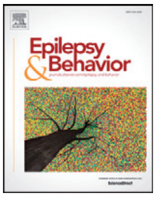
Epilepsy & Behavior 101 (2019) 106399

Contents lists available at ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh



Psychogenic nonepileptic seizures: Comparing what South African healthcare providers communicate to patients at the point of diagnosis against international guidelines

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ARTICLE INFO

Article history:
Received 4 February 2019
Revised 13 June 2019
Accepted 27 June 2019
Available online 4 November 2019

Keywords:
Psychogenic nonepileptic seizures
Diagnosis communication
International guidelines
South Africa
Healthcare providers

ABSTRACT

The process of communicating a diagnosis of psychogenic nonepileptic seizures (PNES) has been widely studied internationally and found to be an important factor in the reduction of symptoms as well as promoting the uptake of treatment. To date, no research has focused on diagnosis communication in the South African context. This study used applied thematic analysis to explore the content addressed by a sample of 11 South African healthcare providers (HCPs) when presenting a diagnosis of PNES to a patient. The purpose was to investigate the areas of alignment between the international guidelines and what is done in practice and to identify other elements communicated by South African HCPs that were not addressed in the guidelines.

The key communication elements described in five international guidelines were grouped into nine main themes, and coding frequencies were used to identify areas of alignment. In general, the practices of the participants aligned closely to the international guidelines. There was close alignment between the guidelines and the practices of HCPs in respect of six themes, namely: that the diagnosis was not epilepsy; how the diagnosis was made; that PNES was a real, debilitating condition; an explanation of possible causes and maintaining factors; that antiepileptic drugs are not effective in treating PNES; and a description of appropriate treatment. Participants suggested four additional subthemes that may be included when presenting a diagnosis: what to do in the event of future seizures; that further investigations are not helpful; enquiry into the link between stressors and seizures; and a discussion about comorbid conditions.

Participants noted the value of utilizing a guideline as a means to ensure that all HCPs involved with a patient communicate a consistent message. They emphasized that diagnosis presentation must be relevant to the South African population and discussed the need to tailor explanations for the patient's home language and level of education. Cross-cultural barriers and different cultural health beliefs may require a specially tailored communication approach grounded in a clear cultural understanding.

1. Introduction

Psychogenic nonepileptic seizures (PNES) are a complex neuropsychiatric condition classified as a conversion disorder in the diagnostic and statistical manual of mMental disorders, fifth edition (DSM–5) [1], ranked as one of the top three neuropsychiatric problems [2]. The seizures resemble epileptic seizures [3] but have a multifactorial biopsychosocial rather than a physiological etiology [4–6]. The seizures are not initiated intentionally by the patient [4,7]. International research suggests that 20% to 30% of patients referred for assessment of seizures at epilepsy units have PNES [3,8] but that patients with PNES are often misdiagnosed as having epilepsy [5]. No detailed statistics regarding the incidence and prevalence of PNES in South Africa have been published [9,10].

1.1. Communication of a PNES diagnosis

The way in which healthcare providers (HCPs) communicate a PNES diagnosis is an important determinant in facilitating the patient's willingness to engage with and understand their diagnosis, to encourage cooperation with appropriate interventions, and to enable effective engagement with the healthcare system [3]. There is a growing body of evidence that the presentation of the diagnosis is in itself a key therapeutic element of the management process for patients with PNES [11]. Furthermore, the clear communication of a PNES diagnosis to the patient may lead to a short-term reduction in episodes or even the complete resolution of seizures [12–14], and can have a positive effect on healthcare utilization behaviors, including the uptake of

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https://doi.org/10.1016/j.yebeh.2019.06.042
1525-5050/

psychotherapy [11,14–16]. For example, Farias et al. [17] reported on the number of PNES that was reduced in the 24 h after the diagnosis was explained. Eighteen of twenty-two patients with PNES had no further events during an acute follow-up period. A number of retrospective studies suggest that approximately one-third of patients will report that PNES have stopped when asked 3–6 months after diagnosis with no further intervention [12,18,19]. Most patients who became PNES-free stopped having seizures immediately after the explanation of the condition [13,14]. However, the presentation of a PNES diagnosis can also have negative outcomes if it is not well-communicated or if it is received negatively by the patient; for example, patients may be left confused or angered when receiving the diagnosis, which may decrease the likelihood of the patient engaging in psychotherapy or other treatment [11,20].

