

‘An autoethnographic Salon des Refusés of spiritual experiences of epilepsy’

Abstract

In this autoethnography, I share an extension of an evocative narrative using poetry and painting that problematizes the materialist and normativist medical understanding of notions of wellbeing and what counts as a ‘normal’ spiritual experience. The autoethnography follows a journey of my experiences as a person with epilepsy, offering a reflexive engagement with chronic illness and an eventual understanding of the exceptional experiences I have during my seizures, resulting in an understanding of them as being part of a profound spiritual journey. Through a series of paintings, poetic and autoethnographic writings, I invite others into my lived, embodied experience of epilepsy, into the feelings and the complexity of living with an invisible condition that moulds and defines my life experience and interaction with the world. In my poetry, I explore what it feels like to be a citizen of this other place, and the stigma associated with it from the position of wellness. The reflections, poems, prose and paintings I share have been written over the last four years, whilst I have been researching my PhD into spiritual experiences in epilepsy. A large part of my research has been inter-relational, presenting autoethnographic material about ecstatic experiences in epilepsy to a wider academic audience. The personal material in this chapter include a reflection of others' responses to my experience, to autoethnography, and to the idea that exceptional human experiences are real and not hallucinations.

Keywords

Temporal lobe epilepsy, autoethnography, illness, spirituality, ecstatic experiences

“Without the spiritual, observe,
The natural’s impossible, - no form,
No motion: without sensuous, spiritual
Is inappreciable— no beauty or power:
And in this twofold sphere the twofold man
(For still the artist is intensely a man)
Holds firmly by the natural, to reach
The spiritual beyond it”
Aurora Leigh, Elizabeth Barret Browningⁱ

Rejecting content

This chapter considers the role of the audience of an autoethnographic work, and their relationship with the autoethnographer when they engage with the content of an evocative narrative. In order for the autoethnography to have meaning, there needs to be an iterative relationship between the two. Although the narrative is subjective and intensely personal, it is a reflexive relationship of a ‘story-teller’ and ‘story-listener’ (Bochner, 2012). The story-teller shares their narrative, and they also reflect on any response from the story-listener. An autoethnography without a listener does not do the work it was intended for. By presenting their narrative, the autoethnographer is engaged in an act of meaning (Bruner, 1990), where they share their lived experience and the mirror that this holds up to society (Frank, 1995) and they, in turn, consider the response. I am interested in considering what happens when there is a parallel and that both the form and also the content, the narrative itself, are contested – and therefore marginalised.

In the artworld, it is common for curators to decide which works are hung in an exhibition, based on their taste and the prevailing interests of the time. Famously, in 1874, the impressionists were refused exhibition in the usual Salon, and instead showed their work in a Salon des Refusés. I am choosing to adopt the metaphor of the Salon des Refusés to offer this

autoethnographic material, a work of poems, prose and paintings that I have previously shared with academics and medical professionals at conferences. There have been notable occasions when, in one way or another, the content of the narrative has been denied; not queried as narcissistic (Sparkes, 2002), or regarded as invalid or controversial, just plain dismissed, refused, marginalised. The key thing to note is that in presenting the autoethnography, the academics who have denied the *content* of the autoethnography have also rejected the *form* it takes. I find this interesting and challenging, to consider that one person's preference or dislike of poetry, or painting, or prose, has the effect of negating the content or veracity of the experience that it represents. Medical professionals have similarly pathologized the content of epilepsy experiences, dismissing them as hallucinations and delusions. My feeling is that, in fact, both groups are uncomfortable with the ontological status of the often spiritual nature of the experiences themselves. They may feel epistemologically challenged by what I have presented and have chosen to refuse the content. Typically, this has been defended through a dislike for the form – or of autoethnography itself. When the content of the autoethnography is queried, it is a defensive mechanism against the challenge that this experience represents.

Reflecting on this, I feel silenced, delegitimized. I have re-created a narrative of my experiences of having epilepsy and the spiritual experiences that this involves. In re-presenting my experience using reflections, poems, prose and paintings, I offer again the opportunity for the many voices it holds to be heard (Frank, 1995). This is, I hope, not a petulant endeavour – rather, it is a part of the iterative nature of autoethnography that feeds it, making each telling of the story richer and deeper. The prose, poetry, and paintings in this narrative span a period of around four years. It starts at the moment that I realised that the epilepsy that I have had since 18 was not as well-behaved as I had thought, to the moment when, through sharing my experience using autoethnography, I have seen my condition

transformed into a spiritual gift, a way of knowing myself and understanding the world around me.

