

BRIEF COMMUNICATION

Stop saying “epileptic”

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SUMMARY

The purpose of this study was to evaluate the impact upon attitude and perceived stigma of using different terms for referring to persons with epilepsy among teenagers. High school students received one of two versions of a brief questionnaire and of the Stigma Scale of Epilepsy (SSE). The versions differed only in the term used: “people with epilepsy” (PWE) in the group-1 (N = 109) and “epileptics” in group-2 (N = 105). Group-1 responded that 62% of PWE and group-2, that 93% of epileptics have more difficulty finding employment. Group-1 responded that 37% of PWE and group-2, that 70% of epileptics have more difficulties at school. Group-1 responded that 41% of PWE and group-2, that 87% of epileptics are

rejected by the society. None of individuals in group-1 indicated that they were prejudiced toward PWE, whereas 3% of group-2 indicated that they were prejudiced toward epileptics. The SSE score (range from 0 to 100, higher the score, higher the degree of perceived stigma) was 49 [confidence interval (CI) = 46.9–52.0] for group-2 and 45 (CI = 42.4–48.2) for group-1 ($p = 0.03$). In conclusion, the words we use can influence our perceptions and have consequences in terms of social stigma associated with epilepsy. We should refrain from using the term “epileptic” to refer to a person with epilepsy, and consider the importance of our choice of words as part of the effort to bring epilepsy out of the shadows.

KEY WORDS: Stigma, Epilepsy, Language expression, Perception.

Epilepsy is a common neurologic condition, and the term epilepsy has negative connotations. This negative perception of epilepsy impairs the patient’s quality of life and reinforces the stigma (Scambler & Hopkins, 1990). This has been observed in different societies (Herodes et al., 2001; Baker, 2002). This label has implications on work (Salgado & Souza, 2002), school (Baker, 2002; Fernandes et al., 2005), social interaction (Baker, 2002; Fernandes & Li, 2006), and stigma perception (Baker, 2002; Fernandes & Li, 2006; Fernandes et al., 2007b).

Generally in the health area, the diagnosis of an illness involves a process of classifying and attaching a label. Over the last two centuries, medical classification has increasingly been based on the underlying pathologic lesion or process (McPherson & Armstrong, 2006).

Fundamentally, the more common classification is based only on symptoms of the disease (McPherson & Armstrong, 2006) and does not take into account characteristics of the person: biologic, psychological, religious, and social. The label is often associated with a negative perception (Finlay & Lyons, 2005). When we use diagnostic labels to refer to a person, this tends to obscure the individual human being and focus only on the negative attribute (disease). This can result in a negative general perception and attitudes (Finlay & Lyons, 2005).

Language conveys information and allows construction of definitions or labels. In doing so, it may also shape or constrain how one thinks or perceives. This can be very dependent on the culture and language, as demonstrated by Winawer (Winawer et al., 2007). In their study on Russian Blues, they demonstrated that categories in language affect performance on color perception.

Currently the terms “person with epilepsy” and “epileptic” are used almost interchangeably by lay people, the media, and even healthcare professionals. Does the language used in this case shape the way we perceive the subject? Does the terminology matter?

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Nevertheless, this difference has never been shown to bear different consequences in regard to stigmatization. In practical terms, is there an advantage to using “person with epilepsy” instead of “epileptic.”

The purpose of this study is to assess whether there is a difference in perception and stigma elicited by the expressions “epileptic” compared to “person with epilepsy” in a group of Brazilian teenagers.

METHODS

Subjects

This study was conducted during the summers of 2006 and 2007 at a summer camp program for gifted students. The students in this program were chosen based on a public examination involving a writing test and school grades. Questionnaires were administered during a weekly workshop. The students were divided into four groups each year by the organizing committee of the program, using alphabetic order of the student’s first name. We then combined even-number groups into group-1 (person with epilepsy) and odd-number groups into group-2 (epileptic).

Instrument

Two versions of a four-question questionnaire were used. In one, the term “epileptics” was used, whereas in the other we used the expression “people with epilepsy.” The subjects answered “yes” or “no” to 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 to get employed?”
- 3 “Do you think that people with epilepsy/epileptics have more difficulties at school?”
- 4 “Do you have prejudice toward people with epilepsy/epileptics?”

In addition, we applied the Stigma Scale of Epilepsy (SSE), which was developed and validated by our group (Fernandes et al., 2007a,b). The SSE contains 24 items

using a four-point scale (1 = not at all, 2 = a little, 3 = a lot, 4 = totally) about perception of epilepsy for the community, and the total score reflects the level of stigma perceived (0 = no stigma; 100 = highest level of stigma). Two versions of the SSE were prepared. The term “epileptic” appeared in one version and the expression “person with epilepsy” in the other.

Assessment

The first group of teenagers referred to our activity was assigned to group-1 = “person with epilepsy” and the second group to group-2 = “epileptic.” The other groups followed the same method of allocation. All participants were asked to complete the four questions and the SSE. One of the investigators (PTF) conducted the data collection. First, study participants were asked to imagine a “person with epilepsy” in group-1 or an “epileptic” in group-2. The questions were then read aloud. The conditions of administration were similar for both groups, and all subjects answered all questions.

