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Management of uncertainty in the diagnosis communication of psychogenic nonepileptic seizures in a South African context

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ABSTRACT

The process of communicating a diagnosis of psychogenic nonepileptic seizures (PNES) is an integral part of the treatment process. Many international studies have therefore focused on the PNES diagnosis communication process, but to date, none with a specific focus on the South African context. This current study considered the factors that influence the patient's experience of uncertainty and the strategies employed to manage that uncertainty within the provider–patient communication. This was considered from the healthcare provider's point of view, within the specific context of diagnosis communication. We conducted 13 semi-structured interviews with providers, eliciting their perceptions related to the communication of a PNES diagnosis to patients. Data were analyzed using thematic analysis, and themes were grouped according to the main tenets of the interpersonal health communication theory of uncertainty management, which included, the experience, appraisal, and management of uncertainty.

The results revealed medical, personal, and social forms of uncertainty. The social sources of uncertainty, which include challenges related to the South African healthcare system, cultural, and language variability within the South African context, as well as possible stigmatization, seemed to have the biggest influence not only on the other areas of uncertainty, but was also indicated as a barrier to effective uncertainty management by providers. Providers in this study identified the importance of building the provider–patient relationship and ensuring patient understanding, as the main strategies used to reduce uncertainty. There was some evidence to suggest varied emotional appraisals of uncertainty by patients, but because of the subjective nature of this information, further research would be needed to confirm these findings.

These findings suggest that as providers, one cannot apply a one-size-fits-all approach when aiding in uncertainty management. Furthermore, it is pertinent to remain cognizant of the social realities of the South African context and its impact on the patient's uncertainty experience. More research is needed to understand patients' perceptions of uncertainty management within the context of PNES diagnosis communication, and how they align with the perceptions of the providers provided here.

1. Introduction

Illness-related uncertainty in health communication has been well-documented [1–7]. Uncertainty and confusion on the part of the provider and the patient have been reported in relation to accurate diagnosis [8,9], diagnosis communication [10,11], treatment options and outcomes [12], and prognosis [13,14].

1.1. Diagnosis and management of PNES

Psychogenic nonepileptic seizures (PNES) resemble epileptic seizures, but without epileptiform activity (abnormal electrical discharges in the brain) as underpinning [15]. The diagnosis of PNES can be confirmed using video-electroencephalography monitoring and the induction of a seizure [16]. In fact, PNES have a psychological etiology and are considered to be psychosomatic in nature. Currently, this diagnosis is classified as a type of conversion disorder or functional neurological symptom disorder, according to the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5) [17].

Psychogenic nonepileptic seizures are accepted as challenging both in diagnosis and treatment [8,10]. Patients are hesitant to accept the diagnosis because of its psychogenic nature, which they find to be inconsistent with their own experience [16]. Providers also find it difficult to communicate the diagnosis to patients, which adds to the barrier of access to the appropriate services [18].

There seems to be a relationship between the level of experience and extent of the provider's knowledge about this diagnosis and their attitude and perception of PNES [19,20]. This becomes important as research reveals that diagnosis communication practices not only have an impact on possible adherence to treatment in the future, but that

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the attitude and manner of communication could in fact have iatrogenic effects on the patient [8,19,21]. Despite the existence of several protocols for the communication of a diagnosis of PNES, only one has been tested for effectiveness [22], with no research focused on diagnosis communication within the South African context.

Psychotherapeutic approaches are accepted as the main component of the treatment of PNES, but the necessity to view the diagnosis communication as an integral part of the treatment process has been highlighted in various studies [11,16,23].

1.2. PNES and related uncertainty

1.2.1. Uncertainty in illness

Uncertainty can be understood as the subjective experience of discrepancy between one's preferred and actual state of knowledge and understanding, where there is a reduced predictability of and control over events [3,24]. Theories that focus on uncertainty in communication view interpersonal communication as an important part in the production, maintenance, and management of uncertainty [24]. Mishel [2] proposed an initial model of uncertainty in illness that considered the patient's cognitive processing of illness uncertainty and its related sequelae. Uncertainty is influenced by the patient's subjective perception of stimuli related to health communication, and is thought to be increased by the patient's experience of inconsistent symptom patterns, lack of congruence between actual and expected illness outcomes, and unfamiliarity with providers and procedures.

Brashers [3] expanded on this by postulating that individuals appraise uncertainty for its meaning, and that it does not necessarily invoke anxiety or negative responses. According to what is referred to as the uncertainty management theory (UMT) [6], anxiety could be viewed as positive and be accompanied by corresponding emotional experiences, all depending on the appraisal of the patient. The patient will try to maintain uncertainty if certainty about a condition would likely produce distress [1,6,25,26]. In these cases, the presence of uncertainty could present hope, where the certainty of an unwanted diagnosis dashes hope. Here the maintenance instead of reduction of uncertainty becomes a priority.

