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A life with seizures: Argentine patients' perspectives about the impact of drug-resistant epilepsy on their lives

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ABSTRACT

Purpose: To understand the experience of drug-resistant epilepsy in patients from Argentina, a developing nation.

Method: A qualitative approach using semi-structured interviews was used to gain an in-depth and contextual understanding of the perspectives of 20 patients with DRE. Data collection and analysis were followed by an inductive and interpretive approach informed by the principles of thematic analysis.

Results: Six main themes emerged: 1) Characteristics of the illness, including seizure features -unpredictability, presence of auras, physical and cognitive consequences- and how patients relate with the use of antiepileptic drugs; 2) interactions with health system, regarding the features of the Argentine's health system, and patient's health-seeking behaviours; 3) beliefs about the illness, including psychosocial, biological and folk explanatory models; 4) beliefs about how other people perceive them, which included prejudice, responsibility and over-protection; 5) self-perception, and 6) impact of the illness on their activities.

Conclusions: This information might be useful to help in the development of a conceptual model of the impact epilepsy on patients' lives. Many of the topics mentioned as relevant in Argentina coincide with those highlighted in studies that were carried out in first-world countries. However, additional topics were also reported including the role of traditional healing in health-seeking behaviour and explanatory models of illness. It is important to understand these perspectives to develop appropriate psychosocial interventions for this specific population.

1. Introduction

Worldwide, an estimated 60 million people have epilepsy [1]. Approximately one-third of people with epilepsy (PWE) do not respond satisfactorily to antiepileptic drugs. When more than two combinations of antiepileptic drugs have been tried without satisfactory response, patients are considered to have drug-resistant epilepsy (DRE), which has a significant impact on their lives [2,3].

In recent years, researchers have highlighted the importance of considering patients' perspectives in evaluating the outcomes of medical treatments [4]. This is particularly relevant for chronic conditions, such as DRE. It is possible that professionals' perspectives on what is important for treatment may differ from patients'. For example, some

authors have found that the frequency of epileptic seizures – one of the main objectives of pharmacological treatments – may not be the variable that has the greatest impact on patients' lives [5]. Instead, psychiatric comorbidities, secondary effects of medication, or the sense of lack of control over their own lives could have more significant effects on their quality of life [6–9]. In a previous report published by our research team, significant differences regarding the patients' perspectives about their quality of life and the physician's assessment of their general functioning were found [3]. Some authors argue that if physicians fail to consider patients' perspectives, the doctor-patient relationship could be affected [10], and treatment compliance may be at risk [11]. Improving doctor-patient communication could help the patient feel more understood and improve treatment outcomes.

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Patient reports, which represent the “voice of patients” in treatment outcome evaluations, are often assessed through semi-structured questionnaires, analysed quantitatively [12]. However, questionnaires may be difficult to apply in cross-cultural contexts, due to translation errors, lack of validated versions, or differences in response styles [13]. For these reasons, it is useful to use qualitative methods, to understand and interpret the perspectives and beliefs of patients “in their own words”, without restricting their comments to topics predetermined by professionals [14–16].

In a systematic review of 18 qualitative studies, Kerr and colleagues [7] developed a conceptual model in which they identified 24 categories relevant to the impact of epilepsy on the lives of adults, adolescents and children. This conceptual model allows treatment to focus on different, and perhaps more relevant, targets. Their review focused on qualitative studies about patients’ perspectives on their epilepsy, conducted in developed nations worldwide. The authors specifically decided not to include developing nations in their review. Besides, only one of them focuses specifically on DRE [17]. Since 80% of PWE live in developing countries [18,19], and between 20 and 40% of patients with epilepsy have DRE [20–22], a significant gap in understanding remains. The goal of this paper is to add information about patients’ perspectives on DRE from a developing nation, specifically Argentina, to help in the development of a conceptual model of the impact of this illness on patients’ lives.

2. Methods

2.1. Recruitment and sampling

Adult patients (> 18 years) with DRE admitted to the video-electroencephalography (v-EEG) units at Ramos Mejia and El Cruce Hospitals between November 2015 and May 2016 were invited to participate. Patients were admitted to confirm the diagnosis of epilepsy and to determine

the possibility of surgical treatment. They all underwent a complete clinical protocol, which included neurological, neuropsychological, neuroimaging and psychiatric assessment. Ramos Mejia Hospital is located in the city of Buenos Aires, whereas El Cruce Hospital is located in Florencio Varela, a low-income suburb outside the city. Both are public general hospitals and referral centres for epilepsy. Patients were excluded if they did not have seizures during a five-day v-EEG, if they had non-epileptic seizures, if their IQ was less than 85 according to the Wechsler Intelligence Scale for Adults [23], or if they were in a severe psychotic episode at the time of the evaluation [24].

Of the 42 patients admitted to both v-EEG units during this period, 22 were excluded because 12 were found to have psychogenic non-epileptic seizures, 5 did not have a seizure while monitored, and 5 earned an IQ that fell below a standard score of 85. Ultimately, 20 patients were included.

The ethics committees of both hospitals approved this investigation. All of the patients signed informed consents. Pseudonyms were used to ensure anonymity.

