



# Working restrictions and disability benefits eligibility in patients with functional (psychogenic) seizures: An international survey of physicians' opinions

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## ABSTRACT

**Objectives:** In this international study, we aimed to investigate the opinions of physicians dealing with patients with functional seizures (FS) worldwide on working restrictions and disability benefits eligibility.

**Methods:** International online survey of neurologists/ mental health professionals from Argentina, Venezuela, Colombia, Italy, France, Iran, Iraq, United Arab Emirates (UAE), Qatar, Saudi Arabia, Georgia, and Russia.

**Results:** Six hundred and twenty-seven physicians from 12 countries participated in the study. Working as a neurologist was a predictor to think that patients with FS should not be counseled to avoid performing all jobs or professions as long as they have active disease (OR: 0.46; 95% CI: 0.30 to 0.68;  $p < 0.001$ ). Having managed more than 200 patients was associated with the opinion that patients should not be counseled to avoid performing any type of work (OR: 2.17; 95% CI: 1.02 to 4.59;  $p = 0.043$ ). Working as a psychiatrist/psychologist was associated with the idea that patients with FS should be qualified for disability benefits (OR: 1.97; 95% CI: 1.21–3.21;  $p = 0.006$ ), and receive these benefits lifelong (OR: 0.43; 95% CI: 0.22–0.84;  $p = 0.014$ ).

**Conclusion:** Neurologists and mental health professionals have different attitudes and opinions toward working restrictions and disability benefits for patients with FS. Further studies should investigate the reasons for these differences, and propose solutions to avoid discrimination and unequal access to employment and disability benefits.

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## 1. Introduction

Functional seizures (FS) or psychogenic nonepileptic seizures (PNES) are characterized by paroxysmal, involuntary, and time-limited changes in behavior, motor activity, sensation, autonomic functions, and/or cognition (including impairment in responsiveness) [1]. These signs/symptoms resemble those encountered in epileptic seizures, but are neither explained nor explainable by abnormally excessive neuronal activity [1]. They represent a subtype of conversion disorder or functional neurological symptom disorder [2], and are commonly seen at neurology and psychiatry clinics worldwide [3]. They often affect young adults and may influence many aspects of a person's life, often impairing the health-related quality of life [4]. Patients with FS often have a lower employment rate than that in the general population, with devastating socioeconomic consequences [5,6].

As FS often affect the working-age populations, questions on job consultation and disability benefits eligibility may arise in clinical practice; patients may ask their healthcare provider if they qualify to receive such social supports, and authorities may ask the healthcare provider if these people are eligible to receive disability benefits [7]. While there exist regulations and guidelines on working restrictions and disability benefits for people with epilepsy, we are not aware of similar guidance for patients with FS. Furthermore, so far this topic has received very little attention from the medical community [7,8].

In this international study, we aimed to investigate the opinions and attitudes of physicians working with FS patients worldwide on job restrictions and disability benefits eligibility.

## 2. Methods

### 2.1. Participants

International experts in the field of FS (selected by AAP) from many countries around the world were invited to participate in an online predesigned questionnaire and asked to share it with their colleagues in their respective nations. Nations were categorized according to their cultural and socioeconomic status. All participants were neurologists or psychiatrists/psychologists. Six hundred and twenty-seven physicians from 12 countries participated in this study.

### 2.2. Data collection

The survey included 10 questions (Appendix 1): one question about professional qualifications, one on participants' personal experience with patients with FS, five questions investigating their opinions about the issue of job consultation, and three questions on the issue of disability benefits eligibility.

### 2.3. Data analysis

We descriptively summarized the demographic variables and responses from the whole cohort. Univariate comparisons were made through the Chi-squared test. Logistic regression analyses were performed to explore the associations between baseline characteristics of survey participants and responses to selected questions (questions n. 3, 6, 8, and 10); baseline predictors included age, years in practice, sex, discipline (neurology, psychiatry/psychology), and number of patients with FS seen and managed (<20, 20–100, 101–200, >200). Odds ratios (OR) and 95% confidence intervals (CI) were estimated. Results were considered significant for  $p$  values <0.05 (two-sided). Data analysis was

performed using STATA/IC 13.1 (StataCorp LP, College Station, TX, USA).

### 2.4. Standard protocol approvals, registrations, and patient consents

The Shiraz University of Medical Sciences Institutional Review Board approved this study. The participants took part in the study voluntarily and anonymously. No written consent was obtained.

### 2.5. Data availability statement

The data are confidential and will not be shared.

