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# Could Neuro-Phenomenology Deepen an Interpretative Phenomenological Analysis of Seizure Consciousness Drawings

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## Could Neuro-Phenomenology Deepen an Interpretative Phenomenological Analysis of Seizure Consciousness Drawings

### **Abstract**

This article proposes a methodological stance, an Interpretative Phenomenological Analysis (IPA) of participants' drawings as one that is useful for research into people's experiences of seizure consciousness. Using empirical examples located in an original, larger study, this article offers a rationale for, and illustrates the analytic potential of, this combination. It also considers that elicitation interviewing techniques and methods from the field of neuro - phenomenology could take this work further in terms of deepening the analysis by reaching people's pre - reflexive conscious experiences. This theoretical and practical combination has the potential to develop this work significantly.

### **Keywords**

Interpretative Phenomenological Analysis (IPA), Consciousness, Art Work, Seizures, Neuro Phenomenology, Elicitation interview techniques, Pre Reflective Experiences

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## Could Neuro-Phenomenology Deepen an Interpretative Phenomenological Analysis of Seizure Consciousness Drawings?

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*This article proposes a methodological stance, an Interpretative Phenomenological Analysis (IPA) of participants' drawings as one that is useful for research into people's experiences of seizure consciousness. Using empirical examples located in an original, larger study, this article offers a rationale for, and illustrates the analytic potential of, this combination. It also considers that elicitation interviewing techniques and methods from the field of neuro-phenomenology could take this work further in terms of deepening the analysis by reaching people's pre-reflexive conscious experiences. This theoretical and practical combination has the potential to develop this work significantly. Keywords: Interpretative Phenomenological Analysis (IPA), Consciousness, Art Work, Seizures, Neuro Phenomenology, Elicitation interview techniques, Pre Reflective Experiences*

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The focus in this paper on seizure consciousness in the context of an Interpretive Phenomenological Analysis (IPA), is underpinned by the long standing clinical issue of differentiating epilepsy from non-epileptic seizures (NES), and not the result of abnormal brain activity and that these states are described very differently by people with both seizure types (Furchner, 2002). It is important to differentiate epilepsy from NES because both types of seizures require very different treatments and procedures, some epilepsy treatments being unnecessary, inappropriate and potentially dangerous for people with NES (Ali, Rickards, Bagary, Greenhill, McCorry, & Cavanna, 2010; LaFrance & Benbadis, 2006; LaFrance, Gates, & Trimble, 2008). Given that there is no single clinical (Avbersek & Sisodiya, 2010; Devinsky, Gazzola, & LaFrance, 2011) or historical feature that can pinpoint that seizures are not epileptic (Alsaadi & Marquez, 2005), this has opened up the arena for methods other than medical techniques to explore the differences.

Research using Conversation Analysis (CA) for example, has gone far in identifying linguistic hints relating to either diagnosis and pinpointing further avenues to explore (Featherstone & Sandfield, 2013). This work has provided evidence that there are reliable differences between the way in which people with epilepsy and NES talk about their experiences of seizure consciousness (Furchner, 2002; Gülich & Schöndienst, 1999; Plug, Sharrack, & Reuber, 2008, 2009; Reuber & Plug, 2007). Seizure consciousness is thus the focus of this article and Reuber and Kurthen (2011) identified two linked concerns to work on further here. The first was to define what consciousness *is* for people with seizures because how people with seizures experience consciousness has not been fully explored in terms of its phenomenological quality and what, if any, higher cognitive processes a person is using (what Reuber and Kurthen termed, access consciousness). Present definitions of consciousness cannot adequately capture experiences or variations across subjective accounts (Engel, 2001); the International League of Epilepsy (ILEA) definition not fully accounting for "alterations in the subjective content of ictal consciousness" (Cavanna et al., 2008, p.

184). In neurological settings if patients do not remember things, they are often perceived as having been unconscious and measurements of “behavioural, constituent functions of consciousness” along with descriptions by patients and observers may not represent the “vividness” of a phenomenological seizure experience (Cavanna et al., 2008, p. 185).

Reuber and Kurthen’s (2011) second concern is that given reflecting on consciousness is an introspective act (Vermersch, 2009) the “methodologically impossible” task of accessing this from ‘a third person perspective’ (Reuber & Kurthen, 2011, p. 102) constitutes a hurdle to undertaking this work. Because we cannot see directly into “other minds” (Reuber & Kurthen, 2011, p. 102) we can only try and make sense of another person making sense of a particular phenomenon—a double hermeneutic (Smith, 2011). A way in which to do this is to use a methodology that can access “first person experience of conscious states” (Moran, 2000, p. 15) and which IPA aims to do.

A related concern for us is that words for describing synesthetic sensations for example, are not in everyday parlance and the lack of such a discourse could further hinder our understandings of seizure experiences (Petitmengin, 2006). The “paucity of vocabulary for describing these subtle sensations” is considered a main stumbling block to gathering subjective descriptions (Petitmengin, Navarro, & Quyen, 2007, p. 751). Explicating these from a phenomenological stance therefore, could be advantageous.

During the course of a larger exploratory IPA study I (VF) undertook, experiences of consciousness were verbally described in great detail by two participants with epilepsy diagnoses. These were supplemented with drawings by them. This paper describes the interpretation of this data and begins an exploration of the concerns above. The paper also suggests that using neuro-phenomenological elicitation interview techniques which aim to reach people’s pre-reflective conscious experiences could add to this exploration. Husserl’s existential, transcendental phenomenology challenged traditional science and third person accounts because it explained consciousness by examining its structures within a person (Moran, 2000). It is these structures neuro-phenomenological elicitation interview techniques access, data from which can be subsequently entered into a “pheno-dynamic analysis.” That is, the techniques can access the “pre-reflective micro-structure” of subjective processes which mirror the “dynamical structure of the neuro-electric activity of the brain” (Petitmengin et al., 2007, p. 746). Often data from neuro imaging are not enough in themselves, requiring verbal descriptions of how they were experienced in order for them to be interpreted fully (Petitmengin, 2006). Using a pheno-dynamic analysis, it becomes possible to combine and analyse neural (medical) information alongside subjective experiences (Petitmengin, 2006). This opens up the potential of phenomenological methods to be included in empirical studies on seizure consciousness. Given its integration into previous studies, a phenomenological attitude is the mode of access which could be operationalised in the context of seizure consciousness reassessing the terrain in which phenomenology can work. Scientific knowledge can then be supported by adding in the roles of consciousness and subjectivity (Gallagher & Sørensen, 2006).

