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REVIEW ARTICLE

Neurology and literature

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Abstract

Introduction: Literature complements medical literature in the academic and clinical development of neurologists. The present article explores the contributions of writers of fiction on neurology.

Sources: Literary works of fiction with particular reference to neurology.

Development: Asymbiosis between writers of fiction and doctors has been well recognised. From Shakespeare to Cervantes by way of Dickens and Cela to writer —physicians such as Anton Chekhov or António Lobo Antunes have contributed through their medically informed literature to the better understanding of neurology. Some writers like Dostoevsky, Machado de Assis and Margiad Evans have written about their own experiences with disease thus bringing new insights to medicine. Furthermore, some neurological disorders have been largely based on literary descriptions. For instance, Dostoevsky's epilepsy has been retrospectively analysed by famous neurologists including Freud, Alajouanine or Gastaut, whilst his writings and biography have prompted others like Waxman and Geschwind to describe typical behavioural changes in temporal lobe epilepsy, finding their source of inspiration in Dostoevsky. Likewise, Grignotta et al have named an unusual type of seizure after the Russian novelist. Inspired by Lewis Carroll, Todd introduced the term *Alice in Wonderland Syndrome* to refer to visual distortions generally associated with migraine.

Conclusions: Writers of fiction offer a humanised perception of disease by contributing new insights into the clinical history, informing about the subjective experience of the illness and helping to eradicate the stigma associated to neurological disorders.

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PALABRAS CLAVE

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Neurología y literatura**Resumen**

Introducción: La literatura de ficción complementa a la literatura médica en la formación continuada del neurólogo. En el presente artículo se analiza la influencia de los escritores de ficción sobre la neurología.

Fuentes: Obras literarias de ficción relacionadas con la neurología.

Desarrollo: Escritores de ficción y médicos han mantenido una relación de simbiosis a lo largo del tiempo. Grandes literatos desde Shakespeare a Cervantes hasta Dickens o Cela y escritores-médicos como Anton Chéjov o António Lobo Antunes han contribuido con su literatura al conocimiento de las enfermedades neurológicas. Otros como Dostoyevski, Machado de Assis o Margiad Evans han sabido utilizar su enfermedad inteligentemente enriqueciendo su obra literaria y transformando así la adversidad en oportunidad. Grandes neurólogos como Freud, Alajouanine o Gastaut se han inspirado en la epilepsia de Dostoyevski para desarrollar sus ideas. Waxman y Geschwind, por su parte, describieron cambios en el comportamiento característicos de la epilepsia del lóbulo temporal basándose en la enfermedad Dostoyevski, mientras Cirignotta y colaboradores utilizaron el epónimo del novelista ruso para definir un tipo infrecuente de epilepsia del lóbulo temporal. Asimismo Todd se inspiró en Lewis Carroll para denominar las metamorfosis generalmente asociadas a la migraña *Síndrome de Alicia en el País de las Maravillas*.

Conclusiones: La literatura de ficción ofrece una perspectiva humanizada del relato patográfico, aportando la vivencia de la enfermedad, informando sobre aspectos no atendidos por la ciencia y contribuyendo a erradicar el estigma social asociado al paciente neurológico.

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Introduction

Among the priorities in epilepsy research for the next decade, as expressed by the European scientific community, the main objective of neurology is to protect the condition of healthy individuals, promoting adequate preventive measures and spreading knowledge of them among the population. The idea includes making the public aware of neurological diseases, their most well-known aspect being integrated care and treatment of neurological patients. This covers a wide range, from surgical or pharmacological treatment to social care.¹ In this sense, social stigma represents one of the aspects that most seriously compromises quality of life for a patient, with epilepsy being the most notorious neurological disorder. This may be due to the dramatic character of its manifestations, its atavistic demonisation, its aetiological and clinical heterogeneity or its negative social connotations and restrictions (such as not being allowed to drive), coupled with the fact that it goes unnoticed most of the time. At any rate, it is exceptional to find relevant characters in the fields of culture, sport or science who admit to suffering from it, despite its high incidence, its well established scientific foundation and its normally good response to treatment. The message from Classical Greece, supported later by modern science, which regarded it as a cerebral disorder as natural as any other condition of the organism, does not seem to have made an impression in the collective conscience.² In this sense, fiction contributes a lucid view

