Educational achievement, employment, marriage, and driving in adults with childhood-onset epilepsy

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A B S T R A C T

Background: People with epilepsy (PWE) beginning in childhood often experience psychological and social hold-ups in addition to seizures. The hold-ups relate to education, employment, driving, and marriage.
Objective: The objective of this study was to document the impact of long-standing, childhood-onset epilepsy on sociopersonal accomplishments of adults pertaining to education, employment, marriage, and driving.
Methods: A prospective, questionnaire-based survey was undertaken in a hospital-based sample of PWE and their unaffected (by epilepsy) older siblings within the immediate/extended family unit.
Results: People with epilepsy were significantly more likely to abandon formal education after primary (6; 2.4% compared to none in controls) or secondary (69; 31.1% compared with controls 58; 26.1%) school, less likely to be currently married (97; 43.7%) when compared with their elder siblings (158; 71.2%) (P = 0.0001), and less likely to be currently employed (103; 46.4%) (P = 0.0001) or driving (111; 50%) (P = 0.0001) compared with the older same-gender siblings (employed: 148; 66.7%; driving: 165; 74.3%). In multivariate models, having epilepsy and age were associated with employment status, whereas age and education and employment status were associated with both marriage and driving.
Conclusion: Notwithstanding the influence of a number of socioeconomic and epilepsy-related variables, childhood-onset epilepsy stands apart in exerting a huge negative impact on educational achievement, employability, marital status, and driving in adulthood.

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1. Introduction

People with epilepsy (PWE) endure seizures, which are often recurrent and at times hard to treat [1]. However, their predicament is not limited to the occurrence of seizures but comprises, for a greater part, a range of problems in their social and personal spheres [2]. Some of these have been systematically evaluated in selected populations while others have been addressed in cursory manner [3–6]. Indicators of sociopersonal competence in PWE are mostly related to education, employment, driving, and marriage [7]. Reduced literacy rates, subpar higher educational achievements, poor scholastic performance, and learning difficulties have been described in different populations of epilepsy [8–11]. Likewise, reduced rates of employability and a range of problems at work have been reported [12–15]. Somewhat sparingly, reduced marital prospects and adverse marital outcomes have also been documented [16]. Finally, driving issues have remained a matter of considerable controversy despite substantial variations in regulations, practices and attitudes in relation to driving across the world [17–20]. These

sociopersonal problems seem to be adversely affected most of all by the onset of epilepsy in childhood [21,22]. Hence, we undertook to determine the influence of childhood epilepsy on educational achievement, employability, marriage, and driving (including the possession of a driving license) in a facility-based sample. In order to do so, we compared the sociopersonal indicators in adults with childhood (onset <15 years) epilepsy with their family-based older siblings.

2. Methods

A prospective, questionnaire-based survey was undertaken in a hospital-based sample of PWE and their unaffected (by epilepsy) older siblings.

2.1. Sampling frame and technique

The sampling frame included PWE attending an epilepsy or general neurology clinic of Dayanand Medical College, Ludhiana in Northwest India between April 2016 and October 2017. In order to be eligible, consenting respondents had to be 21–60 years old, with active epilepsy, which began before the age of 15 years. Those with nonepileptic attacks or an unsure epileptological diagnosis were excluded. A nonprobability

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sampling strategy was adopted. Unexposed subjects comprised older siblings of the same gender, unaffected by epilepsy from the immediate/extended family of cases.

2.2. Design and description of questionnaire

A structured questionnaire of 52 questions covering sociopersonal accomplishments including education, employment, driving, and marital status in adults with long-standing epilepsy was initially framed by two of the authors. The questionnaire was then reviewed independently by two experts, who scored the questions on basis of their importance. Items with bracketed scores were resolved by consensus. After serial iterations, the final version comprising 30 items was prepared. The questionnaire comprised demographic (which documented age, gender, and residence [rural vs. urban] of respondents) and epilepsy-related data sections in addition to another four sections, each exploring sociopersonal accomplishments, opinions, attitudes, and practices in relation to education, employment, marriage and driving.

The questionnaire was translated into Punjabi and Hindi languages and then back-translated into English language by two different sets of bilingual experts unconnected with the survey. The back-translated and original versions were compared for correspondence. The translated versions were then administered to five PWE, not included in the survey to determine sociocultural acceptability and linguistic comprehensibility.

