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Review

The promises and pitfalls of seizure phenomenology

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ABSTRACT

The typical adult patient presenting with a first seizure has a normal clinical examination, uninformative investigations, and often has no witness to their episode. The assessing clinician, therefore, has one primary source of information to guide their assessment; the patient's experience. However, seizure *phenomenology* – the subjective seizure experience – has received relatively less attention by researchers than objective semiology or investigations.

This essay reviews the clinical importance of seizure phenomenology, and the challenges clinicians face in eliciting accurate and clinically relevant descriptions of ictal experience. I conclude by discussing tools that clinicians may use to support the clinical application of seizure phenomenology, and exploring the subjectivity of epilepsy more broadly.

1. Introduction

> *Language is demanded by epilepsy, as by poetry, that simply does not exist; and no amount of agility can create it any more than tight-rope walking or dancing can create wings. Language can, however … suggest that greater wordless language within from which mental and spiritual discovery issues. It can suggest truths which are the more certain for being inarticulate.* – Margiad Evans, *A Ray of Darkness* [1](p172)

The typical adult patient presenting with a "first seizure" has a normal clinical examination, uninformative investigations, and is asymptomatic at time of presentation [2,3]. A witness report may be, but is not invariably, available; and will not reliably identify features of greatest interest [4]. This leaves clinician and patient with one key source of information for understanding the patient's complaint; the patient's own experience.

The subjective seizure experience – the *phenomenology* of seizures – is thus clinically indispensable. It guides the differential diagnosis of paroxysmal events like seizures, even in presentations involving apparent loss of awareness [5]; it aids distinction of focal from generalised seizures [6], or recognition of a prior history of multiple seizures [2,7]; it can be used to guide behavioural or psychotherapeutic adjunctive management strategies for people with epilepsy [8,9]. However, understanding seizure phenomenology has received relatively less attention from researchers than investigations. Consequently, subjective aspects of seizures are under-described and under-recognised [10].

This relative neglect compounds the difficulties already inherent in 'taking the history' from people who experience seizures. More focused study of the ways in which phenomenological accounts of seizure experience are constructed reveals some of the challenges and pitfalls inherent in this act. People who experience seizures often find it difficult to describe their seizure experiences [11,12] due to problems of articulation [13] or recall [14], or stigma and embarrassment surrounding certain types of experience [6,15,16]. More fundamentally, work in both the philosophy of medicine and neuroscience of perception and memory challenges the idea that there is a single valid description of 'what it is like' for that person to have a seizure [16–19].

This paper reviews the clinical significance of, and challenges in describing, seizure phenomenology. It concludes with a discussion of recent efforts to improve elucidation and clinical application of the subjective experience of seizures.

2. The clinical significance of seizure phenomenology

> *Listen to the patient. He is telling you the diagnosis.*- attr. William Osler

The proliferation of video recordings of seizures – whether from formal video-EEG, or increasingly from home or smart phone recordings – has produced a wealth of valuable research on semiology – the external, observable appearances, or 'signs' – in the assessment of seizure disorders. What these videos – and thus research based on them –

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fails to capture, however, is the inside, first-personal experience of the seizure – its phenomenology, or *symptoms* [20].

The under-recognition of seizure phenomenology has implications for assessment, diagnosis, and management of seizure disorders. Time to diagnosis from first seizure in those with 'non-motor' seizures (i.e. with predominantly subjective manifestations) is over 20 months, 10 times longer than in people with (visible) motor seizures. The fact that 'non-motor seizures' are essentially characterised by episodic subjective symptoms does not mean that they are clinically irrelevant; 82.6% of motor vehicle accidents in those with undiagnosed epilepsy occur in those who experience nonmotor seizures [7]. The failure to identify subtle subjective symptoms (such as those caused by focal epileptic discharges prior to a generalised seizure) can also affect treatment; epilepsy is likely to be misclassified as generalised when initial ictal 'aura' symptoms have been missed [6]. Consequently they may receive antiseizure medicines with suboptimal effectiveness for their particular epilepsy syndrome or they may not be considered for treatments such as epilepsy surgery. Even if considered, we lack adequate research on how seizure symptoms might support localisation. Despite the value of certain seizure symptoms for localisation being established at least as far back as Hughlings Jackson's writings on the "dreamy state", amongst studies of localisation value of seizure signs or symptoms, only 25% of the most-commonly studied seizure manifestations were subjective [21].