International literature indicated that there is significant variability in how a PNES diagnosis is communicated to patients and how follow-up care was applied [15]. A 2018 international survey by the International League Against Epilepsy (ILAE) PNES Taskforce of HCPs involved in PNES diagnosis presentation identified the elements or statements most commonly addressed by HCPs when discussing PNES with patients [21], although results showed variation in themes and emphasis. A 2013 international consensus review of literature [11] identified four published communication strategies or guidelines for communicating a diagnosis of PNES, by Shen et al. [22], Mellers [20], Hall-Patch et al. [23], and Duncan [24]. Subsequently, a randomized control trial by Drane et al. [15] introduced a fifth scripted diagnosis guideline. This study showed that patients whose diagnosis was communicated by means of a standardized approach, involving a scripted diagnosis and psychiatric consultation, experienced decreased PNES frequency as well as improved quality of life [15]. To date, the only standardized communication procedure that has been tested for effectiveness and acceptability is that of Hall-Patch et al. [23,25].

As indicated, the methods and content used to communicate the diagnosis are an important element to the reduction of PNES symptoms as well as to the uptake of treatment. The five international guidelines [15,20,22–24] were all published internationally. The authors of the guidelines were from the United States [15,22] and the United Kingdom [20,23,24], and to date, there has only been limited research on PNES in developing countries and specifically the South African context, and no research focused specifically on the communication of the diagnosis [10,26].

The present study, therefore, formed part of a broader qualitative project that sought to expand understanding within the South African context, by seeking to identify the strategies used and challenges experienced by HCPs in communicating a diagnosis of PNES. The objectives of the broader study were to understand HCPs level of experience with and knowledge of PNES; to understand their attitudes towards patients diagnosed with PNES; to understand what is communicated and how they communicate a PNES diagnosis to patients; and to understand the subjective difficulties experienced by HCPs when communicating a diagnosis of PNES. The present study aimed to specifically explore the content addressed by HCPs in the South African context when presenting a diagnosis of PNES to a patient and to compare this against international guidelines.

Ethical approval for the broader project was granted by the Research Ethics Committee at Stellenbosch University (SU-HSD-002582).

2. Methods

2.1. Study design

A qualitative design was used because of the paucity of research regarding the PNES diagnosis communication in the South African context and to understand the nuances of the participants' experiences regarding the subject of diagnosis communication. The present study utilized data from semistructured interviews conducted as part of the broader project.

2.2. Participants and procedure

Purposive and snowball sampling techniques [27] were used to identify a total of 38 HCPs considered to have knowledge and/or experience regarding the diagnosis and/or treatment of patients with PNES in the South African context. The snowball sampling process was initiated by identifying two neurologists with extensive experience with PNES, one at a Cape Town public tertiary hospital and one at a Cape Town private hospital. An attempt was made to ensure that both public and private sector perspectives were included. The inclusion criteria were fourfold: (1) practice areas of neurology, psychiatry, or clinical psychology; (2) currently registered with the Health Professions Council of South Africa; (3) available and willing to be interviewed; and (4) with experience or knowledge in diagnosing or treating conversion disorders.

Participants were requested to take part in a semistructured interview, conducted either telephonically or in person. An email describing the study was sent to the identified participants, together with a letter of invitation to participate in the study, an informed consent document, a biographical questionnaire, and a copy of the semistructured interview questions.

A sample of thirteen HCPs participated in the broader project, and at this point, it was considered that theoretical saturation had been reached [28]. Two of these thirteen HCPs indicated that they did not have responsibility for the actual communication of a PNES diagnosis and were therefore excluded from the present study. The sample for the present study was therefore eleven HCPs. Table 1 summarizes the demographic and professional characteristics of the participants from the present study.

2.3. Data collection

Semistructured interviews were conducted with each participant after written informed consent had been obtained. Interviews lasted between 30 min and 1 h, depending on the HCP's experience with PNES and time availability. Audio recordings were made with the consent of the participants.

The questions included in the interview guide were aligned to the five identified existing international guidelines [15,20,22–24] and a similar study recently conducted in Namibia [29], and were designed to address the aims of the broader project. The content of these questions addressed the HCP's experience, knowledge, and attitudes regarding PNES, the content addressed when presenting a diagnosis to a patient, the HCP's awareness and attitudes regarding guidelines, and the challenges experienced in presenting a PNES diagnosis. The questionnaire was designed to enable appropriate questions for all three disciplines and for varying roles and degrees of expertise. Table 2 provides an extract of selected questions relative to the present study.

