This is a repository copy of *What patients say about living with psychogenic nonepileptic seizures: A systematic synthesis of qualitative studies.*.

White Rose Research Online URL for this paper:
http://eprints.whiterose.ac.uk/104019/

Version: Accepted Version

Article:

Rawlings, G.H. and Reuber, M. (2016) What patients say about living with psychogenic nonepileptic seizures: A systematic synthesis of qualitative studies. Seizure, 41. pp. 100-111. ISSN 1059-1311

https://doi.org/10.1016/j.seizure.2016.07.014

Article available under the terms of the CC-BY-NC-ND licence (https://creativecommons.org/licenses/by-nc-nd/4.0/)

Reuse

Unless indicated otherwise, fulltext items are protected by copyright with all rights reserved. The copyright exception in section 29 of the Copyright, Designs and Patents Act 1988 allows the making of a single copy solely for the purpose of non-commercial research or private study within the limits of fair dealing. The publisher or other rights-holder may allow further reproduction and re-use of this version - refer to the White Rose Research Online record for this item. Where records identify the publisher as the copyright holder, users can verify any specific terms of use on the publisher's website.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.

eprints@whiterose.ac.uk
https://eprints.whiterose.ac.uk/

Abstract

Purpose: This qualitative study aimed at examining the subjective experiences of patients during the complicated and often prolonged diagnostic process of psychogenic non-epileptic seizures (PNES).

Methods: Thematic analyses were used to explore the semi-structured interviews that were conducted with ten individuals who have been diagnosed with PNES.

Results: Six main themes, namely inexpert healthcare providers, limited medical insurance and loss of independence were identified as barriers, while social support, comprehensive medical insurance and knowledgeable healthcare providers were identified as facilitators through the process of thematic analysis.

Conclusions: The patients' perspectives revealed that an earlier diagnosis of PNES is essential to address the loss of independence and limit inappropriate and potentially harmful treatment as well as the costly burden of this condition on both the patient and the healthcare system. It was evident in this study that healthcare providers play an essential role in the subjective experiences of these individuals during the diagnostic process. The implementation of continuous education programmes for healthcare providers in particular could contribute positively to the diagnostic process of PNES for patients.

Highlights

- Medical professionals occupy key roles both as a barrier and facilitator
- Loss of independence were described as a major barrier
- Financial implications of the prolonged diagnostic process were identified as a major barrier.
- Patients value well-resourced services and good social support

Barriers and facilitators to reaching a diagnosis of PNES from the patients' perspective: Preliminary findings

Corresponding author

Chrisma Pretorius*, Lecturer, Stellenbosch University, Department of Psychology, Private Bag X1, Matieland, Stellenbosch

e-mail: chrismapretorius@sun.ac.za

Phone: +27 21 808 3453

Mobile: +27 83 545 8999

Fax: +27 21 808 3584

Abstract

Purpose: This qualitative study aimed at examining the subjective experiences of patients during the complicated and often prolonged diagnostic process of psychogenic non-epileptic seizures (PNES).

Methods: Thematic analyses were used to explore the semi-structured interviews that were conducted with ten individuals who have been diagnosed with PNES.

Results: Six main themes, namely inexpert healthcare providers, limited medical insurance and loss of independence were identified as barriers, while social support, comprehensive medical insurance and knowledgeable healthcare providers were identified as facilitators through the process of thematic analysis.

Conclusions: The patients' perspectives revealed that an earlier diagnosis of PNES is essential to address the loss of independence and limit inappropriate and potentially harmful treatment as well as the costly burden of this condition on both the patient and the healthcare system. It was evident in this study that healthcare providers play an essential role in the subjective experiences of these individuals during the diagnostic process. The implementation of continuous education programmes for healthcare providers in particular could contribute positively to the diagnostic process of PNES for patients.

.