of neurological diseases in general and of epilepsy in particular, bridging the gap between doctors and patients and also bringing readers closer to a more accessible reality, free from the complicated medical jargon, helping to create a meeting point within the social framework. Another aspect of literature is its possible role in the professional development of neurologists, complementing medical literature in continuous training and contributing concision and clarity to the expression of ideas. There are relevant scientific publications such as BMJ, JAMA, JRSM, Clinical Medicine, Neurology or NEUROLOGIA that include a section dedicated to humanities. In the words of Gregorio Marañón, "If we doctors were not only fond of literature, but proficient in its technique —great poets, in short —it is obvious that we would be much closer to being understood by all, and therefore, closer to curing all those disorders of the organism that are cured, above all, with clarity".³

Which brings us to the legendary reply by Thomas Sydenham (1624-1689) to his disciple Richard Blackmore on what book to read to become a better doctor: "Read *Don Quixote*"⁴ was the reply of the so-called *English Hippocrates*, whose eponym is associated with transitory chorea, traditionally associated with rheumatic fever. In turn, Peter Davies thinks that the poem *Do Not Go Gentle into That Good Night* by Dylan Thomas —which is also the title of a novel by António Lobo Antunes —reveals more about the reactions of man to death than any textbook.⁵ For John Quin, the observations of writer John Updike have generated conclusions as exact as those revealed in the *New England*

Journal of Medicine.⁶ According to neurosurgeon João Lobo Antunes, a good doctor must have a combination of scientific knowledge and cultural awareness, for it is another type of medicine practiced by educated doctors.⁷

Today, the possibility of including literature in a medical syllabus is currently being considered. The reasons to support its inclusion, along with other humanities, include the different perspective of the human condition that it presents, the confidence that it instils in professional development and the capacity for empathy that it brings to the doctor-patient relationship.⁸ To all those reasons, we must add the source of inspiration that fiction literature has represented for medicine and particularly for neurology, as we set forth.

Development

Evolution, language, neurology

One of the first links established between neurology and language corresponds to the structural location of language expression over the bottom of the third left frontal convolution, as confirmed by a brain necropsy practiced on a patient with a 20-year history of progressive nominal aphemia.⁹ Influenced by Charles Darwin (1809-1882), the first neurologists began to appear during the second half of the 19th century. From Broca to Gastaut (1915-1995), including Seveking (1835-1911), neurology and medical anthropology are unconceivable as separate entities. As an example, one of the pioneers of the specialty, John Hughlings Jackson (1835-1911), based his ideas about the functioning of the nervous system on concepts of the philosopher of evolution: Herbert Spencer (1820-1903). Contemporary with Darwin and precursor of the three brain or triune theory (currently being developed by the Bolognian epileptologist Tassinari),¹⁰ Spencer proposed organising the nervous system into a three-level hierarchy, determined by complexity.¹¹ Hughlings Jackson used this model to develop a neurology based on epilepsy, whose range of symptoms would depend on the nervous structure originating them: the lowest level on the scale of evolution would correspond to the brainstem and the spinal cord; the middle level, to the basal ganglia and the motor region located in the precentral gyrus; and the most complex would correspond to the prefrontal cortex or *mind organ*. Clinically observing the progression of an epileptic crisis, Hughlings Jackson described an inverse process to evolution —which Spencer called *dissolution*— by which the most elaborated ideas and actions would decline to the most rudimentary or less evolved expression,¹² in what we would define today as a *seizure with Jacksonian gait* and secondarily generalised.

If the so-called Hippocratic Medicine represented the first step taken by medical literature in favour of science and progress, the scientific foundations of modern clinical neurology took 24 centuries to become established, and it was thanks to the works of Broca and Hughlings Jackson, among others. Nevertheless, beyond the scientific and philosophic domains, we would have to look for the links between language and neurology in the first noises articulated by man in prehistory. Complementing

paleopathology, fiction has managed to transport us to that moment: “*After thousands of millions of years, / long after / dinosaurs became extinct, / he reached this place. He was accompanied by others like him, / upright like him / (probably slightly hunched, like him). // From onomatopoeias, / from monosyllables, grunts, / he developed a sound sequence system. / That way he was able to memorize events from the past, / articulate his guesses, / for the present —he could sense it —does not start or end in itself, but rather is a crossing point / between what happened and what will happen, / the flame between wood and ash. // The domesticated sounds told / much more than what they said / (they originated concentric circles / —like a stone thrown into water — which multiplied, expanded, / diminished back to smoothness and stillness): / and all perceived the mysterious essence / which they could not decipher*”.¹³

