

## "Are You Saying She's Mentally Ill Then?" Explaining Medically Unexplained Seizures in Clinical Encounters

*Catherine Robson & Olaug S. Lian*

**Key words:**

medical sociology;  
social construction  
of illness and  
disease; health  
communication;  
neurology; patient-  
provider  
relationships; film  
recordings;  
observational  
study; discourse  
analysis; critical  
discourse analysis

**Abstract:** Bodily phenomena that are difficult to identify, localize, explain and cure with the aid of modern biomedical knowledge and technology leave ample room for cultural influence. That makes them a perfect case for studying the cultural dimension of medical knowledge and practice. Building on this assumption we qualitatively explore the communication between neurologists and women with seizure disorders of uncertain etiology, often labeled psychogenic non-epileptic seizures (PNES), in a specialist clinic in England. Based on an interpretation of film-recordings of eight naturally-occurring clinical consultations we discuss the following questions: How do neurologists explain the name, the cause and the treatment options to these patients? How do patients and their companions respond to these explanations? And finally, what makes these interactions so difficult? Our interpretation of the data is inspired by critical discourse analysis, and framed within a social constructionist perspective on medical knowledge and practice.

We found that the neurologists presented the diagnosis and its cause—inappropriate stress management—through objective language that conveyed a high degree of certainty. Patient-parties often disagreed, and found it hard to believe that these physical symptoms had a psychological origin. Companions often acted as advocates for the patients in negotiations with the doctors. The polarized debate between psychogenic and somatic understandings of the seizures that emerged illuminates how the Cartesian dualism between body and mind complicates clinical encounters—a dualism doctors explicitly reject, but presumably accept. We argue that it is impossible to overcome this polarization without acknowledging the cultural dimension of medical knowledge and practice.

### Table of Contents

- [1. Introduction](#)
- [2. Methodology](#)
  - [2.1 Empirical data](#)
  - [2.2 Participants](#)
  - [2.3 Data analysis](#)
  - [2.4 Ethics](#)
- [3. Findings](#)
  - [3.1 Diagnosis](#)
  - [3.2 Explaining the cause](#)
  - [3.3 Suggesting treatment](#)
- [4. Discussion: Naming and Explaining the Seizures](#)
  - [4.1 Doctors argumentation](#)
  - [4.2 Patient and companion argumentation](#)
  - [4.3 Strengths and weaknesses](#)

## [5. Conclusion: Why Do Conversations Break Down?](#)

### [5.1 Body-mind dualism](#)

### [5.2 Blaming the victim](#)

### [5.3 Explanation and objectification](#)

## [Acknowledgment](#)

## [References](#)

## [Authors](#)

## [Citation](#)

# 1. Introduction

In Western health care systems, doctors are increasingly confronted by patients with so-called medically unexplained physical symptoms (MUPS). About one in four patients seen in primary care settings are estimated to have a condition that could be classified as such (OLDE HARTMAN, 2011). Prevalence estimates are just as high, if not higher, in secondary care settings (NIMNUAN, HOTOPF & WESSELY, 2001). [1]

In dealing with patients presenting with medically unexplained conditions, doctors are placed in a difficult position. The modern biomedical cosmology is a way of knowing based on scientific knowledge and medical technology. Technologically generated findings provided by laboratory procedures and by mechanical and electronic devices, play an important role in the diagnostic process (JEWSON, 2009). Within this cosmology, invisible and medically unexplained symptoms become incomprehensible, but they are often assigned to psychological, social and environmental factors (KIPEN & FIEDLER, 2002). Doctors and patients often disagree on the nature of these illnesses, including their names, their etiologies, and their treatments (BANKS & PRIOR, 2001; LIAN & NETTLETON, 2015; NETTLETON, 2006), and patients experience consistently poor outcomes (ROSENDAL et al., 2005). Doctors sometimes report feeling inadequate, resentful and fearful of these patients (WILEMAN, MAY & CHEW-GRAHAM, 2002). Patients, on the other hand, report feeling misunderstood and rejected (EDWARDS, STERN, CLARKE, IVBIJARO & KASNEY, 2010; SALMON, 2000). [2]

In this article, we report on an observational study about the naming and explaining of medically unexplained seizures in clinical encounters. In current medical nomenclature, this condition is often labeled psychogenic non-epileptic seizures (PNES), sometimes referred to as "non-epileptic attack disorder" (NEAD), "hysterical seizures" or "pseudo-seizures" (STONE et al., 2003). Functional neurological symptoms (FNS), where PNES are grouped, were recently voted last on a list of "most likeable conditions" by neurologists (EVANS & EVANS, 2010). The seizures are defined by their resemblance to epileptic seizures, but unlike epileptic seizures, they are not considered to be caused by abnormal electrical discharges in the brain. The diagnosis of PNES is reached through an elimination process, where differential diagnosis are excluded by means of technological tests and assessing reported symptoms against

diagnostic criteria (NICE, 2012). Up to one-fifth of patients in specialist epilepsy clinics are diagnosed with the condition (BENBADIS & ALLEN, 2000). Prevalence estimates vary between 2 and 33 per 100,000 of the population (ibid.), and approximately 75% of patients diagnosed with PNES are women (McKENZIE, OTO, RUSSELL, PELOSI & DUNCAN, 2010). [3]

The etiology of PNES is poorly understood (MELLERS, 2005), but they are usually interpreted as physical manifestations of psychological distress with multiple possible emotional etiologies (LESSER, 2003; REUBER, 2008). Based on these theories, people with PNES are typically offered psychiatric treatment. However, no reliable evidence supports the use of any intervention in this patient group (LaFRANCE, REUBER & GOLDSTEIN, 2013), and around 70% remain disabled several years after the diagnosis (MAYOR, HOWLETT, GRUNEWALD & REUBER, 2010; REUBER et al., 2003). [4]

According to previous research, doctors find consultations with these patients challenging because of interactional problems (MONZONI, DUNCAN, GRUNEWALD & REUBER, 2011a, 2011b). Patients often react unfavorably to the PNES diagnosis: they report anger, doubt, and confusion about it, especially when psychogenic explanations are involved (CARTON, THOMPSON & DUNCAN, 2003; GREEN, PAYNE & BARNITT, 2004; MELLERS, 2005; MONZONI et al., 2011a, 2011b; STUMP, 2008; THOMPSON, ISAAC, ROWSE, TOOTH & REUBER, 2009). In dealing with patients with PNES, doctors are left with little help from scientific knowledge and technological devices to explain the patient's symptoms, and they have likened communicating the diagnosis to "negotiating a minefield" (THOMPSON et al., 2009, p.508). [5]

Knowing these challenges, we ask: How do neurologists explain the name, the cause and the treatment options to these patients? How do patients and companions respond to these explanations, and what makes these interactions so difficult? These questions are based on a social constructionist perspective on medical knowledge and practice, meaning that we perceive medical knowledge and practice as socially conditioned and contingent upon (but not reducible to) the cultural and historical context in which it originates. Emphasizing this cultural sensitivity means accommodating health and illness as meaningful phenomena that transcend what they represent with regard to underlying biological pathology (LIAN & BONDEVIK, 2015). In line with this perspective, we base our discussion on a qualitative interpretation of film-recordings of eight consultations between neurologists and patients with seizure disorders of uncertain etiology. [6]

The structure of our presentation is as follows: After presenting the methodology, we present our empirical data through three main themes: 1. the diagnosis, 2. the cause, and 3. the treatment options. In the next section we synthesize, interpret and discuss the presented data material. Finally, we go on to discuss why these conversations appear to break down, what might be done to bridge doctor-patient understandings, and how medical encounters might benefit from incorporating a cultural understanding of medical knowledge and practice. [7]

## 2. Methodology

In line with our social constructionist perspective on medical knowledge and practice, we explore the communication in eight naturally-occurring clinical consultations between doctors, patients and accompanying persons. Their communication is captured by film-recordings. The advantage of this data-capture method is that it enables us to capture both verbal and non-verbal communication in the consultations. Recordings of actual consultations also have the advantage that it grants minimal researcher influence (HARRISON, 2002). [8]

### 2.1 Empirical data

Our empirical data consist of film-recordings of eight complete consultations between neurologists and patients at a specialist (adult) outpatient seizure clinic at a hospital in England. The sample was collected from a total of 50 consultations recorded between January 2010 and March 2012 (Table 1). Patients were eligible for inclusion in the study if they had been referred to the clinic because of a seizure disorder of uncertain etiology for a first initial (diagnostic) consultation with a consultant neurologist who they had not met previously (Table 1). Consecutive eligible patients (and where applicable their companions) were invited to take part in the study, and if they agreed, provided written informed consent to participate. This study is based on eight of these 50 consultations. [9]

The sample of eight was deliberately and purposely selected to create a homogenous sample of patients, based on the following criteria: the patient had received a tentative diagnosis of PNES before attending the clinic, the patient received a diagnosis of PNES during the consultation, *and* the diagnosis was subsequently confirmed at six-month follow-up. This sampling method involves the logical selection of similar "information rich" cases that can illuminate the questions under study (PATTON, 2002). Our material includes all patients of the original 50 patients that met our inclusion criteria (Table 1). [10]

Researchers were not present during the consultations, which were filmed using a stand-alone device. Detailed verbatim transcripts of all recordings were produced. The transcripts include words, sounds and pauses (the latter interpreted as a possible indication of uncertainty or hesitation). Non-verbal communication was not a focus of the analysis, but transcripts were analyzed alongside video-recordings to help ensure that the transcription was correct and to aid our interpretation. As BAILEY (2008, p.128) has pointed out, "the meanings of utterances are profoundly shaped by the way in which something is said in addition to what is said." The data amounts to 303 minutes of film and 200 pages of transcript.

