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The impact on life in people with dissociative seizures or drug-resistant epilepsy

Camila Wolfzun[1,2,3]*, Mercedes Sarudiansky[1,2,3], María Marta Areco Pico[1,3], Cristina Tenreyro[1,3], Alejandra Lanzillotti[1,2,3], Luciana D'Alessio[3,4], and Guido Pablo Korman[1,2,3]

[1]Institute of Research, Faculty of Psychology, University of Buenos Aires, Ciudad Autónoma de Buenos Aires, Argentina

[2]Consejo Nacional de Investigaciones Científicas y Técnicas, Ciudad Autónoma de Buenos Aires, Buenos Aires, Argentina

[3]Ramos Mejía Hospital Epilepsy Center, Ciudad Autónoma de Buenos Aires, Buenos Aires, Argentina

[4]Instituto de Biología Celular y Neurociencias, Faculty of Medicine, University of Buenos Aires, Ciudad Autónoma de Buenos Aires, Buenos Aires, Argentina

Abstract

The aim of this study was to analyze and compare the impact on life in people with dissociative seizures (DS) and drug-resistant epilepsy (DRE). A qualitative approach was employed using the McGill Illness Narrative Interview, which was conducted and analyzed following thematic analysis principles. Ten women diagnosed with DS or DRE participated, all from underserved sectors in Argentina. Three major themes emerged from the interviews: (1) role of emotions (emotional experiences related to the disease, both preceding the seizure and as a consequence of them). Both groups reported unpleasant emotions as a consequence of seizures, such as fear, shame, and sadness. Emotional states, including stress and anxiety, were also described as seizure triggers in both conditions. (2) Impact on social interaction (the way in which the disease impacted on social relationships). Participants with DS experienced interpersonal conflicts, mistreatment, and disbelief more frequently than those with DRE, who reported a higher perception of overprotection and hesitancy to disclose their condition. Both groups acknowledged the importance of social support from family and friends. (3) Impact on daily life activities (the way in which people discontinued activities due to the disease or continued despite it). Seizures disrupted autonomy, work, and recreational activities, though some participants continued working despite limitations. These findings provide insight into the challenges of living with DS and DRE. A deeper understanding of these experiences can inform targeted interventions to improve the quality of life for these patient populations, particularly in resource-limited settings.

Keywords: Dissociative seizures; Drug-resistant epilepsy; Impact on life; Psychogenic non-epileptic seizures; Quality of life

***Corresponding author:**
Camila Wolfzun
(cwolfzun@conicet.gov.ar)

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1. Introduction

An epileptic seizure (ES) is defined as "a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain."[1] Epilepsy is a disorder characterized by a predisposition to generate ES and is diagnosed if a person has presented: (a) at least two unprovoked seizures occurring >24 h apart, (b) one unprovoked seizure and probability of further seizures similar to the general recurrence risk after two unprovoked seizures, or (c) diagnosis of an epilepsy syndrome.[2] It is estimated that 6.38/1000 people have active epilepsy.[3] Nearly one-third of people with epilepsy have drug-resistant epilepsy (DRE).[4] This condition is defined as a failure to achieve seizure freedom after adequate trials of two tolerated and appropriately chosen and used antiepileptic drug schedules.[5]

Dissociative seizures (DSs) are considered one type of functional neurological disorder (FND). FND encompasses a wide range of symptoms that can resemble neurological conditions but without similarly identifiable biomarkers.[6] DSs are defined as episodes of altered subjective experience, involuntary movements, and reduced self-control; although they may resemble an ES, they are not caused by hyper-synchronous neuronal activity.[7] Their prevalence is estimated to be 2 – 33/10000,[8] though 20 – 40% of patients attending specialized centers present DS.[9]

Both conditions significantly impact the quality of life. Jones *et al.*[10] have reviewed quantitative studies on the quality of life in people with DS and found that psychological factors (such as depression, dissociation, anxiety, and avoidance) and socio-environmental factors (such as family functioning) were more strongly associated with the quality of life than seizure-related variables. Conversely, Taylor *et al.*[11] have reviewed quantitative studies on the quality of life in people with ES. The frequency and severity of seizures as well as the presence of psychiatric comorbidity (especially depression and anxiety) were found to be associated with a reduction in quality of life. Likewise, in the past decade, studies quantitatively comparing the quality of life in both groups of patients were published, mostly reporting that people with DS have a poorer quality of life compared to those with ES.[12-15]

