

La piel del miedo: epilepsy in the novel by the Ecuadorian writer Javier Vásconez

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ABSTRACT

Introduction. Seldom in literature has epilepsy been the main focus of a novel. In *La piel del miedo* (“The skin of fear”), the Ecuadorian writer Javier Vásconez focuses on the disease in the context of fear. This study reviews the novel’s portrayal of fear caused by epilepsy from a multidimensional viewpoint.

Development. The author read the novel *La piel del miedo* and analysed the clinical symptoms, the protagonist’s perception of epilepsy, and external perceptions of the disease. The novel provides several descriptions of epileptic seizures, the postictal state, treatment, and prognosis. The main character’s perceptions include clairvoyance, self-pity, insecurity, concealment, dependence, isolation, identity, confidentiality, powerlessness, secrecy, stigmatisation, and fear. External perceptions of epilepsy include fear, confidentiality, revelation, and hostility. These findings stand in contrast with the positions or descriptions of other authors who have the disease or who have employed it in their works.

Conclusions. *La piel del miedo* provides a subjective, human view of epilepsy. The true scope of epilepsy transcends the clinical aspects of the disease; this novel provides a comprehensive view by addressing its psychological and social aspects.

KEYWORDS

Epilepsy, fear, literature, medical humanities, narrative-based medicine, stigma

Introduction

Fear caused by epilepsy is the central theme of the novel *La piel del miedo* (“The skin of fear”), by the Ecuadorian writer Javier Vásconez.¹ The main character has epilepsy, which is approached from the multidimensional perspective of fear. In his treatment of this fear, the author explores aspects including the associated clinical symptoms and social perception; this is an integral part of the plot and important to the characters themselves. This study reviews the novel’s portrayal of fear caused by epilepsy from a multidimensional viewpoint.

Development

The author read the novel *La piel del miedo* by Javier Vásconez and analysed the clinical symptoms, the protagonist’s perception of epilepsy, and external perceptions of the disease.

Clinical symptoms

The novel portrays epileptic seizures, postictal state, treatment, and prognosis.

a) Epileptic seizures. The following fragment gives a detailed description of one of the character’s seizures:

After the shot rang out, the room suddenly began to split apart; something was happening to me. Ramón backed away to the door. Objects moved away at tremendous speed; I waited for the convulsions, the fear, to stop, because they were beating me from within like a dislocated drum. I had the vague sensation that there had once been a real world. I remembered the door was to my right; I even managed to slip through it, but an uncontrollable tide in the corridor dragged me into a wall rather than leading me out. I could hear the distant beating of my own heart; I knew that I was hunted. Then I saw the horror in Adela's and Ramón's eyes. The strangest thing was that I couldn't perceive time; I felt that I was different to them. I disagreed with the objects and words around me. I had a feeling of instability, of rupture, accompanied by violent flashes. As if I were a powerless witness to my own acts, unable to participate or engage with what was happening; lightning flashed and I felt a sort of combustion inside my brain, while a gripping anguish moved forward, consuming me from inside.

This sudden-onset episode has the disperceptive characteristics of distortion of space and time, restriction of autonomy, poor motor coordination, impaired object naming, a feeling of tremor, and visual hallucinations. These symptoms may point to the left temporal lobe as the epileptogenic focus.

b) Postictal state. The novel includes the following descriptions of the postictal state:

As I awoke, I had a vague recollection of what had happened, but couldn't identify where I was. I felt a shiver in my chest. (...) I was anxious, scared, could feel my arms tightening, my cerebral cortex tearing. (...) I suddenly fell into a deep sleep, as if sleeping were a way to escape the solitude of epilepsy. (...)

Beyond the place where I was confined, words began to reach me, insufficient, deconstructed, unruly and disorganised. I felt relief and infinite terror. Where were they coming from? I looked around me and had the impression that I had never been here before. I could discern a woman before me. Once more I heard the boisterous chatter of life, then the words faded, along with the seizure. I wondered where I was, since I seemed not to have existed for a long time.

Vásconez describes frequent features of the postictal state, such as headache, drowsiness, and muscle pain. He gives a more detailed description of disorientation and emotional and cognitive recovery. The calm associated with the recovery of language, memory, and orientation stands in contrast with the overwhelming fear of disorientation and the unmanageable loss of autonomy.

c) Other clinical features. Vásconez also remarks on the pharmacological and non-pharmacological treatments received by the main character and on the prognosis of the disease.

"I feel really drowsy after lunch. It happens to me all the time, I often fall asleep in class."

"We can do something about that. It's your medicine, we have to try a different drug. But you have to sleep well, get plenty of rest. Avoid alcohol. It might take time to get cured, even if waiting feels unbearable. The disease will loosen its grip with the years. I don't know anybody whose seizures are as violent at age fifty as they were in their youth. You may never be completely cured, however."