Study exclusion criteria <sup>1</sup>	Not fluent in English Has learning disabilities Previously assessed for major neurological surgical intervention
Sample inclusion criteria	A diagnosis of PNES was confirmed by the consultant neurologist at six-month follow-up (14/50 patients). The patient had previously received a diagnosis of PNES <i>before</i> attending the clinic (typically from a neurologist at their "local" hospital who did not specialize in seizure disorders) and a specialist opinion was required by the referring neurologist or the patient's GP (10/14 patients). The patient received a diagnosis of PNES <i>during</i> the consultation (8/10 patients).

Table 1: Inclusion and exclusion criteria [11]

## 2.2 Participants

All participants in this study are women (this occurred "by chance," as gender was not an inclusion criteria), aged between 18 and 65, who had experienced seizures for a median of 12.5 years, and had previously received a diagnosis of PNES (Table 2). Three of these (Agata, Lilly and Mary)<sup>2</sup> also had a historic diagnosis of epilepsy, and were still taking anti-epileptic drugs (AEDs) at the time of their consultation. All patients had been asked to bring along a witness of their seizures, if possible, and five patients were accompanied to their consultation by a spouse or a parent. Patient age, gender, accompaniment status and relationship to the companion (where applicable) were recorded before consultations commenced. Seizure onset (length of time experiencing seizures), previous medical investigations and previous diagnoses were identified from history-taking during the consultations.

1 Patients were approached to re-check their eligibility while they waited to be seen.

2 All data has been anonymized by removing any information that might disclose participants' identities and pseudonyms have been used.

Patient	Patient age (range)	Onset (years)	Companion	Previous tests <sup>3</sup>	Consultation length (minutes)
Sheila	50 – 65	3	Spouse (male)	ECG, EEG, MRI	31
Agata	35 – 50	17	Spouse (male)	ECG, EEG, CT, MRI	47
Margaret	35 – 50	20	Spouse (male)	ECG, EEG, CT	38
Helen	35 – 50	5	Spouse (male)	ECG, EEG, MRI	58
Elizabeth	35 – 50	15	Mother	ECG, EEG, MRI, Video-EEG	35
Lilly	18 – 35	12	None	ECG, EEG, CT	36
Mary	50 – 65	13	None	ECG, EEG, CT, MRI, Video-EEG	34
Christine <sup>4</sup>	50 – 65	1	None	EEG, MRI	24
Median or mode	35 – 50	12.5	Spouse (male)	ECG, EEG, MRI and/or CT	36

Table 2: Participants [12]

### 2.3 Data analysis

In our material, the typical consultation passed through five main stages (partly overlapping), often in the same order (Table 3). Although we analyzed complete consultations, we mainly present data from Phase 2 and onwards, either in the form of freestanding statements or extracts of dialogues. Negotiations between doctors and patients/companions usually occurred in Phase 4 or 5, and so these are the phases in which dialogues are most important.

<sup>3</sup> Previous bio-medical diagnostic tests for seizures as reported in the consultation:

- MRI: Magnetic Resonance Imaging. Produces detailed images of the brain using magnetic fields and radio waves
- CT: Computed Tomography. Produces x-ray images of the brain (less detailed than MRI)
- ECG: Electrocardiography. Measures the electrical activity produced by the heart
- EEG: Electroencephalography. Measures the electrical activity produced by the brain
- Video-EEG: Video-Electroencephalography monitoring. Brain- and heart-activities simultaneously monitored, seizures are video-recorded (usually done over 48 to 72 hours).

<sup>4</sup> She had experienced (other) neurological symptoms for 20 years.

Phases	Main activities
1. History taking	The doctor asked the patient/companion to describe her symptoms, from onset, and her clinical and social history,
2. Naming	The doctor presented and explained the diagnosis,
3. Explaining test-results	The doctor presented and explained bio-technological test-results,
4. Explaining the cause	The doctor explained what he thinks might have caused the seizures,
5. Recommending treatment	The doctor suggested possible treatments and the reasons for these.

Table 3: Main phases in consultations [13]

Our analytical approach was inspired by critical discourse analysis (CDA), but framed within a social constructionist perspective on medical knowledge of diseases and clinical practice (WRIGHT & TREACHER, 1982). We used this combination of theoretical inspiration without altering the core ideas in discourse analysis, namely that it is "concerned with language-in-use; that is, how individuals accomplish personal, social, and political projects through language" (STARKS & TRINIDAD, 2007, p.1374). We also explored the cultural assumptions and presuppositions that underlie what doctors, patients and companions said, and did not say. [14]

Both authors participated in reading, selecting and analyzing the data, first individually and then together. During the analysis, we looked for *what* is said (what messages did the texts convey?), and *how* it is said (what kind of rhetorical techniques did they use to convey them?). Rhetorical devices are important because they aid as well as shape the reader's interpretation. Emphasizing the role of discourse and communication do not imply leaving our cultural perspective: discourses are embedded in, positioned within, and inseparable from a social context, and therefore historically and culturally contingent. In BAKHTIN's words: any utterance is a social phenomenon in its "entire range and in each and every of its factors, from the sound image to the furthest reaches of abstract meaning" (1981 [1975], p.259). Framing a critical discourse analysis within a socio-cultural understanding of health, illness, disease, diagnosis and medical knowledge enabled us to destabilize the discrete borders of a discursive site or situation (socio-cultural dimensions do not reside in fixed sites), and situate the actors we study in a broader context of interaction (EDBAUER, 2005). [15]

## 2.4 Ethics

The regional NHS Research Ethics Committee (kept anonymous for reasons of confidentiality) gave ethical approval for this study. The Teaching Hospitals NHS Trust (where the research took place) also granted research governance approval for the study<sup>5</sup>. Eligible patients were informed about the study and invited to take part (by the first author), and all patients (and where applicable companions) gave informed consent prior to the consultations. [16]

## 3. Findings

We structure the presentation of our results in relation to three main themes that were derived from the data: 1. explaining the diagnosis, 2. explaining the cause, and 3. explaining the treatment options. In the first theme, we explore how doctors deliver the diagnosis of PNES; the names and labels they use to describe the condition, and their presentation of technological test-results. In the second theme, we investigate the psychological and physical reasons doctors give to patients to explain what might have caused their seizures, and how the body comes to be viewed within these descriptions. In the third theme, we examine the treatment options recommended to patients, and doctors' explanations about how the treatment (psychotherapy) works. For all themes, we describe how patients (and accompanying persons, if present) typically respond to doctors' explanations. [17]

### 3.1 Diagnosis

In the first phase of the consultations, the doctors received information from patients and accompanying persons (if present) about the patient's clinical and social history, current family- and job-situation, and descriptions of their seizures. The doctors then started on two closely entwined tasks: delivering the diagnosis, and presenting technological test-results. [18]

During the naming process, the doctors typically used the terms "attack" (293 times) and "blackout" (31 times). In all consultations, the doctors named the condition "non-epileptic attacks":

"I think um it's almost certain that these are non-epileptic attacks" (to Lilly).

"... gives me an idea what it is likely to be and that, that is a non-epileptic attack" (to Helen).