Although quantitative data provide valuable insights, qualitative methods provide more detailed information about the patient's experience[16] and allow a better understanding of the complexity of these conditions.[17] In addition, qualitative methods enable participants to express their emotions and thoughts in detail and choose what they consider important to tell, beyond forcing them to answer closed questions.[18]

The impact on life of DS and ES has been investigated through qualitative approaches. Kerr *et al.*[19] conducted a systematic review of qualitative studies focusing on individuals with ES, identifying 23 areas of impact, including cognitive, emotional, and disclosure-related challenges, among others. Similarly, Rawlings and Reuber[18] conducted a systematic review of qualitative studies exploring the experiences of DS patients, identifying five key themes: seizure events, diagnosis, treatment and management, emotional experiences, and the impact on daily life. Both reviews mainly include studies conducted in developed countries, with little research in low-income countries.[16] Some exceptions can be found in Keikelame and Swartz's report,[20] where women with ES were interviewed in South Africa's popular sectors. In Argentina, Sarudiansky *et al.* have published studies both on people with ES[21,22] and DS.[23]

Although multiple studies have explored the impact of both types of seizures from a qualitative methodology, few articles compare the reports of people with ES and DS. Rawlings *et al.*[24] analyzed written accounts of people with ES and DS and categorized the responses into five themes: seizure onset, emotional tone, seizure symptoms, treatment, and daily life. They compared the responses of both types of patients and observed differences in the experiences of both groups.

Thus, studies comparing the impact of ES and DS on individuals' lives are still in their early stages, primarily focusing on individuals with ES rather than those with drug-resistant epilepsy (DRE). However, it would be valuable to compare the experiences of people with DS and DRE, as both groups consist of patients with seizures that do not respond to pharmacological treatment. Therefore, the aim of this study is to compare the life impact of DS and ES in individuals with DRE from underserved contexts in Argentina using a qualitative approach.

As previously discussed,[21] this approach is expected to enhance our understanding of the experiences of both patient groups from their own perspectives. Such information would help guide professionals and patients in developing strategies to improve quality of life, while considering the specificities of the local context.

2. Materials and methods

2.1. Materials

A semi-structured interview based on the McGill Illness Narrative Interview[25] in Spanish[26] was used and adapted into Argentinian Spanish by M.S., considering local language variations. The adaptation was informed by cultural and linguistic considerations specific to the Argentinian context, and it was reviewed and tested in prior studies with people diagnosed with DS or DRE.[22,23] This interview was developed to elicit patients' illness experiences.

2.2. Participants

All participants were admitted to the video-electroencephalogram (VEEG) unit, where a comprehensive neurological, neuropsychological, and psychiatric evaluation was performed. This study involves continuous recording of the patient's behavior through video and electroencephalogram (EEG) activity, with the aim of correlating between clinical and electrical activity[27] and it is the gold-standard method for differential diagnosis between DRE or DS.[28]

Patients over 18 years old were included, with a confirmed diagnosis of DRE or DS by VEEG. Patients were excluded if they had not completed all diagnostic steps, had an IQ <70 according to the Wechsler Adult Intelligence Scale, third edition,[29] or had both types of seizures (DS and ES).

To ensure comparability between groups, participants were selected using a paired sampling approach, where patients with DRE and DS were matched based on demographic factors such as age and gender. This method allowed for a balanced comparison between the two groups.

2.3. Procedure

This study was conducted in the epilepsy center of two public hospitals in Buenos Aires, Argentina: Hospital General de Agudos José María Ramos Mejía and Hospital El Cruce. Both centers are reference centers, free of charge, and are attended by people from across the country and neighboring countries. Most of the patients are from low-income sectors without access to health insurance.

DRE patients' interviews were conducted in the VEEG unit. In the case of patients with DS, the interviews were conducted at the hospital offices after the communication of the diagnosis and the psychoeducation process. All interviews were conducted face-to-face by trained psychologists (M.S., M.M.A.A.P., G.K., C.T., A.L.) between February and November 2018. During the interviews, only the interviewers and the interviewee were present.

Sociodemographic and clinical data were obtained from electronic medical records.

All participants signed an informed consent. This study was approved by the Ethics Committee of Hospital Ramos Mejía and Hospital El Cruce.

