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Life after being diagnosed with psychogenic non-epileptic seizures (PNES): A South African perspective

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ABSTRACT

Purpose: The aim of the study was to explore the life experiences of South Africans who have been diagnosed as having PNES, with a focus on the aspects of the challenges which these individuals face, as well as the resources and coping strategies which are either made available to them or used by them in order to cope with PNES.
Methods: Ten semi-structured interviews were analysed by means of thematic analysis in order to explore themes around challenges and resources for those diagnosed with PNES.
Results: Various challenges were revealed by participants, as well as the resources used in order to deal with these challenges associated with being diagnosed with PNES. Some of the challenges included unexpected seizures, medical professionals, belief systems as well as family. However, resources to counteract these challenges were social support, medical professional as well as religion and spirituality.
Conclusion: Although many challenges are encountered by those who are diagnosed with PNES, there are substantial resources from which these individuals draw in order to live fulfilling and satisfactory lives. As more information and research is accumulated, more resources may become available to benefit these individuals and allow them to recover from PNES. It should be noted that medical professionals were described as both a challenge as well as a resource for people with PNES. Therefore, we can conclude that these individuals are key in the experiences of those who have been diagnosed with PNES, and that they play a role on not only a diagnostic level, but also in providing support, information, as well as therapeutic benefits.

Introduction

"But for me, it's a death sentence." This is how a woman described her diagnosis with Psychogenic Non-epileptic seizures (PNES). PNES is seizure-like episodes which occurs suddenly, involuntary and is associated with no electroencephalogram (EEG) change during the seizure, nor any evidence for other somatic causes for the seizures (such as cardiac disease). The seizures are believed to be psychosomatic in nature [1,2]. PNES is often found in those who have experienced severely stressful situations and adverse conditions, which lead to the somatisation of these unconscious processes [3]. It is often misdiagnosed as epilepsy [4], which may lead to many complications. However, once diagnosed, the challenges do not disappear.

The study's purpose was to explore the various challenges which those who are diagnosed with PNES may face, as well as exploring various resources and coping mechanisms which may be utilised to change a diagnosis of PNES from a "death sentence" to a bump in the road to recovery.

Living with PNES

PNES is currently categorised as a type of conversion disorder, according to the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5) [5]. PNES is a type of somatoform disorder, and differs only in the expression of the psychopathological symptomology and therefore diagnostic aspects [6]. PNES is experienced as a paroxysmal episode often visibly similar to an epileptic seizure which is believed to stem from a psychological

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basis [1,2]. It is essential to note that PNES is not a factitious disorder, and is not resultant of malingering [1].

It has been found that severe stress, such as socio-economic problems, death of family members, dysfunctional familial dynamics and cultural incongruence can lead to PNES [2,7]. It was also found that those diagnosed with PNES had a higher amount of stressful and adverse events during their lifetime [3].

A South African study showed that 85% of women diagnosed with PNES were single mothers, and many had experienced sexual or physical abuse in their lifetime, as well as familial problems, such as alcoholism, depression, and socio-economic problems [8]. PNES in females may be the somatisation of strong emotions, such as anger, being afraid and feeling helpless, resulting from severe abusive perpetrated by a dominant male figure [9]. However, sometimes men also experience PNES, and gender is not a criterion for PNES [10].

Those who suffer from PNES have been found to have a high comorbidity rate with other psychiatric conditions [11], such as depression, anxiety, post-traumatic stress and personality disorders [12], as well as eating disorders or substance abuse [13]. Suicidal ideation and attempts are also higher for those suffering from PNES [14].

The symptomology of PNES is strikingly similar to epilepsy, which may explain the prevalence of its misdiagnosis as epilepsy [4,6]. Receiving the correct diagnosis of PNES impacts emotionally and cognitively [15]. This depends on the manner in which the diagnosis is presented to the patient, because the more traditional "we have good and bad news, you don't have epilepsy but you do have PNES" is very different than a comprehensive body-mind explanation of PNES. Ideally, the correct diagnosis, as well as the way in which the diagnosis is communicated to the patient could bring a form of existential recognition from medical professionals finally acknowledging the legitimacy of sufferers' symptoms [16]. It may take many years for a person to receive the correct diagnosis of PNES [17,18]. A mean delay of 7.2 years for receiving the correct diagnosis has been reported [19].

When PNES is suspected, correct diagnosis can be ensured by using EEG video monitoring and inducing a seizure [15]. A video-EGG telemetry unit, which makes use of monitoring individual brain and seizure activity over a period of time, may also be used to ensure an accurate diagnosis [20].

