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ARTICLE

The social context and the need of information from patients with epilepsy: evaluating a tertiary referral service

O contexto social e a necessidade de informações de pacientes com epilepsia: avaliando um serviço terciário de referência

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ABSTRACT

Objective: Characterize the social profile and the need of information from patients with refractory epilepsy. **Method:** A semi-structured questionnaire was applied to 103 patients to investigate sociodemographic aspects, pharmacotherapy and any doubts about epilepsy. **Results:** Patients were highly dependent on having a free and accessible supply of antiepileptic drugs. Sixty-eight percent of the population was unemployed, and 26% confirmed receiving social security benefits due to epilepsy. Twenty-nine percent of the population reached high school. Eighty-five percent of the patients had at least one doubt about epilepsy; treatment and epilepsy aspects in general were the main topics. **Conclusion:** As observed in developed countries, patients with refractory epilepsy from a developing country also have high rates of unemployment and low educational levels. The results raise a concern about the need of information about epilepsy by patients and their families, urging the necessity to invest in strategies to solve this deficiency in knowledge.

Keywords: epilepsy, social evaluation, information, outpatient service.

RESUMO

Objetivo: Caracterizar o perfil social e a necessidade de informações por parte de pacientes com epilepsia refratária. **Método:** Um questionário semi-estruturado foi aplicado a 103 pacientes para investigar aspectos sociodemográficos, farmacoterapia e quaisquer dúvidas sobre epilepsia. **Resultados:** Os pacientes mostraram-se altamente dependentes de um fornecimento gratuito e acessível de drogas antiepilépticas. Sessenta e oito por cento da população estava desempregada, e 26% confirmaram receber algum benefício social devido à epilepsia. Vinte e nove por cento da população alcançou ensino médio. Oitenta e cinco por cento dos pacientes tinha ao menos uma dúvida sobre epilepsia; tratamento e aspectos gerais da epilepsia foram os principais temas. **Conclusão:** Tal qual observado em países desenvolvidos, pacientes com epilepsia refratária em países em desenvolvimento também apresentam altas taxas de desemprego e baixos níveis educacionais. Os resultados são preocupantes no que diz respeito à necessidade de informações sobre epilepsia por parte dos pacientes e seus familiares, apontando a necessidade de se investir em estratégias que solucionem esta deficiência de conhecimento.

Palavras-chave: epilepsia, avaliação social, informação, serviço ambulatorial.

Epilepsy, a chronic disorder affecting 1% to 2% of the world population, is mainly characterized by the recurrence of epileptic seizures[1]. It has been observed, on few last decades, an increased concern from health care professionals towards other aspects related to the quality of life from patients with epilepsy that are not only the control of seizures recurrence[2,3,4,5]. Publications suggest that patients might be treated in a broader approach, giving importance to psychosocial

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aspects, satisfaction with the medical treatment and their necessity to obtain information about epilepsy from health care professionals[6,7].

Surveys conducted in different countries show that there are patients who do not know basic aspects related to the epilepsy and its treatment, and often have mistaken beliefs[8,9]. The patients' knowledge about their own medical condition is associated with a better physician-patient relationship, improved patients' ability to inform about their situation and better therapeutic compliance[10].

The present study aimed to characterize the social profile and evaluate the need of information from adult patients with refractory epilepsy attending a tertiary referral service in Brazil.

METHOD

The protocol was approved by the Ribeirao Preto Clinical Hospital's Ethics Committee and was performed in accordance with ethical standards. The sample evaluated was composed of outpatients ≥ 18 years old attending the refractory epilepsy clinic at the Ribeirao Preto Clinical Hospital, Brazil. In case of incapability to understand, the questionnaire was answered by the patient's responsible caregiver/accompanying family member. All subjects gave their informed consent prior to the inclusion in the study.

The semi-structured questionnaire was elaborated by the Brazilian Association for Epilepsy (Chapter: Ribeirao Preto) and applied to 103 patients (approximately 10% of all adult patients attending the refractory epilepsy clinic), randomly chosen, while waiting to the medical visit. Questions evaluated sociodemographic factors and aspects related to pharmacotherapy, so as patients' preferences regarding the health service level and if they knew the Brazilian Association for Epilepsy. If patients had doubts about epilepsy, questions could be specified in an open field at the end of the questionnaire. Complementary clinical data was obtained from medical records. The SPSS 17.0® software was used to verify for a possible relation between sociodemographic data and presence of doubts about epilepsy (Chi-square test, χ^2). Level of significance adopted: $p < 0.05$.

RESULTS

Patients and treatment

Ninety-eight patients answered the questionnaire. The demographic characteristics of the sample population are displayed in Table 1.