2.4. Analysis

Data were analyzed using an inductive and deductive approach, following thematic analysis guidelines.[30] Atlas.ti software (version 7; ATLAS.ti GmbH, Germany) was used. Audio tapes of the interviews were listened to, transcribed verbatim and read multiple times. Independently, two researchers (C.W. and G.P.K.) identified codes and categories. Subsequently, topics were discussed and formulated. These themes and the relevance of the fragments included were later discussed in two meetings where M.S. and M.M.A.P. participated, where the codes and themes were redefined.

3. Results

Five interviews with DRE patients and five with DS patients were included. All participants were women, aged between 18 and 44 years. Table 1 shows sociodemographic data.

The average duration of the interviews was 50.29 min, with the shortest being 36.08 and the longest 60.34 min.

Three main themes related to the topic "impact on life" were identified:

(i) *Role of emotions.* Emotional manifestations linked to the disease, both preceding and as a consequence of the seizures.
(ii) *Impact on social interaction.* How the disease impacted relationships with others.
(iii) *Impact on daily life activities.* The way in which people discontinued activities due to the disease or continued despite it.

3.1. Role of emotions

Both groups of patients spontaneously shared emotion-related accounts during the interviews.

DS patients reported that emotions could trigger their seizures, particularly stress and joy. They also expressed feeling shame to a greater extent, followed by fear, anguish, discomfort, and irritation. To a lesser extent, they reported feeling worry, hopelessness, frustration, and sadness. Themes, subthemes, and illustrative quotations are listed in Table 2.

On the other hand, DRE patients also perceived emotions (anxiety, stress, and sadness) as triggers of seizures. As a consequence of the disease, fear, discomfort, sadness, and anger were identified to a greater extent, followed by hope and finally anguish and shame. Themes, subthemes, and illustrative quotations are presented in Table 3.

3.2. Impact on social interaction

Almost all DS patients reported a reduced frequency of contact with others as a consequence of the disease. They also described experiencing various types of interpersonal conflict, including mistreatment by health professionals, schoolmates, friends or responsible adults, disbelief, and fear of others. Some (fewer than half) reported receiving support from their partner, friends, and family. Themes, subthemes, and illustrative quotations are presented in Table 4.

Table 1. Sociodemographic characteristics and psychiatric comorbidity

S. No.	Diagnosis	Sociodemographic characteristics				Seizure characteristics		Psychiatric comorbidity
		Age	Occupation	Residence	Education	Onset	Frequency	
1	DS	37	People carer	CABA	Completed high school	37	Daily	Conversive disorder
2	DS	46	Domestic worker	GBA	Completed primary school	42	Weekly	Conversive disorder
3	DS	18	Student	CABA	Unfinished university	13	Biweekly	Dysthymia; conversive disorder; agoraphobia
4	DS	18	Employee at a family business	GBA	Complete high school	16	Weekly	Conversive disorder
5	DS	44	Unemployed	GBA	Completed primary school	5	Weekly	Conversive disorder; PTSD
6	DRE	22	Student	La Plata	Unfinished university	12	Weekly	Major depressive disorder; anxiety disorder; PTSD
7	DRE	22	Student	GBA	Unfinished university	11	Daily	-
8	DRE	29	Unemployed	GBA	Completed high school	4	Daily	PTSD
9	DRE	21	Nanny	CABA	Completed high school	2	Daily	Postictal psychosis
10	DRE	38	Unemployed	Tucumán	Completed high school	12	Daily	-

Abbreviations: CABA: Ciudad Autónoma de Buenos Aires; DRE: Drug-resistant epilepsy; DS: Dissociative seizures; GBA: Gran Buenos Aires (CABA suburbs); PTSD: Post-traumatic stress disorder.