2.2. Data collection

A qualitative method using semi-structured interviews was chosen to gain an in-depth and contextual understanding of the patients’ perspectives of their illness. We used the Spanish version of the McGill Illness Narrative Interview Schedule (MINI) [25,26]. This was edited into Argentine Spanish by the first author (MS), i.e. social and regional variations of Spanish language in this context were considered. This interview explores the patients’ narratives of their disease, focusing on their personal and clinical experiences [25]. It has a specific section about the impact of the illness on their lives, but on analysis, many interesting details derived from other sections of the interview as well.

Table 1

Examples of questions from McGill Illness Narrative Interview Schedule [30].

INITIAL ILLNESS NARRATIVE	
a.	When did you experience your seizures for the first time?
b.	We would like to know more about your experience. Could you tell us when you realized you had epilepsy?
c.	Can you tell us what happened when you had your seizures?
d.	Did something else happen?
EXPLANATORY MODEL NARRATIVE	
a.	According to you, what caused your seizures?
b.	Are there any other causes that you think played a role?
c.	Why did the seizures start when they did?
d.	Is there something happening in your family, at work or in your social life that could explain the seizures?
IMPACT ON LIFE	
a.	How have your seizures changed the way you live?
b.	How have your seizures changed the way you feel or think about yourself?
c.	How have your seizures changed the way that others look at you?
d.	What has helped you through this period in your life?

Some of the questions corresponding to each section of the interview are listed in [Table 1](#).

2.3. Data analysis

Data collection and analysis followed an inductive and interpretive approach, informed by the principles of thematic analysis [27]. Data analysis was assisted by use of the qualitative data analysis package Atlas.ti. First, researchers listened repeatedly to the original audios and read the verbatim transcripts. Next, they generated initial codes and grouped them into themes. The relevance of the fragments corresponding to each code was discussed in order to achieve consensus and agreement from the members of the research team.

3. Results

Twelve men and eight women, with ages ranging from 22 to 52 (mean 32.8), participated. Fourteen were Argentinian, three were from Paraguay, two were born in Bolivia and one in Peru. Fourteen lived in Buenos Aires and its suburbs; six lived elsewhere in Argentina. Nine were unemployed; five were day labourers, working off the books without state benefits; two were university students; one worked inside her home; one was a fire-fighter and two were self-employed. Patients’ first epileptic seizure occurred between 1 and 26 years of age (mean 12.1 years). Sociodemographic characteristics of participants are shown in [Table 2](#).

3.1. Life impact of epilepsy

Six themes and 36 subthemes emerged: Characteristics of the illness; interactions with the health system; beliefs about the illness; beliefs about how other people perceive them; self-perception, and impact of the illness on activities. Themes, subthemes and illustrative quotations are listed in [Table 3](#).

3.1.1. Characteristics of the illness

Many patients said the unpredictability of their seizures had an impact on their lives (A.1.1). Patients also described the features of their seizures, including the presence or absence of auras (A.1.2), and whether they lose consciousness or not (A.1.4). Many underscored the physical consequences of the seizures, such as headache or fatigue (A.1.5). Patients also said they had problems with concentration and memory in their everyday life (A.1.6). Secondary effects of anti-epileptic drugs (A.2.1) and difficulties with medication compliance (A.2.2) were also important issues.

Table 2
Socio-demographic characteristics of participants.

N	Patient	Age *	Gender	Nationality	Residence	Marital status	Level of schooling	Occupation	Age at onset of epilepsy	Frequency of seizures	Treatment medication +
1	Sofía	26	F	Argentinian	City of Buenos Aires	Single	Unfinished university	Student	9	Everyday	LMT; LVT; CLB
2	Juan	50	M	Peruvian	City of Buenos Aires	Married	Unfinished high school	Unemployed	23	Weekly	CBZ; LMT; CLZ
3	David	33	M	Argentinian	Province of Salta	Single	Unfinished university	Employee	16	Weekly	PNT; LVT; CLZ
4	Noemí	35	F	Argentinian	Province of Buenos Aires	Single	Complete high school	Domestic worker	5	Everyday	CBZ; CLZ
5	Fabián	25	M	Argentinian	Metropolitan Area of Buenos Aires	Single	Complete high school	Unemployed	18	Monthly	LMT; CBZ
6	Alberto	33	M	Paraguayan	Metropolitan Area of Buenos Aires	Single	Complete primary school	Unemployed	4	Monthly	CBZ; PNT
7	Andrés	22	M	Argentinian	Metropolitan Area of Buenos Aires	Single	Complete high school	Employee	1	Monthly	TPM; LVT
8	Daiana	24	F	Paraguayan	Metropolitan Area of Buenos Aires	Couple	Unfinished high school	Domestic worker	22	Monthly	LCS; SVP
9	Estela	24	F	Argentinian	Metropolitan Area of Buenos Aires	Single	Unfinished high school	Unemployed	14	Weekly	LVT; OXC
10	Claudia	37	F	Argentinian	City of Buenos Aires	Married	Unfinished high school	Unemployed	6	Everyday	LVT; PB; LMT; CLZ
11	José	36	M	Argentinian	Metropolitan Area of Buenos Aires	Married	Unfinished primary school	Unemployed	13	Weekly	PB; PNT
12	Mariano	33	M	Argentinian	Province of Misiones	Single	Unfinished university	Student	13	Weekly	CBZ; TPM; LMT; LVT; CLZ
13	Lorena	25	F	Bolivian	Metropolitan Area of Buenos Aires	Married	Complete high school	Employee	12	Weekly	CBZ; LVT
14	Federico	27	M	Argentinian	Province of Entre Ríos	Couple	Complete high school	Volunteer fireman	21	Monthly	LVT; MgV
15	Nicolás	28	M	Argentinian	Province of Santa Fe	Single	Unfinished University	Unemployed	2	Everyday	LVT; CBZ
16	Walter	40	M	Paraguayan	Province of Buenos Aires	Married	Complete primary school	Businessman	26	Weekly	SVP; LVT
17	Lidia	24	F	Bolivian	Metropolitan Area of Buenos Aires	Single	Unfinished high school	Unemployed	5	Everyday	LVT; CBZ
18	Norma	48	F	Argentinian	City of Buenos Aires	Married	Unfinished high school	Unemployed	13	Weekly	LMT; CLZ
19	Lucas	34	M	Argentinian	Metropolitan Area of Buenos Aires	Single	Complete high school	Employee	1	Weekly	LVT; LCS; CBZ; LRZ
20	Silvio	52	M	Argentinian	Province of Buenos Aires	Couple	Unfinished high school	Businessman	18	Weekly	LVT; CBZ; CLZ

