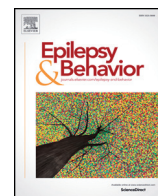


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Should we stop saying “epileptic”? A comparison of the effect of the terms “epileptic” and “person with epilepsy”

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ABSTRACT

Objective: The advantages and disadvantages of using “epileptic” as a noun to describe someone with epilepsy have long been debated. Recent high-profile recommendations have stated that the term should not be used, including in English, as it perpetuates stigma. This decision was largely informed by a Brazilian *Global Campaign Against Epilepsy* study that reported experimental evidence indicating that, with students, the label evokes more negative attitudes than “person with epilepsy”. The generalizability of this effect to different countries/cultures, and thus the justification for the recommendations, has never been tested.

Methods: We replicated the Brazilian study in the UK, in English, while also addressing methodological limitations. It was powered to detect the effects reported by the Brazilian study, with 234 students completing a survey regarding epilepsy attitudes. Half were randomized to Group 1 and half to Group 2. In Group 1, patients were referred to as “people/person with epilepsy” within the attitudinal measures, while in Group 2 they were referred to as “epileptic/s”. Measures included translations of the questions used in the Brazilian study and the Attitudes and Beliefs about Living with Epilepsy scale. Participants’ epilepsy familiarity and knowledge were also assessed.

Results: The two groups were comparable in characteristics. A comparison of their responses to the attitude measures revealed no statistically significant or meaningful differences.

Conclusions: In this English replication, the word “epileptic” did not provoke more negative attitudes. This suggests that the effect reported by the Brazilian study might be culturally dependent. Methodological limitations to that study might also be relevant. Our results have implications for the global debate about how negative attitudes towards epilepsy might be addressed. Simply not saying “epileptic” may not promote the positive attitudes towards epilepsy that had been expected. To know how to best refer to those with epilepsy, evidence on the preferences of those actually living with epilepsy is needed.

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1. Introduction

The history of epilepsy shows that the condition has attracted many wayward theories about its cause and treatment [1]. Surveys from around the world show that those with epilepsy can still be viewed negatively and subject to derogatory stereotypes [2–5]. Feeling stigmatized because of one’s epilepsy is associated with increased psychopathology and reduced quality of life [6,7]. Therefore, it is important to identify ways to address negative attitudes and attenuate stigma. One way might be through language. It has been suggested that the language and terms used when talking about epilepsy may shape attitudes towards the condition and not just reflect them [8–14].

The word “epileptic”, when used as a noun to describe someone with epilepsy, is one term that has, for a long time, attracted particular attention [15]. Although still widely used [16], it can be divisive [17,18]. To date, those with epilepsy have not been systematically asked for their views. However, some commentators contend that the term renders the individual human being as ‘invisible’ and equates them completely with an attribute (i.e., epilepsy) that has negative connotations [8,12,19,20]. For this reason, some epilepsy advocacy groups in different countries ask for the term not to be used and recommend ‘person-first language’ instead (i.e., “person/people with epilepsy”) [15,21–24]. ‘Person-first language’ is considered less negative as it affirms personhood before disability, and so, may not negatively constrain expectations of those being referred to.

On the other side of the debate, there are those who disagree with attempts to dictate what language can and cannot be used. One reason is that the process might be counterproductive in promoting contact between those with and without epilepsy. For example, at a recent

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patient-led debate on the topic [25], it was suggested that identifying some terms as acceptable and others as not could inhibit people from talking about and asking about epilepsy through fear of causing offense. It was also seen to risk alienating those who have or who do use ‘unacceptable’ terms. One further reason why some do not agree with the move is that ‘person-first language’ has been argued to preclude the possibility of pride in one’s identity by purposefully separating the individual from his/her disability. Indeed, Vaughan [26] suggests ‘person-first language’ violates a common principle that most adjectives with positive connotations precede nouns.

