

Research Paper

Education and employment among patients with childhood-onset epilepsy in adulthood: A population-based cohort study

Christian Starck^{a,*}, Mika Helminen^{b,c}, Anssi Auvinen^{c,d}, Olli PO Nevalainen^{c,e,f}, Kai Eriksson^{a,g,h}

^a Faculty of Medicine and Health Technology, Tampere University, Tampere, Finland

^b Tays Research Services, Tampere University Hospital, Finland

^c Faculty of Social Sciences, Health Sciences, Tampere University, Tampere, Finland

^d Child Health Research Center, Pirkanmaa Hospital District/TA4, Tampere University Hospital, Tampere, Finland

^e Faculty of Medicine, University of Helsinki, Helsinki, Finland

^f Hatanpää Health Center, Wellbeing Services County of Pirkanmaa, Tampere, Finland

^g Tampere Center for Child, Adolescent and Maternal Health Research (TamCAM), Tampere University, Tampere, Finland

^h Department of Pediatric Neurology, Tampere University Hospital, Tampere, Finland



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ABSTRACT

Objective: This study explored the association of childhood-onset epilepsy (COE) with educational attainment, adulthood employment, and income.

Methods: A population-based cohort of 312 children with COE was identified from Tampere University Hospital, Finland. Population Register Center formed a matched random population sample of 1248 children without COE as a reference cohort. The two cohorts were linked to the Statistics Finland database to obtain information on educational attainment, employment status, and income. Fisher's exact test was used to compare employment and graduation. Independent samples *t*-test was used for analyzing graduation grades and the Mann-Whitney test was used for analyzing yearly income. Results were stratified by sex and disability.

Results: During a follow-up of 25 years, a substantially higher proportion of the patients never entered the workforce, 37 % (109/312) compared with 4 % (44/1248) for the referents without COE ($p < 0.001$). A two-fold difference was observed for COE patients without other disabilities (7.7 %, 13/169, $p = 0.01$). No clear difference was found in long-term employment between the COE without disabilities and the referents (67 %, 114/169 versus 74 %, 920/1248, $p = 0.087$). The patients with COE had worse lower secondary school graduation grade averages (7.36 vs 7.6, $p = 0.004$) and graduation rates (64 % vs 98 %, $p < 0.001$), the patients without disabilities had similar results to referents (7.43, $p = 0.07$, 98 %). Of the patients with COE, 18 % graduated from college compared to 38 % of the referents ($p < 0.001$). The median income was lower in males and females with COE of all ages compared to the referents. The COE patients without additional mental or physical disabilities had income comparable to the healthy referents. 143 patients (46 %) had additional disabilities.

Significance: Patients with COE have lower educational attainment, stable employment, and income. Patients without disabilities also have an increased risk of unemployment, but those capable of entering the workforce have stable careers with earnings comparable to the rest of the population.

1. Introduction

Epilepsy is one of the most common chronic neurological diseases in childhood. While approximately two-thirds of pediatric patients with epilepsy attain terminal remission from seizures in the long term, [1,2] childhood-onset epilepsy (COE) is associated with social disadvantages

that can have a lasting impact on an individual's social and economic outcomes. [3].

Children with epilepsy have an increased risk of failing compulsory primary education and reaching lower educational attainment compared to their peers. [4,5,6] Lower income has also been reported in patients with COE. [7] These problems may also affect children with

* Corresponding author.

E-mail address: christian.starck@tuni.fi (C. Starck).

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uncomplicated epilepsy.[8].

The purpose of this study was to examine lower secondary school graduation grades, college graduation, adult employment, and income in a comprehensive population-based cohort of individuals with COE. We used a reference cohort matched by age, gender, and municipality. Finnish registries are legally mandated to collect and maintain comprehensive nationwide registries on all persons living in Finland, providing accurate and reliable data. Such an environment offers opportunities for valuable contributions to existing literature through retrospective studies.

No meaningful differences were expected between genders, but few articles have reported on this subject. Patients without disabilities were expected to perform at most marginally worse than healthy referents.