Keywords:

Psychogenic non-epileptic seizures

Barriers

Facilitators

Diagnosis

Healthcare providers

Introduction

Psychogenic nonepileptic seizures (PNES), are events that mimic epileptic seizures (ES) but in reality are episodes of involuntary movement or behaviour that are not the result of abnormal cortical discharges but rather of underlying psychological stressors [1]. PNES is a complex and controversial disorder that remains poorly understood and managed in the clinical setting [2]. Nevertheless, PNES is a common neuropsychiatric condition which is often misdiagnosed as ES due to the similarities in presentation, frequently resulting in prolonged treatment with anti-epileptic drugs (AED), and avoided by many healthcare providers [1,3,4,5]. Associated stigma and loss of quality of life are compound consequences of misdiagnosis [6].

The gold standard for diagnosing PNES is through the use of video electroencephalography (vEEG) over a prolonged period [3]. However, the majority of patients in South Africa do not have access to vEEG monitoring equipment [4,7,8]. Without access to vEEG and expertise and the right level of expertise, PNES can be challenging to diagnose. PNES rarely presents as an isolated symptom. Other accompanying complaints, including cognitive and sleep problems, usually add to the intricacy of this disorder [9]. In addition, many healthcare providers do not have the expertise to diagnose and treat PNES and subsequently, patients with PNES may find themselves on the border between neurology and psychiatry with neither of these professions prepared to take responsibility for treating this complex condition [1]. Studies indicate that the average period between seizure manifestation and correct diagnosis of PNES is about seven years [10]. During the diagnostic process patients are often confronted with extensive and expensive testing [11] as well as a lack of understanding of this condition from healthcare providers [1,5,8,12]. Early diagnosis of PNES is therefore not only important in reducing the significant costs to the patient and healthcare systems, or in decreasing the major side-effects due to incorrect treatment [1]. It is also important because an accurate diagnosis is the first step in PNES treatment and the outcome is better in people with a shorter history of PNES; while the longer the delay in diagnosis, the worse the prognosis for individuals with PNES [10,11]. The delay between the onset of seizures and the correct diagnosis of PNES represents a public health problem resulting from diagnostic difficulty, poor prognosis, disability, distress, financial implications and unemployment status [4,13]. All these factors emphasise the need for accurate diagnosis of PNES early in the course of seizures. There seems to be a major lack of literature with regard to the experiences of individuals who are in the process of reaching a diagnosis of PNES. This is an important, but clearly neglected, area of research [1]. The present study sought to explore the barriers and facilitators to reaching a diagnosis of PNES from the patients' perspective.

Method

Study design

An explorative qualitative design was implemented in this study for two reasons. First, the process of reaching a diagnosis of PNES is a relatively unexplored topic, not only in South Africa, but worldwide. Second, this pilot study made use of semi-structured interviews which aimed at identifying the barriers and facilitators to reaching a diagnosis of PNES, to be addressed in a large-scale questionnaire survey.

Participants and procedure

The participants of this study consisted of a convenience sample of ten individuals who have been diagnosed with PNES. Table 1 summarizes information from the participants in the sample.

Table 1

Characteristics of participants (n =10)

Participant[a]	Age	Gender	Race	Marital status	Time to reach a diagnosis of PNES[c]	Employment status	Public / Private healthcare
1	48	Female	Coloured[b]	Married	0.5 years	Employed	Private
2	46	Female	White	Divorced	> 7 years	Employed	Private
3	51	Male	Coloured	Married	0.5 years	Employed	Private
4	41	Male	White	Married	1 year	Employed	Private
5	26	Female	White	Single	1 year	Employed	Private
6	44	Female	Coloured	Married	1-2 years	Unemployed	Private
7	19	Female	White	Single	4-5 years	Unemployed	Private
8	19	Female	White	Single	1-2 years	Unemployed	Private
9	43	Female	Coloured	Married	0.5 years	Unemployed	Private
10	55	Female	White	Single	1-2 years	Employed	Private

[a] A participant number were assigned to each participant

[b] "Coloured" is a term used in South Africa, including in the national census, for persons of mixed race ancestry

[c] Time from onset of seizures to reaching a diagnosis of PNES

Two hospitals (one public and one private) were approached to assist with the identification of potential participants. These hospitals were carefully chosen because they are some of the very few hospitals in South Africa (and the only ones in the Western Cape) that have specialised video/EEG equipment to diagnose patients with PNES. The participants therefore came from all over the country and have been treated by numerous other healthcare providers in their hometowns by the time that they are referred to one of the abovementioned hospitals. Notably, all the participants in this study were referred by the neurologist from the epilepsy unit at Constantiaberg Mediclinic, which is a private hospital in the Western Cape, South Africa, so all ten participants had access to private healthcare. This fact will of course limit the generalizability of the study, but given the lack of services and the lack of referrals from the public hospital despite numerous attempts to recruit participants there, this sample was viewed as adequate for an initial exploratory study.