All patients were in regular treatment. The mean number of antiepileptic drugs (AEDs) per patient was 2.6 ± 0.7 (mean ± standard deviation, SD), ranging from one to four.

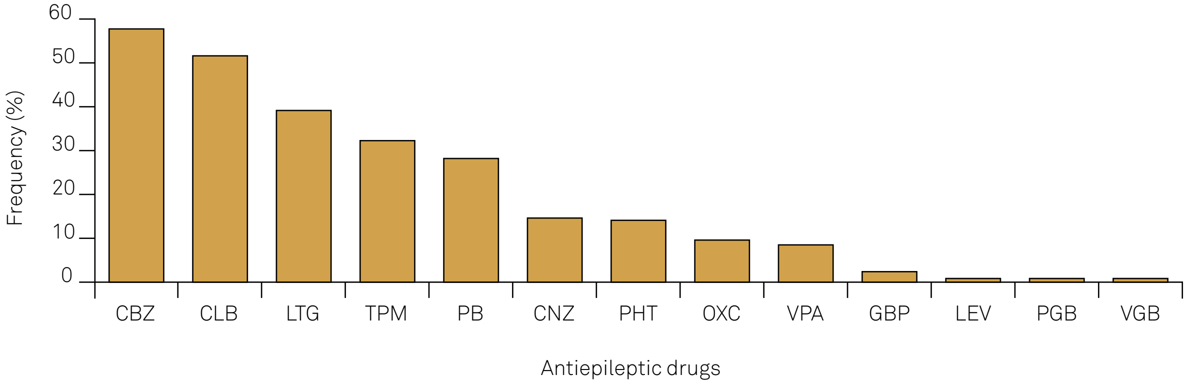
Table 1. Patients' clinical and demographic characteristics (n = 98).

Characteristics	Number of patients (%)
Sex	54 F (55); 44 M (45)
Age (years ± SD)	37.4 ± 10.5
Age at epilepsy onset (years ± SD)	12.6 ± 9.9
Epilepsy syndromes	
Localization-related epilepsies	93 (95)
Cryptogenic	13
Symptomatic	80
Generalized epilepsies	2 (2)
Idiopathic	1
Symptomatic	1
Undetermined whether focal or generalized	3 (3)
Seizure types[1]	
Complex partial	49 (50)
Simple partial	10 (10)
Secondarily generalized tonic-clonic	27 (27)
Absence	2 (2)
Tonic	7 (7)
Clonic	1 (1)
Myoclonic	1 (1)
Primarily generalized tonic-clonic	9 (9)
Atonic	2 (2)
Not classified	1 (1)
Comorbidities[2]	
Medical	20 (20)
Neurologic	10 (10)
Psychiatric	25 (25)

[1] The classification of seizure types does not consider seizure-free patients (5/98); some patients presented more than one seizure type. [2] Some patients had more than one comorbidity. F: Female; M: Male; SD: Standard deviation.

Carbamazepine (CBZ) was the most commonly prescribed AED (Figure). Of the second generation AEDs, lamotrigine (LTG) was the most common. At the time of data collecting, LTG, TPM, vigabatrin (VGB) and gabapentin (GBP) were the second generation AEDs provided free of costs by the Brazilian public health care system, in addition to the first generation CBZ, phenytoin (PHT), phenobarbital (PB) and valproic acid (VPA). Within the 71 patients in treatment with ≥ 1 second generation AED provided free of costs, 22 reported having difficulties to obtain their AEDs at the time of the interview (lack of medications at the health units). From the 82 patients in treatment with ≥ 1 first generation AED provided free of costs, 54 patients (66%) reported getting their AEDs in health units (free of costs), and 12 patients said they did not refer to the public health system to obtain their first generation AEDs. Sixteen patients did not answer to this question.

Regarding patients' preferences for sharing the medical care for epilepsy among different health services levels, approximately 27% of the patients confirmed receiving medical care with a neurologist both at the hospital and at another (primary or secondary) health care level.



CBZ: Carbamazepine; CLB: Clobazam; LTG: Lamotrigine; TPM: Topiramate; PB: Phenobarbital; CNZ: Clonazepam; PHT: Phenytoin; OXC: Oxcarbazepine; VPA: Valproic Acid; GBP: Gabapentin; LEV: Levetiracetam; PGB: Pregabalim; VGB: Vigabatrine

Figure. Frequency of AEDs utilization (n = 98).

Social aspects

The majority of the patients (68%) declared not to have a job at the time the study was conducted (Table 2). From these, only three individuals declared themselves as students. Regarding social security benefits such as pension or retirement, 26 patients (26%) confirmed receiving social security benefits due to epilepsy.