2. Methods

2.1. Study population

The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist for cohort studies was followed in this report. The study cohort is a population-based prevalence sample of 329 patients with COE.[9] The cohort inception date was December 31, 1992, and it comprised all patients with COE treated for epilepsy at the Tampere University Hospital (TAUH) departments of pediatric neurology and pediatrics during 1980-1992. Additionally, patients with COE were identified from Pirkanmaa Social Services Association of Communes medical records, the only organization providing services for children with intellectual disabilities in the catchment area. In Finland, all new pediatric cases with suspected epileptic symptoms are referred to a local central hospital pediatric neurology department, leading to a population-based cohort. The catchment area population included residents in the Tampere city and the 34 mainly rural municipalities around Tampere comprising the TAUH district. The size of the catchment area population at cohort inception was 431,963 with 83,464 children aged 0-15 years. TAUH was the only hospital in the district with pediatric

departments and was responsible for providing all pediatric neurology services for this population. Computerized databases of treated patients have been in use since 1974.

Epilepsy was defined as a condition in which epileptic seizures result from abnormal and excessive activity of cerebral neurons without extracerebral cause. Our patient identification and diagnosis were done according to International League Against Epilepsy (ILAE) guidelines by two pediatric neurology specialists in following the ILAE definitions from 1981 and 1989 in use at the time.

Both mental and motor disability were considered, including mild to moderate ($70 > IQ > 50$) and severe ($IQ < 50$) mental disability or evident developmental delay. Motor disabilities included diagnosis of cerebral palsy, plegia and paresis, but also any other motor control deficits due to developmental or neurological cause. Neurological or neuropsychiatric impairments related to attention, perception or learning difficulties such as ADHD and autism were also included.

During a retrospective review of patient charts for this publication (by author C.S. in 2017), one more eligible patient not included in the original cohort was identified and included in the study cohort. Three patients in the original cohort were excluded from the analysis due to incomplete identification data. Ten patients had died during the data collection period and before the actual inception date and were therefore excluded. Five patients had sent a privacy request to the Population Registry Center (PRC) prohibiting any use of their data, and these patients were excluded. Finally, 312 patients were eligible for linkage to the PRC database. A retrospective review of the whole catchment population for new cases could not be provided by the authors.

A reference population of 1248 persons (four referents per patient) was randomly selected by the PRC out of children alive at the inception date, with matching by year of birth, sex, and municipality based on characteristics on the inception date (Fig. 1). The selection of the study population has been described in more detail in an earlier research article published by the authors.[10].

Statistics Finland is responsible for gathering census data including employment and education. Statistics Finland also compiles