If, however, a patient appraises uncertainty as negative and anxiety-provoking, they would attempt to reduce their uncertainty by managing it through information- and treatment-seeking practices, as illustrated in Fig. 1. They will aim to reduce uncertainty and the accompanying anxiety. This theory provides a lens to study different appraisals of uncertainty, but also different reactions to uncertainty, and how they could potentially influence treatment seeking and outcomes.

This framework supports the idea that the communication practices of providers and what they deem to be important in managing the uncertainty and the resulting emotions of patients could be a vital element in reducing illness-related anxiety [6]. It also highlights the potential influence of patient factors and their own attributions of uncertainty, on how they will relate to the information provided.

1.2.2. Uncertainty and PNES

Psychogenic nonepileptic seizures seem to be a source of uncertainty for both the patient and providers. It is often misdiagnosed as epilepsy, and even when accurately diagnosed, the condition itself presents as nebulous and hard to explain to patients [27]. The mean latency between onset and final diagnosis is estimated at approximately seven years [28], which often leads to great frustration and confusion on the part of the patient and the medical professionals involved. To complicate matters even further, there is relatively little published evidence on therapeutic interventions for PNES, and the efficacy of these psychological treatments vary according to different reports [29]. In the South African context, access to providers specializing in the management and treatment of PNES is very limited, and the lack of adequate information on PNES could add to the uncertainty [30]. The discrepancy between the diagnosis as a mental health problem and the patient's experience of their illness as being physical often leads to uncertainty and confusion [12,20]. Uncertainty about the diagnosis within the medical field persists as well. Although a heterogeneous collection of causative factors have been identified, a conclusive and specific relationship still has to be established between seizure presentation and the underlying psychological etiology [21,28].

The patient's own conception of their illness can undeniably be influenced by the perceptions and attitude of the provider, and the provider–patient interaction related to their diagnosed PNES [8,19,20]. Within health communication research, UMT has thus far mainly been used to gather information from the patient's perspective regarding different health-related issues [1,7,26]. It is important however, to discuss the provider's point of view in the case of diagnosis communication practices for PNES, as research highlights the impact of the provider–patient communication on possible treatment outcomes [18–21]. It could assist in providing a basis for further research to assess whether provider–patient perspectives on uncertainty management align or not. Research within this framework could also provide valuable information that could inform future communication practices for other providers.

The present study formed part of a broader investigation, with its aim to identify strategies employed, and challenges experienced by providers, while communicating a diagnosis of PNES. The objectives of the broader study were to understand the providers' level of experience with and knowledge of PNES, their attitudes toward patients with diagnosed PNES, the content and process of the diagnosis communication, and the subjective challenges inherent in the provider–patient communication, as it relates to the diagnosis of PNES. This current study considers the factors that influence the patient's experience of uncertainty and the strategies employed to manage that uncertainty within the provider–patient communication. This is considered from the provider's point of view within the specific context of diagnosis communication.

2. Methods

2.1. Procedure and participants

This study made use of secondary data obtained from a sample that included 13 providers from different groups (neurologists, psychiatrists, and psychologists), with varied experience and exposure related to PNES. The main aim of the broader project was to compare what South African healthcare providers communicate to patients at the point of diagnosis against international guidelines.

After receiving ethical clearance from the Research Ethics Committee at Stellenbosch University for the broader study (SU-HSD-002582),

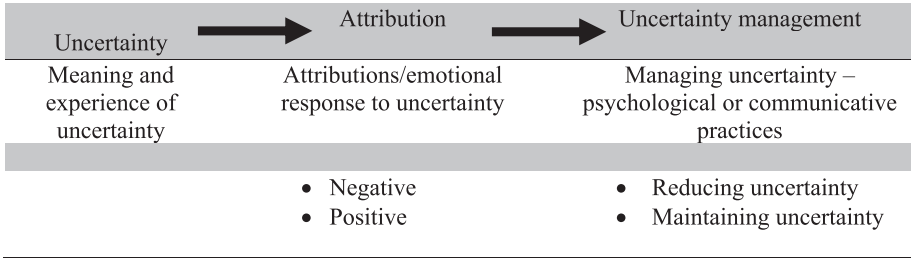

Fig. 1. Uncertainty management theory.

telephonic and/or e-mail contact was made with the providers that were considered specialists in PNES or epilepsy at a private and public hospital in the Western Cape province, inviting them to take part in a once-off semi-structured interview. Verbal consent to conduct an interview was established, after which an e-mail was sent with an official letter of invitation and informed consent attached. Interviewees were identified by means of purposive and snowball sampling techniques and were asked to provide a list of other potential providers who could be contacted. This process continued until saturation was reached. The demographic details of the participants are presented in Table 1.