2.4. Data analysis

The audio recordings of the interviews were transcribed verbatim. The transcribed interviews were coded and analyzed in Nvivo 11 [30], using applied thematic analysis [31] with theme coding guided by the thematic analysis methodology set out by Braun and Clarke [32]. After data immersion by reading the transcripts multiple times, a mixed deductive and inductive approach was utilized to develop codes. A priori codes were generated from the international guidelines [15,20,22–24] and grouped into nine main themes that best summarized the key elements of the guidelines. New codes were developed to capture new themes arising from the data. Using these codes, the transcribed interviews were then coded for manifest and latent content.

Table 1
Demographic and professional characteristics of participants.

P	Practice area	Years in practice	Sector	Gender	Race	Province
1	Neurology	32	Public tertiary hospital	M	White	Western Cape
2	Neurology	29	Private hospital	M	White	Western Cape
3	Neurology	22	Public tertiary hospital	M	White	Western Cape
4	Neurology	10	Public tertiary hospital	F	White	Western Cape
5	Psychiatry	17	Public tertiary hospital	F	White	Western Cape
6	Psychiatry	40	Private psychiatric hospital + public tertiary hospital	M	White	KwaZulu-Natal
7	Psychiatry	16	Public tertiary hospital	F	Indian	Western Cape
8	Psychiatry	10	Public tertiary hospital	F	Colored	Western Cape
9	Psychiatry	11	Public tertiary hospital	F	White	Western Cape
10	Clinical Psychology	30	Public tertiary hospital	F	White	Western Cape
11	Clinical Psychology	20	Public tertiary & secondary hospital & private practice	F	White	Western Cape

The study utilized the international guidelines as a lens through which the data were analyzed. The results were tabulated to summarize the themes and to enable analysis of relative coding frequencies, providing a comparison between what the HCPs reported against the international guidelines. Representative quotes by participants were identified for themes and subthemes, to illustrate commonalities between the guidelines and the data, as well as where participants spoke to new themes and elements. The interviews were also coded to identify whether HCPs used or found international guidelines helpful for PNES diagnosis communication in the South African context and to identify their recommendations.

2.5. Trustworthiness

Table 3 documents the strategies followed to maintain trustworthiness in the context of qualitative research, in order to ensure transferability, credibility, dependability, and confirmability [33–35].

3. Results

3.1. Themes from international guidelines

The key elements of the content described in the identified international guidelines [15,20,22–24] were grouped into nine main themes that best summarized the data. These themes were as follow: (1) that the diagnosis was not epilepsy; (2) how the diagnosis was made; (3) what the condition was called; (4) that PNES was a real, debilitating condition; (5) an explanation of possible causes and maintaining factors; (6) a model or analogy for PNES; (7) that antiepileptic drugs are not effective in treating PNES; (8) appropriate treatment; and (9) prognosis.

Subthemes within the main themes were also identified to enable the nuances of each guideline to be incorporated and are included in Table 4.

Table 2
Selected questions from the questionnaire used for semistructured interviews.

1) Please provide your views about the effectiveness or ineffectiveness of the communication of a diagnosis of PNES.
2) What elements do you cover (i.e., what information is given) when you communicate a PNES diagnosis to the patient? Please try not to leave anything out.
3) Are you aware of any international protocols/guidelines regarding the communication of a PNES diagnosis?
   If yes:
   a) Please tell me about the protocols you are aware of?
   b) Do you use them?
   c) Do you find them helpful for the context within which you work?
   If no:
   d) Do you think it would be helpful if there were guidelines/protocols regarding the communication of a PNES diagnosis?
4) Please tell me anything you know about your patients' experiences with regard to the communication of the diagnosis of PNES.
5) In your experience (relating to other HCP's), what elements are being "left out" of the communication diagnosis process that could benefit the patient, or are being done incorrectly?

3.2. Contrasting the content of diagnosis communication against international guidelines

In order to contrast the content addressed by participants against the content proposed in international guidelines, coding frequencies of each of the themes and subthemes were identified in respect of the

Table 3
Strategies followed to maintain trustworthiness.