Inclusion criteria were a formal diagnosis of PNES of individuals older than 18 years of age by an experienced neurologist according to the results of Video/EEG monitoring. The participants' ages ranged between 19 and 55 years (X = 39.2 years). Eighty percent of the participants were female. Five of the participants were married, with four being single and one divorced. Only three of the participants were correctly diagnosed with PNES fairly soon after experiencing their first seizure, with most taking up to a year. However, for some participants it took up to five years, and another participant took 24 years to receive the correct diagnosis of PNES. Forty percent of the participants were unemployed. Ethical approval was granted by the Health Research Ethics Committee at the university (S14/04/096).

After informed consent was obtained from the participants, a semi-structured interview that lasted approximately 60 minutes was conducted with the participants. The interviews were guided by the following broad open-ended questions:

- Could you tell me a bit about yourself and your experiences up until you were told that your seizures are not due to epilepsy?
- What were some of the barriers that you experienced during the process of being diagnosed with PNES?
- What were some of the factors and/or resources that made it easier for you to cope with the diagnostic process of PNES?
- What do you think could make the diagnostic process of PNES easier?

Data collection was discontinued after ten interviews, because theoretical saturation was reached [14].

Data analysis

The interviews were audio recorded with the permission of the participants and transcribed verbatim. The transcribed data were analysed by making use of thematic analysis [15]. The researcher familiarised herself with the data, coded relevant text sections, organised codes into categories and developed categories into underlying themes. Themes were illustrated through the utilisation of direct quotations from the interviews.

Results

Thematic analysis of the interviews revealed three barriers which may appear during the process of reaching a diagnosis of PNES. However, participants did identify ways of coping with this difficult and often prolonged process.

Barriers

With regard to the barriers that participants had to endure prior to their diagnosis of PNES, three main themes emerged: inexpert healthcare providers; limited medical insurance; and loss of independence.

Inexpert healthcare providers

Dealing with healthcare providers such as neurologists, psychiatrists, paramedics and psychologists was a barrier for participants due to misdiagnosis, inappropriate treatment with AEDs that caused negative side effects and healthcare providers that are unfamiliar with PNES. Seven of the participants reported that they were initially misdiagnosed with epilepsy. This was identified as a major challenge as there were many negative consequences, such as prolonging the diagnosis of PNES and taking AEDs which often had negative side effects for the participants:

> …I was in the hospital a couple of times. They told me I had epilepsy. (Participant 7)

> …they initially thought that it was epilepsy and I was prescribed tablets for it… (Participant 5)

> … from 2010 to 2011 I saw five different neurologists…each started me on different medication…they all diagnosed me with epilepsy. (Participant 6)

> But for some or other reason the pills made me sicker, not better… I think the medication was the worst…because it makes you feel really clumsy and confused. (Participant 2)

Healthcare providers who are unfamiliar and inexperienced with PNES were also identified as a major barrier during the diagnostic process. As a consequence of this, all of the participants had to consult numerous doctors before reaching an accurate diagnosis of PNES. The following statements highlight this frustrating experience:

> …doctors were a huge challenge for me; constantly put me on medication without knowing what was going on. (Participant 8)
>
> …couldn't find what was wrong, the doctor couldn't understand it. (Participant 9)
>
> I struggled for a long time…it felt like I was going from one doctor to another and nobody had a clue. (Participant 2)
>
> In my experience most of the medical staff has little understanding of my illness. (Participant 10)

The attitudes of many healthcare providers were reported to be very challenging for the participants to deal with:

