



# The reality of epilepsy in primary care in Rio de Janeiro: the importance of educational projects for better patient care

## *A realidade da epilepsia na atenção primária no Rio de Janeiro: a importância de projetos educacionais para o melhor cuidado ao paciente*

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### Abstract

**Background** The Basic Health Unit (Unidade Básica de Saúde – UBS, in Portuguese) is the first point of contact in the public healthcare system for people with epilepsy. Primary care professionals need to appropriately diagnose, treat, and refer, if necessary, to tertiary services.

**Objective** To evaluate the knowledge of UBS professionals on the management of patients with epilepsy in Rio de Janeiro.

**Methods** Online questionnaires were performed on the topic of epilepsy before and after exposure to classes taught by epileptologists.

**Results** A total of 66 doctors participated, 54.5% of whom were residents or trained in family medicine. The majority had from 1 to 3 years of practice. Insecurity prevailed in the management of pregnant women and the elderly. Around 59.1% of the participants referred patients with seizures without examinations. A total of 78% of the participants did not correctly classify seizure types, and 2/3 did not define drug-resistant epilepsy. Induction and broad-spectrum drugs were common. The therapeutic decision depended on availability in the basic health unit (UBS) (81.8%), dosage (60.6%), side effects (34.8%), and age (36.4%). Comorbidities and sex influenced less than 1/4 of the sample. For 23% of the participants, the type of crisis did not affect the choice. Regarding typical non-pharmacological options, 75% of the participants were aware of

### Keywords

- ▶ Epilepsy
- ▶ Primary Health Care
- ▶ Health Centers
- ▶ Drug Resistance

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cannabidiol, 40.9% of surgery, 22.7% of ketogenic diet, and 22.8% of deep brain stimulation/vagus nerve stimulation (DBS/VNS). A total of 90.2% indicated the need for training.

**Conclusion** There are deficits in the knowledge of UBS professionals in the management of epilepsy. Specialized training is imperative to optimize the care offered within SUS.

## Resumo

**Antecedentes** A Unidade Básica de Saúde (UBS) é o primeiro contato no sistema público de saúde para pessoas com epilepsia. Profissionais de atenção primária precisam diagnosticar, tratar e encaminhar adequadamente, se necessário, a serviços terciários.

**Objetivo** Avaliar o conhecimento dos profissionais das UBSs sobre o manejo de pacientes com epilepsia no Rio de Janeiro.

**Métodos** Foram realizados questionários online sobre o tema da epilepsia pré e pós exposição a aulas ministradas por epileptólogos.

**Resultados** Participaram 66 médicos, sendo 54,5% residentes ou formados em medicina da família. A maioria tinha de 1 a 3 anos de prática. A insegurança prevaleceu no manejo de gestantes e idosos. Cerca de 59,1% dos participantes encaminhavam pacientes com crises sem exames. Um total de 78% dos participantes não classificou corretamente tipos de crises, e 2/3 não definiram epilepsia farmacorresistente. Fármacos indutores e de amplo espectro foram comuns. A decisão terapêutica dependeu da disponibilidade na Unidade Básica de Saúde (UBS) (81,8%), posologia (60,6%), efeitos colaterais (34,8%) e idade (36,4%). Comorbidades e sexo influenciaram menos de 1/4 da amostra. Para 23% dos participantes, o tipo de crise não afetou a escolha. Quanto a opções não farmacológicas típicas, 75% conheciam o canabidiol, 40,9% a cirurgia, 22,7% a dieta cetogênica, 22,8% a estimulação cerebral profunda/estimulação do nervo vago (ECP/ENV). Um total de 90,2% dos participantes indicou necessidade de treinamento.

**Conclusão** Há déficits no conhecimento dos profissionais das UBSs no manejo da epilepsia. O treinamento especializado é imperativo para otimizar o cuidado oferecido no âmbito do SUS.