Individuals suffering from PNES face several challenges. As previously mentioned, PNES is commonly misdiagnosed as Epilepsy [4]. Epilepsy is usually treated with antiepileptic drugs (AEDs), which expose the sufferer to risks associated with the medication [18]. When medication does not produce results, medical professionals might unduly increase the dosage, instead of searching for alternative reasons for the person not responding to the medication [21].

PNES may be associated with stigmatisation and discrimination [22]. Stigma may be the result of being labelled as suffering from a specific illness, which may lead to discriminatory behaviour [23], the perception that they have control over their seizures [24], or that they are malingering or faking their seizures [25]. Stigmatisation often has devastating effects on the sufferer and their family members [26] and may result in sufferers having fewer opportunities in occupational, social and other areas of functioning, which in turn impacts their suffering [21,27]. This may result in financial complications, as well as limiting everyday life activities [18]. Thus, stigma combined with the experience of having PNES and seizure frequency may compound to form a cycle of difficulties. Seizure frequency may be associated with increased anxiety regarding engaging in activities and social situations, leading to social isolation and being home bound [28]. This may be exacerbated by an inability to drive due to high seizure frequency [21]. Seizures may also result in physical injuries, such as burns, bruises and bone breakages [28].

Social problems, especially with regards to the familial system, may dramatically affect sufferers of PNES [21,29]. Parents suffering from PNES are at times not able to provide adequate care for their children [21]. Family members may also feel anxiety or frustration about the disorder and the diagnosis, and may be over-protective of their loved one, which may infringe on the sufferer's personal space, independence and individuality [29].

These problems may all play a role in making the life of the person with PNES extremely challenging, and at times unbearable. Suicide may seem to some to be the only way out, which corresponds with the high rates of suicidal ideation and attempts [14]. Thus, it is essential to explore adaptive and innovative ways of dealing with challenges related to PNES.

Human beings are resilient in nature, and thus develop coping mechanisms and utilise various resources to deal with adverse conditions [30]. Thus, despite the challenges that they face, people have developed a wide variety of ways of dealing with their diagnosis of PNES.

Psychotherapeutic techniques may be an effective treatment for improving the quality of life and is often the main resource for those with PNES [4,31–33].

Due to the psychological basis of this disorder, it has been suggested that psychotherapeutic approaches play an important role in treatment of PNES [31]. The communication of the diagnosis and the actual treatment should be interwoven to maximise optimal outcomes [11,15]. According to Brown et al. [4], one of the benchmarks for epilepsy research of the National Institute of Neurological Disorders and Stroke (NINDS) is to develop treatments for PNES, because of the incidence and prevalence of the disorder and the lack of treatment efficacy data. The most common treatment plans, based on the PNES aetiology, include cognitive-behavioural therapy (CBT), psychodynamic orientated psychotherapy, group psychotherapy, family therapy and a multidisciplinary approach [34]. In the literature, no consensus exists about the types of treatment that may be most effective for treating PNES [35]. It also does not seem possible to develop a "one-size fits all" treatment, because of the multifactorial aetiology of this group [36]. However, in a pilot randomised controlled trial study in the United Kingdom, it has been found that cognitive-behavioural therapy is more effective than standard medical care alone in reducing seizure frequency in people with PNES patients [37]. These findings are forming the basis for a major multicentre trial now underway in the United Kingdom. Furthermore, a recent study of La France et al. [34] indicated that PNES can be effectively treated with manualised CBT.

It has also been suggested that psycho-education for the individual as well as the individual's family might be effective in increasing quality of life for sufferers of PNES [35]. Having knowledge and information readily available empowers the sufferer and their families to understand both the aetiology and treatment of the disorder and thus feel less hopeless and helpless [38]. Family therapy might also have many benefits for the patient and their family support structures [29]. This may be expanded on by educating medical professionals about PNES to improve attitudes and misperceptions about the disorder, and thus also speed up diagnosis and thus treatment [39].

Although very little information is available on resources available specifically for people with PNES, it can be implied that the resources which are available for those who have been diagnosed with other mental illnesses would also be beneficial to those diagnosed with PNES. An example of this would be various forms of social support, which could include familial support [40,41], improving the person's social support systems with an emphasis on a nurturing system of support [38,42], as well as programmes which offer support [43].

