



Work difficulties, work restrictions, and disability benefits in people with functional seizures: A survey study



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ABSTRACT

Purpose: Functional seizures (FS) cause significant long-term disability and clinicians offer differing views on proper work restrictions and qualifications for disability benefits in this population. We assess the views and perspectives of experienced disability and work limitations in people living with functional seizures.

Methods: Between (4/29/2020–1/13/2021) an open-access 21-item internet survey was conducted via FNDHope.org; allowing for people living with self-reported functional seizures to remark on topics of work difficulties, work restrictions, qualifications for disability benefits, and driving. Demographic information was collected, and univariate and multivariate logistic regressions were used to evaluate potential predictors of current employment status.

Results: One hundred eighteen (118) responses were received, of which 92 (84.4%) completed > 50% of the survey; they were predominantly (92%) female. Most respondents (88%) reported some personal difficulty at work and nearly all (99%) believed that others with FS would experience difficulties in the workplace. A majority (71%) felt that work restrictions should apply to people living with active FS, at least in certain lines of work. Most (64%) felt people with FS should qualify for disability benefits; however, 35% stated work accommodations or a new job compatible with FS was more appropriate. Of those who felt people with FS should qualify for disability, 60% thought recipients should remain eligible for disability while symptomatic and 38% felt benefits should be lifelong. In univariate and multivariate logistic regressions, older age was predictive of unemployment (univariate OR 0.95 ± 0.02, 95% CI 0.92–0.98, p-value 0.002).

Conclusion: Our results suggest that work difficulties are common in people with FS, with older age being a predictor of unemployment. A majority of people with FS support work restrictions for those with their disorder, at least in some lines of work. In comparison to a prior study of clinicians, a higher percentage of people with FS supported work restrictions. These results may help facilitate productive discussions between people with FS, providers, and policymakers regarding appropriate work and disability limitations.

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1. Introduction

Functional seizures (FS), also known as psychogenic non-epileptic seizures (PNES), are paroxysmal non-volitional clinical events resembling epileptic seizures that are thought to be caused by a complex interplay of biopsychosocial vulnerabilities, often in the setting of psychosocial and/or physical triggers, and are not caused by abnormal excessive neuronal activity [1]. FS are a com-

mon and disabling subtype of functional neurological disorder, also known as conversion disorder [2–4]. While functional seizures can arise at any age, most present in young adulthood with a strong female predominance [5]. A growing body of evidence suggests elevated mortality in people with FS, similar to people with drug-resistant epilepsy [6]. FS impair quality of life to an equal or greater extent than epilepsy [7]. Contributing factors include the person's perception of the diagnosis, psychological comorbidities, disability, and driving limitations [7,8]. Compounding the affected person's perception of disability are those held by their medical providers, employers, and loved ones, which can vary widely. An international survey found that clinicians treating

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people with functional seizures have differing opinions regarding work restrictions and disability benefits; with mental health professionals favoring lifelong benefits and neurologists favoring limited working restrictions [9]. Given uncertainty and disagreement among clinicians, disability services, and patients, it is important to assess patients' perspectives. Evaluating patients' perspectives may also help to alleviate the historical stigmatization and disempowerment of people with functional neurological disorders [10]. In this study we assess the experience of disability and work limitations among people with functional seizures. Prior single-center studies have identified unemployment as a serious issue among people with FS [11]. By collecting patient perspectives across multiple nations, we aim to provide unique insights into the topic of employment challenges among those with FS. Based on prior single-center studies, we hypothesize that difficulty at work, functional seizure frequency, and driving restrictions predict lower rates of employment [12].

2. Methods

2.1. Study design/data source

Between April 29th, 2020 and January 13th, 2021, an open-access 21-item internet survey [Appendix A] was conducted in collaboration between the patient advocacy organization, FND Hope (FNDHope.org), and Yale School of Medicine. FND Hope is an international charity organization that offers information, resources, and support to those affected by functional neurological disorders. Our study collected demographic information, including age, sex, gender identity, seizure frequency, duration of illness, employment status, and employment type. This study was determined to be exempt from IRB review by the Yale University Human Subjects Committee (HSC), study #2000027923.