The charge of navel gazing is often levelled at autoethnographic works (Allen-Collinson & Hockey, 2008) and in so doing, the veracity of the data used can be questioned. Subverting this criticism, Ellis (personal communication, 2019) states that, in being authentic to the phenomenology of experience, we need *more* navel gazing, because we then pay attention to the embodied nature of our experience. In the material I present in this chapter, I am focusing authentically once more. My need to engage again with the phenomenology of my experience creates a vulnerability, and, as always with re-counting my narrative, I trust that this will offer me further an insight into and understanding of my experience, and that the intimacy it necessitates will be of value to both researcher and reader (Ellis, 1999).

Epilepsy and spirituality

Epilepsy is one of the oldest and most common neurological conditions, affecting 50 million individuals globally (Reynolds, 2002). Some believe that individuals with epilepsy are doubly cursed – first with the condition, and then with the attitude of others who view them as possessed or crazy (Bstan-'dzin-rgya & Engel, 1997). The first recorded mention of epilepsy is Babylonian, on the Saikkiku, or 'All Diseases', a cuneiform clay tablet dated c. 2000 BC (Wilson & Reynolds, 1990). For the Greeks, epilepsy was the 'sacred disease', divine in nature (Temkin, 1994). Hippocrates denied this divine origin and identified it as bodily disease located in the brain, and suggested physical, rather than supernatural, cures (Temkin, 1994). This understanding did not prevail, however, and Christianity reverted to previous conceptions of supernatural agency, with symptoms being the manifestation of possession, lunacy and a misunderstood confusion with mental illness (Temkin, 1994) and

religious figures the divine sources of healing this affliction (Devinsky & Lai, 2008). In the Middle Ages in Europe, epilepsy was regarded as a punishment for sin, and convulsions were symbolic of the torment of the sinner's soul (Ladino, Rizvi & Téllez-Zenteno, 2016b). Treatment involved a combination of cauterisation (Ladino, Rizvi & Téllez-Zenteno, 2016b), trepanning, magical cures and herbal remedies until the development of asylums, when epileptics were confined alongside the insane (Temkin, 1994).

Temporal Lobe Epilepsy (TLE), is its most common form and is characterised by seizures that originate in the temporal lobes and involve a short period of impaired consciousness. Some individuals with TLE have feelings and sensations associated with a state of consciousness that is qualitatively different from anything that they have in normal waking consciousness (Åsheim Hansen & Brodtkorb, 2003). Medically called 'auras', they include symptoms of nausea, smells, tastes and emotions (NNID, 2016). However, there is an additional element to them for some experiencers, who also describe their auras in terms of their ineffable and numinous quality (Dolgoff-Kaspar et al., 2011). The medical establishment would pathologize them as sufferers. At first Hughlings Jackson referred to epileptic experiences with a religious connotation as 'dreamy states' (Jackson & Coleman, 1898, after Jackson, date). The actual experiences include descriptions of déjà-vu (Picard & Craig, 2009), jamais-vu (Sacks, 2012), out-of-body experiences (e.g. Neppe, 1981, 1983, 2011; Palmer & Neppe, 2003), mystical states (Ramachandran & Blaksee, 1999), cosmic spirituality (Dolgoff-Kaspar et al., 2011) and ecstatic feelings (Åsheim Hansen & Brodtkorb, 2003).

For experiencers, these often have profoundly spiritual connotations. The Abbess Hildegard von Bingen composed music in the 12th Century that is now seen as mystical, that is, concerned with her relationship with God, yet in relation to her supposed epilepsy is deemed symptomatic of her condition and the so-called ecstatic nature of her epilepsy.

Dewhurst and Beard (2003) reported six cases of individuals with epilepsy who underwent ‘sudden religious conversion’, and Picard and Craig (2009) interviewed 5 people, whose experiences included seeing the world in a different way, and a deep sense of joy and harmony with the universe. Dostoyevsky (cited in Alajouanine, 1963) recounted feeling “such a happiness that it is impossible to realize at other times, and other people cannot imagine it... a complete harmony within myself and in the world”. One woman explained their transformative nature by saying: “It is a big happening in your life to have these seizures. Thanks to these experiences, I do not fear death anymore. I see the world differently” (Picard & Craig, 2009, p.540).

I name such spiritual experiences Epileptiform Events (EFEs), as a more neutral description than the medically oriented terms ‘seizure’ and ‘aura’, and the colloquial terms ‘fit’, and ‘outburst’ (Admi & Shaham, 2007), with their unpleasant connotations of being socially inappropriate or unwanted. I identify a tension that exists between the medical understanding of these experiences and the meaning typically attributed to them by those who have them. This tension is worthy of deeper consideration because society silences those who experience it in favour of medical diagnosis.

