



## Labels and epilepsy – An online survey of patients and those close to them



Latica Friedrich\*, Ana Sruck, Ivan Bielen

Department of Neurology, "Sveti Duh" University Hospital, School of Medicine Josip Juraj Strossmayer, University of Osijek, Sveti Duh 64, Zagreb, Croatia

### ARTICLE INFO

#### Article history:

Received 25 November 2018

Revised 10 January 2019

Accepted 11 January 2019

Available online 3 February 2019

#### Keywords:

Epilepsy

Labels

Language

Terminology

Epileptic

### ABSTRACT

Publications on the topic of appropriate labels for someone with diagnosed epilepsy have so far almost exclusively consisted of views of professionals in this field. We conducted an online study of patients treated for epilepsy and persons close to them with the aim of identifying which label they prefer, whether they oppose the term "epileptic", and which characteristics are related with their preferences. In total, 328 responses were analyzed. Subjects mostly favored "person-first" terminology ("person having epilepsy" and "person with epilepsy"), and 53.9% disapproved of the term "epileptic". Parents of patients are more likely than patients themselves to favor the label "person having epilepsy" and to disapprove of the label "epileptic". These results can help with shaping future terminology recommendations.

© 2019 Elsevier Inc. All rights reserved.

### 1. Introduction

Although the term "person/individual/people with epilepsy" has for a long time been the dominant one in professional language, the debate on how a person with diagnosed epilepsy should be referred to still continues, in professional as well as common language. Some patients object to this term and its abbreviation [1], while others believe that forced avoidance of the term "epileptic" could actually have counterproductive effects [2]. Furthermore, some of the most recent studies fail to prove that the label "epileptic" leads to negative public attitudes [3]. As International League Against Epilepsy (ILAE) does not suggest a specific label, the discussion on terminology remains open [4]. Under these circumstances, it is highly important that people with epilepsy express their preferences about how they should be referred to, as a part of an informed debate among the epilepsy community in the broadest sense [5]. With this in mind, a study on a large sample from the UK and the Republic of Ireland was published in 2017; analysis revealed that the most favored was person-first terminology [6]. As no similar research from countries of other linguistic and cultural settings has yet been published, we conducted a study in Croatia, based on a short questionnaire, the goal of which was to assess preferences of patients and the ones close to them regarding aforementioned terminology and, specifically, if they oppose the term "epileptic". We also tried to find characteristics that were associated with their choices.

### 2. Methods

For one month, starting from 28th May 2017, an anonymous online questionnaire about the most appropriate label for a person being treated for epilepsy was offered to all visitors of the Croatian Association for Epilepsy's website [www.epilepsija.hr](http://www.epilepsija.hr), through a pop-up invitation window. This invitation was also published on the Facebook page of the Croatian Association for Epilepsy, and users were invited to share it further. The first question was "What do you think is the most appropriate label when talking about someone treated for epilepsy?", with 5 possible answers: 1. Epileptic, 2. Person with epilepsy (or depending on the context child/older person/woman with epilepsy), 3. A person having epilepsy (or depending on the context child/older person/woman having epilepsy), 4. Patient with epilepsy/diseased with epilepsy, and 5. I think all the suggested labels are equally appropriate. The labels offered were the ones that are most commonly used in the Croatian language, and although we are aware that the term "diseased with epilepsy" is not a common one in the English language, it is a more direct translation of the Croatian term, which is frequently used. The second question was a yes/no question: "Would you mind if someone called you (or your child/family member/friend/acquaintance) an 'epileptic'?" The remainder of the questionnaire collected respondents' demographic data (age, gender, country of residence, level of education) and the relationship with a person with epilepsy. The questionnaire was designed in a way that answering the first two questions was mandatory in order for the system to record the response, and allowed for skipping answers to the remaining questions. Inclusion criteria for respondents were age 16 years or more, living in Croatia, and being close to someone with epilepsy (i.e., those who stated that

\* Corresponding author at: Department of Neurology, Sveti Duh University Hospital, School of Medicine Josip Juraj Strossmayer, University of Osijek, Sveti Duh 64, 10000 Zagreb, Croatia.