Meyer, Moore, and Viljoen [44] state that much of psychological research has been developed in the Western world and then transferred directly to the people of South Africa, with little consideration for cultural and historical implications. In a South African context, this has direct implications, due to its history of disempowerment, political instability and violence [45]. Thus, this direct transfer of research results is not feasible in application to the population of South Africa. In reference to this, it is highlighted how little information has been generated in a South African context concerning PNES as a disorder. No statistics are available with regard to the prevalence of PNES, and only a few studies have been completed on this disorder. In addition, in a South African context it might be challenging to address treatment from a psychotherapeutic context, which has been identified in the literature as a major resource for people with PNES. In a study by Foyaca-Sibat and Ibañez-Valdés [8], patients were negative towards, or blatantly refused further psychiatric or psychological referral. This was due to the financial strains associated with referral, as well as a lack of transportation; this was applicable to 25% of the participants. A further 18% refused referral due to the fact that they deemed further treatment as being unnecessary. Many South Africans who suffer from mental health problems have major barriers to seeking help from medical professionals. These include structural problems such as lack of transport, knowledge and attitudes regarding mental illness, as well as psychosocial problems such as embarrassment and shame [46,47]. Another barrier in a South African context might be the lack of professionals who speak the indigenous languages; errors may thus occur due to the incorrect translation of what the patient is relaying to the professional [48]. A South African study also revealed that many who have chronic mental health disorders are unaware that they could have a diagnosable condition, and that treatment is available for their illness, and thus they do not seek help [47]. It is extremely challenging for medical professionals to correctly diagnose PNES in patients, and it requires knowledge and expertise, skills which cannot be attributed to all medical professionals [39]. Eastman [49] stated that in personal communication with the Neurological Association of South Africa it became clear that the health care system cannot cope with the amount of people presenting with seizures, and thus there is a gap between treatment and seizure activity. Thus, a study of this nature would be extremely valuable in laying the foundation for future South African studies.

Aims and objectives

The study therefore aimed to explore the experiences of South Africans who are diagnosed with PNES, with the primary focus on what challenges these individuals face, as well as the various resources and coping strategies which are utilised, or made available.

Research methodology

This qualitative study employed an explorative research design. The study made use of semi-structured interviews. Each interview was transcribed and then thematically analysed.

Participants and procedure

Participants were recruited from the Epilepsy Unit at the Constantiaberg Medi-Clinic and the Department of Neurology at the Tygerberg Hospital in the Western Cape of South Africa. Patients with PNES (aged 18 years and older) with confirmed video-EEG were included in the study. Patients with PNES with comorbid epilepsy were excluded from the study. With their permission, the contact details of potential participants, who were eligible for the study, were passed on to the researchers by their neurologist. The biographical data of the participants are reported in Table 1. Participants fell between the ages of 19 and 55 ($\bar{x}$ = 39.2 years). Eighty percent of the participants were female. Five of the participants were married, with the other five being either single or divorced. Only three of the participants were correctly diagnosed from their first seizure with PNES, with most taking just under or 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. Three of the participants are not receiving any treatment for PNES, with seven receiving treatment from either a psychologist, or a psychiatrist, or both.

Ethical approval was granted by the Health Research Ethics Committee at the university (S14/04/097).

Data was collected to the point of data saturation by making use of in-depth semi-structured interviews. Each interview lasted about 60 min, and the interviews were recorded with the permission of each participant. Informed consent was obtained prior to the interview. Each participant was also required to fill in a biographical questionnaire, which provides a basic overview of aspects such as gender, age and other important information (refer to Table 1). The interviews were guided by the following questions:

Table 1
The biographical details of participants.

Participant[a]	Gender	Age	Race[b]	Language	Marital status	Current frequency of seizures	Time from onset of seizures to diagnosis of PNES	Employment status	Currently receiving treatment	Type of treatment
Grace	Female	55	White	English	Single	Every 2nd week	1–2 years	Employed	Yes	Medication
Linda	Female	46	White	Afrikaans	Divorced	Half yearly	>7 years	Unemployed	Yes	Medication
Mrs. Brits	Female	43	Coloured	Afrikaans	Married	Once a day	0	Unemployed	No	–
Kara	Female	19	White	Afrikaans	Single	Once a week	4–5 years	Unemployed	Yes	Psychotherapy
Shantelle	Female	19	White	Afrikaans	Single	Once a month	<1 year	Unemployed	Yes	Medication Psychotherapy
Bianca	Female	48	Coloured	Afrikaans	Married	>Once a day	0	Employed	Yes	Medication
Andre	Male	41	White	English	Married	>Once a week	0	Employed	Yes	Medication
Bill	Male	51	Coloured	English	Married	Half yearly	<1 year	Employed	No	–
Amy	Female	26	White	English	Single	>Once a day	<1 year	Employed	Yes	Psychotherapy
Estelle	Female	44	Coloured	English	Married	None	1–2 years	Employed	No	–

[a] Pseudonyms were used for the participants.