The protagonist's perception of epilepsy

We will now address the following perceptions:

a) Clairvoyance, supernatural ability: "A beam of light allowed me to shamelessly observe other people's thoughts. (...) I imagined that I could enter other people's minds."

b) Self-pity: "My fantasies and the horror of the seizures made me think that everybody should love me."

c) Insecurity: "Gripped by a feeling of insecurity, surely caused by the seizures themselves, I paused for a moment, watching the speed at which Ramón stripped off his clothes before diving into the water."

d) Preconceived notions and self-stigmatisation:

How would I find the courage to be myself again at home a few hours later, to behave as though nothing had happened the following day? I would do anything not to have to face Ramón Ochoa at school. But nobody seemed to notice I was there. Perhaps that was what tormented me the most, that deceptive calm, the indifference around me. (...) At break, there was an ominous silence around me and I sensed a vague inner murmur. Everything felt as menacing as a storm about to break.

e) Concealment: "I could see myself creeping through life. I guess I wanted to hide from the life I was given, or to hide the disease, this burden I bore, behind a veil of mystery."

f) Sadness/dependence/surrender:

Although the disease laughed uncontrollably, ostentatiously, I was attacked by sadness. My consciousness was yet to be emancipated from the disease. I was its slave, and I needed to overcome my almost servile bewilderment before it. I would have liked to smile when I suffered those attacks, but I was limited to recognising them, as though the disease were the familiar face of my mother. Coldly, unemotionally, distancing myself as though I were looking at a mask, I had to learn to accept it.

g) Isolation: "I had just turned seventeen and I missed a friend's party, claiming to be sick."

h) Dual personality/disarray: "I sometimes feel like there's someone else inside me," I told him. "It's like somebody wants to say something that I can't. I have fits."

i) Phonological and semantic variability of words: "I'd discovered that the sounds and meanings of words were different before and after a seizure. In many ways, epilepsy discredited words, and even took away their common meaning as soon as I saw them in books."

j) Identity:

In those distant days, I was in radical disagreement with existence, on account of the ups and downs of my disease, in which I took refuge as though it were a fort, or proof of the cruelty of the world; now, in turn, my dreams were fed with the insidious torment of having met Fabiola Duarte. (...) Compared to Rosendo's world, what was I? A disease.

k) Confidentiality/secrecy: "Who could I talk to about my fears? Who could I tell that my sight became clouded in the face of danger, when I was about to be brought down by a seizure?"

l) Fear:

Fear stopped me from seeing the world; without a doubt, I had yielded to the seizures and the fits striking my head. So long had I been overcome by fear and remorse, so long wanting to escape. (...)

While I did manage to control it, my fear of the seizures was so deeply rooted in me that it flowed

like the blood through my veins. (...)

Like an unexpected caller, the disease would creep out from the shadows at any time, bringing the same unspeakable fear and familiarity with horror.

m) Powerlessness/asthaenia:

There is an uncontrolled, nearly lethal area where our darkest side will suddenly show itself. On my worst days, when I stayed in bed, devastated by the seizures, I was afraid of those moments where I skirted the forbidden, alone and powerless to help myself.(...)

I would have shown it off, had I not been haunted by the humiliating ghost of my disease, always waiting for it to show its face.

Javier Vázquez gives a detailed account of countless perceptions that are likely to be experienced by patients with epilepsy, going beyond the tangible ictal or perictal phenomena. The seizures are the cause of fear; however, the multiple perceptions of the disease, most of which are negative, leave the protagonist with a permanent air of melancholy and anxiety. Fear does not only occur during seizures; rather, it perversely invades the interictal periods, surreptitiously conditioning the character's fate.

External perceptions of the disease

a) Fear/flight from seizures:

Or she may be in the bathroom, scared to death, sobbing and urinating drop by drop, in a typical display of panic after witnessing one of my fits. (...) I remember the horror in her face as she stepped away from the bed, her silhouette moving away and eventually disappearing behind the door.

b) Revelation: "Ramón's face changed; he suddenly became very serious when I told him that I had epilepsy."

c) Confidentiality/complicity: "Without releasing me, he clasped my bleeding hand in his; dropping the knife to his feet, he exclaimed: 'We are now joined by brotherhood! Your secrets are mine, and so are your misfortunes!'"

d) Hostility and fear:

I must admit that nothing had changed in the city; it continued to be enveloped in its own carelessness, as rainy and shut off as always, while I collapsed with the violent assaults of epilepsy. (...)

I was aware of symptoms of collective fear around me, in the rain-lashed city, in the doorways where the homeless huddled, in the trembling smiles of children, in women's eyes as they rushed out of work, but I have never been able to determine the true reasons or the origin of that fear.

The writer captures fear in secondary characters including the protagonist's sister and mother, who not only panic immediately before his seizures, but also have a distant, fearful relationship with the protagonist, even when he is not experiencing seizures. Vásconez describes fear and powerlessness, which are relatively frequent among the relatives of patients with epilepsy. Another interesting feature is the confidentiality, or rather complicity, when the main character reveals that he has epilepsy. Choosing an "accomplice," making the decision to reveal his secret, and performing a ritual of confidentiality, similar to that of a fraternity, shows the enormous power of the stigmatisation and psychological isolation associated with epilepsy, which limits patients' unencumbered development. With his gloomy, pessimistic description, Vásconez projects his protagonist's fear onto the city of Quito and onto society in general.

