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Epilepsy, literature and linguistics: spotlighting subjective symptoms

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Abstract

Literature can offer a wealth of information about epilepsy: from complex narratives to children's picture books, it can help broaden people's understanding, show what it is like to live with epilepsy, and provide a medium to which people with epilepsy can relate. The latter being particularly important in such cases where seizure experiences are highly subjective, such as those associated with 'focal seizures', a common seizure type, which are known for their variable and hard-to-describe symptoms, causing complications with diagnosis as many of the symptoms overlap with those of other psychological health conditions.

Literature, however, has more to offer than acting as a source for demystifying epilepsy. On a disciplinary level, literature is surrounded by different frameworks for linguistic analysis which, importantly, are also applicable to real-life discourse. In particular, the well-established discipline, cognitive stylistics, provides ample theory for analysing the different facets of literature, from narratological and storyworld level, to the intricacies of characterisation revealing the structure behind the presentation of fictional characters' experiences, attitudes and personalities. Such methods have the potential to transform and decode complex, subjective experiences into manageable pieces of information. This, then, holds great potential for shedding light on the experiences of real-life seizure narratives to the extent that the identified seizure's linguistic 'profiles' can be used to aid real-life situations. Therefore, the present study calls to attention the potential evoked through the convergence between literature, linguistic analysis, fictional characters, PWE, and seizure narratives. Extrapolating the qualities of these converging strands can enrich our understanding of the seizure experience as well as bring to awareness the areas of risk that surround aspects of the diagnosis process.

INTRODUCTION: EPILEPSY, FOCAL SEIZURES AND SEIZURE SYMPTOMS

Research on the epilepsies and seizures is primarily medical or clinical based and deals mainly with the physiological manifestation and characteristics of the condition. The present study sits in the health humanities discipline and addresses the importance and significance of seizure narratives—individual accounts of seizures experiences—in literature and real-life. First, it showcases literature as a rich resource for deepening our understanding of the subjective experiences afforded by epileptic seizures, specifically focal seizures. Second, it demonstrates how literary analysis can reveal the structure underlying highly experiential narratives through a close linguistic analysis. Third, drawing on the methods of analysis used, it reflects on real-life seizure descriptions and considers the impact the practitioner has on the construal of the patient's symptoms when writing the patient's notes.

Epilepsy is one of the most common neurological disorders affecting approximately 50 million people worldwide, with 80% living in low- and middle-income countries.[1] In the UK alone, 600,000 people are living with epilepsy.[2] Epileptic seizures can drastically effect quality of life and, without treatment, people with epilepsy (PWE) are at risk of serious issues, including (fatal) injury caused by seizures, permanent impact on short/long-term memory, cognitive impairments, and sudden unexpected death from epilepsy.[3] Finding the correct medication in itself can be a long process taking months, or even years, to find the right (combination of) treatment. Approximately 70% of PWE respond to treatment.[1] Therefore, the faster the treatment gap is closed, the healthier and safer the individual will be.

One seizure type that is particularly problematic in terms of diagnosis is the focal seizure. Focal seizures can be divided into two subtypes (although this specification is optional): 'focal aware' (formerly, 'simple partial') wherein the individual's consciousness remains intact, and 'focal with impaired awareness' (formerly, 'complex partial') wherein the individual's will be either lost or impaired at some point during the seizure.[4] The former is also referred to as an 'aura', a popular lay term.[4] Usually originating in the temporal lobe, which is important for feelings, emotions and memories, Reuber et al. define focal seizures as follows:

> Seizures from the temporal lobes often begin with a warning (aura). This can last several seconds or longer. During an aura, people may experience feelings, emotions, or thoughts that appear very familiar or completely alien to them. Auras are often difficult to describe. People may also be aware of a sensation rising up in their stomach or they may hear voices or experience an odd taste or

> smell. Following this, they become unresponsive or they respond oddly when spoken to. People may carry out strange actions like lip-smacking, rubbing their hands together, laughing, shouting, or fiddling with buttons or clothes.
>
> Often people stare at something and cannot be distracted from it. The seizure stops after 1-5 minutes but people remain confused or tired afterward. Some people complain of a headache.[5]

Focal seizures are known for their highly subjective nature, and wide range of symptoms, often making them difficult to describe which can impede an accurate depiction of what these seizures feel like.(6–8) At first glance, the majority of the symptoms listed above do not appear to be too problematic to identify, yet they vary from person to person and can manifest in different ways. To illustrate this, the following quotations are genuine descriptions of focal aware seizures from Epilepsy Foundation's online forum thread, 'How exactly do auras feel?'. [9]

> 'i usually feel like i am spaced out, and i can hear things and am somewhat there but if someone is talking to me i get irritable and tell them to shut up because i feel so weird...it is frustrating because no one understands what its[*sic*] like...'
>
> 'Imagine that feeling of going on a roller coaster and you just went down the peak of that first hill.....that's the closest thing I can think of to describe what my auras feel like.'
>
> 'out of breath, can't think, almost as if someone is holding you up and dangling you over a cliff by your ears'
>
> 'like flicking throu[*sic*] the TV, missing a programme, and being unable to go back'
>
> 'Since I've started medicine the auras are very persistent and a bit more creepy feeling I can't explain it exactly like someone raking their fingers inside of you...I also get tightness in my palms w/burning, sometimes I'll get trembles in the arm and I usually start to space out and lose focus.'