[b] Coloured is a term used in South Africa, including in the national census, for persons of mixed race ancestry [50].

1. Tell me about the process of being diagnosed with PNES?
2. Tell me about the experience of being diagnosed as suffering from PNES?
3. How does it feel to experience a seizure?
4. What are some of the challenges which you experience or things which make it difficult to cope with suffering from PNES?
5. What are some of the things that make it easier to cope with suffering from PNES?

To assist the transcription process, each interview was audio-recorded with permission from each participant.

Data analysis

The interviews were analysed by means of thematic analysis. According to Braun and Clarke [51], thematic analysis occurs in six successive stages after the data has been collected in the form of a recorded interview.

Ensuring rigour

Various methods exist to establish rigour in qualitative research. Several of these methods were utilised in this study, namely reflexivity, member checks, and peer debriefing.

Reflexivity necessitates carefully reflecting on the phenomenon which is being studied and ensuring that the researcher's own behaviour and ideologies do not affect the study [52]. This might have an impact on the development of an accurate emic viewpoint. The primary researcher enhanced reflexivity by discussing emergent findings with the project leader, who has extensive knowledge of PNES and experience of qualitative research. Member validation (or checks) involves checking the findings of the collected data with the members of the participant group [53]. This process was undertaken during data collection, where the primary researcher confirmed points that were made by participants during the interviews. Peer debriefing can be pursued by discussing emergent findings at regular intervals with knowledgeable colleagues. This stimulates exploration and consideration of additional explanations and perspectives at different stages of data collection and analysis [53]. This method was utilised by discussing and comparing ideas, methods, and findings with the project leader throughout the research process.

Results

Thematic analysis of the interviews revealed many challenges which may appear after the diagnosis of PNES. However, there are multiple ways in which people adapt and show resilience in order to overcome the challenges associated with the symptoms and the new diagnostic label. Identified themes manifested in different ways with different individuals, yet it was clear that the underlying constructs were the same.

Data analysis was completed through the lenses of Bronfenbrenner's ecological systems model which consist of four levels that are continuously interacting [54]. The Microsystem is best described as the immediate environment surrounding the individual, thus people with whom the individual has proximal relationships. The mesosystem can be described as the way that various systems of the Microsystem interact with one another. The exosystem involves the systems which have a direct impact on the behaviours of the individuals in the Microsystem. Thus, it would be larger bodies which regulate and control the behaviour of the individuals through various influences, such as church councils, school boards, etc. The macrosystem involves broader societal and structural issues, which usually involve governmental ideologies and policies, as well as cultural and traditional belief systems [55,56]. Data analysis thus took a system's approach to the challenges and resources for those diagnosed with PNES.

Challenges

Unexpected seizures

Microsystem

In the microsystem, unexpected seizures might have consequences on an individual level, as well as an impact on those in the immediate surroundings of the person such as family, friends, and academic or occupational peers and colleagues.

The person might be injured due to not being able to control their surroundings or movements during seizures.

> "I smacked my arm so hard that I broke my arm."(Grace)

> "I struggled with my knees because I was injured twice, I fell from the stairs twice also... I've had how many operations on my knees." (Estelle)

Safety becomes a grave concern, which may cause the person to feel housebound. One person described being house bound as a "*death sentence". (Bianca)*

In turn, these unexpected seizures may also impact the person's access to either transportation or driving themselves to where they needed to go.

> "Because if you're... for example, if I'm driving and I get it (seizure), and another vehicle comes, what will happen automatically is that person might also get hurt. And according to... If you drive, you're not allowed to if you get epileptic or other attacks." (Mrs Brits)

Participants had to ensure their bodily and psychological integrity was protected, as well as their possessions. From a South African perspective, crime was seen as a threat to the personhood, and involved the participants always ensuring that they were in the presence of someone who was able to protect them and their possessions. This has direct implications on their independence as well as their privacy.

> "There was a case... that was really difficult for me... I know about a guy that said that if he gets me alone and I have a seizure, then at the end you pass out. You don't know what's happening to you. If you get a seizure, it's like a blank... And he said that if we were alone and I got a seizure he would have sex with me." (Kara)

> "I was on my way to work and I had a blackout, I got robbed in the bus." (Bianca)

This may increase the person's fear of being out alone, and make them feel that they are unable to trust the world. Thus, the person becomes homebound and socially isolated if no one is able to accompany them.