* Age in years at the moment of the interview.

+ Anti-epileptic medication at the moment of the interview (self-reported): LMT: Lamotrigine; TPM: Topiramate; LVT: Levetiracetam; CLB: Clobazam; CBZ: Carbamazepine; LCS: Lacosamide; LRZ: Lorazepam; MgV: Magnesium Valproate; SVP: Sodium Valproate; CNZ: Clonazepam; PNT: Phenytoine; OXC: Oxcarbazepine; PB: Phenobarbital.

Table 3
Themes, subthemes and illustrative quotations about life impact of epilepsy.

Theme	Subtheme (Freq*)	Typical statement
A. CHARACTERISTICS OF THE ILLNESS		
A.1. Seizure features	A. 1. 1. Unpredictability (15)	The other day I was cooking and I had a hot pan boiling there, I was about to make <i>milanesas</i> and I had an attack. Luckily, I fell back, otherwise... The pan didn't fall on me, otherwise I would have been all burned. Things like these make me angry, I don't know. See? I can't do anything because perhaps I will have an attack. (Patient 11: Mariano, Male, 36)
	A. 1.2. Aura (7)	I know it is coming, in general. What I am not able to do is to inform it. (Patient 19: Lucas, Male, 34)
	A.1.3 Consciousness (14)	This is the thing. I don't know what I do. Everything I do [during the seizures], someone tells me about it. What I know now is that I don't react, I turn my head to the left, and then I do some movements. There, I stay still and I start to do like discharges. The attack is very short. What they say is that they ask me the same thing many times, but I say I don't know. It's like I'm lost in time and space. I don't know. I have a hard time to come to my senses (Patient 1: Sofia, Female, 26)
	A.1.4. Physical consequences (13)	Sometimes, when it comes, I hurt myself. This last time I hurt myself a lot. Here I have a bruise, see? I was taking a shower and it came. And I fell. It has been very unfortunate for my wife. (Patient 2: Juan, Male, 50)
	A.1.5. Memory/concentration (7)	When it comes, I want to sleep. Then I wake up and I can't bend over, it's terrible. I sleep, I sleep. That is my problem. I want to sleep. (Patient 16: Walter, Male, 40)
2. DAE	A.2.1. Secondary effects (8)	Memory... I don't have memory any more. I don't remember things. If someone tells me, 'do you remember this?'. No. 'Do you remember this person?' No. (Patient 18: Norma, Female, 48)
	A.2.2. Compliance (9)	I had to take the medication in the afternoon during my class; then, at a particular moment, I started feeling a little sleepy. After the first half an hour I began to feel sleepy. (Patient 10: Claudia, Female, 37)
		I don't know if it's because my body is adapting to Logical (Valproate), but it also makes me gain a lot of weight. I can't see myself any more. Because this pill has something that makes you fat. I don't remember the name. I don't remember. And if I'm not under constant physical training it makes me fat and lets me down. I eat a lot because I'm big. (Patient 15: Nicolás, Male, 28)
		- I was seizure free for one year, so I stopped taking my medication - Why? - Just because... But then I had a big seizure and I ended up in an ambulance (Patient 20: Silvio, Male, 52)
B. INTERACTIONS WITH HEALTH-CARE SYSTEM		
B.1. Health-care system features in Argentina	B.1.1. Public Hospital (9)	The last time we came to Buenos Aires we went to the Ramos Mejía [hospital]. They told us there might have been a chance for surgery there. And they didn't give us a lot of hope because there were lots of people before us (Patient 3: David, Male, 33)
	B.1.2. "Obra social" (6)	After that, we came here, to the Rossi Hospital, where our doctor works. We did that because there are more specialists, or they told me so. They took care of me for a long time at the San Roque's hospital, but since I'm getting worse they recommended to go there because there are more specialists. So, then I went there with my doctor. (Patient 16: Walter, Male, 40)
	B.1.3. Private practice (4)	So, thanks to the <i>obra social</i> and all that, my mom told me: 'let's make the most of it, since you have an <i>obra social</i> '. I didn't have one when I was younger. (Patient 5: Fabián, Male 25)
	B.1.4. Disability insurance (9)	Well, we couldn't find anyone at the <i>obra social</i> , so we had to find this neurologist in private practice. He was the only one who took care of my case. Well, I came here after he told me to. (Patient 9: Estela, Female, 24)
B.2. Dealing with the system	B.2.1. The specialist quest (10)	[That medication] is expensive, but since I have a social disability certificate and an <i>obra social</i> , they give it to me [for free]. (Patient 7: Andrés, Male, 22)
	B.2.2. Migration (11)	Now they don't want to renew my disability certificate because they say that what I have is not a disability. That I can get a job, and that there are thousands of jobs I can do off the books. They recommended me to look for an illegal job (Patient 11: Mariano, Male, 36)
	B.2.3. Doctor-Patient communication (14)	They didn't want to help me because they said that they were not epilepsy specialists. Or perhaps they were not interested. It was very difficult to find a neurologist who knows about epilepsy (Patient 9: Estela, Female, 24)
B.3. Non-conventional medicine (9)		It was a disaster. Really. What I had to come with doctors was a disaster. Because each one has their own rules (Patient 10: Claudia, Female, 37)
		That medicine was very expensive in Lima. 'In Argentina these medicines are easy', my brother said. 'I will help you there, we will see the doctors and you can be treated in the hospital'. So, he suggested me to go to the Ramos Mejía Hospital. So I came to live with my brother [to Argentina] (Patient 2: Juan, Male, 50)
		When I was twelve my mom came [to Paraguay] looking for me. So, then I started the treatment (Patient 6: Alberto, Male, 33)
		When they make you wait, after waiting for so long, they don't take the time to listen to you... I'm aware when someone wants to end the conversation. The neurologist wasn't interested in my case. She seemed to be overwhelmed with her work; she wasn't interested in me. She didn't care. She didn't care. (Patient 3: David, Male, 33)
		The doctor explained it very clearly. She explained why I had this epilepsy attacks. She said it was because of nerves, or because of different reasons. She said that it was like there were two wires in short circuit, and that was why I had the seizures. Every time I went to see her, I asked her what was going to happen to me, what were the consequences, or if I could die. Things like that. I didn't have a clue at first. (Patient 11: Mariano, Male, 36)
		We are Bolivians and we believe in healers (...) My mom took me to see more than fifteen. Fifteen healers. Everywhere. They said it was fright [<i>susto</i>] (...) they said that my soul was in this pit, in the river. (...) We went there, and we started to call for it [my soul]. They made me drink some water from that river, and they also called [my soul] with bread. And then I had to eat the bread (...). They tried to bring my soul back to me. I had to drink the water, eat the bread and take some little rocks [with me], so my soul could cling to me again (Patient 17: Lidia, Female, 24)

