



What patients think about psychogenic nonepileptic seizures in Buenos Aires, Argentina: A qualitative approach



Mercedes Sarudiansky^{a,c,d,*}, Alejandra Inés Lanzillotti^{a,c,d}, María Marta Areco Pico^{a,c,d},
Cristina Tenreiro^c, Laura Scévola^{b,c,e}, Silvia Kochen^{b,c}, Luciana D'Alessio^{b,c},
Guido Pablo Korman^{a,c,d}

^a CAEA, CONICET, Buenos Aires, Argentina

^b ENyS, CONICET, Buenos Aires, Argentina

^c Epilepsy Centre, Ramos Mejía and El Cruce Hospital, Argentina

^d Facultad de Psicología, Universidad de Buenos Aires, Argentina

^e Mental Health Center, Ramos Mejía Hospital, Buenos Aires, Argentina

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ABSTRACT

Purpose: To analyse the methods of reasoning with regard to patients' experiences of living with psychogenic nonepileptic seizures (PNES) in Buenos Aires, Argentina.

Method: A qualitative approach using semi-structured interviews was used to gain an in-depth and contextual understanding of the perspectives of five patients with PNES. Data collection and analysis were followed by an inductive and interpretive approach informed by the principles of thematic analysis.

Results: Explanatory models and prototypes were identified from the patients' narratives. Four patients related their suffering regarding psychosocial causes –family conflicts, sexual harassment, and life changes, among others–. Hereditary and organic hypotheses appeared to be unspecific. Folk explanations were common to all participants (magic, witchcraft, energetic causes). Four patients used the term *epilepsy* as an illness prototype, focusing on seizures and the use of antiepileptic drugs. Three of them also compared their illness to other people's "attacks" (heart attacks, panic attacks, nervous breakdown). Only one of them referred to someone who was suspected of having epilepsy.

Conclusion: Patients' psychosocial explanatory models are different from the results of previous studies because these studies indicate that most patients support somatic explanations. Patients also use folk explanations related to traditional medicine, which highlights the interpersonal aspects of the disease. Doctor-patient communication is essential for a correct understanding of PNES, resulting in better outcomes. It could also help to reduce the cultural distance between professionals and patients, leading to narrowing inequalities present in multicultural healthcare services.

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1. Introduction

Psychogenic nonepileptic seizures (PNES) are defined as paroxysmal changes in behaviour, sensory or cognitive activity, limited in time, that simulate epileptic seizures, but not as a result of abnormal brain electrical discharges [1–3]. In psychiatric diagnostic systems, PNES are categorized as conversion [4] and dissociative disorders [5]. Patients with PNES present a high rate of comorbidity with other psychiatric disorders [6–10]. In addition, many patients with PNES were previously misdiagnosed with

epilepsy [11–13], leading to delays in receiving appropriate treatment [14–17].

The video-electroencephalogram (VEEG) is considered the gold standard for differential diagnosis between epileptic seizures and PNES. However, other data, such as the semiology of the seizures and specific clinical information, also have been considered potentially useful to complement differential diagnoses [18–21].

Many studies have focused on the subjective experience of patients with PNES [22]. The heterogeneity of the clinical manifestations of PNES and the relevance of subjective symptoms make it difficult to reflect patients' experience quantitatively [22]. In addition, some authors emphasize that in specific populations, for example, people with a low level of education and a low socioeconomic status, the questionnaires used are biased and have limited reliability [23]. Therefore, qualitative methods that focus

* Corresponding author at: Av. de Mayo 1437 1A, Ciudad Autónoma de Buenos Aires, Argentina.

E-mail address: msarudi@gmail.com (M. Sarudiansky).

on understanding or interpreting patients' perceptions and beliefs [24] are useful [22]. Most qualitative approaches to PNES focus on understanding patients' ictal experiences, perceptions, beliefs, and attitudes toward PNES diagnosis and treatment.

Since the 70s, cross-cultural research in mental health has noted the importance of studying patients' explanatory models (EM) regarding their illness. These models often reflect social class, cultural beliefs, religious affiliation, and past experiences with illness and healthcare systems [25]. Kleinman, Eisenberg and Good [26] proposed that failing to consider the differences in explanatory models between doctors and patients could result in rejection, poor adherence or abandonment of supposedly effective treatments in specific populations [27,28].

Research shows that while neurologists believe that PNES are caused by psychological factors, most patients believe that they are caused by biological factors [29]. If physicians fail to consider the patient's perspectives, the patient-physician relationship can be negatively impacted [30], perhaps leading to poor adherence to treatment. Improving patient-physician communication such that patients feel understood by their doctors may improve patient outcomes.