Table 2. Role of emotions in patients with DS

Theme	Subtheme	Sub-subtheme	Quote
Role of emotions in DS	As a consequence	Fear (2)	P: I live locked up at home… isolated, isolated, isolated… from the outside world. Err… I'm afraid of… not sometimes, always… of… my reactions.
		Worry (1)	P: My concern is that… if it gets resolved or if it keeps going on.
		Shame (3)	P: And the truth is that at first, I locked myself up a bit because I was embarrassed to be seen with those things…
		Anguish (2)	P: That makes me anguished.
		Discomfort (2)	P: I get through this… and that… it's a hell, hell.
		Sadness (1)	I: And now that you know that your diagnosis is… psychogenic non-epileptic seizure….? P: That also makes me sad, but… to a lesser extent, like… my concern is that… whether it will get fixed or keep happening.
		Hopelessness (1)	P: I don't know if I'm going to have a normal life.
		Irritation (2)	P: They already bothered me.
		Frustration (1)	P: As I need to take the carbamazepine, I have to take the *luminal* right away, otherwise if not it will catch me, since it used to catch me anyway. I: Did it frustrate you a lot? P: Yes.
	As a trigger	Stress (3)	P: I've had, on a bus I've had an attack because... because a boy was crying... I mean, errr, but not because it bothers me, but because it hurts. It hurts me... (...) it drives me crazy... or seeing a mom beating a child. eh. it makes me very sad.
		Joy (1)	I: It is when you are very well, for example when you get good news, does it also happen to you? P: Yes. It's not that… it's not just because I'm sad.

Note: I: interviewer. P: Patient. The numbers in brackets indicate the frequency with which each subtheme appears. *Luminal* is the trade name for phenobarbital.
Abbreviation: DS: Dissociative seizure.

All patients with DRE expressed a perception of overprotection by relatives, and almost all expressed concerns about disclosing their illness to friends, partners, or employers. They also reported having faced conflictive

Table 3. Role of emotions in patients with DRE

Theme	Subtheme	Sub-subtheme	Quote
Role of emotions in DRE	As a consequence	Fear (3)	I: What do you feel at that moment? P: Fear. Because it never ends. I ask for help and nobody listens to me.
		Shame (1)	P: So, maybe, I was very embarrassed to say that I had epilepsy until I was 24 years old. At school, a friend or a boyfriend. For the simple fact of saying "I have epilepsy" and they treat me, I don't know, better.
		Anguish (1)	P: I used to cry because I didn't know what was happening to me.
		Discomfort (3)	P: And well, I wasn't well informed about the disease. It's shitty, but you can cope with it. But sometimes you can't… You get tired.
		Sadness (3)	P: Because I say "this shitty disease, when is it going to be cured?" There are some times in which I feel down in the dumps.
		Hope (2)	P: I will go through surgery, and all that, they're going to see if they can find a way out. Even if afterward I continue taking the medication, I would stop having the seizures, so it would be much easier to work, get my money, make a living, my stuff.
		Anger (3)	P: There's the anger, I can't find the difference. Why did someone who had gone through the same took the medication until the age of 12 and never again... Being younger than me... And I will turn 30, always took my medication and this happens to me (…) I get angry.
	As a trigger	Anxiety (2)	P: I got really anxious and had a seizure. And I was told when they treated me, that was because of anxiety.
		Stress (2)	I: And do you think, for example, that arguing or being very stressed could have something to do with what is happening to you? P: And, it could be. Maybe emotions, nerves, bad... bad... because of the emotions I say. ('Maybe...') I: And what kind of emotions? P: I don't know... Because of a problem, or maybe sometimes I argue, or I get upset, I don't know, or something upsets me and it's what for…
		Sadness (1)	P: So the emotional, it does, it influences a lot. And if I'm sad I even get more (seizures).

Note: I: interviewer. P: Patient. The numbers in brackets indicate the frequency with which each subtheme appears.
Abbreviation: DRE: Drug-resistant epilepsy.

situations with others (including teasing, exclusion, and disbelief), although these situations were less frequent compared to patients with DS. They reported perceiving interpersonal support (from friends, family, teachers, and partners) more frequently than patients with DS. Themes, subthemes, and illustrative quotations are listed in Table 5.

3.3. Impact on daily life activities

People with DS reported a loss of activities due to the illness. They mentioned having interrupted recreational activities, physical activity, driving, and studying and perceived their autonomy limited. Almost everybody reported having continued working despite the illness. Themes, subthemes, and illustrative quotations are listed in Table 6.

All the participants with DRE reported having discontinued different types of activities due to the disease: mostly, in relation to autonomy and study, as well as in different recreational activities. Some reported difficulty with work, driving, or sleeping. However, some participants reported continuing to work and engage in recreational activities, and to a lesser extent, studying. Themes, subthemes, and illustrative quotations are listed in Table 7.

