



A Survey on Epilepsy and Work: Profiles and Challenges

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Abstract

Objective Epilepsy can have a chronic course in a subgroup of people and may impact the ability to study, marry or earn a living thereby increasing significantly the burden of the illness. For a person with epilepsy (PWE), beyond seizure control, being participative and productive in life is a crucial factor for a good quality of life. The aim of the study was to explore factors that help and/or hinder PWE find work / employment.

Materials and Methods Data was collected via a self-reported structured questionnaire from PWE in the age group 21 to 60 years, who had completed their education, and had a confirmed diagnosis of epilepsy for at least a year with no known psychiatric ailment or psychiatric morbidity. Binomial logistic regression was used to determine factors that impact employment.

Results Sixty-three percent of our cohorts ($n = 119/190$) were employed. Factors that supported employment were higher education, late age of epilepsy onset, and better maternal education. The odds of being employed decreased significantly with increasing seizure frequency (odds ratio [OR] = 0.749; 95% confidence interval [CI] = 0.586–0.957) and occurrence of cluster seizures (OR = 0.348; 95% CI = 0.163–0.742; $p < 0.05$).

Conclusion PWE can secure employment when their seizure frequency is low and epilepsy onset is after the age of 5 years. However, high job stress and cognitive and emotional difficulties are barriers and reasons for resignation from work. PWEs and their caregivers need to be empowered with psychoeducation and receive counselling support for their mood and cognitive issues to help them reach their full work potential.

Keywords

- unemployment
- seizure-onset
- seizure frequency

Introduction

Epilepsy, a brain disorder, presents multiple neurocognitive as well as psychosocial challenges, due to the sudden loss of control during seizures, the consequent sense of anxiety, and the effects

of antiseizure medications. Additionally, ignorance, associated myths, and misconceptions make people with epilepsy (PWE) vulnerable to perceived and enacted stigma. This hinders full participation in major life areas such as education and

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employment and affects not just the PWE but also the family members.¹ The burden of epilepsy increases tremendously, when one has no job, suffers poor health, and has no monetary government compensation, as is the case for PWE in India. Apart from serving as a source of livelihood, being employed is an essential contributor to one's self esteem and independence. There are at least 1.2 million PWE in the city of Mumbai alone and over 9 million in India.² An understanding of the factors that impact employment would therefore help greatly in supporting occupational rehabilitation of PWE.

A 2007 literature review on epilepsy and employment³ reports that unemployment and underemployment of PWE continue to be a serious problem, and opportunities to find and maintain regular employment are often restricted. A 2015 literature review⁴ on employability in PWE concluded that the adjusted employment rate of people with uncontrolled seizures was comparable to those with controlled seizures and proposed the need to explore nonclinical factors.

Published research on epilepsy and employment in India is sparse. A 2006 survey conducted in Kerala⁵ revealed 58% unemployment among PWE in their study sample, compared with 19% of the general population, the predictive factors for employment being seizure remission for more than or equal to 2 years, monotherapy, ability to travel alone, and ability to drive. A 2019 study in Ludhiana⁶ revealed that adults with childhood-onset epilepsy were less likely to get employment.

The paucity of data available on epilepsy and work indicated a strong need to understand the clinical and psychosocial variables that influence the employment status and work life of PWE in India.

Materials and Methods

A cross sectional study was undertaken, using a self-report structured questionnaire, at 4 centers: three hospitals that have specialty epilepsy services and an epilepsy nongovernment organization, from January 2020 to December 2021. During the coronavirus disease 2019 pandemic and lockdown, data was obtained using an online Google Form with clear instructions on criteria for participation. Patients who fit the criteria were given either the physical form or the Google Form link, with a request to fill in their pre-pandemic work details.

Operational Definitions

Employed PWE: Those who hold any kind of paid or voluntary work/job (full time or part time).

Unemployed PWE: (never been employed): Those who have never held any kind of work/job in their life; (currently unemployed) and those who had prior work experience who were unemployed at the time of answering the survey.

Mild/small seizures: Seizures that have low impact, low intensity, no injury, and quick recovery.