Issues regarding how best to refer to someone with a health condition are not unique to epilepsy [27,28]. However, something which has recently set epilepsy apart is Fernandes et al.’s study [8], conducted as part of the *Global Campaign Against Epilepsy*. In an article titled *Stop saying “epileptic”*, they presented experimental evidence, which appeared to demonstrate that, when compared to the appellation “person with epilepsy”, “epileptic” provoked more negative attitudes towards those with epilepsy.

Their study was conducted with Portuguese speakers in Brazil. Participants were students without epilepsy who had been identified as being academically “gifted” ([8], p. 1281). Two groups were formed from those recruited, and participants were individually read four questions by an experimenter. These asked the participants whether they believed those with epilepsy would be rejected by society, have difficulties with employment, and have difficulties in school and whether they themselves were prejudiced towards those with epilepsy. For one group, “people with epilepsy” was used within the questions to refer to those with epilepsy, while for the other, “epileptics” was used. The subtle difference appeared to have a large effect, with those asked about “epileptics” anticipating significantly more social discrimination. They said patients were more likely to be “rejected” by society (87% vs. 41%) and that they would experience more employment (93% vs. 62%) and school (70% vs. 37%) difficulties.

On the basis of these results, Fernandes et al. [8] made the broad recommendation that “epileptic” be abandoned and “person with epilepsy” used. Their findings have since been well cited [12,29–31]. The study is, for example, the only scientific study cited by the US Institute of Medicine to support its recent recommendation that “epileptic” not be used when speaking in English [12]. It remains unclear, however, whether such a move is justified as Fernandes et al.’s study was not without limitations. Their allocation of participants to the two conditions was not randomized nor was the knowledge of epilepsy of those in the two groups or their familiarity with the condition compared. Consequently, unknown differences between the participants in the two groups might account for their different responses. The attitudinal questions used by Fernandes et al. also principally related to a person’s expectation of society’s reaction to those with epilepsy. The effect of the label on a person’s own attitudes was not sufficiently assessed.

Perhaps most importantly, however, it remains unclear whether the effect found in Brazil generalizes to different languages, cultures, and contexts. It has been largely assumed that it does. That this assumption has been made and that such limited evidence has formed the basis of recommendations are disappointing. Discussions about such a serious and emotive issue as epilepsy-related stigma need to be grounded within robust scientific evidence. To not do so could mean that any resulting recommendations are viewed with cynicism, not adhered to, and so not bring about the beneficial impact that they aim to.

The main aim of the present study was, therefore, to replicate Fernandes et al.’s [8] study in a different language and culture to determine if the effect is as universal as has been assumed. Using English translations of the questions used by Fernandes et al. [8], we completed the study in the UK. English is the third most widely first-spoken language worldwide [32] and the international language of science. To overcome the limitations of Fernandes et al.’s study, we randomized our participants to groups and included additional measures to allow

us to examine the effect of the label on participants’ attitudes and to permit us to compare the equivalence of our two groups’ preexisting knowledge and familiarity with epilepsy.

2. Methods

2.1. Participants

Participants were students studying psychology or medicine at the University of Liverpool. All were aged ≥ 17 years, lived in the UK, and were able to access the internet. People were excluded if they could not provide informed consent or independently complete questionnaires in English.

2.2. Procedure

During November 2015, we completed a cross-sectional online survey. Participants were recruited by an advertisement sent to those within the schools of psychology and medicine. Persons wanting to take part were directed to an online survey page hosted by Qualtrics. Those agreeing to participate were randomly allocated by computer software to one of two conditions. For Group 1, the term “person with epilepsy” was used in the attitudinal measures when referring to an individual and “people with epilepsy” when a group was referred to. For Group 2, the terms “epileptic” and “epileptics” were used. Randomization was 1:1 between the two conditions. Participation was anonymous.

The University of Liverpool’s Institute of Psychology, Health and Society Research Ethics Committee approved the study (IPHS-1516-33). Informed consent was obtained from all participants.

