



# Disability benefits in patients with psychogenic nonepileptic seizures: a survey of physicians' opinions

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## ABSTRACT

**Objectives:** The aim of the current study was to gather the views of healthcare providers practicing in the field of psychogenic nonepileptic seizures (PNES) on the issue of “disability benefits eligibility and PNES”.

**Methods:** This was a questionnaire study that was sent to all neurologists and psychiatrists practicing in Fars province, Iran. The survey included seven questions: one question about professional qualifications, one question on the participants' personal experience with the topic of interest (i.e., PNES), and five questions probing their opinions about the matter of interest (i.e., the issue of disability benefits eligibility in PNES).

**Results:** The response rate was 72%. Respondents included 32 psychiatrists and 31 neurologists. In response to the question “Do you think that patients with PNES should be counseled to avoid performing all jobs or professions as long as they have active PNES?”, 47 (75%) physicians answered “no” (22 neurologists and 25 psychiatrists;  $P = .5$ ). In response to the question “Do you think that patients with PNES should be qualified for disability benefits?”, 47 (75%) physicians answered “Patients with specific jobs or professions should be qualified for disability benefits” (23 neurologists and 24 psychiatrists;  $P = 1$ ); while, nobody believed that “All of them should be qualified for disability benefits”.

**Conclusion:** While collection of the opinions of physicians is valuable, this is just one piece of the puzzle; future studies should investigate the opinions of other stakeholders. More importantly, investigators should explore whether patients with PNES have any job-related difficulties.

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## 1. Introduction

Psychogenic nonepileptic seizures (PNES) are common occurrences at neurology clinics [1]. This condition may affect many aspects of a person's life. For example, health-related quality of life is often worse in patients with PNES as compared with those with epilepsy [2]. In addition, PNES may have substantial socioeconomic consequences for patients, their partners, and society [3]. For example, these patients often have a lower employment rate than that in the general population [3,4]. As PNES often affect the working age populations, particularly young adults [1], the questions on the issue of disability benefits (i.e., sick pay and disability pension) eligibility may arise in clinical practice (personal experience); patients may ask their healthcare provider if they qualify to receive such social benefits and support, and authorities may ask the healthcare provider if the individual with PNES is eligible to

receive disability benefits. While, there are guidelines available for people with epilepsy, we are not aware of such resources and guidelines for patients with PNES.

The aim of the current study was to gather the views of healthcare providers practicing in this field on the issue of “disability benefits eligibility and PNES”. This could provide only one piece of the puzzle, of course! The opinions of other stakeholders (e.g., patients, authorities, employers, etc.) and the potential effects of PNES on fitness for employment are other important issues that should be investigated in the future.

## 2. Methods

On October 10, 2019, we sent a questionnaire designed by AAP (the corresponding author) to all (46) neurologists and all (41) psychiatrists practicing in Fars province, Iran, who were accessible at the time of the study. The lists of physicians were obtained from their respected associations (i.e., Fars Neurology Association and Fars Psychiatry Association). The survey included seven questions (Appendix 1): one question about professional qualifications, one question on the participants' personal

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experience with the topic of interest (i.e., PNES), and five questions probing their opinions about the matter of interest (i.e., the issue of disability benefits eligibility in patients with PNES). Demographic variables and responses were summarized descriptively. Pearson Chi-square was used for statistical analyses. P value less than 0.05 was considered as significant. This study was conducted with the approval by Shiraz University of Medical Sciences Review Board.

### 3. Results

Of the 87 physicians approached, 63 responded to the questionnaire (response rate: 72%). Respondents included 32 psychiatrists and 31 neurologists (24 women, 28 men, and 11 missing data on sex). Age of the respondents was  $44 \pm 9$  years (range: 31–67 years), and they were  $10 \pm 7$  years in practice (range: 1–35 years). The proportion of each profession in this study in the province was well representative of the rest of the country; there are about 900 neurologists and 1000 psychiatrists in Iran.

Twenty-five (40%) physicians reported having experience with at least 100 patients [8 people with more than 200 patients and 17 with 100–200 patients; 9 neurologists and 16 psychiatrists ( $P = .08$ )]. Fifteen (24%) physicians had experience with less than 20 patients. In response to the question “Do you think that patients with PNES should be counseled to avoid performing all jobs or professions as long as they have active PNES?”, 47 (75%) physicians answered “no” (22 neurologists and 25 psychiatrists;  $P = .5$ ); while 10 (16%) people were not sure of the answer. In response to the question on the definition of “active PNES”, the responses were as follows: 1 month (9 physicians; 14%), 3 months (10 physicians; 16%), 6 months (13 physicians; 21%), 12 months (15 physicians; 24%), others (10 physicians; 16%), and six people skipped this question. In response to the question “Do you think that patients with PNES should be qualified for disability benefits?”, 47 (75%) physicians answered “Patients with specific jobs or professions should be qualified for disability benefits” (23 neurologists and 24 psychiatrists;  $P = 1$ ); while, nobody believed that “All of them should be qualified for disability benefits” and 16 (25%) physicians said that “None of them should be qualified for disability benefits”. Table 1 shows the details of the responses to the question “If some patients with PNES with specific jobs or professions should be qualified for disability benefits, what are those jobs?”. Finally, in response to the question “If patients with PNES should be qualified for disability benefits, how long they should receive such benefits?”, 7 (11%) physicians answered “lifelong” and 44 (70%) people said “as long as they have active PNES” [12 (19%) people skipped this question].