Table 2. Patients' social characteristics (n = 98).

Aspects	Number of patients (%)
Employment	
Employed	31 (32)
Unemployed	67 (68)
Social security benefits	
Retirement[1]	18 (18)
Pension	3 (3)
Disability benefit	8 (8)
Other	9 (9)
Marital status	
Single (never married)	44 (45)
Married	40 (41)
Divorced	7 (7)
Widowed	1 (1)
Common-law marriage	6 (6)
Education (years)	
0	5 (5)
1 to 4	22 (22)
5 to 8	28 (28)
9 to 11	29 (29)
> 11	3 (3)
Special school	11 (11)

[1] Retirement obtained due to epilepsy.

Doubts about epilepsy

The questionnaire had an open field so patients and/or caregivers could express any doubts they might have about epilepsy (Table 3). Only 15 patients declared having no doubts. No significant relationship was found between the presence or absence of doubts and the level of education ($\chi^2 = 8.8$; p = 0.1), sex ($\chi^2 = 2.5$; p = 0.1) and mean age ($F_{1;\,2.22} = 0.14$).

According to Table 3, the most frequently asked topics referred to: (1) treatment, with doubts about a possible cure and/or surgery as the most frequent; (2) epilepsy in general ("what is epilepsy?" and "what causes epilepsy?", for example); (3) employment and social security benefits, including what limitations epilepsy inputs over job activities and what are the procedures to obtain social security benefits; and (4) nonspecific epilepsy questions (all patients with such questions reported as having "doubts about everything").

Patients were asked if they knew the Brazilian Association for Epilepsy; 23 patients (23%) answered that they were aware of the organization.

DISCUSSION

Aspects related to social functioning are, in general, considered as highly relevant by patients with epilepsy and their family members[11]. Regardless of the sociodemographic context, patients worldwide, especially those with refractory epilepsy, present common characteristics that claim for the need of not only treating the seizures recurrence, but also of providing assistance for psychosocial aspects that are increasingly being recognized as significant for a well-succeeded treatment as a whole.

It is interesting to observe the relationship between a social (AEDs accessibility) and a clinical aspect (the characteristics of pharmacological treatment). As reviewed by Mbuba and co-workers[12], the AEDs costs and accessibility are important factors behind the treatment gap seen in developing countries. The prescription patterns in our service are in congruence with the nationally-established determinants that

Table 3. Doubts about epilepsy (n = 98).

Topics and main questions	Number of patients (%)[1]
Treatment	42 (43)
Cure	
Surgery	
Medications	
Epilepsy	30 (31)
What is epilepsy	
Cause	
Symptoms	
Seizures	
Employment and social security benefits	13 (13)
Limitations over job activities	
Obtaining a social security benefit	
Nonspecific	11 (11)

[1]Some patients had more than one type of question.

regulate the use of second generation AEDs (considered as high cost medications) for treatment of refractory epilepsy in the Brazilian public health care system. The restricted access to new AEDs in public services certainly plays a role on the treatment profile demonstrated in Figure, especially regarding the low frequencies of use of modern agents such as oxcarbazepine (OXC), levetiracetam (LEV) and pregabalin (PGB), widely used in developed countries[13,14]. Although we have not directly evaluated the patients' satisfaction with the health care service provided, it is known that the burden of the medication costs and the accessibility difficulties are determinants for the treatment success and, consequently, for patients' satisfaction[12,15].

Approximately 27% of the evaluated patients confirmed sharing the medical care between the hospital and another health care level. Patients with refractory epilepsy usually need to be followed in specialized tertiary services due to the complexity of the neurological condition and the frequently seen comorbidities (Table 1). In general, patients in such circumstances are satisfied with the tertiary service, although they still have criticisms regarding the resolvability of their seizures, the short period of time spent in medical visits, and the deficiency in information provision both in general aspects and specifically to their cases[7,16,17,18]. As discussed by Poole and colleagues[7], such critiques of the tertiary level service commonly motivate the patients to, in parallel, look for medical care on other levels, where they report having more personalized and familial care. Nonetheless, sharing health care in different levels do not necessarily result objectively in higher quality of care, as highlighted by Pugh and co-workers[19].

The majority of the patients confirmed not to have a job by the time of the interview (Table 2). In fact, labor restrictions are frequent in patients with epilepsy, especially in those with refractory epilepsy[2]. The implications of unemployment or non-formal job on patients quality of life are being increasingly investigated[2,4,5]. Although part of the patients are indeed unable to work, the prejudice by employers is still a significant barrier faced by the patients able to work, as highlighted by Smeets and colleagues[20] in a vast literature review.