Recent attempts to redress this imbalance show the potential for clinical application of seizure phenomenology. Systematic enquiry regarding seizure symptoms can improve differential diagnosis of epileptic seizures from functional/dissociative seizures and syncope [5,22]. Detailed phenomenological interviewing shows potential of identifying prodromal symptoms that patients find difficult to articulate, but once identified could be used as target for seizure self-control. Identifying such symptoms now forms part of behavioural interventions in epilepsy [8,23].

Such results have prompted a renewed interest in characterising seizure phenomenology in greater detail [9,10,20]. Describing the experiences of seizures, however, is not a straightforward task.

3. Challenges in eliciting the seizure history

3.1. Describing the indescribable

> *[I]t's a feeling that I don't know and cannot associate with something. It's as if you had to describe the colour blue but you don't know what blue looks like.* – Anon. 48-year old male with right temporal lobe epilepsy [9]

In order to make clinical use of seizure phenomenology, the person with seizures has to be able to share that experience with others – most notably, their clinician. We are accustomed to thinking of the sharing of symptoms in clinical encounters as a straightforward issue – the patient comes in with a 'presenting complaint', which the clinician then interprets with reference to other data regarding their history, examination, and investigations. However, in arriving at this 'presenting complaint' the initial experience has already undergone several stages of interpretation –the patient's becoming consciously aware of an anomalous experience [24], the initial parsing of that experience with reference to our prior expectations [18,19], and the personal and social negotiations that transform an anomalous experience into one that is a candidate for explanation in pathological terms – a potential 'symptom' [25,26]. Cultural, social and economic context affects 'candidacy' for such explanations [27], and patients undertake specific conversational manoeuvres in the consultation to represent these experiences as 'doctorable' [28].

Studies in the phenomenology of illness highlight that, even once in the clinic room, aspects of illness experience can convey its sharing between patient and clinician. Philosophers of medicine Havi Carel and Ian James Kidd argue that illness experience is often *inarticulable* – they may lack the words or concepts to translate those experiences into terms another can understand. Beyond that, it may be *ineffable* – that is, of a kind that can be understood only by going through the experience personally [17,29].

There is strong reason to believe that people with seizures often find their experiences inarticulable, and some propose that they are ineffable. Attempts to elicit seizure phenomenology in the clinic recurrently demonstrate the difficulties people with epilepsy have in articulation. They will say 'this is hard to describe', or 'I don't know how to say this' [11]; linguistic studies have demonstrated that their attempts to relate these experiences are marked by a very high degree of 'formulation effort' – hesitations, false starts, rephrasings and recapitulations, as they struggle to put into words what it is like for them to have a seizure [11,13,30]. They often resort to metaphor as a means of articulating experience for which – as the opening quotation suggests – "language does not exist" [9,31]. People with epilepsy – and with other seizure disorders like functional/dissociative seizures (FDS) – are more likely than healthy controls to struggle particularly with identifying and describing emotional experiences; rates of alexithymia in people with epilepsy range from 25.9–76.2%, and 30–90.5% in people with FDS [32].

