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The Coconut Day: A Poetic Interpretation of Seizure Experiences

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Abstract: This article presents a fraction of an interpretative phenomenological analysis (IPA) of people's seizure (ictal) experiences. In addition to undertaking individual analyses and across case analyses, a poetic interpretation (SZTO, FURMAN & LANGER, 2005) of participant's words was undertaken which focussed on bodily experiences and consciousness. The interpretations indicate participants' awareness of biological events unfolding; their abilities (or not) to interact with others; personal resignation to having the condition; and the effect epilepsy has on their lives. Although people are not always able to respond appropriately to events external to them during a seizure, having some conscious awareness allowed one man to act to save his life.

Findings from the study shed light onto subjective seizure experiences of consciousness. Collecting similar accounts could begin a corpus of data to inform research on ictal consciousness. The poetic interpretations below provide a porthole to a large vista of subjective seizure experiences, and could be considered both as research and clinical texts, being valuable to lay/professional carers and to the differential diagnosis of seizures.

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1. Introduction

This article represents a fraction of a study (FEATHERSTONE, 2010), which examined four people's experiences of seizures using interpretative phenomenological analysis (IPA) and which itself stemmed from an earlier, exploratory study (FEATHERSTONE, 2005). The motivation for undertaking both studies was the gap in knowledge about what it is like to live with epilepsy and of people's subjective experiences of consciousness during seizures—an important consideration in seizure diagnosis. [1]

Section 1 will describe the aims and rationale for the study, its methods and design. It will also describe previous work and why IPA was an appropriate methodology for this work. Section 2 will discuss how we can represent our participants' experiences in terms of moving beyond presenting findings more traditionally. It discusses the emergence of poetry as a form of representing research findings giving examples of other authors' work. How the poems in this article were crafted is described. Section 3 includes the three poetic interpretations. The discussion focuses on the conscious experiences of two men, other linguistic characteristics they employ and the usefulness of poetic interpretations for research and clinical practice. [2]

1.1 Aims of the study

The aims of the study were to explore subjective seizure experiences and to inform practice by adding to an emerging seizure discourse which could contribute to differentiating between epilepsy—"[a] sudden, involuntary, time-limited alteration in behaviour, motor activity, autonomic function, consciousness, or sensation, accompanied by an abnormal electro-graphic pattern (EEG)" (THOMPSON, OSORIO & HUNTER, 2005, p.71)—and non epileptic seizures (NES): "paroxysmal changes in behaviour that resemble epileptic seizures, have no electrophysiological correlate or clinical evidence for epilepsy, whereas there is positive evidence for psychogenic factors that may have caused the seizure" (BODDE et al., 2009, p.2). [3]

Differential diagnosis is a long standing clinical conundrum in neurology, estimates suggesting that between 15% and 30% of people seen in epilepsy centres do not have epilepsy but have NES (BODDE et al., 2009). To create further clinical confusion, between 3.6% and 58% of people can have both conditions, one study suggesting that 58/329 of NES patients could be thus

diagnosed (REUBER, 2008). It is important clinically and psychologically to distinguish between the two seizure types (BODDE et al., 2009): NES is a physical manifestation arising from emotional problems a patient has (LANGFITT, 2007), people often being diagnosed as having "dissociative convulsions"—and a recognised psychiatric condition defined in the ICD-10 (BROWN & TRIMBLE, 2000, p.286). People with NES only, therefore, do not require anti-epileptic treatments and procedures—indeed these can be dangerous (LaFRANCE & BENBADIS, 2006; LaFRANCE, GATES & TRIMBLE, 2008)—but require psychological support and treatment. [4]

1.2 Study design

The study design was an "extensive idiographic design" whereby all participants were experiencing one or more common property of a condition (SMITH, HARRÉ & VAN LANGENHOVE, 1995). That is, they were all experiencing seizures, were all newly referred patients at an epilepsy clinic, and their seizure diagnosis was in question. Participants were seen twice—this being justifiable in hermeneutic interpretative phenomenological research (FLOWERS, 2008), first when they were newly referred to neurology and again, eighteen months later, for around three hours each in total. The status of being a new patient was important because they would be unfamiliar with technical terms and seizure language. The nature of their experience could change, for example, seizures could cease or cognitions could alter (DODRILL, 2002), there being a relationship between seizures and adverse cognitive change and epilepsy can be progressive in terms of cognitive deficits (DEVINSKY, 2003). This second meeting also allowed participants to comment on the poetic interpretations, to complete their stories and conclude their research participation. [5]