With the benefit of knowing that these individuals have epilepsy, the seizure symptoms can largely be identified within these quotations. However, if, for example, these experiences are being raised for the first time with the GP, this is where these subjective symptoms cause trouble. In fact, Malmgren, Reuber and Appleton state that 'surprisingly, there are no generally accepted and validated diagnostic criteria for the diagnosis of epilepsy at present'.[3] The elusive nature of these symptoms can be very problematic for diagnosis; if brain scans are inconclusive as are many, the practitioner must often rely on the patient's articulation of their

symptoms.[10] Unsurprisingly, patients' descriptions of their seizures can easily be misinterpreted resulting in a prolonged diagnosis or even misdiagnosis. Further still, such descriptions are not ascribed the same value as other methods for supporting a diagnosis such as EEG video, whereby the patient's brainwaves are recorded whilst being filmed to determine whether they are having an epileptic seizure and to observe the behavioural characteristics; this is considered the 'gold standard' diagnosis.[3,11–13] However, the subjective experiences and 'odd' feelings that focal seizures cause can, in fact, be utilised in diagnosis as they can indicate the localisation of seizure onset, i.e. from where in the brain the seizure originates.[13] Therefore, in consultations, history-taking to establish the context, the sequence and manifestation of the symptoms can be key to a swift trajectory to diagnosis.[14] However, with subjectivity often comes impressionistic, and connotative descriptions that require *decoding* to extract this information. To this end, such experiences are often underreported, and even dismissed in patient notes. Herein lies the impetus for the present paper.

EPILEPSY AND LITERATURE

Literature is a quietly powerful tool which, through careful presentation of events and fictional characters, can offer a window into 'experience(s)' of medical conditions. A frequently referenced example in relation to epilepsy is Fyodor Dostoyevsky's, *The Idiot*,[15]. Since Dostoyevsky himself had epilepsy, he was able to mediate the experience through the character, Prince Myshkin:

> '[W]hat does it matter that it's an abnormal tension, if the result itself, if the moment of sensation, recalled and examined in a condition of health, turns out to be the highest degree of harmony and beauty, yields a hitherto unheard-of and undreamed-of sense of completeness, proportion, reconciliation and an ecstatic, prayerful fusion with the highest synthesis of life?'[15]

This is a key example of how knowledge of health conditions, such as epilepsy, can be expanded on through art as it provides a stage for the composition of rich, revisable, detailed accounts of different conditions.[16,17] Wolf notes that 'in literary accounts of epilepsy the aura has a prominent place as the subjective aspect of the seizure experience. Descriptions by authors with their own aura experiences stand out *by their precision and authenticity*' (my emphasis).[17] Nonetheless, this does not mean to say authors who do not have epilepsy provide less precise and inauthentic accounts, especially when they conduct research into the condition prior to

writing. Schiffrin emphasises the role narrative plays—with its property of being able to situate and display experience—in presenting our identity and sense of self:

> One reason that narrative can have this self-transforming role is that narrative language provides a process of subjunctivization: it reveals our presuppositions (our implicit meanings), permits multiple perspectives (different prisms through which we can view the world), and allows subjectification (reality can be filtered "through the consciousness of protagonists in the story").[18]

Crawford et al. bring this into a medical context and celebrate the potential of literature in helping to understand the multiple contexts and roles that comprise a medical condition:

> Literature–both fiction in a range of forms and autobiographical narratives, including pathographies–can tell us not only about medicine or doctors, but also about the experience of health, sickness, illness, encounters with clinics and clinicians, the reactions of significant others, the support found in the strangest of places, the role and impact of informal caring, and the radical reordering necessary after the dramatic rift that significant illness causes through an individual life.[19]

Crawford et al. focus on the genre of pathography and, while they primarily address mental illness, the points they raise are widely applicable to other health conditions and are by no means limited to this genre. Crawford et al. observe how fictional texts 'set in motion our interpretative capabilities in a different way […] the way we read fictional works can then in itself offer a space for reflection on the ways in which illness is encountered by us either as observers or experiencers'.[19] Crawford et al. continue to explain how mental illness narratives 'provide insights into the experience of madness that is both different from and complementary to that found in a clinical textbook'.[19] They explain how these texts can also be used to refine the practitioners' skills at 'listening for' these kinds of narratives and that this can then be integrated into clinical pedagogy. Crawford and Baker explain that:

> The most wonderful element of literature is that it reflects and refracts the uniqueness of humanity.[…] If a mere acknowledgement of the multiplicity of human responses and experiences is the only gained benefit from reading fiction, then it is a worthwhile pursuit.[20]

This is particularly noteworthy regarding focal seizures. It is highly important that practitioners become familiar with, and perceptive to the subjectivity and experiential quality of these seizures and the multiple ways they can be communicated is key. Possessing a deep understanding of the seizures can facilitate the negotiation of meaning in complex seizure

narratives. In other words, as simply, yet eloquently, put by Crawford et al.: 'literature can offer insights into the *experience of experiences* which may be unfamiliar to the reader' (original emphasis).[19] By this, they refer to others' (the characters') experience of health-related experiences.

ANALYSING WRITTEN EXPERIENCE

Stylistics is a branch of applied linguistics responsible for the systematic study of *style* in both literary and non-literary texts.[21,22] Style, as defined by Leech and Short in their seminal work, *Style in Fiction*, 'refers to the way in which language is used in a given context, by a given person, for a given purpose'.[22] The discipline stems from Russian Formalism and structuralism, key literary theoretical and philosophical movements in the twentieth century which embraced the characteristics and function of 'poetic language', most notably in the work of Roman Jakobson during the 1960s.[23,24] Today, stylistics can be defined as:

> [T]he study of the ways in which meaning is created through language in literature[…] stylisticians use linguistic models, theories and frameworks as their analytical tools in order to describe and explain how and why a text works as it does, and how we come from the words on the page to its meaning. The analysis typically focuses qualitatively or quantitatively on the phonological, lexical, grammatical, semantic, pragmatic or discoursal features of texts, on the cognitive aspects involved in the processing of those features by the reader as well as on various combinations of these.[24]

Moreover, stylistics is a discipline that thrives on interdisciplinarity, drawing on literary criticism, linguistics, and cognitive science.[21] When the latter features prominently, the sub-discipline, 'cognitive stylistics', arises. Cognitive stylistics, as put by Semino and Culpeper, 'combines the kind of explicit, rigorous detailed linguistic analysis of literary texts that is typical of the stylistics tradition with a systematic and theoretically informed consideration of the cognitive structures and processes that underlie the production and reception of language'[25].[see also 21,26,27] Stylistics takes a holistic approach to studying texts as it puts the intrinsic relationship with the production and reception of text at the fore.[21] Naturally, this makes it an ideal foundation for analysing healthcare discourse, specifically that which deals with 'the experience of experiences'.[19] Ranging from close micro-analysis to wide scale macro-analysis, cognitive stylistics holds a plethora of analytical methods and descriptive frameworks which can be utilised for different research questions.