Some authors [31,32] have proposed that EM are insufficient to explain how people reason about health and disease. They claim that patients also use other ways of reasoning, such as analogical thinking (e.g. "María was coughing and then was diagnosed with pneumonia. I was coughing, therefore, I think I might have pneumonia"). The identification of a prototypical illness experience in themselves or others can affect their health behaviours. For instance, in patients with PNES, those who used epilepsy as an illness prototype were less receptive to psychosocial interventions [33] and were less likely to adhere to psychological treatment [34]. As psychotherapy is the treatment of choice by health professionals for PNES, this study highlights the importance of investigating illness prototypes and explanatory models.

Thus far, most of the work in this area has been carried out in health centres in North America and Europe, mainly in the United Kingdom [22]. The experiences of patients and professionals in Latin America have not been studied. The objective of our study is to investigate both illness prototypes and explanatory models as they relate to patients' experiences of living with PNES in Buenos Aires, Argentina. This is the first qualitative study of the experience of patients with PNES in South America.

This work was carried out in the Epilepsy Center of the Ramos Mejía Hospital, a referral centre in the public health system of Buenos Aires and the first facility to offer VEEG, beginning in 2002. People from Argentina and immigrants from neighbouring countries benefit from this free service. Most of the patients tend to be from disadvantaged socioeconomic segments without health insurance. For this reason, cultural differences in communication between practitioners and patients are common.

1.1. Recruitment and sampling

In this study, we included all patients admitted to the VEEG unit to confirm a PNES diagnosis between December 2014 and December 2015. All PNES-diagnosed patients over the age of 18,

identified by a neurologist and confirmed through VEEG results, were invited to participate. Those patients who were also diagnosed with epilepsy, had an IQ < 85 according to the Wechsler Intelligence Scale for Adults (WAIS-III) [35], or were in a severe psychotic episode at the time of the evaluation were excluded.

Thirty patients were admitted to the VEEG unit. Eight patients were diagnosed with PNES and evaluated by the mental health team. Seven patients agreed to be interviewed. Five patients completed the evaluation process. Patients who declined to participate did not return for future interviews and did not explain their decision. The sociodemographical characteristics of the five participants are shown in Table 1.

Approval by the ethics committee of the Ramos Mejía Hospital was obtained for this investigation. All the patients signed informed consents. Pseudonyms were given to each of the participants to ensure their anonymity.

1.2. Data collection

All patients were assessed by neurologists, who conducted a full medical evaluation and confirmed the psychogenic origin of the seizures. They communicated this to the patients according to their own clinical training, without following any particular guidelines. Trained psychiatrists assessed for comorbid diagnoses and other psychosocial antecedents, such as trauma (Table 2).

After these assessments, three psychologists (MS, GPK, and MMAP) interviewed each patient. The interviews were recorded and transcribed. The average duration of each interview was 64 min.

1.3. Instruments

A qualitative method using semi-structured interviews was chosen to gain an in-depth and contextual understanding of the patients' perspectives of PNES. For this purpose, we utilized the Spanish version of the McGill Illness Narrative Interview Schedule (MINI) [32,36], which was modified to be used with this specific population by the first author (MS). According to Grouleau, Kirmeyer, and Young [32], this interview explores the narratives of the disease, focusing on the patients' experiences along with their health trajectories. It enables the description of metonymical, analogical, and causal ways of reasoning. In this paper, we focus on analogical and causal reasoning. Analogical reasoning is based on relevant events or episodes from the patient's or others' experiences, which enable the identification of illness prototypes. Causal reasoning can include conventional models, causal attributions, or more elaborate models in which patients identify events or experiences that they attribute to their illness onset [32].

Some of the questions corresponding to each section of the interview are detailed in Table 3.

1.4. Data analysis

Data collection and analysis followed an inductive and interpretive approach, informed by the principles of thematic analysis [37].

Table 1
Socio-demographic characteristics of participants.

Patient	Age ^a	Gender	Nationality	Residence	Marital status	Level of schooling	Occupation
Juan	23	Male	Argentinian	C.A.B.A.	Single	Incomplete Secondary school	Unemployed
Ana	24	Female	Argentinian	A.M.B.A.	Unmarried couple	Incomplete University	Housewife
Sonia	39	Female	Paraguayan	C.A.B.A.	Unmarried couple	Full Primary school	Unemployed
Laura	18	Female	Argentinian	A.M.B.A.	Single	Incomplete Secondary school	Student
Inés	21	Female	Argentinian	C.A.B.A.	Single	Complete Secondary school	Unemployed

^a Age in years at the time of the first consultation.

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