1.3 Methodology

IPA is a qualitative methodology rooted in phenomenology, encompassing, hermeneutics (the theory of interpretation), and idiography (a concern with the particular rather than the general) (SMITH, FLOWERS & LARKIN, 2009). IPA has a commitment to cognition, not in terms of experimental work but by reworking the notion of cognition, relating it to language and exploring it in-depth (SMITH, 2011). Through person-centred interviews, systematic analysis and interpretation, a researcher attempts to understand how participants are making sense of a phenomenon—a double hermeneutic (SMITH, 2011). It examines what is of existential importance to people, believing in an inextricable connection between embodied experiences, people's talk about that experience, their making sense of, and emotional reaction to, that experience (SMITH, 2004). An IPA "applied in a proper ontological context" (VAN LANGENHOVE, 1995, p.11) is experiential. That is, it searches for a person's "cognitive and affective reaction to what is happening to them" (SMITH, 2011, p.10). [6]

The way in which an IPA is practically undertaken is well documented (SMITH et al., 2009). Rather than following a set of prescribed procedures, it constitutes a qualitative, dynamic, iterative process involving a complete immersion in

someone's talk in real time, and in the transcript subsequently generated. This is at several levels incorporating a repeated reading of the transcript, exploring how people verbally describe what is happening to them with the aim of interpreting their lived experiences of a particular phenomenon. Because IPA reifies the individual's voice above all others (LARKIN & CLIFTON, 2006), distinguishing it from many other qualitative methods, it does not make general claims about larger populations than those studied (LANGDRIDGE, 2007). Individual cases are thus interpreted separately before any attempt is made to look "cautiously" across cases (SMITH, 1999, p.412). Small participant numbers are advocated and N=1 is being increasingly adopted by IPA researchers (LANGDRIDGE, 2007). [7]

IPA does not import external theories in order to fit the data although these can inform the interpretation, initially being speculative, to be linked more formally after the interpretation is near completion (SMITH, 2004). IPA studies can, potentially, help develop theories and models can emerge from an interpretation based on theory underpinning IPA, these being firmly rooted in the data (SMITH, 1999). In addition to undertaking individual interpretations for each participant and an interpretation across cases, poeticised accounts of some participants' words were offered so that readers could read condensed, "experience full" impressions of what were anomalous occurrences. [8]

1.4 Previous work

A decade of work already done in the area of differential diagnosis drawing on insights from conversation analysis (CA), has been developed by German researchers and linguists, under the umbrella of a German project.[1] This has highlighted non-random differences between epilepsy and NES and patients' descriptions of unconscious/conscious states in terms of the degree to which these are experienced. Early work by FURCHNER (2002) showed clear verbal markers of consciousness in epilepsy patients—in that the "gap" in consciousness was clearly marked. Memories of before and immediately after the gap pointed to a movement in state from "dynamic to static", the end of which was often characterised by something unusual having occurred. The temporality of consciousness was recognised and people reconstructed their time spent being unconscious. People with NES however, often equated a seizure with complete unconsciousness and offered no reconstruction of this period (FURCHNER, 2002). Recent work has reinforced these findings, people with epilepsy still verbally placing the unconscious experience in the temporality of the seizure as a whole, defining between levels of consciousness and clearly marking the beginning and ending of unconscious periods. With some exceptions, people

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1   The project "Linguistic Differential-typology of Epileptic and other Seizure Disorders—Diagnostic and Therapeutic Issues" was subsidised by the German Research Association being undertaken at the Mara I Clinic, Epilepsy Centre Bethel, Germany (Chief Consultant: Prof. Dr. Peter WOLF). Members of the project were: Ingrid FURCHNER, Elisabeth GÜLICH, Martin SCHÖNDIENST, Meike SCHWABE, Nicolas TSAPOS. Between 1996 and 1997, this project was named "Formulation Patterns in Illness Narratives of Patients who suffer from Seizures" and supported by the University of Bielefeld, Germany. A corpus of transcripts was thus developed. Research has been continued in the UK with Professor Markus REUBER, Leendert PLUG and others and includes a research group entitled, NEST (Non-Epileptic Seizures Treatment) Group.

with NES continue to be unable to give detailed accounts of conscious ictal experiences (PLUG, SHARRACK & REUBER, 2008, 2009; REUBER & PLUG, 2007). [9]

Although the CA work has contributed greatly to differential diagnosis, exploring experiences of consciousness is a definite departure from CA because cognitions of conversation partners are peripheral to this method (Te MOLDER & POTTER, 2005). Cognitions of seizure participants are thus neglected to date and important to capture because they could potentially offer an additional understanding of seizure experiences. [10]

1.5 Rationale for using IPA

People with seizures are introducing concepts which require cognitive appraisal and it is important to explore them in this context given that descriptions of consciousness are implied in the differential diagnosis of seizures. IPA sees cognition as one "aspect of being in the world", and these cognitions are accessed through stories people tell us, the language they use and by our interpretation of these, cognition being "dynamic, emotional and embodied" (SMITH et al., 2009, p.194). It is because of this major theoretical difference between CA and IPA, that IPA could potentially uncover new aspects of the phenomena of seizure consciousness. [11]