2.3. Survey methods

Questionnaires was administered by a study team member, who was not part of the treatment-providing team in a neutral and comfortable environment (outside of the clinic) after written, informed consent in vernacular language from both PWE and their unexposed older siblings. Questionnaires were self-administered whenever possible but for illiterate respondents, the questions and responses were read twice in a neutral manner and the rejoinders thereof recorded. No leading questions were asked or explanations offered. All responses were anonymized.

2.4. Analysis plan

Responses were double entered in to an Excel database and exported to Stata ver. 12 (StataCorp, Texas, USA) for analysis. Each item was analyzed separately. The answers provided by the respondents to each item constituted the dependent variables. The main outcomes of interest were highest educational achievement, employment, marital status, and driving status of and possession of driving license by PWE and their unexposed older siblings. The association of the above listed outcomes with age, gender, educational achievement, employment position, marital status, and driving was first explored in univariate analyses. Those with $P < 0.1$ were entered into a multivariate logistic regression analysis to determine the contribution of each to variance in the outcomes. $P < 0.05$ was considered significant in the final analyses.

Ethical approval was taken from the institutional ethics committee.

3. Results

3.1. Demographic features

We surveyed 250 PWE and 225 gender-matched older siblings but were unable to recruit 25 controls because of the absence of a gender-matched, older sibling (n = 6), inability to approach controls either in person or via telephone (n = 14), and denial of consent (n = 5). Accordingly, those with epilepsy correspondingly matched to the 25 missing unexposed were also excluded. In addition, we inadvertently included 3 cases with ages below 18 years, and for this reason another 3 exposed–unexposed pairs were excluded. Hence, we finally analyzed

222 PWE and their gender-matched, older siblings. Various demographic characteristics of the respondents are shown in Table 1. Unexposed subjects (median age: 31 ± 6 y; $_{95\%}$Confidence Interval (CI): 31, 32; interquartile range (IQR): 27–36 y) were older than PWE (median age: 27 ± 6 y; $_{95\%}$CI: 27, 29; IQR: 23–32 y) (P = 0.00001). Other demographic features were similar in both subgroups.

3.2. Univariate analyses

People with epilepsy were significantly more likely to abandon formal education after primary (6; 2.7% compared to none in controls) or secondary (69; 31.1% compared to controls 58; 26.1%) school, and on the contrary, their older gender-matched siblings pursued graduate (101; 45.5%) and postgraduate (31; 13.9%) studies more often (p = 0.0001) (Table 1). When scholastic achievements were coalesced into low (No formal education, below primary, class I–IV, class V–VIII, class IX–X or senior secondary) and high (diploma/graduate/postgraduate) groups, there were fewer PWE in the high-scholastic category (89; 40.1%) in comparison with their older siblings (132; 59.4%) (P = 0.0001). Cases (97; 43.7%) were also less likely to be currently married when compared with their elder siblings (158; 71.2%) (P = 0.0001). Likewise, they were less likely to be currently employed (103; 46.4%) (P = 0.0001) or driving (111; 50%) (P = 0.0001) as compared with their older same-gender siblings (employed: 148; 66.7%; driving: 165; 74.3%). Finally, 68 (30.6%) PWE were in possession of a valid driving license in comparison with 133 (59.9%) of their elder siblings (P = 0.0001).