The medical establishment unfortunately views EFEs with a diagnostic and materialist lens. Medical professionals regard EFEs as symptoms of the condition to be pathologized and medicated away. They assume that no sane individual with epilepsy would want them; indeed, if they do, this is indicative of a specific form of epilepsy-related psychosis (Trimble, 1991). From the biomedical perspective, these experiences are interpreted as symptomatic of either an epileptic or psychiatric disorder (Gaber, 2017). They are regarded as individually and culturally unlike usual, ordinary or expected experiences (Braud, 2012). As such, they are deemed neither authentic nor appropriate to the hegemony of neurotypical functioning, and the conventional reaction of the medical profession to an individual reporting such an

experience is to pathologize it (Evrard, 2012); regarding it as, at best, delusional (e.g. Kasper, Kasper, Pauli, & Stefan, 2010) or hallucinatory (Penfield & Jasper, 1954) and, at worst, symptomatic of Geschwind syndrome, a contested behavioural diagnosis still used by clinicians (e.g. Veronelli, Makaretz, Quimby, Dickerson & Collins, 2017). identified by hypergraphia, an intense mental life, hyposexuality, irritability and hyper-religiosity. I find, along with William James (1902), that this materialist understanding of EFEs to be too reductive.

Engaging with embodied, meaningful experience

Oliver Sacks (2012) highlighted that a strictly biomedical perspective offers no insight into the meaning that these spiritual experiences have in the lives of those with epilepsy. Through prose and poetry I attempt to cast a light on these concepts as they are experienced in my life, problematizing the traditional understanding of them.

Falling Free

If I fall

Down,

Down,

Onto the ground,

Who will catch me?

When I go, who will be there.

A balm to the anguish

Of my defenceless state

Falling free, born into body shame.

Trusting no-one

For there is no-one to trust

Illness is the night-side of life, a more onerous allegiance. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick (Sontag, 1978). Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. The stigma of illness is linked to the bearer's role as being one with a spoiled social identity (Goffman, 1963) and story-listeners do not want to consider that they may one day have to use the unwanted passport, or wear a tainted social identity.

Broken Brain

The leafy loneliness of this empty echoing avenue

Reminds me that I am

Stuck,

Stu..tter..ing

in my head.

How we all are.

But my head is

Broken

Epilepsy is the illness of stigma par excellence (Baker et al., 1997). My epilepsy is unpredictable, generally completely absent. Whilst some individuals have a warning, or aura, the seemingly sudden, erratic nature of seizures, even with mostly effective medication, can be a distressing symptom. I always reflect on this when new people enter my life. 'Bathroom Cabinet' reflects my emotions concerning my body's ability to fall into seizure activity with no prior warning - and my fear of other people's negative responses.

Bathroom Cabinet

Piles of boxes in my bathroom cabinet

*Crisp foil blisters of chemical shame
Perfect pressed pink tablets
How I hate you flowing through my veins.
Without you no control
Distorted, contorted, gnarled and twisted
A reminder that I am not whole
Calling out like a soul darkness has visited.*

*Turning hateful labels one by one
Hiding packets of personal potency
Normalcy, so hard won
Masking my shameful latency.
My longing to be held mixed with fear of judgement
Most deeply unseen, you wouldn't know
It creates this bathroom cabinet predicament
For I set myself in the Shadow, and you didn't even show*

The struggle of disclosure

The singer Neil Young (1975) describes the experience of a seizure as a void where we epileptics go, and from which it is hard to come out. For him, what is frightening is not being present in what would normally be regarded as reality, but being present in a void he finds more real, and that realisation makes it hard to re-enter the neuro-normative world. Despite the medicalised understanding of the condition, public perception and treatment of those with epilepsy continues to be poor. In contemporary society, individuals often choose not to disclose their condition and therefore the status of epilepsy as a so-called 'invisible' disability is ambiguous and complex (Rhodes et al., 2008). I wrote the poem 'Show and Tell' to reflect my own struggle with disclosing my epilepsy, unsure of the outcome, and

concerned that, even when the person I tell is supportive, they do not know what they are really being open to.

Show and Tell

*When I told you
That I am sometimes not here
That I travel to another place
You thought I meant a daydream*

*When I told you
That you will feel helpless
That you will realise this is real
Even if you can't stand in it*

*When I told you
That this is not straightforward
That it is deep
You thought I was being poetic*

*When I asked you
If you want to go now
You showed me love
And held your nerve*

*When I showed you
You could not travel with me
And were left to watch
You were scared*

The status of epilepsy as a so-called 'invisible' disability is ambiguous and complex. Individuals ignore their condition or hope it will subside; with adolescents this may be an

internalised desire for neuro-normativity. Hayden, Penna and Buchanan (1992) likened the disclosure to 'coming out of the closet, having found that 52% of their survey respondents would not disclose their condition to acquaintances, 21.5% would not tell close friends and 13.6% would not tell anyone at all,. In her autoethnographic dance, Marcelo (2012) explains:

As a performer my work is about 'exposure', but as an epileptic I constantly work very hard at 'hiding' my condition. For once in my life I was interested in exploring what it would mean for me to 'expose' my epilepsy instead of hiding it away. (p. 57)