> I encountered many doctors who were rude, patronizing, and who didn't understand PNES. (Participant 8)
>
> The first doctor told me that I will never get better and that there was really no help for me. This was a very time difficult for me. I had no hope. (Participant 6)
>
> I was also told several times I was faking it for attention…not only in the emergency room, also by my psychiatrist. (Participant 2)
>
> I felt like I was irritating the doctors. The one doctor became frustrated and said, "I don't know. I don't know what else to do". (Participant 4)
>
> In my experience many doctors were not supportive or empathetic when they realised that it was a mental health problem and not a medical issue. (Participant 10)

Inadequate medical insurance

The second major barrier that was raised by the participants was that of medical insurance. Six of the participants reported that although they had access to medical insurance, it did not cover all their medical expenses. Medical bills were always increasing and many doctors charged fees that were out of medical insurance rates. Some of these frustrations are evident in the following statements:

> …whenever I went to the psychologist I hadn’t been able to afford it because medical insurance hadn’t paid for it…so we couldn’t afford to…to carry on. (Participant 10)
>
> Medical insurance didn’t cover all the doctors, as some of the doctors were out of medical insurance rates…and, that was like, go to the best one, you know. But it’s hard because at the end your, like ah, it was such a waste going for all those tests and we wasted so much money but at the time, like what do you do? (Participant 5)

Loss of Independence

The third major theme that was identified was the loss of independence. All ten participants reported a loss of independence in some form or another. The participants reported that they had to become dependent on others in most areas of their lives due to their seizures. This loss of independence was related to three areas in particular: driving; not being allowed to be alone; and loss of employment due to seizures.

Eight of the participants reported that a major part of their independence and sense of freedom had been lost because they were not allowed to drive:

> I couldn’t go or drive somewhere quickly and just get away; there always had to be someone who came with, always someone to drive me around. (Participant 8)
>
> If you drive, you’re not allowed to if you get epileptic or other attacks…it’s quite difficult. (Participant 9)

All ten participants reported that during the process of reaching the diagnosis of PNES, they were not allowed to be left alone. As a result, they had felt that they had lost their privacy, independence as well as freedom due to their seizures:

> I found it hard to always have someone around me to look after me. (Participant 9)
>
> I wasn’t allowed to be alone; I had to have somebody with me 24/7… I felt like it took away my independence. (Participant 1)

> My life felt out of control. (Participant 7)

Four of the participants reported that their seizures prohibited them from continuing work, resulting in feelings that their independence was lost. This sentiment is evident in the following statements:

> The doctor said it would be best, because I work with patients, it's for the best… I stopped working. (Participant 9)
>
> …due to the seizures I had to stop working. (Participant 6)

Facilitators

Although the participants endured many barriers during the process of reaching a diagnosis of PNES, they also reported that there were three facilitators in particular that assisted them to cope during the process. Social support, comprehensive medical insurance and healthcare providers were identified as major facilitators.

Social support

Nine of the participants emphasised the importance of social support during the process of reaching a diagnosis of PNES. Social support appeared to come from various sources such as family, partners, friends, and people in their workplace and school. Social support can be identified in the following statements:

> So I think in high school that things were easier, I had teachers who immediately knew, and who could help immediately. (Participant 7)
>
> …my mom doesn't like not knowing what's going on…she actually tried to make plans quite quickly. (Participant 8)
>
> …the person or people who helped the most…were my husband and my two children who are with me now, and my neighbour… (Participant 9)
>
> … my mother and father, they've been there through thick and thin…my in-laws and then my wife's aunt. (Participant 4)

Comprehensive medical insurance

Although medical insurance was identified as an important barrier, it was also acknowledged as a major facilitator by four of the participants. During the process of reaching a diagnosis of PNES, patients have to endure numerous medical expenses from various expensive tests and treatments, so knowing that that they have access to comprehensive medical insurance was helpful. This is evident in the following statements:

> …our medical insurance…covered almost everything. (Participant 8)
>
> I went to the best medical plan…that helps a lot. (Participant 2)
>
> I'm still lucky to be on my husband's [medical insurance]; I wouldn't say that I abuse it or misuse it, but I am grateful. (Participant 1)