Authors of the CA work have recently suggested that a comparison of individual ictal signs of consciousness and post ictal reports might extend our knowledge of consciousness in this context. It could shed more light on "phenomenal consciousness" and what it feels like to be in either an epileptic or non epileptic seizure, and on "access consciousness", that is, having certain "higher" cognitive processes at one's disposal" (REUBER & KURTHEN, 2011, p.95). Also lacking are subjective descriptions of people's experiences of differing levels and contents of consciousness (JOHANSON, VALLI, REVONSUO & WEDLUND, 2008; REUBER & KURTHEN, 2011). [12]

Knowledge about physiological events is only one view of what is happening to people during seizures. Subjective experiences are beginning to be recognised as important to consider along with their related, cognitive processes (PETITMENGIN, 2006). In neurology, a person's conscious state is often assessed from witness descriptions and individual vocabularies and may not illustrate the "vividness" of phenomenological seizure experiences (CAVANNA et al., 2008). This could seriously limit our understanding and definitions of ictal states relating to consciousness given the lack of a vocabulary available to people attempting to describe these phenomena (PARNAS et al. 2005; PETITMENGIN, 2006). 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 (PETIMENGIN, 2006). [13]

2. Representing Our Participants' Experiences

The motivation to represent data in this way came directly from *FQS*, being one of the first the first author (VF) accessed when embarking on her doctoral seizure research. As a "young" researcher, it provided a "model" of how qualitative findings could be expressed (GERGEN & JONES, 2008). Rudolf SCHMITT's (2002) review of BRÜNNER and GÜLICH's seminal work on people's descriptions of their seizure experiences sparked a personal interest in VF for using both metaphor and poetry. Thus support was available for moving beyond presenting findings more traditionally, i.e., from strictly reporting interview statements "impersonally" (ibid.; our translation) to offering up opportunities to "open doors for dialogue" and, importantly for this study, to find a way to write between disciplines (HANRAHAN, 2003). To be able to present what amounts to thousands of participants' words in a relatively short piece of work containing one, two or three poems is the result of a deep engagement with, and reflection upon, one's findings over time (BREUER, MRUCK & ROTH, 2002), observing the effect of having epilepsy had on two particular men. It goes without saying that these particular findings have undergone stringent methodological processes which are available for others to see, these being "complex" (HANRAHAN, 2003, §1). More importantly however, the findings herein embrace what HANRAHAN describes as having "ecological" meaning (§5) That is, they combine neurology, medicine, biology, psychology, philosophy, researcher reflections and reflections of participants (who have expert, subjective, tacit knowledge of their own biological systems fundamental to seizure experiences). Indeed, their temporarily, disrupted systems may even affect how they think and feel about these experiences (HANRAHAN, 2003). This new "voice" (MacKENZIE, 2008), that of performative social science (GERGEN & JONES, 2008) facilitates the portrayal of findings to an academic audience, offering an understanding of how people come to know what they know within a particular ecological context (HANRAHAN, 2003). [2] [14]

How we represent our participants' words is important, and has been long debated (GLESNE, 1997). Qualitative researchers have always exploited the possibilities of various ways of doing this (SPARKES, 1999). Presenting findings in different modes and foci may allow previously hidden aspects of the objects of our interest to be seen (BLUMENFELD JONES, 1995). Medical sociology points out the potential of using novel methods of collecting and interpreting data and that there is "uncharted terrain" and there are "missing voices" within this literature (LAWTON, 2003, p.25), valuable in their own right. Experimenting with different methods can enhance findings and, potentially, make them accessible to wider audiences (RICHARDSON, 1998). Findings can be presented in such diverse forms of performance science as screenplays, artwork, dance (BAGLEY & CANCIENNE, 2001), metaphor, quilt making, plays and pastiche (HUNTER, LUSARDI, ZUCKER, JACELON & CHANDLER, 2002), or "writing with light"— using photography (SZTO et al., 2005, p.140). These techniques can all be

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2 This includes our participants. That patients have their own expertise which is neither inferior nor superior to that of doctors (TUCKETT, BOULTON, OLSEN & WILLIAMS, 1985) and researchers, is acknowledged by this study, by seminal researchers undertaking the work at the Epilepsy Centre Bethel (see Note 1) and by other *FQS* authors (BOLAM, GLEESON & MURPHY, 2003).

subsumed under the terms "expressive and creative arts research", and are grounded "in the empirical world" (p.138). [15]