Dreams as a bridge into the spirituality of dreams

Responding to Marcelo's call, I reflect that I, too, have always hidden my epilepsy, but have been transformed during my PhD journey .? Where my poetry used to be private and personal, I now make it public. Phenomena that were considered taboo even by the experient are now a matter of public record, so that they can enable others to recognise that their experiences are shared, and form part of the rich tapestry of 'normal'. As a practising therapist, one of the greatest taboos is around disclosing details about myself and the confidences of my own therapeutic sessions. sacred . In sharing these with the story-listener, I have chosen to expose the hidden realm of my therapy and rediscovery of my dreamworld. I invite you to step into my dream to glimpse how it feels to be in a seizure, and consider how this may be understood by the experient in terms of some fundamental spiritual nature.. By opening up this intimate personal space, I am honouring the autoethnographic demand to take risks and be personally vulnerable, venturing into the unknown and unexplored in a reflexive context (Behar, 1996). In this narrative, I become a story-teller, and wonder, if this invisible,

ineffable, rejected part of my experience is exposed, will the content of my story be heard or will it, once again, be criticised?

In am in my therapy session, settled into my usual chair, my bare feet on the soft sheepskin rug My therapist looks, expectantly.

Me: I want to work with my dream, I feel it had an important message for me

Therapist: Ok, close your eyes and take yourself, as you have so many times before, to the dream. Describe to me the scene, setting and atmosphere...

The dream of the seven flowers



Fig. 1 Seven Italian Flowers, 24th June 2015, Milan. My photograph.

An unmarried woman who collects seven different kinds of flowers and puts them under her pillow on Midsummer, says a Finnish legend, will see her future husband in a dream (Snyder, 2014). I offered my spirit up to the dreamworld and collected flowers and placed them under my pillow. I dreamed that night, and in my dream, I saw three identical men with long, flowing robes and grey beards, looking like Rabindranath Tagore, a wise and spiritual poet. Floating in a featureless void, each man held on his flat palm a pristine green silken purse with golden thread. I knew that he was offering me choices between things of great value; they feel like sacred votive offerings. I knew, looking at them, that my job was to choose between the purses.



Fig 2. The fish. My painting.

Reaching inside the first purse, there was a piece of blank, snow-white paper. I was puzzled, confused. What was this meant to be, to tell me? I turned the paper over in my hands, curious – would a message emerge? Moving it, I felt the paper, it spoke to me through the contact in my hands as I waved it in the air. And as I did so, the paper created a movement all of its own, moving through me, focusing my attention and flowing through me. I stood up and moved. I was flexible and fluid, and as my body took the sensual shape of this movement, with no friction, effortless, I transformed into a fish, moving through a deep, inky dark blue sea. I looked at the fish I had become, fins and scales of metal, precious gold, glistening when the sun permeated the depths of the deep blue water and caught the flash of a turn. My graceful twists created the sign of figure 8 in my hips, and as it did, the symbol of infinity entered my being. Gold - perfection in alchemy. But perfection became boring, never ending perfection, unseen in the stillness of the depths. I moved to examine the second purse.



Fig. 3 The quartz crystal mountain. My painting.

The second purse seemed as flat as the first. Reaching inside, I was surprised to find a large, craggy, unpolished lump of rose quartz. Placing my hands firmly on its jagged edges, focusing on my bodily awareness, it emanated a warm glow flowing to my heart, radiating outwards, pulsing each heartbeat from the core of my being to the tips of my fingers, the ends of my toes, the top of my head, vibrating a warmth and energy connected to the universe beyond myself. As I felt its energy flowing through me, I saw ahead of me a mountain range, as huge as the highest mountain, reaching up into the sky, range upon range unfolding in the distance ahead. I was tiny in this enormous landscape, alone on a rose quartz mountain at the top of the world. My body felt as if this was a place I knew, intimately. The urge to climb and explore was strong. I felt the fear of falling great depths, moving tentatively, scrabbling as I went. And in that moment, I transformed into the mountain range, looking at this tiny creature. She could not see that I had made alpine paths for her, beautifully laid with flowers, wooden posts and protective ropes to ease a gentle walk along the sides of my glistening pink heights. Here was a little creature making it difficult for herself, tripping and scrabbling, moving over the most craggy of my surface, climbing the hard way – missing the path of ease ahead. I rumbled, a deep, bass shaking from my core, creating a terrible quaking, sliding in a great rocky avalanche. And, then, in that moment, I became a huge bird, picking up the tiny

human and dropping her on my beautiful alpine path. Delighted, she walked on with ease and joy. I moved on to the third purse.



Fig. 4. The sand dune. My painting.