Severe/big seizures: Seizures that have high impact, high intensity, likely to cause injury, take a long time to recover.

Participants

PWE (a) aged between 21 and 60 years, (b) having more than or equal 1 year of confirmed epilepsy diagnosis, (c) with no known psychiatric ailment or psychiatric morbidity, (d) patients who completed their formal education were included. The criteria for defining epilepsy were per the International League Against Epilepsy official report.⁷ The study was approved by the Institutional Ethics Committees of the three participating hospitals (Ref nos.: EC/GOVT-09/2019, C-3/13/2019, 1036). Informed consent was obtained from all the participants.

Sample Size: Based on literature, the unemployment rate in epilepsy ranges from 25 to 69%.⁸ An average 50% unemployment rate was considered to calculate sample size at confidence level of 80% and margin of error of 5%. Sample size was thus calculated to be a minimum of 164. Considering incomplete information from some participants, we decided to recruit 15% extra participants. Our study had 205 respondents. All patients attending and satisfying our inclusion criteria at the approved centers and those who filled the online form, during the study period (January 2020 to December 2021) were included.

Questionnaire Development and Data Collection

Questions were developed through a literature review, and consensus was obtained after several consultations with subject experts consisting of epileptologists and psychologists. The questionnaire (**►Supplementary Appendix A** [available in the online version]) was created in English using simple language. Face validity was established through a pilot study in a small cohort.

There were four main parts to the questionnaire:

- *Sociodemographic details:* Patient's Age, gender, marital status, current residence, level of education and parents' education, work status, and family income.
- *Seizure details:* Seizure onset age, duration of epilepsy, frequency of seizures, presence of cluster seizures, symptoms and state of awareness during a seizure, number of anti-seizure medications, and compliance. The questionnaire had descriptions of "Mild or Small Seizures," "Severe or Big Seizures" & "Cluster Seizures."
- *Patient employment details:* Job profiles, duration of work, annual income.
- *Perceptions of PWE:* Reasons for not working, impact of seizure at workplace, disclosure, reasons for leaving work, employment securing process.

The English questionnaire was translated into three local languages, Hindi, Marathi, and Gujarati using language professionals following the forward-backward translation method. Thereafter, it was administered as per the patient's preference during their visits to the clinic. After the lockdown, participants answered an online version in either English, Hindi, or Marathi.

A neurologist determined the seizure type based on the seizure details captured in the questionnaire and classified them into either "Focal Onset," "Generalized Onset," or "Onset Unknown."

Statistical Analysis

Analyses were performed using SPSS software for Windows (version 25) for all data. Data was presented as frequencies/percentage. Cross-tabulations were computed based on employment status and were compared using chi-squared test. Binomial logistic regression model was used to analyze factors that predict employment status. Employment status was considered as binomial-dependent variable (employed vs. unemployed), whereas age, education (patients as well as parents), age of epilepsy onset, frequency of seizures, presence of cluster seizures, and number of drugs consumed were considered as independent variables. Sensitivity, specificity, positive, and negative predictive value were calculated. Fit of the regression model was assessed using Hosmer and Lemeshow test and the variance was explained using Cox & Snell R² / Nagelkerke R² test. Odds ratio and 95% confidence interval (CI) for significant factors are reported for regression model. *p*-Value less than 0.05 was considered statistically significant.

Results

Two-hundred five PWE responded to the questionnaire. Data of 190 respondents was analyzed after exclusion of eight homemakers and seven students who had just completed their education. The final sample consisted of two groups: an "Employed Group" (63%, *n* = 119) and the "Unemployed Group" (37%, *n* = 71). Employed group refers to all people who are currently employed in either a part time or full-time position, and the unemployed group consists of people who are currently unemployed and those who have never been employed. Majority of the employed (*n* = 104) were working full time and the remaining (*n* = 15) were working part time. The "Unemployed Group" had an almost equal number of "currently unemployed" (*N* = 37) and "never been employed" (*N* = 34).