"... non-epileptic attacks is quite a common word for the whole thing" (to Margaret). [19]

By using epistemic markers such as "think" and "idea," they introduced a certain degree of uncertainty. The naming sequence was often followed by explanations of the difference between epileptic seizures (sometimes using the words "seizure"

---

5 All medical research involving people in the UK, whether in the National Health System (NHS) or the private sector, has to be approved by an independent (regional) NHS Research Ethics Committee. Research governance approval is also required at a local level, from the (NHS) setting where the research is to be conducted.

and "epilepsy" synonymously) and "non-epileptic attacks": "often people um get mixed up between these attacks and, and epilepsy" (to Margaret). [20]

The doctors seemed to think it important to get the patients to "approve" the diagnosis, which they sometimes did—directly or indirectly—usually by using minimal acknowledgement tokens (e.g. "mmh"), or (in one case) replying confirmative:

Doctor: "um ((2 seconds)) I, I think you need to be convinced of the diagnosis ..."

Sheila: "Yeah, definitely." [21]

However, she later withdrew her agreement (using the term "seizure" as synonymous with epilepsy):

"I've had doctors that say they are definitely seizures without ((1 second)) hesitation ... And I don't want to harp on, I know my friend's not a specialist, but she's a nurse ... Who saw it when I, when I had that really bad one on the Friday, and she says she's seen non-epileptic and etel, epileptic ... And she said "what I saw was epileptic" (Sheila). [22]

While delivering the diagnosis, the doctors described how various bio-technological test results eliminated other possible diagnoses, and explained why the condition was not epileptic, not faints (syncope) and not heart related:

"Um, so you, you know, these, these tests mainly tell us what it is not, it's not heart related, it is not epilepsy ..." (to Helen). [23]

Test results from ECG and EEG were the prime focus of doctors' deductive bio-medical explanations:

"In some ways it looked like epilepsy, you lost consciousness, um but it wasn't because there was no abnormal electrical activity, so that's why, where the name non-epileptic comes from" (to Elizabeth).

"You had a seizure in the EEG test, which was a non-epileptic attack ... That wasn't associated with any changes in the EEG, um so that makes it impossible that that particular attack was an epileptic seizure" (to Agata). [24]

The doctors tended to present bio-medical tests as objective facts, in a language that depicted interpretation of the tests results as infallible and beyond doubt. The omission of agents, or more precisely, treating technology as the agent ("these tests mainly tell us," as to Helen quoted above), promoted this pictured objectivity; doctors' presented what was done and what it meant, rather than who performed or interpreted the test. [25]

The doctors sometimes referred to symptom descriptions made by patients and companions, respectively, when they gave the diagnosis:

"... and, and of course I've listened to what you've described as well" (to Margaret).  
"Um ((3 seconds)) the description that you gave of the attacks does very much sound like the typical er description of, of, of non-epileptic attacks, and not like fainting and not like um e, epilepsy" (to Helen). [26]

Beyond minimal agreement and acknowledgment tokens ("mm," "yeah," etc.), patients and companions rarely responded to doctors' initial presentations of test results. A rare example is shown below. Agata tried to negotiate with the doctor by referring to test results presented by a previously visited doctor:

Agata: "But what about the, er abnormality he said that there was on the, on the left-hand side of me brain?"

Doctor: "... But the EEG tests you've had subsequently have not shown any kind of abnormalities at all, any electrical abnormalities or any kind of asymmetries or anything, yeah?"

Husband: "That surprises me." [27]

### 3.2 Explaining the cause

After delivering the diagnosis, doctors usually explained to the patient what might have caused their seizures. Patients (and where applicable, companions) rarely asked for this information, but the doctors presented it anyway. The doctors did not describe the etiology of PNES as unknown, contested or uncertain, but sometimes they sent signals that the explanations are not easy and straightforward:

"Mm. Um, well ((1 second)) it, I think the, the, the cause of non-epileptic attacks are complicated ..." (to Helen).

"... so that's one way in which non-epileptic attacks might happen" (to Elizabeth). [28]

Occasionally, they also suggested that given enough time, they (referred to as "I" or "me") could uncover the reasons:

"Um, I'm, I'm not going to be able to, to tell you in, in a minute um, you know, or two what has caused your particular non-epileptic attacks" (to Elizabeth).

"... it is difficult for me in um, you know, in a, in a sing, single consultation like this to um, to put my finger on why um you have them" (to Helen). [29]

#### 3.2.1 Psychological explanations

The most common etiological explanation was that the seizures are a bodily, physical reaction to previous traumatic life experiences. Sometimes the doctor related these explanations to information disclosed by the patient earlier on in their consultation:

"Well obviously the first attack happened at a time when you were particularly um upset ..." (to Margaret). [30]

Other times, they presented this theory in a less personal way:

"... people that, you know, they first have attacks like this at times when there, you know, when there's extreme stuff going on" (to Margaret).

"Quite often is um they initially start in the context of somebody being really quite upset and, you know, there's quite a lot of stuff going on in their lives" (to Agata).

"Um ((1 second)) you know, we, we know from a number of, of different um types of research that, that when people have had those er bad experiences for many years" (to Agata).

"... I can only really tell you why other people get them" (to Mary). [31]

As shown in these quotes, doctors assumed casual relations between the illness and previous "bad experiences" in life, sometimes substantiated by referring to previous research. During these explanations, they usually used second-person pronouns (e.g., plural "you," third-person "they," and indefinite "somebody"), or collective nouns (e.g., "people"). They defined people's coping mechanisms (maladaptive ones) as the main cause (e.g. not the traumatic incidence in itself), which they also presented in generic terms: people *generally* develop seizures because of their inability to cope with stress, particularly stress caused by suppressed emotions related to previous traumatic events:

"So sometimes these attacks, non-epileptic attacks, happen because people have learned in their lives to, to suppress their own emotions, or suppress messages from their body about how they're feeling" (to Elizabeth).

"... they then save stuff, they don't, you know, um ((1 second)) and put memories away" (to Agata). [32]

At a later stage, doctors often switch from "people" to the individual:

"... you might have trained yourself to cut all that out so you don't realize it ... you've trained yourself not to notice it" (to Agata).

"So, so that, so in order, usually to, to be able to cope with stress in their lives ... You know, there's lots of stuff going on, you know ((1 second)) you're meant to do twenty different things at once ... And you want to get on um and you can't afford to, to think about yourself so you don't, so you don't, so you don't and then it's too much and your brain shuts down, yeah?" (to Elizabeth) [33]

Suppressed feelings related to traumatic experiences, the doctors explained, can result in a state of alertness:

"... so at all times they're at a sort of slightly increased state of, of um, of alertness ... Like when you're a fire, fireman ... And you're, and you're on call, you know, you're

not, not quite as relaxed ... As you, as you, you know, as you would be when, when you're, when you're, when you might be called" (to Agata). [34]

By using the fireman analogy, the doctor equated the PNES-patient with a person who is highly alert, e.g. prepared to act immediately in the event of a situation of emergency. Doctors connected this alertness to people's assumed individual personality:

"... but um if somebody who um, who is feeling insecure or has a, a tendency perhaps to, to become anxious when, when they lose control ..." (to Helen).

"... um with people who have got low self-esteem ... somebody who's not very good at noticing their own emotions" (to Elizabeth).

"So people ... find it difficult to, to chill out and relax so they're always slightly on edge" (to Agata).

"... you don't feel you're in control of the situation or can't change it" (to Lilly). [35]

Patients and companions sometimes responded to this information, which they might have perceived as accusations (of being insecure, anxious, in need of control, and "always slightly on edge"), by defending themselves. Some also tried to convince the doctor that they are not malingerers, and that their symptoms are "real":

Lilly: "(Laughs) No, I mean um ((0.5 seconds)) like how can ((0.5 seconds)) that do it to like the physical thing, is it me doing it to myself or is it, is there a, do I, can, can I control it, is there anything I can?"

Doctor: "... I think what you're trying to ask is ((1 second)) are you doing, is this some sort of um."

Lilly: "I don't know."

Doctor: "Malingering or something, and it certainly is not ..."

Lilly: "I just had to make sure I, it's not me doing it to myself because it's, um."

Doctor: "No, it is not something you're deliberately doing to yourself. It is something your brain is doing to you in order to try and um ((0.5 seconds)) cope with whatever it is." [36]

Mary is even more direct in her reply:

Mary: "But I'm not making 'em up." [37]

Usually, patients interpreted these explanations as psychological, something the doctors tried to deny—in various ways:

Husband: "(2 seconds) Is most non-epileptic attacks psychology, um psychological?"

Doctor: "Well um ((3 seconds)) what is psychological? You see, you know." [38]

The most intense debates usually occurred when the companion (husband) did the negotiation, as in Helen's consultation:

Doctor: "Um, you know, if you twist your ankle playing football ... you're about to get the, the Cup, chances are you won't feel much pain, you'll get up and you run the last five minutes and get that Cup, yeah? Whereas if your team is losing, chances are you'll be much more aware of the pain."