2.2. Data collection

Semi-structured interviews, partially based on five different international protocols related to communication diagnosis, were conducted with each of the participants [22,31–34]. The interview schedule was divided into subsections that included professional information and experience with PNES, knowledge and attitudes toward PNES, and diagnosis communication.

The section on diagnosis communication addressed the following: a) a thorough explanation of the procedure followed and the information conveyed to the patient during the diagnosis communication process; b) the subjective difficulties that interviewees encounter when delivering a diagnosis of PNES; and c) their subjective difficulties relating to the communication process. Interviews lasted between 30 min and 1 h. Permission to record the interview was included in the informed consent process. Ethical approval for the current study was granted by the Research Ethics Committee at Stellenbosch University (PSY-2018-6572).

2.3. Data analysis

The audio recordings of the interviews were transcribed verbatim. The transcribed interviews were uploaded to Nvivo qualitative data analysis software [35] and analyzed by means of thematic analysis [36,37]. This type of analysis allows for the recognition of salient themes that emerge from the data. The data analysis was guided by a mixed deductive and inductive approach, with themes identified from the data being combined with the principles of the UMT [6,38]. During initial analysis, broad coding was done of all transcribed text related to the process of diagnosis communication for PNES. This revealed a broad theme of "uncertainty". Next, the data were coded specifically for this identified code of uncertainty. The data were then subsequently coded according to the categories related to the UMT. The following steps were used to code the data according to the tenets of this theory under the domains of 1) experience of uncertainty; 2) appraisal of uncertainty and the corresponding emotional response; and finally, the 3) ways of managing uncertainty (illustrated in Fig. 1) from the perspective of the provider. During this round of coding, the conceptual categories and subcategories were refined and the interrelationships explored [39].

2.4. Maintaining trustworthiness

This study employed reflexivity, peer debriefing, and peer examination as methods to establish rigor, which ensures transferability, credibility, dependability, and confirmability [40,41]. The process of assuring trustworthiness is summarized in Table 2.

3. Results

Thematic analysis of the dataset revealed broad themes from the provider's perspective, namely the uncertainty around the diagnosis of PNES, the uncertainty the patient is left with, and the nebulous nature of the diagnosis itself. These themes reinforced the suitability of the uncertainty management framework as theoretical lens. The role and nature of illness-related uncertainty has been well-documented [3,4,26,42,43] and also pervaded the data of this study. According to all the providers interviewed, the lack of a definitive diagnosis is a source of uncertainty for patients: *"these things that are happening are frightening and confusing to them"* and *"there are so many confusing factors"* (P11). Once a diagnosis of PNES is made, the uncertainty does not cease, and this usually perpetuates the confusion patients are experiencing: *"They are confused because it is like one plus one isn't making two for them"* (P11).

The themes were organized in accordance with the three core features of the UMT: 1) The experience of uncertainty; 2) Appraisal of uncertainty; and 3) Uncertainty management strategies [38]. This provided a structural outline to illustrate, firstly, the potential factors influencing the patient's experience of uncertainty, and ultimately the strategies for reducing uncertainty within the context of provider–patient communication. Some of the other tenets, such as the appraisal of uncertainty and the related emotional responses, were touched on briefly in an attempt to acknowledge their significance, but were not the focus of this study (see Fig. 1). Table 3 provides a summary of the findings and indicates the main areas of interest. Illustrative quotes from the dataset are provided throughout, to substantiate our findings.

3.1. Uncertainty

Consistent with other studies on illness-related anxiety [4,26], our data revealed broad themes that could influence the uncertainty experience of the patient, as identified by the providers and explored from their point of view. These themes are medical, personal, and social uncertainty, and the relevant findings are grouped accordingly (Table 4).

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[a]	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
12	Clinical Psychology	26	Private Practice	M	White	KwaZulu-Natal
13	Clinical Psychology	2	Secondary Hospital & Private Practice	M	White	Western Cape

[a] The term "colored" is currently treated as a neutral description in South Africa, classifying people of mixed race ancestry

Table 2
Process of maintaining trustworthiness.