E-mail address: [latica@kbsd.hr](mailto:latica@kbsd.hr) (L. Friedrich).

no one close to them had epilepsy were excluded). As a statistical tool IBM SPSS Statistics, Version 20.0, was used. Chi-square tests and logistic/multinomial regressions were used to find associations between patients' characteristics and 1) label preference 2) opposing the term epileptic. When conditions for performing chi-square tests were unmet because of a large number of cells with expected counts less than 5, categories were either merged (level of education to secondary school or less and postsecondary education), or only the 2 largest categories were analyzed (patients and parents of patients). For contingency tables larger than  $2 \times 2$  that had a significant result, posthoc analysis was performed according to MacDonald and Gardner [7]. The  $p$  value  $< 0.05$  was used as a criterion for significance of the statistical findings.

Our work has been carried out in accordance with the Helsinki Declaration. The study was approved by the local ethical committee, and respondents were guaranteed data confidentiality.

### 3. Results

The total number of respondents was 417, but when excluding criteria described in the *Methods* were applied, the number of subjects was 328. Age range was 16–66 years, with a mean of  $35 \pm 9.6$  years, and the vast majority of subjects were women (85%). About half of the respondents were subjects with epilepsy (53%); further, 31% were parents of someone with epilepsy, and the remainder stated other kind of relationship with someone with epilepsy (Table 1)

The majority of subjects preferred the label “person having epilepsy” (28%) followed closely by “person with epilepsy” (27%) (Table 2). Only 3% found the label “epileptic” the most appropriate one. Twenty-three percent of subjects did not have a preference among the suggested labels. In total, 177 subjects (53.9%) stated that they would mind themselves or someone close to them being called an “epileptic”.

#### 3.1. Characteristics related to labels

Regression model between age and the preferred label was not significant (data not shown), and there was also no association with either gender or level of education (Table 3). There was a difference between patients themselves and parents of patients with epilepsy ( $\chi^2 = 10.48$ ,  $df = 4$ ,  $p = 0.033$ ), where parents favored the term “person/child having epilepsy” (38/102) more frequently than patients (38/173).

Neither age or gender or level of education was significantly related with the disapproval of the term “epileptic”. However, the disapproval of the term was significantly different among the different categories of relation with someone with epilepsy ( $\chi^2 = 21.799$ ,  $df = 4$ ,  $p < 0.001$ ), with a posthoc analysis revealing a significant difference in the patient and parent categories, i.e., parents were more

**Table 1**  
Subject characteristics. N = 328.

	N (%)
Age (years)	$35 \pm 9.6^*$
Gender	
Male	50 (15%)
Female	276 (85%)
Level of education	
Elementary School	11 (3%)
Secondary School	189 (58%)
College/School of higher education	45 (14%)
University	82 (25%)
Relation with someone with epilepsy	
Myself	173 (53%)
Parent	102 (31%)
Partner	12 (4%)
Other family member	30 (9%)
Friend	11 (3%)

Missing data: age 6, gender 2, level of education 1, relation 0.

\* Mean  $\pm$  SD.

**Table 2**  
Most appropriate label when talking about someone treated for epilepsy.

	N (%)
Epileptic	10 (3.0)
Person (or depending on the context child/older person/woman) with epilepsy	87 (26.5)
Person (or depending on the context child/older person/woman) having epilepsy	92 (28.0)
Patient with epilepsy/diseased with epilepsy	65 (19.8)
I think all the suggested labels are equally appropriate	74 (22.6)

likely to mind the term “epileptic” (73/102), while the opposite was true for patients – only 75/173 opposed the term (Table 4).

### 4. Discussion

Our study has provided an insight into the preferences of patients treated for epilepsy and those surrounding them regarding labels. To our best knowledge, a similar study was previously done only by Noble et al. [6], and ours is the first research of this kind in a non-English linguistic setting.