Process	Subprocess	Steps taken
Credibility	Peer examination	Prior to commencement of the study, the research proposal was reviewed by the Departmental Ethics Screening Committee and Research Ethics Committee: Human Research (Humanities) at Stellenbosch University.
	Peer discussion	Discussions were held between authors at various stages of the project to ensure sound methodology, rigor of analysis, and conceptualization of themes.
	Angles	A range of perspectives was obtained by engaging with neurologists, psychiatrists, and psychologists, thereby enhancing credibility.
	Time	Sufficient time was allocated to the interviews to elicit detailed qualitative data from the participants.
	Identifiability	Themes and codes that the participants are readily able to identify as being derived from the interviews were used thus, ensuring harmony between the raw data and the researcher's interpretations.
	Member checks	Verbatim transcriptions of the interviews were provided to a sample of the participants to enable them to verify the contents of the interview.
Transferability		The findings of this study were considered within the background context, including factors such as the geographic and socioeconomic limitations and organizational characteristics, to enable the reader to determine whether the conclusions are appropriately transferable to other contexts.
Dependability		The semistructured interview framework was used consistently for all interviews. Methodological steps were suitably outlined to enable replication. Samples of the coding were peer-reviewed for coding categorization accuracy.
Confirmability	Reflexivity	The researcher considered interpretations and potential biases via the supervision process.
	Limitations	Limitations in the scope of the study and the potential effects thereof are described.

Table 4
Content covered in international guidelines and by participants.

Themes and subthemes	Shen et al. (1990)	Mellers (2005)	Duncan (2010)	Hall-Patch et al. (2010)	Drane et al. (2016)	Frequency (out of 5)	Participant 1	Participant 2	Participant 3
1. Diagnosis is not epilepsy						4			
Seizures are not caused by epilepsy (clearly stated)	x	x		x	x	4	x	x	x
It is good news that it is not epilepsy	x					1			x
2. How diagnosis is made						5			
Reasons for concluding it is not epilepsy		x				1	x	x	x
Explanation of vEEG or EEG findings (and how it is used for diagnosis)	x		x	x	x	4	x	x	x
3. Name the condition						4			
Explain that the patient has PNES		x	x	x	x	4		x	
Give alternative names they may hear				x	x	2	x	x	x
4. Real condition						5			
Assurance that seizures are real/ not being "put on"/you are not "mad"	x	x	x	x	x	5	x	x	x
Seizures are not under conscious control/occur at subconscious level	x	x	x			3	x	x	x
It is a common and recognized condition		x		x		2	x	x	
Seizures are disabling or frightening		x		x		2	x		x
5. Causes						5			
Seizures have emotional/psychological/ stress-related causes (predisposing factors)	x	x	x	x	x	5	x	x	x
Triggers and causes (precipitating factors) may not be apparent	x	x	x	x	x	5	x	x	x
Possible maintaining/perpetuating factors are mentioned and/or explained		x		x		2			
A history of sexual abuse is discovered in many cases.	x					1		x	
6. Model or analogy for PNES						2			
Provide a model or analogy for the events (e.g., brain becomes overloaded,dissociation occurs)		x		x		2	x	x	x
7. AED's						5			
Antiepileptic drugs are not used to treat condition; are not effective; should not be taken; and/or may cause serious side effects.	x	x	x	x	x	5	x	x	x
8. Treatment						5			
Psychological/psychiatric treatment is recommended	x		X		x	3	x	x	x
Psychological/psychiatric treatment is described/ explained briefly		x	X	x		3	x	x	x
Neurologic follow-up will continue	x					1	x		x
Referral is discussed			X	x	x	3		x	x
Evidence that psychological treatment is effective		x		x	x	3	x		
9. Prognosis						5			
Prognosis (e.g., the patient can expect the seizures to reduce/resolve with treatment, or that the condition may improve after correct diagnosis)	X	x	X	x	x	5	x		

international guidelines and the data obtained from the interviews. These are captured in Table 4, and expanded on thereafter.

3.2.1. Theme 1: the diagnosis is not epilepsy

Four of the guidelines [15,20,22,23] recommended explaining to the patient that their seizures were not caused by epilepsy, and one [22] of these also suggested highlighting to the patient that it was good news that the patient did not have epilepsy.

All eleven participants reported that they would include some form of explanation to the patient that their diagnosis was not epilepsy. Nine participants communicated this by specifically stating that the seizures were not caused by epilepsy or that it is *"not a neurological condition"*, where it may be explained that *"the events that you're experiencing, aren't related to abnormal brain activity that one usually sees in epilepsy"*. Five participants suggested explaining that it was *"good news"* that the patient did not have epilepsy, with one describing that *"I'm quite optimistic with patients and communicate to them that it is wonderful that they don't have epilepsy"*.

3.2.2. Theme 2: how a diagnosis of PNES is made

One of the guidelines [20] recommended explaining the reasons for concluding that it was not epilepsy without providing further detail, and the other four guidelines [15,22–24] expanded on this by suggesting that an explanation should be given about how electroencephalogram (EEG) or video-EEG (vEEG) findings were used to rule out epilepsy and enable the diagnosis of PNES.