For the present paper, I draw on the stylistic application of schema theory and foregrounding by way of demonstrating how the trajectory of an experience is linguistically 'signposted' and *schematised* on a deeper level beyond reported symptoms. Both schema theory and foregrounding are described in turn and are used in a literary analysis to demonstrate their representational capacity. This analysis is then reflected on in light of a clinical consultation context to consider how such an approach could facilitate more astute interpretations on part of the clinician.

Schema theory

Schema theory provides a 'model of human knowledge'.[28] With its roots in gestalt psychology and artificial intelligence, schema theory presents the means by which we make sense of the world directly and through text.[29–40] Schemas are borne from the organisation of pre-stored background/ prior knowledge into complex, higher level portions of information, or 'schemas'; they enable learning and comprehension to take place 'by connection strength adjustment, according to some simple scheme'.[38] For example, most people have a RESTAURANT schema (schema names are typically written in small capitals) which would hold information about the routines involved (e.g. what you do when you arrive, the point at which you ask for the bill), knowledge of the layout (the restaurant will probably have tables and chairs, some toilets in a separate room, possibly a bar), participants (waiters, customers, bar staff, chef). Possessing this schema means that you can go to a restaurant you have never been to before and be able to anticipate what and who will be there as well as know what to do at different points throughout your visit. Schemas are established through repetition and sociocultural norms. They are activated when prompted by external textual/situational cues and/or drawn on to make sense of new experiences, be it in real-life or within a storyworld.[28,31,33,41]

Therefore, in the same way we have a RESTAURANT schema, most people would have an EPILEPSY schema, however the detail of this schema drastically varies between people. PWE and healthcare practitioners will most likely have rich schemas knowing about the different types of epilepsy and seizures, what to do/expect when someone has a seizure, and so on. On the other hand, people who know very little about epilepsy will have a comparatively impoverished EPILEPSY schema which may have been constructed through the portrayal of epilepsy in the media, for example they may not realise there are many seizures types, not just one convulsive seizure, they may assume that all epilepsy types are photosensitive, and they

may not know what to do or what to expect if someone has a seizure. However, if they developed epilepsy or befriended someone with epilepsy, their EPILEPSY schema would become richer and more detailed through access to new and different perspectives. Schiffrin asserts that 'when we verbalize an experience, we situate that experience globally: by drawing on our cultural knowledge and expectations about typical courses of action in recurrent situations, we construct story topics, themes, and points'.[18] In other words, when communicated through discourse, experience becomes *schematically aligned* to create an optimal representation. Therefore, it is useful to have a way of accounting for the discoursal 'translation' (the schemas used) of experience.

Cognitive stylistics often draws on Guy Cook's application of schema theory to literature.[33] Cook takes into account that literature can challenge our schemas, and he provides a list of processes for 'schema management': *schema preservation* occurs when the incoming information is consistent with and preserves the knowledge structure of the activated schema.[33] Similarly, *schema reinforcement* occurs when existing schematic knowledge is reinforced through new information, and *schema accretion* occurs when incoming new information broadens the schema.[33] Finally, *schema disruption* occurs when discourse deviates from the norm (defamiliarisation, for example), and thus challenges the existing schema, requiring the activated schema to undergo *schema refreshment* to revise its components.[33] Schema refreshment, however, does not necessarily require deviation to be evoked, it can manifest in less dramatic circumstances such as 'connecting normally separate schemata in the processing of a particular text, becoming aware of one's own schematic assumptions, questioning the validity of one's schemata in the light of new experiences and so on'.[28] These schema management processes demonstrate how the dynamicity of schemas enables them to accommodate the constant intake of information.

Foregrounding

Foregrounding is referred to as 'artistically motivated deviation',[22] and is regarded as a universal, cross-cultural form of 'rhetorical focussing' employed by the author for effect on both local and global levels to signal the reader's attention.[41] Whether it is operating on a lexico-grammatical, semantic, syntactic, graphological, contextual, genre and/or cognitive level, foregrounding is subject to repetition, unusualness, frequency and the manipulation of linguistic and stylistic rules.[42–49] When an element or object is foregrounded it is afforded 'heightened psychological attention'[50], the effects of which on the reader can range from

aesthetic appreciation of word choice, turn of phrase and so on, to attitudinal and emotive changes whereby foregrounded elements alter the reader's perception of the 'storyworld'.[51,49] Leech describes its two key facets: 'formally, foregrounding is a deviation, or departure, from what is expected in the linguistic code or the social code expressed through language; functionally, it is a special effect or significance conveyed by that departure.'[52] Foregrounding, then, is a key principle in (cognitive) stylistics. While the use of foregrounding devices is typically prominent in literary works such as poetry, it also features, in varying degrees, in many forms of discourse from everyday conversation to political speeches.

Russian Formalism was the driving force behind the advancement of the theory of foregrounding.[52–54] The Russian formalists strongly opposed the previously held assumption that a piece of art can be separated into 'content' and 'form', thus they approached it from a structural and semiotic perspective and saw art as representation of reality, not a reflection of it.[52,55,56] Today, foregrounding and its effects continue to undergo investigation, from stylistic analyses of the use of foregrounding in poetry, to empirical stylistic studies testing the effects of foregrounding devices on readers' attention, memory and text processing when they read literature.[46,51,57–59] Whether it is an irregular use of punctuation or a fictional character's actions, foregrounding is context-driven and operates on the premise of throwing something into relief against a normalised, habitual and/or expected background.