Demographics

Demographics and Work Profile of Participants (*n* = 190)

About 80% of the total cohort was from the urban community and 80% were less than or equal to 45 years. There was no gender difference between the two groups. Among the demographic variables, education level, marital status, and family income were significantly different between the employed and unemployed groups (*p* < 0.05). The level of education was higher in the employed group as almost 50% of them had completed postgraduation and above. Regarding parental education, maternal education was significantly higher (*p* < 0.05) in the employed group. Majority (67%) of the employed group had a family annual income of more than or equal to Rs.3.4 lakhs that is above the national urban population average⁹ (►Table 1).

Work Profile

Seventy-five percent of the employed participants had more than 5 years of work experience. Almost 45% of the employed

group had jobs at managerial level and above or worked as professional consultants and 57% had not missed a single day's work due to epilepsy. Seventy-eight percent had epilepsy before employment (►Table 2).

In the currently unemployed group, 19% had been unemployed for more than 5 years. Sixty-five percent of "currently unemployed" and 91% of the "never employed" cohort stated that epilepsy was the reason for their "unemployed" status.

Epilepsy Variables

The association of age of onset of epilepsy and employment indicated a significantly (*p* < 0.05) higher percentage of unemployment among those with seizure onset in infancy and early childhood. Overall, 37% had generalized seizures, 29% had focal seizures, 30% had both seizure types, and 4% provided insufficient data. Seizure "type," "duration," "getting an aura," and "time taken to get back to normal after a seizure" showed no significant difference between the employed and unemployed groups. There was a significant association between "seizure frequency" and employment status (*p* < 0.05). Higher percentage of unemployed participants had weekly/ daily seizures as compared with employed participants (28 vs. 14%). The percentage of unemployed people (47%) who had cluster seizures was significantly higher than that in the employed group (24%; *p* = 0.002). A greater percentage of employed participants reported seizure freedom for over a year.

There was a significant association between polytherapy and being unemployed (*p* < 0.05) with 64.8% (*n* = 46/87) of the unemployed group on three or more different antiseizure medications. ►Table 3 gives details regarding epilepsy-related variables.

Regression Model to Ascertain Factors Affecting Employment

Binomial regression analysis was performed using the significantly associated factors from the demographic data and clinical variables, namely age, education (patient as well as parents), age of epilepsy onset, frequency of seizures, presence of cluster seizures, and number of antiseizure drugs.

The binomial regression model was statistically significant (*p* < 0.05). The Hosmer and Lemeshow test = 0.066 indicated that the model was not a poor fit. The model explained 26.6 to 63.2% variation in the employment status (Cox & Snell R² / Nagelkerke R² test). Sensitivity of the model was 85.7 (95% CI = 78.1–91.5%), specificity was 63.4 (95% CI = 51.1–74.5%), positive predictive value was 79.7% (95% CI = 74.1–84.3%), and negative predictive value was 72.6% (95% CI = 62.2% to 81%).

Among the demographic factors, PWE's education (*p* = 0.029) and mother's education (*p* = 0.039) were found to significantly predict employability. Among the epilepsy variables, age of seizure onset (*p* = 0.001), seizure frequency (*p* = 0.021), and cluster seizures (*p* = 0.006) added significantly to the prediction model (►Table 4).

Table 1 Comparison of sociodemographic data between the employed and the unemployed groups