All eleven participants reported that they would usually communicate the reasoning for their diagnosis to the patient, and ten of them suggested that EEG or vEEG findings be included in this explanation. One participant specifically suggested that it should be done using straightforward language, for example, by communicating that *"if we do the EEG we actually see the short circuit, whereas luckily with you … your scan was normal, and your EEG was normal, but you still sit with these problems."*

3.2.3. Theme 3: give a name for the condition

Four of the guidelines [15,20,23,24] recommended telling the patient that there was a name for their condition, and two [15,23] of these also suggested discussing alternative names for PNES that the patient may hear.

Six of the participants reported that they specifically discussed the name of the condition when presenting the diagnosis, because *"people always like a diagnostic label, and that there is a path for management"*. Four of these participants also mentioned explaining alternative names that the patient may hear, such as *"pseudoseizure"*, *"conversion disorder"*, or *"functional disorder"*.

Table 4
Content covered in international guidelines and by participants.

Participant 4	Participant 5	Participant 6	Participant 7	Participant 8	Participant 9	Participant 10	Participant 11	Frequency (out of 11)
								11
x	x	x	x		x		x	9
		x	x	x		x		5
								11
								11
x	x	x	x	x	x	x	x	
x	x	x	x		x	x	x	10
								6
	x	x					x	4
x								4
								10
								10
	x	x	x	x	x	x	x	
				x	x		x	6
	x						x	4
		x			x	x	x	6
								11
								11
x	x	x	x	x	x	x	x	
								7
x	x			x	x			
								0
								1
								8
			x	x	x	x	x	8
								9
x	x	x	x	x	x			9
								11
								9
	x	x		x	x	x	x	
					x		x	5
				x	x			4
x								3
			x	x			x	4
								4
	x		x			x		4

3.2.4. Theme 4: PNES is a real condition

All five guidelines [15,20,22–24] indicated that the patient should be reassured that they were not crazy and that their seizures were real and not manufactured. Three of the guidelines [20,22,24] also recommended explaining that seizures were not under conscious control. Two [20,23] suggested highlighting that PNES is a common and recognized condition, emphasizing that the HCP understands that the seizures are disabling and frightening.

Ten of the HCPs reported that they would reassure the patient regarding the realness of their seizures. One participant reported that *“the first thing I would say is that their symptoms are absolutely real and we're not doubting them at all”*, and highlighted the importance of *“normalising it; keep saying that it's real; although sometimes you say all those things and they just don't hear you, which is why it has to be done often”*.

Six of the HCPs recommended emphasizing that the seizures were not under conscious control, because *“society knows nothing about these which is the huge problem, and automatically people are assumed to be malingering … and so it's critical to inform the patient that this is truly beyond their control.”*

Four participants suggested explaining to the patient that *“it's an illness that we are familiar with, and many people have it”*, to help the patient understand that it is a common and recognized condition.

Six participants indicated that they would typically reassure the patient that their seizures are *“frightening and confusing”*.

3.2.5. Theme 5: possible causes of PNES

All five guidelines [15,20,22–24] indicated the need to communicate that PNES may be caused by emotional, psychological, or stress-related factors, and also that the triggers or causes of the seizures may not be apparent. Two [20,23] of the guidelines suggested that possible maintaining factors should be explained. Only one of the guidelines [22] recommended informing the patient that a history of sexual abuse is commonly associated with PNES while two guidelines [20,24] questioned the appropriateness of this approach.

All eleven participants reported that they would typically discuss emotional or psychological causal factors with the patient. A common theme was the fact that patients are *“not used to using emotional language”*, and therefore, the explanation of causal factors may need to be explained very simply, using terms such as *“stress, or all the things that are working on your brain, or all the things sitting on you”*. One participant reported that they explained the causal link to the occurrence of PNES as *“when something happens psychologically that you feel unable to cope with and you feel overwhelmed by certain issues, emotions, whatever it is … and if you haven't had help in how to express that verbally then it often becomes a physical symptom”*.

Seven participants noted that they might discuss the fact that precipitating factors were not always obvious or that *“sometimes we can't find a direct link between stress and the symptoms”*. None of the participants made reference to an explanation of perpetuating factors.

One of the participants noted the complexity of discussing the *“prominent association [of PNES] with sexual abuse”* but suggested that it may still be helpful to include if it could be done with appropriate sensitivity.

3.2.6. Theme 6: model or analogy for PNES

Two of the guidelines [20,24] recommended that a model or analogy for PNES should be included in the presentation of the diagnosis.