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Table 3 (continued)

Theme	Subtheme (Freq*)	Typical statement	
C. BELIEFS ABOUT THE ILLNESS			
C.1. What it epilepsy?	C.1.1. "just an illness" (2)	It's an illness. It's an illness and it has a cure, supposedly. They told me so. But that means you have to carry out a treatment. (Patient 5: Fabián, Male, 25)	
	C.1.2. A defect (1)	It's a defect if you neglect it. It is something that is there and annoys you (Patient 1: Sofia, Female, 26)	
	C.1.3. Something unfair (4)	No, I didn't think it was fair. I didn't want that to be happening to me. I wanted to go back in time, so nothing had happened. So, I took everything I had and threw it away. I broke it. It was unfair that all this was happening to me and not to other people (Patient 4: Noemí, Female, 35)	
C.2. Explanatory models (Causal attributions)	C.2.1 Biological (15)	Hormones	I think it came out just in the moment I was experiencing a hormonal change. So perhaps that is why it came out (Patient 9: Estela, Female, 24)
		Birth/Pregnancy	Everyone asked me 'did you have an injury, or something'? Everyone asks me if I had a punch on my head when I was a child. And since this woman [the midwife] was a masseur, perhaps she made something wrong when she tried to put me in place [during my birth]. And perhaps my head was too soft, so if she pulled too much... I don't know. (Patient 13: Lorena, Female, 25)
		Head injuries	I hit my head when I was a child, and perhaps it was because of that. Like a little vein or something like that. It starts not working correctly, and then I started to have seizures. (Patient 16: Walter, Male, 40)
	C.2.2. Psychosocial (14)	Childhood trauma	My mom was in a hurry and I didn't want to bath and she grabbed me by the hair, and she took me into the water. Oh! And then I woke up, doing like this [she moves her hands]. So, I think it might have been because of fear, see? Someone told me about it. So I drowned. And then she took me out of the bath, and I was crying. And then she said 'I'm sorry, my daughter.' (Patient 13: Lorena, Female, 25)
		Emotions	I think it was because of this moment. My mom's surgery (...). It was a very tense moment. I could not sleep... (Patient 7: Andrés, Male, 22) Because I was nervous. Because to me it's all related to emotions (...) It's like I punish myself all the time and that makes me angry, and makes me nervous, and so... I have a seizure. (Patient 10: Claudia, Female, 37)
	C.2.3. Supernatural (9)	'Hand of God'	If this happened to me it was because of something, see? Because... Sometimes I sit down and think about it... perhaps this happened at an age when I could have taken the wrong path, if I had been healthy. During my adolescence we were all alone, because my dad had to go to work. (Patient 3: David, Male, 33)
		Possession	It's because of something bad you have, something bad that's invading you. (...) It expresses very similarly [to possession] (...) It looks alike, in how the body moves, how it reacts, it's very similar (...) When I saw one [exorcism] I was surprised how similar it was. (Patient 9: Estela, Female, 24)
		A course	I heard something in my family. That someone has put a curse to my dad... to my mom. And all that came to me. That's what I think. (Patient 13: Lorena, Female, 25)
		"Susto"	A dog scared me. It scared me a lot, and then they started [the seizures]. I almost die there, they took me practically dead (...) I lost something, I don't know (Patient 6: Alberto, Male, 33)
		Evil eye	It's like they make you an evil eye. And it might affect you, to a relative, or your business. (Patient 3: David, Male, 33)
D. BELIEFS ABOUT OTHER PEOPLE PERCEIVE THEM			
D.1. Prejudice	D.1.1. Lazy (3)	Once, I was standing in the front of my house when a neighbour passed by. 'You're lucky', he said with irony, 'you're at home all day.' I got really mad. I insulted him. It came from my guts, all my anger. So, I said to him 'stay away. I can't work because of this [my seizures]', and I tried to explain him. So he apologized: 'I'm sorry, I didn't know.' People talk without knowing... (Patient 11: Mariano, Male, 36)	
	D.1.2. Mental illness (3)	They saw I had seizures. And the kids who saw me, the day after ran away from me: 'Here comes the crazy lady', they said. (Patient 17: Lidia, Female, 24)	
D.2. Responsibility (8)	The thing is, I think of my daughters and I don't like them to see me like this. I think of them, in my family, in my whole family. Because I know I'm not the only one who suffers, but... in fact, I think my family suffers more than me. (Patient 11: Mariano, Male, 36)		
D.3. Overprotection (8)	My mom says to me 'you have to have someone [near] to [help you] with your medication. Because if you have a seizure in the water you may drown'. My mom is... I mean, most women are like her. She's a lifesaver (...) [She insists]: 'did you take your medication?' 'Yes, mom.' She annoys me. (Patient 15: Nicolás, Male, 28)		
D.4. Revealing (9)	What happened to me is that when I was younger I didn't want to talk about my illness. But then I realized that it was worse. I had to talk about it with other people because they suffered too. They might get frightened, and so they react wrongly. I hurt people, I kicked them because they didn't know what to do (Patient 1: Sofia, Female, 26) If you were a friend of mine and we were going out, before we go out I'd say: 'Look, I have this thing. If anything happens, I have this card in my purse with this telephone number. That's my mom's.' I'd let you know, just in case. (Patient 9: Estela, Female, 24)		
D.5. Support (14)	My family was always like this. We get along with each other. We visit each other. We take care of each other (...) Yes, they always talk to me and help me. For example, if I'm tired, they understand. They do the stuff. My brother and my husband, too. (Patient 8: Daiana, Female, 24) I'm always with my family. I'm ok. And I always had support from the fire station, from my family. (Patient 14: Federico, Male, 27)		
E. SELF-PERCEPTION			
E.1. Accepting illness (9)		When they told me, I tried to be calm. Some people get nervous, I did not. (...) I would like not to have it, see? But, as I told you, I have to face it. (Patient 14: Federico, Male, 27) I don't know whether I was already aware or not. My parents told me what I had, and I am aware of it since then. It's not like cancer, that they don't tell you anything and you don't know what it is. They were straightforward and they said 'you have this.' (Patient 15: Nicolás, Male, 28)	

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Table 3 (continued)