Knowledgeable healthcare providers

The third major resource was healthcare providers. It appears that healthcare providers were both a barrier and a facilitator to the participants. Only three of the participants were lucky enough to receive a correct diagnosis of PNES relatively soon after they experienced their first seizure. Notably, although the remaining participants initially had negative experiences with healthcare providers, all seven of them acknowledged positive experiences with healthcare providers once they were referred to healthcare providers that were knowledgeable about PNES. They also emphasised the healthcare provider's positive attitudes as a major positive contributing factor:

> The fact that I had good doctors… Once I went to Doctor B. He helped me through it, he was a good doctor, always looked after me… (Participant 7)
>
> So then I went to more than one (psychologist) and I sort of found one that I clicked with, and then I started getting better. (Participant 5)
>
> …the only…doctor… that helped me was Doctor B and all the rest made it very difficult for me. (Participant 8)
>
> Almost two years later I was admitted to hospital and had video-EEG monitoring. That is where the doctor told me that I had PNES…I learned what PNES was and was also

> referred for therapy. My psychiatrist was very helpful. He would phone the medical insurance himself and tell them that it's chronic medication… (Participant 6)
>
> I was lucky to recently find someone who is empathetic, kind and have experience in treating patients like me. There is a human factor in her interaction with me which is important to me. (Participant 10)

Discussion

This study is among the first to explore the diagnostic process of PNES from the patients' perspective. Some of the main themes of this study seem to be largely confirmatory and applicable to most chronic conditions where patients value well-resourced services [8,12,16,17], good social support [1,5,16,17,18] and medical insurance that covers the diagnostic process [11].

However, three aspects of the diagnostic process of PNES seem to be more prominent and specific to this patient population. Firstly, the commonly lengthy process of reaching a diagnosis of PNES can be a lot more expensive, when compared to the diagnostic process of other chronic conditions [11]. Financially these patients are often confronted with a delay in confirming a diagnosis of PNES due to numerous doctors' visits, inappropriate treatment and medication that changes constantly [4,5,10,17]. In addition, hospitalizations in speciality units, extensive testing and monitoring with specialised equipment such as video-EEG can be expensive [4,11,12]. Notably, all the participants in this study had access to private and well-resourced healthcare. More than 80% of people in South Africa do not have access to medical facilities with the necessary video/EEG equipment or private medical insurance mainly because they live in rural areas and/or cannot afford it [4,7,8,19,20]. It is important to note that there is a paucity of neurologists in South Africa [21,22]. There are only approximately 100 neurologists to treat a population of almost 50 million South Africans [21]. Furthermore, between 60 – 70 percent of South African neurologists work in private healthcare, this leads to a very limited number of neurologists available, in the under-staffed and under-funded public sector, to treat the vast majority of the population [21,22]. In reality, in both the public and private sectors, neurologists are mainly located in urban parts of the country and this result in a lack of access to specialist services for people who live in rural areas of the country [21,22]. The experiences of the patients reported in this study therefore reflect the experiences of just a very small patient group in the South African context. The barriers faced by PNES patients with only access to public healthcare, which are overburdened and struggle to provide even basic services, are potentially a lot more intense. In addition to the barriers described in this paper, these individuals also face access barriers, such as high transportation costs, vast travel distances, long waiting times to receive services as well as a lack of privacy and confidentiality [23].

Secondly, the diagnostic process of reaching a diagnosis of PNES is generally a lot longer and more complicated, when compared to the diagnostic process of other chronic conditions [1,11,12]. Evident in this study, this long and debilitating process has the potential to affect the patients' independence (i.e., impact on employment, driving, lack of privacy due to the requirement of constant companionship) [5,16,24] and overall quality of life in particular [7,25,26]. The unexpected and frequent nature of PNES also contributes to the experience of these patients in a negative way [5,24]. In this study, the indirect effect through loss of independence and quality of life seems to be much more than direct costs of drugs and expensive assessments.