3.3. Multivariate analyses

Since, the siblings were significantly older than cases, age was included as a covariate in the multivariate regression analysis of broad educational achievement of PWE vs. siblings. When age and educational status were fit into the regression model, the overall association was highly significant (P = 0.0001), with both age (odds ratio (OR): 0.91; $_{95\%}$CI: 0.88, 0.95) and epilepsy (OR: 3.17; $_{95\%}$CI: 2.07, 4.84) being significant predictors of educational achievement. In analyzing the association between having epilepsy and employment status, we first examined data for an interaction between broad educational level and employment status. No interaction was found (P = 0.8). Hence, age alone was again used as a covariate in the analysis of the association between epilepsy and employment. The fitted model was highly significant with both age (OR: 1.06; $_{95\%}$CI: 1.03, 1.09) (P = 0.0001) and epilepsy (OR: 1.92; $_{95\%}$CI: 1.28, 2.86) (P = 0.001) being significant predictors of employment. Likewise, we argued that age, broad educational achievement, and employment might influence marital prospects; hence, we examined the data for an interaction between marital status and both educational achievement and employment. The interaction analysis was significant between education and marital status (P = 0.001) as well as employment and marital status (P = 0.036). Therefore, age, broad educational, and employment statuses were included as covariates in the analysis of the association between epilepsy and marital status. The overall model was also significant (P = 0.0001), with epilepsy (OR: 2.86; $_{95\%}$CI: 1.67, 4.89) (P = 0.0001), age (OR: 1.34; $_{95\%}$CI: 1.26, 1.43) (P = 0.0001), and educational achievement (OR: 0.58; $_{95\%}$CI: 0.30, 0.86) (P = 0.012) significantly predicting being currently married and employability showing a trend toward significance (OR: 0.59; $_{95\%}$CI: 0.39, 1.00) (P = 0.052). While examining the association between having epilepsy and driving, we postulated that age, educational achievement, employment status, and gender would all influence driving status, and therefore, the data were examined for interaction between the potential covariates and driving. The analyses suggested highly significant interaction between driving and educational achievement (P = 0.001) and between employment (P = 0.0001) and gender (P = 0.0001). Hence, age, gender, educational achievement, and employment were thus fitted as covariates in the analysis of the association between driving and epilepsy. The final model for driving status remained highly

Table 1
Demographic profile, educational achievement, employment, marital and driving status, and driving license possession in PWE and their family controls.

	PWE n (%)	Controls n (%)	Statistical significance[*] (P)
Gender — Females	96 (43.2)	87 (39.2)	P = 0.386
Habitation (Rural vs. Urban)			
Rural	135 (60.8)	132 (59.4)	P = 0.77
Age ± SD (in years)	27 ± 6	31 ± 6	P = 0.0001
IQR	23, 32	27, 36	
Educational status			
Low (No formal education up to senior secondary) vs. High (diploma/graduate/postgraduate)			
High	89 (40)	132 (59.4)	P = 0.0001
Employment status (Employed vs. Unemployed)			
Unemployed	119 (53.6)	74 (33.3)	P = 0.0001
Marital Status (Currently married vs. Single or Divorced)			
Currently Married	97 (43.7)	158 (71.2)	P = 0.0001
Driving status (Driving vs. Not Driving)			
Driving	111 (50)	165 (74.3)	P = 0.001
Driving license possession (Yes or No)			
Yes	68 (30.6)	133 (59.9)	P = 0.0001

[*] Significant p-value <0.05.

significant (P = 0.0001) with epilepsy (OR: 3.15; $_{95\%}$CI: 1.81, 5.51) (P = 0.0001), education (OR: 3.67; $_{95\%}$CI: 2.03, 6.65) (P = 0.0001), employment (OR: 2.42; $_{95\%}$CI: 1.39, 4.18) (P = 0.002), and gender (OR: 13.98; $_{95\%}$CI: 7.45, 26.26) (P = 0.0001) being predictors of driving status. Finally, an interaction was found between educational achievement (P = 0.001), employment status (P = 0.0001), gender (P = 0.0001), marital status (P = 0.001), and the possession of a driving license. Hence, all were included as covariates in the analysis of the association between epilepsy and possession of driving license. The overall model remained significant (P = 0.0001) with epilepsy (OR: 3.09; $_{95\%}$CI: 1.84, 5.19) (P = 0.0001), education (OR: 3.30; $_{95\%}$CI: 1.92, 5.66) (P = 0.0001), gender (OR: 14.17; $_{95\%}$CI: 7.39, 27.19) (P = 0.0001), and marital status (OR: 3.30; $_{95\%}$CI: 1.60, 5.77) (P = 0.001) being predictive of the possession of a driving license. (See Table 2.)

