Letter to the Editor

The effect of noun, adjective and possessive noun labels on perceptions of someone with epilepsy

To the Editor,

How to refer to someone with epilepsy can be a divisive topic. In a recent article published in *Epilepsy and Behavior*,[1] we presented findings from the UK showing most with epilepsy appear to prefer the label "person with epilepsy" and dislike the more traditional label "an epileptic" or the disability-first alternative "an epileptic person".

When asked why, many of those with epilepsy and their significant others said they believed the different labels evoke different expectations amongst listeners. To date, there is little evidence to support this.[2-4] In our article’s discussion, we raised the possibility that this though, might be because studies have not yet tested for the nuanced effect our participants appeared most concerned about. Specifically, that more traditional, noun-based terms lead listeners to have more negative expectations about how severe and treatable the target person’s epilepsy is. If true, this could have important ramifications (e.g., in the context of considering which applicants to invite to be interviewed for a job).

There is actually some wider evidence to support the participants’ hypothesis. Psycholinguistic studies [5-6] comparing noun labels (e.g., "Paul is an artist"), adjective labels (e.g., "Paul is artistic") and possessive noun labels (e.g., "Paul has epilepsy") have, for instance, found noun labels can induce greater expectations that the target person will engage in descriptor-congruent behaviours (e.g., number of paintings drawn), that they are less likely to engage in incongruent behaviours and that they lead to the characteristic being described to be interpreted as more permanent and stable. Possessive noun labels implied a more temporary condition, whilst adjectives were intermediate in interpretation.

Given the above, your readers might be interested to hear that we have since subjected the hypothesis to examination. We compared a noun ("he’s an epileptic"), an adjective ("he’s epileptic") and a possessive noun label ("he has epilepsy"). Like prior studies in this area (where funding is difficult to attract), this was completed within the confines of an online experimental study of university students. A total of 407 engineering, environmental science, medical, dentistry and psychology students from our university were recruited. Their mean age was 20.45 (SD=3.46), and most were female (80.6%) and described themselves as white British (85.0%).

A vignette introduced each participant to someone with epilepsy. The only difference was that individuals were randomised to one of 3 conditions. This dictated what label was used within the vignette to refer to the person’s epilepsy. Participants saw the following: “We are going to introduce you to someone. We will then ask you some questions about what you think about them. He is called Harry. Harry is 33 years old. He is epileptic/ is an epileptic/ has epilepsy.”

There were n=138 participants randomised to the possessive noun label condition, n=136 to the adjective condition, and n= 133 to the noun condition. The scores of the individuals in the 3 groups on Jarvie’s [7] Epilepsy Knowledge Questionnaire were comparable, as was their familiarity with epilepsy and demographics (age, sex, ethnicity, area of study).

Having been presented with the vignette, the participants were asked the following questions (with their order of presentation itself being randomised within groups to counterbalance any possible order effect):

1) “How many seizure/ fits do you think Harry has had in the last 12 months?” 0, 1, 2, 3, 4, 5, 6, 7, 8, 9, 10 or more. (Adapted from [8]).

2) How severe/ disabling do you think his condition is? (1= Not disabling at all, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11= Very Disabling)

3) How likely do you think it is that Harry has a full-time job? (1= very likely, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11= very unlikely)
4) How likely is it that Harry will have some intellectual impairment? (1= very likely, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11= very unlikely)

Before each question was presented, the applicable label was presented again on the screen so as to maximise salience.

The responses to the individual questions were treated as continuous, and linear regression, with robust standard errors, tested for the effect of group allocation on participants’ responses to the questions. We found that there was no statistically significant effect of the label used when comparing the groups’ responses to question 1 (number of seizures) or 2 (perceived severity/ disability). There was a statistically significant effect of label on responses to questions 3 (likelihood of full-time job; F(2,404)=3.14, P=0.04, R²=1.65%) and 4 (likelihood of intellectual disability; F(2,404)=3.53, P=0.03, R²=1.96%). However, the size of the effect was slight and, interestingly, the direction of the effect was not what had been anticipated.

Specifically, for question 3, those presented with the adjective label (B=0.59, 95% CI 0.14, 1.03) said it was less likely that Harry would have a full-time job compared to those who were presented with the noun or possessive noun label. The difference was small, with the adjective group giving a lower mean likelihood rating of 7.42 (SD=2.03) on the 11-point scale compared to a mean rating of 7.93 (SD=1.80) given by the two other groups. With respect to the question 4 about the likelihood of Harry having some form of intellectual disability, the group who had seen the adjective label (B=0.49, 95%CI -0.95,-0.04) said it was marginally more likely that Harry would have an intellectual disability (mean 2.40, SD=1.63) compared to those presented with the noun or possessive noun label (mean score 2.93, SD= 1.10). These findings therefore continue to indicate that the different labels used to refer to someone with epilepsy exert only a minimal effect, at most, on the expectations that people report to hold about those with epilepsy.

As an aside, it is important to note that whilst our participants’ epilepsy knowledge coming into the study was relatively high (mean correct answers across groups was 19.6 out of 25), there appeared still to be some noteworthy gaps. Forty-seven percent, for instance, incorrectly stated that it was always necessary to call a doctor or ambulance if a person with epilepsy has a seizure, even if it occurs without complication. The mean number of seizures our participants expected Harry to have had in the prior year is also instructive. It was 6.09 (SD=3.18). We know this is overly pessimistic as most people in the UK with epilepsy will not have had any seizures in the prior year.[9] Findings such as these indicate that within even our relatively young, well-educated student population, some of the classic stereotypes regarding epilepsy and seizures are still exerting an influence on how those with epilepsy are viewed today.

So what are the implications of this latest analysis? Does the lack of effect mean we should not be concerned about the labels we use? This depends on how important one considers such evidence to be in influencing the language one uses. We are of the position that actually it should be the preferences of those with epilepsy and their supporters with regards labels that are most important, even if the labels do not appear to exert different effects on public attitudes or expectations. In the context of a condition that can lead to disempowerment in so many other ways,[10] it would be refreshing if patients and their families were to have the decisive say on how they are referred to.

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References