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The individual with epilepsy: perceptions about the disease and implications on quality of life

A pessoa com epilepsia: percepções acerca da doença e implicações na qualidade de vida

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Keywords

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Knowledge
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ABSTRACT

Purpose: The present study aims to analyze the perceptions of individuals with epilepsy about the disease and its impact in their quality of life (QoL). **Methods**: This is a cross-sectional, qualitative and quantitative study conducted in a tertiary referral hospital associated with the Brazilian National Health System (SUS). Data were collected from 30 individuals with diagnosis of refractory temporal lobe epilepsy (RTLE). The study participants responded to a questionnaire to collect sociodemographic and clinical data, as well as their perceptions about the disease. QoL was assessed by the Subjective Handicap of Epilepsy (SHE) and the Stigma Scale of Epilepsy (SSE). **Results**: Significant correlation was found between stigma and quality of life and the work and activity and social and personal life domains, as well as between stigma and perceptions about epilepsy. The responses provided by the participants were organized into four categories: definitions and causes, seizures and treatment, family and social impacts, and impact on individuals' lives. **Conclusion**: The results show that participants have limited knowledge about epilepsy and that there is a negative impact caused by the stigma related to this disease on their QoL. It was possible to verify that QoL and stigma are directly related to the understanding of participants about epilepsy. Therefore, it is important to implement programs and actions that aim to provide patients and their families with more comprehensive knowledge about epilepsy; promote communication between health professionals and patients; and encourage the participation of patients and their families during treatment.

Descritores

Epilepsia
Conhecimento
Empoderamento
Qualidade de Vida
Estigma Social

RESUMO

Objetivo: Analisar percepções de pessoas com epilepsia acerca da doença e seu impacto na qualidade de vida. **Método**: Trata-se de um estudo qualitativo e quantitativo de corte transversal realizado em hospital de referência terciária, vinculado ao Sistema Único de Saúde. Participaram do estudo 30 pessoas com o diagnóstico de epilepsia de lobo temporal refratária. Foi aplicado questionário para a coleta dos dados sociodemográficos e clínicos, bem como das percepções acerca da doença. Avaliou-se a qualidade de vida por meio do *Subjective Handicap of Epilepsy*e e o estigma pela Escala Estigma na Epilepsia. **Resultados**: Foi encontrada significância na relação entre estigma e qualidade de vida com os domínios trabalho e social/pessoal, entre estigma e percepções sobre a epilepsia. As respostas fornecidas pelos participantes foram organizadas em quatro categorias: definições e causas; crises e tratamento; impacto familiar e social; impacto na vida das pessoas. **Conclusão**: Evidenciou-se o predomínio do conhecimento restrito dos participantes acerca da epilepsia e o impacto negativo que o estigma relacionado a tal doença acarreta na qualidade de vida. Pode-se verificar que a qualidade de vida e o estigma estão diretamente relacionados ao conhecimento dos participantes sobre a epilepsia. Ressalta-se a necessidade do implemento de programas e ações que objetivem: proporcionar maior conhecimento sobre a epilepsia por parte do paciente e de seus familiares; favorecer a comunicação entre os profissionais de saúde e as PCEs; promover a participação do paciente e de seus familiares na gestão do tratamento.

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INTRODUCTION

Research shows that individuals with epilepsy - the most serious chronic neurological disease with the highest incidence globally(1) - must face not only problems and limitations arising from the organic factors of this disease, but also stigma and prejudice, which can lead to social isolation(1,2).

Approximately 30% of epilepsy patients are refractory to drug treatment, which leads to occurrence of seizures with greater frequency and less predictability. It is worth mentioning that this fact, in addition to momentarily increase loss of control, it makes these individuals more susceptible to falls and the occurrence of injuries, which can compromise their autonomy and, therefore, generate greater dependence on the care from others(1-3).

It should be noted that the impact of epilepsy is not only determined by the clinical aspects of the disease and the frequency and severity of seizures, but also by psychological and social factors, as well as by the perception of epileptic individuals (EI) and their families about the implications of epilepsy in their lives(4).