Process	Subprocess	Description of steps taken
Credibility	Peer debriefing	Discussion between authors to explore emerging ideas and themes related to the data. Emergent findings and themes were discussed with the project leader throughout the process. The project leader has extensive knowledge on the topic of PNES and also in qualitative research methods.
	Peer examination	The research proposal for the study was screened by the Departmental Ethics Screening Committee and Research Ethics Committee: Human Research (Humanities) at Stellenbosch University prior to commencement of the study.
Transferability		Detailed contextual information was provided about the research context, processes and participants to ensure that conclusions about the transferability of the findings can be made by individual users of the information.
Dependability		The context, research methodology, implementation and findings are described in detail, should future research seek to replicate the study.
Confirmability	Reflexivity	Emergent findings and themes were discussed with the project leader throughout the process. Ideas and interpretation were reflected on in consultation with the project leader, who has extensive knowledge on the topic of PNES and also in qualitative research methods.

3.1.1. Uncertainty theme 1: medical uncertainty

Medical uncertainty involves uncertainty pertaining to the diagnosis of an illness, the symptom patterns, the implementation of treatment and care, as well as the progression and prognosis of the disease [26]. The main factors that create medical uncertainty were identified as being the complexity of the diagnosis, insufficient information, unclear expectations about treatment and outcomes, and an unpredictable prognosis (Table 4).

The subtheme of complexity of the diagnosis were supported by nine of the providers reporting that patients frequently react negatively to a diagnosis of PNES, possibly because they feel that they are being considered *"crazy"* (P8, P12) or because they feel that their symptoms are not being taken seriously: *"I think that patients generally feel badly treated about this. Often people feel dismissed and angry and that they're just being thrown away"* (P6). This is exacerbated in cases where the patient has had multiple previous interactions with providers who have not accurately diagnosed PNES. Six providers highlighted the challenges caused because of the complicated process to be completely certain of a PNES diagnosis as *"medically unexplained symptoms"* (P11) are seen as *"grey areas"* (P11). As a result, patients could receive ambiguous or conflicting messages from providers.

Insufficient information about PNES is thought to be another source of medical uncertainty. The lack of knowledge and experience regarding conditions like PNES was highlighted by ten participants, because *"the knowledge in the world of nonorganic functional disorders is basically nonexistent"* (P1), and as a result, *"people in primary healthcare have absolutely no idea what to do with this"* (P12). Six participants further noted that there were *"significant barriers to the patient understanding"* (P2) of the diagnosis, which includes patient personality factors. Four participants suggested that the patient's level of education may influence understanding, and highlighted the need to *"tailor [the explanation] according to the level of functioning of the patient, the level of education"* (P4).

Another subtheme was that of unclear expectations about treatment and outcomes. Six providers noted challenges in the referral process, such as cases where patients *"are often confused as to why they are ending up in the psychiatry section"* (P8). Other participants highlighted that patients are frequently shuffled between different providers, with the attitude of *"it's something else and it's in the realm of psychology — off you go"* (P11). Another challenge is that each provider may convey a different message, making it harder for the patient to engage with their diagnosis.

The unpredictability of the prognosis further seems to add to the uncertainty of the patient. One psychologist involved in the treatment of PNES stated that *"in terms of getting them better, some people have got miraculously better and other people not at all — and we have no idea actually why"* (P10). Another psychologist confirmed that "*there's absolutely no way of knowing who will respond to treatment*" (P11).

Table 3
Summary of themes and subthemes.

3.1 Uncertainty	3.2 Appraisals/Role of Emotion	3.3 Uncertainty management
Meaning and experience of uncertainty	Emotional response to uncertainty	Psychological or communicative practices
Medical Sources of Uncertainty	**Positive attributions – Preference to maintain uncertainty**	**Maintaining Uncertainty**
Complexity of diagnosis	Resistance to diagnosis	Avoid follow-up appointments
Insufficient information	Anger at mental health diagnosis	Self-refer to other providers
Unclear expectations about treatment/outcomes		Remain identified with epilepsy diagnosis
Unpredictable prognosis	**Negative attributions – Preference to reduce uncertainty**	**Reducing uncertainty – Uncertainty Management**
Personal Sources of Uncertainty	Anxiety/Distress	**Provider–patient relationship**
Complex identity challenges	Relief	Validation, Empathy
Discrepancy between personal experience and diagnosis		Time
Complex personality characteristics		**Ensure patient understanding**
		Supporting information/education for patient and family
Social Sources of Uncertainty		Team approach in diagnosis communication
Possible Stigmatizing		
SA Context: Healthcare		
SA Context: Culture and language		

3.1.2. Uncertainty theme 2: personal uncertainty

The personal form of uncertainty involves ambiguity relating to the patient's self-identity following diagnosis, which can affect the patient and their entire family [4,26]. The main themes identified were complex identity challenges as a result of the diagnosis of PNES, complex personality characteristics of the patient, and the discrepancy between the patient's experience and the psychogenic nature of the diagnosis (Table 4).

Table 4
Uncertainty: meaning and experience of uncertainty.