### **Consciousness in Philosophy, Neurology and Psychology**

A philosophical understanding of consciousness considers people's subjective experiences and the phenomenal nature of that experience as they describe it. This experience consists of unifying experiences from various sensory modes into a new simultaneous

experience, existing as a state of consciousness in its own right—phenomenological consciousness (Tye, 2003). One way of thinking about whether someone is conscious or not, is to consider the various degrees to which a person is self-aware. A conscious mental state is one which is accompanied by what are termed higher order states—an individual considering some thought or being aware of their mood or a bodily sensation. This constitutes the self-representational theory of consciousness—i.e., a conscious state is only that if they are aware of their own conscious state, external stimuli, their self and their awareness of those stimuli (Uriah & Williford, 2006). Another way of considering whether a person is conscious is to think of him/her being able to interact empathically with others in the social world at a given time (Thompson, 2003) even though they may be experiencing a constant flow of altering mental activity (Kalamangalam, 2001). However, someone could be conscious without any evidence of interacting empathically with others thus further clarification of such terms as, conscious, unconscious, awareness, unawareness and impaired awareness for example (Johanson, Valli, Revonsuo, & Wedlund, 2008) could be useful.

Psychology, neurology, and philosophy—often working in isolation from each other (Campion, 2009) - have differing conceptualisations and explanations of consciousness/awareness (Zappulla, 1997). People experiencing seizures also have expert knowledge of their seizures to impart (Tuckett, Boulton, Olsen, & Williams, 1985) and the wealth of expertise emerging from these different perspectives needs to be combined and realised (Depraz & Gallagher, 2002). Neurological data is becoming increasingly precise, requiring a semantic clearly linked to subjective experiences. Attention should be paid therefore, to what a person may be reflectively conscious of in this context (Vermersch, 2009). The accounts herein offer perspectives on subjective experiences during neurological events and are relevant and timely. In terms of phenomenology and first person subjective descriptions, phenomenology attempts to reach the “truth” of the manner in which “things” appear to consciousness and before everyday common sense or scientific knowledge imposes on what is being explored. This can support, clarify, or reject scientific knowledge by adding in, and defending the need for, the roles of consciousness and subjectivity (Moran, 2000). Given that (a) subjective experiences and descriptions are fundamental to understanding consciousness and major factors in defining seizure types (LaFrance et al., 2008), and (b) that a phenomenological view is absent in this field, a method such as IPA holds promise (Moran, 2000, p. 15) in explicating these.

### **Methodology: Interpretative Phenomenological Analysis (IPA)**

IPA is rooted in phenomenological thought its founding principles being “that experience should be examined in the way that it occurs and in its own terms” (Smith, Flowers, & Larkin, 2009, p. 12). The notion of epileptic qualia—the “what it is like” to experience a seizure (Monaco, Mula, & Cavanna, 2005, p. 155) is the level and quality of analysis an IPA aims to reach and the level adopted to explore the drawings herein. IPA’s main premise is that our body shapes our knowledge about the world, and these “physical and perceptual affordances of the body-in-the-world are significantly more important than abstract or logical ones” (Smith, Flowers, & Larkin, 2009, p. 19). Unlike CA, where the cognitions of conversation partners are peripheral to CA (te Molder & Potter, 2005), IPA as a method has a major interest in cognition (Smith, 1996) and considers this a “science of meaning making” (Smith & Eatough, 2006, p. 325) accessible through language (Smith et al.,

2009). A person's cognitive and affective reaction to a phenomenon and how they speak about their bodies relates to their thoughts and beliefs (Smith, Jarman, & Osborn, 1999). It is this “chain of connection between accounts, cognition and physical state” (Smith & Eatough, 2006, p. 265) that is structured and organised, “open to being appropriated and understood by others” and can thus be considered scientific (Giorgi, 1995, p. 38). IPA's specific focus on individual (idiographic) embodied experiences, its stance on cognition and language and in depth individual interpretations offers an excellent theoretical and methodological ‘fit’ for exploring seizure patients’ experiences. These epistemological roots also lend themselves to developing the method further.

### “Doing” IPA

The way in which an IPA is conducted has been well documented (Smith et al., 2009). The researcher begins by having one or more conversations with an individual in which he/she endeavours to gain an understanding of a phenomenon in question while also *bracketing* his/her pre-conceived ideas about it. Bracketing can be explained in mathematical terms, i.e., the pre suppositions of a phenomenologist are put aside and treated separately, as in a mathematical equation (Smith et al., 2009). However, when what we previously took for granted becomes a phenomenon to be studied more deeply, we need to balance what we already know about it and allow ourselves to discover and take into account what we did not know. Suspending this “natural attitude” edits out temporarily, our previous assumptions, concerns and engagement because we only attend “to what is given to us in intuition” with no prior scientific or philosophical hypothesis being present in our “new” vista essential features of the phenomena being truly isolated (Moran, 2000, p. 10). Suspending “all ontological judgements about the nature and essence of things and events” allows us to reach what is real to people (Holstein & Gubrium, 1998, p. 139). (Finlay, 2008, p. 8). Expanding Smith’s mathematical allegory, our previous understandings, which we initially put aside, are taken into account in light of what we have discovered anew and become part of our calculations or eventual interpretations.

A second level of practice involves putting into operation the phenomenological attitude which is not an easy task (Finlay, 2008). There are arguments for training phenomenological researchers in spiritual methods which share Husserl’s epistemology emphasising “knowledge by presence”, (Louchakova, 2005, p. 87) in order to gain the skills necessary to *do* phenomenology (Berndtsson, Claesson, Friberg & Öhlén, 2007; Varela, 1996). Because it is within the researcher that the interpretation lies, training for phenomenological researchers could, “enhance the capacity for knowledge” of a researcher and “enhance direct intuition” (Louchakova, 2005, p. 87, 108). Asian philosophies are implicated here, being “living manifestations of an active, disciplined phenomenology,” they can be learned and can work to extend and complement science (Varela, 1996, p. 346).