2.1 The emergence of poetry as a form of representing research findings

Poetic representations (RICHARDSON, 1994) emerged from postmodern ethnography, representing "an important turn for both theory and research on social science writing" (RICHARDSON, 1992, p.132), and were welcomed, in particular, by interpretivists. Other terms and methods used for this form of representation include "approximated poetry", which shapes the concentrated language of an individual into a version of the "truth" (GLESNE, 1997) and poetic condensation of narratives (ÖHLEN, 2003). Also, using an original poem as "data", coding this, the emergent themes then being compressed into formal poetic structures, can highlight different aspects of the findings. Honing in increasingly closer to these aspects results in the use of minimal words (FURMAN, 2006). Poetic representations can thus depict core themes and narratives relevant to these themes, using powerful, evocative language economically (POINDEXTER, 2002). Such representations have the potential to illustrate "truth" if they impact on a reader and give a real sense of the phenomenon in question (RICHARDSON, 2000). [16]

2.2 Examples of other authors' work crafting poems

GLESNE (1997) developed her own form of poetic transcription from generating themes in transcripts, coding and sorting them, keeping participants' ways and rhythms of speaking. The resulting work conveyed Puerto Rican political and social history as GLESNE wove the story of her participants' lives and work into "approximated poetry". She swept away research conventions in an attempt to combine both scientific and literary endeavours. Undertaking poetic transcription in this way, she argues, makes the process of analysis even more transparent (GLESNE, 1997). [17]

KILLICK (1997) talking to people with Alzheimer's across a decade, poeticised several aspects of how people lived with this condition. People spoke of their confusion and panic, what it meant to live in a nursing home, family relationships and other subjects, using emotional, metaphoric and sensual language. The poems illustrated that people still maintained some of their humanness, resilience, wit, insight, humour and creativity, mitigating against the myth that people with Alzheimer's lose such personality traits (BENSON, 1997, in KILLICK, 1997, p.5). Their memories and insights helped them come to terms with what life was like for them before and after the disease. In some cases the words were used exactly how they were spoken, the lines simply being rearranged on the page (KILLICK, 2005). [18]

Poems have been used to understand clinical practice. An analysis of poems collected from American midwives' lived experiences championed "multiple ways of knowing" and that intuitive, experiential and contextual knowledge can offer holistic care for women (HUNTER, 2008). Poetry has been used to manage

intense reactions to extremely traumatic events and to help with experiences of grief (BRACEGIRDLE, 2012). [19]

Some authors use formal poetic structures such as *tanka*[3] in order to capture central concepts (FURMAN, 2006). Others have used the collective words of participants to form a story from the memories of a group of people, using central phrases and images from these. Common to all however, is that they are all based on empirical data, use the images the participants' produce and are easy to "consume" (FURMAN, 2006). [20]

2.3 Diamond cutting and crafting the poetic interpretations

Generating poetry from research interviews involves the researcher in bringing out the depth of experiences in various creative ways whilst attempting to illustrate as clearly as possible how they did so. This is not an easy task relying as it does on the instincts, hunches (POINDEXTER, 2002) and creativity and reflexivity of a researcher with no "prescriptive rules" to guide them (BOLAM et al., 2003, §1). However it is done, poeticizing participants' voices remains a controversial undertaking, as there are no formal methods of evaluating it, be it scientifically or artistically (POINDEXTER, 2002), and there is no consensus on what the elements of a good interpretation are (DENZIN & LINCOLN, 1998). [21]

"Diamond cutting" refers to the carving and chipping away in the transcript of material other than that which contains the kernel of the phenomenon (POINDEXTER, 2002, p.709). Compressing participants' words is the major tool in poetic interpretation (SZTO et al., 2005). Poetry can be defined as including, "compression, image and metaphor", "the clarification and magnification of being, through words", or, "the distillation of the essence of being, through language" (p.146). It can involve the lives of the researchers and, potentially, generate theory. [22]

Simple devices such as repetition (ÖHLEN, 2003), word reduction, maintaining the rhythms of people's speech and repeating words and phrases, can be an integral part of a new poetic configuration (GERGEN & JONES, 2008; RICHARDSON, 2000). Taking excerpts from different parts of conversations can also be appropriate, as was done in the poetic interpretations presented here. However, care was taken not to move the words far beyond their original places in texts (GLESNE, 1997) as this can "become a description too far from the narrated experiences of the participant" (ÖHLEN, 2003, p.559) and the narratives need to speak for themselves.[4] The mode in which we write can also affect our poetic interpretations and some argue that computers have transformed this process. Unlike speech, the words on the screen can be moved, deleted, copied

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3 A thirty-one-syllable poem, traditionally written in a single unbroken line or *pantoum*—a modern pantoum being of any length, composed of four-line stanzas, the second and fourth lines of each stanza serving as the first and third lines of the next stanza. The last line of a pantoum is often the same as the first.