Different problems associated with epilepsy, such as psychosocial factors, low self-esteem, and limitations to daily life activities are related to individual/personal aspects of EIs, as well as to the social and cultural context in which they are inserted. In this sense, for a broader understanding of the conditions of life, and specially of health, presented by such individuals, it is fundamental to consider aspects related to educational attainment, working conditions, social and family contexts, psychological factors, and knowledge about the disease and its impacts on their lives(4).

Reiterating this understanding, a study conducted with EIs stresses that they need to be heard about their life histories and the course of their disease, considering that these trajectories are unique. It is necessary to learn about the life conditions of EIs, as well as about how they perceive epilepsy, the difficulties imposed by it, and how they react to them(5). With respect to the importance of knowledge and understanding of EIs about their health/disease processes, the study emphasizes that, in order to cope with the limits and conflicts related to epilepsy, it is essential to implement actions that contribute to the expansion of knowledge and, consequently, empowerment of this population(5).

In this direction, there is growing interest on the part of researchers regarding the knowledge of EIs about their condition. It is noteworthy that, in spite of the advances in medicine that improve the functional aspects of the disease, such as seizure management, EIs continue to face obstacles and prejudice that compromise their social participation and, therefore, their material and subjective living conditions(6).

It should also be noted that studies disseminate the idea that patients who are better informed about their disease can more easily acquire important information to properly follow treatment with medication and, consequently, achieve a better control of the disease(7).

Temporal lobe epilepsy (TLE), which corresponds to approximately 40% of the cases of epilepsy and 60% of those of focal epilepsy, is the most frequent type of this disease in adults and the most refractory to antiepileptic drugs (AED). Complete control of seizures with clinical treatment occurs in less than 50% of these cases(8).

Tumors, cortical dysplasias, vascular malformations, hippocampal sclerosis, and traumas are among the underlying etiologies of TLE. Individuals with TLE are at higher risk of premature death, are more susceptible to falls and injuries, and tend to present psychosocial problems and reduced quality of life (QoL)(9).

In order to analyze the QoL of EIs, multidisciplinary teams should assess the impact that clinical manifestations of this disease have on these individuals' lives. It is worth emphasizing that perceptions on QoL formulated by this population are influenced by social and cultural determinants, beyond the aspects directly related to organic manifestations of the disease(10).

A study indicates the need for communication about the diagnosis of epilepsy, conducted predominantly by physicians, to be conducted in a way that EIs and their families have access to information about the disease, without reproducing prejudice and stigmata, which are historically associated with it(11).

Other studies analyzing epilepsy-related prejudice and stigmata report that seizure unpredictability and the loss of control caused by it tend to expose EIs to awkward situations, considering that during post-seizure, after regaining consciousness, they may encounter negative and prejudiced reactions from the part of those who have witnessed it. It should be stressed that such reactions may be associated with the fact that EIs try to hide their disease from relatives, partners, and workmates(10,11).

It is quite common for EIs to isolate themselves in an attempt to avoid further exposure, which can lead to a state of permanent psychic suffering and serious social consequences such as loss of friends and companions, absence or withdrawal from school, or loss of employment(11,12).

Social stigma is identified as an important aspect to be addressed during treatment of EIs. The feelings of devaluation, shame, and fear experienced by such individuals, arrising from negative views about epilepsy, can result in social isolation, which in turn reinforces the prejudice historically built around the disease(12).

In this context, studies report that, for a significant group of EIs, the stigma is the most difficult problem to be faced, even when compared with the clinical implications of the disease. This fact allows us to understand the reasons that lead epilepsy support groups to define, as one of their main objectives, the reduction of the social stigma associated with the disease(13).

In order for EIs to be able to cope more adequately with the adversities faced in their daily lives, it is necessary that they have access to comprehensive care, which presupposes evaluations, analyses, and interventions that focus on the various aspects involved with epilepsy(5).

Based on the considerations previously made, the objective of this study is to analyze the perceptions of individuals with epilepsy about the disease and its impact on their QoL.

METHODS

The present study was approved by the Human Research Ethics Committee of the aforementioned Institution under protocol number CAAE: 18218413.9.0000.0096. All participants signed an Informed Consent Form (ICF) prior to study commencement.