## 3. Results

Six hundred and twenty-seven physicians from 12 countries participated in this study [Argentina = 118, Venezuela = 105, Italy = 88, Colombia = 64, Iran = 63, France = 51, United Arab Emirates (UAE) = 40, Qatar = 27, Georgia = 27, Russia = 22, Saudi Arabia = 16, and Iraq = 6]. Since we do not know the denominator population (the total number of the people who were invited to participate in each country) we cannot calculate the response rate in this study. The participants included 348 females and 269 males (10 missing on sex) with a mean age (standard deviation) of 45.2 (11.1) years; 411 neurologists and 211 psychiatrists (5 missing). Table 1 shows their responses to the survey questions.

The logistic regression analysis showed that working as a neurologist was a significant predictor of thinking that patients with FS should not be counseled to avoid performing all jobs or professions (OR: 0.46; 95% CI: 0.30 to 0.68;  $p < 0.001$ ) (question 6). Having seen or managed more than 200 patients in the working lifetime was also significantly associated with the opinion that people with FS should not be counseled to avoid performing any type of work (OR: 2.17; 95% CI: 1.02 to 4.59;  $p = 0.043$ ) (question 6). Working as a psychiatrist/psychologist was significantly associated with the idea that patients with FS should be qualified for disability benefits (OR: 1.97; 95% CI: 1.21–3.21;  $p = 0.006$ ) (question 8) and should receive such benefits as lifelong (OR: 0.43; 95% CI: 0.22 to 0.84;  $p = 0.014$ ) (question 10) (Table 2).

Then, we categorized the nations into five different groups based on their cultural and socioeconomic status: South America (Argentina = 118, Venezuela = 105, and Colombia = 64; total: 287), Europe (Italy = 88 and France = 51; total: 139), Iran (63) & Iraq (6) (Shia Muslims and middle income; total: 69), Arab countries (Sunni Muslims and high income; UAE = 40, Qatar = 27, and Saudi Arabia = 16; total: 83), the former Soviet Republics (Georgia = 27 and Russia = 22; total: 49). We compared answers to some of the key questions between the world regions (Chi-squared test). Table 3 shows the responses based on the world region. Physicians from different world regions held different opinions on the issues of job counseling and also on disability benefits eligibility, but most believed that if patients with FS should be qualified for disability benefits, they should receive such benefits as long as they have active FS (Table 3). In none of the participating countries there exist specific regulations and guidelines on working restrictions and disability benefits for people with FS.

## 4. Discussion

While there exist regulations and guidelines on working restrictions and disability benefits for people with epilepsy [9] and even people with psychiatric disorders [10], we are not aware of any specific guidance for patients with FS. Moreover, this study shows that neurologists and mental health professionals have different attitudes and opinions toward disability benefits and working

**Table 1**  
Responses to the survey questions.

The whole group (N = 627)	
<b>How many patients with FS have you seen and managed in your lifetime?</b>	
More than 200 patients	56 (8.9%)
100–200 patients	90 (14.4%)
20–100 patients	273 (43.5%)
Less than 20 patients	208 (33.2%)
<b>Should <u>ALL</u> patients with FS be counseled to pursue any job or profession they would like?</b>	
Yes	185 (29.7%)
No	286 (45.6%)
Not sure	153 (24.4%)
<b>If all patients with FS should be counseled to pursue any job or profession without any conditions, which of the following reasons lead you to this conclusion? (You may select both)</b>	
In my clinical experience these patients do not have difficulty performing duties related to any job or profession	101 (16.1%)
I'm not aware of any scientific evidence that patients with PNES are at increased risk of difficulties with any job or profession	175 (27.9%)
<b>If patients with FS should be counseled to <u>permanently (lifelong)</u> avoid pursuing some specific jobs or professions, which of the following jobs or professions do you endorse in your advice? (You may select more than one)</b>	
Jobs involving many other people (e.g., pilot, bus driver, etc.)	379 (60.4%)
Jobs involving others safety and lives (e.g., EMS, firefighter, etc.)	336 (53.5%)
Jobs predisposing risk to self (e.g., construction worker, working with machinery, etc.)	316 (50.3%)
Jobs involving gun or arms (e.g., police officer, soldier, etc.)	364 (58%)
Jobs with excess stress	325 (51.8%)
<b>Do you think that patients with FS should be counseled to avoid performing all jobs or professions <u>as long as they have active FS</u>?</b>	
Yes	208 (33.2%)
No	289 (46.1%)
Not sure	126 (20.1%)
<b>How long do people need to be FS-free before they should not be considered to have “active FS”?</b>	
1 month	27 (4.3%)
3 months	87 (13.9%)
6 months	147 (23.4%)
12 months	201 (32.1%)
Other	78 (12.4%)
<b>Do you think that patients with FS should be qualified for disability benefits?</b>	
None of them should be qualified for disability benefits	122 (19.5%)
Patients with specific jobs or professions should be qualified for disability benefits	398 (63.5%)
All of them should be qualified for disability benefits	104 (16.6%)
<b>If some patients with FS with specific jobs or professions should be qualified for disability benefits, what are those jobs? (You may select more than one)</b>	
Jobs involving many other people (e.g., pilot, bus driver, etc.)	382 (60.9%)
Jobs involving others safety and lives (e.g., EMS, firefighter, etc.)	313 (49.9%)
Jobs predisposing risk to self (e.g., construction worker, working with machinery, etc.)	313 (49.9%)
Jobs involving gun or arms (e.g., police officer, soldier, etc.)	353 (56.2%)
Jobs with excess stress	281 (44.8%)
<b>If patients with FS should be qualified for disability benefits, how long they should receive such benefits?</b>	
Lifelong	43 (6.9%)
As long as they have active FS	545 (86.9%)