2.3. Measures

2.3.1. Primary outcome measure

Within their article, Fernandes et al. [8] provided only English translations of the four questions they used as their primary outcome measure. We used these as our primary outcome measure, and these were the first questions our participants were asked to respond to. Specifically, participants were asked to select either “Yes” or “No” to each of the following questions.

- 1 “Do you think that people with epilepsy/epileptics are rejected by the society?”
- 2 “Do you think that people with epilepsy/epileptics have more difficulties getting employed?”
- 3 “Do you think that people with epilepsy/epileptics have more difficulties at school?”
- 4 “Are you prejudiced towards people with epilepsy/epileptics?”

2.3.2. Secondary outcome measure

To be able to measure what effect the experimental manipulation had for participants’ attitudes (rather than on expectations of how society would respond to those with epilepsy), participants, after completing the primary outcome measure, completed the Attitudes and Beliefs about Living with Epilepsy (ABLE) scale. The ABLE scale was developed and validated by Dilorio et al. [33] and Kobau and Dilorio [34]. It assesses attitudes and beliefs using 30 items across 4 subscales: (a) Negative Stereotypes (e.g., “I believe people with epilepsy/epileptics should not marry”), (b) Risk and Safety Concerns (e.g., “I believe people with epilepsy/epileptics should not drive, even if the law allows them to get a driver’s license”), (c) Work and Role Expectations (e.g., “I believe people with epilepsy/epileptics can do anything I can do”), and (d) Personal Fear and Social Avoidance (e.g., “I believe being around a person with epilepsy/an epileptic would make me uncomfortable”). Participants rated their level of agreement to each item on a 6-point Likert scale. Possible response options range from “Strongly agree” to “Strongly disagree”. Subscale scores are calculated using the mean

score for items on that subscale. The resulting score range for a scale is, therefore, 1 to 6. After recoding items scored in reverse, higher scores for all subscales indicate more negative attitudes towards epilepsy.

The terms used to refer to those with epilepsy within the ABLE measure were adapted so that they accorded with the condition the participant was randomized to.

2.3.3. Covariate measures

Participants were asked for their age, sex, ethnicity, and education. To obtain information about their knowledge and familiarity with epilepsy, the following instruments were used:

Epilepsy Knowledge: Participants completed 25 items from the Epilepsy Knowledge Profile – General [35]. It requires participants to respond either “True” or “False” to statements that reflect factual information and common misconceptions about epilepsy. Seventeen items related to medical aspects (e.g., “Epilepsy is a symptom of mental illness”) and 8 to social aspects (e.g., “Most children with epilepsy can attend normal schools”). This widely used measure has been found to be valid and reliable [35]. Higher scores indicate greater knowledge.

Familiarity with Epilepsy Questionnaire: This was drawn from established questions from Caveness and Gallup’s [36] survey of public attitudes towards epilepsy. As well as being asked whether they themselves have epilepsy, participants were asked whether they had ever seen anyone having a seizure and whether they knew anyone who had epilepsy, and if so, who?

The latter two measures were completed at the end of the survey, and no adjustment to their original wording was made.

2.4. Statistics

2.4.1. Sample size

The principal aim of this study was to determine if the effect detected by Fernandes et al. could be found when the experiment was completed in English. To ensure adequately powered investigations, we based the study’s sample size on the smallest of the statistically significant differences Fernandes et al. found on their primary outcome measure (namely, Question 2). A sample of $N = 106$ participants (53 per group) with complete data was calculated as being required to provide 95% power to detect the effect using independent samples *t*-tests with 2-sided 1% significance tests.

2.4.2. Analyses

Descriptive statistics were used to examine the participants’ age, sex, education, ethnicity, and familiarity and knowledge of epilepsy and to compare the two randomized groups. Differences in mean and proportions, along with 95% confidence intervals (CIs), are reported.

To test for differences in the two groups’ responses to Fernandes et al.’s questions, chi-square tests were used, while independent *t*-tests were used to compare the two groups’ scores on each of the ABLE subscales.

