

Painting epilepsy – The essence of disease by participants of the Latin American Summer School on Epilepsy (LASSE XIII)

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ABSTRACT

Purpose: The purpose of this study was to present and analyze the way epilepsy researchers and specialists present epilepsy through visual art forms.

Methods: Students and epilepsy specialists, including clinicians and scientists, participating in the Latin American Summer School on Epilepsy (LASSE XIII) 2019 were asked to voluntarily portray epilepsy artistically by painting or drawing what they perceive that represents the feeling or challenges of persons with epilepsy. Resulting artwork was categorized according to several themes. The latter was analyzed in the clinical and social context of the disease.

Results: Twenty-six paintings available for analysis have been reviewed. The three main interpretations of epilepsy were outlined as follows: epilepsy as an identity schism, epilepsy as a loss of control, and epilepsy as a complex condition. Five artworks best suited the first category as they presented people with faces split into healthy and diseased sides, representing the emotional and social burden of seizures. Three drawings defined epilepsy as a loss of control, visualizing that all the phases of seizure activity (ictal, postictal, and interictal) are able to imprison the patient by disrupting mental processes. The last theme included four artworks that defined epilepsy as being a multicomponent enigma: the intertwining of unresolved pathophysiologic processes and psychosocial burden accompanying the disease was emphasized. In addition, the challenges to care for the patients in order to improve not only seizures but also their quality of life were noticed as an idea complementing the visual definition of epilepsy.

Conclusion: Participants of LASSE XIII demonstrated an ability to empathize with their patients in retrospect by portraying the inner feelings of division and imprisonment of those having seizures. Epilepsy specialists visualize the disease as a composite phenomenon both in terms of its neural origin and of multidisciplinary requirements to implement its care.

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1. Introduction

Both art and epilepsy have been coexisting since the very beginning of human history: written descriptions of epileptic seizures existed in Babylonian and Egyptian civilizations and visual representation of this disease became a familiar finding throughout the Middle Ages as they were propagated by religious iconography (for example, Saint Valentine actually was epilepsy's patron saint) [1,2]. To this day, various professional artists and patients with epilepsy have described the disease through different art forms, such as painting, sculpture, dance, etc.

[3–7]. Feelings and thoughts of those having seizures have been appreciated and reviewed in several articles demonstrating how art could exhibit emotional, social, and cultural aspects that other methods were not able to [4,7–9]. Art can be and has been used as an expression of what cannot be said in words, as an instrument for healing, and as a strategy for better empathy between patients, physicians, and society [7,10]. Art methods have also been used as an educational strategy in a few medical schools sharpening diagnostic acuity and as a complementary treatment strategy for some diseases (mostly psychiatric ones) [9,11–14]. Our goal was to analyze the artistic viewpoint of basic researchers and specialists during the Latin American Summer School on Epilepsy (LASSE XIII) in order to understand which aspects of the disease are seen to be most relevant for those consulting and treating people with epilepsy (but not experiencing epilepsy directly).

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2. Methods

Latin American Summer School on Epilepsy XIII took place in São Paulo (Brazil) from March 7th to 15th, 2019 with its topic being “Epilepsy: from connectivity to connectome”. The audience consisted of 57 young Latin American researchers and clinicians with interest in epilepsy. During the third day of LASSE, a lecture titled “Epilepsy revealed: the history of epilepsy through paintings and sculpture” invited willing participants to paint their visualization of epilepsy. Volunteers had a week to prepare their artwork after crayons, watercolors, color pencils, and paper were handed out. During the final day of LASSE, the works were exposed at the venue’s auditorium for participants to share their experience with one another and observe the different interpretations of epilepsy. Authors could disclose their identity and add a title and a written explanation of their artwork. Consent for future expositions and publishing was obtained from the artists.

3. Results

Among students and professors, 32 paintings and drawings were obtained; 27 participants disclosed their identity; and 26 gave their consent to present their work in further expositions or articles. Among the artworks, three ideological aspects of epilepsy could be identified as follows: epilepsy as a dividing factor of one’s identity, a state of imprisonment, and a complex phenomenon. Moreover, a willingness to understand the disease and create new treatment solutions was observed. To present recurring themes and motifs, we included the works that most extensively represent the various faces of epilepsy. Some descriptions alone were included as well to complement the discussion.

3.1. Epilepsy as a schism of one’s identity

The paintings named as “Epilepsy – two sides of the disease” both represented disfigured human faces that are divided into two separate sides (Figs. 1 and 2). One side was illustrated as having more tone and be brighter in coloring; the other, though, has a sad expression and a somewhat darker emotion. The author states to show “two sides of the disease” that is “a normal life with several horrible minutes per month, week, or year”. It might be noticed, however, that those several



Fig. 1. Epilepsy – two sides of the disease pt.1 by Rūta Mameniškienė, Lithuania.