Undertaking an IPA “requires an ability to be reflective, insightful, sensitive to language, and constantly open to experience” (Van Manen, 1998, p. xi). The most important thing being, “that the interpretation is inspired by, and arises” from participants' own words (Smith et al., 2009, p. 90). In addition to an academic endeavour, an IPA is a personal, creative and iterative process (Crist & Tanner, 2003) the researcher’s mind, knowledge and imagination being the analytic tool (Louchakova, 2005). Finlay’s suggestion of “managing

pre-understandings” (Finlay, 2008, p. 5) will also help us conceptualise phenomenon in terms of our own biographies, knowledge and “fore-understandings” (ibid, p. 8).

Very small numbers of participants are advocated in IPA studies (Landridge, 2007), individual cases unfold’[ing] how “something *is*” - even traditional science studying “unique occurrences” (Smith et al., 2009, p. 30). The seminal work using CA mentioned above began with very few cases, accumulating to around 100 in total over a decade and, “it is not uncommon for the first studies in a new field to be descriptive in nature rather than being able to provide robust demonstrations of clinical effectiveness” (Malzfeldt, 2013, p. 377).

### **Recruitment of Participants**

Around 1500 people are referred to the Hull neurology clinic each year. The consultant neurologist and his staff invited newly referred patients, including private patients and patients from an acute admissions setting, to take part in an interview study. This exercise was repeated six months later to maximise recruitment. Patients chosen for inclusion were those newly referred without a clear diagnosis, that is, they could have had epilepsy or NES or a combination of both. (*New* patients did not include those who had been referred on from other hospitals for example, for a second opinion). Patients excluded were those who were involved in court cases and patients with heart disease because seizures would be secondary to their heart disease. From around 15 Patient Information Leaflets/personal letters from me (VF) being distributed, four people expressed an interest in the study and agreed to take part including the possibility of taking part in two interviews 18 months apart, in order to gain a temporal view of their experiences. This appeared to be a hard to reach group because no further patients volunteered to take part in the study. The study had Ethics & Governance approval from Hull & East Yorkshire Hospitals NHS Trust. The data presented below is taken from two conversations I had with both Vince and Dave (pseudonyms) whose descriptions were rich and supplemented by drawings they did. They talked to me in the context of an unstructured research conversation telling their stories on their own “terms” (Haggman-Laitila, 1999, p. 15) and I implemented “... IPA’s inductive epistemology to its fullest extent” (Smith et al., 2009, p. 70).

### **Previous Studies with the Art Work Of People with Epilepsy**

Previous empirical, neurologically related studies heralded the beginnings of differential diagnoses of seizures through an assessment of art work, in children (Kozma, 1978; Stafstrom & Havlena, 2003) and in adults (Anschel, Dolce, Schwartzman & Fisher, 2005). One on-going study <sup>1</sup> includes artwork which represents central experiences people with these conditions would like to be more fully understood. In particular, the need for them to be able to fill gaps in their consciousness upon emerging from seizures was apparent. Another publication showcases over 200 pieces of art work, each created by a person with epilepsy, capturing insightful images about what it is like to have this condition (Schacter, 2003). Art work from people with seizures has also been classified into themes which could

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<sup>1</sup> *Sparks of Creativity: The Influence of Epilepsy and Migraines in Art*. University of Melbourne. [http://sparksofcreativity.blogspot.com/2008/08/artistic-expressions-influenced-by\\_18.html](http://sparksofcreativity.blogspot.com/2008/08/artistic-expressions-influenced-by_18.html). Retrieved from Associated web site-Channel Z Artworks

further understandings of “underlying neurophysiological bases of ictal (seizure) postictal and interictal experiences” (Schachter, 2009, p. 14) including psychiatric morbidity and the psychosocial aspects of the condition. People have depicted visual symptoms (not apparent to others) which can mirror the “anatomic localisation of the seizure focus and/or the network activated by the seizure which offers a window into brain-behaviour relationships and neuroethology” (Schachter, 2009, p. 13), others drawing images depicting out-of-body experiences. Postictal states, involving feeling a loss of contact with reality and distorted visual perceptual, have also been represented as has the process of regaining consciousness. There remains the potential to further interpret visual representations of people experiencing seizures into “testable hypotheses” (ibid, p. 14). Drawings then have been used in neurologically related studies and we consider that there is the potential for systematic methods to elicit a scientific, deep analysis of people’s experiences in this context.

### **The Potential of Using Patient Drawings in IPA**

I (VF) took drawing materials along with me to the interviews in case participants found talking about their experiences difficult or if conversations faltered. When I asked participants if they wanted to draw their experiences, Vince and Dave, did so, the other participants declined. Vince drew one single figure and Dave several. Although the inclusion of participants' drawings is not common in IPA, and this could be considered a definite departure from the method, the drawings by participants in this study, although unexpected, deserved attention (Bell, 2006). They depicted unusual physical experiences which offered some insights into relationships between subjective experiences and external environments (Johanson et al., 2008).

Creating and engaging with participants’ drawings can empower them and researchers to present their stories in different ways. They can uncover interpretations which may have been missed otherwise and/or offer a different view of a phenomenon (Glass, 2008). Using similar non-linguistic forms of data has been used to try and gain descriptions which bypass conventional ways of making sense of things, they can be useful for further discussion and if people are not verbally articulate (Gillies et al., 2005). The art work below has left visual traces of Vince and Dave’s lived experiences “transformed into transcended configurations” (Van Manen 1998, p. 74).