2.2. Participants

This survey allowed access to people self-identifying as living with functional seizures, to report on the following topics: work difficulties, work restrictions, qualifications for disability benefits, length of disability eligibility, necessity of special working accommodations, and driving. All participants were recruited via the FND Hope website (FNDHope.org). The website sees monthly traffic of between 60,000–80,000 visits and an international representation of 212 different countries, with the top five being the UK, USA, Australia, Canada, and India. The majority of users are female, between the ages of 25 and 34, (Source – Google Analytics, supplied by FND Hope).

2.3. Statistical analysis

Descriptive statistics included mean and standard deviation for normally distributed data and median and interquartile range (IQR) for non-normally distributed data. A univariate and multivariate logistic regression were used to evaluate potential predictors of current employment status. Independent variables included in the logistic regressions were age, sex, duration of illness, seizure frequency, difficulty at work, and driving. Odds ratios (OR) with a 95% confidence interval (CI) were recorded. A p value of < 0.05 was considered significant. Statistical analysis was performed using STATA/IC 14.2 (StataCorp LP, College Station, TX, USA).

3. Results

One hundred eighteen (118) responses were received, of which 92 (84.4%) completed the majority (>50%) of the survey. We are

unable to calculate a response rate, as the number of people who viewed the study announcement is unknown, however the total number of monthly respondents is similar to that of prior survey studies conducted via FNDHope.org. The average age of the participants was 37.6 yrs ± 13.5 (range 18–67); 91.7% (n = 100) of the participants were female; median functional seizure frequency was 17 per month (IQR = 2–22) and the median illness duration was 3 yrs (IQR 1–6). In total, 40.8% of the participants (n = 40) were employed, 38.7% (n = 38) were unemployed, and 20.4% (n = 20) were students or volunteer workers (Table 1). The majority [87.9% (n = 80)] reported some personal difficulties at work [Appendix B]; including accidents at work, impaired work performance due to FS, exacerbation of FS due to work, or other unspecified difficulties. Ninety-nine percent (n = 96) perceived that other people with active functional seizures would also experience difficulties in their workplaces; especially if working in jobs that involve driving or operating heavy machinery, safety of others' lives, weapons, interactions with many people, and high levels of stress. The majority, (70.7%; n = 65) of the participants, felt that at least some work restrictions should apply to people living with active functional seizures. Sixty-four percent (n = 59) of the partic-

Table 1
Demographics and Employment Characteristics.

Age [Mean ± Sd]: N=108	37.6 ± 13.5
Age at seizure onset [Mean ± Sd]: N=109	32.2 ± 13.9
<u>Sex at birth: N=109</u>	
Female, N (%)	100 (91.7)
Male, N (%)	9 (8.3)
<u>Gender Identity: N=109</u>	
Male, N (%)	10 (9.2)
Female, N (%)	95 (87.2)
Queer/non-binary, N (%)	2 (1.8)
Trans-man, N (%)	1 (0.92)
Other, N (%)	1 (0.92)
Duration of Illness yrs [Median, (IQR)]: N=108	3 (1-6)
Seizure frequency per month [Median, (IQR)]: N=81	17 (2-22)
	N (%)
<u>Employment: N=98</u>	
<u>Working:</u>	40 (40.8)
working (paid)	28 (28.6)
working (self-employed)	6 (6.1)
working with accommodations	6 (6.1)
<u>Not Working:</u>	38 (38.7)
not working (disabled)	27 (27.6)
working (looking for work)	2 (2)
not working (retired)	2 (2)
not working (other)	7 (7.1)
<u>Other:</u>	20 (20.4)
volunteer working (retired)	2 (2)
full-time student	18 (18.4)
	N (%)
<u>Category of Work: N=95</u>	
Architecture and engineering	1 (1.1)
Arts, Designs, Entertainment, Sports, Media	9 (9.5)
Business and Financial operations	6 (6.3)
Community and social service	10 (10.5)
Computer and mathematical	4 (4.2)
Construction and extractions	1 (1.1)
Educational instruction and library	13 (13.7)
Farming, fishing, forestry	2 (2.1)
Food preparations and serving-related	2 (2.1)
Healthcare practitioners and technical	12 (12.6)
Healthcare support	6 (6.3)
Installations, maintenance, and repair	3 (3.2)
Legal	2 (2.1)
Life, physical and social sciences	3 (3.2)
Management	2 (2.1)
Personal care and services	3 (3.2)
Sales and related	8 (8.4)
Transportation and material moving	1 (1.1)