Theme	Subtheme (Freq*)	Typical statement
E.2. Differences with others (9)		I couldn't go out dancing, I wasn't like my schoolmates. They all were beautiful, with beautiful bodies; I was like a stick, horrible. I was living under medication and sleepy. I didn't have the life of a teenager, as everyone does. That means I was always at home. (Patient 10: Claudia, Female, 37) [One of my brothers] throws in my face that he has a girlfriend and I do not (...). He says 'it's because you don't look for it', and I tell him 'you should be in my shoes, I exchange my illness for your health, and then we'll see if you could stand a week with this. Not being able to do this or that'... (Patient 15: Nicolás, Male, 28)
E.3. Social expectations (5)		Policemen are healthy people. That's what happened to me, I was not. That changed a lot. (Patient 2: Juan, Male, 50) I met some friends to do homework (...) We were starting to know each other... so one of the girls says to me 'how many children do you have?' 'I don't have children', I said. 'Oh, sorry', she said. I told her that it was alright, but... (Patient 4: Noemí, Female, 35) I don't know. It's complicated. They offer job positions I can't take because I can't use the shovel and I can't make any physical efforts. I get angry for that. I always worked, since I was a kid; I left high school so I could work and have my own money, and to help my parents too. My parents always worked, always (...) I feel useless for not being able to work, this is how I feel. (Patient 11: Mariano, Male, 36)
E.4. Autonomy (7)		... I lived in a bubble all my life. I was not able to move on my own. I can't go out because I depend on other people's disposition, not on myself. I can't go where I want. (Patient 15: Nicolás, Male, 28)
E.5. Future (4)		I want to taste the juice of life. That's why I want to heal. Now, I don't know, but I want to be ok. Anyway, I will go to the capital city, so I can progress. I would like to go on with my life. With or without seizures, I will go to the city. So, I can go on and do my best. (Patient 3: David, Male, 33)
F. IMPACT ON ACTIVITIES		
F.1. Restrictions	F.1.1. Work (10)	They were going to help me to have a job, see. And I couldn't, because they found out I had this illness. (Patient 3: David, Male, 37) They said that there was no problem, that I could stay because they were satisfied with my work. So I stayed. But after that I started to have problems with my supervisor. (Patient 7: Andrés, Male, 22)
	F.1.2. Study (9)	Then, when I was in primary school, in second grade, they said I had to go to another school because I didn't have high grades, because I was distracted... (Patient 19: Lucas, Male, 34)
	F.1.3. Other activities (14)	[The doctor] forbid me from riding bikes, motorcycles, climbing stairs, going out dancing (...) I couldn't go out dancing. I could watch TV a little, three hours the most. If I was feeling bad, I couldn't watch. I couldn't eat sweets. I had to be on a diet. (Patient 4: Noemí, Female, 35)
F.2. A life with seizures	F.2.1. Time regulation (5)	a. Medication: I have it all set up. I take ten pills a day, so I take four of them in the morning. So, I have a pillbox and I put them in place. And every time I say 'oh, it's time', and I take them. It is annoying (...) to be watching the clock all the time, to see what time it is. Because I don't have to be late. And I have to be careful with what I eat, what I drink, what I do. (Patient 9: Estela, Female, 24) b. Seizures: Sometimes, when I'm ok, we play [with my son]. When I'm ok, I check [in my notebook] if there is any chance I have a seizure, so we can go out. (Patient 17, Lidia, Female, 24)
	F.2.2. Space regulation (2)	They had to take the bathtub out of my house because I had so many seizures... They took out the bidet too. Because I hurt myself so badly, here in the back of my head. (Patient 10: Claudia, Female, 37)

Freq: Frequency of patients who referred to each subtheme.

3.1.2. Interactions with the health system