To explore if any of the participants’ characteristics were associated with their responses to the outcome measures, unadjusted regression models were run to determine the relationship between each of the characteristics and responses. For Fernandes et al.’s questions, logistic regression, with robust standard errors, was used. For the ABLE scale, scores were treated as continuous, and linear regression, with robust standard errors, was used. Any variables significantly associated ($P < 0.05$) with a dependent variable of interest were simultaneously entered into multiple regression analyses to identify parsimonious predictors. Odds ratios (ORs) along with 95% CIs are presented for logistic regression, while unstandardized coefficients (*B*) and R^2 are presented for linear regression. Analyses were completed using Stata 11 (Stata Corporation, College Station, TX, USA) and StatsDirect 2.7.8 (StatsDirect Ltd., Cheshire, United Kingdom).

3. Results

3.1. Participants

A total of 266 participants were recruited. Of these, 234 (87.9%) had complete data for the primary, secondary, and covariate measures. There were no statistically significant differences between those with and without missing data in age, sex, or ethnicity (all $P > 0.05$). Therefore, subsequent analyses were performed with those with complete data.

The mean age of the 234 participants was 20.4 years ($SD = 3.4$). Most (81.6%) described themselves as being of White British ethnicity and female (82.1%). One hundred and fifty-two (65.0%) were studying psychology, and 82 (35.0%) were studying medicine. One hundred and eighteen (50.4%) of the participants were randomized to Group 1 (“Person with epilepsy”) and 116 (49.6%) to Group 2 (“Epileptic”). Table 1 presents a comparison of the participants in the groups. There were no statistically significant differences between the groups on any measure, including epilepsy knowledge.

3.2. Primary outcome measure

The responses of the two groups to Fernandes et al.’s four questions were similar, with no statistically significant differences being found. Specifically, in response to Question 1, 11.9% of those in Group 1 (“Person with epilepsy”) said they would anticipate that those with epilepsy would be rejected by society, while 9.5% from Group 2 (“Epileptic”) said this (proportion difference = 0.02, 95% CI = -0.06 and 0.11). To Question 2, 75.4% from Group 1 said that they thought those with epilepsy would have more difficulties getting employed, compared to 72.4% of those from Group 2 (difference = 0.03, 95% CI = -0.08 and 0.14). For Question 3, 76.3% of those from Group 1 said that they thought those with epilepsy would have more difficulties at school, compared to 71.6% of those from Group 2 (difference = 0.04, 95% CI = -0.06 and 0.15). Finally, for Question 4, 9.3% of participants from Group 1 said that they were prejudiced towards those with epilepsy, compared to 5.2% of those from Group 2 (difference = 0.04, 95% CI = -0.02 and 0.11).

Logistic regression identified only a small number of statistically significant associations between responses to Fernandes et al.’s questions and participant characteristics (Table 2). In unadjusted analyses, being of non-White British ethnicity was associated with a higher likelihood of reporting on Question 1 that those with epilepsy are rejected by society (OR = 2.89, 95% CI = 1.18 and 7.10). For Question 2, studying medicine rather than psychology was associated with being more likely to report that those with epilepsy would experience more difficulties with employment (OR = 1.93, 95% CI = 1.00 and 3.74), as was having higher preexisting knowledge regarding the medical aspects of epilepsy (OR = 1.02, 95% CI = 1.01 and 1.05). No other significant associations were found.

3.3. Secondary outcome measure

The responses of the two groups to the ABLE questionnaire were comparable (Supporting Information Table 1). There were no statistically significant differences detected between the groups on any of the subscales, and mean difference scores ranged from only -0.02 to 0.14 .

Linear regression was used to determine if any of the participants’ characteristics were associated with reported attitudes (Table 3). For the subscale ‘Negative Stereotypes’, social knowledge score was the only variable that had a significant association, with increased knowledge being associated with more positive attitudes ($B = -0.004$, 95% CI = -0.008 and -0.001).

For the three other subscales, a number of significant associations were identified by univariate screening and entered into multiple regression models. In these adjusted analyses, the variable which remained significantly predictive for the subscale ‘Risk and Safety Concerns’ was

Table 1
Participants' characteristics.