Theory domain	Themes	Subthemes
3.1 Uncertainty experience	Medical Uncertainty	Complexity of diagnosis
		Insufficient information
		Unclear expectations about treatment/outcomes
		Unpredictable prognosis
	Personal Uncertainty	Complex identity challenges
		Discrepancy between personal experience and diagnosis
	Social Uncertainty	Possible Stigmatizing
		SA Context: Healthcare

The diagnosis of PNES seems to present the patient with complex identity challenges. Three participants suggested that patients might struggle to understand that they do not have epilepsy and to recognize the connection between emotional or psychological issues and their condition, especially for *"patients who are quite concrete and not psychologically minded"* (P5). They suggested that patients may find it difficult to let go of an epilepsy diagnosis, because although *"being an epileptic is not socially prestigious… but it's better than having no label, and it's better than being told you're pretending"* (P11).

Consistent with research indicating that the discrepancy in provider–patient views could have significant implications for how the diagnosis is received and communicated [10,12,19], our research found that patients often view their symptoms as being of a purely or partly physiological origin. When confronted with information from a provider who attributes PNES solely to psychological causes, the patient is met with uncertainty and confusion: *"They feel confused because there is this disconnect between what they are experiencing and what the doctor is telling them"* (P11). This discrepancy between personal experience and the diagnosis of PNES is another subtheme that seems to have an impact on personal uncertainty.

One participant suggested that the acceptance of a diagnosis of PNES was complicated by a lack of understanding of the psychological explanation of the diagnosis because "*by definition they have found another way of expressing their signs of distress, they're not coming to talk about their distress"* (P10). Eleven providers discussed how the complex personality characteristics of the patient could make diagnosis and communication more difficult. It was noted that patients *"become more challenging and complex when there's a comorbid personality disorder"* (P5), and *"another challenge is patients who have a fictitious component to the condition"* (P5). Delays in the correct diagnosis of the condition typically exacerbate the situation.

3.1.3. Uncertainty theme 3: social uncertainty

Social uncertainty refers to the way in which someone feels or reacts during social interactions after the diagnosis of an illness or during the life course of the illness, as well as how the disclosure of the disease is communicated [2,5]. According to the providers, the factors that influence social uncertainty in the patient could include possible stigmatization, in a broader social as well as in healthcare contexts, and the South African context as it pertains to the culture and language, and the national healthcare system (Table 4).

Twelve participants emphasized that patients are frequently treated with dismissal by other providers and potential victims to stigmatization, not just in their broader communities, but within the medical community as well. The negative attitudes of providers that patients experience is also likely to *"harden their attitude towards hearing the diagnosis"* (P11) and *"block any chances of them engaging with therapy"* (P11) so that the patient goes to another provider *"and the whole process will start again, which means a financial burden on the patient or the system"* (P11). The participants noted that dismissal was often true both of those providers closely involved with the condition (e.g., neurologists, psychiatrists, and psychologists), as well as of other providers. Five providers commented on the challenges that patients face because of societal stigma and prejudice, because *"society knows nothing about this, which is the huge problem, and automatically people are assumed to be malingering"* (P1). One participant suggested that conversion disorders should be considered within this framework: *"what is wrong with our society's ability to be able to talk and speak and support each other? I'm concerned that people are presenting these symptoms because it's the only way to access care"* (P5).

All the participants discussed the challenges faced within the South African healthcare system. This prominent subtheme identified how the lack of resources in the healthcare system impacted on patients' ability to get appropriate care. This may have an effect on both obtaining a conclusive diagnosis, where *"a lot of the patients with PNES may be sitting at the day hospital, on epilepsy treatment, not getting better and having more epilepsy treatment added"* (P4) as well as communication of the diagnosis, where *"you're in a busy outpatient and you've got 50 patients waiting and here you've got this patient who's clearly not got an organic epilepsy — you don't have half-an-hour to gently ease her into it"* (P11).

Eight participants highlighted the challenges caused by language barriers or culture differences within the South African context. Language barriers can make it harder for a patient to understand the diagnosis being communicated, and *"someone needs to be able to understand the language in which they are communicating in order to understand this very complex concept"* (P8). Participants noted that differences in culture were particularly difficult to bridge, because *"in our population there are things that are attributed to witchcraft"* (P11), but that patients "*feel that they're going to be scorned by the medico-psychological profession if they say they have had exorcism and it hasn't gone away"* (P6), or that "*patients feel that they can't actually talk about it because that's not the field that the doctor or psychologist can talk about"* (P6).