4 Appendices 1, 2, and 3 contain the parts of participant's original transcripts and emboldened text is where the poems' words and phrases originated from.

and added to with ease, always looking professional and complete. We can edit, alter and revise them, until we are satisfied with the finished poems (VAN MANEN & ADAMS, 2009), the form and content of which inform and capture readers' interests (SANDELOWSKI, 1998). [23]

The people who were experiencing epileptic seizures offered moving insightful, in-depth temporal descriptions of these. The terms we use for these constructions are "poetic interpretations"—interpretation meaning moving words and phrases around and placing them to emphasise meanings—rather than interpretation in the sense of interpreting those words and phrases, a different endeavour (SZTO et al., 2005). Our "diamonds" were cut from different parts of the conversations between participants and VF. Repetition emphasised meanings, and maintaining participants' own speech rhythms and reading them aloud helped gather an idea of their impact. The poetic interpretations below are representations of selected incidents and parts of participants' accounts/experiences they described aiming to represent these in short, "elementary" forms (LANGDRIDGE, 2007, p.161) easy to understand and engage with. [24]

3. Three Poetic Interpretations

The first poem depicts this man's perceptions of his first seizure experiences, his awareness and consciousness, bodily sensations and his process of realising and accepting that he had epilepsy. His poem is taken mainly from the beginning of a first conversation with VF, incorporating elements of a written description he provided her with, with his wife's words making up the final two lines of the poem. This poem was one phenomenological moment, existing at one point in time only. When VF met with him again 18 months later, he could not relate his present experiences to what he had written about them earlier. Reading the poem again, he said; "I don't really notice it" ... "*I* don't feel it". [25]

3.1 Poem One

"Going funny"

Drawn away the company I was talking to, this feeling of being with—but totally apart from
I was there but, indeed, I wasn't
I seemed to be totally removed

I have become epileptic

When I came back I knew I'd been—it almost felt as I'd had been somewhere else
I hadn't been *there*
But when I came back I realised that I hadn't left

I had become epileptic

As I pulled away, I seemed to be suspended
I could see the people I was talking to, but the *contact* seemed to be broken
I seemed to have been taken away

I had become epileptic

> The contact I was making, even though I could still see, the contact with them was no longer there
> I was *trying* to speak but it was mumbo jumbo
> The contact had been broken
>
> I had become epileptic
>
> Because I failed to realise just what was actually going on
> And I couldn't understand the reality of why
> He isn't there, he's gone
>
> He has become epileptic

After sharing the poetic interpretation with this man, he endorsed it as epitomising his experiences at that point, "that is exactly it yeah, the second verse actually depicts the reality of the total". He commented on the repeated lines in the poem and agreed that, the first time VF met him, he was coming to terms with having the condition whereas eighteen months later, he told her, "I have to accept it because it's real." [26]

3.2 Poem Two

The second man depicted two similar stories in two poems describing his behaviour "in autopilot". Both poems illustrate behaviours that he is unaware of and cannot control. The surprise he first felt about these experiences is clearly depicted in his first poem, as he realised that he is undertaking complex tasks. This poem illustrates that he could still respond to imminent danger in his environment even though he remembered nothing. This man had also presented in an Accident and Emergency Department following a physical assault of which he also remembered nothing.

> **"In autopilot"**
> But another worrying thing is the black outs
> Yeah, it may not be a fit but—me brain just seems to turn off and I can walk around
>
> Not know where I am
> Not know where I've been
> Not know what I've done
>
> I started to feel rough like something's pressing down, pulling down my head or whatever
> It's like being in a football crowd and everybody's screaming at you for attention
> But you're not able to respond to any of them
> It's basically, how can I put it
>
> Half awake, half asleep and this part—that's where the scream's coming from
>
> I knew I wanted a couple of onions and a bag of potatoes
> The next thing I remember is being stood on the middle of a road looking at a lorry coming towards me
> I'd stopped right bang smack in the middle of Bounty Road looking at this lorry coming towards me

I don't know
I just came to
I can move like a rocket when I want to!

Ah, but this is a weird one—carrying a bag of potatoes, yeah

Autopilot.
I'm in auto pilot
I'm in auto pilot [27]

3.3 Poem Three

The second poem from this participant was constructed from a second interview conversation, eighteen months later. His perception had shifted along a trajectory, from one of his experiences being novel to him, to frustration that these things happen to him, to one of resignation that he can do nothing about them.