Another frequently mentioned topic concerned interactions with the Argentine health system. Everyone in Argentina, including immigrants and the unemployed, has access to a complete public health system, although specialist care assistance is not immediate and the system is underfunded (B.1.1). In addition to universal health care, employed people and their families have access to "obras sociales", a health system subsidized by taxes that theoretically has easier access to caregivers (B.1.2). The unemployed and people who work off the books, including 14 people in this sample, do not have access to this care. In addition to universal health care and "obras sociales", private health insurance is also available, although it is expensive. No one in this sample had private health insurance, but some paid out of pocket to see specialists in private practice (B.1.3).

Many patients received a monthly stipend and reduced costs for medications as part of a program for patients with chronic illnesses and disabilities in Argentina, similar to a disability allowance in other nations. Some patients reported difficulties in accessing these benefits (B.1.4).

Most of them reported how difficult it was to work through the system to find a specialist to identify and treat their illness (B.2.1). Because of this, eleven patients in our sample had travelled from neighbouring countries or different provinces to receive care in Buenos Aires (B.2.2).

Communication issues with providers were mentioned by several patients (B.2.3). One patient, Mariano, said that his neurologist's clear explanation helped him to understand better what was happening to

him. In contrast, David stated that he did not understand his condition and that his doctor seemed to have neither the patience nor the intention to explain it. This made him feel frustrated and bewildered.

Interestingly, many patients reported that they also had sought care for their illness outside the conventional medical system (B.3). For example, a patient from Bolivia, Lidia, was taken by her mother to see more than fifteen traditional healers. She was diagnosed with "susto", a condition in that cultural context that suggests that the patient had endured a major "fright" (literal translation of "susto") and consequently lost her soul. The seizures were considered to be a consequence of such loss. Treatments with these specialists included consuming herbs, applying ointments, or performing rituals invoking deities or the soul of the patient. Three patients consulted with traditional healers before entering the conventional medical system. Most patients said that they did not believe in these traditional healers; if they had sought care from such a healer, they would have done so at the request of a family member.

3.1.3. Beliefs about the illness

Patients expressed a range of beliefs and emotions about their illness. Two of them said that epilepsy is "just an illness", a condition for which it was necessary only to take medication (C.1.1). Another patient said it was a defect to have epilepsy and felt ashamed. (C.1.2). Four patients believed it was unfair that they had this burden and felt angry (C.1.3). Noemí, for example, destroyed all her medical records, out of anger.

Patients had different hypotheses about the origin of their illness.

Many had a biological explanatory model (C.2.1), and believed that epilepsy was caused by birth trauma, a punch to the head, or something hormonal. Others believed their seizures had a psychological origin (C.2.2), due to childhood trauma or “*nervios*”, a local expression used to describe stress. Others related supernatural aspects to its causes (C.2.3). David said that his illness was a sign from God, protecting him from taking the wrong path in life. If he had not had epilepsy, he would have become a criminal, in his opinion. Estela thought she might have been possessed by an evil spirit. She did not understand the difference between her situation and someone who is possessed, because both situations were apparently the same. Lorena said that epilepsy was due to a curse put on her family by someone who was jealous. Other patients also referred to the loss of their soul due to intense fear –“*susto*”– or to the evil eye as possible explanations for the seizures onset.