FOCAL SEIZURES IN FICTION: A SCHEMA ANALYSIS CASE STUDY

A good present-day example of the portrayal of focal seizure experiences can be found in Gavin Extence's prizewinning novel, *The Universe Versus Alex Woods*.[60] The protagonist, Alex, an affable, quirky young boy, has temporal lobe epilepsy with focal seizures and tonic-clonic seizures (for the purpose of this paper, I focus on the former). Alex describes his seizures matter-of-factly and in detail allowing the reader insight into his experiences. It is worth noting that Alex's seizures are based on the author's extensive research into the condition and close study of first-person accounts of the seizures.

The following analyses are of two extracts from the novel, each where Alex has a focal seizure. In the first extract, Alex has a focal aware seizure, and in the second Alex has a focal with impaired awareness seizure, for ease of reference and considering the specification of the

level of awareness is optional,[4] I refer to Alex's seizures as focal seizures throughout. The analyses of both extracts traces the emergence and development of the reader's FOCAL SEIZURE schema in conjunction with the presentation of foregrounded objects (abstract and physical) in the storyworld.

Extract 1

The extract is taken from the beginning of the novel, before the reader is informed that Alex has epilepsy. In the events prior, Alex is in his car at customs in Dover and is trying to return to the UK. However, he does not yet realise that he is a wanted person and the customs officer on duty notices him from inside his booth.

> 'What I remember next is kind of muddled and strange, but I'll try to describe it for you as best I can.
>
> The side door of the booth was swinging open and at the same moment there washed over me the scent of a field full of lilacs. It came on just like that, from nowhere, and I knew straight away that I'd have to concentrate extra hard to stay in the present.[…]
>
> I looked straight ahead and I focussed. I focussed on the windscreen wipers moving back and forth and tried to count my breaths, but by the time I'd got to five, it was pretty clear that this wasn't going to be enough. Everything was becoming slow and blurry. I had no choice but to turn the stereo up to maximum. Handel's *Messiah* flooded the car – the 'Hallelujah' chorus, loud enough to rattle the exhaust.[…] I could see the customs officer in my peripheral vision, hunchbacked at my window in his bright yellow jacket, but I forced myself to ignore him. He shone his torch in my eyes, and I ignored that too. I just kept staring straight ahead and focussing on the music. That was my anchor. The lilacs were still there, trying their best to distract me. The Alps were starting to intrude – jagged, frosted memories, as sharp as needles. I swaddled them in the music. I kept telling myself that there was nothing *but* the music. There was nothing but the strings and the drums and the trumpets, and all those countless voices singing out God's praises. I know in retrospect that I must have looked pretty suspicious, just sitting there like that with my eyes glazed and the music loud enough to wake the dead.[...]
>
> When you get an aura that powerful, there's no chance of it passing of its own accord: to be honest with you, there were several moments when I was right on the precipice. I was just a hair's breadth from convulsions.
>
> But after a while, the crisis abated. Something slipped back into gear. I was dimly aware that the torch beam had moved on. It was now frozen on the space two feet to my left […]
>
> Then he tapped the torch against the window and made an urgent downwards gesture. I don't remember pushing the button, but I do remember the rush of cold, damp air as the glass rolled down. The customs officer mouthed something, but I couldn't make it out. The next thing I knew, he'd reached through the open window and flipped off the ignition. The engine stopped, and a second

> later, the last hallelujah died on the night air. I could hear the hiss of drizzle on tarmac, fading in slowly, like reality resolving itself.'[60]

The reader is first notified of Alex's altered experience when the smell of lilacs washes over him. Stating that 'it came on just like that, from nowhere' strongly implies that it is unlikely—given his current location—that he is near a full field of lilacs. The way Alex presents the experience is particularly interesting: the lilacs *wash over* Alex, ascribing them movement and agency situating Alex as the passive recipient of the experience. The sensation of something washing over oneself is an uncontrollable, quick experience, further emphasising Alex's passive role. The lilacs' potency is reinforced as Alex describes the scent as a 'full field'. The lilac scent is also foregrounded through their unexpected presence. Alex then employs coping strategies to try and control the situation (breathing, counting, concentrating). However, at this early stage in the narrative, readers are unlikely to recognise, or know that this is the onset of a focal seizure, yet the way Alex responds to the situation (through concentration and fixating on something) *is* a recognisable response to several situations. For example, deep breathing to help control and focus one's mind in a stressful situation is a relatable activity. Readers, therefore, may home in on these familiar elements and instantiate a suitable schema, such as a PANIC ATTACK schema. Alternatively, based on their prior knowledge that Alex is a wanted person, it is possible that they may surmise that he has been taking drugs (which, incidentally, is what the customs officer and police assume). This would then characterise his current state as being drug-induced, thus instantiating a DRUG USER schema. However, it is not my place to speculate specific schemas thus, for now, I refer to it neutrally as an UNKNOWN EXPERIENCE schema, as it is safe to say that some form of experiential episode is underway. This means that the readers and Alex are not yet on the same schematic level because the readers will be instantiating the UNKNOWN EXPERIENCE schema or one that, for them, best fits the current circumstances. Alex, on the other hand, recognises that he is having a focal seizure (thus activating the correct FOCAL SEIZURE schema for himself) and, based on that knowledge, carries out the necessary protocol (focusing/ concentrating). It, therefore, becomes a case of bringing the reader and Alex to the same level (i.e. the FOCAL SEIZURE schema) through schema management. To arrive at the correct schema, the reader now must continue to extrapolate the information Alex gives to build an accurate picture of what is happening to him.

Alex's coping strategies (breathing, counting, concentrating) are communicated to the reader through the description of his focus on the windscreen wipers which subtly exemplify his attentional shifts:

> 'I looked straight ahead and I focussed. I focussed on the windscreen wipers moving back and forth and tried to count my breaths, but by the time I'd got to five, it was pretty clear that this wasn't going to be enough.'[60]

The shift from Alex sitting still and looking ahead of him to the moving windscreen wipers, directs the readers' attention in the same way as Alex has focused his attention. More specifically, Alex's attempt to focus his attention is being communicated through the *presentation* of the windscreen wipers and his counted breaths. Consider the extract below *without* the added detail of the windscreen wipers and his breaths:

> I looked straight ahead and I focussed. I focussed on the windscreen wipers and tried to count my breaths, but it was pretty clear that this wasn't going to be enough.