3.4. Attitudes and behaviors toward education, employment, marriage, and driving among PWE

Many respondents with epilepsy (n = 109; 49.1%) admitted to hiding the condition while at school/college. In those (n = 98; 44.1%) who affirmed having disclosed epilepsy to the establishment, it was on account of a seizure happening in school or college. Forty-two PWE (18.9%) reported having taken medical leave on account of seizures, and 4 (1.8%) dropped a complete academic session citing epilepsy as the reason. Of the PWE, 83 (37.4%) reported that they lagged behind in studies, and 22 (9.9%) reported being advised to leave the facility by school/college authorities because of epilepsy. Specifically, 12 (5.4%) were directed to do so because of epilepsy and 10 (4.5%) because of poor scholastic performance. Another 25 (11.2%) reported changing school on account of epilepsy.

Respondents with epilepsy, who were employed, worked full-time (n = 49; 22%), were self-employed (including family business, agriculture) (n = 40; 18%), or worked part-time (n = 11; 4.9%). Nearly one-half of the respondents with epilepsy (n = 101; 45.5%) confessed hiding epilepsy at their workplace to avoid discrimination. Some (n = 21; 9.4%) reported changing their job on account of epilepsy, and still others (n = 20; 9%) felt that they were not suitably remunerated because of epilepsy. Some PWE (n = 29; 13%) also felt that epilepsy and its medications adversely affected their occupational functioning.

Respondents with epilepsy included 113 (50.9%) who were single and 11 (4.9%) who were either divorced or separated. All cited epilepsy as the reason for divorce/separation. There were no divorces or separations among their gender-matched older siblings.

Those respondents with epilepsy who drove (n = 111; 50%) operated either two-wheelers (n = 73; 32.9%), four-wheelers (n = 11; 4.9%), or both (n = 27; 12.2%); the majority (n = 63, 28.3%) were

driving daily. Among those driving, 34 (15.3%) reported having an aura or seizure while behind wheels. In addition, 41 (18.4%) admitted that epilepsy and/or its medications impacted their driving.

4. Discussion

Although several studies have attempted to elucidate impairments in sociopersonal achievements among different populations of PWE, albeit with vastly disparate methods, long-term longitudinal studies of children with epilepsy provide the best resource for studying sociopersonal outcomes in PWE [23–25]. Longitudinal studies such as in the prevalence cohorts from the Ehime prefecture in Japan and Turku in Finland and in incidence-based cohorts from Nova Scotia, Canada, and Connecticut, USA [8,14,21,23] distinguish two subgroups, one with "epilepsy only" and the other with learning disability or mental/neurological handicaps, i.e., complicated epilepsy [25]. Between the two subgroups, the latter demonstrated more severe compromises in educational, employment, marital, and driving-related accomplishments.

Longitudinal studies with prolonged follow-up are difficult to undertake in under-resourced countries because of poor medical record-keeping systems. Hence, we undertook this cross-sectional survey in an unrestricted hospital-based sample of people with onset of epilepsy in childhood (<15 years of age) and compared their sociopersonal outcomes and attitudes thereof with gender-matched, older siblings. By choosing family siblings as controls, we ensured matching on a variety of socioeconomic parameters, e.g., parent education and occupation and family income, religion, and social caste, all of which can influence sociopersonal achievements and hence confound the study outcomes. The only other report of the use of a sibship comparator was from Connecticut, USA [25]. This study had a longitudinal design. In the Connecticut cohort, people with uncomplicated epilepsy had social outcomes, which were similar to their siblings. Those with complicated epilepsy were however less likely to graduate from high school, be employed, or be permitted to drive. Even so, they were as much likely as their siblings to get married.

It might be tempting to attribute the inferior educational status of PWE in comparison to their older siblings to the younger age of the former. However, close examination revealed that more PWE over 21 years of age abandoned primary as well secondary school education in comparison to their older siblings, i.e., early in their life. This implies that childhood epilepsy limits educational achievement at an early stage of life. Moreover, the multivariate analysis confirmed the association between having epilepsy since childhood (<15 years of age) and poorer educational achievement in as much as both age and having epilepsy were significant predictors of educational status. Likewise, the

Table 2

Multivariate analysis of variables influencing educational achievement, employment, marital status, driving, and possession of a driving license.