Thirdly, healthcare providers were identified as key role-players in this study. Two main aspects were highlighted, namely, the healthcare provider's knowledge about PNES as well as their attitudes towards these patients. Knowledgeable, competent and experienced healthcare providers were identified as a facilitator of the diagnostic process, but they were few and far between [8,12,16,17]. In general, healthcare providers were experienced as inexpert and recognised as a major barrier during the diagnostic process of reaching a diagnosis of PNES. Most of the healthcare providers that were involved in this process were unfamiliar with PNES. Misdiagnosis and ineffective treatments resulted in a major delay in reaching a diagnosis of PNES in 70% of the participants of this study. Another issue raised by the participants was their experiences of negative and uncaring attitudes from the healthcare providers towards them during the diagnostic process. In their interaction with healthcare providers the participants experienced emotional distress in the form of helplessness, hopelessness and frustration [5,8,12,13,24]. For a large part of the diagnostic process, the patients felt unsupported by healthcare providers. However, ultimately, all of the participants reported that the healthcare provider who eventually assisted them in reaching an accurate diagnosis of PNES was a major resource. This study supports the view that PNES is a complex and controversial disorder that remains poorly understood and managed in the clinical setting [2]. There seems to be only a handful of healthcare providers that truly understand this patient population, and in South Africa this group of providers may be skewed to the private sector. It is also clear that the process of reaching a diagnosis of PNES often takes long and can be complicated and challenging for both patients and healthcare providers [1,11,12]. Failure to address this delay in diagnosis does not only have negative implications for the patients who suffer from PNES, but also places a major burden on the healthcare system [1].

Strengths and limitations

This study utilised a qualitative methodology to investigate a largely unexplored topic, not only in South Africa, but worldwide. This is potentially advantageous in a context where research findings are usually generated from relatively superficial studies of unselected patient populations. Due to the small sample size, the fact that patients were recruited only from a private hospital, and nature of the data, the findings are preliminary and cannot be generalised, but identified issues that can inform future larger-scale studies.

Conclusion

It is my hope that the patient perspectives that were presented in this study will give a voice to those who suffer with PNES, continuing to increase awareness about this disorder, educate medical professionals, families and friends of those with PNES, and contribute to creating empathy and understanding for these individuals. Very few healthcare providers in South Africa have expertise with regard to the diagnosis, management and treatment of PNES. It is likely given resource constraints that there may be widespread lack of appreciation for PNES in the general population as is the case elsewhere in the world [1,2], and both continuous practitioner education and evidence from community-based epidemiological studies may be helpful to improve the diagnostic process of PNES for patients. Earlier diagnosis is crucial, because it can address patient loss of independence and allow early elimination of inappropriate and potentially harmful treatment as well as the costly burden of this condition on both the patient and the healthcare system.

Acknowledgement

I would like to thank Lisa Farrow for her assistance with the data collection.

References

[1] Smith B. Closing the major gap in PNES research: Finding a home for a borderland disorder. Epilepsy Currents 2014;14(2):63-7. Retrieved from https://www.aesnet.org/sites/default/files/file_attach/epcu-14-2-63%20Clnical%20Review%20Smith.pdf

[2] Dickinson P, Looper KJ. Psychogenic nonepileptic seizures: a current overview. Epilepsia 2012;53:1679–89.

[3] Benbadis S. Psychogenic Nonepileptic Seizures. Differential diagnosis of Epilepsy 2005;Section D(42):623-30.

[4] Pretorius C, Cronje G. People with Psychogenic non-epileptic seizures: A South African perspective. AJOD 2015;4(1):Art#176,7 pages. http://dx.doi.org/10.4102/ajod.v4i1.176

[5] Thimm A, Bellon, M. The psychosocial effects of psychogenic non-epileptic seizures (PNES). Flinders University, Disability and Community Inclusion, School of Medicine. The Epilepsy Report 2011; 4–6. http://dx.doi.org/10.1007/s11357-010-9157-5.