Fig. 2. Epilepsy – two sides of the disease pt.2 by Rūta Mameniškienė, Lithuania.

minutes occupy a larger topographic space in the painting than they ought in respect to the temporal dimension (the seizure itself being several minutes). A similar theme is observed in the painting “Lucy in the forest” (Fig. 3). A girl with epilepsy is standing among trees, and her life is disrupted into antagonizing poles: a “gray part with gray clouds and rain due to epilepsy” with “half of her face covered with tears” and a part “with the purpose of happiness, freedom, and with dreams blowing to the sky”. The work “Area tempestas” emphasizes the feeling of “split of brain” between a peaceful and a stormy zone that vanishes the previous personal identity, adding to the recurring theme of an internal separation of the patient’s healthy self and the self that is abducted by epilepsy as a source of disruption, “storm”, or sadness (Fig. 4). The latter emotional component is once again presented in a drawing “Emotions” that presents anger, sadness, and “normal life” in between (Fig. 5).

Defined by seizures, epilepsy episodically disrupts control of one’s body and sometimes of one’s mind as well. In a drawing called “Puppet of a breakdown moment”, the author sought to “represent the ‘brain state’ which the patients ‘go in’ during and after the seizures [and] express the vulnerability situation imposed by this ‘state’ to the patients” (Fig. 6). Postictally, the patient is also vulnerable to loss of control: “[thinking] how many times he will repeat the same history: to have a seizure, lose consciousness, not remembering how he got there and awakening surrounded with machines and wires” (“Not again”, Fig. 7). Finally, interictally, patients with epilepsy “are imprisoned in their own heads and carry a lifelong conviction” according to the author of “Prisoner” (Fig. 8).

3.2. Epilepsy as a complex condition

Some of the works seek to emphasize that epilepsy is not a single problem, rather a connected mesh of enigmas. For example, in a work called “Where is the light”, the author proposes an anatomical depiction of the human brain with “the broken bulb for the despair of the patient with epilepsy seeking a light and hope in treatment and cure” and entangled representations of ictal posturing hanging from cerebral foci (Fig. 9). As for the social and everyday impact of epilepsy, in a drawing called “Under construction”, the author builds a map of “prohibitions”, “the need to attach to norms and timetable”, “lost opportunities”, and “tears” (Fig. 10). A technique similar to pointillism in the painting



Fig. 3. Lucy in the forest by Guilca Contreras, Venezuela.

“Coming out the shadows” summarizes the notion of epilepsy as a complex disorder – each point represents the multiple variables and distinct elements that constitute the concept of epilepsy. The points convey between themselves giving a sense of light, shadow, or color that stay for the different processes, emotions, and transitions that constitute epilepsy as a “physiopathologic process” (Fig. 11). In the painting “Syntax”, a similar technique is employed “to demonstrate the different brain areas integrated with their diverse functions” throughout the disease (Fig. 12).

3.3. Specialists and their role in the definition of epilepsy

While most epilepsy researchers and specialists portrayed epilepsy on the behalf of their patients, there were occasions when they themselves became active figures of the artwork. In the painting “Coming out the shadows” mentioned before, the author states “the bird represents the patient or the healthcare provider. The bird tries to fly towards the light as the desire of cure or in our case in the search of solutions, treatments, and strengths for a better quality of life for our patients”. The work “Under construction” had a comment about drops of patients’ tears that finally fall like a waterfall after finding a cure and symbolizing

“the rain of ideas that fertilizes knowledge in the area”. Some other participants mentioned the importance of working “more connected for the development of new techniques for the treatment of epilepsy”, trying to express the patient’s “fears to the treating neurologist who shows little interest in their quality of life”.

4. Discussion

4.1. Art as a means to convey understanding

While reviews of artistic representation of epilepsy throughout history link epilepsy and art, there is less information about patients with epilepsy themselves and their artistic views on the disease [6]. The creative potential may be decreased in some patients with epilepsy, but art therapy itself is hinted to be beneficial for psychological aspects of treatment of various diseases (including neurological ones) [8,9,11,12]. There are studies presenting artwork produced by children and adolescents with epilepsy [15,16]. The paintings or drawings are difficult to assess objectively but might be useful to understand both the symptoms (for example, when differentiating migraine auras from occipital lobe seizures) and the psychosocial implications of seizures. Even if some



Fig. 4. Area tempestas by Juan Luis Moya, Chile.



