

Brief Communication

## Kids' perception about epilepsy

Paula T. Fernandes<sup>a,b</sup>, Paula Cabral<sup>c</sup>, Ulisses Araújo<sup>c</sup>,  
Ana Lúcia A. Noronha<sup>a,b</sup>, Li M. Li<sup>a,b,\*</sup>

<sup>a</sup> Department of Neurology, State University of Campinas (UNICAMP), Campinas/SP, Brazil

<sup>b</sup> Departments of Psychology and Education, Assistência à Saúde de Pacientes com Epilepsia (ASPE), Campinas/SP, Brazil

<sup>c</sup> Faculty of Education, UNICAMP, Campinas/SP, Brazil

Received 24 January 2005; revised 22 February 2005; accepted 23 February 2005

Available online 5 April 2005

### Abstract

**Purpose.** Epilepsy remains a stigmatized condition. Lack of information has been pointed to as a cause of the perpetuation of stigma. Our goal was to survey children's perception of epilepsy.

**Methods.** We used a questionnaire to determine if the children knew what epilepsy is and, if they did not know, what did they think epilepsy is. Twenty-nine children (15 girls; mean age 10 years, range 9–11 years) from a fourth-grade class of an elementary school in Campinas, Sao Paulo, Brazil, completed the questionnaires individually at the same time in the classroom. This took about 20 minutes.

**Results.** Only four children said they knew what epilepsy is: a disease of swallowing the tongue (3) and a disease that can kill (1). The perceptions of children who said they did not know what epilepsy is were: a disease that can kill, a disease of swallowing the tongue, a contagious disease, a serious illness, a head injury. Three children knew someone with epilepsy, and only two of them had said they knew what epilepsy is.

**Conclusion.** The perceptions elicited from the children had a negative connotation; only one child mentioned a relationship between epilepsy and the brain. The spontaneous thoughts of children in this age group, without the contamination of political correctness, may reflect society's collective unconsciousness of the prejudice toward epilepsy and people with epilepsy and needs to be further investigated. Continuous, repetitive educational efforts are necessary in elementary school to change these negative perceptions of epilepsy in our society.

© 2005 Elsevier Inc. All rights reserved.

**Keywords:** Epilepsy; Knowledge in school; Stigma; Prejudice

### 1. Introduction

Epilepsy is a common neurological condition that affects people of all ages, races, and social status. Through history, epilepsy had been considered a stigmatized condition [1–5]. Unfortunately this remains true today despite progress in medical science, as the diagnosis of

epilepsy can still have a profound social and psychological impact on patients and their families because of others' lack of information.

This lack of information has been indicated as an important factor in stigma perpetuation [6,7]. Interestingly, surveys in developing countries [8–11] with different cultures reveal common beliefs, for example, that epilepsy is a contagious illness or a kind of mental retardation [12–14]. In addition, some people do not know what to do with a person during an epileptic seizure, which promotes a feeling of impotence and reinforces the misconception that epilepsy has no treatment.

\* Corresponding author. Fax: +55 19 37887483.

E-mail addresses: [limin@fcm.unicamp.br](mailto:limin@fcm.unicamp.br), [li@aspebrasil.org](mailto:li@aspebrasil.org) (L.M. Li).

URL: <http://www.aspebrasil.org> (L.M. Li).

Information campaigns have had little effect on reducing stigma [15]. There may have been an increase in “politically” correct attitudes rather than real changes in society’s perception. In this regard, prejudice has more roots than reason (Machiavelli), and assessment of basic perceptions, should be carried out in the absence of political correctness. Thus, evaluation of children’s perceptions should reflect raw social perceptions derived from elementary information from the family and the local social environment without contamination by political correctness. The objective of this explorative study, part of the National Demonstration Project of the Global Campaign “Epilepsy Out of the Shadows” in Brazil [1], is to survey children’s perceptions of epilepsy.

## 2. Methods

We used a questionnaire requesting basic personal information (age and gender) and asking two questions about epilepsy:

1. Do you know what epilepsy is?—yes—no  
If you answered yes, what is epilepsy for you?  
If you answered no, what do you think epilepsy is?
2. Do you know anyone with epilepsy?—yes—no  
If you know, who is this person?

One of us (P.C.) administered the questionnaire to 29 children (15 girls; mean age 10 years, range 9–11 years). All of them were from a fourth grade class of a public elementary school in Campinas, São Paulo, Brazil. This school was chosen because it is typical of the public schools in this city. It follows the national standards of education. The students were, on average, from lower-middle socioeconomic status families and attended school for 4 hours each day. We chose the fourth grade because it comprises the youngest children capable of expressing themselves adequately in writing and reflecting social perceptions.

The questionnaires were completed individually at the same time in the classroom. The questions were read by the researcher, and the children wrote their answers on a piece of paper without consulting each other or any other source. The process took about 20 minutes. After this survey, the researcher carried out educational activities with these children to improve their knowledge of epilepsy.