[6] Benbadis SR. Errors in EEGs and the misdiagnosis of epilepsy: Importance, causes, consequences, and proposed remedies. Epilepsy Behav 2007;11(3):257-62. doi:10.1016/j.yebeh.2007.05.013

[7] Cronje G, Pretorius C. The coping styles and health-related quality of life of South African patients with psychogenic nonepileptic seizures. Epilepsy Behav 2013;29;581-4. doi:10.1016/j.yebeh.2013.09.045

[8] Pretorius C, Sparrow M. Life after being diagnosed with Psychogenic Non-Epileptic Seizures (PNES): A South African perspective. Seizure 2015;30:32-41. doi:10.1016/j.seizure.2015.05.008

[9] Baslet G, Dworetzky BA, Perez DL. Psychogenic Nonepileptic Seizures: A New Direction Clinical EEG and Neuroscience 2015;46(1):3. doi:10.1177/1550059414564521

[10] Jones SG, O'Brien TJ, Adams SJ, Mocellin R, Kilpatrick CJ, Yerra R, Lloyd JH, Velakoulis D. Clinical characteristics and outcome in patients with psychogenic

nonepileptic seizures. Psychosom Med 2010;72:487-97. doi:10.1097/PSY.0b013e3181d96550

[11] LaFrance C, Benbadis S. Avoiding the costs of unrecognised psychological nonepileptic seizures. Neurology 2006;1620-1.

[12] Reuber M, Elger C. Psychogenic nonepileptic seizures: review and update. Epilepsy Behav 2003;4:205-16. doi:10.1016/S1525-5050(03)00104-5

[13] Carson A, Stone J, Hibberd C, Murray G, Duncan R, Coleman R, Warlow C, Roberts R, Pelosi A, Cavanagh J, Matthews K, Goldbeck R, Hansen C, Sharpe M. Disability, distress and unemployment in neurology outpatients with symptoms ‘unexplained by organic disease’. J Neurol Neurosurg Psychiatry 2011;82;810-3.

[14] Bowen GA. Naturalistic inquiry and the saturation concept: A research note. Qual Res 2008;8:137-52. http://dx.doi.org/10.1177/1468794107085301

[15] Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3:77-101. doi:10.1191/1478088706qp063oa

[16] Reuber M, House AO. Treating patients with psychogenic non-epileptic seizures. Curr Opin Neurol 2002;15(2):207-11. Retrieved from: https://www.docphin.com/research/article-detail/8614881/PubMedID-

[17] Russell A. The diagnosis and management of pseudoseizures or psychogenic non-epileptic events. Ann Indian Acad Neurol 2006;9(2):60-71.

[18] Lawton G, Mayor R, Howlett S, Reuber M. Psychogenic nonepileptic seizures and health-related quality of life: The relationship with psychological distress and other physical symptoms. Epilepsy Behav 2009;14:167-71. doi:10.1016/j.yebeh.2008.09.029

[19] Ataguba JEO, Akazili J. Health care financing in South Africa: moving towards universal coverage. Continuing Medical Education 2010;28(2):74-8.

[20] McIntyre D, Garshong B, Mtei G, Meheus F, Thiede M, Akazili J, Ally M, Aikins M, Mulligan J, Goudge J. Beyond fragmentation and towards universal coverage: insights from Ghana, South Africa and the United Republic of Tanzania. Bull World Health Organ 2008;86: 871-6.

[21] Wesolowski K. In Post-Apartheid South Africa, Health Care Imbalance Persists: Neurology is Stretched Thin. Neurology Today 2010:28.

[22] Harrisa B, Goudgea J, Atagubab JE, McIntyreb D, Nxumaloa N, Jikwanac S, Chersicha M. Inequities in access to health care in South Africa. Journal of Public Health Policy 2011;32:S102–S123.

[23] Sedibe, D. Lack of neurologists prevents effective epilepsy treatment. Diseases and Disorders. Retrieved from http://www.health-e.org.za/2011/06/23/lack-of-neurologists-prevents-effective-epilepsy-treatment/

[24] Carton S, Thompson P, Duncan J. Non-epileptic seizures: patients’ understanding and reaction to the diagnosis and impact on outcome. Seizure 2003;12:287-94. doi:10.1016/S1059-1311(02)00290-X

[25] Karakisa I, Montourisb GD, Piperidouc C, Lucianod MS, Meadora KJ, Colee AJ. Patient and caregiver quality of life in psychogenic non-epileptic seizures compared to epileptic seizures. Seizure 2014;23(1):47-54.

[26] Myers L, Lancman M, Laban-Grant O, Matznerk B. Psychogenic non-epileptic seizures: predisposing factors to diminished quality of life. Epilepsy Behav, 2012;25:358–62.