> "It does restrict you. It feels very restrictive in my life. Things like our social life... Not that we... We don't have a social life, as such... Life is pretty much based around home." (Grace)

Exosystem

People may be disabled by their occupational, academic and daily living environments. The inability to adapt to, particularly, the work and academic environment was described as being the cause of some having to stop working, or stop their academic work.

> "So they kept me away from that and that sort of broke me a little bit… I'm saying to them, I've got a disability and it's recognised by the company but you can't treat me any different… But I can also understand where the employer is coming from." (Keith).

Medical professionals

The term "medical professionals" is an umbrella term including neurologists, psychologists, psychiatrists as well as first responders such as emergency care technicians. The challenge may lie in two specific categories.

Microsystem

In the microsystem, the fit of the medical professional to the person was seen as a major challenge, with personal preferences and trust being indicated as essential for the professional and their client to be able to establish a rapport as well as to make the person feel confident in their ability to provide answers.

> "There's a psychologist that works with him… I was there a couple of times, but I didn't really click… I (later) went to a psychiatrist. Somebody I am more comfortable with."(Linda)

Information was also seen as a challenge for participants. This was both the lack of understanding by medical professionals of PNES, as well as not divulging adequate information to their patients about the disorder.

> "…the doctor couldn't understand or explain it." (Grace)

> "…It felt like I was going from one doctor to another and nobody had a clue." (Linda)

> "… I lost faith in doctors. The doctors continually kept diagnosing me with epilepsy when I knew I did not have it." (Kara)

Lack of information about the disorder may lead professionals to believe the patient is faking their symptoms.

> "Say for example I got a very bad seizure and the… ambulance came and then the paramedics made rude comments because they didn't know what it was. I tell them it's not epilepsy, please don't give me Epilem… (they) treat me because they just want to let me go… and funny commentary. Some of them were really rude and… otherwise it's just doctors that… they almost make you feel like you're the problem."(Shantelle)

Belief systems

Macrosystem

Many participants described a cultural phenomenon of belief systems which did not include mental illness as being a possible cause for medical conditions. The ideas were based on a stigmatised idea of what mental illness is, and that seizures could not be caused by a psychological condition. The general thought behind this was that it can't JUST be a psychological cause.

> "Well there has to be something wrong, like it can't be like just mental." (Amy)

> "(About PNES) Oh no! That's nonsense. It's impossible… Because it's real. It really happens." (Linda)

This often came with finding it a challenge for both themselves and those closest to them to accept the diagnosis as being true and possible. However, this also led to both self-stigmatisation and being stigmatised by others, or being treated differently by others because of the disorder. It sometimes even led to discrimination by others.

> "The biggest challenge was to accept it… There's nothing you can do. A pill is not going to fix it. You need therapy. What the hell! (laughs) Normal people don't go to therapy… When I was affected, 'How crazy are you now?'" (Linda)

Family

Microsystem

Loved ones posed a challenge to participants, with worrying about their loved ones and trying their best to protect them from their condition. Loved ones were often upset by the seizures, especially the participants' children, or if they themselves were children, their parents. Some participants tried their best to hide it from their family members. Others were upset by the difficulties their family members had to face in adapting to and coping with the disorder.

> "It is difficult for me, because you don't want to see your children in tears, I can't touch them or tell them, 'Mommy will be okay.' Because I can't always speak. Because, it's not nice if your children are crying like that and you can't comfort them." (Mrs Brits)

> "My children are the other issue. Because… I tried to hide it from them for a very long time… I can't handle it at all, because I am the mom and they are the children." (Linda)

Resources

Social support

Microsystem and mesosystem. The mesosystem is the interaction of the various microsystems, which comprises of social support. Social support means different things for different people, but comes down to somebody being there for you at the end of the day. People received support from family, friends and work or school colleagues, from their pets as well as from their school teachers or bosses at work. These various systems interplayed to counteract feelings of loneliness, social isolation and sadness. Many times these people did more than just be available to talk to, but also helped with various tasks which made living with PNES easier. They also acted as a buffer against the concerns for safety, as well as allowing the person to be more comfortable with their diagnosis.

