

Stigma of Epilepsy

Nancy F. Bandstra, Carol S. Camfield, Peter R. Camfield

ABSTRACT: Epilepsy directly affects 50 million people worldwide. Most can achieve excellent seizure control; however, people living with epilepsy continue to suffer from enacted or perceived stigma that is based on myths, misconceptions and misunderstandings that have persisted for thousands of years. This paper reviews the frequency and nature of stigma toward epilepsy. Significant negative attitudes prevail in the adolescent and adult public worldwide leading to loneliness and social avoidance both in school and in the workplace. People with epilepsy are often wrongly viewed as having mental health and antisocial issues and as being potentially violent toward others. Twenty-five percent of adults having epilepsy describe social stigma as a result of their epilepsy. They fear rejection and often feel shame or loneliness from this diagnosis. The psychosocial and social impact of epilepsy is significant. Yet few specific interventions have been demonstrated to alter this perception. The effect on public education is primarily short-term, while change over the long-term in attitudes and inaccurate beliefs have not presently been proven effective. School education programming demonstrates improved knowledge and attitude a month after a classroom intervention, but persisting change over a longer period of time has not been evaluated. In-depth adult psycho-educational programs for adults with epilepsy improves knowledge, coping skills and level of felt stigma. However these gains have not demonstrated persistence over time. Myths, misconceptions and misunderstandings about epilepsy continue and programs aimed at increasing knowledge and reducing negative public attitudes should be enhanced.

RÉSUMÉ: Stigmate de l'épilepsie. L'épilepsie atteint 50 millions d'individus à travers le monde. La plupart des patients obtiennent un excellent contrôle des crises. Cependant, ceux qui vivent avec l'épilepsie souffrent dans les faits ou dans la perception d'un stigmate qui est fondé sur des mythes, des conceptions erronées et de l'ignorance qui perdurent depuis des millénaires. Dans cet article, nous analysons la fréquence et la nature des stigmates attachés à l'épilepsie. Des attitudes négatives significatives prévalent dans le public adolescent et adulte à travers le monde, ce qui mène à l'isolement et à l'évitement social à l'école et dans le milieu du travail. Les individus atteints d'épilepsie sont souvent considérés à tort comme ayant des problèmes de santé mentale et des tendances antisociales et comme étant potentiellement violents envers les autres. Vingt-cinq pour cent des adultes atteints d'épilepsie perçoivent une stigmatisation sociale à cause de leur épilepsie. Ils craignent le rejet et ressentent souvent de la honte ou de l'isolement à cause de ce diagnostic. Bien que l'épilepsie ait un impact psychosocial et social important, peu d'interventions spécifiques se sont avérées efficaces pour modifier cette situation. Leur effet sur l'éducation du public est la plupart du temps de courte durée et la persistance des changements d'attitudes et de croyances à long terme n'a pas été démontrée. Les programmes scolaires améliorent les connaissances et les attitudes un mois après l'intervention en classe, mais l'évaluation de la persistance des changements sur une période plus longue n'a pas été faite. Les programmes psychoéducatifs approfondis destinés aux adultes atteints d'épilepsie améliorent les connaissances, les capacités d'adaptation et le niveau de stigmatisation ressenti. Cependant, ces acquis ne persistent pas à long terme. Les mythes, les conceptions erronées et l'ignorance à propos de l'épilepsie persistent et les programmes destinés à améliorer les connaissances et à diminuer les attitudes négatives du public devraient être intensifiés.

Can. J. Neurol. Sci. 2008; 35: 436-440

Epilepsy affects approximately 50 million people worldwide with a current prevalence in Canada of 5-10 per 1000.^{1,2} Despite effective treatments to control seizures, in the majority of people with epilepsy (PWE) there continues to be significant stigma associated with the diagnosis. Kale summarized the history of epilepsy as "4,000 years of ignorance, superstition, and stigma followed by 100 years of knowledge, superstition, and stigma".³ Fortunately, demonic possession is no longer the proposed pathophysiology of epilepsy, as it was in Biblical times and the Middle Ages; however, currently stigmatization continues to persist in our society.

Sociologist Erving Goffman described stigma as a process where the negative reactions of others "serve to spoil one's own

social identity".⁴ He argued that stigmatized individuals are seen as "not quite human" and thereby "rightful" targets for discrimination and prejudice. Accordingly, stigmatized individuals have an undesired characteristic that separates them

From the Department of Pediatrics & Psychology, Dalhousie University and the IWK Health Centre, Halifax, Nova Scotia, Canada.

RECEIVED JANUARY 14, 2008. FINAL REVISIONS SUBMITTED MARCH 17, 2008.

Reprint requests to: Carol S. Camfield, IWK Health Centre, P.O. Box 9700, Halifax, Nova Scotia, B3K 6R8, Canada.

from the general population. This “undesired differentness” is conceptualized as a loss of status and power for the stigmatized individual in the community.