It becomes clear that those details ('moving back and forth' and 'but by the time I'd got to five') helps to home in on the movement of the wipers and the exact number of breaths he has counted. Not to mention the fact that the windscreen wipers' movement effectively contrasts with Alex's stillness. Their foregrounded status is also emphasised as they are physically close to Alex who is sitting in the driver's seat which would accentuate the swooping movement across the windscreen. As for his breaths, they do not hold the same levels of attraction as the windscreen wipers. This is emphasised through the fact that Alex 'tried' to count them and the fact he only got to five which indicates that they (the breaths) did not feature for long and had little effect. In other words, his current state has overpowered his attempt to maintain control. This is confirmed when Alex states 'it was clear that this wasn't going to be enough'. This results in schema accretion as the UNKNOWN EXPERIENCE is attributed a threshold and a scale of intensity.

The construal of the intensification can be observed by a close analysis of the schema's properties. First, the reader is informed that Alex's perception has become 'slow and blurry' which, consequently, occludes the foregrounded movement and proximity of the windscreen wipers which he was trying hard to focus on, making their presence fade into the background, leaving a visually ill-defined representation of the storyworld. Second, Alex's experience of physical storyworld entities (windscreen wipers) have now been superseded by aural

experience (the music). By having 'no choice' but to turn up the stereo implies that it could be a reflex response, rather than a free decision, which Alex shortly confirms: 'But you should understand that at the time I didn't have a choice'. The music, Handel's *Messiah*, becomes foregrounded through its extended description, the volume, and its figurative movement as it 'floods' the car. Similar to focusing hard on the windscreen wipers earlier on, turning up the volume loudly usually drowns out distractions; this could imply that distractions can exacerbate Alex's current state hence his determination to remain focused. This further enhances the UNKNOWN EXPERIENCE schema through schema refreshment, as Alex transfers the focus of his coping strategy from the windscreen wipers to the music. After the onset of the music Alex describes what he can see and hear at that precise moment, which gives the reader an inlet through which they can observe what storyworld aspects are in the foreground of his experience.

> 'I could see the customs officer in my peripheral vision, hunchbacked at my window in his bright yellow jacket, but I forced myself to ignore him. He shone his torch in my eyes, and I ignored that too.'[60]

Here Alex reports on the visually 'obvious' qualities which would be visible in his blurred peripheral vision: the officer's posture, the bright jacket, and the torch light. These objects would intrude into his field of vision through vividness and brightness (a torch beam and high-visibility jacket), and size (posture) since they are very close to him which would make them noticeable, even when he is unable to directly look at them. Interestingly, these objects are foregrounded to the reader both through Alex's perception of them, as well as his conscious effort to ignore them. Trying not to get distracted, ignoring things and focussing hard on something would be all relatable actions to the reader, not to mention the fact that these objects are easy to imagine. However, this changes as the seizure intensifies when Alex (re)introduces two *internally* experienced objects: the lilacs and the Alps, which emphasise the intensity of the seizure. The UNKNOWN EXPERIENCE schema undergoes schema disruption and thus schema refreshment to the unexpected presence of these out-of-context (and consequently, foregrounded) nouns.

The seizure's increase in intensity is also grammatically conveyed, as the officer's bright jacket is in a clause where Alex is the active subject, and the distracting torch is being used by the officer, thus these objects have no agency. The lilacs and the Alps, on the other hand, are presented differently. Firstly, the lilacs are personified as they are actively 'trying to

distract' Alex thus, once again ascribing them agency. Secondly, the newly introduced Alps are also personified as they are portrayed as 'intruding' on Alex which, considering they are mountains makes for a powerful experiential representation. Thirdly, further detailing of the Alps's intrusion ('jagged, frosted memories as sharp as needles') holds connotations of coldness, pain and unpleasantness. Finally, the fact that Alex has to 'swaddle' the Alps and the lilacs in the music and tell himself that 'there was nothing *but* the music', rather than just ignore them as he did for the torchlight and the customs officer, suggests that the Alps and lilac's intrusion is more powerful as he is making a conscious attempt to *counteract* the lilacs and the Alps. This is emphasised further when Alex specifies that 'there was nothing but the strings and the drums and the trumpets, and all those countless voices singing out God's praises' as this tells the reader exactly what Alex is focusing on as he dissects the piece of music into its component parts. The repeated negation, 'nothing but', works towards foregrounding Alex's effort to stay focused as the negative word ('nothing') followed immediately by the negative conjunction ('but') foregrounds Alex's effort to create an absence of distractions. This indicates that there is not just 'nothing but' the music as if there was, Alex would not need to tell himself that. Notwithstanding the fact that the music is at full volume which emphasises the notion that the sensations must be strong considering they are still able to distract Alex amongst the noise. Overall, the music, Alps and lilacs enrich the UNKNOWN EXPERIENCE schema through schema accretion. This occurs on an aesthetic and experiential level through the intrusive, distracting, and overwhelming behaviour of the lilacs and the Alps.

It is only near the end of the event, when the seizure begins to dissipate, that Alex provides a 'label' for the experience: 'When you get an aura that powerful, there's no chance of it passing of its own accord'. The reader's UNKNOWN EXPERIENCE schema can finally become a FOCAL SEIZURE[i] schema to which the events prior can now be attributed. Following this, Alex's gradual recovery is communicated through a rich mixture of sensational experiences in a short space of text demonstrating how his sensations gradually come into effect after being compromised during the seizure. During the recovery, Alex becomes perceptive to objects that are slightly further away from him and notes their location with more precision, for example: 'frozen two feet to my left' and 'he tapped the torch against the window and made an urgent downwards gesture'. Alex also comments on externally caused proprioceptive sensations such as feeling the cold and damp, and hearing the drizzle. The FOCAL AWARE schema undergoes schema accretion as its experiential scope and trajectory is broadening.