> "I've been extremely lucky in that I had such a good support. Like I've had Peter who, as I say is so fantastic… I've had my friends who are so good, you know? And as I say, when I have a seizure, they know exactly what to do. They know exactly how to help." (Grace)

> "And then all the caring and love that, around it… It helps you. So don't push people away. Don't keep it to yourself. Let people help you, to care and love you. Because it is the only thing that will get you through it. You need someone in that moment. You can't handle it by yourself." (Kara)

Medical professionals

Microsystem

Although many participants reported that medical professionals were a real challenge, most reported that once you found the right medical professional, they proved to be a significant resource to enable coping and resilience. Thus, the right diagnosis and finally getting the right answer from the neurologist, getting the right medication for depression and other comorbid mental illnesses from a psychiatrist and speaking things through with a well-fitted psychologist proved to aid participants to recovery or coping.

> "The fact that I had good doctors. Once I went to Doctor X, he helped me through it. He was a good doctor. Always looked after me. And yes, I accept that he is that kind of person. He's there for you, not just a doctor." (Kara)

Macrosystem

However, doctors played a more existential role as well, in convincing the participants that the disorder is in fact real, and not them faking it. The fact that the person with PNES, when faced with someone who does not understand the disorder, is able to contact the medical professional to explain to the person what PNES is, is reassuring. This allows for some existential recognition, and a medical professional's power dynamics facilitating the acceptance of their story as true.

> "The previous manager that I had, very staunch Afrikaans guy, a priest, very militaristic. And Doctor X was trying to find out and he says, "It's a specialist. Doesn't he know what he's doing?" So I said to him, "Listen, there's the doctor's number. It seems like you're an expert, why don't you phone him? Because I've tried to explain to you." (Bill)

Religion and spirituality

Microsystem and Mesosystem

In the microsystem and the mesosystem, prayer from others as well as praying oneself was seen as a helpful way to cope with the challenges of PNES. Prayer was seen as having a buffering effect against the seizures, but also seemed to be cathartic in that participants felt that they could reveal their deepest thoughts to a non-judgmental higher power. This higher power was seen to understand the problems, challenges and frustrations being experienced, and show unconditional positive regard and love.

> "My religion a lot... I prayed about it a lot, to actually get answers, the belief that, just accepting it... Because it was so difficult for me to explain it to other people... I know that things sound weird, until it's happening to you... With God, He knows exactly what you're going through." (Kara)

Macrosystem

This was part of a cultural belief and tradition that PNES and other life circumstances could be seen as only part of the bigger plan for their life by a higher power. The participants reported that even though it was challenging, knowing that God had a plan for their life was a way to make sense of their suffering, and to make it through days which were challenging. This may fall under the idea of meaning making as a motivation for human resilience.

> "I've accepted what He's done for me, because the main thing is Him bringing me out of the coma on the fourth day, like I said sending my cousin to me... Andre had to have the accident so that Andre could stop consuming alcohol." (Andre)

Discussion

This study on the life of those suffering from PNES made use of Bronfenbrenner's ecological systems approach to conceptualise the captured data [56]. The foundational premise of a system's theory is that any form of behaviour is the consequence of an interaction between contextual factors surrounding the individual and the individual themselves.

Challenges

Unexpected seizures

Microsystem

Unexpected seizures were conceptualised at the microsystemic level due to the fact that they might impact not only the individual, but also those in the person's immediate surroundings such as their friends, their family, as well as academic or occupational peers and colleagues. There are various sub-themes for unexpected seizures on this level.

Participants in the study reported various injuries due to their seizures, such as the breakage of bones and other severe injuries. They reported that this was due to not always being able to control their environment during a seizure, and not being able to control their physical movements at this time. Carton et al. [28] concur, stating that seizures might lead to physical injury, such as burns, bruises and bone breakages. This may lead to the person being hospitalised to treat the sustained injury.

PNES sufferers might not be able to drive if they experience frequent seizures. The South African National Road Traffic Act (Regulations 99 and 102, section 15) states that those who have seizures which are not under control are not permitted to drive, to protect not only themselves, but also to prevent the injury and death of others on the road (cited in Western Cape Government Transport and Public works, 2013) [57]. This finding is confirmed by Thimm and Bellon [21]. Being unable to drive was a great cause of concern for participants, and many chose to drive regardless of the regulation due to the necessity for driving in a South African context. Luke and Heyns [58] report that 35% of 1000 participants in a public opinion survey rated safe and accessible public transport as the most important issue for South Africans. Approximately 15 million South Africans make use of taxis for transportation on a daily basis to commute to their place of work, which makes up 70% of the commuting public as well as work force [59].

The interaction of these factors lead to the participants feeling socially isolated unless accompanied by others. Thimm and Bellon [21] state that those who have been diagnosed with PNES may experience detrimental effects due to seizures, and due to this may become isolated and anxious about engaging in activities in their daily life.