Some data were missing.

restrictions in people with FS. These differences may reflect an exposure to different patient populations: mental health professionals usually manage a more selected and homogeneous population of people with seizures, mostly including patients with FS, whereas neurologists see patients with FS and people with epilepsy. However, people with epilepsy often need to see psychiatrists/psychologists as well [for their comorbid psychiatric conditions (e.g., depression) [11]]; therefore, other reasons may exist for the observed differences between the opinions of neurologists and psychiatrists/psychologists.

Epilepsy and FS may be comorbid conditions in a substantial number of people. The mean frequency of epilepsy in patients with FS is about 22%, while the mean frequency of FS in patients with epilepsy is almost 12% [12]. However, many neurologists think that patients with FS should not be counseled to avoid performing all jobs or professions. This could suggest that neurologists do not regard the frequent comorbidity of epilepsy and FS as a major matter of concern about job restrictions. This finding also may suggest that neurologists have a more “liberal” attitude than mental health professionals on restrictions to individual freedoms, being less

prone to advise against restrictions of working activities in these patients.

Most patients with FS may experience loss of awareness during their seizures [13,14], which could lead to injuries [15,16]. However, the evidence for an increased risk of accidents at work among people with FS is insufficient to draw any recommendations on working restrictions in these people. Interestingly, a larger experience with FS patients was associated with the opinion that these patients should not be advised against performing any type of work; this suggests that physicians with larger experience in this field perceive FS as compatible with any job without specific restrictions. However, similar to driving restrictions, if patients experience FS characterized by recurrent and unpredictable loss of responsiveness/consciousness, there may be a public demand for regulations that are similar to those for people with epilepsy, even if the associated risks were lower [17].

Both epilepsy [18] and FS [6] have substantial socioeconomic consequences for individual patients, their partners, and the society. However, remarkably, being a mental health professional was more often associated with the idea that patients with FS should be eligible to receive disability and welfare benefits. This

could suggest that neurologists perceive patients with FS as less qualified for disability benefits compared to those with epilepsy. In one study, patients who achieved freedom from FS and drew disability benefits were five times more likely to have new medically unexplained symptoms compared to those without these benefits [19]. Accordingly, some neurologists may think that receiving disability benefits may negatively affect the functional outcome and the overall prognosis in patients with FS.

In the comparison between different world regions based on their cultural and socioeconomic status, we observed that physicians from different world regions held different opinions on the issues of job counseling and disability benefits eligibility. The observed differences between the world regions could not be jus-

tified according to their economic status (Table 3). Cultural factors probably play important roles in such opinions on the issues of job counseling and also disability benefits eligibility for patients with FS.

This study has some limitations. One author selected the countries to be involved – so there may exist a potential for bias, but a broad range of countries and a very large number of respondents included mitigate this limitation. In addition, the wording of the survey questions and other questions not addressed may have influenced the results. Also, the survey was in English language and this may have affected the interpretation of some of the questions in various countries. Further qualitative work is required to work out appropriate strategies for the questions raised in such

**Table 2**

Associations between baseline characteristics of the survey participants and answers to the selected questions.

