-reports from congenital heart defect patients, with a response rate of 76%, using data from Statistics Finland on the educational level of the general population as a comparison. It was thus susceptible to both information and selection biases and did not control for socio-economic variables.

Several factors affect the interpretation of our findings. The congenital heart defect cohort was defined as individuals with a discharge diagnosis of congenital heart defect according to the Danish National Registry of Patients, and misclassification of exposure status may have occurred. However, the positive predictive value of congenital heart defect diagnoses in the Danish National Registry of Patients is reported to be high,[22] and any misclassification is most likely independent of future educational level.

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Table 3. Educational attainment of all CHD patients and the sub-cohort excluding patients born preterm or with extracardiac defects.

	All patients				After exclusion of individuals born preterm or with ECD or chromosomal anomalies			
Educational level	Number at risk*	Proportion who completed education (%)	Median age at completion (years)	Hazard ratio, adjusted (95% CI)***	Number at risk*	Proportion who completed education (%)	Median age at completion (years)	Hazard ratio, adjusted (95% CI)***
Basic school (born before 1991)**								
Comparison cohort	29,246	87.5	16.5	1	26,904	87.6	16.5	1
CHD patients	2986	85.0	16.6	0.79 (0.75–0.82)	2260	86.6	16.6	0.87 (0.83–0.92)
Youth education (born before 1987)**								
Overall								
Comparison cohort	20,531	67.4	20.4	1	18,923	68.0	20.4	1
CHD patients	2072	57.8	20.6	0.76 (0.72–0.81)	1617	62.3	20.6	0.83 (0.78–0.89)
Upper secondary								
Comparison cohort	20,531	48.1	20.1	1	18,923	48.7	20.1	1
CHD patients	2072	38.8	20.3	0.74 (0.69–0.80)	1617	41.8	20.2	0.80 (0.73–0.86)
Vocational								
Comparison cohort	20,531	24.7	22.1	1	18,923	24.8	22.1	1
CHD patients	2072	24.1	22.2	0.94 (0.79–1.12)	1617	26.6	22.3	1.03 (0.87–1.25)
Higher education (born before 1982)**								
Overall								
Comparison cohort	8554	31.1	25.3	1	7982	31.3	25.3	1
CHD patients	770	26.9	25.1	0.88 (0.76–1.01)	657	28.3	251	0.92 (0.79–1.07)
Short cycle								
Comparison cohort	8554	6.46	24.5	1	7982	6.5	24.5	1
CHD patients	770	6.10	23.8	0.98 (0.72–1.32)	657	6.7	23.8	1.08 (0.79–1.48)
Medium cycle								
Comparison cohort	8554	11.2	25.8	1	7982	11.2	25.8	1
CHD patients	770	8.8	25.8	0.82 (0.64–1.05)	657	9.3	25.8	0.82 (0.64–1.05)
Long cycle								
Comparison cohort	8554	14.1	25.1	1	7982	14.3	25.1	1
CHD patients	770	12.3	24.9	0.89 (0.72–1.11)	657	12.8	25.1	0.91 (0.73–1.14)

CHD = congenital heart defect; CI = confidence interval; ECD = extra cardiac defect

*Conditional on being alive at 13 years of age. Results are also conditional on completion of basic school before youth education and completion of youth education before higher education

**Restrictions based on birth year were made to enable attainment of educational level within the study period

***Adjusted for current age, sex, parental income, number of siblings, having a single parent, and parents' highest educational level

A strength of this study is its population-based design. The Civil Registration System allowed complete long-term follow-up of vital status and linkage to complete and accurate data on educational level, reducing selection and information bias. The public and freely accessible nature of the Danish education system reduced the potential for confounding from differences in socio-economic status among the congenital heart defect patients and the comparison cohort. Furthermore, we were able to adjust for socio-economic and familial factors that influence educational attainment.

As expected, our analysis indicates that the presence of extracardiac defects, chromosomal abnormalities, or preterm birth influences the educational attainments of congenital heart defect patients relative to the comparison cohort, as these conditions are more prevalent among congenital heart defect patients and are associated with decreased educational levels.[23–25]

However, in this study, we can only speculate on the mechanisms explaining the decreased educational attainments of congenital heart defect patients without these conditions. Multiple factors are most likely to interact depending on diagnostic sub-categories of congenital heart defects, including abnormal brain development[26] and brain injury potentially occurring in foetal life,[27] during cardiopulmonary bypass,[28] or post-operatively in the intensive care unit,[29] as well as psychosocial factors.[7] Studies on long-term prognosis are inherently based on patients born and treated in an earlier era where patient management was less advanced. Thus, the educational attainment of patients treated today may turn out differently than the educational attainment of the patients in our cohort.

Conclusion

We found an association between congenital heart defects and a reduced probability of completing basic and upper secondary school, as well as medium- and long-cycle higher education. Attainment of vocational and short-cycle higher education did not differ among congenital heart defect patients and their controls.

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