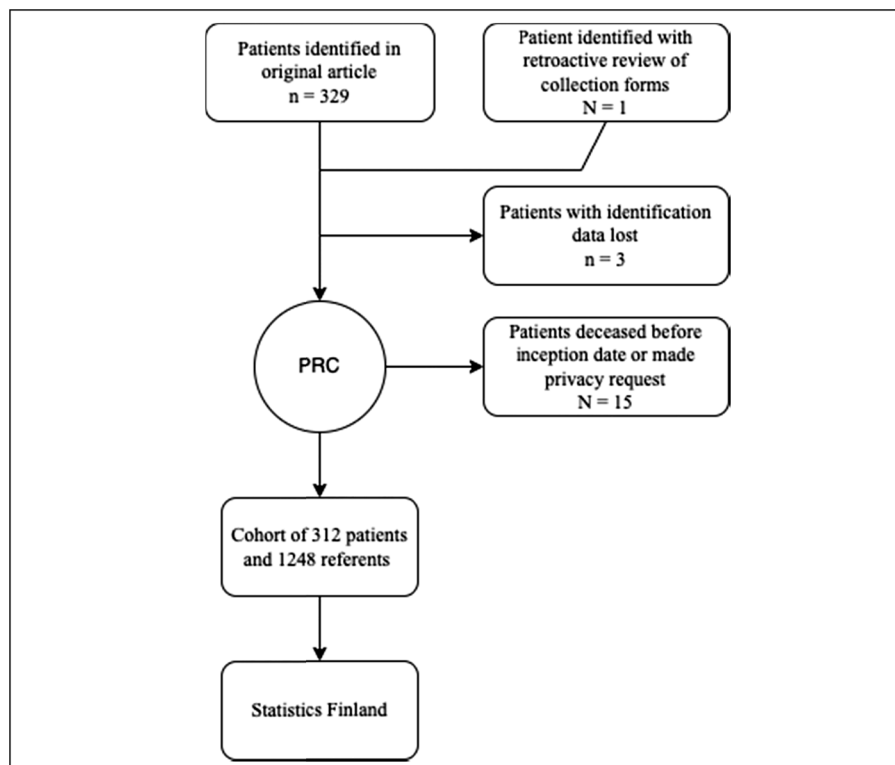


Fig. 1. Development of the study population. PRC, population registry center.

comprehensive financial data from tax records. Due to the sensitive nature of income data, high outliers are replaced using a standard protocol not to provide exact income details. This process was out of the authors' control. Discussions with Statistics Finland indicated that the approximation for a few individuals' yearly incomes would not materially alter our results. The Finnish comprehensive public school system follows a common educational plan resulting in grades that are comparable nationally and are further used in student selection for higher education. These data are available from Statistics Finland for all persons graduating from different levels of the educational system. Statistics Finland maintains records on lower secondary school graduation grade averages, as these averages are used for evaluating admission to upper secondary education nationally. Graduation also marks the end of nine years of compulsory education. Data from Statistics Finland was gathered from 1993 until early 2018.

2.2. Outcomes

The primary outcomes were lower secondary school graduation, lower secondary school graduation grade average, college graduation, employment, and income. Analyses of graduation, grade averages, and income were performed dividing the patient and reference group by sex. Additionally, we separated patients without additional disabilities for all analyses. Employment data in Finland are registered every year, and each person is assigned an employment status once a year. Statistics Finland considers a person unemployed after six consecutive months without work-related income and reports these statistics yearly. For simplicity, employment status was analyzed using two models. In the first, the outcome was permanent unemployment i.e., cases who were never classified as employed. In the second analysis, we evaluated job stability with the mode of the employment indicator as the outcome. People were considered consistently employed if they had more years registered as employed compared to unemployed. For the analysis of income, annual average income by five-year age group was first calculated for each study participant. The median income for the COE and reference group was then estimated from the age-specific average earnings. Income included salaries and capital income, while social benefits were not considered to accurately reflect the ability to earn a living. This resulted in some participants having no documented income. The proportions of participants graduating from each educational level were calculated. When analyzing lower secondary school graduation grade averages, only those who graduated were included. Follow-up ended at death, emigration (dates obtained from the PRC), or the common closing date (January 22, 2018) of the study.

2.3. Statistical analysis

Categorical variables such as employment status and graduation were compared using the Fisher's exact test. Graduation grades were normally distributed and analyzed with the independent samples *t*-test. Yearly income was not normally distributed, and the Mann-Whitney test was used for its analyses. Stata 16.0 was used for all the analyses.

2.4. Ethical issues

The Wellbeing Services County of Pirkanmaa gave organizational permission for the study, and it was exempted from review by the Tampere University Hospital ethics board because it involved no contact with the study participants. For the same reason, no consent was required for an entirely register-based study by the Finnish regulation. A permission to use the registry data was required and issued by the PRC (60653, 17.7.2017) and Statistics Finland (TK-53-574-19, 29.3.2021). Additionally, a record linkage with data from different registries required a separate permission from both institutions, which was acquired accordingly.

3. Results

The COE cohort included 312 eligible patients, 166 men and 146 women. The reference cohort included 1248 individuals, 664 men and 584 women (Table 1). The median age at the end of follow-up was 35.0 years (IQR=30.1, 38.1) for the patients and 35.2 (IQR 31.4, 38.1) for the referents. Of the patient cohort, 86 males and 57 females ($n = 143$, 46 %) had a disability. Information on possible disabilities in the reference cohort was not available. However, the prevalence of significant congenital disability in the Finnish general population has been estimated as approximately 1 % by the Finnish Association on Intellectual and Developmental Disabilities.