Doctors-writers, neurology and society

“*That trigeminus of Ahasuerus, / the zodiac horoscopes / and the cunning trick of the thimble rigger / are actually very similar things*”.¹⁴

During university and first years of practice, doctors acquire a language that will be with them for the rest of their lives. As if it were a universal language spoken by various minorities disseminated around the world, neurologists interpret reality through a complicated semiology. Just think about the dramatic significance of generalised fasciculations associated to extensor plantar responses in a patient who attends the clinic suffering from weakness and a certain respiratory difficulty, which he might attribute to a simple cold. This distance between the informed perspective of a doctor and the helpless uncertainty of a patient is what Hierro refers to in the continuation of the poem in the previous paragraph: “*With fearful reverence / they heard such incomprehensible messages / as those from a flame, a wave, a thunderclap / (perhaps with the same uncertainty with which we listen to a doctor / who diagnoses our illness / using technical terms never heard before / so that we do not know / if — unemotional and professional — / he is announcing our death / or our life...*”.¹³

In contrast with the patient's innocent point of view, the expert and distant look of a doctor reveals interesting aspects of the human condition. In the field of neurology, clinical practice is an excellent thermometer for knowing the health condition of a whole community. A common migraine attack or a simple lumbago can sometimes reveal complex social problems underlying the symptoms. Medical practice and the undertaking of a literary activity are far from being incompatible. The figure of the doctor-writer embodies the symbiosis that has existed between fiction writers and doctors. For the paediatrician and poet William Carlos Williams, “*one activity [literature] complements the other [medicine], (...) while one is relaxing the other is exhausting*”.¹⁵

Apart from scientific-natural medicine, we cannot forget about other pre-existing methods used to fight disease, which have coexisted since Classical Greece. They are, on

the one hand, traditional empirical medicine or “home remedies”; and, on the other, supernatural medicine based on religion or superstition, with quack doctors being halfway between both. They nevertheless remain active beyond the boundaries of scientific and rational medicine, within the so-called alternative medicines, as well as in social thinking and feeling. Writers such as Cela have recognized their presence and have left us a good account of the relevance of these irrational and millenary beliefs: “it is a good idea to feed dog brains to maniacs. The transplanted and magnetic virtues of dog brains are very efficient to fight imbalance. The best are those from Fleiro dogs with a spot on their forehead, and that are neither little nor large, but medium sized. They seem to have transversal radiotherapeutic and harmonic atoms and molecules. Cat brains, on the other hand, can cause madness and epileptic seizures, for in many occasions they are home to the devil”.¹⁶

Still, sometimes it is not easy to recognise the limits established between some types of medicine and others. Being aware of the crossroads between the various ways of understanding disease, the retired Portuguese psychiatrist António Lobo Antunes combined his clinical experience and natural scepticism to grasp the epic situation of a neurological patient facing a doctor (not always trained), amid a hostile environment marked by social lack of understanding: “...The epilepsy clinic at a hospital —Do you wet yourself when you lose consciousness? in which I am prescribed pills I never

take because the manager says they are too expensive, if I eat properly and do not think about Africa, that is not a disease, fainting is not being ill, everybody faints, just pure fantasies, there is not a single problem that a new girlfriend cannot put right (...) Me, when the consultation was over, while Rui got dressed with the help of the nurse —What does the boy have, doctor?— A hereditary problem in the brain, madam, disordered electrical currents, his behaviour may change they pushed him all the way towards the field and then they started to hit him with sticks and hoes (...) Becoming aggressive for instance, becoming rebellious, give him these pills with his lunch and dinner and we will see again in May, bring him back to consultation (...) Rui was not like the others, he did not speak like the others, he would remain motionless during meals with the fork suspended as if he had gone far away”.¹⁷