<b>Question:</b> Should all patients with FS be counseled to pursue any job or profession they would like?				
<b>Answer:</b> Yes versus no				
Independent variables	Unadjusted		Adjusted <sup>‡</sup>	
	OR (95% CI)	p value	OR (95% CI)	p value
Age	1.00 (0.98-1.02)	0.932	1.00 (0.95-1.04)	0.924
Years in practice	1.00 (0.99-1.02)	0.820	1.00 (0.96-1.05)	0.751
Sex	0.85 (0.58-1.23)	0.381	0.78 (0.52-1.15)	0.211
*Discipline	0.99 (0.66-1.47)	0.943	1.00 (0.66-1.52)	0.997
**Patients managed in lifetime				
20-100	0.88 (0.57-1.36)	0.568	0.88 (0.56-1.38)	0.571
101-200	1.31 (0.72-2.37)	0.375	1.37 (0.72-2.60)	0.338
>200	0.52 (0.26-1.04)	0.064	0.58 (0.27-1.21)	0.146

<sup>‡</sup>Adjustment for age, years in practice, sex, discipline, and number of patients managed in lifetime.

\*Discipline categorized as neurology versus psychiatry/psychology; 128 out of 409 neurologists (31%) and 57 out of 211 psychiatrists (27%) answered “Yes”.

\*\*Reference is <20 patients.

  

<b>Question:</b> Do you think that patients with FS should be counseled to avoid performing all jobs or professions as long as they have active FS?		
<b>Answer:</b> Yes versus no		
Independent variables	Unadjusted	Adjusted <sup>‡</sup>

	OR (95% CI)	p value	OR (95% CI)	p value
Age	1.00 (0.98-1.01)	0.672	1.00 (0.96-1.05)	0.960
Years in practice	0.99 (0.98-1.01)	0.437	0.98 (0.94-1.02)	0.376
Sex	1.38 (0.96-1.99)	0.082	1.33 (0.90-1.97)	0.151
*Discipline	0.42 (0.29-0.62)	<0.001	0.46 (0.30-0.68)	<b>&lt;0.001</b>
**Patients managed in lifetime				
20-100	1.38 (0.91-2.08)	0.128	1.24 (0.79-1.94)	0.346
101-200	1.99 (1.12-3.55)	0.020	1.80 (0.95-3.39)	0.072
>200	2.08 (1.05-4.14)	0.037	2.17 (1.02-4.59)	<b>0.043</b>

<sup>‡</sup>Adjustment for age, years in practice, sex, discipline, and number of patients managed in lifetime.

\*Discipline categorized as neurology versus psychiatry/psychology; 118 out of 408 neurologists (29%) and 90 out of 210 psychiatrists (43%) answered "Yes".

\*\*Reference is <20 patients.

Significant *p* values are in bold.

**Question:** Do you think that patients with FS should be qualified for disability benefits?

**Answer:** None versus all patients/patients with specific jobs or professions

Independent variables	Unadjusted		Adjusted <sup>‡</sup>	
	OR (95% CI)	p value	OR (95% CI)	p value
Age	0.99 (0.97-1.01)	0.285	1.00 (0.95-1.05)	0.946
Years in practice	0.99 (0.97-1.01)	0.343	1.00 (0.95-1.05)	0.934
Sex	0.93 (0.62-1.39)	0.727	0.93 (0.61-1.42)	0.733
*Discipline	2.03 (1.28-3.24)	0.003	1.97 (1.21-3.21)	<b>0.006</b>
**Patients managed in lifetime				

(continued on next page)

20-100	0.79 (0.50-1.27)	0.336	0.96 (0.58-1.58)	0.879
101-200	0.87 (0.46-1.65)	0.667	1.17 (0.58-2.38)	0.655
>200	0.54 (0.27-1.08)	0.082	0.77 (0.36-1.68)	0.519

<sup>‡</sup>Adjustment for age, years in practice, sex, discipline, and number of patients managed in lifetime.

\*Discipline categorized as neurology versus psychiatry/psychology; 95 out of 410 neurologists (23%) and 27 out of 209 psychiatrists (13%) answered “None”.

\*\*Reference is <20 patients.

Significant *p* values are in bold.

**Question:** If patients with FS should be qualified for disability benefits, how long they should receive such benefits?