The third purse was empty. I tipped it upside down. Nothing. I looked inside - had I missed something? A solitary grain of sand, and then a pouring, more and more. The dune grew – soon stretching to the horizon. I was hot, the sun beat on me and the dune was scorching my feet. But the dune kept pouring, like some mysterious magic trick. Surveying the landscape, I saw a featureless sea of sand, ripples along its side, stretching into forever. As I looked ahead, I felt it shift and circle, pulling me downward. It was as if someone had pulled an enormous plug and I was being sucked forcefully down a huge drain. I felt suffocated, my chest was restricted, my breathing fast and shallow. It was frightening, dark, fast. The pull kept going for a long, long time. I kept falling. A nausea rose in my throat. Then, suddenly, I was at the bottom of a long, dark well. Looking up, I saw a single star shining in the blackness of the sky above. Shifting my focus to the star above, I began to physically disintegrate. There was no 'me', I was becoming a clear fluid, losing myself. I coated the bottom of the well and began disperse, seeping into the ground. Without coherence or consistency, I had become single molecules mixed with the earth. And as the star shone down, I moved along the shaft of light into it, feeling the connectedness, calm; the unity of

consciousness. As I was drawn to the light on the star, and as I moved towards it, my whole being was taken up by the feelings I experience when I have a seizure. This, this was the other world, the state of spiritual union that the dream wanted me to see. And with that feeling of unity, I knew that I had to return to the light of the star, that this was the source of spiritual importance.

I was beguiled by the light of the star, it seemed to fill the sky and I felt drawn to merge with it, become one. I imagined stretching my arm out to feel it clothe my skin. My therapist invited me to enter its consciousness. As I tried to do this, it was a very, very comfortable feeling, like slipping in to a warm bath. And in that moment, I knew that I was at one with the consciousness of the universe. It whirled like a typhoon inside, and I felt myself whisked around like a rag doll. The energy inside the consciousness of the star was powerful, primal. Having my mind connected to it was at first the calmest, most beautiful experience I had ever had. This seemed like my heart's home, the source of all belonging. I laughed in delight.

And then suddenly, it became a most unpleasant feeling, unbearable almost, and I wanted to scabble out, claustrophobic, suddenly. The light was pure energy, but I had regained my own consciousness and ego again, and in doing this I couldn't meld with the star and it was too much to bear. As soon as I had separated myself from the energy, the star spat me out with huge force. In the session, I was breathless, taken aback by the strength of the experience.

Closing my eyes now, I can re-enter the star's consciousness and I realise that the feelings of disorientation and suffocation are just like those I feel as I have a seizure. And the beautiful calm, the sweetness- that is the cosmic ecstasy that I touch, all too briefly. My seizures connect me with the energy that runs through, and of, and in, all that was, all that is,

and all that will be. It is the spiritual homeland of the awesome cosmic fundament. I know pure joy.

There is something so very special about a personal epiphany, and just how different the experience is of coming to know and feeling a spiritual connection as an ontological reality, rather than accepting the epistemological suppositions of others (Glass-Coffin, 2013). The effect of engaging openly with this dream and the process of painting has been one of a slow transformation for me. Until I shared my story, and the content of my experiences were marginalised, I had not identified them as spiritual and aligned myself with others whom I had been researching. In researching others and their experience and making myself vulnerable to their place in my life through autoethnographic reflexivity, I have recast own my own experiences as having spiritual meaning.

We know ecstasy, but are we mad and dangerous?

Society has built a body of memory that depicts those with epilepsy as dangerous, unreliable, frightening, and unable to function as adults, pervasive across educational level, class, culture and geography. One survey of attitudes to epilepsy (Aragon, Hess & Burneo, 2009) resulted in responses that the researchers found to be inappropriate and ill-informed, including that 5% of respondents objected to a member of their family marrying someone with epilepsy. (Schneider & Conrad (1980) note that Maudsley and Lombroso proposed a causal link in the late 19th and early 20th century between epilepsy and violent crime.

I was brimming with such thoughts following my dream and my understanding of a spiritual life. I visited the neurologist for a follow-up consultation, during which I told him I was visiting the Tablet Room at the British Museum to see The Sakikkū. In the Sakikkū, a Babylonian cuneiform tablet, a symptom of epilepsy is that “a man evolves his own religion” (Reynolds & Kinnier Wilson, p.2616). I showed him a picture of the tablet. He was excited,

and wanted to know about it. Emboldened by this disclosure, I guardedly mentioned my research into spiritual experiences occurring during my own epilepsy. But then something changed, he shifted in his chair and reminded me about his role in court acting as an authority on individuals who have epilepsy and have committed violent acts. He took on the mantle of mental health professional again, and I was put in the position of a patient.