Husband: "So, so."

Doctor: "I'm not saying that, you know."

Husband: "So, so, so, so, so what are you saying, she's, she's mentally ill then?"

Doctor: "((1 second)) No, I'm saying non-epileptic attacks are um."

Husband: "Oh it, it's the way you're putting it across, it's, it's the way you're saying it ..."

Doctor: "... Yeah, can I just, can I just try to ex, that, that's, you're not wrong, er but um, I just want to clarify what I, what I mean. Um, you know, I'm, I'm a bit worried that, that um you're going to think that um ((0.5 seconds)) I'm thinking this is mental, you know, rather than physical. I just want to make sure that you understand that I don't think, think that there's a difference between those two." [39]

The husband's quest for clarity by straightforwardly asking: "so what are you saying, she's, she's mentally ill then?" is emblematic of the ways in which most patients and companions interpret the etiological explanations. The doctor seemed prepared for this question even before it was asked: when the husband first said "so, so" the doctor immediately understood what he was about to say, and he was quick to interrupt him: "I'm not saying that." Some confusion then ensued; the husband was not satisfied with the doctor's response ("Oh it, it's the way you're putting it across ..."). From the doctor's perspective, although the companion was "not wrong," neither was he right. The doctor went on to describe that he did not understand the seizures in dualistic (physical and mental) terms. However, as we will see later, the companion was not convinced by this explanation. This may be due to the doctor's double message: although he attempted to paint a picture of psyche and soma as one in the same, his football-analogy implies "mind over matter." [40]

### 3.2.2 *Physical explanations*

Sometimes, the doctors explained that the triggering factor also could be of a physical kind (mainly pain symptoms, and in relation to first seizures, faints). Usually, they did so *before or alongside* introducing psychological explanations (e.g. trauma, abuse, etc.):

"... the triggers could be physical symptoms, you know ..." (to Margaret).

"Quite often it seems that the, the first thing that happens is a faint ..." (to Helen).

"Now, um, most non-epileptic attacks, um, are related to how er, er people are dealing with, um ((0.5 seconds)) problems. For instance, um, physical problems, like pain, but also emotional problems, like ... Difficult situations or, or, you know, thoughts or emotions" (to Christine). [41]

### 3.2.3 *View of the body*

The doctors described the cause of the illness as localized to the brain:

"... we think of them as um attacks um which are related to the brain dealing with difficult er symptoms, situations, um ((1 second)) or, or even thoughts or memories ... things build up to a point where your brain switches off" (to Elizabeth).

"... that might be enough for the brain to, to, to shut down, yeah? ... it's threatened and it shuts down ... because it's overwhelmed" (to Agata).

"... the brain switches off very quickly when (0,5 seconds) you know, when the situation is, is difficult, or threatening" (to Christine). [42]

The doctors explained causal factors by referring to the brain, and how it functions, in all our consultations. Typical phrases used were "switching off" and "shutting down." They described this mechanism as an "automatic reflex" (e.g. not intended and deliberate), and a result of the way "the body" or "the brain" deals with difficult and potentially threatening situations:

"... the brain uses this reflex to switch off when something distressing or threatening happens ... things that your brain could interpret as potentially threatening" (to Agata).

"... this process goes on subconsciously ... it's not something you're deliberately doing" (to Lilly).

"... your brain, that's the point of the reflex, it kicks in very, very quickly and before you're really aware, yeah?" (to Elizabeth). [43]

Doctors often reverted to analogies to explain what they meant, like learning to walk, tripping over, and—as in the following example—blinking:

"If a fly flies into your eye, your eyelid closes. You don't have to think gosh, there's a fly coming ... you know, it's ... automatic" (to Margaret). [44]

However, this was not presented as something they were born with:

"Um, I would um (2 seconds) interpret them as, as a sort of (1 second) er reflex that your, your brain has, has learned" (to Margaret).

"... in this case it may have learned something that isn't helpful" (to Agata) [45]

They present this process as a powerful "self-reinforcing" vicious circle, triggered by—and a "manifestation" of—emotional stress:

"... the vicious circle ... is quite a powerful process ..." (to Margaret). [46]

In these explanations, the brain played a key role:

"You have a degree of anxiety and it, it causes blocks, you know, it, it occupies some of the, of the computing power of the brain" (to Christine).

"... your brain constantly monitors stuff" (to Agata).

"... your brain can make connections very quickly ..." (to Margaret). [47]

In these statements, the doctors portrayed the brain partly as a complex blend of an intentional agent that can "interpret" and "learn," and partly as a computer, an electric machine, or a surveillance controller that monitors and makes connections between different elements. They also presented the brain as a locus of the psyche, and they explained how psychological strain can cause physical changes in the brain:

"... we only have one brain and it functions physically, yes?" (to Helen)

"... your brain has changed in some way, there's a physical change in the brain" (to Elizabeth).

"... your body is dealing with it, cos it feels it can't deal with it, it converts it into physical symptoms" (to Lilly). [48]

### 3.3 Suggesting treatment

Etiological explanations always led on to treatment advice, which usually was that although tablets (e.g. anti-depressants) are sometimes appropriate, psychotherapy is the best treatment option:

"... tablets are not really going to get rid of something you've learnt. You know, you can imagine tablets might work in this condition but, you know, you, you would be using a sledge hammer ... For a nut ..." (to Elizabeth). [49]

The doctors explained that, through the psychotherapy, the main aim would be to explore reasons why the attacks started, and help the patient to develop ways to manage or suppress seizures (that have been "learned" and can be "unlearned"), such as recognizing warning signs and triggers:

"Um, the best treatment for, for non-epileptic attacks would be to, to learn more about what put you at risk of them, to learn about the situations in which they occur, and whether there's anything that you can learn to snap yourself out of these attacks" (to Christine).

"And, and the best treatment is um, um various forms of psychological treatment which aim at, you know, retraining your brain to do things differently" (to Margaret). [50]

When describing how the treatment works, the doctors—again—turned to analogies:

"To learn Judo or, or parachuting ... that [rolling] bit may become the reflex ... When you're falling ... you've retrained your brain with something else ... Um, so I think these are processes of learning and unlearning" (to Elizabeth). [51]

Many of the negotiations between the parties tended to take place after doctors recommended psychotherapy treatment, during which psyche-soma discussions were rekindled. After long discussions about treatment options in Helen's consultation (mainly between her husband and the doctor), they returned to the psyche-soma discussion:

Doctor: "Um ((3 seconds)) so with the ((1 second)) therapist, sounds like you're ambivalent. I don't know whether I've managed to persuade you, um?"

Husband: "((2 seconds)) It sounds like, it sounds like to me you, you're saying she's, she's, she's got some psychological problem here."

Doctor: "((3 seconds)) Yes, but I've, I hope I've explained to you what I, my understanding is of psychological, yeah?"

Husband: "Yeah, I, yeah."

Doctor: "And I don't think of psychological as made up or as somehow um ((0.5 seconds)) as, as really different from, from physical ((laughs)) you know ((0.5 seconds)) it, you know, it all happens in the brain, yeah? ((1 second)) It's not worth less because it's psychological, yeah?"

Husband: "So what you say is, right, she hasn't got a mental illness then, no?"

Doctor: "Well I don't think this is a mental illness, no. See if you faint, yeah, if you faint, your blood pressure drops, your heart, yeah."

Husband: "I, you, you don't, you don't have to, you don't have to go through it all again, I, I, I, I, I, I clearly understand."

Doctor: "Yeah."