#### **Case 1. Vince**

Vince, at around 60 years of age had experienced around seven seizures in a fifteen month period, and commenced taking anti-epileptic drugs (AEDs) six weeks before I (VF) met him. Between our conversations, neurology services had reconsidered his diagnosis, whether he had post traumatic epilepsy from a road traffic accident (RTA) and/or whether he had suffered a stroke. After being prescribed the AED Tegretol (carbamazepine) his seizures lessened considerably and his diagnosis progressed in his medical notes to ‘probable temporal lobe epilepsy’. Vince was finally diagnosed with complex partial seizures. Upon meeting me, Vince, accompanied by his wife, launched immediately into his own personal embodied experiences:

The way it actually happens when—I am talking normally and I *still* think I am talking normally - but I seem as if I'm got lifted up and away and I am



looking at ... Yes, you know in a sort of—almost in an empty atmosphere ... Because you seem to be lifted as if –the atmosphere that keeps you held down ... No—it lifts you up and you almost feel as if you're floating ... if you're floating then—the normal atmosphere that keeps you held to the ground ... The gravity seems less restricting because you seem to lift up, you can *see* who you're talking to—but even though you can *see* them, they seem to be a long way away, and you know, you sort of come back down and when you come back down, you don't really understand what it was ... well it seems that where I'm concerned it's this thing where I seem to lift away and, I'm not me. I don't know, but I'm looking at the people and even though they haven't changed, *I* seem to have changed. Yeah, when so I come back down, it seems ... as if it's only natural. Yes, you float away and as you're floating you're looking—they seemed to have gone further away from you and - you're thinking - I can't really say whether the thinking is positive or negative.

When I asked Vince's wife (who was present in both our interviews) if she agreed with this description she responded: “Yes I do really. He does seem to be—away” and turning to Vince; “You're in a world of your own.” Disruption in Vince's consciousness is clear as he goes into and out of his seizure. In relation to the self-representational theory of consciousness described above, Vince demonstrates that he retains a conscious state in that he is both self-aware and aware of external stimuli. The complexity and clarity in Vince's descriptions of his different levels of awareness illustrates the inadequacy of polarities of someone simply thought of as being conscious or unconscious (Gloor, 1986). Vince could not articulate his awareness or perform voluntary movements during his seizure, because his attention was being diverted inwards, and being taken over by, his epileptic brain activity. A person in an epileptic seizure observed by others can be perceived as being completely ‘unconscious’ – as evidenced by Vince’s wife’s comments. However, this may not be what the individual experiencing the seizure feels. Their ability to interact is simply temporarily suspended and Vince remained very aware of the continuing presence of other people even though he could not converse with them. However, notwithstanding his personal experience of maintaining an awareness of the presence of others and knowing that others see him as being unresponsive, Vince still perceived other people with epilepsy as being completely unresponsive:

Cos there are some who just, they have no idea what they do because they totally collapse, they are unconscious...Whereas I am still, to a certain extent—conscious in that ... if not fully connected, I am conscious about what is happening and to a certain extent that, I suppose, is good luck.

Towards the end of the first interview, Vince became vigilant in monitoring his thoughts and feelings about his abilities to respond to others and his perceptions shifted towards an understanding of how others could *perceive* him as being unresponsive:

And that is the thing about epilepsy, it is totally unconscious. Even although you can see, when you're speaking you know what you are saying - but from there to there the translation goes totally different, because you're not saying what you're thinking instead of coming out with understandable, understandable, words it's coming out [laughs] as absolute rubbish.

In terms of the development of a seizure vocabulary, noteworthy was a particular linguistic strategy Vince used. His ‘approximations’ of his experiences are rooted in and are simulations of experiences we all have some knowledge of (Gibbs, 2006) and added to our understanding of what he was experiencing (Wilde, 2003). These included: “it *almost* felt as if I’d been somewhere else,” “you *seem* to lift up,” “*as if* I got lifted up and away,” “*almost in* an empty atmosphere,” “*as if*—the atmosphere that keeps you held down,” “it lifts you up and you *almost feel* as if you’re floating,” “it’s this thing where *I seem* to lift away,” “*they seemed* to have gone further away from you,” and, “I’m not me, *I seem* to have changed.” (Italicised words are those that Vince emphasised).

### Drawings: “I’ll Let You Try and Work That Out—Even Though That Looks Like a Fish” (Vince)

When I first offered Vince drawing materials, he did not think he could depict his seizure in this way:

It was all—to draw it, all it would be would be a question mark. Yes, a question mark – because, it is something I so definitely don’t understand so what exactly is happening is totally questionable. Yeah, and that is the obvious question mark and to say it goes back far as where I had the brain damage in the car accident, yes.

However, whilst his wife was talking to me about family events, Vince began a drawing of his seizure (Figure 1) and talked to me as he completed it. In the drawing, Vince drew what he thought simply resembled a fish. However, as he continued to draw he began to construct his experience. This developed into a description of him entering into, being engulfed by, and coming out of, his seizure. Simultaneously he was aware of on-going external events he could not attend to.

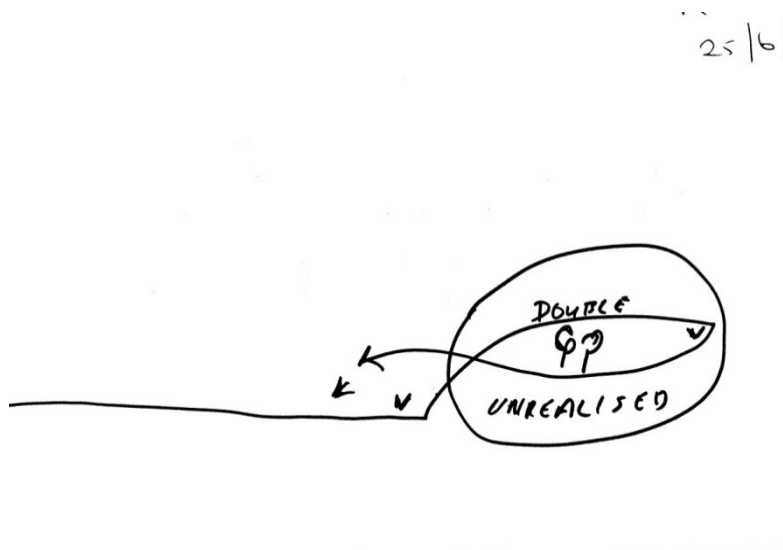


Figure 1: ‘I’ll let you try and work that out—even though that looks like a fish’