The novel *La piel del miedo* demonstrates a profound understanding of epilepsy, suggesting a personal or family experience with the disease. Although the evidence is insufficient to confirm that the novel is autobiographical, several interviews and literary columns imply that this is the case:

I kept it a secret for a long time... What else can I say? *La piel del miedo* is a sort of fantasy treatise on epilepsy and fear, among other things. The type of fear that paralyzes us, but that also encourages us to live and to keep writing. (...) *La piel del miedo* is probably my most personal novel.²

In an interview with Mercedes Mafla, the author admits that this is his most autobiographical novel; the book certainly gives that impression, considering the time and setting of the story.³

Few writers have used epilepsy as the leading topic of their novels. Margiad Evans, for example, dedicated her autobiographical works *A ray of darkness* and *The nightingale silenced* to epilepsy, bringing clinical features closer to the subjective component of the disease. Like Vásconez, she portrays the fear caused by seizures, the perception of horror at the beginning of the disease, and

the fear of her surroundings and even of objects, which are perceived as a threat.⁴ It seems that writers with epilepsy would rather keep their disease a secret. Some do not mention epilepsy, or only allude to it in their works; examples of such writers include Graham Greene, Gustave Flaubert, and Joaquim Machado de Assis. Reasons for their decision not to reveal their condition, or even not to mention epilepsy in their work, probably include the fear of stigma, as they may feel impure and imperfect from the perspective of the prevailing evolutionary thought, and even fear the possibility of losing their social status. Evidence on their diseases is frequently drawn from personal correspondence, clinical histories, and the accounts of friends and acquaintances.⁵⁻⁷

The case of Fyodor Mikhailovich Dostoevsky is completely different. It was public knowledge that the Russian writer had epilepsy, although this may have been against his will. Due to his condition, Dostoevsky was exempted from military service (part of his sentence for opposing the Tsar). The following works by Dostoevsky feature characters with epilepsy: *The landlady*, *The idiot*, *The brothers Karamazov*, *Humiliated and insulted*, and *Demons*. The Russian author celebrated his ecstatic auras, but he also acknowledged the negative impact of the disease on his attention and memory.⁸⁻¹⁰

Many other authors without epilepsy have used the disease in their novels. An in-depth analysis shows high variability in the conception of epilepsy, which often mirrors the knowledge of the disease. Thus, we see portrayals of heaven and hell, salvation and condemnation, suffering and ecstasy, the supernatural and intellectual disability.¹¹⁻¹³ The subjective perceptions of the protagonist of *La piel del miedo* resemble the auras described in Professor Peter Wolf's literary analysis. The auras described in the novels by Nesser, Sand, Jensen, and Harding enable characters (with effort) to stop the episode, or to seek protection or isolation. The main character of *La piel del miedo*, in contrast, cannot predict his seizures and loses control during the episodes; he knows only that waking up suddenly may trigger seizures: "Each morning, when she awoke, [my sister Adela] would run to my mother, fearing that the maid would wake me up, triggering an epileptic seizure."¹⁴ The descriptions in Wagner's novel, described by Wolf as the "inner vision," show the subjective feelings of patients before or during seizures. Vásconez describes similar feelings during the postictal stage, highlighting the personal,

subjective component of seizures (see *b*), *Postictal state* above). Ecstatic auras, localised by Cirignotta et al.¹⁵ in the right temporal lobe, seem to have drawn far greater attention in literature than in clinical practice. This type of aura was described by Dostoevsky, Klaus Merz, Thom Jones, and Bernard MacLaverty, among other writers. *La piel del miedo*, on the other hand, is permeated with fear, terror, and even panic. As described in Richard Muir's novel, epilepsy may increase consciousness and perception to the point that the main character reports being able to enter other people's minds. Similarly, the idea of epilepsy as identity is assumed by Váscenez, as well as by Evans and Salzman; this reflects the power of the disease, which reduces the human condition to the concept of epilepsy.¹⁶ Váscenez uses fear as a metaphor for the anxiety, depression, and solitude experienced by epileptic patients; these feelings not only have an impact on patients' relatives and friends, but also insidiously pervade the patient's surroundings and society in general.¹⁷ The novel reflects the negotiation between a chronic patient suffering from an illness since childhood and his social context, with each trying to adapt to the other. Strikingly, in *La piel del miedo*, this process of negotiation is ruled by fear; epilepsy limits the main character in countless ways.¹⁸ Barceló Rosselló and Llinàs Servera suggest incorporating fiction addressing epilepsy into medical training and professional practice. A literary approach to the more subjective psychological and social aspects of the disease may contribute to more holistic, human treatment of these patients.¹⁹

Conclusions

La piel del miedo, by Javier Váscenez, provides a subjective, human, non-fictitious view of epilepsy. The true scope of the disease transcends the clinical field; the novel gives a comprehensive view by addressing psychological and social aspects. Fiction literature on epilepsy gives insight into the psychological and social dimensions of the disease, complementing the management of these patients. Prejudices and stigma have concealed epilepsy; undressing it and revealing one of its toughest aspects, fear, may contribute to a better understanding of these patients, their families, and society.

Conflicts of interest

The author has no conflicts of interest to declare and has received no funding for the study.

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