The Tablet Room

The appointment clerk looks up, momentarily

I wait for you again

In the bustling antechamber of the brain

The room where heads are categorized

Experience is stigmatized

A stratigraphy of shame

The sands of time have shifted

My distress wasn't buried in your memory

You may think you heal

Measuring with tests and scans

But what your excavation reveals

Is that I am gifted

Dusty Nineveh, just a breath away

In hushed, hallowed halls

They knew it all before, this malaise

Their tablets wiser than yours

You can't see what's inscribed in my mind

Cuneiform reveals meaning today

I present my autoethnography at an international conference about qualitative research into spiritual experiences. It is a mixture of socio-cultural commentary on epilepsy, the

history of spirituality in epilepsy, and my poetry. As usual, I am perturbed by the immediate silence that follows the concluding statements. I feel inadequate, I forget that my aim is to communicate; I wish for the lively questions other presenters have had. It's like a physical movement: I finish, there is a long, long pause where the narrative serves to 'attract, awaken and arouse' (Bochner, 2012). People look down and shuffle uncomfortably in their seats. Sometimes, they are moved emotionally. The story-listeners find the content heavy and hard to reconcile with their view of society as accepting and liberal. And so, the response can be defensive.

Participant: Autoethnography is difficult, though, isn't it, as it is, essentially, prose, not empirical research?

Me: Well... autoethnography is an accepted approach for using narrative to convey the embodied features of personal experiences.

Participant: But can I ask how you came up with all of those ideas?

Me: They are my experiences; I wrote them into poetry and prose

Participant: But you exaggerated the details for effect?

Me: No, I used these forms to explain the experiences.

Participant: But can you explain what these spiritual experiences are, can you tell me more about them?

Me: I have, in the autoethnography.

Participant: I'd like more description, because we all know autoethnography is fictional.

I felt confused and wounded by this response. Confused, because of the rejection of the autoethnographic *form*. We had been asked to offer embodied research methods.

Wounded, that the *content* of my secret, ineffable experience, the one that I had struggled to bring forth was also devalued. In an attempt to understand and integrate my feelings about this experience, I wrote 'Milan'.

Milan

Toe curling, knee knocking, stomach churning, head spinning,

Heart beats, beats, beats, veins alive.

Exposing the inner.
Did they see my recent experience
Of wildly transporting to a place apart
From the rest?
Out of body, mind made manifest.
I told you this was my reality,
Not like everyday generality.
That's very nice, she says
But it's all fiction anyway.
Where's the vulnerability?

There is an element of my narrative that story-listeners find extremely challenging. It demands they consider notions of neuro-normativity and their privilege, how much they 'other' individuals with epilepsy, let alone their acceptance of stereotypes, or the veracity of these experiences. I have to work to understand that by problematising this subject, my voice is shocking. Usually, after the story-telling, people catch me, alone. They want to tell me about their mother/ father/ sister/ brother/friend who has epilepsy, about how hard it is for them, in hushed tones, in private. The storytelling of my narrative re-enacts the taboo for the story-listeners, a sort of psychic transference.

Concluding remarks

There is a transformative process of physical and psychical healing in the very act of telling one's story (Braud, 1998). A story which can also add to the sum of knowledge and understanding acts as a catalyst for mutual understanding that drives the desire for cultural and social change (Ellis, 2000). In this chapter, I have illustrated my experience of living with epilepsy and given insight into experiences of a non-shared reality, the phenomenology of which are generally absent from medical literature. Carel (2018) states that by focusing on its phenomenology, chronic illness holds within the opportunity for growth and self-knowledge.

Rather than being unwanted, the symptoms of epilepsy can offer a transformative, spiritual experience. In doing this, I have seen that Sontag's (1978) unwanted land unfolds ahead of me into an undiscovered land of potential. Through my narrative of rejected experiences, I have problematized the neuropsychiatric perspective of ecstatic experiences in epilepsy. I explore and highlight themes of illness, shame, stigma and transformation. Epilepsy is an enigma, in many ways, as on the one hand, it is truly embodied, being something that the body 'does' to the individual without their consent. On the other hand, many individuals (myself included) experience some loss of bodily awareness or, indeed, a transportation to another state of consciousness; hard to align within an embodied experience.

My accompanying narrative situates these experiences within a transformation of self and a developed spirituality that rejects neuro-normative labelling. My role as a story-teller has allowed me to develop personal meaning by coming into a meaningful relationship with the content of my experience. I am challenging the story-listener to take meaning from it, too; to engage with its content and to break the silence.

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Biography

Louise Spiers is a Senior Lecturer in Psychology and Counselling at the University of Northampton, UK, where she is a Doctoral candidate researching transpersonal understandings of spiritual experiences in epilepsy. She is interested in exceptional human experiences and their phenomenology and research that enables this. She is passionate about the use of autoethnography as a qualitative method for researching experiences that are otherwise pathologized or silenced. Louise is an Integrative Psychotherapist and Counsellor (UKCP, MBACP) and has a private practice in London, where she uses transpersonal therapeutic approaches which include the use of creative expression, dreams and archetypal symbolism to support her clients.