#### Vince’s verbatim explanation of his drawing

V: Do you understand that? (the drawing)

- VF: Erm, This is you – one, minute you are there –
- V: The first I am there, then I come to there and then I come back coming back, coming back, heading back to where I was before...
- VF: Where you were before
- V: on level ground and suddenly I seem to be *above* ...
- VF: Mmm, looking down on people.
- V: Yes above, almost beyond and *then* I come back – but exactly what is happening during *that* period is ...
- VF: Is, inside there? Mmm. What's that?
- V: I'm doing it wrong.
- VF: Do you want a question mark?
- V: Yeah
- VF: It's like that isn't it –Yes. But you don't know what is happening in that space of time
- V: Yeah, That's a Spanish question mark –
- V: A Spanish question actually starts *before* the question and you have that – you have – sort of-this.
- VF: What does that say-double, double?
- V: You're doubling, and in, while you're in, while you're in there is a question going in and a question coming back out because they're unrealised.
- VF: The questions haven't been answered – yes.
- V: Yes, basically (more drawing)
- VF: Unrealised questions or.....
- V: Yes. The whole lot there...
- VF: Mmm, mmm
- V: ...*is unrealised* – to me. *Other* people see it but I don't.
- VF: Mmm
- V: All I see is-sort of coming from there over there and then going back...
- VF: Going back. Yeah I understand. So you *could* draw it.
- V: I have been thinking about how to do it.

Vince continued expanding his descriptions after completing the drawing:

The whole circle around that there that's me—questioning going in, questioning coming out. But still ... mmm, still unrealised because you don't really feel and if you don't really feel, then the realisation is minimal. No the realisation is, if you feel exactly what is going on—but you don't, so that makes it unrealised. Well that's probably why it's so bloody confusing. You are going in with something and you are coming out and other people realise you have gone in—you come out without any realisation.

Vince elegantly articulated levels of awareness never appearing to lose consciousness completely as he appeared to be able to access, and constantly reflect on, subjective experiences during his seizures whilst simultaneously knowing that he could not respond to “exogenous stimuli” (Johanson et al., 2008, p. 170). He described shifts in his conscious state, the illusion of being somewhere else but being cognisant that physically, he had remained stationary. He describes “autoscopy” (out of body experiences; La France et al., 2008, p. 318), differences in his self-awareness, visual and auditory illusions/hallucinations and self-transformations (Parnas, Handest, Jansson, & Saebye, 2005). Also other extraordinary experiences, including visual, auditory, tactile and motor perceptual

experiences as well as “coenaesthesias” -which can include migrating sensations, sensations of movement, lightness, levitation, elevation, somatic depersonalisation (Vollmer-Larsen, Nandest, & Parnas, 2007, p. 346), and mental illusions of derealisation and depersonalisation (LaFrance et al., 2008; Wolf, Schöndienst, & Gülich, 2000).

For Vince this data appeared to belong to one phenomenological moment, that is, at the second interview his previous insights had been forgotten. He continued to ponder on whether things still appear to others as they did 18 months earlier, “I’m wondering instead of, at a point when I’m talking to them, they hear me talking gibberish” to which his wife replied that it did happen now and again. This provided an answer to Vince’s ponderings, “I don’t really notice it.” Similarly when asked if the drawing remained symbolic of his experiences he said, “Well I don’t seem to be getting affected the way I was there ... whether that is to do with this [pointing to the drawing] I’ve no idea.”

At this point, his experiences had reduced into one of simply experiencing a very bad headache, and waiting for this to abate, “No, what seems to happen is that, basically I get pretty hot ... yeah, end up with a really stinking headache, which I can’t get rid of for at least half an hour.”

Although these descriptions continue to give an idea of what a seizure is like for Vince, they did not have the phenomenological quality of his earlier descriptions. The second time I (VF) saw Vince and asked him if he had any ideas for questions to ask of other people he said, “All I say is please attempt to be totally self-descriptive because doctors can give you an idea but the reality must come from the sufferers, because they are the only ones who can or cannot.”

His comments reinforce the importance of subjective experiences in clinical decision making (Olsen & Williams, 1985; Tuckett et al., 1985), that both medical and lay voices and information are valuable and all need to be considered.

## **Case 2. Dave**

Dave, in his forties, was diagnosed with idiopathic generalised epilepsy (a hereditary disposition to seizures, (Baxendale, 2006). His EEG and CT scans were normal and after being prescribed the AED Epilim (sodium valproate) his seizures decreased. Following a physical assault he did not recall happening, a chip pan fire and a “near miss RTA” facts being recorded in his neurology case notes, Dave was then prescribed other medications in order to control his seizures. Immediately upon meeting Val, he expressed concern to her about the danger he finds himself in because of gaps in his consciousness awareness: “My brain just seems to turn off and I can walk around. I’ve had smaller episodes like that inside me flat where I’m looking at me bedroom wall the next thing I know I’m watching TV with a cup of tea in me hand.” He also described times where, “I’m inside me flat, and I remember going ‘aah’ and the next thing I can know is, I know, I’m on the floor, and I’ve pissed meself. So I’ve struggled to get to bed, and I’ve been in bed.”

Dave also recalled another incident which had happened in between our two conversations, in which he scalded his foot as he poured boiling water over it. His injury did not require a skin graft but was obviously painful and not the kind of injury one would want to impose upon oneself:

And erm I have scalded myself before, the worse one was ‘erm I found myself er trying to make trying to make a cup of tea, er stood up-remember, pouring boiling water on me foot, and I’ve got me sock on – right? And I can see myself, actually seeing pouring boiling water on me foot and I can’t, I just

cannot move me foot, it's stuck, it's absolutely stuck... I can't move me hand, can't move me hand, and I can see the water dripping and I'm thinking to myself, move, move, just move. Then I'm thinking, if I can just get the sock off me foot, then it'll, it'll just make it feel better, if I could just get the sock of me foot, it'll make it feel better, And it just will not move...it just slowly started moving, just slowly, very, very slowly.