3.1.4. Beliefs about how other people perceive them

Some patients believed that other people were prejudiced against them (D.1.). For example, Mariano said his neighbour called him “lazy” because he was not working; Lidia said that children called her “crazy”. Patients believed they were a burden to the people around them (D.2), and some tried to reduce it. Many said their caregivers were over-protective (D.3), which led to a sense of dependency.

One recurrent theme involved whether to reveal their illness to others, particularly in social situations. Patients said they might decide to disclose their illness to minimise risky situations or to improve their care (D.4). Most subjects mentioned the importance of the support they received from their family and friends, both in terms of emotional support and concrete help in navigating the medical system (D.5).

3.1.5. Self-perception

Patients said they had to work hard to come to terms with and accept their illness (E.1). Accepting epilepsy as an illness influenced their decisions regarding disclosure to others and participation in activities. Many subjects said their illness gave them a sense of being different from others (E.2). Several mentioned that they were not living up to social expectations due to their illness (E.3). Some reported not feeling comfortable with their life achievements; for example, Noemí said that she feared she could not marry and have children; Juan said that he could not continue being a policeman, because officers are supposed to be healthy. Mariano said he was not living up to what is expected from him, since he cannot economically support his family. Many worried about their lack of independence and autonomy, and complained about not being able to take care of themselves (E.4). However, not all beliefs about the future were negative (E.5). David was hopeful about a cure for his illness: He looked forward to enjoying the “juice of life” and moving to a bigger city to have more opportunities.

3.1.6. Impact of the illness on their activities

Most of the subjects in this sample said they felt restricted in terms of work (F.1.1) and school (F.1.2). In fact, more than half had not completed secondary school, a requirement for many jobs, and reported difficulties in finding and maintaining employment. This impacted on their economic level and sense of autonomy. Patients also reported other restrictions, such as not being able to go swimming, ride a bike or go out with friends (F.1.3).

Seven patients said they had to organise their lives because of seizures (F.2). Interestingly, some monitored their seizure frequency and made decisions about daily activities based on the likelihood that they would have a seizure (F.2.1). Lidia, for example, said that she realized she had not had a seizure for some days, so she would not go out alone with her infant because it was likely that she would have a seizure that day.

4. Discussion

The goal of the present paper was to get patients’ perspectives about epilepsy and the impact the illness has had on their lives. It is the first qualitative study carried out in Argentina on this topic. Besides, there are few studies on patients’ perspectives about epilepsy with DRE worldwide. In this study, cultural and contextual variables -explanatory models, health-seeking behaviours- emerged and enriched the analysis.

Perhaps expectedly, many themes derived from the patients’ interviews mapped onto the categories in the conceptual model developed by Kerr and colleagues [7]. For example, patients in Argentina also said that being a burden to others implies suffering for both the patient and others [28,29]. They reported cognitive impairments, such as difficulties with memory and concentration, which prevented them from carrying out daily activities and generated interpersonal difficulties. Cognitive problems are frequent in PWE [30] and have a great impact on their quality of life. Nevertheless, there are few specific interventions on cognitive failure for these patients [31].

Also coincidentally with other studies [32,33], some patients had positive expectations regarding their future. However, these expectations could clash with difficulties in accomplishing social expectations, such as fulfilling certain jobs or roles, and having a partner or children [34]. This can lead to a sense of losing autonomy, since patients perceive that their possibilities of acting freely are reduced [7,35]. These aspects might be related to the high rates of depression reported in patients with epilepsy [36], including those with DRE [37]. This is important for developing specific psychosocial interventions for this population, which are scarce in Argentina.

Many patients in Argentina also reported internal and external barriers, perceived as restrictions in daily activities and as difficulties for getting and maintaining jobs. In Argentina this aspect should be moderated by the possibility of obtaining a disability pension. However, some patients reported difficulties in getting a disability certificate, a condition to obtain such pension. Besides, this benefit corresponds to natives or people with permanent residency in Argentina, so migrants, like some of the patients in this sample, would be left out. Moreover, foreigners may perceive other barriers, such as migration due to health reasons and cultural distance towards doctors. Since public health in Argentina is open to everyone who needs it, it is essential for health professionals to be aware of their patients’ social realities and cultural variability.

Another aspect coincidental with Kerr’s review is medication issues, both in terms of the difficulties in complying with the medication plan [28] and the side effects [38]. Patients also related the aforementioned issues to financial burden. Besides, they reported physical, cognitive and emotional consequences directly and indirectly related to seizures [39], such as drowsiness, headaches, memory loss, burns and emotional reactions (acceptance, discomfort or anger), especially linked to their beliefs about epilepsy.

Moderating factors were also identified. Most patients emphasized that relatives, friends and physicians offered both moral and practical support. Many considered the health care system of Argentina superior to those of neighbouring countries. In addition, when doctors explained to them their condition clearly, the patients had a better understanding of it and a clearer idea of how to care for themselves. Conversely, patients were dissatisfied with doctors who did not appear to listen to their concerns or who did not give them a clear explanation about their illness. Other studies also have highlighted the impact of doctor-patient communication on the life of patients with epilepsy [40–42], and that this could be improved with training and cultural competency.

Other topics had minor differences with those in Kerr’s review. For instance, educational qualifications, reported mainly by children and adolescents [43], also emerged in this sample where only adult patients

were interviewed. Epidemiological studies assert that PWE have lower educational qualifications than people without epilepsy [44], so this was expected to be a significant aspect, even in adult population.