Husband: "What, what, what you've said, but I, I, I just want to clarify, you know, are you, you know, I'm trying to figure it out whatever you're saying, is it a mental illness?" [52]

Here, the object of the doctor's explanations (convincing the patient to take up psychotherapy treatment) is shown to have been relatively pending ("I don't know whether I've managed to persuade you ...?"). Despite the question being intended for the patient, her husband responded, questioning whether Helen has a "psychological problem." The doctor agreed ("Yes"), "but" did "hope" he had explained what he meant by "psychological" (not "really different from" "physical" because "it all happens in the brain"). Despite no prior mention by the patient or companion, the doctor appeared to pre-empt interpretations that the condition is feigned, "I don't think of psychological as made up," and addressed the status of the condition, "It's not worth less because it's psychological." However, despite listening to the doctor's explanation and initially confirming he understood ("Yeah, I, yeah"), the husband yet again questioned whether Helen has a "mental illness";

he required a definitive answer. The negotiation ended without clarification and mutual understanding. [53]

#### **4. Discussion: Naming and Explaining the Seizures**

In all the eight consultations, all parties involved struggled hard to achieve something that is of vital importance in any doctor-patient relationship: partnership, congruence in doctor-patient beliefs and shared decision-making (KRUPAT, BELL, KRAVITZ, THOM & AZARI 2001; OMMEN, THUEM, PFAFF & JANSSEN, 2011). Something seemed to obstruct their sincere attempts to reach these goals. Before we explore these obstructions further, we synthesize and discuss some of the main findings. [54]

##### **4.1 Doctors argumentation**

When naming the condition and its symptoms, doctors avoided: 1. the term "seizure," which is often perceived as synonymous with epilepsy, and 2. terms more likely to be rejected by patients because they might connote feigning, malingering (e.g., "pseudo") or psychological causes. Instead, they used neutral, non-medical terms and euphemisms such as "attack" and "blackout," which are likely to be perceived as more acceptable to patients. The use of neutral labels, that do not designate the seizures as either organic or psychological, allowed the doctors to navigate between psyche and soma in their explanations. The doctors seemed to seek patients' approval of the diagnosis, perhaps in order to make them comply with the treatment recommendations. By using words such as "convince" and "persuade," the doctors made these purposes explicit. [55]

The doctors presented biomedical tests-results as objective evidence through a language that conveyed a high, if not absolute, degree of certainty. They did *not* say that technologically generated findings are not always available or reliable, or do not necessarily distinguish between the two conditions (e.g., a normal EEG-result does not exclude epilepsy, as around 10% of patients with epilepsy never show epileptiform discharges) (SHORVON, 2009). They also avoided explaining who interpreted the tests, and the uncertainty inherent in this interpretation. Formulations such as "that test tells us" support a view of knowledge in which "instruments rather than people create the data," and they "give an air of infallibility to the quite fallible observations of doctor and laboratory" (FLEISCHMAN, 2001, p.478). When the doctors referred to history-taking from patients and descriptions of seizures from witnesses, they marginalized these narratives and presented consideration of this "subjective data" as an "afterthought," with little (if any) explanation as to how it contributed to their diagnostic reasoning. Doctors may have used this strategy, which is not uncommon in medical encounters (FLEISCHMAN, 2001), in order to "sell" their arguments. [56]

Similarly, when the doctors described the possible causes of PNES, they did not acknowledge the limits of medical knowledge, or describe the etiology as unknown, contested or uncertain; but sometimes they introduced an element of

doubt by using words like "complicated." They also presented their etiological theories in generic terms, by referring to why people *generally* develop seizures; the individuality of the explanatory theory is not made explicit. This communicative strategy might make their explanations more acceptable to the patient (and companion) in front of them. However, their attempts to "socially manage" their psychosocial explanations does (do) not hide the fact that by defining people's abilities to cope with stress as the main causal factor, they locate the cause to the character of the individual. [57]

The mainstay of doctors psychosocial explanations centered on a lack of coping with strain in their lives, which again results in a constant state of heightened alertness. This is consistent with the theory of sustained arousal, saying that "functional" stress can be transformed to "harmful" stress by a person's inability to cope with it: "the arousal response is gradually turned off when successful ("coping"). If not, the arousal may be sustained" (WYLLER, ERIKSEN & MALTERUD, 2009, p.10). This and similar types of expositions are found in several current explanatory models for medically unexplained conditions (VAN RAVENZWAAIJ, OLDE HARTMAN, EVELEIGH, VAN RIJSWIJK & LUCASSEN, 2010). Perhaps to make their arguments more acceptable to patients, doctors tempered these explanations by adding physical factors such as faints, head injuries and pain as possible precipitating and perpetuating factors. [58]

Within these explanations, doctors localized the reactions involved to the brain, and they emphasized that they did not think there to be a difference between psyche (mind, psychological) and soma (body, physical), which is in accordance with general recommendations (MACKIE & FRANK, 2003). Contrary to what they say, however, they do seem to assume a Cartesian dualism where the immaterial mind and the material body are conceptually separated into two contrasted aspects. Their explanations are in line with a current general trend: The brain has become increasingly emphasized in medical approaches to the mind-body problem: "the connection between the mind and body is the brain. The brain is the organ of the mind ... body events are brain events are mind events" (GISLASON, 2011, pp.61-62). The doctors stressed that the brain is both a physical organ and the locus of the psyche: psychological triggers cause physical reactions in the brain. However, whether this "resolves" the "mind-body problem" or simply transforms a Cartesian psyche-soma dualism to a tripartite interpretation consisting of mind, body and brain, remains to be seen. [59]

"Switching off," "automatic" and "reflex" were the most common words used when doctors described the mechanisms involved. They presented the brain as an organ that works automatically, and described that once it is switched on it is self-reinforcing. By using the machine metaphor, meaning is transferred (through the implicit comparison) from the machine to the body. This metaphor works to highlight the physical, mechanical and automatic processes in the body, usually the brain. By so doing, they portrayed the cause of the patient's condition as not a conscious action, but a reaction triggered by mechanisms outside the person's deliberate control. [60]

Throughout the consultations, doctors used a number of figurative devices (such as metaphors, similes and analogies) to substantiate and elaborate their arguments; e.g., a fireman on duty to describe a "heightened state of alert." These arguments achieve their effects via implicit comparisons that can give patients a familiar framework to understand abstract concepts and comprehend new information (HAYES, 2000), and thereby provide "illuminating insights" to the patient (ROSE, 2003, p.111). Didactic metaphors (explaining new concepts using familiar concepts) have been described as "coin of the realm" in doctor-patient communication (CARTER, 1989; FLEISCHMAN, 2001); especially when underlying conceptual systems are described (VAN RIJN-VAN TONGEREN, 1997). However, figurative expressions are persuasive instruments that emphasize some aspects of an argument and hide others (LAKOFF & JOHNSON, 1980), and they can be misleading and subversive (ROSE, 2003). The metaphors used by the doctors in our data seemed to create some confusion, perhaps because the patients perceived them as inconsistent with the doctors' main messages: they build on an underlying assumption of a psyche-soma dualism that the doctors explicitly deny. [61]

In all the consultations, the doctors came to recommend psychiatric treatment that could help patients to explore the reasons why their seizures started, recognize warning signs and triggers, and learn techniques to suppress them. At this point in the consultations, the veil was removed from previous blurred messages from the doctors, and it was no longer possible for them to hide their psychological understanding of the patients' ailments. [62]

#### **4.2 Patient and companion argumentation**

Most patients tended to stay quiet or offer minimal agreement or acknowledgment tokens when the doctors' presented test-results and delivered the diagnosis. This could be because technologically generated findings (as opposed to "subjective" experiential data from patients) are presented as objective data, and therefore less open to challenge and negotiation. However, when the doctors suggested links between their physical symptoms and previous traumatic events in their lives, and therefore needed psychiatric treatment, they occasionally asked questions and made discreet attempts to contest doctors' statements. None of the patients' utterances supported these views, but they did not always actively resist them either. A previous study reported that patient resistance is more common (MONZONI et al., 2011b), but this discrepancy might be due to different interpretation of resistance (we do not interpret lack of confirmation as resistance). Those patients that challenged doctors' presentations did so by tactfully using third party accounts, and reporting what they had been told by other health professionals. By expressing the opinions of others, they distanced themselves from directly contesting the diagnosis. [63]

Patients might contest doctors' explanations because they seek legitimacy for their symptom and their sick-role (ARONOWITZ, 1998). Medically validated disease is one of few socially accepted forms of deviance in our culture, but a diagnosis can also enforce stigma and blame. Psychological conditions are

problematic, both personally and socially (KIRMAYER, 2000), because in our culture, the metaphysic is often perceived as less "real" than the physical. Patients may reject psychiatric diagnoses and treatment because of the potential stigma they entail (KIRMAYER, GROLEAU, LOOPER & DOMINICÉ DAO, 2004; LIAN & NETTLETON, 2015; SALMON et al., 2007). [64]

In many cases, the companion did most of the talking, and acted as advocate for the patient. Except for one case (a mother and a daughter), the companion was a male spouse accompanying his wife. In their efforts to support their wives, these men often asked questions and presented arguments that challenged, contradicted or rejected doctors' stated views. Patients attending alone sometimes undertook this role themselves, but never as openly as the husbands did. Comparatively less negotiation and debate (and resistance to doctors arguments) was observed in the three consultations in which patients attended alone, despite two of these patients having an historic diagnosis of epilepsy and still taking AEDs at that time. This finding is in line with previous research from other clinical settings, where the talk of companions has been shown to be more "active" than that of patients in asking questions, expressing concerns, and stating an opinion (EGGLY et al., 2011; STREET & GORDON, 2008). Likewise, patients have been observed to be significantly less expressive and assertive in accompanied interactions (GREENE, MAJEROVITZ, ADELMAN & RIZZO, 1994). [65]