Education

Log likelihood = −285.06003			Number of Obs = 444 Prob > chi2 = 0.000 Pseudo R2 = 0.0737	
	Odds ratio	P value	95% Confidence interval	
Case/control	3.17	0.0001	2.07	4.84
Age	0.91	0.0001	0.88	0.95

Employment

Log likelihood = −288.03091			Number of Obs = 444 Prob > chi2 = 0.000 Pseudo R2 = 0.0524	
	Odds ratio	P value	95% Confidence interval	
Case/control	1.92	0.001	1.28	2.86
Age	1.06	0.0001	1.03	1.09

Marital status

Log likelihood = −196.59916			Number of Obs = 444 Prob > chi2 = 0.000 Pseudo R2 = 0.3508	
	Odds ratio	P value	95% Confidence interval	
Case/control	2.86	0.0001	1.67	4.89
Age	1.34	0.0001	1.26	1.43
Education	0.58	0.012	0.30	0.86
Employment	0.59	0.052	0.35	1.00

Driving status

Log likelihood = −194.16999			Number of Obs = 444 Prob > chi2 = 0.000 Pseudo R2 = 0.3407	
	Odds ratio	P value	95% Confidence interval	
Case/control	3.15	0.0001	1.81	5.51
Age	0.99	0.731	0.95	1.04
Education	3.67	0.0001	2.03	6.65
Employment	2.42	0.002	1.39	4.18
Gender	13.98	0.0001	7.45	26.26

Possession of driving license

Log likelihood = −209.62467			Number of Obs = 444 Prob > chi2 = 0.000 Pseudo R2 = 0.3144	
	Odds ratio	P value	95% Confidence interval	
Case/control	3.09	0.0001	1.84	5.19
Age	0.96	0.180	0.92	1.01
Education	3.30	0.0001	1.92	5.66
Employment	1.84	0.033	1.05	3.22
Gender	14.17	0.0001	7.39	27.19
Marital status	3.03	0.001	1.60	5.77

multivariate analysis demonstrated that PWE were twice as likely to remain unemployed in comparison to their older siblings.

A test for statistical interaction found no interaction between education and employment. In comparison, an interaction was found between age, educational achievement, employability, marital status, and driving ability/possession of a driving license. In the multivariate analysis of marital and driving outcomes, epilepsy, age, and educational and employment statuses were found to be independent predictors. This is a redeeming finding and suggests that education and employment, both indicators of empowerment might counterbalance the influence of epilepsy on marriage and driving.

The issue of driving in PWE deserves special discussion. The concern herein is the balance between safety on one hand and living rights and practicality of being able to drive for maintaining a living on the other hand [26]. Driving regulations and hence, practices vary widely across countries. In many countries until recently (e.g., Japan and Greece) and in still others even now (e.g., India), seizures and epilepsy completely preclude driving. Because absolute and lengthy sanctions breed repudiation and noncompliance and the proportion of motor vehicle accidents as a result of epilepsy is small (in comparison, for instance, to alcohol intoxication), the trend in most countries is to permit driving after a short period of seizure-freedom. Notwithstanding the antiquated revocation of driving privileges in PWE, driving is frequent in PWE as shown in this survey. Surveys from other locations have likewise shown that 18–50% PWE though unauthorized; continue to drive [27]. Due consideration needs to be accorded to the driving needs of PWE, especially in countries where public transport might not be adequately supportive.

Our survey was hospital-based; hence, extrapolation to the population should not be assumed. Even so, it emphasizes the need for undertaking population-based surveys of the sociopersonal impact of childhood epilepsy. Another limitation inherent to the study design was the choice of controls, which by being older were more likely to have higher educational levels. However, despite including age as a covariate in the outcome analyses, epilepsy was found to be a significant predictor of educational achievement, employability, marriage, and driving. Finally, we did not collect data on epilepsy-related variables, the socioeconomic status, and the presence of mental, neurologic, and psychiatric comorbidities. Previous studies have shown that uncontrolled epilepsy and associated comorbidities such as learning disability, psychiatric disorders, and mental retardation largely determine the social outcome in patients with epilepsy [23–25,28,29]. However, we do not have information on these factors in our study. Hence, our results should be interpreted with caution and further studies evaluating the effects of factors in resource poor setting should be undertaken. Despite these limitations, our study underscores the negative impact of childhood-onset epilepsy on education, employment, marital status, and driving, all crucial sociopersonal determinants and the complex interplay with sociodemographic parameters in its bearing thereof.

Declaration of Competing Interest

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