Eight participants indicated that they would typically include some form of analogy or explanation for how a patient's seizures occurred, but the level of detail mentioned varied by HCP. One participant emphasized the need to help the patient understand that *“the mind and the body aren't separate, that they're very intricately linked”* while another suggested using a picture or model of the brain and explaining that *“there's part of that brain which is subconscious and that the … nonepileptic seizures occur in the subconscious brain”*.

3.2.7. Theme 7: antiepileptic drugs

All five guidelines [15,20,22–24] indicated that the presentation of the diagnosis should include some form of an explanation that antiepileptic drugs were not effective in treating PNES, that they may cause serious side effects, and should not be taken.

Nine HCPs reported that they would typically include a discussion about antiepileptic drugs during diagnosis communication. One of the participant suggested that *“you have to tell them there's no medicine that's going to work; I tell them this emphatically”* while another noted that *“we are quite insistent that people should in general stop their medicines, because you don't want to convey mixed messages”*.

3.2.8. Theme 8: treatment of PNES

All the guidelines address the issue of treatment of PNES. Three guidelines [15,22,24] indicated that psychological or psychiatric treatment should be recommended to the patient. Three guidelines [20,23,24] suggested that psychological or psychiatric treatment should be explained to the patient. One guideline [22] recommended including details about neurological follow-up, and three [15,20,23] included a discussion about referral. Three guidelines [15,20,23] suggested that evidence of the effectiveness of psychological treatment should be discussed.

Nine participants reported that a recommendation for psychological or psychiatric treatment was usually included in the diagnosis discussion. Five participants indicated that it was helpful to provide an explanation of psychological or psychiatric treatment to the patient. Four participants noted that neurological follow-up should be discussed, suggesting that the patient should know that *“both teams are going to be helping the patient recover from this condition; it's important that they don't feel abandoned by either team”*.

Three participants noted that a discussion about the referral process was helpful, *“to be clear that there is a way of managing it, that they will be referred to a psychiatrist, to determine whether or not there's another condition that's contributing towards this, and then from there, therapy is the mainstay of treatment.”*

Four participants suggested that evidence regarding the effectiveness of treatment should be presented to the patient, suggesting that *“the treatment has to be explained to them in detail; the science of the treatment; that there are studies that show that psychotherapy and particularly cognitive behavioural therapy is effective; that there's no other treatment that's ever been shown to be effective”*.

3.2.9. Theme 9: prognosis

All five guidelines [15,20,22–24] recommended including a discussion about prognosis with the patient, such as explaining that the patient can expect seizures to reduce or resolve with treatment or that the condition may improve after correct diagnosis.

Four HCPs made reference to a discussion about prognosis, such as explaining that *“PNES can be successfully treated and they are not going to have this for the rest of their lives … I often don't give a time period”*. This explanation may be linked to the discussion about treatment, perhaps by mentioning that *“these kinds of conditions respond incredibly well to therapy, because your body is speaking, and if we start speaking overtly then sometimes this will dissipate the body's need to speak for you”*.

3.3. New elements arising from how South African HCPs present a PNES diagnosis

Several participants reported elements that they would typically address during diagnosis presentation that could be considered as additions to the guidelines. The elements noted below were mentioned by at least two HCPs and were considered novel when compared with the guidelines.

3.3.1. What to do in the event of a future seizure

Three HCPs noted the need for a discussion about what to do in the event that the patient experienced future seizures. Including the family or parents in this discussion could be helpful because *“families often ask how to respond when someone is having a seizure, if we are saying this is not epilepsy … so I have that conversation with the family in front of the patient in terms of what to do … because families are in distress and are overwhelmed and they want to call an ambulance, but we have to worry about not using that service when it's not necessary”*.

3.3.2. Further investigations are not helpful

Two HCPs reported that it was important to *“emphasise the fact that further investigations are not going to help, they're just going to make it worse”*.

3.3.3. Enquiry into the link between stressors and seizures

Two HCPs reported that they would typically use open and nonthreatening questions to include a discussion about the patient's own understanding of their condition and whether *“they have considered the possibility that some of their symptoms may be caused by difficult situations in their lives, or related to stress which they are struggling to manage”*.

3.3.4. Comorbid conditions

Four HCPs indicated that they may discuss the possibility of comorbid medical or psychiatric conditions with the patient, particularly if the patient had been diagnosed with both epilepsy and PNES. This discussion could address whether *“there is another comorbid mental health condition like depression or anxiety … or post-traumatic stress disorder (PTSD), it could even be an eating disorder, and we need to screen for those and we need to treat those”*.