This is a cross-sectional, qualitative and quantitative study conducted at the outpatient clinic of the Integrated Epilepsy Care Program of a tertiary referral hospital associated with the Brazilian National Health System (SUS). The study sample was composed of 30 individuals selected between September and December 2013 in the outpatient clinic of the aforementioned Program.

The inclusion criteria established for the selection of participants were as follows: individuals diagnosed with temporal lobe epilepsy (TLE), refractory to pharmacological treatment; individuals over eighteen years of age with at least two years of educational attainment. Exclusion criteria comprised individuals with evidence of psychopathology or severe comorbidities.

Three instruments were used for data collection.

The first tool was a questionnaire, prepared by the researchers, composed of questions regarding the following aspects: participants' identification (name, age, educational attainment, occupation, and marital status), clinical condition (onset, duration and type of epilepsy; frequency and severity of seizures; medication), and knowledge and perception about the disease and its implications on quality of life (QoL). The questionnaire was applied to the study participants by means of individual interviews that last approximately one and a half hours. Participants' oral responses were recorded in audio and later transcribed in their entirety. After comprehensive reading of the transcribed material, excerpts of the responses were selected considering relevance criteria and the contents that appeared with greater recurrence. The results were analyzed according to four categories: definitions and causes of epilepsy, seizures and treatment, family and social impacts, and impact on EIs' QoL.

The second instrument was the Subjective Handicap of Epilepsy (SHE) validated for Brazil(14), which was used to assess the QoL of EIs. This scale contains 32 items divided into six domains (subscales): work and activity, social and personal life, physical, self-perception (feelings about oneself), life satisfaction, and change.

The third tool was the Stigma Scale of Epilepsy (SSE) developed and validated in Brazil(15), which was adopted to analyze the aspects regarding perception of stigma related to epilepsy in different contexts: family, society in general, school environment, and health.

Mean and standard deviation were considered to statistically describe the quantitative variables, whereas frequencies and percentages were considered to summarize the qualitative variables. The Mann-Whitney nonparametric test was used for comparing the quantitative variables for two classes, whereas the Kruskal-Wallis nonparametric test was applied to compare variables for more than two classes.

Values of $p<0.05$ indicated statistical significance. In the subsequent analyses, for comparisons involving two classes, we tested the null hypothesis of equal results in the two classes compared with the alternative hypothesis of different results. For comparisons involving more than two classes, we tested the null hypothesis of equal results in all classes compared with the alternative hypothesis of at least one class with results different from the others.

The qualitative data of this study were organized according to content analysis. Content analysis consists in discovering the nuclei of meaning that comprise communication, whose presence or frequency present some meaning for the analytic object targeted. It is divided into three phases: ordering, classification, and final analysis of emerging categories(16).

RESULTS

The sociodemographic and clinical results show that the participants' ages ranged from 19 to 58 years (mean of 44.8 years); disease duration varied between 18 and 54 years (mean of 41.7 years); and monthly frequency of seizures ranged from 1 to 9 seizures per month (mean of 4.4 seizures/month). Regarding gender, predominance of women was observed (56.7%) (n= 17). With respect to marital status, 63.3% (n=19) of the participants were married. Concerning educational attainment, 50.0% (n= 15) of the interviewees did not complete Elementary School. As for monthly income, 56.7% (n=17) of the participants had family monthly income below the minimum wage at the time the study was conducted (R$ 724.00), and only 17.2% (n=5) of them were formally employed.

In the analysis of the quantitative data, significant correlation was observed for the results of quality of life (QoL) and stigma: between stigma and the work and activity domain of the Subjective Handicap of Epilepsy (SHE) (p=0.015); between stigma and the social and personal domain of the SHE (p=0.030), as shown in Table 1.

In the comparison between QoL and sociodemographic and clinical data, no significant correlation was found between the domains of the SHE and age, disease duration, and monthly frequency of seizures.