Corroborating previous findings, the patients included in our study presented low educational levels; less than one-third of the sample reached high school and only 3% studied at university level (Table 2). Additionally relevant are the five patients who stated never having gone to any school. In Brazil, no schooling is equivalent to illiteracy, since home-schooling, common in other countries, is not recognized as formal education. Certainly, the inclusion bias present in our study (only patients with refractory epilepsy) plays a role in the educational level found. High frequency of seizures, polytherapies, adverse events provoked by AEDs and comorbidities (especially psychiatric), among other factors closely related to refractory epilepsy, contributed to high levels of school dropout[21]. Nonetheless, surveys performed in different sociodemographic contexts indicate higher numbers of patients with refractory epilepsy who attained university education, suggesting that simply having epilepsy, even if refractory, do not limit access to education. The socio-cultural environment, independent from the disease, also has a relevant influence on patients' educational progresses[22].

Our results corroborate with data that emphasizes the need of obtaining information about epilepsy by patients and their family members[6,7,8,9,17,18,23,24,25]. It is important to distinguish what is to evaluate the level of knowledge of the patients from what is to evaluate their need of information. Jarvie and co-workers published widely used questionnaires that measure (based on "true/false" questions) the patients' level of knowledge about epilepsy[26,27]. Although such questionnaires indicate the deficient areas of knowledge based on the high rates of wrong answers, we believe that an open answer to the question "Do you have any doubt about epilepsy? If yes, what is (are) your doubt(s)?" indicates more precisely the needs of the patients since it focuses on what is really relevant for them. In addition, as highlighted by Goldstein and colleagues[17], the demand for information is not necessarily related to the level of knowledge already acquired by the patients.

The doubts were more frequently related to the treatment and cure of epilepsy, possible causes and the disease characteristics (Table 3). Through the perspective of health care professionals habituated to work with patients with epilepsy, these can be considered basic questions. However, questions such as "what is epilepsy?", "what causes epilepsy?", "does epilepsy have a cure?" are recurrent even in more favorable socioeconomic contexts[6,7,9,17,18,25], in groups with controlled epilepsy[6,7,18] and in different levels of health service (primary and/or secondary levels)[6,7,8,18,25]. These doubts can be more common than supposed, but are not exteriorized because some patients feel that the physicians are inaccessible and do not care about their questions[6,24]. Also, the short period of time spent at the medical visits, specially at the tertiary level, impairs the establishment of a dialogue that informs the patients considering their specific needs of information, even if basic[8,24]. However, patients with refractory epilepsy frequently have cognitive and memory impairments, hence, it is possible that such patients were informed, but they did not understand and/or retained the information[7,17,24].

Independently from the reasons behind such questions, the data found reinforce the need of investments on educational strategies. There is no consensus about the best way to deal with the information provision. Some authors suggest the incorporation of multidisciplinary teams (psychologists, social workers, nurses) to the health services[16,17,18]. Some authors stress the effectiveness of distributing instructional materials to patients and families[7,17,18], and others highlight the role of recommending associations with whom patients can establish a convenient contact when searching for information[18,25,28]. The low percentage of patients who confirmed having knowledge of the Brazilian Association for Epilepsy opens the perspective of the need to improve strategies to ameliorate the need of information about epilepsy expressed by our patients and their families. There are publications that support the implementation of psycho-educational groups as a way to inform patients about epilepsy[8,29]. As discussed by Prinjha and colleagues, adopting only one strategy to instruct the patients may not be enough to overcome all demands[25].

In spite of the value that the present study portrays, limitations must be taken into account so the data can be interpreted with consideration to some singularities. The inclusion of patients with refractory epilepsy does not necessarily represent all the patients with epilepsy. These are patients in a more severe medical condition which generally have comorbidities that influence psychosocial factors, and patients with comorbidities were not excluded. Although we acknowledge the importance of applying a semi-structured questionnaire, not adopting validated tools resulted in difficulties comparing our data to those in other studies. In addition, deeper investigations are needed to understand if the patients have more general doubts about epilepsy or if their doubts are only related to their own conditions, and if the profile of doubts from the families is different from that presented by the patients.

In conclusion, although inserted in a sociodemographic context different from that usually found in the literature, the patients with refractory epilepsy from a developing country such as Brazil similarly have high rates of unemployment, low educational levels and a tendency to be not married. The data presented raises a concern about the demand for information about epilepsy by the patients and their families. As this need is present in different social, cultural and economic scenarios, it is evident that there is a high need to invest in strategies to solve this deficiency in knowledge.

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