## Palavras-chave

- ▶ Epilepsia
- ▶ Atenção Primária à Saúde
- ▶ Centros de Saúde
- ▶ Resistência a Medicamentos

## INTRODUCTION

Epilepsy poses a global health challenge, affecting a staggering 50 million individuals across the world. A significant majority of these cases, in low-middle income countries.<sup>1-4</sup> This glaring inequality highlights the pressing need for improved epilepsy care and management in regions that often face resource limitations and healthcare disparities.

In the context of Brazil, the landscape of epilepsy is no less intricate. The prevalent population of 1.8 million actively epileptic patients and nearly 340 thousand new cases estimated per year demonstrates the importance of this condition in the country.<sup>3</sup> Epilepsy represents a significant burden on morbidity and mortality rates, with outcomes intertwined with the often-challenging nature of managing the condition.

Around 2/3 of cases can attain such control through a single medication regimen; however, the remaining 33% becomes pharmacoresistant. Because of this subset of patients, management requires not only medical attention but also the expertise of a specialized multidisciplinary epilepsy team.<sup>5,6</sup>

In regions where economic disparities and healthcare infrastructure gaps persist, such as in less developed nations, the scarcity of neurologists and epileptologists compared with the number of individuals afflicted by epilepsy creates a dissonance. This dissonance, prominently evident within the framework of public health, underscores the need for strategic resource allocation and priority setting. This decision-making process dictates who should be granted access to specialized interventions and when such interventions are warranted. The gateway to the public healthcare system, in many instances, is the primary care unit, which facilitate referrals to tertiary reference centers.<sup>7</sup> Consequently, the competence of these primary care practitioners takes on importance, spanning a spectrum from accurate comorbidity diagnosis, adept management of controllable cases, mitigation of treatment-induced effects, and identification of patients who require specialized care.<sup>8,9</sup>

The mentioned study aimed to assess the knowledge of primary care medical professionals in the state of Rio de Janeiro regarding a range of topics associated with epilepsy. The initiative sought to contribute to the planning of

educational intervention measures that could enhance the understanding and treatment of epilepsy by these professionals.

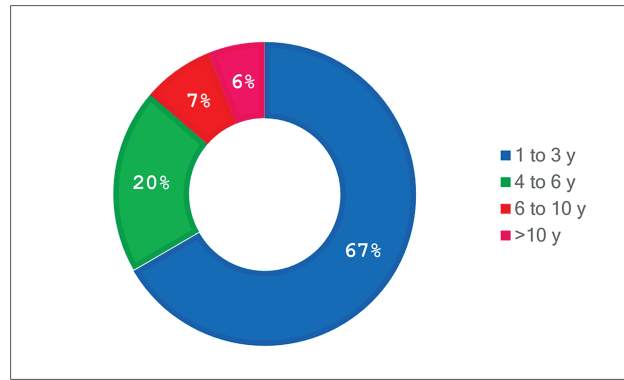
**METHODS**

Specialists in the field of epilepsy at Instituto Estadual do Cérebro Paulo Niemeyer (in Rio de Janeiro/RJ) developed a course covering critical concepts related to epilepsy. The course had a total duration of 8 hours and addressed essential topics, including: epidemiology, diagnosis, classification, treatment modalities, prognosis, pertinent societal matters, and the evolving landscape of epilepsy policies as exemplified in ►Table 1.

The methodology employed in the course entailed the distribution of questionnaires that delved into the specified topics, aiming not only to evaluate participants' knowledge levels but also to discern the characteristics of the population they served. Through their answers in a precourse questionnaire, we summarized the main points involving the reality of caring for patients with epilepsy in primary centers, from concepts about the disease, reasoning for therapeutic decisions and the difficulties in managing these patients in the public health context. The questionnaire is described in ►Supplementary Material S1 (<https://www.arquivosdeneuropsiquiatria.org/wp-content/uploads/2024/04/ANP-2023.0259-Supplementary-Material.docx>).