Table 1. Correlation between the variables stigma, age, disease duration (in years), monthly frequency of seizures, and the six domains of the Subjective Handicap of Epilepsy (work and activity, physical, feelings about oneself, life satisfaction, change, and social and personal life) (n=30)

Variable	Correlation	p value
AGE	-0.23	0.221
DISEASE DURATION (in years)	-0.20	0.285
SEIZURE MONTHLY FREQUENCY	-0.25	0.183
QUALITY OF LIFE		
Work and activity	-0.44	0.015
Physical	-0.29	0.117
Feelings about oneself	0.15	0.434
Life satisfaction	0.00	0.986
Change	-0.08	0.655
Social and personal life	-0.40	0.030

Kruskal-Wallis nonparametric test; p<0.05

A trend towards difference (*p*=0.05 to 0.10) was observed between the domain work and activity of the SHE and Elementary School educational attainment (*p*=0.067), as described in Table 2.

A trend towards difference (*p*=0.05 to 0.10) was also found between the domain social and personal life of the SHE and gender (*p*=0.053), as shown in Table 3.

In the analysis of the qualitative data, significant correlation was observed between stigma and perceptions about epilepsy (*p*=0.014), as presented in Table 4. It should be noted that, in Table 4, the value of *n* differs between variables, considering that the participants opted for an alternative.

Also in the analysis of the qualitative data, significant correlation was found between the domain self-perception (feeling about oneself) of the (SHE) and perceptions about the definitions of epilepsy (*p*=0.065), as displayed in Table 5.

The responses provided by the study participants, based on the application of the questionnaire, were organized into four categories, as described ahead. It is worth emphasizing that the excerpts herein presented, referring to each of the categories, were selected considering those that presented contents that appeared with greater recurrence.

1 - Perceptions about epilepsy: definitions and causes

> *"They said something about it, but I forgot, I think it was pork worm"* (S 6).
>
> *"Well, the doctor from "Santa Casa" said it's a birthmark. And that when I get nervous, the scar grows and does something in my head, and then the dizziness begins"* (S 8).

Table 2. Correlation between the six domains of the Subjective Handicap of Epilepsy (SHE) and educational attainment (n=30)

Variable	Educational attainment	N	Mean	Standard deviation	P value
Work and activity	**Elementary school (Incomplete)**	15	23.3	12.0	0.067
	Elementary school (Complete)	5	21.8	9.4	
	High school (Complete)	10	43.7	25.6	
Physical	**Elementary school (Incomplete)**	15	23.3	22.0	0.305
	Elementary school (Complete)	5	28.7	25.6	
	High school (Complete)	10	38.7	25.6	
Feelings about oneself	**Elementary school (Incomplete)**	15	11.7	14.2	0.121
	Elementary school (Complete)	5	16.0	8.9	
	High school (Complete)	10	26.0	24.2	
Life satisfaction	**Elementary school (Incomplete)**	15	46.2	16.1	0.606
	Elementary school (Complete)	5	45.0	20.4	
	High school (Complete)	10	55.6	22.3	
Change	**Elementary school (Incomplete)**	15	57.6	18.5	0.403
	Elementary school (Complete)	5	44.2	17.4	
	High school (Complete)	10	56.7	22.4	
Social and personal life	**Elementary school (Incomplete)**	15	50.8	32.6	0.565
	Elementary school (Complete)	5	50.0	26.2	
	High school (Complete)	10	37.5	35.2	

Kruskal-Wallis nonparametric test; p<0.05

Table 3. Correlation between the six domains of the Subjective Handicap of Epilepsy (SHE) and gender (n=30)

Variable	Gender	n	Mean	Standard deviation	p(a) value
Work and activity	**Female**	**17**	**33.8**	**21.4**	**0.157**
	Male	**13**	**24.7**	**16.4**	
Physical	**Female**	**17**	**30.9**	**23.7**	**0.652**
	Male	**13**	**27.4**	**25.2**	
Feelings about oneself	**Female**	**17**	**17.9**	**21.3**	**0.591**
	Male	**13**	**16.2**	**14.2**	
Life satisfaction	**Female**	**17**	**47.8**	**16.8**	**0.742**
	Male	**13**	**50.9**	**22.1**	
Change	**Female**	**17**	**51.6**	**17.9**	**0.281**
	Male	**13**	**59.6**	**21.7**	
Social and personal life	**Female**	**17**	**55.9**	**26.7**	**0.053**
	Male	**13**	**33.6**	**35.2**	