Moreover, some such experiences are held not just to be inarticulable, but ineffable. This is particularly the case with 'ecstatic' seizures – focal aware seizures, usually (but not invariably) localising to the temporal lobes; those who experience them may fail to describe them ("*these sensations are outside the spectrum of whatever I have experienced*"); or describe them in nonsensical terms ("*an oscillating erotic sensation, like twinkling polar light*"; "*I can sense the colours red and orange without seeing them*") [33,34]. They may draw from spiritual, religious, or erotic metaphor to give some indication of the nature of these experiences [35], but ultimately find them so far outside the normal realms of intersubjectively understood human experience that they cannot be shared in words.

To Kidd and Carel's list, we can add the difficulties some people with seizures face in finding their experiences *unspeakable* – that is, unable to be shared due to concerns regarding the social or psychological consequences of admitting to them. Some people with seizures report difficulty or unwillingness to describe their experiences due to fears of being labelled mad or otherwise stigmatised; they are surprised and relieved to find, on direct questioning, that their symptoms represent recognised ictal phenomena [6].

For people with FDS, meanwhile, the unspeakable nature of their symptoms may even play an aetiological role. The role of shame, stigma, and trauma in the precipitation and perpetuation of FDS is nuanced and still controversial, but all three are related both to each other and FDS in ways that may render seizure experiences unspeakable. FDS is a stigmatised condition [36]; such stigma is experienced by people with stigmatised conditions as "shame anxiety", or the chronic anticipation of shame [37]. Shame – a self-conscious emotion of being inadequate, immoral, or otherwise negatively-evaluated in the eyes of (real or imagined) others – provokes responses of withdrawal or attempts to conceal [38]; mechanisms of shame regulation such as self-directed aggression or social withdrawal share semiological characteristics with FDS [39]. Prior traumatic experiences, while not necessary for developing FDS, are seen more frequently in people with FDS than controls (OR 3.1 [1.7–5.6]), and emotional neglect may be still more common [40]. Such experiences both increase general shame-proneness, and can be a source of shame [39]; most strikingly in FDS associated with 'unspeakable dilemmas', where people with FDS experience seizures in the context of apparently irremediable social conflicts [15]. This combination renders the experience of FDS particularly vulnerable to being held unspeakable. If the seizure is understood as a dissociative release from intolerable experiences [41]; the reason for their being intolerable is intrinsically linked to events the person finds shameful [39,40]; and the disclosure of seizure experience might result in a diagnosis that is stigmatised, and thus a source of further shame [36]; then it is not hard to

understand how it may be particularly difficult for the person with FDS to share their experiences. Consequently, in initial clinical encounters they expend little effort in, and volunteer little information about, the subjective experience of their seizures – emphasising instead the subjectively-barren 'gap' in their experience [11].

3.2. Recall, responsiveness, and awareness

> *[R]etained awareness usually includes the presumption that the person having the seizure later can recall and validate having retained awareness.* – the Operational Classification of seizure types by the International League Against Epilepsy [42]

If the above problems highlight the difficulties in converting a first-person seizure experience into an interpersonally-shared seizure history, the challenges for seizure phenomenology go still further – the person who experiences seizures may have different recollections of that experience, depending on when and how they are asked to describe the experience. A person's subjective seizure experience, described at one time, may fundamentally differ from that described at another.

This is most strikingly illustrated in the difference between seizure descriptions captured intra-ictally, and from recall afterwards. The difference between seizure experiences narrated intra- and post-ictally is so marked that, as quoted above, the ILAE deemed it necessary to clarify the time point at which 'awareness' is assessed for the definition of focal aware seizures [42]. Intra- and post-ictal accounts differ systematically. Even for some of the most basic ictal features, such as whether or not a person is able to respond to others, post-ictal subjective reporting shows poor concordance (Cohen's $\kappa = 0.434 \pm 0.006$) with ictal assessment [43].