ipants felt that people with functional seizures should qualify for disability benefits in at least some circumstances, and another 34.8% (n = 32) indicated that work accommodations or a new job compatible with functional seizures were more appropriate. Of those who felt that people with functional seizures should qualify for disability benefits, 60.3% (n = 35) thought they should remain eligible for benefits as long as seizures persist, 37.9% (n = 22) felt that disability benefits should apply lifelong, and 1.7% (n = 1) endorsed a fixed and limited period of eligibility.

Regarding driving [Appendix C], 41.3% (n = 38) reported operating a motor vehicle, mostly (67.6%; n = 25), for occasional errands or recreation. Of those driving, 7.9% (n = 3) reported experiencing a functional seizure while driving resulting in an accident of any kind. Most drivers (53.3%; n = 49) recalled being instructed by a clinician not to drive, while 15.2% (n = 14) reported they had not been counseled to avoid driving, and the remaining 31.5% (n = 29) had never been counseled to avoid driving, but voluntarily restricted themselves.

A univariate logistic regression [Table 2] was performed to assess potential predictors of current employment (age, sex, illness duration, FS frequency, driving, and difficulty at work). Of these covariates older age alone was predictive of unemployment (OR 0.95, 95% CI 0.92–0.98, p-value 0.002). This association remained statistically significant in the multivariate analysis (OR 0.93, 95% CI 0.89–0.98, p-value 0.008).

4. Discussion

These results suggest that the majority of people with FS experience difficulty with work. Nearly all survey participants felt that others with FS would experience difficulty with work performance, especially in positions of high stress. Most felt that at least some work restrictions should apply to people living with FS; including limiting access to high-risk or high-stress work environments and jobs that require operating a vehicle, firearms, or heavy machinery. This survey group was more supportive of work restrictions than an international group of clinicians in a prior survey. In that study, 46% suggested some restrictions, 24% expressed uncertainty, and 30% stated that people with FS should be counseled to pursue any job they liked [9]. These differing responses might suggest that people with FS have greater concern and ambivalence about their ability to work than the clinicians caring for them. In contrast, clinician perception may be the result of stigma and skepticism about the experience of patients or may represent a belief among clinicians that receipt of benefits affects prognosis [10,13]. Patients may also be discouraged by the lack of available treatments that sustainably reduce seizure frequency [14].

Most participants felt that at least some people with functional seizures should qualify for disability benefits and remain eligible as long as they are symptomatic; with most answering that all people with FS should qualify, regardless of job type. These results are similar to a prior survey of clinicians, which found that 80% felt at least some people with FS should qualify for disability; with

17% answering that all people should qualify, regardless of job type [9]. A key difference in our survey regarding the question of disability was the option to choose “work accommodations or a new job compatible with their seizures” separate from disability qualification [Table 2]. This option was selected by 35% of participants, suggesting that rather than dichotomizing disability, healthcare providers should review alternative job opportunities that may be preferable for people with FS. Providers may also consider contacting patients’ employers to explain the diagnosis and providing documentation for reasonable accommodations, which may reduce rates of employer termination.

Our results suggest that a minority, but non-trivial number of patients with FS drive a vehicle. Lower rates of driving in patients with FS have been described [12]. Few drivers reported experiencing an accident related to a functional seizure. This is consistent with a prior study showing that the rate of accidents in people with FS is not statistically different to the general population [15]. Driving did not predict current employment status in our study, which contrasted with a prior study showing that employment correlated with driving in people with FS [12]. The prior study was conducted in Iran and the disparate findings may be explained by cultural differences. Though most participants recalled being instructed by a clinician to avoid driving, a large minority answered that they had not, but voluntarily restricted their driving. This may suggest that people with FS understand the potential dangers of driving and may benefit from additional counseling regarding what types of restrictions apply and for what duration. Though guidelines and research are lacking in this area, a consensus statement released by the ILAE PNES Task Force on driving could serve as a useful resource for clinicians in evaluating patients on an individual basis [16].