4. Discussion

The aim of this study was to assess qualitatively the impact of seizures on people from Argentina's low-income sectors with DRE and DS. To our knowledge, this is the first study to explore qualitatively the lived experiences of individuals with these conditions. After the analysis, three themes were identified: the role of emotions, impact on social interaction, and impact on daily activities.

Seizures were found to impact patients' emotions. Previous studies reported that both DS and ES patients experience unpleasant emotions such as anger, frustration, sadness, and fear.[18-20] In our study, patients expressed similar emotions, with those facing DRE also expressing hope for surgery. This might be due to the data collection method in the VEEG unit, where the focus was on identifying the epileptogenic zone and surgical options, which has been associated with greater hope.[31]

Table 4. Impact on social interaction in DS patients

Theme	Subtheme	Sub-subtheme		Quote
Impact on social interaction in DS	Support (2)			P: They encouraged me to keep doing things. There was a time when I wanted to give up, I didn't want to... it was the last semester, as I had many seizures at school, I didn't want to continue and... However, teachers, friends told me "do it, it's only one semester to go."
	Isolation (4)			P: And the truth is that at the beginning I shut myself up a bit because I was ashamed to be seen with those things, errr… I: With the seizures. P: Of course... yes, I isolated myself...
	Interpersonal conflict	Mistreatment	Health professionals (2)	P: And on top of that she yelled at me, (the neurologist) told me "you have epilepsy! Don't you understand? (...) You have epilepsy!" and I froze... there I realized that I couldn't move, because I wanted to "eat her up" and I couldn't.
			Others (3)	P: I've always had a bad time. Last year it was worse because I didn't go (to school) and everyone was waiting to see if I got expelled because it was unfair to others... They said... "why isn't she coming?"... I don't know. don't piss me off (...) because they thought it wasn't fair for them that I wasn't going (...) they didn't share the homework, the director had to speak with them.
		Disbelief (2)		P: No, before…My mum asked me, "do you really faint?"
		Reaction of others to seizures (2)		P: And he told me "you're scary," and that's ugly. The fear. I mean, I don't like it... that's one of the reasons why I also isolate myself, I scare others.

Note: I: interviewer. P: Patient. The numbers in brackets indicate the frequency with which each subtheme appears.
Abbreviation: DS: Dissociative seizure.

In our sample, both patients with DRE and DS recognized emotions as possible seizure triggers. The study of emotions as seizure triggers has been carried out separately for both types of conditions. Rawlings *et al.*[32] found that tiredness and anxiety were common triggers for DS. This phenomenon was also described in studies with people with ES. For example, stressful events have been reported to trigger seizures[33] and it has even been reported that the onset of epilepsy in some cases can occur after stressful events.[34] In fact, recent studies have evaluated biological indicators linking stress to epilepsy, finding changes in EEG (exaggerated spiking, paroxysmal activity, or epileptiform complexes), increased cortisol levels,[35] or an inhibitory hippocampal mechanism[36] In the case of DS, hyperreactivity in the amygdala and increased connectivity with motor and autonomic regions have been found, which could arise from early adversity or chronic stress.[37]

Thus, although the emotions experienced as a consequence of the seizures differ slightly between both groups, the perception of emotion as a triggering factor of a seizure was observed in both. Although in our sample both groups acknowledged their emotions, the recognition of emotions in both groups of patients is still controversial in the existing literature. A recent review showed that there are no significant differences in alexithymia levels between both groups,[38] although previous studies have also found that people with DS and ES have differences in emotional processing.[39]

Another possible explanation for this phenomenon can be found in the fact that all the patients included were women. It has already been described that there are differences in the expression and recognition of emotions between both sexes.[40] Thus, including only women in the sample may explain the perception of emotions through gender-related factors, in addition to those related to the disease.

Finally, this finding may be related to the fact that the perception of emotions is not universal and it is mediated by culture.[41] Previous local studies[21,23] highlighted cultural differences in Argentina, where there is greater diffusion of psychotherapy and one of the highest rates of psychologists in the world.[42] This may contribute to greater openness in sharing emotional experiences, which could explain the high emotional expression found in the participants.