It might be the case that accompanying persons are better placed than patients to negotiate and challenge what doctors say: as they are distanced from the medical problem and the stigma and "blame" associated with it, their arguments might be perceived as more neutral (and perhaps more objective). Moreover, through the active role of an accompanying "advocate," the person with the seizures avoids being labeled a "difficult patient." [66]

### **4.3 Strengths and weaknesses**

Our data is comprised of a relatively small homogenous sample of patients, and where applicable, their companions. Their responses to doctors' explanations may be different from patients who have experienced seizures for less time, those that have not previously received a label for their condition, and male patients. In addition, just two consultant neurologists from the same clinic, who both specialize in seizure disorders, were involved in the study. Explanations of PNES given by other or less experienced clinicians might be different from those presented here. For example, interview and survey based research has shown that substantial proportions of health practitioners in other clinical settings consider the seizures "voluntary" or "faked" (SAHAYAA, DHOLAKIAB, LARDIZABALB & SAHOTAB, 2012; SHNEKER & ELLIOTT, 2008). [67]

Despite these potential limitations, our study has considerable strengths. The foremost of these is our exploration of actual interactions in naturally occurring medical encounters through methods inspired by critical discourse analysis. Although the presence of the camera might have affected the participants, researcher influence is probably less than with alternative methods. In addition,

the role of accompanying persons in these encounters became a focus of our analysis. The contributions of companions has received marginal attention in other studies involving patients with medically unexplained conditions, and has not previously been explored in any great depth in this patient group. [68]

## 5. Conclusion: Why Do Conversations Break Down?

Conversations tended to break down at key points in the consultations, most noticeably when the causes of patients' seizures were discussed (in relation to psyche and soma), and when treatment (psychotherapy) was recommended. The conversations appear to fall apart for at least three interrelated reasons: [69]

### 5.1 Body-mind dualism

Negotiation between the parties (particularly companions and doctors) tended to develop when the doctor related the patient's seizures to their inability to cope with difficult life experiences, and recommended psychiatric treatment. The patient-party often found it difficult to believe that the patient's physical symptoms had emotional causes, and asked the doctor to clarify whether the condition is "psychological" and a "mental illness." This sometimes resulted in intense debate. The doctor typically responded by stating that the seizures are not a "mental illness," and reiterated that he did not separate "psychological" from "physical." Patient-parties, however, often appeared unconvinced. This could be because being in a constant state of alertness—the "bottom line" in the etiological explanation—for them means being in a *certain state of mind* that they do not recognize. Regardless of doctors' explanations, the treatment and—by implication—the problem had (finally) been rendered psychological. [70]

The confusion observed between the parties seems to be rooted in somewhat contradictory messages from the doctors: they explicitly described psyche and soma as one in the same, but their argumentation was not always in line with this view. For instance, when they said that the brain "functions physically," "there's a physical change in the brain," and "the brain scan didn't show anything" (presumably physical), they implicitly juxtapose the physical and the metaphysical. An underlying but unspoken presumption is therefore a Cartesian mind-body dualism. Patients grasp and adhere to these implicit assumptions, and they contest—as most other patients with physical ailments do—any attempt to explain their illness psychologically. This is in line with previous survey based research: PNES-patients typically conceptualize their seizures as physical and not associated with psychosocial "stressors" (STONE, BINZER & SHARPE, 2004). [71]

The body-mind dualism is deeply embedded in our culture, with the mind element as the least "real" and the most stigmatized of the two. Indeed, the dichotomy is so socially pervasive that authors have noted the possibility that these are an irreconcilable set of concepts (WRIGHT & POTTER, 2000). Moreover, irrespective of moves towards theoretical integration of psyche and soma, illness is overwhelmingly divided into the organic and the non-organic, and treated

accordingly. From medical training to health care services, there are huge divides between somatic and mental health. In this context, it inevitably becomes difficult to talk of psyche and soma in an integrated way, for both patients and doctors. [72]

### **5.2 Blaming the victim**

Doctors (indirectly) described the individual patient in front of them as predisposed, by virtue of their personality ("anxious," "low self-esteem," "on-edge," and "stressed") and maladaptive coping behaviors (suppression of emotions related to previous life events), to developing PNES. By doing so, they implicitly locate the cause within the individual. Despite describing the processes involved as an automatic reflex, these were presented not as something the patients were born with, but as something that their brain has "learned" to do. Irrespective of doctors' intentions and strategies, the patient emerges as the one who is to be blamed for her ailment, and the one who is responsible for sorting it out. [73]

The psychological understanding of PNES presented by the doctors in this study can be interpreted as an expression of one of the main hallmarks of modernity in Western societies and modern medicine: the individualistic "triumph of the will" (BROWN & BAKER, 2012, p.32). This ideology constitutes the core of a neoliberal medical system, in which personal choice, followed by responsibility and accountability, are emphasized (MOULDING, 2007; PORTER, 2006). Psychological explanation of medically invisible and unexplained conditions is only one way in which this ideology is expressed: "The ideological privilege granted to the individual means that where illness cannot be located within the space of the anatomy, the most readily available discursive space is the individual's mind" (NETTLETON, O'MALLEY, WATT & DUFFEY, 2004, p.62). The PNES case is similar to how other conditions are presented to the lay public in a neoliberal way: individuals are blamed for their health problems, and induced to self-care management by pulling themselves together and taking responsibility for their own health. Within this ideology, the patient "emerges as both victim and responsible agent" (SONTAG, 1978, p.57). [74]

### **5.3 Explanation and objectification**

A key element of the modern biomedical cosmology is the imperative to explain everything, scientifically. Current explanatory models for medically unexplained conditions are primarily hypothetical; in so much as there is "little or no biological justification for the belief in 'psychogenic' causation" (GISLASON, 2011, p.63). The theories are based on a myriad of (non-causal) findings and hypotheses, often described in relation to predisposing, precipitating, and perpetuating factors. Within these models, a complex interplay between the psyche and soma is described. [75]

In our data, doctors present the brain both as a bodily organ and the locus of the psyche. However, this does not necessarily mask the absence of a holistic understanding of the patients' ailment. Despite a gradual disentanglement of how

brain functions relate to mental functions, how these concepts relate to other biophysiological processes in the body, and how all the above are embedded in environmental, emotional and behavioral events or expressions, there is yet no coherent picture as to how these come to cause physical symptoms. Still, doctors choose to present these explanations to patients, who easily unveil their inconsistencies and contradictions. This is almost bound to create tension and resistance. [76]

However, there is an alternative route. If we set aside all questions about the "real" existence of an illness, as well as all questions about causal explanations (when we do not have this knowledge), what would we lose? Although modernity has equipped us with a strong belief in scientific knowledge, we would not—as patients or otherwise—necessarily react negatively to honest information that we do not have the necessary medical knowledge to explain and cure our ailments. [77]

The medical constructions given to the patients in this study, which in this case is not scientific knowledge but a theory, represent an outsider's perspective. For the patient, illness is something she experiences and understands from within. Although the women were all allowed to express their perceptions, meanings, interpretations and sense of the world, this information was not taken as "face value," it was transformed to fit into the doctors' theories. Most noticeably, the doctors took information about previous difficulties in the patient's lives and placed it into a pre-determined psychological theory of stress management, as previously reported from Margaret's consultation: "Well obviously the first attack happened at a time when you were particularly um upset." Not acknowledging the value of the experiential perspective, which is often noticed by those whose experiences are devaluated, is usually not a road that leads to successful communication (BEACH et al., 2013; KRUPAT et al., 2001). [78]

A more useful strategy could be to approach patients with medically unexplained conditions not as objects but as subjects that experience and interpret their condition, and—not the least—act accordingly. Rather than destroying the basic foundation for communication, this opens up for a dialogue in a partnership where patients feel safe enough share their own experiences with doctors. This information could be of vital importance for the medical encounter because it fosters basic values all in medical practice: congruence in doctor-patient relationships and shared decision-making. These values are fostered by accepting the limits of medical knowledge and technology, and letting the voice of the patient's be heard, understood and acknowledged. In order to do so, we need to rethink the hierarchical understanding of expert versus lay knowledge that modern biomedical cosmology is founded on, and define the gap between illness-as-experienced and the theoretical account of it is not simply a matter of different levels of knowledge, but something much more profound: it involves seeing different things from different perspectives. Acknowledging the cultural dimension of medical knowledge and practice is a vital part of this objective. [79]

## Acknowledgment

We would like to thank all patients, doctors and accompanying persons who agreed to participate in the study, the funders of the research and the anonymous referees for useful comments to the first draft of this article.