	Group 1 "Person with epilepsy" (n = 118)	Group 2 "Epileptic" (n = 116)	Difference (95% CI)
Age			
Mean (SD)	20.16 (2.26)	20.69 (3.93)	−0.52 (−1.39, 0.34)
Range	18–33	18–42	–
Sex (n/%)			
Female	95 (80.5)	97 (83.6)	−0.03 (−0.13, 0.06)
Ethnicity (n/%)			
White British	94 (79.7)	97 (83.6)	−0.03 (−0.14, 0.06)
Degree course (n/%)			
Psychology	75 (63.6)	77 (66.4)	−0.02 (−0.14, 0.09)
Epilepsy knowledge			
Medical knowledge (mean % SD)	80.36 (12.43)	79.36 (12.52)	0.99 (−2.22, 4.21)
Social knowledge (mean % SD)	81.46 (15.65)	80.93 (15.24)	0.54 (−3.45, 4.52)
Known anyone who had epilepsy? (n/%)			
No	85 (72.0)	89 (76.7)	−0.04 (−0.15, 0.06)
Ever witnessed a seizure? (n/%)			
No	68 (57.6)	61 (52.6)	0.05 (−0.07, 0.17)
Do you have epilepsy? (n/%)			
No	117 (99.2)	115 (99.1)	0.00 (−0.03, 0.03)

Notes: CI = 95% confidence interval, n = number, SD = standard deviation.

whether the participant reported having previously seen a seizure ($B = 0.33$, 95% CI = 0.05 and 0.62). To have done so was associated with a more negative attitude. For the subscale 'Work and Role Expectations', higher social knowledge was associated with a more positive attitude ($B = -0.01$, 95% CI = -0.02 and -0.01). Having each been found to hold significant unadjusted associations with scores on the 'Personal Fear and Avoidance' subscale, the variables age, medical knowledge, social knowledge, whether the person knew anyone with epilepsy, and whether they had seen a seizure were all entered into multiple regression analyses. None remained significant in this adjusted analysis.

4. Discussion

4.1. Main findings

Fernandes et al. [8] presented evidence from their study with Portuguese-speaking students in Brazil indicating that the label "epileptic" provoked more negative attitudes towards those with epilepsy than "person with epilepsy". Despite important limitations to their study, their finding has had a substantial impact, and their broad recommendation to stop saying "epileptic" has been widely cited. It has been assumed that the effect detected by this study is robust and transcends language and culture. The Institute of Medicine has, for example,

acknowledged the finding and recommended that "epileptic" should not be used at all in English [12]. We, for the first time, replicated Fernandes et al.'s study in a different language and culture to explore how universal the effect of the label is.

Despite using close translations of the questions Fernandes et al. used and having sufficient statistical power (indeed, we overrecruited), we did not find any effect of using the different terms on our student participants' views towards those with epilepsy. We also found no effect of the different terms on a secondary outcome measure – namely, the Attitudes and Beliefs about Living with Epilepsy (ABLE) scale [33]. The ABLE scale is an established method by which people's attitudes towards epilepsy can be measured in a standardized way [37,38]. One advantage is that its construction recognizes that attitudes are multidimensional [33]. It is possible that alternative approaches to capturing attitudes towards epilepsy, such as detailed interviews, might have revealed more subtle differences in attitudes that were evoked by the different terms and which were not detected by our two measures. This remains to be determined.

Our findings do not rule out the possibility that the term "epileptic" might provoke more negative attitudes than "person with epilepsy" in parts of the UK population other than students. This is something that future studies should consider exploring. What our finding does show, however, is that the effect of this term is not universal as has been

Table 2
Association between participants' characteristics and responses to Fernandes et al.'s primary outcome questions.