Social interaction was significantly affected by the disease, with both DS and DRE patients reporting experiences of discrimination, ridicule, and exclusion. Perceived discrimination and lack of understanding from others have already been reported in DS and DRE patients in previous studies.[19,20] Even so, in our sample,

Table 5. Impact on social interaction in DRE patients

Theme	Subtheme	Sub-subtheme	Quote
Impact on social interaction in DRE	Support	Friends (3)	P: I've always felt support, even at school. My friends have always supported me in this.
		Family (4)	I: What people do you think helped you in this period of your life? P: Err... And mainly mom, my dad, my sisters.
		Teachers (2)	P: So I spoke with the professor and the adjunct professor and she told me that if I asked my neurologist for a certificate stating that I had to be calm to be able to study, I could sit for the exam on another date.
		Partner (2)	P: I do feel supported. For example, with my boyfriend, who was here yesterday.
	Interpersonal conflict	Teasing (1)	P: Then my schoolmates did tease me a little. But I didn't care so much. I: And how did they tease you? P: Yes... sometimes they told me things that they didn't. that they didn't know. I: They yelled at you, they made fun of you… P: Kids are cruel.
		Exclusion (1)	P: I used to go near my house, some blocks away, two blocks away, there was a gym. I would to go and do aerobics. And one day, it seems to me, I fell and me like "what for." The girl, she, they also asked for. well, that "it's not that I don't have problems, better if you don't hit yourself here." "No problem," I tell her, "I understand you."
		Disbelief (2)	P: I think that's why she thought I was manipulating her. When I had a strong argument with my mom, it was when I had a lot of seizures. And maybe she... I think, that she associates it with the fact that I wanted to manipulate her. But no. It was actually because, well, the argument affected me quite a bit, it got on my nerves or something.
	Overprotection (5)		P: They wouldn't let me go to a park, they wouldn't let me, I don't know, go on a carousel for more than three laps. For fear of having a seizure... He wouldn't let me, I don't know, get on the trampoline because he was afraid I was going to hit my head. Or play in a round.
	Disclosure (4)		P: So, maybe, I was very embarrassed to say that I had epilepsy until I was 24 years old. At school, a friend or a boyfriend. For the simple fact of saying "I have epilepsy" and they treat me, I don't know, better. Or there are people who don't know, who are ignorant, they don't know when the person falls on their side, errr... I don't know, that one is comfortable, don't get in the way, that one doesn't hit with something hard. Then out of ignorance they scare you and leave you aside.

Note: I: Interviewer. P: Patient. The numbers in brackets indicate the frequency with which each subtheme appears.
Abbreviation: DRE: Drug-resistant epilepsy.

Table 6. Impact on daily life in DS patients

Theme	Subtheme	Sub-subtheme	Quote
Impact on daily life in DS	Loss of activities	Study (1)	I: Well, your social life was affected by these blackouts...? P: Yes, because... I didn't go to school anymore.
		Physical activity (1)	P: I stopped doing gymnastics, for example. I wanted to ask if I could start because that's very good for me going to the gym, errr, spinning, aerobic boxing.
		Driving (1)	P: "I want to drive," at that moment I was picky with driving.
		Recreational activities (2)	P: I stopped... wishing things or, or feeling the same about things. There was something that I liked, going to the riverbank, having some *mates*...
		Autonomy (2)	P: Sometimes I can't go out alone, I can't, I have to be with someone or something.
	Continuity of activities	Work (4)	P: Let's say, in 2 h, can a person clean eight, nine classrooms? (...) In 2 h, I do it, doctor. But I do it because I can't lose my job.

Note: I: Interviewer. P: Patient. The numbers in brackets indicate the frequency with which each subtheme appears.
Abbreviation: DS: Dissociative seizure.

many individuals with DRE were hesitant to disclose their condition, consistent with previous studies in adults.[19,43]

Previous research[44] found higher levels of stigma in DS patients compared to DRE patients, despite that both groups reported high levels overall. Notably, stigma