"The coconut day"

How can I put it—the coconut day
The coconut day, yes
When I have my little day dreams where things, where I'm walking, or whatever
When I went out for some food, well I went out for milk, something to eat

I noticed the day previous, I noticed you know
I noticed the day previous—coconuts 60p

I went out with three quid, walking down the street and I had me rucksack on
Anyway, I gets home, thought never occurred to me
I gets home, and guess what's in me rucksack

Five bloody coconuts
Five bloody coconuts
Five bloody coconuts

It still bugs me now
How on earth do you walk into a shop to buy five coconuts
How do you do it
Well, I mean

Obviously I do [28]

4. Discussion

Re-presenting findings in this way is just one prism in a crystal which, potentially, offers many different views of the same phenomena (DENZIN & LINCOLN, 1998), the crystal being a central image which reflects and refracts angles of approach and pictures of reality. This deconstructs the traditional notion of validity and that there is one single triangulated truth, and offers us instead "a deepened, complex, thoroughly partial, understanding of the topic" and, emerging from this complementarity would be "overlapping and different facets of a phenomenon" (CRESSWELL, 1994 in JOHNSTONE, 2004, p.264). [29]

The men used their personal vocabulary and lexicons to express their embodied and emotional experiences and these translated readily into poetic evocations of their experiences. The placing of some of these words, both temporally and physically on the page, captures the essence of particular aspects of their ictal conscious experiences and give an idea of "what it feels like to be" in an epileptic seizure. [30]

As early experiences, the first man's are particularly valuable and irretrievable because he was unable to relate to his poem the second time we met. By then, he conceptualised his experiences by using everyday examples of things we may all have experienced to describe his seizures, "you come out, you go to get in your car, another car, there's another car, the exact same car, put your key in, you wonder why you can't open it." Although useful analogies, and a common strategy for people when describing their gaps in consciousness (THOMPSON et al., 2005), a poem constructed from these words would be very different to what is shown above. [31]

After reading his poems, they triggered a memory for the second man of a similar event in his childhood when he was around eight years old, "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 and of which I have no memory!" His poems remained stable as experiences, although it was clear when VF met with him a second time that he wanted to dissociate from the experiences depicted in the poems. [32]

4.1 Conscious experiences

The men's experiences are very different but the poetic interpretations clearly illustrate that "higher" cognitive processes are at work and different levels and contents of consciousness are recalled. This is clear in the first man's poem as his internal world alters and he becomes aware that he is unable to communicate with others while being aware that he is "still there". He utilises embodied language and "conceives of abstract concepts in physical terms" (GIBBS, 2006, p.440). Because as human beings we have shared experiences such as what it feels like to float, to look down on other people from a height, or to daydream (ibid). We can, therefore, "understand something of what other's experience" (WILDE, 2003, p.171). This man also comes to some reconciliation of the fact that he had epilepsy. [33]

Cognitive processes are also evident in the poetic interpretations associated with the second man. Although he calls his experiences "black outs", and suggests that his "brain just seems to turn off", he knows he can also still "walk around". He alludes to a period of "partial absorption", whereby he is aware of what is going on around him even though his attention is directed inwards (JOHANSON et al., 2008). He says he is not conscious but half awake and half asleep, i.e., "in autopilot". These experiences point to him being able to somehow perceive what is going on around him—after all he (or his perceptual system) takes avoiding action and he is not killed by an oncoming lorry. That perception can exist without

awareness is an on-going debate between sceptics and believers (SIMONS, HANNULA, WARREN & DAY, 2007). The subjective experience of this man and others like him are worthy of study in their own right, could contribute to a debate on what consciousness *is,* and have implications for medicine, neuropsychology, neurophenomenology and philosophy. [34]

4.2 Other linguistic characteristics

Some of the language in the second man's poem, "pressing down", "pulling down", "everybody's screaming at you", and "stopped right bang smack", resemble what are described as "metaphorical predications". Metaphorical predicates in general help express the qualities of things and experience (TYE, 2003) and can be useful for people when describing something. The use of words such as "sharp", "stabbing", "pointed", "pinched", "lightening", "cutting", "dull", "burning", "convulsive", "tickling", "prickling", "electric" could be valuable linguistic resources for people because they add depth to the meanings of experiences (MENZ, LALOUSCHEK, REISIGL, SATOR & FRICKEY, 2005) without them having to formulate more complex metaphors. This man uses these linguistic devices to describe auditory sensations (JOHANSON et al., 2008) for example, when he interprets his feelings of people in a crowd shouting at him, as their voices hitting the top of his head. [35]

4.3 The usefulness of poetic interpretations

As people attempt to live with a medical condition, their body becomes the focus of their attention. ÖHLEN (2003) argues that bodily experiences can shape participants' narratives and, as the findings of this study illustrate, these are often poetic, evocative and powerful. Poems stemming from individual narratives rooted in a person's embodied experiences can include symbols, images and metaphor, and can reveal unconscious knowledge (BRACEGIRDLE, 2012). [36]