Characteristic	Question 1		Question 2		Question 3		Question 4	
	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Gender (0 = male, 1 = female)	0.51 (0.20, 1.33)	–	1.16 (0.55, 2.46)	–	0.86 (0.39, 1.89)	–	0.49 (0.16, 1.48)	–
Age (years)	0.96 (0.87, 1.05)	–	1.06 (0.97, 1.17)	–	0.98 (0.90, 1.08)	–	0.96 (0.84, 1.09)	–
Ethnicity (0 = White British, 1 = other)	2.89 (1.18, 7.10)	–	2.02 (0.85, 4.84)	–	0.89 (0.42, 1.87)	–	1.96 (0.65, 5.91)	–
Degree (0 = psychology, 1 = medicine)	1.26 (0.54, 2.97)	–	1.93 (1.00, 3.74)	1.56 (0.77, 3.16)	1.73 (0.91, 3.32)	–	2.21 (0.82, 6.00)	–
Medical knowledge (higher = more knowledge)	0.98 (0.95, 1.02)	–	1.02 (1.01, 1.05)	1.02 (0.99, 1.04)	1.01 (0.98, 1.03)	–	1.01 (0.96, 1.04)	–
Social knowledge (higher = more knowledge)	0.99 (0.96, 1.01)	–	1.00 (0.98, 1.02)	–	1.01 (−0.99, 1.02)	–	0.99 (0.96, 1.03)	–
Know anyone with epilepsy (0 = Yes, 1 = No)	1.14 (0.45, 2.89)	–	0.85 (0.44, 1.65)	–	0.77 (0.39, 1.47)	–	1.22 (0.41, 3.65)	–
Seen a seizure (0 = Yes, 1 = No)	1.51 (0.64, 3.58)	–	0.88 (0.48, 1.59)	–	0.74 (0.41, 1.34)	–	1.53 (0.55, 4.32)	–
Model summary		$\chi^2 (1) = 5.39$, $P = 0.020$		$\chi^2 (2) = 7.06$, $P = 0.029$		–		–

Notes: OR = odds ratio, CI = 95% confidence interval, $P < 0.05$ shown in bold, Question 1 = "Do you think that people with epilepsy/epileptics are rejected by the society?", Question 2 = "Do you think that people with epilepsy/epileptics have more difficulties getting employed?", Question 3 = "Do you think that people with epilepsy/epileptics have more difficulties at school?", Question 4 = "Are you prejudiced towards people with epilepsy/epileptics?". An answer of "No" to a question was coded as 0, while an answer of "Yes" was coded as 1.

Table 3
Association between participants' characteristics and responses to Attitudes and Beliefs about Epilepsy subscales.