When looking at more fine-grained description of subjective seizure experience, the differences are still more striking. In one study, only 45.6% of seizure symptoms described by participants intra-ictally were recalled post-ictally [44]. For most symptoms, reporting was greater intra- than post-ictally; given seizure activity often disrupts mesial temporal networks essential for memory encoding and consolidation (and seizure recall correlates with EEG activity in these regions) [45,46], this is perhaps unsurprising. However, disparities between intra- and post-ictal accounts of seizure phenomenology are not simply a function of memory impairment; visual phenomena were found to be more likely to be reported post- than intra-ictally (reported intra-ictally in 4 seizures vs. 8 seizures post-ictally) [44]. Seizures with non-dominant parieto-occipital foci have also been reported to produce transient neglect or anosognosia [47], or transient Anton's syndrome [48]; ictal disruption of attention networks may transiently and selectively impair awareness of or engagement with certain sensory experiences, or produce disconnection syndromes, just as these networks are more persistently impaired with structural lesions affecting those networks [49].

3.3. Whose story?

> *The whole of medical discourse on epilepsy is underpinned by the belief that seizures are sudden, that they cannot be anticipated by the patient. We have observed that this belief considerably hampered the awareness and description by the patient of the early symptoms that could enable him to anticipate and manage his seizures.* – Claire Petitmengin [50]

If these phenomena prove troubling for the clinician attempting to construct a clear account of a person's seizure experience, they at least allow for a single such account in principle to exist – they simply highlight that the patient may find themselves unwilling or unable to share that account, or ictal network disruption may impede its reporting or recollection. Beyond this, however, the clinician must acknowledge that our phenomenal experiences – and their subsequent reports – do not allow for a single, privileged version; they are shaped by our prior expectations, conceptual resources, and intended purposes.

The general phenomenon of top-down influences on perceptual processing has been a subject of neuroscientific research for some decades. Well-established results demonstrate that cognitive manipulations can influence subjective experiences as diverse as sight [51], sound [52], pain [53], and body ownership [54]. More recently, the predictive processing paradigm has explained this by modelling perception as a constructive and active process; internal representations of experience – shaped by past experience, socially-shared conceptual resources, and contextual factors – are contrasted with sensory input, discrepancies ('prediction error') between these modifying subsequent experiential representation [18,19,55].

Such expectational influences not only moderate our perceptions, but also our memories of them. Prior expectations shape new episodic memories, and bias our recollection of characteristics according to our categorisation of experiences [56]. Translated into clinical terms, this could imply that symptom experiences may be biased toward those expected by prior descriptions of symptom experience – people will remember their illness experiences more, and more in line with, their expectations of how the illness 'should' feel. Experimental evidence of this demonstrates recalled symptom reporting differing systematically from contemporaneous reporting, influenced by psychological conditions (such as negative affect) at the time of reporting, as well as features such as time from the initial experience [57].

Well before the development of such neuroscientific models, philosophers of perception drew attention to the ways in which our prior concepts shape our experience of the world. As Heidegger puts it: "We never really first perceive a throng of sensations, e.g. tones and noises … rather we hear the storm whistling in the chimney, we hear the three motored plane … we hear the door shut in the house" [58](pp126–127). However, our world of storms, planes, and doors leaves us open to surprise – sometimes a loud bang will provoke only the response, 'what was that?' Moreover, our response to that question will depend on the reasons for which we wish to answer it; depending on our perspective, 'rapid combustion-induced gas expansion', 'a mistimed ignition spark', and 'a car backfiring' might all be appropriate responses [16]. Each of these descriptions may be adequate for its purposes, while still not capturing all of what is held within the others. The philosopher Paul Ricoeur describes this as the "surplus of meaning" [59] inherent in any description of a phenomenon; the tension between a given interpretation of a phenomenon and this surplus of meaning leaves our description of sensory experience always iterative and ongoing. Hans-Georg Gadamer calls this the "hermeneutical circle", through which our interpretations are shaped by expectation, those expectations then revised in light of new information [60].