### 4. Discussion

In this study, we observed that most physicians, who are dealing with patients with PNES, believed that no all patients with PNES should be counseled to avoid performing all jobs or professions as long as they have active disease. In defining active PNES, they mentioned a wide range of time periods that people need to be PNES-free before they should not be considered to have “active PNES”; though, many endorsed

a 6- to 12-month seizure-free period. In addition, many physicians believed that patients with specific jobs or professions (e.g., pilots, bus drivers, firefighters, etc.) should be qualified for disability benefits, as long as they have active PNES. These are interesting and intriguing results.

Psychogenic nonepileptic seizures are associated with significantly higher health-related and other costs and lower levels of employment and income than those in patients with epilepsy [3,5]. A meta-analysis that synthesized data from 13 previous studies on 228 patients with PNES [6] demonstrated that only 47% of patients with PNES achieved seizure freedom upon completion of a psychological intervention. While patients with drug-resistant epilepsy are often considered to be eligible to receive disability benefits, the rules are not consistent for patients with PNES around the world. In a study by the International League Against Epilepsy (ILAE) PNES Task Force, a short survey was sent to all 114 chapters of the ILAE and a longer survey was completed by healthcare professionals who see patients with seizures. Questions were on the professional role, diagnostic methods, management, etiology, and access to healthcare. No respondent from low-income countries stated that their patients could receive state disability benefits for PNES, compared to 23% in the middle-income and 50% in high-income countries [7]. Ironically, a major risk factor for early disability pension in patients with epilepsy is psychiatric comorbidity [8] and more patients with PNES suffer from other psychiatric comorbidities (e.g., depression and anxiety) than those with epilepsy [9]. In addition, patients from low-income countries are probably more vulnerable. This paradox is likely related to the economic status, public politics and social and cultural issues in low-income countries.

Many patients with PNES experience loss of responsiveness with their seizures [10] and they may also experience severe consequences such as severe injuries with their seizures [11]. Therefore, it is plausible to assume that people with PNES could be at increased risk of having job-related difficulties (e.g., hardship performing duties related to their jobs, accidents, etc.). However, there is currently no evidence supporting or refuting this proposition.

This study highlights that the issue of welfare and disability benefits in patients with psychogenic nonepileptic seizures is a complicated issue. While collection of the opinions of physicians is valuable, this is just one piece of the puzzle; future studies should investigate the opinions of other stakeholders (e.g., patients, authorities, employers, etc.). More importantly, investigators should study and explore whether patients with PNES have any job-related difficulties (e.g., difficulty performing their duties, job-related accidents, etc.). These data would clarify whether and which patients with PNES are eligible to receive disability and welfare benefits and also the details (e.g., duration) of such benefits. Clarification of these issues, regardless of the potential medicoethical consequences, is also important for legal reasons.

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### Declaration of competing interest

Ali A. Asadi-Pooya: Honoraria from Cobel Daruo and RaymandRad; Royalty: Oxford University Press (Book publication); Grant from the National Institute for Medical Research Development. Others: no conflict of interest.

### Appendix 1. PNES & welfare benefits eligibility

#### Your Data:

Age:

Years in practice:

Sex:

**Table 1**  
If some patients with psychogenic nonepileptic seizures (PNES) with specific jobs or professions should be qualified for disability benefits, what are those jobs?

	Number of responses (%)
Jobs involving many other people (e.g., pilot, bus driver, etc.)	41 (65%)
Jobs involving others safety and lives (e.g., firefighter, etc.)	38 (60%)
Jobs predisposing risk to self (e.g., construction worker, working with machinery, etc.)	29 (46%)
Jobs involving gun or arms (e.g., police officer, soldier, etc.)	37 (59%)
Jobs with excess stress (e.g., air traffic control, etc.)	33 (52%)
Others	3 (5%)

**1. What is your discipline?**

- Neurology
- Psychiatry

**2. How many patients with PNES have you seen and managed in your lifetime?**

- More than 200 patients
- 100–200 patients
- 20–100 patients
- Less than 20 patients

**3. Do you think that patients with PNES should be counseled to avoid performing all jobs or professions as long as they have active PNES?**

- Yes
- No
- Not sure

**4. If individuals with active PNES should be counseled to avoid performing their jobs or professions, please specify your definition of “active PNES”: How long do people need to be PNES-free before they should not be considered to have “active PNES”?**

- 1 month
- 3 months
- 6 months
- 12 months
- Other

**5. Do you think that patients with PNES should be qualified for disability benefits?**

- None of them should be qualified for disability benefits
- Patients with specific jobs or professions should be qualified for disability benefits
- All of them should be qualified for disability benefits

**6. If some patients with PNES with specific jobs or professions should be qualified for disability benefits, what are those jobs?**

- Jobs involving many other people (e.g., pilot, bus driver, etc.)
- Jobs involving others safety and lives (e.g., EMS, firefighter, etc.)
- Jobs predisposing risk to self (e.g., construction worker, working with machinery, etc.)
- Jobs involving gun or arms (e.g., police officer, soldier, etc.)
- Jobs with excess stress (e.g., air traffic control, etc.)
- Others (specify:.....)

**7. If patients with PNES should be qualified for disability benefits, how long they should receive such benefits?**

- Lifelong
- As long as they have active PNES

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