As for education, 200 patients (64 %) had completed lower secondary school compared to 1225 persons (98 %) in the reference cohort. Graduation grades in lower secondary school are on a scale from four to ten, where four represents the lowest and ten is the highest grade. The graduated male patients ($n = 97$) had a mean grade of 7.03 overall compared to 7.33 among the reference males ($p = 0.01$). The mean grade was 7.66 for the female patients and 7.89 among the female referents ($p = 0.03$). The Male patients without disabilities who graduated ($n = 77$) had a lower mean grade (7.07, $p = 0.02$) compared to the referents. All female patients without disabilities had graduated and no difference in the mean grades were observed relative to the referents ($n = 89$, 7.75, $p = 0.22$).

College graduation was less common in the patient cohort (18 % vs. 38 % $p < 0.001$), though the difference was smaller among the patients without disabilities (33 % $p = 0.18$). Male patients without disabilities graduated from college equally often as male referents (26 % vs. 29 % $p = 1.0$).

A substantially larger proportion of the patients (109 patients, 34.9 % vs. 44 referents, 3.5 %, $p < 0.001$) never entered the workforce (Table 2). This difference was smaller but significant even after excluding the disabled patients (7.7 %, $p = 0.01$). In this group, employment stability, on the other hand, was more comparable to the referents (68 % vs. 74 %, $p = 0.087$).

The median income was analyzed by gender and age group (Fig. 2). Yearly median income increased with age, but the increases were noticeably smaller in the patient population. At 25 to 29 years of age, male patients had 64 % lower median income ($p < 0.001$), this difference remained stable during follow-up. Female patients had a 33 % lower median income during the same time ($p < 0.001$), this difference also remained stable. Among patients without disabilities, incomes were comparable to healthy referents.

4. Discussion

In this retrospective, population-based long-term follow-up study using national registries, patients with COE had lower educational attainment and employment than referents without COE. Overall patients without disabilities had comparable results to healthy referents, although male patients without disabilities had lower secondary school graduation grade averages. This did not seem to affect college graduation rates perhaps indicating adequate support for such patients in pursuing higher education. Moving from school to employment saw some difficulties, although when employed these patients held employment consistently with income comparable to healthy referents. These findings suggest positive outlook for patients without disabilities in later life even with issues in primary education. Unsurprisingly, for the whole patient population including patients with disabilities, the results in all outcomes measured were materially worse.

Some studies in Finland have focused on these outcomes. Overall patients without disabilities and well controlled disease have outcomes comparable to controls, although employment has repeatedly been lagging.[11,12].

A strength of our study is the 25-year follow-up with nationwide and comprehensive registries. Our material is population-based, and the

Table 1
Educational success during 25 years of follow-up in childhood-onset epilepsy and referents without childhood-onset epilepsy.

Variable	All patients, n = 312	No disabilities, n = 169	Referents, n = 1248	P-value (all patients)	P-value (no disabilities)
Graduated lower secondary school, n (%)	200 (64)	166 (98.2)	1225 (98.1)	< 0.001	1.000
Mean grade	7.36	7.43	7.60	0.004	0.07
Graduated college, n (%)	59 (18.4)	55 (32.5)	477 (38.2)	< 0.001	0.18
Male, n	166	80	664		
Graduated lower secondary school, n (%)	97 (58.4)	77 (96.3)	652 (98.2)	< 0.001	0.21
Mean grade	7.03	7.07	7.33	0.01	0.04
Graduated college, n (%)	21 (12.7)	21 (26.3)	191 (28.8)	< 0.001	0.7
Female, n	146	89	584		
Graduated lower secondary school, n (%)	103 (70.5)	89 (100)	570 (97.6)	< 0.001	0.24
Mean grade	7.66	7.75	7.89	0.03	0.22
Graduated college, n (%)	38 (26.0)	34 (38.2)	286 (49.0)	< 0.001	0.07

Table 2
Entering the workforce in a follow-up of 25 years of patients with childhood-onset epilepsy and referents without childhood-onset epilepsy.