These events assumed more gravity when they began to happen out of doors, Dave narrowly missing being killed by an oncoming lorry, having 'come to' just in time to avoid this. He twice arrived home with planned purchases, not recalling actually buying either of them. He described one of these:

So I'd ran through it in me 'ead, what I was gonna do ... so I've gone onto automatic and actually done it. The next thing I remember is being stood on the middle of a road looking at a lorry coming towards me. You see, the trouble is I've got no memory in the gaps. I've tried to remember what I did, I've zero, zilch. There are only the clues of the potatoes. So I've done something, must have done something to there.

Dave was undertaking "complex behaviours without conscious awareness" (Seligman & Kirmayer, 2008, p. 48). He retained "cognitive consciousness" which allowed him to act to save his life, and his accounts offer some evidence of him using higher cognitive processes during his seizure. At other times, he lacked, temporarily, "phenomenal" consciousness (Monaco, Mula, & Cavanna, 2005, p. 156). Dave's experiences of 'going onto automatic' are similar to these common everyday experiences we all have of walking or driving home without an introspective awareness of the journey (Tye, 2003). These fluctuations in everyday conscious experiences can result in "normative dissociative experiences" which can happen spontaneously and merely involve "functional shifts in attention and information processing" (Seligman & Kirmayer, 2008, p. 34). We can shut out our external environment and perceive time as being suspended, (a suspension of self-reflective consciousness) (ibid). Some level of consciousness obviously remains however, or accidents would occur (Monaco, Mula, & Cavanna, 2005). Everyday dissociative experiences can be pleasurable and contribute to enhanced functioning or performance, whereas abnormal ones, such as those Dave is experiencing can be associated with "clinically significant distress" (Monaco et al., 2005, p. 35). Dave perceived his experiences as abnormal and remained perturbed about them.

Dave exhibited components of dissociation which interfere with his normal perceptual, cognitive and attentional processing. His memory is disrupted for periods of time; he experiences feelings of altered consciousness as being, "in a different world" until "somebody breaks that world." When asked what is happening to him whilst in this state, he replied, "I don't know! It's basically [poses as a person having an 'absence' seizure, i.e., staring and immobile] that's it." [PC: You feel you can't move?] "Yeah, basically, I'll try again [another, similar pose] there you go!"

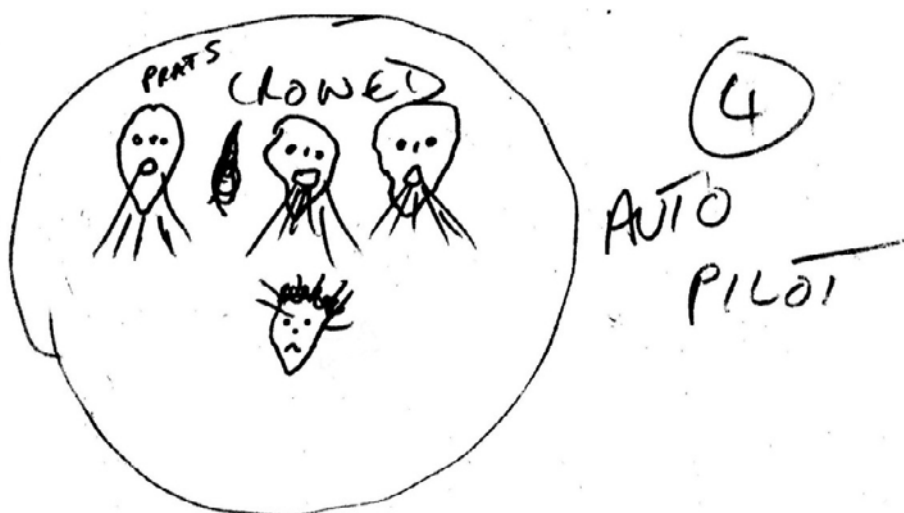
He based these poses on a flat mate's description of what he looked like during these times: "I'd go like that, he'd hear me mouth goes (smack smack) or hear me moan or something. That's when he'd say, 'are you alright?' I'd go what, what? He just says that I go blank- just blank... apparently I just look away."

The conversation triggered a memory from Dave's childhood, to which he added his newly acquired knowledge of seizure terminology, in a written postal communication to me;

At approximately the same age we had Christmas dinner at me grandparents and I must have had what I now know to be a Complex Partial because apparently I had a dazed look in me face tried getting into me grandparents gas cupboard and had a good chat with no one in particular of which I have no memory! My mother noted later about this period and me she said I just suddenly went cold towards her and my memory seemed slightly different. At the age of 14-15 I was tearing apart sheets and blankets in my sleep and waking up very tired. Doc gave me iron med.

### Drawings (1): 'What It Feels Like In My Brain'

Following an initial query from Dave: "What do you mean by draw?" Val, "Well, whatever you think it feels like, just draw it", Dave drew two drawings depicting how he perceived his brain as working. These helped him expand upon how he felt on occasions when he undertakes behaviours he can neither control nor remember. The first of the two individual drawings (Figure 2, drawn in his first conversation with Val) described how he felt immediately prior to his near miss RTA.



**Figure 2: What it Feels Like in My Brain**

The drawing depicts a crowd of people trying to attract Dave's attention, but he (drawn below them) is unable to respond. When asked what this felt like Dave replied:

Rough, er like something's pressing down, pulling down my head or whatever. And I can just remember it's like being in a football crowd and everybody's screaming at you for attention and you're not able to respond to any of em... what it feels like, in my brains, that's a crowd, I'm half awake, half asleep and this part (pointing to the front of his head) is where the scream is coming from.

Again, considering contributions to a seizure discourse, Dave also uses a particular linguistic strategy in his descriptions. "Metaphorical predicates" including "pressing down," "pulling down," "everybody's screaming at you," help to express the qualities of things and experiences. Words such as "sharp," "stabbing," "pointed," "pinched," "lightening,"

“cutting,” “dull,” “burning,” “searing,” “gnawing,” “convulsive,” “tickling,” “prickling,” “electric,” and “pressing down” are other examples of words which could be valuable for people. They add depth to the meanings of experiences without a person having to formulate more complex metaphors (Menz, Lalouschek, Reisigl, Sator, & Frickey, 2005).