Our results demonstrate that person-first language is the preferred mode of addressing someone with epilepsy, as more than half of the subjects chose either the term “person with epilepsy” or “person having epilepsy” as the most appropriate one. This is in line with the recommendations of many epilepsy organizations [8,9], and has been advocated for a long time as the suitable way of addressing people with disabilities [10]. Person-first language was favored by those with epilepsy and their significant others in the work of Noble et al. as well [6]. Our results have shown that “person/child having epilepsy” was more frequently the best option for parents of patients with epilepsy than for patients themselves. A reason for this might be that parental concerns for their child with epilepsy also encompass the choice of the most appropriate wording regarding their child's condition. Labels in which the disease is emphasized by putting it in the first place (“patient with epilepsy”/“diseased from epilepsy”) came in our study as the third most favorable option. As argued by many disability groups and professionals [11], the reasons for choosing this label might be not to downsize the seriousness of the condition [6]. It should be noted here that, unlike in English-language settings, the term “epileptic person”, referred previously as adjective-first or disability-first label [6,12], is not used in Croatian, so a direct comparison of the results is not possible. The label “epileptic” was chosen as the most suitable one by only 3% of the subjects. This might suggest that raising epilepsy to the level of defining a person is not something that people with epilepsy and those surrounding them would usually choose as the most desirable option. Although in Croatia even if there was never a real campaign advocating for usage of “correct” labels concerning epilepsy, the results of our previous work that suggest that the word “epileptic” might provoke more negative attitudes compared to “person with epilepsy” [13] have been presented in the media several times, so there is a chance that views of those concerned were partly shaped by those results. It is interesting to note that almost a quarter of subjects did not have any preference among the suggested terms. Some patient groups have previously expressed their views that implying the existence of right and wrong language terms might actually limit open debates on epilepsy and in that way be counterproductive [2]. Also, as our results have shown that there was not a single, dominant, preference among the suggested labels, it might be worthwhile considering, at least in a nonmedical setting, asking a person how he/she would like to be addressed when referring to his/her epilepsy.

When specifically asked about whether they would mind being called an “epileptic” (themselves or someone close to them), about half of the subjects opposed it. Although the use of this term has for a long time been discouraged in the professional language, whether it actually shapes negative attitudes is something that is still not entirely

**Table 3**  
Association of subjects' characteristics with the preferred label for someone treated for epilepsy.

	Most appropriate label for someone with epilepsy N(%)					$\chi^2$	p
	Epileptic	Person with epilepsy	Person having epilepsy	Patient with epilepsy	No preference		
Gender						3.74	0.442
Male	1(2.0)	9(18.0)	13(26.0)	12(24.0)	15(30.0)		
Female	9(3.3)	77(27.9)	78(28.3)	53(19.2)	59(21.4)		
Level of education						7.95	0.093
Secondary school or less	6(3.0)	57(28.5)	47(23.5)	38(19.0)	52(26.0)		
Postsecondary education	4(3.1)	30(23.6)	45(35.4)	27(21.3)	21(16.5)		
Relation with someone with epilepsy						10.48	0.033
Myself	8(4.6)	48(27.7)	<b>38(22.0)</b>	37(21.4)	42(24.3)		
Parent	1(1.0)	29(28.4)	<b>38(37.3)</b>	15(14.7)	19(18.6)		

Bold values denote cells where counts were statistically different than expected.

**Table 4**  
Association of subjects' characteristics with the disapproval of the label "epileptic".

	Do you mind the label "epileptic"? N(%)		OR (95%CI)/ $\chi^2$	p
	Yes	No		
Age			0.99 (0.97–1.01)	0.351
Gender			0.094	0.759
Male	26(52.0)	24(48.0)		
Female	150(54.3)	126(45.7)		
Level of education			0.868	0.833
Elementary School	7(63.6)	4(36.4)		
Secondary School	99(52.4)	90(47.6)		
College/School of higher education	26(57.8)	19(42.2)		
University	44(53.7)	38(46.3)		
Relation with someone with epilepsy			21.799	<0.0001
Myself	<b>75(43.4)</b>	<b>98(56.6)</b>		
Parent	<b>73(71.6)</b>	<b>29(28.4)</b>		
Partner	5(41.7)	7(58.3)		
Another family member	17(56.7)	13(43.3)		
Friend	7(63.6)	4(34.3)		

Bold values denote cells where counts were statistically different than expected.

clear, with conflicting results so far [3,12–14]. Parents more frequently disapproved of the term than the patients themselves. Previous research has also shown that parents are less likely to favor the term "epileptic" compared to other type of significant others [6].

Limitations of our study include recruiting the subjects through the Internet, which automatically excluded those without Internet access and resulted in a study population with underrepresentation of males, and which were more educated than the general Croatian population [15]. In order to obtain better compliance, the questionnaire included only a small number of questions, so issues like reasons for choosing or opposing the labels or clinical characteristics of epilepsy were not assessed. For reasons of simplicity, the question about the most appropriate term was regarding a person being treated for epilepsy, so we cannot be certain that the preference data also extends to those with epilepsy who are currently not on treatment. Furthermore, a larger sample would have probably enabled us to compare the categories as they were, without the need to merge or exclude some of them from the statistical analyses. Therefore, more studies on this topic are required.