	All patients, n 312	No disabilities, n 169	Referents, n 1248	P-value (all patients)	P-value (No disabilities)
Never entered the workforce, n (%)	109 (34.9)	13 (7.7)	44 (3.5 %)	< 0.001	0.019
Consistently employed, N (%)	127 (40.7)	114 (67.5)	920 (73.7)	< 0.001	0.087

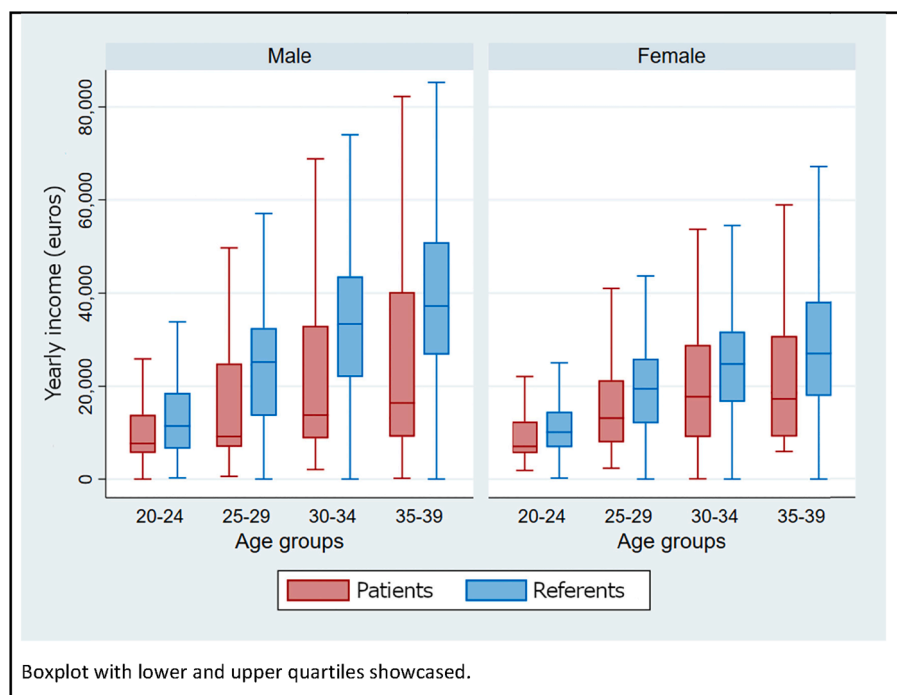


Fig. 2. Yearly median income in euros for patients and referents by age group and gender. Boxplot with lower and upper quartiles showcased.

coverage of the cases was high, which enhances the representativeness of our patient population. In addition, the comprehensive register-based follow-up likely improves the applicability of the data. Unfortunately, we could not retrospectively review all the medical records for the study population or estimate possible incompleteness of patient coverage.

Nevertheless, the comprehensive register data maximizes the generalizability of our findings to population with widely available pediatric neurologic treatment and social services.

The size of our patient population limits the precision of our results. We performed subgroup analyses by gender and disabilities, but could not analyze the impact of clinical features due to the small population size. We accounted for death and immigration in the income analysis, which together with tax data resulted in complete data coverage. Unfortunately, we had only data on completed graduation and records of employment but could not separate missing data from failure to achieve

these endpoints. Hence, could not account for missing data or evaluate its impact on our results. Further, we had no information on parental education or income, and could not control for their possible effects.

Gender differences have rarely been reported in studies of social outcomes of COE and our findings provide additional insight into the issue.

5. Conclusions

Adults with COE have lower graduation grade averages and lower rates of college graduation than the general population. COE patients without disabilities are less affected. Patients with COE have difficulties entering the workforce and they earn lower incomes. Patients without disabilities also have an increased risk of unemployment, but those capable of entering the workforce have stable careers with earnings

comparable to their peers.

CRediT authorship contribution statement

Christian Starck: Writing – original draft, Investigation, Funding acquisition, Data curation, Conceptualization. **Mika Helminen:** Writing – review & editing, Visualization, Software, Formal analysis, Data curation. **Anssi Auvinen:** Writing – review & editing, Supervision, Project administration, Methodology, Funding acquisition, Conceptualization. **Olli PO Nevalainen:** Writing – review & editing, Supervision, Methodology, Conceptualization. **Kai Eriksson:** Writing – review & editing, Supervision, Project administration, Funding acquisition, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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