For statistical analysis we used a chi-square test for the four questions and independent *t*-test for the SSE scores to test group differences. We also performed linear and binary regression analyses to determine whether sex, religion, or access to information about epilepsy explained the differences between the two groups. We did not use age, as it had a minimum variability. The level of significance was set at $p < 0.05$.

RESULTS

Group-1 had 105 subjects (mean age = 16 years; CI = 15.9–16.3, SD = 1.0; 23.8% men; 83.8% of these students did not have information about epilepsy) and group-2 had 109 subjects (mean age = 16 years; CI = 15.8–16.1; SD = 0.8; 33.9% men; 82.6% of the subjects did not have information about epilepsy).

The differences between group-1 and group-2 for the four questions are shown in Table 1. All indicated more negative perceptions in group-2 than in group-1.

Table 1. Difference between “epileptics” and “people with epilepsy”

Questions	People with epilepsy % (n = 105)		Epileptics % (n = 109)		p
	Yes	No	Yes	No	
Do you think that people with epilepsy/epileptics are rejected by the society?	41.0	59.0	87.2	12.8	<0.001
Do you think that people with epilepsy/epileptics have more difficulties to get employed?	61.9	38.1	93.6	6.4	<0.001
Do you think that people with epilepsy/epileptics have more difficulties at school?	37.1	62.9	69.7	30.3	<0.001
Do you have prejudice toward people with epilepsy/epileptics?	0	100	2.8	97.2	0.08

The SSE score was higher indicating greater perceived stigma in group-2 (49, CI = 46.9–52.0) compared to group-1 (45, CI = 42.4–48.2) ($p = 0.03$). The linear and binary regression analyses using variable, sex, religion, access to information on epilepsy showed no significant differences between the two groups, and also they do not influence perceived stigma between groups 1 and 2.

DISCUSSION

The results of this study demonstrate the importance of choice of language on perception and stigma. The term “epileptic” tends to elicit more negative perceptions and a higher degree of stigma than does “person with epilepsy.”

According to the first four questions, we observed a large difference in responses depending on whether the expression used in the questionnaires was “epileptic” versus “person with epilepsy.” In addition, the SSE scores suggested higher stigma perception in teenagers using the term “epileptics” than in teenagers using the term “people with epilepsy.”

The two expressions we used are distinct; one is an adjective (epileptic) and the other a noun (person). Both of them carry some stigma “potential” (Schneider & Conrad, 1980); however, we found substantial differences when the emphasis was on the person compared to when it was on the disease. One study suggested that to “have” can imply possession and “to be” may imply identity. For this reason, it is less stigmatizing to use “to have” (Zola, 1988). Consequently, when the characteristic is negative, as is a disease, the recommendation was to use an expression that referred to a person with some characteristic. In some instances this is called person-first language (Zola, 1988).

Most models of stigma generally do not consider the subjective perception of stigma and emphasize the social context instead. A difference in perception is apparent between the two terms we used. This difference cannot be explained by social context alone. A model to explain social stigma must, therefore, consider more than a social context and include linguistic and other factors as well (Schneider & Conrad, 1980). The people learned, for example, how to proceed during an epileptic seizure, and this process can be maintained for one’s whole life. Maybe, for this reason, the learning process is very important to explain the differences between the two terms of this study; on one hand you learn about a human being and on the other about a disease, with which you share no sympathy. This process of learning and consequent behavior is in part explained by our previous study on teenagers exposed to two situations of management of an enacted seizure: adequate versus inadequate approach. A group of teenagers exposed to an adequate management had a lower perception of

epilepsy stigma than a group of teenagers exposed to inadequate management (Reno et al., 2007). So, also important is the emphasis on correct attitudes and correct information.

Another important aspect is the role of language in the thought process. In addition to differences seen on the effects of language on color discrimination (Winawer et al., 2007), Boroditsky (2001) has shown that cultural background rooted on different language construction (English vs. Chinese Mandarin) can influence the thought about abstract domains such as time. Nevertheless, Chen (2007) was not able to replicate the findings of Boroditsky (2001). In a discussion with colleagues conducting a Demonstration Project in China, whereas epilepsy stigma is high, it appears that in Chinese Mandarin there are no such distinctions between epileptic (adjective) and person with epilepsy (noun) (W. Wenzhi, personal communication). Therefore, it reinforces the notion that the perception of stigma can also be influenced by language in the context of a given society.

Our study reflects the social attitude to epilepsy in a group of adolescents. At this age they are still forming values, attitudes, and behaviors, and consolidating their processes of concept building. The adolescents are part of a potential segment within the society in which intervention by means of adequate information could serve ultimately to reduce myths about epilepsy and minimize the effects of stigma.

In summary, the words we use can influence our perceptions and have consequences for social stigma. The use of “inadequate labels” hides the true identity of the person and can contribute to increase the psychosocial difficulties. We recommend that we all refrain from using the term “epileptic,” and consider the effect of our choice of language and the consequences it may have in our efforts to bring epilepsy out of the shadows.

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We confirm that we have read the Journal’s position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

Limitations: This study was conducted with teenagers and cannot be generalized to other age groups. It should also be observed that the study was carried out in a Brazilian culture and the main determinant of the result was the local language (Brazilian Portuguese—Latin origin). It is necessary to conduct future studies in different societies, cultures, and to particularly assess this issue using other languages, such as those of Anglo-Saxon origin.

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