But the stigma of neurological diseases is not limited to the so-called underdeveloped world nor is it solely focused on epilepsy. In *The Tree of Knowledge*, Pío Baroja describes a macabre case of involuntary cannibalism by a neurologist in 20th century Spain: “One of the doctors in the hospital, who specialised in nervous diseases, had ordered an autopsy to be practiced on one of his patients who had died in his operating theatre. The brain was to be extracted and taken to his home. The resident extracted the brain and sent it with a young errand boy. The housemaid, upon seeing the parcel, thought they were cow brains, and took them to the kitchen, prepared them, and served them to the family”.¹⁸ In relation to the work of Baroja, *Time of Silence* by Luis Martín Santos recounts the vicissitudes of a young research doctor in that same Madrid without any expectations of progress in which the medicine student from *The Tree of Knowledge* lived: “A creased suit might hide the lucky owner of a brain which —although feeble and voluminous — will emanate thoughts never suspected by anybody, formulae for new elementary particles, anti-universes and semi-electrons; behind a face of dull appearance and a narrow forehead may lie a capable archivist, an insatiable devourer of palimpsests and microfilms. (...)”.¹⁹

Yet, without a doubt, the most universal doctor-writer of all was Anton Chéjov, who managed to put his clinical experience at the service of a literary talent not totally unconnected with neurology. In his most famous work, *Ward Number Six*, he described the tortuous path followed by a doctor to achieve empathy, for which he turned to a severe neurological affection (possibly a burst cerebral aneurysm): “The following morning he woke up with a tremendous headache. He felt his whole body broken; he was submerged in a total miasma (...) At night Doctor Ragin suffered an apoplexy attack”.²⁰ After twenty years of seeing patients, the doctor and main character manages to sympathise with the suffering of others, listening first and feeling condolences for one of his patients, and later suffering the disease in his own flesh.

Neurological diseases in fiction literature: what can fiction writers contribute to neurology?

“(...) yet, as always, before the men of science, poets knew the truths about the mysterious abyss of my kingdom”.²¹



Figure 1 Drawing inspired by the book *Alice's Adventures in Wonderland* by Lewis Carroll.

Migraine

In 1955, Todd suggested the term *Alice in Wonderland Syndrome*²² to define the metamorphosis generally associated with migraine, inspired by the deformed visual perceptions typical of the characters in the famous book by Lewis Carroll (fig. 1). Within the so-called *American Dirty Realism*, we find a complementary description that offers a less idealised and more empathic view of the usual experience of a patient with common migraine: “*It started at work. The first stab left her breathless, and she was under the impression that her eyes would pop out of their sockets. Then the pain eased and was reduced to a light nape pressure. Joyce left her hands on either side of the keyboard and waited. She heard the constant noise of other keyboards in the surrounding cubicles. She knew what was happening; she knew it so well that when the second wave of pain came she did not feel it as pain, but rather as fear of what would come afterwards*”.²³

Multiple sclerosis

In *The Journal of a Disappointed Man*, W.N.P. Barbellion (pseudonym used by the naturalist Bruce Frederick Cummings) goes into his own illness (multiple sclerosis) to describe his day-to-day experiences, as it progressed.²⁴ With it, as well as familiarising people with a barely understood disease and giving rise to associations that helped patients, like the *MS Society*, Barbellion makes interesting clinical observations, such as the one corresponding to the first outbreak that affected the brainstem. He also recalls the dilemma faced by doctors upon having to communicate the diagnosis of a neurodegenerative disease.

Dementia

A recent article in *Brain* analyses Alzheimer's disease as suffered by the popular English writer Iris Murdoch through three novels written at three different points of her life. The first symptoms of her dementia were made obvious by the cold reception of her last work (*Jackson's Dilemma*), for it lacked the literary wit of her previous productions, just as her editor had noticed a few years before the signs of her disease became evident. Gerrard et al²⁵ remind us in their study that the subtlety of the first manifestations of a degenerative process escape any neuropsychological exam or present-day standard measurement, when dealing with a person with a rich intellectual background.