Characteristic	Negative Stereotypes		Risk and Safety Concerns		Work and Role Expectations		Personal Fear and Avoidance	
	Unadjusted B (95% CI)	Adjusted B (95% CI)	Unadjusted B (95% CI)	Adjusted B (95% CI)	Unadjusted B (95% CI)	Adjusted B (95% CI)	Unadjusted B (95% CI)	Adjusted B (95% CI)
Gender (0 = male, 1 = female)	-0.10 (-0.22, 0.02)	-	-0.30 (-0.67, 0.06)	-	-0.18 (-0.41, 0.05)	-	-0.15 (-0.35, 0.057)	-
Age (years)	-0.01 (-0.01, 0.01)	-	-0.01 (-0.05, 0.03)	-	-0.02 (-0.05, 0.01)	-	-0.03 (-0.05, -0.01)	-0.02 (-0.04, 0.34)
Ethnicity (0 = White British, 1 = other)	0.09 (-0.02, 0.22)	-	0.07 (-0.14, 0.29)	-	0.23 (-0.001, 0.471)	-	0.020 (-0.03, 0.43)	-
Degree (0 = psychology, 1 = medicine)	-0.05 (-0.14, 0.03)	-	-0.17 (-0.46, 0.12)	-	-0.12 (-0.28, 0.02)	-	-0.14 (-0.31, 0.02)	-
Medical knowledge (higher = more knowledge)	-0.01 (-0.01, 0.01)	-	-0.01 (-0.02, 0.01)	-	-0.006 (-0.013, -0.001)	-0.002 (-0.008, 0.004)	-0.009 (-0.014, -0.003)	-0.005 (-0.012, 0.001)
Social knowledge (higher = more knowledge)	-0.004 (-0.008, -0.001)	-0.004 (-0.008, -0.001)	-0.01 (-0.02, -0.001)	-0.01 (-0.02, 0.01)	-0.01 (-0.015, -0.004)	-0.01 (-0.02, -0.01)	-0.008 (-0.011, -0.004)	-0.003 (-0.008, 0.001)
Know anyone with epilepsy (0 = Yes, 1 = No)	-0.04 (-0.12, 0.03)	-	0.08 (-0.21, 0.38)	-	0.11 (-0.06, 0.29)	-	0.20 (0.02, 0.39)	0.14 (-0.04, 0.33)
Seen a seizure (0 = Yes, 1 = No)	-0.02 (-0.13, 0.08)	-	0.38 (0.11, 0.66)	0.33 (0.05, 0.62)	0.09 (-0.07, 0.25)	-	0.19 (0.05, 0.35)	0.08 (-0.07, 0.24)
Model summary	$F(1,232) = 7.46$, $P = 0.0068$, $R^2 = 0.03$		$F(2,231) = 5.32$, $P = 0.0055$, $R^2 = 0.06$		$F(2,231) = 6.17$, $P = 0.0024$, $R^2 = 0.06$		$F(5,228) = 6.71$, $P = 0.0000$, $R^2 = 0.09$	

Notes: B = unstandardized coefficient, CI = 95% confidence interval, $P < 0.05$ shown in bold. Higher scores for all subscales indicate more negative attitudes towards those with epilepsy.

assumed. In showing this, our study represents a demonstration project, serving to illuminate just how limited the body of research is that has informed the recently made recommendations. Fernandes et al. detected the effect in a single student sample (within a study with important methodological limitations), but the recommendations that have since been made apply to all people in all contexts. Epilepsy-related stigma deserves more careful and informed consideration than this. To not do so risks any resulting recommendations being viewed with cynicism within the parts of the community where they are needed most and having limited impact. Indeed, it is for this reason that we, despite personally favoring the use of the term “person with epilepsy” with in our own research and clinical practice, conducted this study so as to draw attention to the limited evidence base that has so far been afforded to this important topic.

4.2. Why might we not have found the same effect in English?

Firstly, the effect might depend on the connotations that the word “epileptic” has within a culture. While the etymology and direct meaning of the word “epileptic” in English and Portuguese are similar, the attitudinal and informational schemata evoked by the term within student populations in the UK and Brazil may not be. In support of this possibility, it is known that attitudes and stigma towards epilepsy do vary between cultures [39]. Indeed, there are epidemiological differences between the UK and Brazil that could mean some of the older myths concerning epilepsy remain prevalent in Brazil and attitudes more negative. Infectious diseases, for instance, have a key role in causing epilepsy in Brazil [40], and because of a large treatment gap, uncontrolled epilepsy is common [41]. Our study did not directly measure or compare the connotations that the two terms held for our participants. Future studies should consider capturing this information and comparing what is found in different cultures.

Further support for the explanation that the effect might be culturally dependent comes from Friedrich et al.'s [19] recently published study. They asked Croatian students some locally developed questions about their attitudes towards those with epilepsy. For half of the students, those with epilepsy were referred to as “people with epilepsy”, while for the other half, the terms “epileptics/epileptic children” were used. The effect of the manipulation was negligible. On only 3 of the 9 questions they used was a statistically significant difference detected, and these disappeared when a correction for multiple comparisons was applied. The size of the effect was also small (average difference = 0.16, possible difference range: -3 to +3).