Dave appears to exhibit what could be seen as components of dissociation (i.e., an interference with his normal perceptual, cognitive and attentional processes), his memory is disrupted for periods of time. He has feelings of altered consciousness and of being, “in a different world.” However, he can become aware of other people around, all of a sudden somebody can break into this world, “Are you alright? Really, are you alright?”

When asked about his awareness of this other world he described it as feeling like:

It's like a daisy dream world ... it's like a black hole, if you went into a black hole, time and space gets squashed, everything's starting to sloooow down, that's how it feels ... My mind just tried to blank it out.

### Drawing (3): Divide My Head Into Quarters

Early in our second conversation, Dave explained through another drawing (Figure 3) two distinct elements of his seizure experiences. One was how he perceived his brain as working and the other was how this affected him emotionally.



**Figure 3: Divide My Head Into Quarters**

The first element is related to the physical attributes of his seizures:

Divide my head into quarters. That's me front [front of head depicted with letter “F”] that's me right I get headaches there, I get headaches roundabout that area and that area [areas marked with a black/grey scribbles] these are *intensities*, like the darker it is, the more intense the pain *can* be. It doesn't mean that it *is* going to be *that* intense, but that's how it *can* be intense. Er, er and there ... Headaches and pains, that there could be lower back, sort of there [indicates the back of his neck] this part, this part here, there, seems to be the only part of my head that seems to be unaffected [the empty quartile in his

drawing].’ That seems to be the only part of my head that seems to be unaffected, there—seems to *feel*? Seem to have something at the time.

The second element was his negative perceptions of his brain function, and his feeling that there was some lessening of his cognitive abilities. He described how this felt:

I think I'd be oh, oh sort of erm ... more stupider erm, that's sort of—one quart less intelligent. Yeah—one quart less intelligent’ (the aforementioned empty quartile in his drawing). There's a D\*\*\*\*\* inside that's always screaming to be let out no, the good one.

In Dave’s second conversation with me, his attitude had shifted towards his seizures beginning with frustration that these events happen to him and pose a grave danger, to accepting that he can do nothing about them and with the knowledge that his cognitive abilities were temporarily, severely compromised, to finally attempting to disassociate from this part of himself:

I don't want to know it, I don't want to know it the thing that I've just, I don't want to know. In general I don't want to know it. Oh yes I do stupid things, I know I do stupid things. I don't want to know it, coconuts I don't wanna know that I done the coconut things, I don't want to know I've walked across the road that I could have killed myself, I don't want to know.

Vince, Dave too dismissed the relevance of this drawing when asked about it at his second interview saying that he did not feel this anymore, putting it down to the side effects of medication.

## Discussion

We have offered a trail of evidence suggesting the value of drawings in elaborating seizure consciousness in an IPA. Some of Reuber and Kurthen’s (2011) concerns have been addressed. An IPA is useful for exploring the phenomenological quality of seizures and doing this is not methodologically impossible. An IPA offers some idea of what seizure consciousness consists of, it illustrated the vividness of the men’s accounts and that things are not always what they seem to in terms of people’s apparent awareness/unawareness. The IPA given the method’s focus on cognition also identified times at which Vince and Dave used access consciousness and the phenomenological component of the method obviously holds potential in this area of work. Vince and Dave described their conscious experiences as both experts (in their seizure experiences) and novices (in seizure language). Bodily experiences can shape participants' narratives (Öhlen, 2003) and most striking was the complexity and insightfulness of Vince's initial descriptions contrasted with later ones. Initially, he described his seizure experiences using language which facilitated powerful images of his cognitive functioning during a seizure. He articulated cognitive and affective reactions to bodily and visual sensations and also complex alterations in his levels of consciousness. Talking to me and being able to draw his seizure facilitated Vince in reaching this awareness over time. He demonstrated that he knew when he moved from being able to communicate with others, to a complete inability to do this. He offered complex linguistic reconstructions which illustrated Furchner’s seminal concept of a shift from “dynamic to static” state (Furchner, 2002) a central feature in the accounts of people with epilepsy. He also became aware of how difficult it was for others to understand the subjective nature of his experiences.



Similarly, in an amalgam of lay and medical terminology Dave described how experiences consisting of modality specific sensations, auditory and anomalous visual perceptions and different levels of awareness and unawareness felt to him. His drawings communicated further his experiences and his narrative was coloured with his own idiosyncratic terminology including symptoms he described as, “hot poker,” “a needle stuck in the foot,” “day dreams and weird worlds.” Dave's experiences contained instances of him retaining some “cognitive consciousness” allowing him to act to save his life, others illustrate his “phenomenal consciousness.” Dave's seizures were observed occasionally by friends and once by a clinic nurse corroborating his descriptions.

Creating the drawings facilitated “a special conversation” between participants and Val and ‘complex interview interactions’ whereby participants explored and expanded upon details, meanings and connections as they interpreted their work (Esin & Squire, 2013, paragraph 2). The drawings succeeded in turning the conversations (Roberts, 2008) into ones in which Vince and Dave offered their unique, linguistic contributions as well as insights into their multiple, temporal experiences all breathing life into the data (Glass, 2008). In terms of managing their condition, the drawings offered information about their seizures, information about themselves, their day to day lives and the resources they had to manage their conditions (Gillies et al., 2005). Interpreting visual representations of people experiencing seizures has not been done to date in an IPA and more work is needed with both epilepsy and NES patients with a view to exploring the differential diagnosis of both types of seizures. Introducing patients’ drawings into the health community (Glass, 2008) could offer alternative perspectives and interpretations of their situations (Battisti & Eiselen, 2008) and could add value to time limited clinical conversations. Art used in psychoanalytic therapy for example, has helped illustrate coping skills and strategies of people with seizures (Cregeen, 1996).