3.2. Appraisal of uncertainty

Brashers [3] argued that negative emotional responses to uncertainty occur when uncertainty is seen as a dangerous state (i.e., not knowing could lead to harm). Positive emotional reactions result from a sense that uncertainty is a preferred state (i.e., not knowing is better than knowing that harm is inevitable), and neutral emotional responses can occur when the uncertainty about the issue is not particularly relevant or important to the person. This subjective emotional experience will then inform what uncertainty management strategies the patient will prefer, depending on whether they appraise this uncertainty as positive or negative. Our data supported a wide spectrum of responses to uncertainty (Table 5), but because of the subjective nature of this study, they would need to be explored from the patient's perspective in future research.

3.2.1. Appraisal of uncertainty theme 1: preference for maintaining uncertainty

According to the providers in this study, some patients showed positive attributions (or a preference for) uncertainty when it comes to a diagnosis of PNES, as they would "*reject it completely*" (P10), are "*angry and resentful, feel humiliated*" (P11), and rather than accepting the diagnosis, will repeatedly opt for "*another test*" (P1).

3.2.2. Appraisal of uncertainty theme 2: preference for reducing uncertainty

Being cognizant of the subjective nature of the data, a range of emotional responses were identified from the providers' point of view ranging from anger, denial and distress to relief. Some are "*glad to hear the diagnosis*" (P1) because "*epilepsy has got a terrible quality of life*" (P1).

3.3. Uncertainty management strategies

Strategies employed as a result of appraisal of uncertainty and emotional responses could either reduce uncertainty or maintain it [1,25]. This research focused on the ways providers aim to reduce uncertainty, specifically in the context of the diagnosis communication, but some patient strategies to maintain uncertainty were identified and noted briefly (Table 6).

Table 5
Appraisal of uncertainty: the role of emotion.

Theory domain	Themes	Subthemes
3.2 Appraisal of Uncertainty	Preference for maintaining uncertainty	Resistance to diagnosis Anger at mental health diagnosis
	Preference for reducing uncertainty	Anxiety/Distress Relief

3.3.1. Maintaining uncertainty

3.3.1.1. Maintaining uncertainty theme 1: rejection of diagnosis. There was evidence that suggested that some patients prefer to maintain uncertainty: *"Sometimes [for the patients] a bad thing that is named is better than not having a name"* (P11). Uncertainty is preferred by some patients as this could be less anxiety-provoking than an unwanted diagnosis or health-related information [25]: *"there is a well-known phenomenon amongst functional disorders that there is always another test"* (P1). These patients are thought to be less likely to seek information or related treatment [1,6,25].

3.3.1.2. Maintaining uncertainty theme 2: avoidance of treatment. Some patients reportedly avoid follow-up appointments, self-refer to other providers or remain identified with their epilepsy diagnosis, which could be ways of maintaining uncertainty. *"More often than not, the patients do not show up for their appointments at the psychiatrist"* (P8). Another provider said *"It is a feature of people with conversion disorders, they move; when they don't get the answer they like they move off and they don't come back"* (P11).

3.3.2. Reducing uncertainty

Given the fact that patients who choose to maintain uncertainty are more likely to reject a diagnosis or avoid seeking treatment altogether, the following provider strategies aimed at managing uncertainty are applicable only to patients who view uncertainty as undesirable. Providers identified the following as being pivotal in the management of uncertainty in the context of provider–patient diagnosis communication:

3.3.2.1. Reducing uncertainty theme 1: provider–patient relationship. Five participants stressed the importance of building a relationship of trust with the patient: *"They've got to trust the person. It has to be the person that they are most likely to accept the diagnosis from and not become defensive and not become angry"* (P11). Where a patient is referred to another provider after diagnosis, it is preferable for the person who diagnosed the condition to "*remain involved and … still follow up our patients, to make sure that they're on the right track and that the patient doesn't feel … abandoned*" (P4), and to increase the likelihood that the patient does not become lost in the system. Eight participants noted that it was important for the person who made the diagnosis (usually the neurologist) to be involved in communicating it to the patient, and seven suggested that the person with the strongest relationship with the patient should be involved if possible.

Twelve of the thirteen participants emphasized the value of treating patients with empathy, respect, and validation; and spoke extensively about this theme. This is particularly important where patients have been treated dismissively by other providers or where past communication has left the patient confused: *"so you try and reposition their understanding in a way that makes them feel validated and heard, and empathize with a sense of uncertainty that they're feeling and not knowing"* (P11). All four psychologists who participated in the study spoke in detail about the importance of validating the patient's experience, especially as it pertains to the discrepancy between their own experience and the psychogenic nature of the diagnosis: *"It was a two-session discussion, trying to reassure her that she's not crazy, that she's not manufacturing the symptoms; that just because we don't have a nice little box for the symptoms with nice black and white tests, it wasn't to say that she wasn't in extreme distress"* (P12). Two of the providers noted that their own ability to remain empathic increased as their experience with, and knowledge about the diagnosis increased. Where initially they felt *"frustrated"* (P8) when treating these patients, there is now a sense of *"privilege to be able to see the difference that the work with the patient can do"* (P8).