Both men's experiences point to the usefulness of collecting further experiences from people experiencing seizures—epileptic seizures in the case of these two particular men. Using IPA, there is the potential for remembered subjective descriptions to be "collected" over time, to compare them to other people having the same seizure types and to correlate them with objective measurements such as EEG, brain imaging and behaviour for differentiation of epilepsy and NES. Shared with participants, poems could be used to support people in their acceptance, understanding and management of the conditions they find themselves coping with. They could form part of patient information booklets for patients and carers so that aspects of a condition (such as seizure consciousness) could be more easily assimilated and understood. Poems could play a role in clinical practice because they can inform lay and professionals about what "it is like to" live with certain conditions in a concise form within a time limited consultation. Encountering a patient's poem could add to a professional's understanding and engagement with them. It could add a hermeneutical element to their consultation styles as they move beyond their pre-formed ideas and established consultation practices towards those that "recognize the equal

legitimacy of the patient's need for self expression" and, consequently, fuse scientific knowledge with human experiences (CLARKE, 2008, p.60). They could be also used in counselling practice, for example to make sense of distressing events or situations (BRACEGIRDLE, 2012). [37]

5. Conclusion

KILLICK's "poets" impressed upon him that "[a]nything you can tell people about how things are for me is important" (2005, L.147). As editors of other people's words, and as qualitative researchers, we write their stories (VANDERFORD, JENKS & SHARF, 1997). The responsibility remains with us to represent these stories in ways which are easily understood by others. These particular poetic interpretations extend the boundaries of IPA, being rooted in subjective, qualitative descriptions of seizures—something rarely studied (VOLLMER-LARSEN, HANDEST & PARNAS, 2007*).* They herald the potential to function as both research (SHINEBOURNE, 2012) and clinical texts, offering up new vistas on seizure consciousness. [38]

With its specific focus on individual, embodied experiences and commitment to cognition, IPA is ideally located theoretically to extend our knowledge of "phenomenal" and "access consciousness" during seizures. Poetic interpretations offer us a version of a person's narrative of their experiences and can be used to punctuate in-depth phenomenological descriptions. Accumulating a corpus of "seizure discourse" data would represent a shift from subjective to intersubjective knowledge. Giving patients space and time, using an appropriate methodology, to verbalise what are "fleeting" and "ineffable" experiences (PARNAS et al., 2005, p.237) could serve to enhance and inform our understanding of the experiences of ictal consciousness. [39]

Acknowledgements

Appendix 1: Poem One, Participant's Original Words[5]

The paragraph below is a fragment of this participant's written description of his experiences given to VF when they met for the first time:

> "At first these feelings were difficult to understand and even harder to explain. You see I felt that I was drawn away the company I was with and talking to; there was this feeling of being with, but totally apart from. It seemed to me to be quite inexplicable! You see I was there but, indeed, I wasn't. Even now I find it hard to explain the reality of what was going on; it is still confusing to me. The feelings of these moments are in fact quite altruistic to me and yet, like cubism, not really understood."

First conversation between participant (V) and VF: Lines 25-43

V: Ok well basically it started off—I was having these "situations" and they started last year—where I was talking to, talking to people and **I seemed to be totally removed** and well, E***** [* ensures anonymity to wife's name] will be able to tell you much better, how my voice went—. How did my voice go E*****?

WF: Well, just went funny—couldn't understand him

VF: Couldn't understand him? Incoherent sort of—you couldn't understand the words?

V: and basically that is, is what happened and—**when I came back I knew I'd been, it almost felt as if I'd been somewhere else. I hadn't been there, but when I came back I realised I hadn't left**. So I didn't, I didn't comprehend it at all, so I saw Dr D***** [general practitioner] about it and Dr D***** got in touch with Dr M*** [neurology specialist]. And Dr M*** put me through these tests and found there that er, there was something going on up here in the brain and that I, **I had become epileptic** and that's about, the whole thing. I can't really describe it any better, other than the fact that I. **As I pulled away, I seemed to be suspended**—I was slightly moving away from—and that I can't comprehend at all.

First conversation, Lines 76-113

V: yes that's what it felt like as if I was lifted away ... **I could *see* the people I was talking to** but as the ... erm what's the word?—**the *contact* seemed to be broken** and that's one of the points that erm, I *don't* understand—it didn't seem to make an awful lot of sense.

VF: Did the, the fact that you broke contact with somebody—that didn't make sense to you?

V: What—was the fact that **I seemed to have been taken away—and the contact I was making—even though I could still see**

VF: You could still see them?

V: yeah ... but **the contact with them was no longer there**.

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5   V = participant; VF = Val FEATHERSTONE; WF = wife; "..." = pause in speech; italics depict verbal emphasis by the participant; emboldened text is that used in the poem.