**RESULTS**

The course engaged a total of 66 participants, with an impressive completion rate of 92.4% (61 individuals). Within this cohort, 54.5% (36) were engaged in the pursuit of studies or were undergoing residency in family medicine, while 45.5% (30) were general physicians serving within basic health units (UBS). The profile from years of practice is resumed in ►Figure 1. The participants' epilepsy-related knowledge had primarily been acquired through their graduation for 41 individuals (62.1%), residency for 19 (28.8%), and self-guided learning for 6 (9.1%).



**Figure 1** Profile of professionals by time of clinical practice.

In exploring epidemiological aspects concerning their patients with epilepsy, the predominant age group was adults (78.8%), trailed by adolescents (27.3%), children (21.2%), the elderly (10.6%), and infants (3%). Among these age groups, a proportion of patients remained under seizure control for more than 6 months (39/59.1%) or were seizure-free for more than 2 years (15/22.7%).

The survey uncovered that 16 participants (24.2%) had pregnant patients, all of whom expressed a lack of confidence in managing such cases. Additionally, 28 participants (42.4%) attended to elderly patients, out of which 75% expressed discomfort treating them without specialist follow-up.

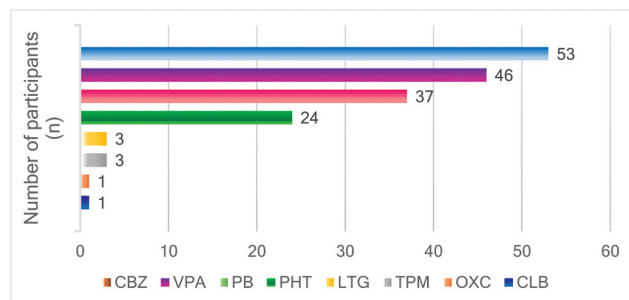
Addressing therapeutic adherence barriers, participants highlighted limited medication availability through the public system (50/75.8%), patients' financial constraints (34/51.5%), challenges in comprehending dosage instructions (31/47%), concerns about drug interactions (14/21.2%), and reservations surrounding controlled medications (4/6.1%).

When confronted with a report of a single suspicious event with negative investigation outcomes and no initial anti-epileptic drug use, or the use of a single medication without seizure control, 43 participants (65%) referred their patients to a tertiary service. Among the physicians, 30 (45.5%) requested specialized assessments without the preliminary test results due to regulatory delays. Among those who initiated the

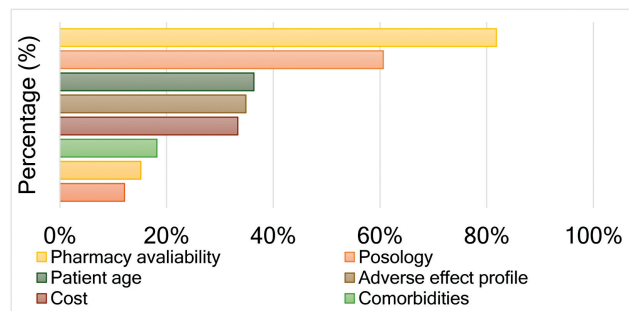
**Table 1** Course schedule

<b>Week one:</b> Introductory class part I: Basic concepts in epilepsy	ILAE's semiology classification and Amaneses
<b>Week two:</b> Introductory class part II: Basic concepts in epilepsy	Differential diagnosis, PNES, and epilepsy pharmacoresistance
<b>Week three:</b> When to refer?	When to refer patients to a tertiary center? Which exams are necessary?
<b>Week four:</b> Pharmacology part I	What do primary care physicians need to know?
<b>Week five:</b> Pharmacology part II	Adverse effects and main interactions
<b>Week six:</b> Special populations	Pregnancy, elderly and when to think about "unprescribing" medications
<b>Week seven:</b> Pharmacology part III	Psychiatric disorders and convulsive initial management
<b>Week eight:</b> Non-pharmacological treatments	Surgery, VNS, DBS, ketogenic diet, and cannabidiol

Abbreviations: DBS, deep brain stimulation; ILAE, International League Against Epilepsy; PNES, psychogenic nonepileptic seizures; VNS, vagus nerve stimulation.