	Unemployed (n = 71)		Employed (n = 119)		Total (n = 190)		p-Value
	Freq.	%	Freq.	%	Freq.	%	
Gender							
Male	40	56.3	75	63	115	60.5	0.443
Female	31	43.7	44	37	75	39.5	
Age							
21–30 years	31	43.7	36	30.3	67	35.3	0.139
31–45 years	26	36.6	59	49.6	85	44.7	
46–60 years	14	19.7	24	20.2	38	20	
Marital status							
Single	50	70.4	61	51.3	111	58.4	0.034 ^a
Married	18	25.4	51	42.9	69	36.3	
Divorced/separated	3	4.2	7	5.9	10	5.3	
Current place of residence							
Rural	4	5.6	0	0	4	2.1	0.031 ^a
Semiurban	13	18.3	21	17.6	34	17.9	
Urban	54	76.1	98	82.4	152	80	
Education							
Up to 10 th	15	21.1	7	5.9	22	11.6	0.001 ^a
Up to 12 th	12	16.9	11	9.2	23	12.1	
Diploma/vocational	5	7	7	5.9	12	6.3	
Graduate	21	29.6	35	29.4	56	29.5	
Postgraduate and above	18	25.4	59	49.6	77	40.5	
Family income							
Less than 1.5 lakh	25	35.2	6	5	31	16.3	0.001 ^a
1.5 to 3.4 lakhs	17	23.9	33	27.7	50	26.3	
3.4 to 17 lakhs	24	33.8	61	51.3	85	44.7	
More than 17 lakhs	5	7	19	16	24	12.6	
Mother's education							
No formal education	12	16.9	9	7.6	21	11.1	0.041 ^a
School	26	36.6	40	33.6	66	34.7	
Graduate	20	28.2	55	46.2	75	39.5	
Postgraduate	13	18.3	15	12.6	28	14.7	
Father's education							
No formal education	5	7	4	3.4	9	4.7	
School	19	26.8	34	28.6	53	27.9	
Graduate	31	43.7	58	48.7	89	46.8	
Postgraduate	16	22.5	23	19.3	39	20.5	

^aStatistically significant $p < 0.05$.**Perceptions of PWE: Employment Challenges****Reasons for Never Having Been Employed**

Thirty-four respondents had never worked and 91% of them gave epilepsy-related reasons for the same. The most common reasons for this were rejection from employers as they had epilepsy, and their inability to travel alone. Least

common reason for unemployment was “discouragement / lack of family support” or “no need to work as family provided support.”

Disclosure of Epilepsy Status

Of the 119 employed respondents, 61% had informed their boss/colleague about their epilepsy. Thirty-two percent

Table 2 Work-related details of the employed group ($n = 119$)

	Employed group ($n = 119$)	
	Freq.	%
Job profile		
Manager / dept head/ director/govt official/ exec. level	35	29.5
Teacher/ paramedical / support staff / skilled worker	35	29.5
Unskilled worker	25	21
Professional consultants	18	15
Work in family business	6	5
Number of workdays missed due to epilepsy annually		
None	68	57
1–7 days	35	29
8–14 days	9	8
More than 14 days	7	6
Epilepsy onset in relation to employment		
Before employment	93	78
After employment	26	22

Table 3 Age of epilepsy onset, frequency, cluster seizures, drug therapy, and work status ($n = 190$)

	Unemployed (n = 71)		Employed (n = 119)		Total (n = 190)		p-Value
	Freq.	%	Freq.	%	Freq.	%	
Age of epilepsy onset							
Early childhood (birth to 5 years)	27	38	11	9	38	20	0.001*
Middle childhood and adolescence (6 to 19 years)	36	51	74	62	110	58	
Adulthood (45–60 years)	8	11	34	29	42	22	
Frequency of seizures							
None in last 12 months	15	21	44	37	59	31	0.001*
Once in last 12 months	4	6	21	17.5	25	13	
Once every 3 to 6 months	18	25	18	15	36	19	
Once every month	14	20	22	18.5	36	19	
Weekly/daily	20	28	14	12	34	18	
Has cluster seizure							
Yes	33	47	29	24	62	36	0.002*
No	38	53	90	76	128	67	
Number of drugs							
1 drug	12	16.9	35	29.4	47	24.7	0.001*
2 drugs	13	18.3	43	36.1	56	29.5	
3 or more drugs	46	64.8	41	34.5	87	45.8	

revealed their epilepsy status prior to joining work (either in the job application or at the interview, or after receiving a conditional job offer). Forty-nine percent revealed after joining work (either formally to their superior or informally to a colleague).