Nevertheless, to get an idea of the impact caused by the dementia of a loved one, we need to turn to a poem by Emilio Pedro Gómez, in which the author gives an account of Alzheimer's disease as suffered by his mother: “*She cannot recall that she cannot remember. / Whatever she invents, happened: / the light switch / changed place / it grows dark at ten in the morning / her parents resuscitated / in the adjoining room*”.²⁶

Rabies

In the same way as the great French chemist Pasteur developed the first effective vaccine against rabies and, together with Koch, contributed to microbe theory, from his condition as macroscopic observer, Camilo José Cela contributed a suggestive description of the process of

suffering the human form of rabies: “*Two days had my father been locked up in the pantry when Mario came to this world; he had been bitten by a rabid dog, and although at first he seemed to have escaped rabies, later on he was overcome by shakes, which put us all on guard. Mrs Engracia told us that his stare would cause my mother to miscarry and, because there was no cure for him, we managed to lock him up with the help of some neighbours and as many precautions as we could take, for he threw bites which would have torn an arm off anyone who had been caught; ...my father finally went quiet the following night... and when we went to get him out, thinking he had died, we found him crouching on the floor and with such fear on his face, it seemed he had entered hell*”.²⁷

Von Recklinghausen's syndrome or Proteus syndrome?

One of the most famous screenplay adaptations by David Lynch recounts the vicissitudes of a man marked by a deformed body as a consequence of a rare congenital disease only identified in the late 1970s that causes macrocephaly, skull hyperostosis and generalised hamartomatosis: Proteus syndrome. Based on the novel by the renowned London surgeon Sir Frederick Treves, *The Elephant Man* is the story of a social stigma set in the end of the 19th century that reflects both the degree of cruelty and of humanity that human beings can reach.²⁸ Within its historical context, the disorder of the famous character was first called “elephantiasis”, only to later be recognised as a typical case of type I neurofibromatosis. Hence, it is also the story of how a pathology has changed its identity as scientific parameters have been adjusted, in accordance with new discoveries and the due reinterpretations.

Stroke

Forever interested in neurosciences, David Lynch himself adapted the novel *The Straight Story* by Boach and Sweeney into a screenplay, which tells the odyssey of an elderly man who decides to cross the United States on a lawnmower to make amends with his brother, whom he had not spoken to in years, upon learning he had suffered a stroke.²⁹ Not focused solely on semiology or the after-effects of a cerebral vascular disease, it also reminds us of the capacity to transform human relations.

Epilepsy

“*This morning you fainted / and came back afterwards with a minute of terror / upon your tongue*”.³⁰

Writers such as Shakespeare or Cervantes have included unmistakable descriptions of epilepsy in their literature. As Heaton pointed out, the tragedies of the Shakespeare canon teach us not to underestimate the power of emotion when it comes to causing organic disorders such as syncope or epileptic fits,³¹ the latter reflected in *Julius Caesar* and especially in *Othello*. Cervantes, in relation with a case of epilepsy described in chapter 47 of *El Quixote*, offers a view of medicine in his time, subject to the theory of humours with bloodletting as the main therapeutic basis. In one of the bizarre suggestions to Sancho Panza that took place during the organization of the management of the property,

a fake farmer requested help to consummate the marriage of his epileptic son with a paralytic girl, probably as a consequence of neurological sequelae caused by a smallpox epidemic that affected several members of the family, leading them to be known as the “*Perlerines*” —from palsied or paralysed—: “*I plead, Sr, —said the farmer— that Your Worship grant me the favour of writing me a blessing letter for the father-in-law of my son, begging him to allow this wedding to take place, for we are not unequal either in the gifts of fortune or of nature; because to be honest, Mr. Governor, my son is possessed and no day goes by in which the evil spirits do not torment him three or four times; and from having once fallen into the fire, his face is wrinkled like a piece of parchment and his eyes are watery like springs*”.³²