Based on our data and previous research in this field, we believe recommendations could be made to use the person-first terminology in publications, formal texts, and public speech. But as sometimes it can be more appropriate to use the variations of the term "patient with epilepsy" (i.e., studies comparing different antiepileptic drugs), the final choice of wording is dependent on the context. As our results show that the label "epileptic" is offensive to a large proportion of

those concerned, this term should be used only in specific, well-justified cases.

## 5. Conclusions

We believe our study has brought an additional insight from those living with epilepsy into the language debate. Majority of them prefer the "person-first" language, although almost half of the subjects do not directly oppose the label "epileptic". Parents of patients are more likely than patients themselves to choose the label "person having epilepsy" as the most appropriate one and to disapprove of the label "epileptic". These results can help with shaping future recommendations for terminology in epilepsy.

## References

- Hatcher JL. Replacing the stigma of "epileptic" with a tasteless acronym and coming full circle. *Seizure* 2014;23:408. <https://doi.org/10.1016/j.seizure.2014.01.023>.
- Epilepsy debate: that the language of epilepsy shapes attitudes – YouTube. [n.d.] <https://www.youtube.com/watch?v=WPwCbsdGcJQ&feature=youtu.be>, Accessed date: 13 September 2018.
- Noble AJ, Marson AG. Should we stop saying "epileptic"? A comparison of the effect of the terms "epileptic" and "person with epilepsy". *Epilepsy Behav* 2016;59:21–7. <https://doi.org/10.1016/j.yebeh.2016.03.016>.
- Reuber M. "Epileptics", "people with epilepsy", "PWE", "epilepsy patients"—what is the best label? *Seizure* 2014;23:327. <https://doi.org/10.1016/j.seizure.2014.01.014>.
- Jacoby A. Labels and lingo in epilepsy: a response to Dr Hatcher. *Seizure* 2014;23:409. <https://doi.org/10.1016/j.seizure.2014.01.015>.
- Noble AJ, Robinson A, Snape D, Marson AG. 'Epileptic', 'epileptic person' or 'person with epilepsy'? Bringing quantitative and qualitative evidence on the views of UK patients and carers to the terminology debate. *Epilepsy Behav* 2017;67:20–7. <https://doi.org/10.1016/j.yebeh.2016.10.034>.
- MacDonald PL, Gardner RC. Type I error rate comparisons of post hoc procedures for I j chi-square tables. *Educ Psychol Meas* 2000;60:735–54. <https://doi.org/10.1177/00131640021970871>.
- Facts about epilepsy | Epilepsy Queensland. [n.d.] <https://www.epilepsyqueensland.com.au/facts-about-epilepsy>, Accessed date: 13 September 2018.
- Epilepsy factfile – epilepsy terminology | Epilepsy Society. [n.d.] [https://www.epilepsysociety.org.uk/epilepsy-terminology#\\_VW\\_rHghjKjIU](https://www.epilepsysociety.org.uk/epilepsy-terminology#_VW_rHghjKjIU), Accessed date: 25 November 2018.
- Zola IK. The language of disability: problems of politics and practice. *Aust Disabil Rev* 1988;1:13–21. <http://www.disabilitymuseum.org/dhm/lib/detail.html?id=813&page=all>, Accessed date: 15 August 2015.
- Dunn DS, Andrews EE. Person-first and identity-first language: developing psychologists' cultural competence using disability language. *Am Psychol* 2015;70:255–64. <https://doi.org/10.1037/a0038636>.
- Noble AJ. The effect of noun, adjective, and possessive noun labels on perceptions of someone with epilepsy. *Epilepsy Behav* 2017;68:236–7. <https://doi.org/10.1016/j.yebeh.2017.01.011>.
- Friedrich L, Taslak M, Tomasović S, Bielen I. How does the label "epileptic" influence attitudes toward epilepsy? *Seizure* 2015;33:54–9. <https://doi.org/10.1016/j.seizure.2015.10.012>.
- Fernandes PT, De Barros NF, Li LM. Stop saying epileptic. *Epilepsia* 2009;50:1280–3. <https://doi.org/10.1111/j.1528-1167.2008.01899.x>.
- Croatian Bureau of Statistics. Statistical yearbook of the Republic of Croatia 2017. [n.d.] [https://www.dzs.hr/Hrv\\_Eng/letopis/2017/sljh2017.pdf](https://www.dzs.hr/Hrv_Eng/letopis/2017/sljh2017.pdf).