Extract 1 has shown that in Alex's communication of his experience, certain aspects—physical, proprioceptive, perceptual—are foregrounded in varying degrees at different points throughout the seizure. From this, the following properties can be drawn from the analysis and ascribed to the FOCAL SEIZURE schema:

1. It affects perception (lack of clarity)
2. It affects function (formulating thoughts/ coordinating movement)
3. It affects memory (memories can be patchy and unclear during and after)
4. It manipulates specific experiences (e.g. olfactory, visual)
5. It influences behaviour (e.g. unable to move, staring/ concentrating)
6. It is strong/ powerful (overriding feeling, it controls Alex)
7. It progresses in intensity (shifts in perception)
8. It is potentially controllable (concentrating can sometimes help to control it)
9. It requires recovery (it takes Alex a while to return to normal)

In the second extract below, the readers witness Alex having a focal seizure for the second time. This affords a good opportunity to demonstrate how Alex's focal seizure in the passage below corresponds to the knowledge structure represented by the reader's pre-existing FOCAL SEIZURE schema.

Extract 2

Prior to the seizure, Alex was chased by school bullies and he took refuge in somebody's garden shed. The bullies smashed the windows of the adjacent greenhouse by throwing stones over the hedge. When the bullies had gone, the stress of the situation triggers the seizure.

> '[A]t the time, I was in too much of a daze to take in details. Now that the chase was over and I was no longer focussed on the necessities of self-preservation, my mind had started to spin in a familiar, juddering dance. I knew that I had to calm myself again. I had to sit still and concentrate and wait for this to pass.
>
> I got back in the gloomy shed, my refuge from the destruction outside, and I sat on the floor against the far wall with my head in my hands. I was, by then, extremely disorientated. I tried to focus but the whole place smelled of marzipan and creosote, and this was preventing my mind from settling. It was too late to move, though. At this point, movement would make things worse. I had to sit motionless and work through my exercises. I could see chariots and unruly horses. I tried to breathe. I started listing prime numbers. I could see blackbirds circling. I felt extremely exhausted.
>
> I've no idea how much time passed, but when I came round from my dream, the atmosphere had changed. Something had awoken me. There was a

> current of air cutting through the creosote; the shed door had been pushed fully open, and in the doorway was a figure – a silhouette framed in sinking sunlight.'[60]

At the onset of the seizure, rather than just stating that his 'head started to spin', the addition of 'familiar, juddering dance' provides an interesting modification. First, 'familiar' implies that it is a recognisable—thus specific—sensation; the specificity is emphasised and refined through the novel combination, 'juddering dance' as it suggests a choreographed, yet shaky rhythm. This interesting choice of language echoes the description of the Alps in extract 1 ('jagged, frosted memories, as sharp as needles'). The novelty and specificity of these sensations could arguably be considered as being 'seizure specific'. Alex immediately responds to the recognisable sensation and employs the coping strategies (breathing and counting) we became accustomed to in extract 1, which contribute to schema preservation of the FOCAL SEIZURE schema.

Like extract 1, Alex's references to objects within the storyworld also reflect the strength and phases of the seizure. We begin with scene-setting items referring to physical objects: the shed, the floor, and the far wall. At this point, Alex is still perceptive of his surroundings. After this, when the seizure strengthens, Alex then reports only what he feels, sees (chariots and horses), and is doing (breathing and counting), with no references to the physical storyworld. Alex communicates this through a succession of short sentences with minimal detail, preceded by a direct zoom in to the immediate present 'At this point':

> 'At this point, movement would make things worse. I had to sit motionless and work through my exercises. I could see chariots and unruly horses. I tried to breathe. I started listing prime numbers. I could see blackbirds circling. I felt extremely exhausted.'[60]

This helps communicate the intensity of his experience as it implies that Alex does not have the freedom to offer elaborate descriptions. Furthermore, there are two instances of modality in ('I *could* see…') which is interesting because Alex is explaining what he is *able to see*, rather than reporting what he saw (e.g. 'I *saw* chariots and unruly horses'). This encourages the idea that *what* he is able to perceive is subject to the seizure. After the seizure, when Alex awakens, references to objects which populate the storyworld spatially and physically emerge, for example:

1. '**the atmosphere** had changed.'

2. '**Something** had awoken me.'
3. '**a current of air** cutting through the creosote'
4. '**the creosote'**

Alex's increased perception of his surroundings indicate that he has recovered from the seizure, yet the objects Alex has foregrounded, and the way he has foregrounded them suggests that he is perhaps not as alert as he can be. For example, until he sees the silhouette as the end, the majority of what he perceives in the storyworld after he wakes up cannot be perceived visually—they must be sensed.

Alex's seizure also reflects the FOCAL SEIZURE schema trajectory as identified in extract 1, thus contributing to schema reinforcement. The confusion, blurriness and distortion appear at the beginning of the seizure which is followed by an olfactory sensation as Alex can smell creosote and marzipan, the former can be attributed the contents in the shed (e.g. wood varnishing products), as for the marzipan, this could likely be an olfactory hallucination (like the lilacs). This bundle of experiences during seizure onset reflects those in extract 1. Consistent with extract 1, Alex remains still and focuses on his coping strategies. Alex visualises chariots and unruly horses which could be déjà-vu (like the Alps), or perhaps a visual hallucination, contributing to schema reinforcement or schema accretion, respectively. As for the blackbirds he sees, which come into view as the seizure withdraws, it is likely Alex can see them through the shed window. The black moving figures against a bright background would be foregrounded and easy to perceive. Similarly, the change in atmosphere, the creosote and the figure in the doorway indicate that, as in extract 1, Alex's senses are coming together as he is more perceptive on a proprioceptive level, he is aware of subtle and indefinable feelings/sensations and becomes visually aware. Schema accretion also occurs as Alex appears to lose consciousness during this seizure.