We disclosed receipt of the following financial support for the research, authorship, and or publication of this article: Epilepsy Action, United Kingdom (first author) and The Norwegian Research Council, Research Program of Health and Care Sciences, grant no. 212978/H10 (second author).

## References

- Aronowitz, Robert (1998). *Making sense of illness*. Cambridge: Cambridge University Press.
- Bailey, Julia (2008). First steps in qualitative data analysis: transcribing. *Family Practice*, 25(2), 127-131. <http://fampra.oxfordjournals.org/content/25/2/127.full.pdf+html> [Accessed: August 31, 2015].
- Bakhtin, Mikhail (1981 [1975]). *The dialogic imagination*. Austin: University of Texas Press.
- Banks, Jonathon & Prior, Lindsay (2001). Doing things with illness. The micro politics of the CFS clinic. *Social Science and Medicine*, 52(1), 11-23.
- Beach, Mary; Roter, Deborah; Korhuis, Todd; Epstein, Ronald; Sharp, Victoria; Ratanawongsa, Neda; Cohn, Jonathon; Eggly, Susan; Sankar, Andrea & Moore, Richard (2013). A multicenter study of physician mindfulness and health care quality. *The Annals of Family Medicine*, 11(5), 421-442.
- Benbadis, Selim & Allen, Hauser, W. (2000). An estimate of the prevalence of psychogenic non-epileptic seizures. *Seizure*, 9(4), 280-281.
- Brown, Brian & Baker, Sally (2012). *Responsible citizens: Individuals, health and policy under neoliberalism*. London: Anthem Press.
- Carter, Albert (1989). Metaphors in the physician-patient relationship. *Soundings: An Interdisciplinary Journal*, 72(1), 153-164.
- Carton, Simone; Thompson, Pamela & Duncan, John (2003). Non-epileptic seizures: Patients' understanding and reaction to the diagnosis and impact on outcome. *Seizure*, 12(5), 287-294.
- Edbauer, Jenny (2005). Unframing models of public distribution: From rhetorical situation to rhetorical ecologies. *Rhetoric Society Quarterly*, 35(4), 5-24.
- Edwards, Todd; Stern, Anthony; Clarke, David; Ivbijaro, Gabriel & Kasney, Michelle (2010). The treatment of patients with medically unexplained symptoms in primary care: A review of the literature. *Mental Health Family Medicine*, 7(4), 209-221.
- Eggly, Susan; Harper, Felicity; Penner, Louis; Gleason, Marci; Foster, Tanina & Albrecht, Terrance (2011). Variation in question asking during cancer clinical interactions: A potential source of disparities in access to information. *Patient Education and Counseling*, 82(1), 63-68.
- Evans, Randolph & Evans, Rochelle (2010). A survey of neurologists on the likeability of headaches and other neurological disorders. *Headache*, 50(7), 1126-1129.
- Fleischman, Suzanne (2001) Language and medicine. In Deborah Schiffrin, Deborah Tannen & Heidi Hamilton (Eds.), *The handbook of discourse analysis* (pp.470-502). London: Blackwell.
- Gislason, Stephen (2011). *Human brain in health and disease*. Sechelt: Persona.
- Green, Andrew; Payne, Sheila & Barnitt, Rosemary (2004). Illness representations among people with nonepileptic seizures attending a neuropsychiatry clinic: A qualitative study based on the selfregulation model. *Seizure*, 13(5), 331-339.
- Greene, Michelle; Majerovitz, Deborah; Adelman, Ronland & Rizzo, Connie (1994). The effects of the presence of a third person on the physician-older patient medical interview. *Journal of the American Geriatric Society*, 42(4), 413-419.

- Harrison, Barbara (2002). Seeing health and illness worlds—using visual methodologies in a sociology of health and illness: A methodological review. *Sociology of Health & Illness*, 24(6), 856-872.
- Hayes, Patricia (2000). Analogy: Clarification or obfuscation?. *Clinical Nursing Research*, 9(1), 3-5.
- Jewson, Nick (2009). The disappearance of the sick-man from medical cosmology, 1770-1870. *International Journal of Epidemiology*, 38(1), 622-633, <http://ije.oxfordjournals.org/content/38/3/622.full> [Accessed: August 31, 2015].
- Kipen, Howard & Fiedler, Nancy (2002). Environmental factors in medically unexplained symptoms and related syndromes: The evidence and the challenge. *Environmental Health Perspectives*, 110(4), 597-599.
- Kirmayer, Laurence (2000). Broken narratives: Clinical encounters and the poetics of illness experience. In Cheryl Mattingly & Linda Garro (Eds.), *Narrative and the cultural construction of illness and healing* (pp.153-180). Berkeley: University of California Press.
- Kirmayer, Laurence; Groleau, Danielle; Looper, Karl & Dominicé Dao, Melissa (2004). Explaining medically unexplained symptoms. *Canadian Journal of Psychiatry*, 49(10), 663-672.
- Krupat, Edward; Bell, Robert; Kravitz, Richard; Thom, David & Azari, Rahman (2001). When physicians and patients think alike: Patient-centered beliefs and their impact on satisfaction and trust. *Journal of Family Practice*, 50(12), 1057-1062, <http://www.jfponline.com/home/article/when-physicians-and-patients-think-alike-patient-centered-beliefs-and-their-impact-on-satisfaction-and-trust/03837ec65a4f877648377f2bab378cb2.html> [Accessed: August 31, 2015].
- LaFrance Jr., Curt; Reuber, Markus & Goldstein, Laura (2013). Management of psychogenic nonepileptic seizures. *Epilepsia*, 54(1), 53-67.
- Lakoff, George & Johnson, Mark (1980). *Metaphors we live by*. Chicago, IL: The University of Chicago Press.
- Lesser, Ronald (2003). Treatment and outcome of psychogenic nonepileptic seizures. *Epilepsy Currents*, 3(6), 198-200.
- Lian, Olaug S. & Bondevik, Hilde (2015). Medical constructions of long-term exhaustion—past and present. *Sociology of Health & Illness*, 37(6), 920-935.
- Lian, Olaug S. & Nettleton, Sarah (2015). "United we stand": Framing myalgic encephalomyelitis in a virtual symbolic community. *Qualitative Health Research*, 25(10), 1383-1394.
- Mackie, Sarah & Frank, Andrew (2003). Medically unexplained symptoms. *Journal of the Royal Society for Medicine*, 96(8), 422.
- Mayor, Rebecca; Howlett, Stephanie; Grunewald, Richard & Reuber, Markus (2010). Long-term outcome of brief augmented psychodynamic interpersonal therapy for psychogenic nonepileptic seizures: Seizure control and healthcare utilization. *Epilepsia*, 51(7), 1169-1176.
- McKenzie, Paul; Oto, Meritxell; Russell, Aline; Pelosi, Anthony & Duncan, Roderick (2010). Early outcomes and predictors in 260 patients with psychogenic nonepileptic attacks. *Neurology*, 74(1), 64-69.
- Mellers, John (2005). The approach to patients with "non-epileptic seizures". *Postgrad Medical Journal*, 81(958), 498-504, <http://pmj.bmj.com/content/81/958/498.full> [Accessed: August 31, 2015].
- Monzoni, Chiara; Duncan, Roderick; Grunewald, Richard & Reuber, Markus (2011a). How do neurologists discuss functional symptoms with their patients? A conversation analytic study. *Journal of Psychosomatic research*, 71(6), 377-383.
- Monzoni, Chiara; Duncan, Roderick; Grunewald, Richard & Reuber, Markus (2011b). Are there interactional reasons why doctors may find it hard to tell patients that their physical symptoms may have emotional causes? A conversation analytic study in neurology outpatients. *Patient Education & Counseling*, 85(3), 189-200.
- Moulding, Nicole (2007). "Love your body, move your body, feed your body": Discourses of self-care and social marketing in a body image health promotion program. *Critical Public Health*, 17(1), 57-69.
- National Institute for Clinical Excellence (NICE). (2012) The epilepsies: The diagnosis and management of the epilepsies in adults and children in primary and secondary care: Clinical Guideline 137, <http://www.nice.org.uk/guidance/cg137> [Accessed: August 31, 2015].
- Nettleton, Sarah (2006). "I just want permission to be ill": Towards a sociology of medically unexplained symptoms. *Social Science & Medicine*, 62(5), 1167-1178.