References

- Admi, H., & Shaham, B. (2007). Living with epilepsy: Ordinary people coping with extraordinary situations. *Qualitative Health Research*, 17(9), 1178-1187.
- Alajouanine, T. (1963). Dostoiewski's epilepsy. *Brain*, 86, no. 2 (1963): 209-218.
- Allen-Collinson, J., & Hockey, J. C. (2008). Autoethnography as 'valid' methodology? A study of disrupted identity narratives. *International Journal of Interdisciplinary Social Sciences*, 3(6), 209-217.
- Aragon, C. E., Hess, T., & Burneo, J. G. (2009). Knowledge and attitudes about epilepsy: a survey of dentists in London, Ontario. *Journal of the Canadian Dental Association*, 75(6).
- Åsheim Hansen, B., & Brodtkorb, E. (2003). Partial epilepsy with "ecstatic" seizures. *Epilepsy & Behavior*, 4(6), 667-673. <https://doi.org/10.1016/j.yebeh.2003.09.009>
- Baker, G. A., Jacoby, A., Buck, D., Stalgis, C., & Monnet, D. (1997). Quality of life of people with epilepsy: A European study. *Epilepsia*, 38(3), 353-362. <https://doi.org/10.1111/j.1528-1157.1997.tb01128.x>
- Behar, R. (1996). *The vulnerable observer: Anthropology that breaks your heart*. Beacon Press.
- Bochner, A. P. (2012). On first-person narrative scholarship: Autoethnography as acts of meaning. *Narrative inquiry*, 22(1), 155-164.
- Braud, W., Integral Inquiry in Braud, W., & Anderson, R. (Eds.). (1998). *Transpersonal research methods for the social sciences: Honoring human experience*. Sage.
- Braud, W. (2012). Health and well-being benefits of exceptional human experience, (pp. 107-124). In C. Murray (Ed.). *Mental health and anomalous experience*. Nova Science Publishers, Inc. New York; Palmer, J., & Marcusson-Clavertz, D. (Eds.). (2015). *Parapsychology: A handbook for the 21st century*. Jefferson, NC: McFarland & Company, Inc.
- Bruner, J. (1990). *Acts of meaning*. Cambridge, MA: Harvard University Press.
- Bstan-'dzin-rgya XIV, D. L., & Engel, J. (1997). *Sleeping, dreaming, and dying: An exploration of consciousness*. Boston, MA: Wisdom Publications.
- Carel, H. (2018). *Illness: The cry of the flesh*. Routledge. <https://doi.org/10.4324/9781315197999>

- Crowe, C. (1975). *Rolling Stone, August 14th, 1975*. Retrieved 16th April 2020.
<https://www.rollingstone.com/music/music-news/neil-young-the-rolling-stone-interview-123513/>
- Devinsky, O., & Lai, G. (2008). Spirituality and religion in epilepsy. *Epilepsy & Behavior*, 12(4), 636-643. <https://doi.org/10.1016/j.yebeh.2007.11.011>
- Dewhurst, K., & Beard, A. W. (2003). Sudden religious conversions in temporal lobe epilepsy. *Epilepsy & Behavior*, 4(1), 78-87.
- Dolgoff-Kaspar, R., Ettinger, A. B., Golub, S. A., Perrine, K., Harden, C., & Croll, S. D. (2011). Numinous-like auras and spirituality in persons with partial seizures. *Epilepsia*, 52(3), 640-644. <https://doi.org/10.1111/j.1528-1167.2010.02957.x>
- Ellis, C. (1999). Heartful Autoethnography. *Qualitative Health Research*, 9(5), 669–683.
<https://doi.org/10.1177/104973299129122153>
- Ellis, C. (2000). Creating criteria: An ethnographic short story. *Qualitative Inquiry*, 6(2), 273-277.
- Evraud, R. (2012). Clinical psychology of anomalous experiences: Roots and paradigms, p.89-106 in C. Murray (Ed.). (2012) *Mental health and anomalous experience*. New York: Nova Science Publishers, Inc.
- Frank, A. W. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago; ILL: University of Chicago Press.
<https://doi.org/10.7208/chicago/9780226260037.001.0001>
- Gaber, A. (2017). Semiological Bridge between Psychiatry and Epilepsy. *Journal of Psychology and Clinical Psychiatry*, 8(1), 00467 (1-7).
- Glass-Coffin, B. (2010). Anthropology, Shamanism, and Alternate Ways of Knowing—Being in the World: One Anthropologist's Journey of Discovery and Transformation. *Anthropology and Humanism*, 35(2), 204-217.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York: A Touchstone Book Published by Simon & Schuster Inc.
- Hayden, M., Penna, C., & Buchanan, N. (1992). Epilepsy: patient perceptions of their condition. *Seizure*, 1(3), 191-197.