Overall, both extracts illustrate how the storyworld is filtered through Alex's experience, making the storyworld's perceived physicality particularly significant in conveying Alex's experience. By drawing attention to foregrounding patterns and textual cues that traverse a seizure narrative, it is indeed possible to trace the ebb and flow of experience and relate it back to the FOCAL SEIZURE schema. Within Alex's seizure narrative the following symptoms can be isolated: déjà-vu, confusion, olfactory hallucinations, lack of control, impaired awareness, sensitivity to movement. However, they require interpretation to be extrapolated from the rich subjective narrative. The Alps on their own, for example, do not

represent a specific 'Alps' symptom. They are, however, a memory of Alex's and in the present context are likely to be déjà-vu. The feeling of the onset ('jagged, frosted') of this memory is also characteristic of the feelings and sensations these seizures can bring, as PWE can describe (variations of) tingling feelings across the body, and unpleasant sensations in the head. Therefore, to gauge the significance of the Alps, one must address their manifestation and relevance to the individual.

FROM STORYWORLD TO REAL-WORLD

Experiential accounts, such as in *Alex Woods*, are effective resources for understanding the presentation of focal seizures. Gaining insight into seizures through circumstantial evidence in the form of rich, boundless narratives is an invaluable resource for gaining access to manifold and lateral depictions of seizures. Such narratives offer details that extend beyond the generic visual and behavioural symptoms often seen in lists on various information sources (patient leaflets, websites). Returning to Crawford et al.'s statement that 'literature can offer insights into the *experience of experiences* which may be unfamiliar to the reader', this notion can, and must, be extended to real-life. First, however, the assumed barrier between literary language, or 'literariness', and everyday language must be broken. Carter, who disregards the notion that there is a distinction between literary and non-literary language, proposes that the two should be considered as points on a continuum: 'a cline of literariness in language use with some uses of language being marked as more literary than others in certain domains and for certain judges within that domain'.[61] In the context of the present study, contextually impoverished lists of standard seizure symptoms—typical of sources such as information websites, leaflets, text books—represent the extreme of the non-literary dimension; they function as a referential source of information. The literary end of the cline can be associated with individual and idiosyncratic seizure narratives, as these are representative of experiences; they go beyond referential content and require negotiation of meaning. What is most important to bear in mind is that it is the *literary* end of the cline that features in clinical consultations when patients describe their experiences, which are then interpreted by the clinician to identify the symptoms. Correctly interpreting the patient's narrative requires the correct schema to be activated. Schema activation, however, is subject to different factors such as the context of a clinical consultation; the patient's history; their ability to articulate the experiences clearly (within the time constraints of a consultation), for example a child or a non-native speaker may not have

the vocabulary to capture what they experience; the way they present the information, such as what it foregrounded; and so on. Indeed, schema activation is in a delicate balance dependent on how the seizure narrative is articulated, and what aspects are foregrounded, as well as how this is interpreted by the practitioners.

Linguistic entrapment and the 'fictional distance'

The portrayal of focal seizures is also subject to how the medical practitioner represents the symptoms in the patient's records. Crawford, Nolan and Brown discuss how patient records are effectively 'biographies', but the objectivity of these biographical accounts is questionable as they can be more fictional than factual.[62] While their study focuses on psychiatry and mental health, their observations and findings can be applied to the representation of symptoms for focal seizures. They explain that 'a "fictional distance" opens up between patients and the records which are kept about them'.[62] They highlight how misuse of language in representing patient symptoms can easily misrepresent the patient within their record, creating a greater distance between the patient's actual symptoms and the written interpretation thereof. Indeed, an experienced epileptologist with a rich FOCAL SEIZURE schema will be far more perceptive to a patient's description of a potential focal seizure. However, a junior doctor, or even a neurologist with a different specialisation, can easily instantiate a schema for another medical condition and thus misrepresent the patient's description by perhaps foregrounding specific segments of information over others, homing in on the wrong aspects of the patient's narrative, not noting the chronological manifestation of the symptoms.[see also 63] This 'selective monitoring' means that, once a schema is activated, the individual will partly begin to 'look for' symptoms.[63] Just as a fictional character's narrative undergoes interpretation by the reader, so does a patient's narrative by the clinician. However, in a consultation when the doctor writes the patient's notes, this goes to another level: at first, the clinician is the patient's reader (when listening to the patient's descriptions), they then come to be the patient's *author* when writing their notes (see figure 1). In terms of Carter's cline of literariness,[61] the patient's description—which is likely located towards the literary end—is then interpreted and re-presented into a form of discourse that is more reductive and situated in the 'non-literary' end. The interpretation of the patient's narrative is also subject to the physician's skill and knowledge, for example, an expert will arguably recognise the condition quicker and, through their experience, may *re*present the patient's narrative with greater lucidity and richer detail. Patient notes are critical; the Nottingham University Hospital's 'Health Record Keeping Policy' document, for example, describes patient records as:

> '[A]n effective communication tool' and that 'a health record should inform any clinician who has a responsibility for the patient of all the key features which might influence the treatment proposed[…] Good record keeping safeguards both patients and professionals from unsafe practice through the misrecording or misunderstanding of health record information.'.[64]

[Insert figure 1]

Crawford, Nolan and Brown explicate five ways through which 'fictionalism of an individual' takes place. The first is through autobiography which, due to the time constraints and purpose of a consultation, makes it near impossible for the patient to provide a blow-by-blow representation of the experiences of the self; some aspects may be more foregrounded than others, others may be disregarded and so on. In terms of focal seizures, some symptoms may stand out more than others for the PWE: the intense feeling of fear may be more powerful than the feeling of confusion, thus that symptom may receive more emphasis when described. Likewise, the patient may also focus heavily on the experience rather than the circumstances and context. The second way is a mistake that is made by practitioners where they try to take a patient's *dialogic* account—a dynamic amalgam of memories—and attempt to detect 'a single true nature of the patient's self or problems from these materials is an activity which we might characterise as "monological"'.[62] Third, when 'corporate biographies' (those written by the health professionals) mediate autobiographical accounts, the 'fictional distance' grows between the actual experience and the reported experience. The fourth way concerns how the corporate biographies will be interpreted when they are read by another person, i.e. another practitioner. This offers yet another layer of interpretation and thus another potentially compromised representation. The final way in which an individual can be fictionalised is an extension of the former as it refers to how the reader of a patient's records recounts the patient information and resultantly, 'flesh and blood patients may receive interventions directed at a "personality" quite unrelated to them'.(62] Stone, Reuber and Carson, for example, explain that 'the commonest source of diagnostic error is when the clinician pays too much attention to the patient's psychosocial history and not enough to the presenting symptom'. Incidentally, panic and anxiety is a relatively common misdiagnosis.