**Answer:** Lifelong versus as long as they have active FS

Independent variable	Unadjusted		Adjusted <sup>‡</sup>	
	OR (95% CI)	p value	OR (95% CI)	p value
Age	1.03 (1.00-1.07)	0.037	1.00 (0.92-1.08)	0.940
Years in practice	1.03 (1.00-1.07)	0.041	1.04 (0.96-1.12)	0.376
Sex	1.05 (0.56-1.96)	0.891	0.89 (0.46-1.72)	0.727
*Discipline	0.38 (0.20-0.72)	0.003	0.43 (0.22-0.84)	<b>0.014</b>
**Patients managed in lifetime				
20-100	1.43 (0.72-2.86)	0.307	1.21 (0.58-2.56)	0.610
101-200	1.60 (0.57-4.46)	0.371	1.10 (0.37-3.29)	0.869
>200	1.58 (0.45-5.61)	0.475	0.89 (0.23-3.41)	0.860

<sup>‡</sup>Adjustment for age, years in practice, sex, discipline, and number of patients managed in lifetime.

\*Discipline categorized as neurology versus psychiatry/psychology; 18 out of 377 neurologists (5%) and 24 out of 206 psychiatrists (12%) answered “Lifelong”.

\*\*Reference is <20 patients.

Significant *p* values are in bold.

Some data were missing.



**Table 3**

Responses to the survey questions based on the world region.

	South America (N = 287)	Europe (N = 139)	Arab countries (N = 83)	Iran & Iraq (N = 69)	Former Soviet Republics (N = 49)	p value
<b>Should <u>ALL</u> patients with FS be counseled to pursue any job or profession they would like?</b>						
Yes	110 (38%)	23 (17%)	35 (42%)	7 (10%)	11 (22%)	0.0001
No	102 (36%)	85 (61%)	35 (42%)	37 (54%)	27 (55%)	
Not sure	75 (26%)	29 (21%)	13 (16%)	25 (36%)	11 (22%)	
<b>Do you think that patients with FS should be counseled to avoid performing all jobs or professions <u>as long as they have active FS</u>?</b>						
Yes	153 (53%)	19 (14%)	12 (14%)	8 (12%)	16 (33%)	0.0001
No	65 (23%)	99 (71%)	55 (66%)	48 (70%)	22 (45%)	
Not sure	69 (24%)	20 (14%)	14 (17%)	12 (17%)	11 (22%)	
<b>Do you think that patients with FS should be qualified for disability benefits?</b>						
None of them should be qualified	45 (16%)	35 (25%)	10 (12%)	17 (25%)	15 (31%)	0.0001
Patients with specific jobs or professions should be qualified	175 (61%)	82 (59%)	63 (76%)	50 (72%)	28 (57%)	
All of them should be qualified	67 (23%)	21 (15%)	8 (10%)	2 (3%)	6 (12%)	
<b>If patients with FS should be qualified for disability benefits, how long they should receive such benefits?</b>						
Lifelong	23 (8%)	6 (4%)	4 (5%)	7 (10%)	3 (6%)	0.43
As long as they have active FS	264 (92%)	108 (78%)	78 (94%)	50 (72%)	45 (92%)	

Some data were missing.

future studies. Finally, due to marked heterogeneity between the world regions, the comparative results on ideas/attitudes toward disability benefits and working restrictions in patients with FS should be interpreted with caution.

## 5. Conclusion

The present study represents a first step to the development of a guideline for patients with FS concerning working restrictions and disability benefits eligibility. Opinions and attitudes toward working restrictions and disability benefits eligibility differ between neurologists and psychiatrists/psychologists. This could be a source of confusion for the patients and the community and could lead to unequal access to specific employments or social and economic benefits, potentially affecting the quality of life and the ability of patients to manage their lives.

The reasons for the differences between the opinions of neurologists and psychiatrists/psychologists and possibly other groups should be explored in the future. The opinions and attitudes of physicians dealing with these patients should be studied alongside those by other stakeholders (i.e., patient groups, caregivers, authorities, employers, etc.) in order to fully represent the multitude of relevant perspectives on these complex issues, with the final aim of avoiding discrimination and inequality of access to employment and disability benefits.

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## Conflicts of interest

Ali A. Asadi-Pooya: Honoraria from Cobel Daruo, RaymandRad and Tekaje; Royalty: Oxford University Press (Book publication). Francesco Brigo: received travel support from LusoFarmaco. Mansur A. Kutlubaev: Honoraria from Merk, Pfizer and Abbott Laboratories. Others: no conflict of interest.

## Availability of data and material

Data sharing is not possible for this article. The data are confidential.

## Contributions

Ali A. Asadi-Pooya & Francesco Brigo: Designed and conceptualized the study; collected the data; analyzed the data; drafted and revised the manuscript. Simona Lattanzi: Analyzed the data; revised the manuscript. Others: Collected the data; revised the manuscript.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.yebeh.2020.107678>.

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