Exosystem

High seizure frequency and intensity was found by the participants to have a disabling impact on their daily life, due to the fact that their environment did not ensure the completion of daily tasks, and occupational or academic endeavours. Participants oftentimes had to either stop working, struggle to find work, or give up their academic goals due to their PNES symptoms [21,27–29,60,61]. Gaynor et al. [61] state that oftentimes those who have a high seizure frequency may lose their employment, placing financial strain on family members as well as the state, as well as incurring large expenditures on treatment, which may not always be effective. A study by Thimm and Bellon [21] revealed that unemployment and lack of academic and educational options may be a great challenge for those who are diagnosed with PNES, and may infringe on their abilities to feel that they are leading a satisfactory and fulfilled life.

Medical professionals

Microsystem

One of the challenges for the participants was a lack of information on PNES, not only for the participants, but also for medical professionals. There are very few health care professionals in South Africa who specialise in the diagnosis, management and treatment of PNES. This may relate to the high rate of misdiagnosis in participants. It may also lead to a high level of confusion about the disorder, marked by inaccurate and incorrect information. Rapposelli [62] states that resources need to be made available for family members and patients who have been diagnosed with PNES, in order to educate and inform them about the disorder and various options which are available to them. However, these resources are a scarcity. There is inadequate information available to patients in both verbal form and written form [21]. This seems to be a major problem that is specifically pertinent to South Africa.

Belief systems

Macrosystem

The participants in the study found it challenging to accept the psychological causes behind their disorder, and struggled to understand how it could be "JUST" psychological causes. Dekkers and van Domburg [63] state that often when a diagnosis of PNES is made, both the doctor and the patient might start believing that it is a non-disease, which might imply that it does not exist. However, the disorder is very real, and it is important for both the doctor and the patient to understand this in order for effective treatment to take place. Carton et al. [28] elaborate that in treating PNES as being "all in the mind" is very different to what the patient understands about and experiences during their seizures, and this may lead to the patient feeling anger as well as confusion about their diagnosis. McMillan et al. [64] describes that acceptance is often a problem for patients, due to the fact that they may reject the diagnosis of the medical professional entirely, as well as feel confusion about the diagnosis, and not even believe or understand how the seizures could be related to mental health problems. Due to this, it becomes evident that the correct medical professional is essential in minimising the challenges associated with PNES. Previous literature emphasises the role of medical professionals in PNES [24,64–66].

Participants related that this became even more challenging due to the stigma surrounding mental disorders, from within themselves and from others. Stigma has been found to have a dramatic and detrimental impact on those who are diagnosed with mental disorders [26]. Cronje and Pretorius [67] report that avoidance coping techniques may be utilised in order to cope with the stigma which may be associated with PNES, as well as the stigma when the public witnesses seizures during social activities and normal daily living tasks. For example, if a person felt that people treated them as inferior because of their nonepileptic seizures, it would be understandable if they avoided certain social activities which led to them feeling stigmatised [67]. However, the repeated use of avoidant coping could lead to failure in seeking psychological help and maintain psychological distress. Unexpressed, unresolved emotions can, in turn, negatively affect their health. Those who are stigmatised may also have fewer opportunities in their occupation, as well as being treated differently or rejected by society, which in turn may have detrimental effects on the person's well-being and satisfaction with their lives [27].

Disbelief in the psychological causes of a mental illness might result in a failure to address these causes. It is also usually very emotionally packed events which may lead to the development of PNES. Social stigma was found to be a prominent effect of a diagnosis being of a psychological nature in that the seizures are not a manifestation of physical causative factors, but rather emotive and psychological causation [68].

Family

Microsystem

Many participants expressed that it was a challenge for their loved ones to deal with the symptoms of seizures as well as the diagnosis of PNES. This was especially apparent in participants who had children, and who felt that they needed to protect their children from the disorder, and felt unable to fill their roles as caretakers and protectors. Thimm and Bellon [21] found that participants found it challenging to be the caretaker of children, and did not feel that they were providing sufficient care for their children. Family members may become distressed when witnessing a seizure, and are reported to have poorer health and high levels of distress, which should be addressed in family therapy sessions in order to minimise the negative effects [65]. If the person experiences a high frequency rate of seizures, and cannot take part in normal daily living tasks and cannot find or hold employment, it may further place strain on the family and the family's resources [61].

Resources

Social support

Microsystem and mesosystem

Participants reported that social support from friends, family and even family pets had helped to counteract feelings of loneliness, social isolation, as well as sadness. Thimm and Bellon [21] report that social support is an essential, influential positive factor for those diagnosed with PNES, and may be a resource for recovery and adaptation.