(a) Mann-Whitney nonparametric test; p<0.05

Table 4. Correlation between the variables Stigma Scale of Epilepsy (SSE), the Subjective Handicap of Epilepsy (SHE) (domains: feelings about oneself, life satisfaction, and personal and social life), and perceptions about epilepsy

Variable	Perceptions about epilepsy	n	Mean	Standard deviation	p[a] value
STIGMA SCALE OF EPILEPSY	**Cause**	4	73.2	9.7	0.014
	effects*	3	49.5	2.9	
	medication/control of seizures*	2	80.5	13.7	
	Cure	4	51.7	14.2	
	does not respond*	3	63.8	1.4	
	has no doubts	14	50.1	10.9	
FEELINGS ABOUT ONESELF	**Cause**	4	20.0	30.3	0.955
	effects*	3	13.3	5.8	
	medication/control of seizures*	2	22.5	10.6	
	Cure	4	16.3	16.0	
	does not respond*	3	6.7	2.9	
	has no doubts	14	18.9	20.5	
LIFE SATISFACTION	**Cause**	4	48.4	21.9	0.791
	effects*	3	41.7	26.0	
	medication/control of seizures*	2	34.4	30.9	
	Cure	4	43.7	8.8	
	does not respond*	3	62.5	6.3	
	has no doubts	14	51.8	19.7	
SOCIAL AND PERSONAL LIFE	**Cause**	4	43.7	29.3	0.953
	effects*	3	52.1	29.6	
	medication/control of seizures*	2	25.0	35.4	
	Cure	4	45.3	30.3	
	does not respond*	3	52.1	34.4	
	has no doubts	14	47.8	37.3	

* Classifications not considered in the statistical test due to the small number of cases; [a] Kruskal-Wallis nonparametric test; $p<0.05$

Table 5. Correlation between the variables Stigma Scale of Epilepsy (SSE), Subjective Handicap of Epilepsy (SHE) (domains: feelings about oneself, life satisfaction, and personal and social life), and perceptions about epilepsy

Variable	Perceptions about epilepsy	n	Mean	Standard deviation	p[a] value
STIGMA SCALE OF EPILEPSY	**organic aspect**	7	54.1	13.6	0.896
	psychic aspect	7	54.9	10.8	
	Effect	9	53.3	10.7	
	spiritual*	2	88.9	1.9	
	does not know	5	56.1	15.2	
FEELINGS ABOUT ONESELF	**organic aspect**	7	28.6	21.5	0.065
	psychic aspect	7	11.4	15.5	
	Effect	9	14.4	11.8	
	spiritual*	2	40.0	35.4	
	does not know	5	5.0	5.0	
LIFE SATISFACTION	**organic aspect**	7	56.2	25.5	0.502
	psychic aspect	7	52.6	8.7	
	Effect	9	46.5	18.2	
	spiritual*	2	43.8	44.2	
	does not know	5	41.2	12.2	
SOCIAL AND PERSONAL LIFE	**organic aspect**	7	31.2	35.5	0.319
	psychic aspect	7	49.1	34.9	
	Effect	9	60.4	26.1	
	spiritual*	2	18.8	26.5	
	does not know	5	48.7	31.4	

* Classifications not considered in the statistical test due to the small number of cases; [a] Kruskal-Wallis nonparametric test; $p<0.05$

2 - Perceptions about epilepsy: seizures and treatment

> *"I know what I'm talking about! I ask and they explain it to me, I know a little about it"* (S 12).
>
> *"It depends on the professional that I'm consulting with, if we get along well, I have the urge to say what I'm feeling, if the doctor doesn't open space for that, it's like give me my prescription 'cause I'm out, just like that, I have to feel safe with the doctor I'm consulting with"* (S 20).
>
> *"I didn't feel comfortable with it, the appointment last a short time, the doctors talked more to each other, and I was in the middle, to tell you the truth, the doctor who was attending me spoke only with the other doctors, now and then he would ask me something, and I knew he had to ask the others about it. So, it was this quick thing, nonsense"* (S 2).

3 - Perceptions about epilepsy: family and social impact

> *"My mother speaks like that, be patient, you know she's got a problem, that's what she says"* (S 1).
>
> *"At home, they treat me well, but my other relatives treat me badly. My father and my brothers no longer care about me, they don't want to help me with the health treatment anymore"* (S 15).
>
> *"Sometimes I think I don't treat my family well, they treat us differently. It seems like I'm harming them"* (S 3).
>
> *"I can sense it. With some of them, yes. I notice that they get away from me. When they realize I've got it, they feel suspicious and get away from me"* (S 7).