- Kasper, B. S., Kasper, E. M., Pauli, E., & Stefan, H. (2010). Phenomenology of hallucinations, illusions, and delusions as part of seizure semiology. *Epilepsy & Behavior, 18*(1), 13-23.
- Jackson, J. H., & Colman, W. S. (1898). Case of epilepsy with tasting movements and “dreamy state”—very small patch of softening in the left uncinat gyrus. *Brain, 21*(4), 580-590.
- James, W. (1902). *The varieties of religious experience. A study in human nature*. New York, NY: Longmans, Green.
- Ladino, L. D., & Téllez-Zenteno, J. F. (2016a). Tlazolteotl, the Aztec goddess of epilepsy. *Epilepsy & Behavior, 57*, 60-68. <https://doi.org/10.1016/j.yebeh.2016.01.020>
- Ladino, L. D., Rizvi, S., & Téllez-Zenteno, J. F. (2016b). Epilepsy through the ages: An artistic point of view. *Epilepsy & Behavior, 57*, 255-264. <https://doi.org/10.1016/j.yebeh.2015.12.033>
- Marcalo, D. R. (2012). Involuntary dances. *Research Ethics, 8*(1), 57-59. <https://doi.org/10.1177/1747016112437686>
- Neppe, V. M. (1981). Symptomatology of temporal lobe epilepsy. *South African Medical Journal, 60*(23), 902-7.
- Neppe, V. M. (1983). Temporal lobe symptomatology in subjective paranormal experiments. *Journal of the American Society for Psychical Research, 77*(1), 1-29.
- Neppe, V.M., (2011). Models of the Out-of-Body Experience: A New Multi-Etiological Phenomenological Approach. *NeuroQuantology, 9*(1), 72-83. <https://doi.org/10.14704/nq.2011.9.1.391>
- NINDS (2016), *The epilepsies and seizures: Hope through research*, National Institute of Neurological Disorders and Stroke (NINDS), U.S. National Institutes of Health (NIH). Retrieved from <https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Hope-Through-Research/Epilepsies-and-Seizures-Hope-Through>.
- Penfield, W., & Jasper, H. (1954). *Epilepsy and the functional anatomy of the human brain*. London: Churchill.
- Picard, F., & Craig, A. D. (2009). Ecstatic epileptic seizures: A potential window on the neural basis for human self-awareness. *Epilepsy & Behavior, 16*(3), 539-546. <https://doi.org/10.1016/j.yebeh.2009.09.013>

- Ramachandran, V. S., & Blaklee, S. (1999). *God and the limbic system. Phantoms in the brain: Probing the mysteries of the human mind*. New York: William Morrow.
- Reynolds, E. H. (2002). The ILAE/IBE/WHO epilepsy global campaign history. *Epilepsia*, 43(Suppl. 6), 9-11. <https://doi.org/10.1046/j.1528-1157.43.s.6.5.x>
- Reynolds, E. H., & Kinnier Wilson, J. V. (2008). Psychoses of epilepsy in Babylon: The oldest account of the disorder. *Epilepsia*, 49(9), 1488-1490. <https://doi.org/10.1111/j.1528-1167.2008.01614.x>
- Rhodes, P., Nocon, A., Small, N., & Wright, J. (2008). Disability and identity: The challenge of epilepsy. *Disability & Society*, 23(4), 385-395. <http://hdl.handle.net/10454/7051>
- Sacks, O. W. (2012). *Hallucinations*. London: Picador.
- Schneider, J. W., & Conrad, P. (1980). In the closet with illness: epilepsy, stigma potential and information control. *Social problems*, 28(1), 32-44. <https://doi.org/10.2307/800379>
- Snyder, R. (2014) <https://finland.fi/life-society/enjoying-midsummer-the-finnish-way/>. Retrieved on 16th April 2020.
- Sontag, S. (1978). *Illness as metaphor*. Farrar, Straus.
- Sparkes, A. C. (2002). Autoethnography: Self-indulgence or something more. *Ethnographically speaking: Autoethnography, literature, and aesthetics*, 9, 209-232.
- Temkin, O. (1994). *The falling sickness: A history of epilepsy from the Greeks to the beginnings of modern neurology*. (2ND edition). London: The John Hopkins University Press.
- Trimble, M. R. (1991). *The psychoses of epilepsy*. Raven Press, Publishers.
- Veronelli, L., Makaretz, S.J., Quimby, M., Dickerson, B.C., & Collins, J.A. (2017). Geschwind Syndrome in frontotemporal lobar degeneration: Neuroanatomical and neuropsychological features over 9 years. *Cortex*, 94, 27-38.
- Wilson, J. K., & Reynolds, E. H. (1990). Translation and analysis of a cuneiform text forming part of a Babylonian treatise on epilepsy. *Medical history*, 34(2), 185-198.