The weight of prior expectations on shaping experience – or experiential recollection – may thus render certain forms of seizure experience more accessible, while concealing others. Experts in the assessment of seizure disorders typically structure seizure experience in specific ways: irrespective of the precise content of seizure accounts, they expect the symptoms to be: sudden and unprovoked, thus unpredictable; short-lasting (excepting status epilepticus); strange or unfamiliar; stereotyped; and followed by fatigue [61]. Clinicians will look for experiences articulated in such terms in their efforts to understand their patients' seizure phenomenology. It is not just clinicians, however, that may adopt these categorisations. People with seizures – who may be most closely challenged by clinicians to describe their experience, and then learn from the clinician's recapitulating of that experience, may come to adopt this framework too.

In a series of studies using an interview method designed to enhance focus on specific experience without conceptualising or categorising, Claire Petitmengin and colleagues demonstrated that many people – given the right environment – come to identify certain features of their seizure experience that do not readily fall within that description. These patients described a more vague, less abrupt, and more prolonged prodrome – such as fatigue, or being 'ill-at-ease' – for up to 24 h prior to the onset of clinical or electrographic seizures [23,50,62]. People with both focal and generalised epilepsy may report such prodromes [63,64];

however, reporting varies widely with the mode of interrogation, with highly heterogeneous rates of prodrome reporting (7–87% of people with epilepsy) between studies asking about these in different fashions [65]. However, without direct prompting or specific interrogation, such reports are rarely volunteered spontaneously. Petitmengin and colleagues directly relate this to the clinical conceptualisation of seizures – as the quotation at the start of this section describes, they found that the clinician's picture – of the seizure as an unpredictable and paroxysmal event – impeded the patient's ability to articulate the prodrome.

Allowing for these phenomena, we see that no one seizure description will capture all that can meaningfully be said of the phenomenal experience of that seizure; indeed, the phenomenology itself will depend upon current and previous descriptions. Adding this to the difficulties with ictal recall and responsiveness, and the challenges in describing alien experiences, demonstrates just how challenging eliciting seizure phenomenology in the clinical setting may be. In the next section we survey some present and future directions by which clinicians and patients may navigate a course through these challenges.

4. New directions in the subjectivity of epilepsy

> *When I was young, I saw this phenomenon for the first time in a 13-year-old boy (…). I heard the child tell that the condition had begun in his leg, and then had gone up straight to his neck, going through the thigh, groin, ribs, and neck up to the head; as soon as his head was reached, he lost consciousness of himself. When questioned by the physicians about the nature of what he felt moving up to his head, the child was unable to answer. Another young man, who was intelligent enough, capable of feeling what was happening to him and more able to explain it to others, answered that a sort of cold breeze [ἀῦρα, 'aura'] was rising in him.* – Galen*, Galeni Opera Omnia,* quoted in [66]

To say that experiential accounts of seizures are incomplete, variable, or contradictory, is only to recognise that – like any tool in epileptology – they have their limitations that the clinician must navigate. Compare the situation with observable semiology: lay-witness reports of seizure semiology are notoriously unreliable [4], but the descriptions obtained from such reports can nonetheless reliably support differential diagnosis [20,67]. Moreover, supporting non-experts with targeted education can improve identification of relevant features and subsequent clinical assessment [68]. Likewise, few would underestimate the value of EEG in the management of epilepsy, even if it is "one of the most abused investigations in clinical medicine […] unquestionably responsible for great human suffering" [69]. We close by exploring some approaches available to help clinicians and researchers navigating the challenges in exploring seizure subjectivity.

One suite of tools can be found in the clinical applications of the field of research that takes as its starting point the detailed analysis and description of subjective human experience – both normal and anomalous. Phenomenological research in psychology and neuroscience takes the subjective experience as its starting point – the foundation of all attempts at enquiry. It aims to explore such experience by: setting aside preconceived notions about the content of experience, aiming to focus on our experiences prior to conceptualisation; looking within this content to identify certain core features; and contrasting between subjects to identify areas of consonance and dissonance in different individuals' subjective experiences [58]. Recognising that subjective experiences represented the primary *explananda* of the field, psychiatry has been the area of medicine that has the most-devloped phenomenological research programme [70], helping to delineate models of mania and delusions able to support new lines of mechanistic enquiry [71].