4 - Perceptions about epilepsy: impact on the QoL of EIs

> *"I can sense it. With some of them, yes. I notice that they get away from me. When they realize I've got it, they feel suspicious and get away from me"* (S 7).
>
> *"Awful, it really messes my life up, and when I try to do something I can't, I've tried everything, it feels almost like I'm retarded. It bothers me a lot* [...]*"* (S 5).
>
> *"Nowadays, I can live with it, but I don't accept it. It's a very sad illness, I don't accept it, I've had a seizure in the street and nobody helped me, people run away, scared. I don't accept being chosen for this kind of thing"* (S 24).
>
> *"I have many dreams for my life, but when I remember this damned epilepsy, it's all over. And I know that if I try to get my driver's license I will have a seizure"* (S 5).

DISCUSSION

The results of this research demonstrated that the knowledge that epileptic individuals (EI) have about their disease is limited with regard to the aspects that characterize it, as well as about its treatment. This fact indicates the need for studies that analyze the effectiveness of communication and information shared between EIs and health professionals involved in the treatment.

Regarding what has been observed about the diagnosis of epilepsy and the knowledge and perceptions of EIs about the disease, it is worth noting that a significant number of individuals were not able to formulate answers about such aspects. Studies show that limited knowledge about epilepsy hinders the possibility of effective participation of EIs in their treatment and in the ways they cope with the various implications and difficulties resulting from the disease(4,5).

Another study points to the fact that EIs had no knowledge about the causes and treatment of epilepsy, in addition to showing that the higher the educational attainment, the more consistent the answers given by these individuals about these aspects(17). Thus it indicates that socioeconomic characteristics may reflect the level of knowledge of EIs about the disease.

When study participants were asked about how they felt during the appointments with the health professionals involved in their treatment, they presented different responses, such as having no problem; it depended on the professional who attended them; they felt partially at ease; they did not feel comfortable. A study conducted to assess the topics of satisfaction with care and epilepsy in adults and children, based on a literature review comprising 25 articles, evidences the importance of patient participation in the care of this disease. The study reports that considering the perspectives of EIs to define intervention may favor adherence to medical recommendations and improvement of seizure management(18).

Some studies have reported no significant statistical correlation between the variables attitude in face of a seizure and stigma. The unpredictability of seizures, the ineffective control, and the behavior during and after seizures can cause feelings of guilt, shame, and dependence, leading EIs to isolation(10,11).

As in other studies(13), the fear of having seizures has been described by the participants of this research as one of the worst implications of epilepsy. Such feelings can lead to low levels of self-esteem and self-confidence(5).

Concerning the attitude of the families in face of epilepsy, the participants of this study reported feeling protected; distancing and withdrawal of relatives; feeling as a burden to their family. In relation to this aspect, other studies(19,20) have presented results similar to those of this research. Aiming to analyze patient perceptions about epilepsy and family support and their correlation with QoL, such studies showed that participants believed that family members offered them understanding and compassion(19,20). The findings of these studies also revealed that EIs reported a constant feeling of being different, devalued, and a nuisance to their relatives(19,20).

It is possible to observe that EIs seek encouragement, acceptance, and support in the various personal relationships, especially within their families. Families capable of coping adequately with the implications of epilepsy tend to assist EIs in overcoming fear, isolation, and dependence, thus contributing to improve their QoL(21).

Most of the participants in this study reported a certain withdrawal with respect to friends. These results corroborate the findings of other studies(19,22) from which it was possible to verify that EIs present difficulties establishing interpersonal relationships and that epilepsy is seen negatively by the society. According to these studies, EIs reported having lost friends and having felt isolated and rejected by the community after a seizure(19,22).

It is also noteworthy that findings obtained in other studies(23), similarly to the ones found in this research, show that individuals with limited knowledge about epilepsy may be frightened by the physical manifestation of seizures, characteristic of epilepsy, which may contribute to the perpetuation of stigma.