> The mimics and chameleons of functional symptoms could be a whole textbook of neurology, but when things go wrong, there are some recurring themes, notably:

> diagnostic bias introduced by the presence or absence of psychiatric comorbidity or by life events; neurological diseases that look 'weird'; and a lack of appreciation of the more unusual features of functional symptoms themselves.[10]

Based on the above literary analysis of *Alex Woods*, I propose another dimension through which the fictionalism of a patient takes place: *schema deflection*, which concerns the influence of practitioners' schemas. To illustrate this, I must briefly return to the reader of *Alex Woods*: their FOCAL SEIZURE schema enables them to be attuned to the characteristics of the seizure and they are likely to be able to recognise future occasions when Alex has them. Further to this, when Alex has another focal seizure in the novel, the reader is most likely to activate the FOCAL SEIZURE schema, rather than starting at square one with an UNKNOWN EXPERIENCE schema. This illustrates how context and prior knowledge play a big part in schema activation. Schemas function to make sense of a situation whilst using minimal cognitive effort. Healthcare practitioners possess a wealth of knowledge about multitudinous health conditions, from symptomatic knowledge to management and treatment of different conditions. This allows them to listen to patients, assess and evaluate their descriptions, and propose an appropriate course of action. To put it another way, they have a plethora of schemas relating to different health conditions which are activated and developed constantly on a day-to-day basis. Naturally, some schemas are activated more frequently than others, for example: practitioners will likely see more common ailments than rarer ones, some conditions are more common in certain demographic groups, and so on. Therefore, when faced with a patient who is experiencing focal seizures and reports symptoms such as intense fear, perspiration, difficulty focusing, heart racing—typical of panic attacks—it would be unsurprising that a PANIC ATTACK schema is activated instead of a FOCAL SEIZURE schema. Especially considering, in comparison to epilepsy which affects 1 in 103 people in the UK,[2] mental health conditions affect 1 in 4 people in the UK each year.[65] PWE are also more likely to experience anxiety and depressive disorders,[66] which increases the likelihood of someone experiencing focal seizures also having panic attacks. Further still, some practitioners, especially juniors may not have even come across an epilepsy case in their career. Malmgren, Reuber and Appleton found that the level of experience of the physician impacted on the number of misdiagnosis cases.[3] Whichever scenario, misattributing a patient's description to the wrong schema results in schema *deflection* whereby the wrong schema is activated. This will then make practitioners more perceptive of features for *that* schema and, consequently, can lead to certain reported symptoms being foregrounded over others when they resonate with the active schema.

Resultantly, the patient's notes will be subject to the schema deflection which, in turn, will create distance between the patient and the actual medical condition that is affecting them. This distance is one of the key contributors to prolonging diagnosis and even misdiagnosis.

LOOKING FORWARD

Fictional characters are essentially 'described written people' which is precisely what a patient becomes when represented in their health records. Observing real-life diagnostic issues and looking to literature and cognitive stylistic analysis has demonstrated how insightful literary analysis can be in terms of unpicking idiosyncratic subjective seizure narratives.

The aim of the present paper was to explore the convergence of literature, linguistic analysis (through schema theory and foregrounding), fictional characters, PWE, and seizure narratives, and from that bring to awareness the areas of risk that surround aspects of the diagnosis process. This paper alone cannot—and does not—propose an implementable solution to overcome schema deflection in a clinical context. The paper has, however, delivered five points to be taken into consideration for further research.

First, it has demonstrated how cognitive stylistic analysis provides a method for managing and understanding idiosyncratic subjective narratives; careful selection of schema theory has demonstrated how it is possible to systematically track experience. In turn, it has demonstrated the potential of interdisciplinary research using linguistic analysis to highlight where the pitfalls of interpreting experience can lie and supply theoretical frameworks to help tackle such communicative issues. Second, it has emphasised that a rich FOCAL SEIZURE schema promotes deeper understanding of the seizures which is essential in minimising the risk of schema deflection. A working knowledge of the symptoms is certainly key to building the foundations of the FOCAL SEIZURE schema and will facilitate the identification of symptoms *in situ* through their manifestation, characteristics and how they affect the individual's perception of the world. Third, it has highlighted that having an understanding of schema activation and schema deflection can help to encourage self-awareness when interpreting and reporting on seizure narratives. Bringing to light the role schemas for different health conditions play in the diagnosis process is an important step towards enhancing a physician's diagnostic toolkit. Practically speaking, an awareness of schemas alone is not enough to make use of them. To 'put the theory into practice', two key elements are required: policy and accessibility. Further

developed and made accessible through abstraction and implementable strategies, such research has the potential to inform policy, and act as the basis for learning resources and training for healthcare professionals. Of course, this must be closely aligned with the variable and multitudinous symptoms that focal seizures evoke. Finally, it has shown that building awareness through exposure to subjective seizure narratives, whether in literature or using real-life examples, can be an effective way of building an awareness of the range of seizure experience, and thus enriching FOCAL SEIZURE schemas.

Figure legend

Figure 1. Creating the 'fictional distance'

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Footnotes

[i] I refer to the schema as a FOCAL SEIZURE schema, rather than an AURA schema, as the former is the most up to date classification for these seizures.