## 3. Results

Only four children (13.8%) said they know what epilepsy is: a disease of swallowing the tongue (3) and a disease that can kill (1).

Table 1  
Perceptions of children about epilepsy

Epilepsy is:	N (%) <sup>a</sup>
Disease that can kill	6 (24)
I don't know	5 (20)
Disease of swallowing the tongue	4 (16)
Contagious disease	4 (16)
Only a disease	3 (12)
Serious illness	2 (8)
Head injury	1 (4)

<sup>a</sup> Total = 25.

The perceptions of those children who said they did not know what epilepsy is are summarized in Table 1. Only three children (10.3%) knew someone with epilepsy (neighbors); two of them had said they know what epilepsy is.

## 4. Discussion

In this study, the perceptions observed among the children had a negative connotation. Only one child mentioned epilepsy in relation to the brain (head injury). Knowing someone with epilepsy did not necessarily improve their knowledge or perception. Interestingly, we detected in this small group common perceptions: a disease that can kill, swallowing the tongue, and contagiousness. The spontaneous thoughts of this age group, in the absence of political correctness, may reflect society’s collective unconsciousness of prejudice toward epilepsy and people with epilepsy. These features should be further investigated.

Another point in this study is related to what epilepsy represents, which, to some extent, was expressed by the children as either its causes (head injury, contagious) or its consequences (death, swallowing the tongue); this illustrates that our community is not familiar with epilepsy, which, in turn, can lead to perpetuation of stigma [16].

This exploratory study can guide future studies with larger samples in different social strata to provide more definitive answers in this area. Nevertheless, we conclude from our results that any information campaigns should target young age groups as the misperceptions are there, as is the opportunity to change them [15]. This, however, will require continuous and repetitive educational efforts in elementary schools.

In Brazil, after an initiative by the ASPE (executor of National Demonstration Project), the theme of epilepsy has been included in a major educational program of the Ministry of Education that involve more than 26,000 schools in Brazil. We are planning educational activities related to citizenship, ethics, and health subjects. This proposed intervention has as its objective introduction of the theme of epilepsy into the different disciplines of

the curriculum, trying to discuss not only the biological aspects of the condition but also the daily psychosocial problems faced by people with epilepsy. The overall effort is to bring global awareness of the issue in the context of health and citizenship in our society.

The long term changes remain to be seen, and we hope this selective action improves the understanding of stigma and is a major step toward bringing epilepsy out of the shadows.

### Acknowledgment

Study supported by FAPESP 02/11871-8.

### References

- [1] Li LM, Sander JW. National demonstration project on epilepsy in Brazil. *Arq Neuropsiquiatr* 2003;61:153–6.
- [2] Fernandes PT, Souza EA. Identification of family variables in parents' groups of children with epilepsy. *Arq Neuropsiquiatr* 2001;59:854–8.
- [3] Meinardi H, Scott RA, Reis R, Sander JW. The treatment gap in epilepsy: the current situation and way forwards. *Epilepsia* 2001;42:136–49.
- [4] Jallon P. Epilepsy in developing countries: ILAE workshop report. *Epilepsia* 1997;38:1143–51.
- [5] Fernandes PT, Souza EA. Perception of epilepsy stigma in fundamental school teachers. *Estud Psicol* 2004;9:189–95.
- [6] Baker GA. People with epilepsy: what do they know and understand, and how does this contribute to their perceived level of stigma? *Epilepsy Behav* 2002;3:26–32.
- [7] Schneider JW, Conrad P. Having epilepsy: the experience and control of illness. Philadelphia: Temple Univ. Press; 1983.
- [8] Baker G. The psychosocial burden of epilepsy. *Epilepsia* 2002;43:26–30.
- [9] DiIorio C, Osborne Shafer P, Letz R, Henry T, Schomer DL, Yeager K. The association of stigma with self-management and perceptions of health care among adults with epilepsy. *Epilepsy Behav* 2003;4:259–67.
- [10] Ablon J. The nature of stigma and medical conditions. *Epilepsy Behav* 2002;3:2–9.
- [11] Jacoby A. Stigma, epilepsy, and quality of life. *Epilepsy Behav* 2002;3:10–20.
- [12] Baker GA, Jacoby A, Buck D, Stalgis C, Monnet D. Quality of life of people with epilepsy: a European study. *Epilepsia* 1997;38:353–62.
- [13] Gummit RJ. Living well with epilepsy. New York: Demos Vermande; 1997.
- [14] Devinsky O, Penry JK. Quality of life in epilepsy: the clinician's view. *Epilepsia* 1993;34:s4–7.
- [15] Stuart HMA. Stigma and stigma reduction: lessons learned. *Sante Ment Que* 2003;28:54–72.
- [16] MacLeod JS, Austin JK. Stigma in the lives of adolescents with epilepsy: a review of the literature. *Epilepsy Behav* 2003;4:112–7.