Table 7. Impact on daily life in DRE patients

Theme	Subtheme	Sub-subtheme	Quote
Impact on daily life in DRE	Loss of activities	Working (2)	P: Before the status epilepticus, I worked and had a normal life, coming and going everywhere... and after the status epilepticus, no longer.
		Sleeping (1)	I: And what makes you most uneasy about having a seizure? P: That I can't sleep at night.
		Study (4)	I: What things do you think were disrupted or... or cut short by epilepsy? P: The study. The study. I was also studying nursing. Which I liked a lot. And I also had to drop it. I had to drop it.
		Driving (1)	P: Not going out on a motorcycle, which I used to do. Not riding a motorcycle.
		Recreational activities (3)	P: I like riding a bike, I can't do that either.
		Autonomy (4)	P: I can't go out with friends... (my mum) She doesn't like to go out at night, she doesn't like me to go out alone, I'm go shopping, "(I want) someone to go with her." I go for bread to the corner, (she wants) someone to go with me. And I do not feel well.
	Continuity of activities	Working (2)	P: As I told you, I work as a computer teacher.
		Study (1)	I: And what things, on the contrary, do you feel that helped you in this period of your life? (...) P: My friends or taking different courses to distract myself. I: What courses did you take? P: I did cooking, makeup, fashion design, now I'm with drama classes, guitar classes, I've done a lot of things.
		Recreational activities (2)	P: What I am sure is that the problem is not drinking alcohol. Because in the first place I'm not a drinker, and secondly that... if I know that on a Saturday night, I'm going to go out to my friends' house… the medication I take it as early as possible at night, then I drink plenty of water and have the stomach (full), that way... I: So that it doesn't... P: ... mix a lot and have no problem.

Note: I: interviewer. P: Patient. The numbers in brackets indicate the frequency with which each subtheme appears.
Abbreviation: DRE: Drug-resistant epilepsy.

perception correlated negatively with quality of life in DS patients, as shown in other studies.[45] In our sample, the differences in some emotional experiences, such as shame and overprotection, between DS and DRE patients may be partly explained by the higher stigma associated with DS. The stigma surrounding DS, being associated with mental health conditions, likely contributes to the greater experience of shame among DS patients. On the other hand, DRE patients, whose condition is perceived as a neurological disorder, are generally subject to less stigma and report more experiences of overprotection, as they may be viewed more sympathetically by others. In turn, all patients with DRE perceived overprotection from others, which also aligns with the previous studies.[19,46] Future studies could address the consequences of overprotection in these patients, as it appears to impact all patients.

In our sample, interpersonal conflict was more frequent in patients with DS, a finding previously noted by Gupta *et al.*[47] One possible way to explain our findings may lie in the ability of people with DS to attribute emotions and intentions to others. Schönenberg *et al.*[48] studied theory of mind abilities in patients with DS and found that DS patients had impaired mentalizing skills compared to healthy controls. Gürsoy *et al.*[49] reported similar results that people with DS exhibited worse results in tests of theory of mind compared to the control group and people with epilepsy. This difficulty in understanding the emotions of others could contribute to higher level of conflict with others.

Interpersonal conflicts in DS patients may also stem from psychiatric comorbidities. Diagnostic criteria for mental disorders often reference interpersonal difficulties, such as unstable relationships in borderline personality disorder or social avoidance in anxiety disorders.[50] A systematic review of 32 studies concluded that samples of people with DS show greater comorbidity than those with ES, with post-traumatic stress disorder, depression, and personality disorders being more notable.[51] Thus, the higher psychopathology in DS patients may contribute to increased interpersonal conflicts.

In our study, patients with DS reported isolation, while patients with DRE experienced it less frequently. No studies have directly compared social isolation between these groups, as this topic was explored individually. Kerr *et al.*[19] noted that ES patients often experience loneliness, social isolation, and difficulty maintaining friendships. On the other hand, social isolation in people with DS has also been studied. Unlike they had anticipated, Vaidya-Mathur *et al.*[52] found that patients with DS tended to be socially connected, most of them maintaining daily communication with relatives. Pretorius and Sparrow[53] also found that family, friends, and significant others functioned as a source of support. Although people with DS perceive others as sources of support, they also report feelings of isolation and loss of social life.[18] These mixed findings highlight the need for further research, especially considering evidence linking social isolation to poorer physical and mental health in the general population.[54]

Seizures impact not only interpersonal and emotional aspects but also the daily activities of both patient groups. Similar to our findings, Kerr *et al.*[19] reported that ES patients experience limitations in autonomy, independence, and engaging in enjoyable or academic activities. Studies on DS patients[18,24] also highlight losses in independence, freedom, physical activities, and challenges in securing and maintaining employment.[55] However, our study is distinctive in that it focuses specifically on individuals from Argentina's low-income sectors, a demographic often underrepresented in research. This may represent additional barriers to autonomy and employment, particularly due to the social and economic constraints faced by these individuals. In our sample, four out of five DS patients continued working despite seizures, though only one held formal employment, reflecting the difficulty in accessing and retaining formal jobs.