**Figure 2** Treatment preferences per participant.



**Figure 3** Main considerations for treatment choice in percentage.

regulation process, a substantial 86.4% (57) reported a lack of feedback from subsequent neurological follow-ups.

Participants identified key diagnostic tests, as electroencephalogram (EEG) (49/74.2%), serum laboratory tests (53/80.3%), and cranial tomography (CT; 39/59.1%). Only 3 (4.5%) indicated that they would request a brain magnetic resonance imaging (MRI).

Turning to general epilepsy concepts, 51 participants (78%) struggled to accurately classify seizure semiology and types and 13 (19.6%) were proficient in defining the concept of pharmacoresistance. A consensus emerged that normal electroencephalogram (EEG) and computed tomography (CT) scans do not rule out epilepsy, yet half of the participants equated an altered EEG with epilepsy.

Their treatment preferences are summarized in ► **Figure 2**. No professional reported prescribing levetiracetam, despite its availability in the public health system.

In addition, 15 participants (22.7%) did not consider seizure type a determining factor in therapeutic decisions. Their main considerations for treatment choice are described in ► **Figure 3**.

Regarding non-pharmacological therapies, a significant proportion of participants were aware of the potential use of cannabidiol (50/75.8%), followed by surgical options (27/40.9%), the utility of the ketogenic diet (15/22.7%), and neuromodulation methods (deep brain stimulation/vagus nerve stimulation, DBS/VNS; 15/22.7%).

## DISCUSSION

Epilepsy ranks as the second most burdensome neurological disorder.<sup>10</sup> Its trajectory hinges on the effective control of

seizures through diverse interventions, ranging from medications to surgical procedures. The condition also has a social stigma reverberating into different areas of an individual's life, thereby incurring indirect costs for society.<sup>11,12</sup>

In Brazil, the primary care interface enables the assessment of referral necessity to tertiary and quaternary centers.<sup>13,14</sup> However, these higher-tier centers remain scarce, giving rise to a dearth of available slots relative to population demand. Consequently, stringent criteria become imperative to discern cases warranting specialized attention from those feasibly managed within primary care.<sup>15–20</sup>

This situation stems from issues spanning not only the capabilities of family and community medicine (FCM) units but also the professionals' unease in managing epilepsy comorbidities.<sup>21,22</sup>

Our study, involving FMC professionals in Rio de Janeiro, highlights gaps in management: as outdated concepts about epilepsy due to the greater proportion of education on the topic coming only from undergraduate level. This training also impacts the choice of therapy, as despite newer, and more tolerable medications are provided by public health, there is a persistence toward first and second-generation drugs, misunderstanding around newer drugs, like levetiracetam, and the idea that gender and comorbidities do not have much impact on the choice of medication.

It was noted that referral to tertiary centers occurs even in cases of pharmacosensitive monotherapy and are referred even without the necessary mandatory exams due to the delay in carrying them out by the SUS. This highlights challenges linked to the availability of the necessary exams and with the absence of a coherent referral pathway for tertiary centers.

In summary, our study illuminates the pressing requirement for sustained education in epilepsy care for primary care professionals aiming to provide better patient care and optimize the resources of the public health system.

### Authors' Contributions

VCCL, IDAM: conceptualization or design of the work, data acquisition, analysis or interpretation, and writing or reviewing the manuscript. MBMM, ASCV, LAA: data acquisition, analysis or interpretation, and writing or reviewing the manuscript. All authors approved the final version of the manuscript and agree to be responsible for all aspects of the work.

### Conflict of Interest

The authors have no conflict of interest to declare.

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