Related to the above, but noteworthy in itself, twelve of the providers emphasized the need for time in building the provider–patient relationship and also in relaying and explaining the diagnosis: "*You can't think you can do this in five minutes, ever*" (P4). One provider noted that "*once one has spent some time with the person and you often get to understand where it's coming from*" (P3), it becomes "*rewarding*" (P3) to treat these patients".

3.3.2.2. Reducing uncertainty theme 2: ensure patient understanding. Nine of the providers focused on ensuring that the patient understands the diagnosis clearly, possibly reinforcing the process in subsequent consultations where the provider would focus on *"normalising it; keep saying that it's real, but although sometimes you say all those things, they may just not hear you, which is why it has to be done often"* (P10). This again highlights the need for the time to build a relationship with the patient and to establish trust, but in reality, time is not always available. Six participants highlighted the importance of starting at the point of the patient's current understanding, *"asking the patient what they do understand"* (P3). Seven providers focused on avoiding any ambiguity in the message given to the patient, with consistency from all providers involved with the patient, so that the patient *"understands those teams are certain of the diagnosis, both teams agree with the diagnosis"* (P5). This approach means "*giving people no way out… telling them there's no medicine that's going to work, there's no operation that's going to work… you alone can't fix this… because if you tell patients that it's in their control, you give them a way out of psychotherapy"* (P2).

Ten providers suggested that it was preferable to communicate the diagnosis using a team approach, ideally involving the neurologist, psychiatrist, and/or psychologist, *"with a whole team always saying the same thing"* (P4), although several noted that in practice, this did not usually happen. Eight participants discussed the need for a united approach from providers involved in treating the patient so that the patient receives a consistent message from all parties involved in diagnosis and treatment. Following the communication of a diagnosis, it is helpful to *"revisit while in hospital preferably by a team, social worker, psychologist, and then a follow-up visit that's close to that hospital visit"* (P1).

Another subtheme identified was the need for supporting information and education about PNES for patients and their family members. Four providers commented on the value of helping the patient's family to understand the diagnosis, and five suggested that supporting education (like a brochure explaining the condition) was very useful to help both the patient and their family, because "*patients always feel more comfortable when they have something that they can tell their friends and family, this is what the doctor says I have*" (P4).

Table 6
Uncertainty management strategies.

Theory domain	Themes	Subthemes
3.3.1 Maintaining uncertainty	Rejection of diagnosis	Remain identified with epilepsy diagnosis Self-refer to other providers
	Avoidance of treatment	
3.3.2 Reducing uncertainty	Provider–patient relationship	Trust Empathy, respect, and validation Time
	Ensure patient understanding	Supporting information/education for patient and family Team approach in diagnosis communication

3.4. Needs identified: role of the provider in the management of uncertainty

Six participants commented on the need for an improved understanding among providers regarding PNES and similar conversion disorders. It was noted that simple guidelines could be valuable, especially in contexts like primary healthcare facilities, although *"people are poor at reading guidelines let alone following them"* (P2).

One neurologist discussed the difficulty of referring a patient for therapy because of the paucity of psychologists with appropriate knowledge and expertise in the field of PNES, especially outside of

major cities, and suggested *"a network of clinical psychologists in the country… who are proficient in this area"* (P2).

4. Discussion

There is no one-size-fits-all approach when it comes to managing patient uncertainty related to PNES. There are various medical, personal, and social factors that add to the patient's experience of uncertainty [7,26], and it is important to consider them within the context of provider–patient communication. There are different uncertainty needs that correspond to different emotional expressions and different personality factors that potentially influence those needs at the outset, like psychological mindedness and comorbid personality traits. If the different individual attributions of uncertainty are taken into account, it becomes clear that one standard approach of merely providing information is not adequate and, in fact, a standardized approach could have totally different outcomes dependent on patients' unique uncertainty management needs. For example, a patient who wants to maintain uncertainty will avoid gathering information, and receiving that information could actually increase anxiety [3,25]. In contrast, someone who wants certainty will probably seek information, but the kind of information a diagnosis like PNES provides, would perhaps not be satisfactory in managing their uncertainty either.