Patients claimed to be treated differently from others due to their epileptic seizures. They also experienced prejudice and had difficulties in complying with social expectations. Unlike what was reported in other qualitative research [29,32,45], patients in Argentina did not expressly say that their illness was a stigma. Stigma theory in epilepsy is controversial, and was criticised by medical anthropologists, given the passivity it ascribes to patients [46,47].

While losing control was a significant aspect in other studies [5,39], this was not explicitly reported in Argentina's sample, perhaps due to its characteristics. Our population had a chronic refractory condition, whereas Velissaris' research was oriented towards newly diagnosed patients. Adjustment to illness might be a difference between newly and drug-resistant patients with epilepsy. Although the actual number of seizures might not be a major issue for patients, learning how to live a life with seizures might be [45]. Emphasizing how to organize one's life around unpredictable seizures may prove to be useful for psychosocial interventions [48,49].

Also, it would be interesting to analyse whether categories such as medication issues, external barriers and loss of control would be relevant in the same way for patients with well-controlled epilepsy in Argentina.

Driving was not a relevant issue in our population. Patients did not mention feeling restricted by not being able to drive, in comparison with more developed nations [32,38,50], either because they can rely on public transportation or because they cannot afford a car.

In relation to the impact of conventional and traditional health care systems, almost half of the patients of our study had gone to healers before entering the conventional health system. Similarly, in Pakistan, Rhodes et al. [51] showed that many patients sought conventional medical care because traditional treatments were ineffective. Other patients may visit traditional healers instead of seeking conventional care for epilepsy. Medical professionals –especially those treating chronic conditions– need to know about the use of traditional medicines, since their preparations could interact with conventional medications [11]. Since traditional healers are more accessible than specialised epilepsy care in certain contexts, treatment by traditional medicine might be associated with delays in starting biomedical treatments [52].

Also, patients' illness attributions were complex, interweaving in many cases biological, psychological, and supernatural aspects. Biological explanatory models were expected in this population, since they had been receiving care in conventional hospitals for several years. In addition, psychological explanations about epilepsy were common, which is consistent with other studies [6,53] and with the cultural acceptance of psychological interventions in Argentina [54,55]. Patients also reported supernatural causes for their epilepsy: a sign from God, the consequence of the loss of their soul, or the result of a curse from people close to them. These beliefs, and patients' decisions to seek care from traditional healers, suggest that for these patients, epilepsy is not just a neurological disease, but has to be seen in a cultural context [47]. Patients' attributions, beliefs and emotional responses to their conception of their illness may differ significantly from those of the specialists who treat them, and lead to misunderstandings. Being attentive to these differences might improve therapeutic alliance and improve care [56–59]. Further research must be done about explanatory models in this population, since it might be affecting health-care and their lives.

Differences in patients' belief systems about their illness appeared to contribute to their subsequent emotional and behavioural responses. In many patients, emotional responses differed according to their illness perceptions: those who thought that having epilepsy was something unfair felt ashamed or angry; those who believed that God was teaching them a lesson had positive responses. Consequently, these beliefs might impact on their self-perception, social expectations and self-esteem.

Shallcross (2015) noted that illness perceptions are an important link between depression and quality of life in PWE. These beliefs are apparently related to a local context that might differ from the one in developed nations, so investigating this may enhance future studies of similar topics.

5. Limitations

The sample size, while small, is consistent with other works with similar methodology [35,38,60].

Efforts were made to minimize biases in data analysis through peer debriefing and discussion regarding the original materials [61]. Future research should also consider additional steps, such as member-checking [62], to see if our interpretations coincide with their intentions.

The hospital context may affect the result of the interviews, interfering with the patients' openness to discuss beliefs about their illness, particularly with traditional explanations. Farmer [63] found that, in Ecuador, many PWE who sought care from traditional healers, did not disclose this to doctors. In our study, all the patients who reported having consulted traditional healers said they did not believe in them and had done so at the recommendation of an acquaintance. In a previous study, patients with non-epileptic seizures were also reluctant to share this information with the research team [64]. In another setting, these reports might have been different.

We did not consider the differences among types of epilepsy or psychopathological aspects. Also, the IQ standards might be broader, in order to include more subjects. In future studies, patients could be grouped according to seizure characteristics, localization of the epileptogenic zone or psychiatric comorbidities.

6. Conclusion

This paper offers information about Argentinian patients' perspectives on the impact of epilepsy. We relied mostly on the conceptual model proposed by Kerr et al. in their review of this topic in first world nations.

Our results suggest that many topics highlighted in other studies coincide with those mentioned as relevant in Argentina, such as illness characteristics, views of others and self-perception. Additional topics were also significant, such as the role of traditional healing in health-seeking behaviour and explanatory models of the illness. The use of traditional, non-conventional medicines is frequent, a fact that should be acknowledged by the conventional medical system to improve the doctor-patient relationship. Training in cultural issues should be recommended to conventional doctors. In addition, patients' explanatory models included biomedical, psychosocial, religious and folk beliefs, consistent with their health-seeking behaviours. These cultural beliefs about illness impact on how patients deal with their illness in practical terms and how they respond emotionally. In a multicultural context, it is important to understand these complex perspectives to develop appropriate psychosocial interventions.

Conflict of interests

We declare there are no conflict of interests.

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