Meanwhile, there were other writers who suffered from epilepsy and reflected their experiences with the disease in their literature: Margiad Evans (1909-1958), Machado de Assis (1839-1908) and Fyodor Dostoyevsky (1821-1881). Just as neurologist Andrew Larner noticed, *A Ray of Darkness* (the autobiographical novel by Margiad Evans), represents a confession of the impact of epilepsy and the anti-epileptic medicines available in the mid 20th century (phenobarbital and phenytoin).³³ Reluctant to reveal his illness, Machado de Assis did not use the term “epilepsy” in his texts, although he knew how to skilfully use the disease in his literary production, just as his admired Dostoyevsky³⁴ had done before him. Contrary to the optimism of some of his “epileptic” characters, for the Russian novelist epilepsy meant a considerable handicap, of which he left a good account in his correspondence. Aware of its heterogeneity, Dostoyevsky attributed epilepsy to novel characters of different genders, characters and social backgrounds: from the old Murin in *The Landlady* (1847), or the defenceless orphan Nelly from *The Insulted and Humiliated* (1861), the celestial Myshkin or the suicidal Kirillov from *The Devils* (1872), to the simulating and resentful Smerdyakov from his most outstanding novel *The Brothers Karamazov* (1880).³⁵ Written a year before his death, *The Brothers Karamazov* represents an example of courage and a stimulus for those who suffer epilepsy, in addition to being a medicine classic and a legal-medical treatise that highlights the difficulty entailed by the diagnosis of epilepsy. Dostoyevsky was diagnosed with epilepsy in Russia at the same time as the first effective anti-epileptic medicines (bromides) were being introduced. Although there is no evidence that he took them, there is proof he intended to consult with the great specialists of the time, such as Pomberg and Trousseau. The literary recreations of his illness have inspired later generations of neurologists such as Freud, Alajouanine and Gastaut, among others. On their own account, Waxman and Geschwind described characteristic changes in the behaviour of temporal lobe epilepsy³⁶ based up to a certain point on the hypergraph and moral and religious worries of Dostoyevsky, as suggested by a manuscript of *The Devils* (fig. 2); meanwhile, Cirignotta and his collaborators used the eponym of the Russian novelist to define a rare type of temporal lobe epilepsy with ecstatic aura.³⁷ In accordance with the biographical and bibliographical information available, and taking modern scientific concepts into account, it is nonetheless difficult to venture a different



Figure 2 Handwritten page by Dostoyevsky, with a portrait included in his novel *The Devils*.

retrospective diagnosis other than cryptogenic focal epilepsy of likely temporal origin.³⁸ Apart from other considerations, the novel by Dostoyevsky constitutes a reference in medicine, history and literature. In a passage from *The Idiot*, he described the epileptic process as follows: “*Then, all of a sudden, something seemed to open before him: a strange inner light flooded his soul. That instant lasted maybe half a second, but he remembered the beginning precisely and consciously, the very first sound of the terrible scream which escaped his chest of its own accord and which no effort of his could have stopped. His consciousness was extinguished and a total darkness overcame him. He had an epileptic fit, the first one in a long time. It is well known that epileptic fits, or episodes of “falling sickness” as it is popularly known, occur instantly. At that moment, the face is horribly altered, especially the look. Spasms and convulsions affect the whole body and all facial features. An atrocious, unimaginable scream, unlike anything else, escapes the chest; one would say that with that scream, all that is human vanishes, and it is impossible, or at least very difficult, for an observer to imagine that he who screams in*

such a way is that same man; furthermore, one is under the impression that the one screaming is another person inside that man. At least that is how many people explain their impression, and many of them, upon the sight of a man suffering an epileptic fit, feel absolute and intolerable horror which even has a mystic component about it (...). They took the prince to his bedroom; he came around, but he did not recover full consciousness for a long while".³⁹

A bullet in the brain

Lastly, Tobias Wolff attests the existing symbiosis between writers and neurologists when depicting a near death experience when one of his characters is injured in the head by a bullet: *"The bullet bored into Anders' skull, went through his brain and exited behind his right ear, spreading bone fragments in the cerebral cortex, the callous body, behind it towards the basal ganglia and, further down, into the thalamus. But before all this happened, the first impact of the bullet against the brain burst a brittle chain of ions and neurotransmitters. Due to their peculiar origin, they described a likewise peculiar route, which made him relive a long forgotten summer afternoon, an afternoon 40 years back, at least; why that one and no other was nothing more than sheer coincidence. After crushing his skull, the bullet entered at a speed of 300 meters per second, a pathetically slow speed, glacial even, when compared to that of the synaptic flash it triggered on its way. Once inside the brain, the bullet came under the mediation of cerebral time, which gave Anders a paused lapse to contemplate the scene".²⁴*

Conclusions

Fiction complements medical literature in the continuous training of neurologists, offering a humanised view of the pathographic account, contributing to the experience of the disease and helping to eradicate the social stigma associated with certain neurological disorders such as epilepsy. On the other hand, the observations made by fiction writers have led to hypotheses that have been incorporated into the scientific environment of neurology.

Presentations

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Conflict of interest

The author declares no conflict of interest.

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