Seizures associated with epilepsy are unpredictable and often quite dramatic; the public finds them frightening. The Epilepsy Foundation summarizes this aspect of living with epilepsy in its Recipe for Stigma: “Take one cup of ignorance and blend in a heaping teaspoon of fear. Let the ingredients stand for about 5,000 years and then wait for discrimination to rise”.⁵

How much stigma exists?

In 2001 a questionnaire developed by the Epilepsy Foundation of America was distributed to 19,441 American high school students by 20 Epilepsy Foundation affiliates.⁶ Surprisingly, 19% of the respondents reported that epilepsy was a form of mental illness and another 30% were unsure. Only 27% were sure that epilepsy was not a mental illness. More than 50% were uncertain if PWE could drive cars, could work or should have children. Although 51% thought that people died from seizures, only 33% thought they would know what to do if someone had a seizure. Only 50% confidently believed epilepsy was not contagious. One third (31%) indicated that they would not date a person with epilepsy and 63% believed that youth with epilepsy were or might be more likely to get bullied or picked on than others. In fact, more than 50% thought it was possible to tell if someone had epilepsy by looking at her or him. Unfortunately, the reasons for these inaccurate beliefs and negative attitudes about epilepsy were not explored.

A recent community-based survey conducted by the UK Office of National Statistics (1600 randomly selected adults, response rate 62%) identified important negative attitudes toward PWE thought to contribute to continued stigmatization.⁷ Despite familiarity with epilepsy (25% reported knowing someone with epilepsy), respondents ranked working alongside someone with the disorder as causing the second highest concern (the highest was a person with stress or depression). Twenty-two percent endorsed the statement that PWE suffered from more personality problems than those without the disorder. This unfavorable perception is further supported by other large-scale community-based surveys^{8,9} suggesting that PWE are often characterized as retarded, frail, antisocial, hostile and potentially violent, slow, and physically unappealing. Reis argues that although these classic stereotypes may no longer carry the same weight, new stereotypes have taken their place.¹⁰ These new social labels characterize PWE as withdrawn and overly anxious. While it is true that many PWE suffer from psychosocial difficulties, the widespread application of these stereotypes to all PWE is obviously unfounded.

Stigma against PWE may be less now than 50 years ago. For example, Caviness and Gallup conducted a series of interviews every five years between 1949 and 1979.¹¹ One question from these interviews asked: “Would you object to having any of your children at school or at play associate with persons who sometimes have seizures (fits)? In 1949, 24% answered “yes”, while in 1979, 6% answered “yes”. An additional question asked: “Do you think people with epilepsy should be employed in jobs like other people?” In 1949, 35% answered “no” and in 1979 the number had reduced considerably to 9%. Although these data suggest improvement, they also reflect a continued

persistence of misconceptions and misunderstandings related to epilepsy.

Fisher and colleagues assessed the perceptions and subjective experiences of over 1,000 PWE with a national postal survey in 1999, as well as a brief interview with callers to the Epilepsy Foundation of America.¹² Subjects were asked about characteristics of their epilepsy (e.g., seizure type and frequency), perceived personal triggers of seizures (e.g., stress), and the impact of epilepsy on their own lives. Almost a quarter (24%) of those surveyed spontaneously reported elements of social stigma in their lives as a result of epilepsy. They often feared the reaction of others to their diagnosis and felt personal shame or loneliness resulting from the diagnosis itself. Younger PWE felt shame and/or loneliness more frequently, while older respondents were more concerned about adverse changes in their lifestyle. Another recent community based survey of 165 PWE found that 42% felt that the general public harbored negative feelings and reactions toward individuals with epilepsy and 41% felt that this belief negatively affected how they viewed themselves.¹³

Perceived and Enacted Stigma

Goffman and others distinguish between stigma that is enacted (i.e., actual instances of discrimination because of the diagnosis of epilepsy) versus stigma that is felt (i.e., the embarrassment/disgrace of having epilepsy or the fear of being discriminated against).^{4,9} Enacted stigma for PWE can be blatant, such as job discrimination and/or job loss. Subtler forms of enacted stigma may consist of social rejection or disapproval.¹⁴ On the other hand, stigma may be “felt” even if it does not actually exist. Additional research suggest felt stigma may be more prevalent than enacted stigma and is troubling for the individual even if it does not arise from a social interaction or accurately reflect the evaluative views of others. A UK cohort of 607 PWE in remission highlights this possibility. Although only a small percentage of this large sample attributed specific work-related difficulties to their diagnosis, approximately a third of respondents reported that they perceived that their diagnosis of epilepsy had made it difficult for them to secure a job.¹⁵

PWE are viewed as violent

The PWE are often characterized as aggressive and potentially violent.^{9,10} We disagree with Reis who argues that this classic stereotype no longer has an important impact.¹⁰ In Nova Scotia, we assessed the public’s perceptions of PWE as violent in 1981 and again in 2006 using a series of vignettes depicting hypothetical PWE responding aggressively or violently to a variety of situations.¹⁶ Two examples of these vignettes are shown here:

“Jane accidentally bumped into John, who has epilepsy, in the cafeteria. John became very angry and stabbed Jane repeatedly with a fork. He explained that he was not to be blamed because he was suffering from an epilepsy seizure.”