Although protocols exist that could be helpful in PNES diagnosis communication [22,31–34], the providers illustrated that *how* the diagnosis is communicated is as important as *what* is communicated. To this end, the need for validation, empathy, and respect in provider–patient communication was highlighted throughout, as well as determining the patient's understanding of their symptoms. There seems to be a perceived discrepancy between the endorsement of this approach, and what happens in practice, as many providers stressed the dismissive nature of diagnosis communication to which patients are often exposed. Providers' ability to accept the emotional response or attribution to uncertainty, as influenced by multiple factors, seems pertinent. Awareness of these medical, personal, and social factors that influence patient uncertainty, might lead to more empathy and a better understanding of the patient, as well as more appropriate management of uncertainty. Research has indicated that PNES could be interpreted as an "externalized form of abnormal emotion processing" [44 (p. 5)]. It seems as if these challenges that make patients vulnerable to the development of a conversion disorder in the first place [15,45,46], such as impaired emotion processing and regulation [44], could in itself present as a barrier in diagnosis communication and treatment seeking. These complex personality factors, including the presence of comorbid personality disorders, were viewed as an additional complication that could in fact have a negative impact on the provider's ability to remain empathic. Our findings did however echo other research [19,20] that suggested an increase in empathy and more favorable attitudes towards patients, as the providers' experience of and knowledge about PNES expanded.

The medical, personal, and social factors that influence patient uncertainty also seem to have an interrelated relationship. Within the context of a developing country like South Africa, it is not surprising that the social sources of uncertainty seem to have the most profound impact and is perceived to influence the medical and personal spheres of uncertainty. There seems to be a discrepancy between the perceived ideal way of diagnosis communication that would assist in reducing uncertainty and what happens in reality. Most of the providers acknowledge the need for time to build a relationship with the patient and to explain the diagnosis in detail, often multiple times. In practice, however, this does not seem to be possible in the public health sector due to the lack of resources. The sociocultural climate in South Africa might have direct effects on the medical, personal and social sources, as well as the management, of the patient's uncertainty. In general, patients do not have a choice about whom they receive the diagnosis from, despite the emphasis placed on the importance of the provider–patient relationship. There is not enough time to build a robust, trusting provider–patient relationship, not enough resources for appropriate referrals, and not enough time for multidisciplinary meetings with the patients to discuss the diagnosis within a consistent team approach. This means that even if effective uncertainty management strategies were identified, they might not be implementable because of social realities.

Finally, most of the providers highlighted the need for raising awareness of conversion disorders like PNES at especially the primary level of healthcare and an increase in expertise to treat these disorders in general. The need for experienced and trained psychologists to refer the patients to once diagnosed with PNES was also identified.

5. Limitations

The providers who participated in this study were all located in Cape Town and are not representative of providers across the entire country. The sample was not homogenous in terms of qualifications and level of experience.

This study focused on the uncertainty management within the context of the diagnosis communication of PNES. Some patient variables that could influence the patient experience of uncertainty were identified by the providers as they perceived them. However, this is a very subjective interpretation and does not claim to capture the full and true experience of patients with new diagnoses. Given the importance and potential impact of the provider–patient communication, this information can be used in future, to assess whether the patient and the provider perspectives align. This could ultimately serve to improve provider–patient diagnosis communication, which, especially in the case of PNES, is crucial and has bearing on the ultimate treatment uptake and outcomes.

6. Conclusion

Given the interplay of the different sources and individual appraisals of uncertainty, the management of uncertainty in the diagnosis communication of PNES is complex. The social sources of uncertainty, which include challenges related to the South African healthcare system, cultural and language variability within the South African context, and possibility of stigmatization seemed to have the biggest influence not only on the other areas of uncertainty, but was also indicated as a barrier to effective uncertainty management by providers. Practical recommendations for practitioners based on this study could include the following: 1. Validation, empathy, and respect in provider–patient communication are important; 2. Providers should determine the patient's understanding of their symptoms; 3. Raising awareness of conversion disorders, like PNES through inclusion in general training of doctors working at the primary healthcare level, and disseminating literature at Community Health Clinics (CHCs); 4. Generating a database of psychologists who specialize in the treatment of conversion disorders, like PNES.

As interpersonal provider–patient communication can be viewed as a co-construction between the two parties involved [24,38], it is unclear how the provider's own personal uncertainty management factors may influence the diagnosis communication. This was highlighted by a provider noting that a nebulous diagnosis like PNES may cause anxiety in the provider as it relates to their own professional uncertainty. Future research could indicate how practices to manage their own uncertainty potentially influence provider–patient communication.

Research has indicated that the congruence between providers' and patients' beliefs about an appropriate communication style proved to be strongest predictor of trust and satisfaction in the management of illness-related uncertainty [1]. Therefore, future research is needed to determine the patient perspective as it pertains to uncertainty management and diagnosis communication and how that aligns with the providers' perspective provided here.

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Declaration of Competing Interest

None declared.

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