Vince and Dave’s verbal contributions and their drawings illustrate that complex descriptions of seizures and consciousness are available and could be ‘accumulated’. In terms of how the men’s experiences reflect back onto neurological data these descriptions could potentially,

- 1) contribute towards diagnostic specific seizure discourses and
- 2) be combined with objective measurements such as EEG, brain imaging and behaviour

In terms of (1), given the lack of knowledge about subjective seizure experiences of consciousness and a lack of a consciousness discourse, building up a corpus of data from an IPA would be valuable. Vince himself advocated the value of a lay addition to this discourse - a factor also recognized in the CA work (Gulich, 2003; Schwabe, Howell, & Reuber, 2007). Although Vince and Dave articulated their experiences well, the lack of an available seizure vocabulary may inhibit others in describing these phenomena. Val not being a neurologist may also have elicited data which were removed from definitions of consciousness rooted in epileptology.

Most importantly for us was that capturing Vince and Dave’s descriptions and drawings early mitigated against the loss/disappearance of their phenomenological experiences over time. This being an issue to consider because medication and familiarity with seizure language can alter patients’ perceptions of their experiences. The following paragraph outlines the potential of (2) that is, the potential combination of phenomenological and neurological data.

## **Future Work: Combining Participants' Drawings of Seizure Consciousness with Neuro-Phenomenology**

Neuro-phenomenological techniques (described briefly below) facilitate the detection of deep experiential structures. Uncovering these structures could present us with 'a rich and largely unexplored source of information and data with dramatic consequences' (Varela & Shear, 1999, as cited in Petitmengin, 2009, p. 9; see also Landridge, 2007). Neuro-phenomenology utilises the ideas of systems theory and that, in terms of epileptic seizures, these are not a sudden and unexpected occurrences but one which can be anticipated being the result of a elements of a system and "its general (spatial and temporal) dynamics" (Petitmengin et al., 2007, p. 747). That is, seizure onset is seen as an on-going, dynamic process which can begin days, hours or minutes beforehand (Petitmengin et al., 2007). It follows that the subjective cognitive experiences of epileptic seizures also unfolds and this takes time to become aware of as happening and, subsequently, to describe (Petitmengin, 2006, p. 230).

Brain patterns are known to be related to people's "subjective states" (Petitmengin, 2006, p 125), descriptions being correlated with "neuronal dynamics of the electro-clinical onset of a seizure" (Petitmengin, 2006, p. 124). In terms of 2) above, these subjective experiences represent first person direct descriptions of cognitive processes which can help with the interpretation of other data such as that being recorded with neuroimaging techniques and could form the basis of new "paradigm for a neuro-scientific approach to epilepsy" (Johanson et al., 2008, p. 171). Potentially these could harbour the possibility of differentiating these from NES. Generating a large corpus of data has the potential to be translated into concrete, practical ideas as heuristics, concepts or principles, which could inform the neurosciences, moving towards an "objective interpretational empirical framework" (Gallagher & Sørensen, 2006, p. 131). IPA studies for example, have the potential to help develop theory through a process of "analytic induction" (Smith, 1999, p. 413), Neuro-phenomenology could then form an integral element of multi-method interdisciplinary approaches. There are however, issues to consider when exploring consciousness further and the task of knowing and describing subjective experiences is not an easy one for people because they can perceive phenomena pre reflectively without being consciously aware of this. To develop descriptions requires a phenomenological reduction and a direction of attention exclusively to one's own personal experience of the world, putting aside other ideas, beliefs or theories about that experience (Gallagher & Sørensen, 2006). Thus, there is also the potential for participants as well as researchers, to be trained in such methods (Finlay, 2008; Varela, 1996). This would facilitate the knowing of experiences and offer findings that are even more "experience-close" (Smith et al., 2009, p. 204).

### **Neuro-phenomenological Elicitation Interview Techniques**

The process of becoming aware of one's pre reflective experiences consists of coming into closer contact with something that was previously unknown. Describing these can be facilitated at two levels; the level of experience, and at the level of becoming aware of the *how* of this experience (Petitmengin, 2009). The how can be reached by incorporating interview techniques which access the "pre-reflective micro-structure" of subjective processes (Petitmengin et al., 2007, p. 746). Elicitation interview techniques (Petitmengin,

2009) facilitate a finely detailed and guided exploration of important elements of people's recent experiences so that they can become aware of pre reflexive processes and develop their phenomenological descriptions of these (Gallagher & Sørensen, 2006). These techniques—much like Wundt's participants in his experiments on introspection in the 19th century and who were asked to describe the “pure” perceptions as they appeared in ‘their consciousness, (Gallagher & Sørensen, 2006) render the descriptions of lived experience reproducible thus offering scientific validity (Petitmengin, 2009). Memories, images, sensations, sounds and the fragmentation of the temporal course of an experience all have the potential to be evoked by an elicitation interview. The participant relives the experience, their attention being directed towards visual, kinaesthetic, auditory or olfactory triggers, felt emotions or internal dialogues, all of which may have been pre-reflective until expertly elicited and brought into consciousness.

The alliance of IPA with neurology has already been mooted (Smith et al., 2009) and phenomenological methods have already been assimilated into empirical studies exploring patients' experiences of epileptic seizures (Le Van Quyen & Petitmengin, 2002; Petitmengin et al., 2007). However, there is the question of whether the close focus integral to neuro-phenomenological techniques and methods fit into the current spirit of IPA. Although some argue that accessing pre-reflective conscious experiences could sit well with IPA (Landridge, 2007; Willig, 2001) this explicit focus would go beyond its boundaries as they stand today.

### Conclusion

Our study has demonstrated for the first time how an IPA of participant drawings has generated in-depth, first person embodied descriptions of seizure consciousness. The approach has the theoretical and methodological potential to uncover conceptualizations of seizure experiences previously unheard. This work formed the basis for our ideas for using neuro-phenomenological interview methods and techniques to explore seizure consciousness with participants' articulations about their drawings. . If it is the case that self-expression through various forms of art is an underused tool in neurology (Stafstrom, 2005) we suggest that this could add significantly to work in the field.

All of this indicates the usefulness of a paradigm shift in seizure exploration in terms of locating new vistas to explore.

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