- Nettleton, Sarah; O'Malley, Lisa; Watt, Ian & Duffey, Phillip (2004). Enigmatic illness: Narratives of patients who live with medically unexplained symptoms. *Social Theory & Health*, 2(1), 47-66.
- Nimnuan, Chaichana; Hotopf, Matthew & Wessely, Simon (2001). Medically unexplained symptoms: An epidemiological study in seven specialities. *Journal of Psychosomatic Research*, 51(1), 361-367.
- Olde Hartman, Tim (2011). Persistent medically unexplained symptoms in primary care. The patient, the doctor and the consultation. *Dissertation, Radboud University Nijmegen Medical Centre, Netherlands*, [http://www.movemens.nl/dynamic/media/1/documents/artikelen/%20movemens/2013-03/Proefschrift\\_Tim\\_olde\\_Hartman.pdf.pdf](http://www.movemens.nl/dynamic/media/1/documents/artikelen/%20movemens/2013-03/Proefschrift_Tim_olde_Hartman.pdf.pdf) [Accessed: September 2, 2015].
- Ommen, Oliver; Thuem, Sonja; Pfaff, Holger & Janssen, Christian (2011). The relationship between social support, shared decision-making and patient's trust in doctors: A cross-sectional survey of 2,197 inpatients using the Cologne Patient Questionnaire. *International Journal of Public Health*, 56(3), 319-327.
- Patton, Michael Quinn (2002). *Qualitative research and evaluation methods* (3rd ed.). Newbury Park, CA: Sage.
- Porter, Dorothy (2006). How did social medicine evolve, and where is it heading? *PLoS Medicine*, 3(10), e399, <http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.0030399> [Accessed: August 31, 2015].
- Reuber, Markus (2008) Psychogenic nonepileptic seizures: Answers and questions. *Epilepsy & Behavior*, 12(4), 622-635.
- Reuber, Markus; Pukrop, Ralf; Bauer, Jürgen; Helmstaedter, Christoph; Tessendorf, Natalie & Elger, Christian (2003). Outcome in psychogenic nonepileptic seizures: 1 to 10 year follow-up in 164 patients. *Annals of Neurology*, 53(3), 305-311.
- Rose, James (2003). Analogies in medicine. *British Medical Journal*, 326(1), 111.
- Rosendal, Marianne; Bro, Flemming; Sokolowski, Ineta; Fink, Per; Toft, Tomas & Olesen, Frede (2005). A randomised controlled trial of brief training in assessment and treatment of somatisation: Effects on GPs' attitudes. *Family Practice*, 22(4), 419-427, <http://fampra.oxfordjournals.org/content/22/4/419.full> [Accessed: September 2, 2015].
- Sahayaa, Kinshuk; Dholakiab, Swapan; Lardizabalb, David & Sahotab, Pradeep (2012). Opinion survey of health care providers towards psychogenic non epileptic seizures. *Clinical Neurology and Neurosurgery*, 114(10), 1304-1307.
- Salmon, Peter (2000). Patients who present physical symptoms in the absence of physical pathology: A challenge to existing models of doctor-patient interaction. *Patient Education and Counseling*, 39(1), 105-113.
- Salmon, Peter; Wissow, Larry; Carroll, Janine; Ring, Adele; Humphris, Gerry; Davies, John & Dowrick, Christopher (2007). Doctors' responses to patients with medically unexplained symptoms who seek emotional support: criticism or confrontation? *General Hospital Psychiatry*, 29(5), 454-460.
- Shneker, Basil & Elliott, John (2008). Primary care and emergency physician attitudes and beliefs related to patients with psychogenic nonepileptic spells. *Epilepsy & Behavior*, 13(1), 243-247.
- Shorvon, Simon (2009). *Epilepsy*. Oxford: Oxford University Press.
- Sontag, Susan (1978). *Illness as metaphor*. New York: Picador.
- Starks, Helen & Trinidad, Susan (2007). Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative Health Research*, 17(10), 1372-1380.
- Stone, Jon; Binzer, Michael & Sharpe, Michael (2004). Illness beliefs and locus of control: A comparison of patients with pseudoseizures and epilepsy. *Journal of Psychosomatic Research*, 57(6), 541-547.
- Stone, Jon; Campbell, Karen; Sharma, Neelom; Carson, Alan; Warlow, Charles & Sharp, Michael (2003). What should we call pseudoseizures? The patient's perspective. *Seizure*, 12(8), 568-572, <http://www.sciencedirect.com/science/article/pii/S1059131103000554> [Accessed: September 2, 2015].
- Street, Richard & Gordon, Howard (2008). Companion participation in cancer consultations. *Psycho-Oncology*, 17(3), 244-251.
- Stump, Elizabeth (2008). The seizures no one wants to talk about. *Neurology Now*, 4(6), 23-26.
- Thompson, Rebecca; Isaac, Claire; Rowse, Georgina; Tooth, Claire & Reuber, Markus (2009). What is it like to receive a diagnosis of nonepileptic seizures? *Epilepsy & Behavior*, 14(3), 508-515.

van Ravenzwaaij, Jos; Olde Hartman, Tim C; Eveleigh, Riske; van Rijswijk, Eric & Lucassen, Peter (2010). Explanatory models of medically unexplained symptoms: A qualitative analysis of the literature. *Mental Health in Family Medicine*, 7(4), 223-231, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3083258/> [Accessed: August 31, 2015].

van Rijn-van Tongeren, Geraldine (1997). *Metaphors in medical texts*. Amsterdam: Rodopi.

Wileman, Lindsey; May, Carl & Chew-Graham, Carolyn (2002). Medically unexplained symptoms and the problem of power in the primary care consultation: A qualitative study. *Family Practice*, 19(2), 178-182, <http://fampra.oxfordjournals.org/content/19/2/178.long> [Accessed: August 31, 2015].

Wright, John & Potter, Paul (2000). *Psyche and soma: Physicians and metaphysicians on the mind-body problem from antiquity to enlightenment*. Oxford: Oxford University Press.

Wright, Peter & Treacher, Andrew (1982). *The problem of medical knowledge: Examining the social construction of medicine*. Edinburgh: Edinburgh University Press.

Wyller, Vegard; Eriksen, Hege & Malterud, Kirsti (2009). Can sustained arousal explain the chronic fatigue syndrome? *Behavioral and Brain Functions*, 5(10), 5-10, <http://www.behavioralandbrainfunctions.com/content/5/1/10> [Accessed: August 31, 2015].

## Authors

**Catherine M. ROBSON** completed her doctoral studies at the Centre for Advanced Study in Language and Communication, University of York, United Kingdom; where she explored the differential topical, linguistic and interactional features of seizure patient talk (differences in how people with epilepsy and psychogenic non-epileptic seizure (PNES) describe their seizure experiences). Her PhD studentship was fully funded by Epilepsy Action UK. Before joining the Centre Catherine worked as a medical social worker, National Health Service (NHS) clinical auditor, and as a research consultant on numerous health, social care and redevelopment projects throughout England. Her research interests include medical sociology, health communication (particularly doctor-patient interactions), social inequalities in health, and applied research methods. She is currently on maternity leave and living in South Africa.

Contact:

Catherine M. Robson

Centre for Advance Study in Language and Communication  
University of York, Heslington  
York, YO10 5DD, United Kingdom

E-mail: [catherinemaryrobson@gmail.com](mailto:catherinemaryrobson@gmail.com)

**Olaug S. LIAN**, Dr. Polit. in sociology (1999), is a professor of medical sociology and chair of the research group Medical Humanities at the Department of Community Medicine, Faculty of Health Sciences, University of Tromsø, The Arctic University of Norway. She also works as a research advisor at the University Hospital of Northern Norway. Her research relates to a wide range of topics within the field of medical sociology, with a special interest in culturally contingent aspects of health and illness, medical knowledge, medical practice, and the organization of health care services. During her academic life she has published three books, in addition to many journal articles, both nationally and internationally. She is currently working on a research project financed through a grant from the Norwegian Research Council that relates to medically contested chronic conditions.

Contact:

Olaug S. Lian

Department of Community Medicine, Faculty of Health Sciences  
University of Tromsø, The Arctic University of Norway  
N-9037 Tromsø, Norway

E-mail: [olaug.lian@uit.no](mailto:olaug.lian@uit.no)

## Citation

Robson, Catherine & Lian, Olaug S. (2016). "Are You Saying She's Mentally Ill Then?" Explaining Medically Unexplained Seizures in Clinical Encounters [79 paragraphs]. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, 17(1), Art. 2, <http://nbn-resolving.de/urn:nbn:de:0114-fqs160122>.