Phenomenological research in practice involves in-depth qualitative interviewing that invites subjects to return to the experience in question, using cues that encourage focus on the precise nature of the experience and avoiding prior conceptualisations [50,72]. The rich first-personal accounts thus generated are then suitable for within- and cross-subject analyses to identify persistent and intersubjectively shared features, that can then be used to support others in articulating their experiences [73], or combined with investigation results to look for anatomical or physiological correlates of certain experiences [23]. As described above, Claire Petitmengin and colleagues have previously used this technique to characterise previously-neglected seizure prodromes, and identify correlative EEG changes [23]; more recently, a similar technique has been used to identify patients' self-understanding of seizure experiences in order to support tailoring of adjunctive psychotherapeutic interventions [9].

This latter project invites the clinician to integrate the patient's subjective seizure experiences with its broader effects on their life and worldview. This is taken further by narrative medicine projects that seek to enrich clinical and research practice by engaging with the stories patients tell about their lives with and through illness, and encourage clinician competence in the interpreting of these stories [74]. The proliferation of autopathographical accounts of living with seizures (to the point of hypergraphia being suggested – in the Geschwind syndrome – as a core component of the personality profile of some people with temporal lobe epilepsy [75]), combined with the clear social and psychological ramifications of seizure disorders, have made them a particular focus of interest for studies in narrative medicine [74,76-78]. While clinical application beyond the context of medical education has been limited, a recent Italian pilot project demonstrated that, with the support of digital tools to aid communication, patients responded positively to attempts to articulate their illness narrative with clinicians, and clinicians reported the approach enabled clinical application of information that otherwise would not have become apparent in the course of their clinical encounters [79].

If such phenomenological methods help patients to articulate seizure experiences in their own words, other approaches may provide patients with the words to describe the indescribable. Symptom inventories have been used in phenomenological psychiatry to support patients in articulating anomalous experiences by drawing on the conceptual resources afforded by the descriptions of those who have had similar experiences [73]. The use of such inventories – with lists of potential seizure experiences that patients can either endorse as forming part of their seizures, or reject as being unfamiliar to them – provides more detailed descriptions of seizures than can be obtained through open questioning alone [80]. Patients report experiences on direct questioning that they might otherwise be afraid to share [6]. Automated classification of ictal descriptions obtained through such systematic enquiry improves differential diagnosis of seizure disorders over the present standard of care [5,22]; similar techniques could also be used to support seizure localisation [21].

5. Conclusion

> *My epilepsy started with the smell of jasmine, and that smell moved into my mouth. And when I opened my mouth after that, all my words seemed coloured, and I don't know where this is my mother or where this is my illness, or whether, like her, I am just confusing fact with fiction, and there is no epilepsy, just a clenched metaphor, a way of telling you what I have to tell you: my tale.* – Lauren Slater, *Lying: A Metaphorical Memoir* [81]

What Margiad Evans called 'the patient's half' of understanding seizures – their experience of the events – are often the most important information available in the clinic for the diagnosis, assessment, and management of seizure disorders. But understanding the patient's half is no easy task – for clinician, or indeed for the patient herself. Whether through the limitations of language, the barriers of stigmatisation, the inconsistencies of memory or the feedback effects of our conceptual resources on shaping self-understanding, the process by which seizure experience is converted from subjective phenomenon to an interpersonally-shared list of symptoms is subject to many pitfalls. However, a range of interrogative tools are available for the motivated

clinician or researcher to work with their patients in addressing this lack – placing seizure phenomenology alongside semiology and pathophysiology in understanding and treating seizure disorders.

Declaration of Competing Interest

The author has no relevant conflicts of interest to declare.

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