Regarding the statistical significance between stigma and QoL in the work and activity and social and personal life domains, the findings of this study are similar to those of another research(24), considering that they indicate the fact that stigma and social situation directly influenced the QoL of EIs.

The study showed that even when EIs reported having appropriate relationships with their families, they claimed that they had withdrawn from their friends and suffered a drawback in their social lives. Problems related to the establishment of relationships by EIs have been associated with stigma and, therefore, with the prejudice that has historically accompanied these individuals(12).

In the present study, most participants were unemployed or on disability benefits. Similar data were found in other studies, which concluded that working conditions were one of the aspects in which EIs suffered the most losses(25, 26).

Evidencing the problems that EIs encounter in their working contexts, some studies have shown that 40% to 60% of participants had stable jobs, 15% to 20% were unemployed, and 20% were retired due to epilepsy. It is also verified that restrictions on labor activities may limit the participation of EIs in other social spheres(27,28).

Regarding the feelings of having epilepsy, the participants in this study mentioned revolt, anger, and embarrassment. These positions are in agreement with data collected from a study(29) conducted with EIs whose purpose was to evaluate the correlation between stigma and epilepsy. From that research, it was possible to verify that EIs reported feeling "very" or "totally" ashamed of having epilepsy and that they faced many difficulties in their daily life owing to the stigma associated with this disease. Another study(17) found that epilepsy is considered a shameful condition, which corroborates the findings of this research.

The results of this study also show that, for most of the interviewees, epilepsy generates dependence, limitations, and changes in emotional state. Similar findings were analyzed in another study(17), in which EIs confirmed that epilepsy causes restrictions in several activities of daily living.

Studies have repeatedly indicated that EIs claim to have difficulty maintaining normal living standards, because they have fewer opportunities to study, work, and establish social relations(22).

The impact of epilepsy on individuals' lives was also the object of study of authors(30) concerned with investigating the relationship between the limitations caused by the disease and the perception of QoL. In compliance with the findings of the present study, the most common complaints reported by participants in that previous study were difficulty in getting or even keeping a job, dependence on other individuals for social life, and difficulty in studying. The authors concluded that the limitations faced in the performance of daily life activities and, therefore, the restrictions of social inclusion have a negative impact on the QoL of EIs(30).

Difficulties with the working context have been referred as harmful to EIs, considering that keeping a job and being able to perform working activities do not exclusively meet a financial need, but are directly related to self-esteem, the feeling of belonging to a group, and the possibility of social interaction(30). It can be easily conceived that, from the standpoint of EIs, finding a job and remaining employed is a decisive factor in QoL.

However, even when employed, EIs may be victims of prejudice and/or embarrassing situations due to the lack of knowledge of their colleagues about the disease and the inability and fear of helping the epileptic colleague during a seizure(27,30).

The present study also showed that, for individuals with epilepsy, social and personal relationships are factors that negatively interfere in QoL, which in turn compromise the knowledge and self-perception of such individuals about their disease, which in general leads to isolation, family dependence, and low self-esteem. The domains social and personal life, self-perception (feeling about oneself), and change, which in the mentioned study showed lower scores, may lead EIs to family withdrawal and limited social life, as well as to restricted participation in their treatment and, therefore, in the relations established with the professionals in charge(9,10).

CONCLUSION

The results of this study show that participants have limited knowledge about epilepsy and that there is a negative impact caused by the stigma related to this disease on their QoL, especially with regard to working conditions and personal and social relationships. It was also possible to verify that QoL and stigma are directly related to the understanding of participants about epilepsy.

The results of this research and the analyses developed herein indicate the need to implement programs and actions that aim to provide patients and their families with more comprehensive knowledge about epilepsy; favor communication between health professionals and patients; and encourage the participation of patients and their families in treatment management.

To this end, it is worth mentioning the importance to conduct studies that offer elements for analysis of the various determinants involved in the quality of life of individuals with epilepsy and that, consequently, are committed to discussions about the aspects related to the stigmata and prejudice formulated around this disease.

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Author contributions

CDCH and APB participated in the study design, analysis and collection of the data, and discussion, editing and final revision of the manuscript; GM, MHW and RT participated in the discussion, editing and final revision of the manuscript.