Previous single-center studies have shown that unemployment is a serious issue in patients with FS, especially among females [11]. Our study, which included more female participants (92% vs 62%), found that gender was not predictive of current employment status. This could potentially be explained by cultural and gender norms in the prior study’s country of origin, Iran. Our results identified older age as predictive of unemployment among those with FS, even prior to legal retirement age (typically 65 yrs in the USA). Our results suggest that a 10-year age difference would imply a 0.60 odds ratio for employment. A rapid diagnosis and referral for evidence-based treatment of FS may be helpful in preventing long-term unemployment. Our study also suggests that some people with FS feel work restrictions should apply only to those working in high stress or high-risk professions. In these cases, an informed discussion to explore alternative employment could enhance quality of life. Contrary to our predictions, difficulty at work did not significantly affect rates of employment. This finding may reflect an individual’s concern regarding finances, difficulty obtaining disability for psychiatric disorders, and overall stigma surrounding unemployment.

These findings may suggest that people with FS realize their limitations and may look to medical professionals to provide appropriate advice when considering employment opportunities.

Table 2
Univariate & Multivariate Analyses – Predictors of current employment.

Variables	Univariate Odds Ratio (95% CI)	Univariate p value	Multivariate Odds Ratio (95% CI)	Multivariate p value
Age	0.95 (0.92–0.98)	0.002*	0.93 (0.89–0.98)	0.008*
Sex	2.04 (0.43–9.64)	0.370	2.29 (0.27–19.54)	0.370
Illness Duration	1.01 (0.95–1.07)	0.766	1.07 (0.98–1.16)	0.126
Functional Seizure Frequency	1.00 (0.99–1.02)	0.913	1.00 (0.98–1.02)	0.768
Difficulty at Work	0.56 (0.14–2.28)	0.421	0.32 (0.04–2.71)	0.294
Driving	1.66 (0.71–3.87)	0.242	1.11 (0.34–3.66)	0.864

*: Statistically significant at a p value of < 0.05.

To address ambivalence, motivational interviewing (MI) has proven to be an effective modality for counseling and achieving behavioral change among people with FS [17]. Cognitive behavioral therapy (CBT) has been shown to improve psychosocial functioning in people with FS [14]. The combination of MI and CBT may be helpful for improving patient engagement with work by resolving ambivalence and improving psychosocial functioning. In addition, new more effective treatment modalities may increase the ability and willingness of people with FS to engage in work. Under the guidance of clinicians some patients may be able to expand work involvement and reduce work limitations.

Limitations of this study included recruitment only among those with internet access and a proficiency in the English language. Our study had a larger female predominance than would be typically expected when compared to prior epidemiological studies and survey studies conducted through FNDHope.org [5,18]. Participants were also self-reporters of their diagnosis of FS. Though participant diagnoses were not validated, their self-identification as a person experiencing work difficulties as a direct result of presumed functional symptoms should not be minimized. By launching the survey through the FND Hope website we were able to obtain a broader, more international, segment of the FS population, however these means of data collection may have resulted in a biased sample population with respondents more concerned about work issues, wealthier, and better educated than the general population of people with FS. Additionally, as this was an online survey without a dedicated research coordinator, participants could not clarify confusion or uncertainty regarding specific questions or whether they felt the survey was applicable to their current employment situation. The views of the respondents may not be generalizable to others with more limited access to external support and knowledge of their diagnosis. Potential confounders contributing to disability in this population, such as physical and mental health disorders, were not examined. Geographic location of survey participants was not known, so it is unclear what types of social and cultural influences may have impacted their responses. Further studies to include the opinions of people with a documented diagnosis of functional seizures, family members, and employers on these important issues are warranted.

5. Conclusion

In conclusion the majority of people with FS experience difficulties at work and support work restrictions to those with their disorder. Older age is predictive of unemployment among those with FS. These findings demonstrate the importance of detailed counseling between patients and clinicians to identify and address barriers to employment.

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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.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ebr.2023.100610>.

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