While this study offers novel insights, it has several limitations. The non-probabilistic, intentional, and paired sampling, along with the small sample size, limits the generalizability of the findings. Furthermore, participants were selected based on their access to a reference center with VEEG, further restricting the applicability of the results to those without such access. In addition, interviews were conducted in different settings: patients with DRE were interviewed in the VEEG unit, while those with DS were interviewed in hospital offices. The hospitalization context of the VEEG unit may have influenced the openness of DRE patients to discuss certain topics.

Moreover, only women were included in the study as a result of paired sampling. While this approach ensured comparability between groups and enhanced the credibility of the findings by reducing potential sociodemographic confounders, it also limits the transferability of the results to male patients. Future studies should explore gender differences in the lived experiences of DS and DRE.

Efforts were made to reduce bias by independently categorizing data followed by group discussions. However, future studies could incorporate member checking to enhance credibility.[56] Finally, many existing ES studies involve participants without DRE, complicating comparisons of their findings with our results. Future research could also include perspectives from family members, caregivers, and other sources to deepen our understanding of the impact on life.

5. Conclusion

This study aimed to analyze the impact of seizures on patients with DRE and DS in Buenos Aires, Argentina. Through semi-structured interviews, three main themes emerged: emotional impact, social interaction, and daily activities. Both groups reported emotional difficulties, often unpleasant, which stem from or can trigger seizures. Social interaction was notably affected, with both groups reporting having received support but experienced distinct challenges: interpersonal conflicts were more frequent in DS, while overprotection and hesitancy to disclose their condition were prevalent in DRE. Isolation was also more common among DS patients.

Seizures disrupted daily life in both groups, though the specific areas impacted varied. These findings underscore the need for tailored mental health interventions to address the unique challenges faced by each group. Treatment programs for these patient groups could benefit from incorporating modules on emotional regulation, assertive communication, conflict management, behavioral activation, and fostering independence. Given the emotional impact of the disease, strategies such as cognitive-behavioral therapy, mindfulness, or acceptance and commitment therapy could help patients manage stress and other emotions. Addressing interpersonal difficulties through psychoeducational programs for family members and healthcare professionals may also reduce stigma and improve social support. In addition, promoting autonomy by facilitating the continuation of studies, recreational activities, and workplace accommodations could enhance patients' quality of life.

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Conflict of interest

The authors declare that they have no competing interests.

Author contributions

Conceptualization: Guido Pablo Korman, Luciana D'Alessio, Mercedes Sarudiansky, Camila Wolfzun
Formal analysis: Camila Wolfzun, Guido Pablo Korman
Investigation: Mercedes Sarudiansky, Maria Marta Areco Pico, Guido Pablo Korman, Cristina Tenreyro, Alejandra Lanzillotti
Methodology: Alejandra Lanzillotti, Mercedes Sarudiansky, Camila Wolfzun
Project administration: Guido Pablo Korman
Writing – original draft: Camila Wolfzun, Guido Pablo Korman
Writing – review & editing: Mercedes Sarudiansky, Maria Marta Areco Pico, Guido Pablo Korman, Cristina Tenreyro, Luciana D'Alessio

Ethics approval and consent to participate

All participants signed an informed consent indicating their agreement to participate in the study. This study was approved by the Ethics Committee of Hospital Ramos Mejía and Hospital El Cruce.

Consent for publication

All patients signed a written informed consent for their data to be published.

Availability of data

The data cannot be obtained as it would violate the confidentiality of the interviews conducted.

Further disclosure

Part of the findings have been presented at conferences: 24th Argentine Congress of Neuropsychiatry and Cognitive Neuroscience – Argentine Neuropsychiatric Association, Autonomous City of Buenos Aires, Buenos Aires, Argentina, 2022; 30th International Congress of Psychiatry – Argentine Association of Psychiatrists, Autonomous City of Buenos Aires, Buenos Aires, Argentina, 2022; Argentine Congress of Psychiatry – Association of Psychiatrists of Argentina, Mar del Plata, Buenos Aires, Argentina, 2022.

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