Medical professionals

Microsystem

Participants reported that even though it was a challenge to find the appropriate medical professional, once the right professional was found, they proved to be a great resource for coping with their diagnosis of PNES, as well as other disorders which were comorbid with their diagnosis of PNES. Medical professionals may make use of various treatment styles to not only ease the suffering associated with PNES, but also to treat comorbid psychopathology often found in people with PNES [4,11,34,35,37]. Treatment has been associated with fewer seizures and lower intensity of seizures, a higher level of psychosocial functioning, as well as lower levels of anxiety and depressive symptoms [11,34,37,69].

Macrosystem

The participants found that doctors played an important role, in that they gave the participant the belief that their disorder was a real disorder, and that they were not faking their symptoms. This was especially helpful in relaying the diagnosis to those who did not understand or trust the diagnosis, and thus allowed for some existential recognition. Lind et al. [16] report that doctors play an essential role in giving the person existential recognition that their disorder is real, and may bring great relief to those who have been accused of malingering or faking their symptoms.

Religion and spirituality

Microsystem and mesosystem

Prayer was seen as an important resource for those who have PNES, and was seen as being beneficial not only in communicating with a higher power, but also by having others pray for them and hold them in their thoughts. Barnett and Johnson [70] elaborate on how important religion and spirituality might be in the psychotherapeutic client's life, and how it might be useful to incorporate belief systems and religion into the psychotherapeutic process. However, it should be noted that this would only be important for those who are religious or spiritual.

Macrosystem

On the macrosystemic level this was reiterated in that the participants believed that a higher power had a plan for their lives, which made their suffering more endurable. This is supported Viktor Frankl's belief that finding meaning in any suffering is motivation for enduring. "Those who have a 'why' to live, can bear with almost any 'how'." (p. 126) [71]. Meaning making is seen as an important component of resilience, and can be meaning created within religion or spirituality, but may also incorporate non-spiritual meaning making and having purpose in one's life [72].

Limitations

One of the limitations of this study was that only those who have been diagnosed with PNES could take part in the study. The fact that the results represent the experience of people with PNES from only two epilepsy centres (both of which are in the Western Cape region of South Africa) may reflect biases of the epilepsy practices involved and can be seen as a limitation of the study. Furthermore, it is important to note that the social and ethnic mix of the study sample is not representative of the general South African population. This may be because the majority of the sample was recruited from private health care services. Thus, generalising the results of the current study to the general South African population of people with PNES would be inappropriate because this study is more reflective of a particular niche within the South African health care system, than representative of the South African health care system in general. However, the researchers would like to note that the people with PNES recruited from the epilepsy unit of the Constantiaberg Medi-Clinic were from across the country, as that unit is the best equipped in South Africa to diagnose PNES. It should furthermore be noted that there are very few epilepsy centres available in South Africa. In a South African context, the majority of people do not have adequate access to medical facilities or medical insurance mainly because they live in rural areas and/or are low in socio-economic status. In addition, there are very few health care professionals in South Africa who specialise in the treatment of people with PNES. Thus, the scope of the study only covers those who have been lucky enough to receive the diagnosis.

Another limitation lies in the small sample size. Although adequate for a qualitative study, other studies would have to be carried out in order to verify the generalisability of the study to the entire South African population.

Conclusion

This study was aimed at qualitatively analysing the lives of those who have been diagnosed with PNES in the South African context, in order to set the foundation for future studies. Participants were referred by a neurologist, and had been diagnosed with PNES by V-EEG technology. The themes which emerged centred on both challenges and resources to those who have been diagnosed with PNES, and were divided into categories according to Bronfenbrenner's ecological model. The challenges which were identified were unexpected seizures, medical professionals, belief systems, as well as family. However, various resources were also identified, such as social support, medical professionals, as well as religion and spirituality. Exploring the lives of those diagnosed with PNES in South Africa is a new chapter in helping to discover methods to make the lives of those diagnosed easier, and ensuring that knowledge is disseminated in order that those who have the symptomology can be readily and accurately diagnosed, and given adequate information about their disorder. By uncovering life experiences, those who are diagnosed can know that they are not alone.

It should be noted that medical professionals were described by participants as both a challenge as well as a resource for those diagnosed with PNES. Therefore, we can conclude that these individuals are key in the experiences of those who have been diagnosed with PNES, and that they play a role, not only on a diagnostic level, but also in providing support, information, as well as therapeutic benefits.

Conflict of interest

None.

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