VF: By contact you mean you couldn't speak to them.

V: I mean **I was *trying* to speak** but as E*****'s just told you, **it was mumbo jumbo**.

VF: Mmmm

V: and **the contact had been broken because I failed to realise just what was actually going on**.

VF: You failed to realise

V: Yeah

VF: That you were—because you said that you had been lifted—felt as though you had been lifted away.

V: **And I couldn't understand the reality of why**—you know. what it meant.

First conversation, Line 551

W: He isn't there, He's gone

Appendix 2: Poem Two, Participant's Original Words

First conversation, Lines 183-260

D[6]: Well I told you, it's on record with Dr C*** **but er another worrying thing is the black outs**.

VF: on top of the fits?

D: **yeah, it may not be a fit but ... me brain just seems to turn off and I can walk around, and not know where I am where I've been, what I've done**

VF: right

D: for example, em the worse one I'd been to me doctors, on A******** Road, picked up a prescription, er went to Boots, got me prescription and **I knew I wanted a couple of onions and a bag of potatoes**. So I thought, I'll go down N****** Ave, into a veg shop get the onions and potatoes. So I went to the er veg shop near er Nag's 'ead, looked at the price of potatoes and thought, well I'm not buying 'em here. I got a couple of onions, and I thought well, I may as well go to Aldis, or Netto's

VF: yeah

D: so I though I know where I wanna go, down at bottom of Newland, round the bend, cross into P****** Park, through P****** Park, well back of Aldis, P*** street or was it C*** Street? Aldis, get the potatoes and back home again. 'Cos I live just off S*********. I could remember er getting up to about er P****** Ave, **I started to feel rough**

VF: how does rough feel like?

---

6   D: Participant

D: 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**

VF: right

D: **and you're not able ter** ...

VF: respond?

D: **respond to any of 'em**.

VF: but they weren't—nobody was screaming at you

D: No, no, course not, no and I said I can remember just getting to Pearson Park, and **the next thing I remember is being stood on the middle of B******* Road, looking at a lorry coming towards me**.

VF: oh gosh

D: **ah but this is a weird one, carrying—a bag of potatoes**

VF: oh my goodness, you must have done all that unconsciously then

D: yeah. So I'd ran through it in me 'ead, what I was gonna do,

VF: yeah

D: so I've gone onto automatic and actually done it

VF: yeah

D: but unfortunately, **I'd stopped right bang smack in the middle of B******* Road looking at this lorry coming towards me**

VF: did you stop there because you, why did you stop in the middle of the road do you think?

D: **I don't know, I just came to**

VF: ah you came to, that's what I mean that's where you came too then

D: yeah,

VF: and you didn't get killed obviously!

D: laugh, I can move like a rocket when I want to!

First conversation, Lines 650-693

D: what it feels like .... in my brains.

VF: explain that then

D: that's a crowd,

VF: I see, right, that's a crowd of people, demanding attention, yeah, right and you're you, there, right are you sort of conscious then then?

D: nnn, no

VF: but you still remember that?

D: yeah

VF: right, ok, right?

D: **It's basically** em ... **how can I put it**? Em, **half awake, half asleep**, semi conscious **and this part**

VF: the front of your head?

D: yeah, and **that's where the scream's coming from**.

VF: right, and then what happens?

D: mmm

VF: you can turn over if you like

D: just a minute, I'm just gonna,

VF: oh is that the potato business?

D: **autopilot**

VF: but you, so somewhere in there, you've bought the potatoes? And come round again

VF: because you make cups of tea and put the telly on

D: I'm in auto pilot

Appendix 3: Poem Three, Participant's Original Words

<u>Second conversation, Lines 84-103</u>

D: **When I have my little er day dreams where things where I'm walking or whatever** where things er How can I put it, the coconut day.

VF: **The coconut day**

D: The coconut day, yes. **When I went out for some food, well I went out for erm milk em, something to eat**, I was getting paid the next day, well I want some milk, I'll get some fish and chips or, a snack of something 'cos I get paid tomorrow. I noticed the day previous, **you know** on N****** Ave

VF: Yeah

D: **I noticed the day previous—coconuts 60p** right? **I went out with three quid, walking down De G**y Street**, anyway walking back down Q****s road **and I had me rucksack on. Anyway, I gets home, thought never occurred to me**, you know **I gets home, and guess what's in me rucksack, five bloody coconuts**, five bloody coconuts, **it still bugs me now**, five bloody coconuts, loudly

VF: Right

D: **how on earth do you walk into a shop to buy five coconuts**, loudly

VF: you've done this before though haven't you?

D: I know but **how do you do it** (loudly)

VF: You do it

D: **Well, I mean er, well obviously I do** 'cos er, but er, the ...

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