Fig. 6. Puppet of a breakdown moment by Noemi dos Santos Araújo, Brazil.

studies give a glimpse into patients' imagination of a disease, to our knowledge, there is little experience with the doctor's artistic expression [9]. Historically, there are descriptions of doctors who painted, for example of "how Charcot used his artistic approach to observe human form so that the artist and the doctor worked hand in hand" [17]. This initiative of visualizing epilepsy from the viewpoint of the specialists during LASSE XIII was therefore a stimulus to reflect on one's relation with the field of epilepsy and an opportunity to empathize with the

patient experience once again. One interesting aspect of this project was that merely several paintings represented an external impression of epilepsy (that is, emphasized diagnostic, therapeutic, or research-related areas). To our knowledge, the participants themselves did not have epilepsy. However, they made the effort to imagine the internal world of the patient and drew impressions of living with epilepsy,



Fig. 5. Emotions by Rūta Mameniškienė, Lithuania.



Fig. 7. Not again by Juan Luis Moya, Chile.

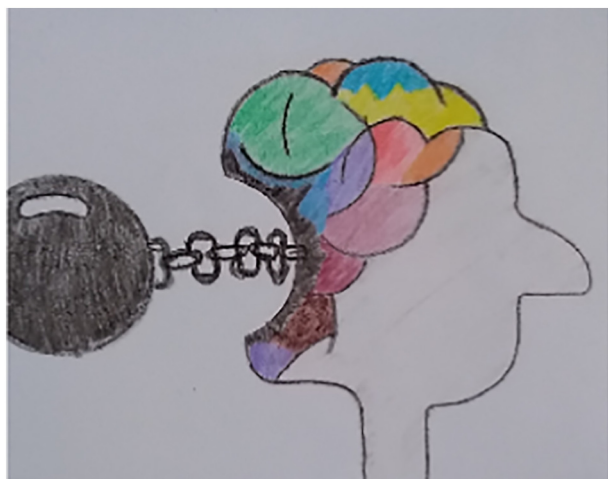


Fig. 8. Prisoner by José Castaneda Cabral, Mexico.

enduring the social stigma, or even having a seizure. This finding allowed us to divide the analysis into three parts and observe how epilepsy is portrayed dividing the patient's inner self (1), imprisoning the patient (2), and being a complex enigma (3). Finally, we could include the described implications for the specialists themselves in the discussion.

4.2. Epilepsy that divides the patient's world

Etymologically, schizophrenia is the disease that is literally splitting the mind. Epilepsy and schizophrenia have some epidemiologic and even pathophysiologic commonalities (as patients with epilepsy more often have schizophrenia than the general population) [18,19]. Several participant artworks described the division in one's identity as a main pillar of epilepsy. Differently from schizophrenia as a continuous mental disorder, however, the "splitting of the mind" is more episodic (ictal and postictal disruption of mental processing) or linked to the emotional state ("normal" versus sad or angry). Thus, participants of LASSE reveal

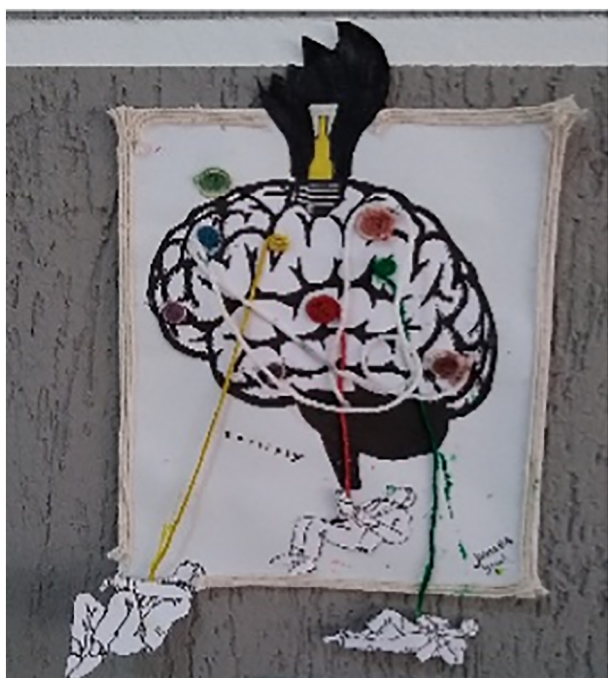


Fig. 9. Where is the light by Marcos Costa Gomes de Lima, Brazil.

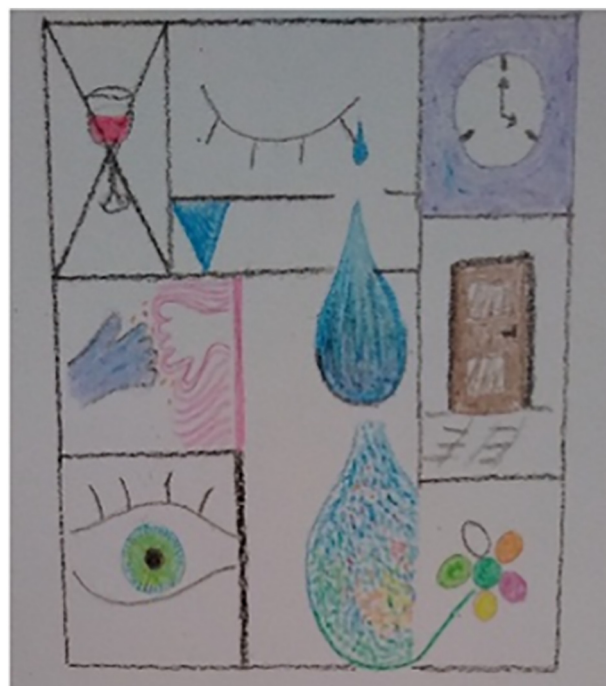


Fig. 10. Under construction by Patricia Braga, Uruguay.