3.4. Awareness and attitudes regarding guidelines

It is helpful to understand the awareness and attitudes of the HCPs towards the international guidelines, to understand their usefulness for the South African context.

Four participants were aware of published international guidelines regarding the presentation of a PNES diagnosis, and a further three participants were aware of more general guidelines regarding the presentation of a conversion disorder diagnosis. Four participants were not aware of international guidelines.

Six participants indicated that they were in favor of the use of such guidelines (after a brief example of the international guidelines had been provided to those participants who were not aware of them). A particular strength noted was that the use of consistent protocols by different HCPs treating a patient meant that the message was reinforced, so that *"the patient hears the same content from both teams, which improves trust and acceptance of the diagnosis"*. It was suggested that guidelines could be helpful within primary and secondary healthcare contexts, to educate HCPs who may have very limited knowledge or experience regarding PNES, but that such guidelines should encourage the referral of patients to tertiary healthcare facilities to ensure accurate diagnosis.

Five participants expressed mixed views about the usefulness of the international guidelines, where the major concern and related recommendation was that international guidelines should be adapted to be sensitive to South African cultural dynamics, because *"often with international protocols, one size does not fit all"*. Further, information tailored to unique cultural characteristics would be helpful for cases where the HCP's ethnicity or cultural beliefs differed from those of the patient. Guidelines could also be tailored to the *"local language context"*, to be more understandable.

Finally, in contrast to various suggestions regarding additions to the guidelines, it was also noted that resource constraints within the public healthcare system could mean that *"practically, you want eight to ten bullet points"*, because *"people are poor at reading guidelines, let alone following them"*.

4. Discussion

The present study's primary purpose was to contrast the content addressed by South African HCPs when presenting a PNES diagnosis against the elements suggested by international guidelines. This is the first PNES study in South Africa that included participants from both the private and public healthcare sectors, and these participants were considered by their peers to have reasonable to expert knowledge and experience. The present study, therefore, provides valuable insights into the communication practices of HCPs regarding the field of PNES in the South African context.

4.1. Frequencies of themes across guidelines and participants

4.1.1. Areas of close alignment between guidelines and participants

There was complete alignment in respect of three themes, where all five guidelines (100%) and all eleven participants (100%) included discussion elements for these themes.

The first point of complete alignment was the explanation regarding how diagnosis is made, where a discussion regarding the use of EEG or vEEG monitoring for diagnosis [6,36] was a prominent subtheme.

The second point of complete alignment was the theme of causality (although there was some variation in terms of which subthemes were addressed, and none of the participants addressed the subtheme of perpetuating factors such as family stressors or health issues [11, 37]). The high emphasis placed on explaining the causes of PNES is reasonably consistent with the results of the ILAE PNES Taskforce survey, where 81% of all respondents (for low-, middle-, and high-income countries combined) indicated that they would typically explain that the causes of PNES are complicated, and 68% of respondents referenced that the events are a response to stress [23].

The third point of complete alignment was the need to discuss treatment with the patient at the point of diagnosis, although there were a range of approaches regarding this discussion in the subthemes. By contrast, only 45% of respondents to the ILAE PNES Taskforce survey referenced a discussion about psychotherapeutic treatment [21] while a 2015 Brazilian study [38] noted that 78% of participants gave a recommendation for treatment.

There was also very close alignment across guidelines and participants in respect of another three themes. Firstly, four out of five guidelines (80%) and all eleven participants (100%) included an explanation that the diagnosis is not epilepsy. Secondly, all five guidelines (100%) and ten out of eleven participants (91%) addressed the fact that PNES is a real condition. By contrast, only 52% of respondents to the ILAE PNES Taskforce survey reported that they would explain that the events are not a form of epilepsy [21]. These two points (that the diagnosis is not epilepsy and that PNES is a real condition) are key components to assisting the patient in understanding the identity of their condition, which has been noted as a required foundation before a patient can clearly conceptualize the other elements of their illness [40].

The third point of close alignment was the explanation that antiepileptic drugs are not effective in treating PNES [11,41], where all five guidelines (100%) and nine out of eleven participants (82%) addressed this theme. Respondents to the ILAE PNES Taskforce survey also indicated high emphasis on this issue, with 77% of respondents reporting this element as part of their discussion with patients [21].

4.1.2. Areas of divergence between guidelines and participants

In contrast to the abovementioned six themes where there was close or complete alignment, there were also three themes where the frequencies reported by HCPs deviated from the frequencies evident in the guidelines.