Greater methodological rigor on the part of our study may also help explain why we did not replicate Fernandes et al.'s [8] finding. Firstly, our participants were randomly allocated, and our two groups were comparable in their baseline characteristics. Fernandes et al.'s participants were not randomized, and there may have been systematic differences between their two groups, with no measure having been made of their participants' preexisting knowledge of epilepsy, familiarity with the condition, or ethnicity. Unknown differences between their two groups in these respects could account for why their two groups appeared to respond quite so differently to the attitudinal questions, while ours did not. Secondly, our study was potentially less susceptible to “demand characteristics” influencing how participants responded to the questions. Participants completed our study online and anonymously. In contrast, Fernandes et al.'s study was completed in person, with the questions being read by the experimenter.

One final explanation is that the characteristics of our participants were slightly different to Fernandes et al.'s [8]. Their participants were high school students identified for being academically “gifted” ([8], p. 1281). Ours were university students studying two subjects and slightly older (by 4 years on average). These differences could have reduced the likelihood of us detecting the effect. Age might, for example, moderate the effect the term “epileptic” has. Even if age or another characteristic does moderate the effect, this though would not alter

our conclusion that the effect of the label “epileptic” is not universal as has been assumed.

4.3. Implications

While our results suggest the term “epileptic” may not have as negative an effect on attitudes as has been contended, it remains the case that the term is a divisive one. So how should we proceed, and what words can one use and not use? At present, more evidence is needed to permit a truly informed debate. In particular, we have no evidence on the preferences of those actually living with epilepsy and their reasons. This is something we are currently obtaining for those in the UK.

Should it be found that there is a preference among those with epilepsy for ‘person-first language’, recommendations to move away from terms such as “epileptic” would become justified, and this evidence could help promote adherence to associated recommendations. We would encourage colleagues from other countries to obtain evidence on the preferences of those with epilepsy in their communities. It should not be assumed that the views of health professionals, the voluntary sector, or those reflected in health policy always align with those of patients [42]. An example of this comes from the UK where there have been moves for health professionals, particularly those working within mental health, to say “service user” or “client”, rather than “patient” [43,44]. “Patient”, it has been argued, implies passivity, lack of personal agency, and lack of value. However, like the recommendation regarding “epileptic”, the call (however well-intentioned) was arguably premature and not subject to the level of consideration required [45]. Various surveys have since revealed how, for people using mental health services, the term “patient” is actually preferred [46–48]. Reasons proffered for this include the following: “I believe addiction is an illness. If I was in with cancer, I would expect to be called a cancer patient, so what is the difference?” and “I see mental health problems in the same way as physical problems, and therefore, being called a patient is appropriate for both” [46].

Another implication of our study is that the consistent use of ‘person-first language’ may not be able to promote the positive change in attitudes towards epilepsy that had been hoped for. Other interventions are likely needed. The results from our examination of what factors were associated with attitudes towards epilepsy may be helpful here. Factors we examined included participant age, sex, and ethnicity, as well as familiarity with epilepsy and knowledge. We found lower epilepsy knowledge to be the factor most consistently associated with negative attitudes. This suggests that an educational intervention targeting knowledge might improve attitudes. It should be emphasized, however, that the size of any change in attitudes resulting from such an intervention might be small since our final predictive models for participants’ scores on the ABLE scale accounted for between only 3 and 9% of variance. A similar finding was reported by Dilorio et al. [33]. That interventions to increase knowledge about epilepsy among the public may not always result in improved attitudes or behaviors has been previously highlighted [49] and is in line with evidence from the more extensive research literature on mental health stigma [50,51].

4.4. Conclusions

Epilepsy-related stigma deserves careful and informed consideration. We found that, when used in English, the term “epileptic” does not necessarily provoke more negative attitudes towards those with epilepsy than “person with epilepsy”. While this finding does not argue against the use of the phrase “person with epilepsy”, nor does it support previous recommendations to stop saying “epileptic”. More evidence, including on the preferences of those living with epilepsy, is required before any recommendation can be said to be evidence-based.

Supplementary data to this article can be found online at <http://dx.doi.org/10.1016/j.yebeh.2016.03.016>.

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Conflict of interest

The authors state that they have no conflicts of interest to declare.

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