that in their understanding, the "mental schism" during epilepsy is related more to the affective consequences of having seizures ("storms") than to epilepsy as a chronic disease per se. In addition, as discussed by L. Kesner in relation to Bohumil Kubišta's painting "Epileptic Woman", a visual representation of the patient's with epilepsy face and emotions has been linked to the theory of mind and even the artist's perspective on divine human nature [20]. In this case, the reflection of



Fig. 11. Coming out the shadows by Natalia Buitrago Ricaurte, Colombia.



Fig. 12. Syntax by Paula Vaudagna, Argentina.

one's experience with patients (by painting their emotions) might reveal itself as a translation of the specialist's strong empathetic outlook towards people facing epilepsy.

4.3. Epilepsy that imprisons

An epileptic seizure as a state of disorganization is observed in both "Transcending" by Jennifer Hall and "Postictal" by Jacqui Streeton (representing ictal and postictal confusions, respectively) as reviewed by Schachter et al. [4]. Selected artworks from LASSE XIII find the disorderly and uncontrollable nature of epilepsy important as well. As a continuation of the first section of our selection (the schism of self), loss of control during and after a seizure adds to the debilitating nature of epilepsy. One LASSE XIII participant depicted how the brain becomes attached to a ball and chain, thus the patient is a prisoner of his disease. L.D. Ladino et al. reviewed contemporary representations of epilepsy ("Epilepsy, leaving the nightmare behind" by Eduardo Urbano-Merino and "Wired" by Iris Hauser) which project the idea of "rewiring" the brain and escaping the burden of epilepsy [6]. That is, epilepsy is seen as a metaphorical state of imprisonment as well, from which one seeks to escape through medical action.

4.4. Epilepsy as a puzzle

The last section of selected artworks consists of a more conceptual characterization of epilepsy – that of a multidimensional condition. In part, expressible social and research related questions are emphasized in the selected works. On the other hand, two of the selected artists use pointillism-like techniques to define epilepsy because "in reality, it is difficult to put it in words". Such visual style might, according to N. Krüger et al., be seen as an adaptation of art to the anatomic structure of the visual cortex [21]. Thus, the technique chosen by some LASSE XIII participants to depict the magnitude of epilepsy-related components is in itself linked to the complexity of neural function. In this way, the third group of artworks concludes the problematic nature of epilepsy. That is, epilepsy as a disorder not only divides and imprisons the patient but is also rooted in the enigmatic connectome that is the human brain.

4.5. The importance of specialist engagement

Finally, some participants involved the care provider as part of their work and expressed the need for a proactive position towards epilepsy. Not only the specialists did perceive epilepsy itself as a complex disorder (mentioned above), but they also described the need for variability in care actions. While new treatment options are one of the ways to improve care, the patients' overall quality of life is another large area to be explored. Psychosocial factors, the adverse effects of medication, and common comorbidities add to the burden of epilepsy and become part of the challenge for the caring specialist [22,23]. As examples of the difficulties of a multidisciplinary approach might be observations of the pediatric-to-adult care transition or the empowering of nurses for patient care, such cases demonstrate that without "interest in quality of life" (as one participant formulates), little effective care can be provided [24,25]. Subtle details of the participants' comments let us believe that participants are beginning to grasp the concept that caring for persons with epilepsy is a multidimensional undertaking.

5. Conclusion

Our project showed that specialists and students engaged in the field of epileptology often imagined the disease not as outsiders but entered the viewpoint of the patient – components of the patient's inner world (emotional situations) or social repercussions of the disease were presented and described; one of the selected works even presented a first-person view of a postictal confusion. The following three recurring themes summarized most of the participants' artworks: the identity-dividing nature of epilepsy, its tendency to take away freedom from the patient, and the fact that epilepsy consists of a great multitude of problematic components, which yet cannot be easily solved. Such a thematic spectrum could point to a tendency to empathize with the patient's situation (both its individual and social consequences) and a broad outlook on epilepsy as a disorder requiring multidisciplinary action and novel solutions. This experience reveals that visual art forms might not only help better understand the mind of a drawing patient but could also be useful in asserting the specialist's perspective on epilepsy as well.

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Declaration of competing interest

The author reports no conflict of interest.

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