In respect of the prognosis theme, there was alignment across all five guidelines (100%), but only four of the participants (36%) included this theme. However, the ILAE PNES Taskforce survey also indicated a lower emphasis on this point by respondents, with only 45% addressing this theme with a patient [21]. This theme may have been less frequently mentioned by the participants because it was considered implicit in the discussion about treatment.

Four out of five guidelines (80%) indicated that a name should be given to the condition while only six out of eleven participants (55%) discussed this theme. However, it is possible that this theme was underreported by the participants because the interview was specifically about PNES, and so the point may have appeared self-evident to them.

Although only two out of five guidelines (40%) incorporated a model for PNES, eight out of eleven participants (73%) included a model or analogy for PNES. This may suggest that participants were particularly aware of the need to explain the workings of PNES in a way that was understandable to patients. This theme may be emphasized more by HCPs in the South African context because of the lower adult literacy levels (79.3%) in the South African context [42] when compared with the United Kingdom and United States, where the international guidelines were developed. Additionally, South African HCPs have to be cognizant of the heterogeneity of the population, given that there are 12 official languages and the patients may not be receiving their diagnosis in their mother tongue. This finding may also be transferable beyond the South African context to other countries where language and literacy levels need to be taken into account.

However, in providing a model for PNES, none of participants made reference to any particular theoretical underpinning for their explanation, such as the Integrative Cognitive Model suggested by Brown and Reuber [43].

4.2. The use of guidelines in the South African context

The use of a defined communication strategy in presenting a PNES diagnosis can enable a reduction or cessation of seizures in the short term [16,20]; however, the key benefit of the guidelines noted by participants was the fact that it enables a more consistent message to be conveyed in the cross-disciplinary treatment of the patient [20,21,44]. Further, participants suggested that guidelines may help to address the lack of knowledge of PNES among nonspecialist HCPs. All participants made reference in some way to the difficulty experienced in helping patients to understand their diagnosis. Level of education as well as language and cultural differences were frequently identified as particular challenges in the communication process (although misunderstanding of a PNES diagnosis has been noted as a common occurrence even in patients with tertiary education in the United States where there is only one official language [45]). The use of guidelines tailored for the South African context may assist in ensuring that patients are both emotionally prepared and receive a clear diagnosis communication [45]. However, cross-cultural barriers and different cultural health beliefs [46] are likely to remain challenging and may require a specially tailored communication approach grounded in a clear cultural understanding.

4.3. Limitations

Given the small sample size, the limited geographic spread across the country, the concentration of participants from tertiary healthcare facilities or private hospitals, and the nature of the data, the findings cannot be generalized, although findings may be partially applicable in similar middle-income countries [21]. This has implications in the applicabilit of the result to low-resourced facilities and rural settings, and it is possible that people working at lower order healthcare facilities may have different experiences and recommendations for these contexts. Furthermore, this study only included PNES expert and does not necessarily reflect the way in which the vast majority of South African patients may be diagnosed and treated. The participants in future studies should also include HCPs who are not regarded as experts in the field of PNES in order to get a better reflection of how these patients are diagnosed and treated.

Although many of the participants spoke to issues of cultural beliefs and language, the sample of participants was culturally and racially skewed, in that the majority of participants were from the Western Cape, were White and English speaking, and not representative of the demographic composition of the South African population. However, the patients seen by those participants working in the public health sector do represent a wide cross-section of cultural backgrounds and are representative of the demographic composition of the Western Cape.

5. Conclusions

The present study confirms that, in general, the practices of the participants align closely to the international guidelines, despite the fact that only four participants were aware of the guidelines. Participants were generally in favor of the guidelines, although complexities were highlighted. The participants emphasized the need for all HCPs involved with a patient to communicate a consistent message, to ensure that the message is consistently reinforced. This is a particular strength of utilizing guidelines, since the consistent use of a protocol creates alignment across HCPs.

The participants demonstrated a keen awareness of the need for the communication of a PNES diagnosis to be relevant to the South African context. Emphasis was placed on the need for explanations to take cognizance of the patient's level of education and language, and it was noted that these factors could be impediments to the effectiveness of the process. However, participants highlighted the complexity introduced by the multicultural South African context as an element that had to be addressed appropriately.

There are two recommendations that have arisen from this study. Firstly, it is recommended that a similar study with a broader inclusion criterion threshold be conducted across a broader cross-section of healthcare settings. It is also recommended that this study be extended to specifically include a more in-depth understanding of what aspects of culture and language to incorporate to enable guidelines to be suited to the South African context.

Funding

None.

Declaration of Competing Interest

None declared.

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