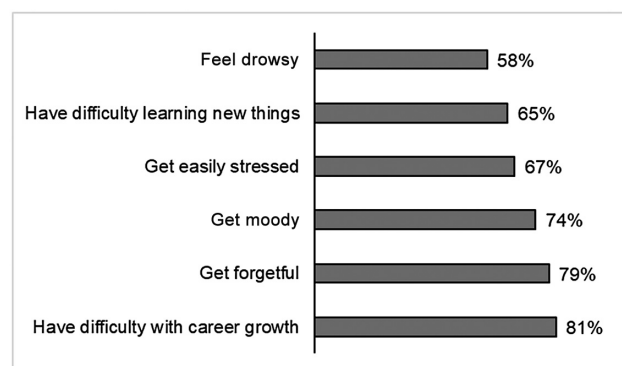
Difficulties Faced by PWE at Work

PWE who were employed faced challenges at work. Twenty-eight percent of the employed and temporarily unemployed cohort ($n = 43/156$) informed that they resigned from work for epilepsy-related reasons. Seventy-four percent

Table 4 Binomial logistic regression model for predictors of employment in epilepsy

	B	p-Value	Exp (B)	95% CI for Exp (B)	
				Lower	Upper
Age	0.367	0.146	1.443	0.881	2.366
Patient's education	0.295	0.029*	1.343	1.031	1.749
Mother's education	0.562	0.039*	1.754	1.029	2.992
Father's education	-0.474	0.101	0.622	0.353	10.98
Age at which seizures started	1.111	0.001*	3.038	1.653	5.584
Presence of cluster seizure	-1.055	0.006*	0.348	0.163	0.742
Frequency of seizure	-0.289	0.021*	0.749	0.586	0.957
Number drugs	-0.367	0.120	0.693	0.436	1.100

Abbreviation: CI, confidence interval.

**Fig. 1** Epilepsy-related challenges reported by those who resigned from work ($n = 43$).

($n = 32/43$) of them stated they were pressured into resigning, 50% informed that they were considered a risk/ liability, 39% found the job too stressful, 25% had colleagues who had objections / negative attitudes toward them, 5% had seizures at work, 20% had not informed their employer about epilepsy, and 11% felt epilepsy was the reason they were not given a promotion. The same cohort also reported cognitive and emotional challenges at work (► **Fig. 1**).

Discussion

Our study cohort was largely urban, well educated, having a family income that was above average with only epilepsy as their main problem. Results indicate that the odds of being employed increased with an increase in education level and the later onset age of epilepsy. Similarly, the odds of being employed decreased significantly with an increase in seizure frequency and presence of cluster seizures.

In our cohort, 37% patients were unemployed. This is in contrast with the Indian urban unemployment rate of 10.3%,⁹ “unemployed” being defined as one who has “sought work or did not seek but was available for work.” The unemployment percentage in our study is higher than the European studies that had similar patient cohorts. In Spain (2011),¹⁰ the unemployment rate among PWE was 10.9% (unemployed actively seeking work) and another 12.5% were

on disability pension. An earlier study from Sweden (1998)¹¹ had 9% unemployment among PWE and 16% on disability pension. A US study of 2007¹² had 12% looking for work and a much higher percentage (48.5%) on disability pension. However, 57% of the US cohort had additional medical problems. Other studies have had even higher unemployment rates: A Malaysian study¹³ reported 47.6% unemployment but the sample size was small ($n = 21$) and included only those with uncontrolled seizures. Likewise, a study conducted in India⁵ had an unemployment rate of 58%, but their sample population included only those with epilepsy onset in childhood.

In terms of education, in our cohort, 76% had completed formal education of 13+ years with 70% completing college education. This is comparable to the national average (69%) of the Indian urban population.⁹ Our cohort had higher education levels compared with other international research data. The Spanish studies of Falip¹⁴ and Marinas¹⁰ reported university-educated cohorts of 13.9 and 26%, respectively, and a British study¹⁵ had 36.6% of PWE with an education at or beyond “A” levels. In urban Mumbai, our experience with family members of PWE at the epilepsy NGO, Samman Association, suggests that there is enormous family support when it comes to completion of education, with parents employing private tutors or having siblings tutor the PWE. At times parents even join the same study course as their offspring. Besides the obvious psychological, social, and employability advantages that can go with higher education, other factors that appear to motivate PWE to complete education in India are (a) lack of disability benefits (monetary) to support oneself if unemployed (b) university education / tuitions are relatively inexpensive (c) improve prospects of getting married (d) PWE might not be ready for work or unable to get work and so continues with education. The employed group of PWE had significantly higher education levels and better-educated mothers ($p < 0.05$) than the unemployed group. The unemployed group also had a higher percentage of early seizure onset that could have hampered their education.

The clinical factors that impacted employability were age of epilepsy onset, frequency of seizures, and occurrence of cluster seizures. These findings are like those found in

reviews by Smeets et al.³ and Wo et al.,⁴ which report that when seizures are well controlled, and employment is not an issue.

In terms of challenges faced by PWE, the employed and temporarily unemployed groups felt that epilepsy was a barrier to career growth. In our study, among those who were pressured to resign, majority were graduates/postgraduates or professionally qualified, suggesting that pressure to resign was not because of lack of training or competence. Those who resigned for epilepsy-related reasons reported cognitive and emotional difficulties such as “forgetfulness,” “difficulty learning new things,” “moodiness,” “easily stressed,” and “drowsiness.” Such difficulties can pose huge problems depending on the complexity and challenges faced at work. In the USA study by Fisher et al.,¹⁶ respondents ranked “cognitive impairment” the highest in the list of potential problems. Strine et al.¹⁷ reported that PWE had higher levels of unemployment, pain, hypersomnia, insomnia, psychological distress, and insufficient leisure time. An Indian study by Gosain and Samanta¹⁸ revealed that at workplaces, epilepsy is often perceived as being a condition that interferes with cognitive capacities and that the quality of work of PWE is impacted by reactions from their colleagues who witness seizures.

PWE who can secure and hold jobs also face the unique stress of “if and when” to disclose epilepsy status at work. If undisclosed, the anxiety of having a seizure takes its own toll. However, it is very encouraging that 61% of our cohort had disclosed epilepsy status before starting employment, which indicates a possible lessening of perceived and/or actual stigma, at least in the urban setting.

In many countries, travel to work is another major hurdle for PWE to maintain employability. Legally PWE are not allowed to drive in India,¹⁹ irrespective of seizure control. As most of our cohort was based in Mumbai city where public transport is an easily available and cheap mode to commute, the inability to drive is not a major challenge. However, 47% of those who had never been employed had indicated “inability to travel alone” as a reason for their unemployment.

In this study, participants were selected through purposive sampling, which could have led to selection bias. Additionally, the participants from rural India were very few.

Conclusion

The majority of PWE in this study resided in an urban setting were employed, well-educated and held jobs of responsibility. However, they did face epilepsy-related challenges that hampered their work. A small cohort had poorly controlled seizures with early onset of epilepsy and this was a factor for low employment. Supportive counseling and cognitive rehabilitation are very important for this group of PWEs to help them optimize their work life. People with severe epilepsy who cannot engage in competitive employment need opportunities for skill-based training. A concerted effort by all stakeholders—caregivers, employers, national epilepsy associations, and the government is required to ensure that a fair opportunity is provided for all PWEs to become contributing members of society.

Strengths and Limitations of the Study

The data for our study was collected through convenience sampling using a self-report questionnaire. The advantage of convenience sampling method is ease of administration and access to responses of large number of PWEs in a short time. The self-report offers anonymity and privacy to respondents to answer honestly and there is no interviewer bias. However, the limitations of this method need to be acknowledged. Convenient sampling lacks generalizability. The self-report questionnaire has an inherent “self-selection” sampling bias. The decision to participate in the study is left entirely to volunteers whose motive to participate in a research study may be different from those who chose not to and hence the sample may not represent the population.

Conflict of Interest

None declared.

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This study has been sponsored and conducted by Samman Association, an association that has been working to empower PWE since 1972, and has been holding support group meetings for PWE for over 30 years. We thank all the participants who participated in the survey.

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