“As Tom was riding his bicycle to school, he ran over his mother’s favorite tulip plants and continued to pedal toward school. When questioned about this, he said that he was suffering from an attack of epilepsy.”

Participants were asked whether the vignettes were believable. The response choices they were given included “Very

Likely”, “Possible”, and “Unlikely”. In addition participants were asked direct questions (e.g., “Could a person with epilepsy punch you in the face if you held him or her down during an epilepsy seizure?”). Groups included in this study were law and medical students, physicians, youth care workers, the general public, and PWE. Almost half of all of the respondents reported that violence was possible and even likely during a seizure. All responded to at least 40% of the vignettes/questions incorrectly (including medical students), except physicians who were incorrect 20% of the time. Sadly, the responses were nearly identical in 1981 and 2006. We concluded that the stereotype of PWE as potentially violent might be an important factor in the continued stigmatization over the 25 year-span of the study.

Stigma and its interaction with psychosocial problems in PWE

Although seizures and medication side effects are obviously a burden for PWE, the psychological and social impact of living with epilepsy may be the most troubling. Both adults and children with epilepsy are affected by personal psychosocial difficulties,¹⁷⁻¹⁹ which may interact with stigmatization and make coping with it more complex. These problems include poor self-esteem, social isolation, anxiety, improper social skills, loss of a sense of control of their life, depression, emotional distress, and psychosis.¹⁷⁻¹⁹ In addition, PWE have reduced marriageability, less years of education, and more unemployment or under-employment than population controls or other chronic diseases.²⁰ It is perhaps understandable that PWE are at an increased risk for suicidal ideation and suicide attempts.²¹ Stigma may then worsen these psychological problems through obvious routes such as poor living and work conditions, as well as relationship problems with family, friends, and co-workers.

Stigma contributes to what is often characterized as a “hidden burden” that occurs in a variety of chronic disorders and conditions. The shame of such a stigmatizing disorder coupled with the fear of being discriminated against often result in PWE and their parents’ adopting a strict policy of non-disclosure.¹ The diagnosis and the effects of the disorder are hidden from acquaintances, co-workers, teachers, close friends, and even some family members.^{9,15} We suspect that this atmosphere of secrecy can be very socially disabling and isolating.

Psychological health outcomes associated with the stigma of epilepsy were highlighted in a survey of over 5,000 people recruited from epilepsy support groups in 15 different European countries.²² Stigma was assessed using a three-item self-report measure. Participants were asked whether they felt they were ever treated as inferior, avoided by others or made others uncomfortable because of their diagnosis. About half of respondents (51%) reported feeling stigmatized with 18% describing high levels of stigmatization. Stigma was closely correlated with elevated levels of worry and an overall negative outlook on life. In a separate North American community-based participatory study of 165 PWE, 19% felt that the most common misunderstanding of the public was that “persons with epilepsy should be socially avoided”.¹⁹ These studies suggest that high feelings of stigmatization in PWE may exacerbate the psychosocial impact of epilepsy on PWE. However, the results from this study should be interpreted with some caution. The questionnaires were self-report and many of the measures used in Europe were translated into language for which they were

never validated. In addition, most of the participants were recruited from epilepsy support groups, which likely attract participants having more serious problems. In the American study, the sample was relatively small and from those attending a single tertiary centre. It is possible that participants provided socially acceptable answers to their medical treatment facility.

Stigma & Seizure Control

Baker and colleagues have shown that seizure frequency is a major contributor to an individual’s psychosocial difficulties, decreased quality of life, and perceived stigma.²² Respondents described increased effects of stigma with poor seizure control resulting in frequent seizures. Those with the highest seizure frequency were three times more likely to report elevated feelings of stigmatization as compared to those who were seizure-free. Furthermore, even those on medication with infrequent seizures were more likely to report elevated levels of stigmatization, when compared to those in remission. A separate study from the UK made the same observations.¹⁹ In this community-based sample, information was retrospectively collected from medical charts and from self-report questionnaires from 1,341 patients who were currently taking antiepileptic drugs and/or had a recent history of seizures. A clear relationship between seizure frequency and perceived stigma emerged in this sample. Overall, 62% of those with frequent seizures also reported feeling stigmatized by their diagnosis. However, only 40% of those with less frequent seizure felt stigmatized. Each of these studies examining the relationship between seizure control and stigma are co relational in nature. Because they cannot speak to cause and effect, it is possible that perceived level of stigma may simply reflect overall negative feelings about quality of life in those with poor seizure control.

Stigma-Mitigating Strategies/Interventions

Public Interventions

Few interventions have specifically addressed the stigma associated with epilepsy, but some strategies have been proposed to counter stigma in other health conditions, such as HIV/AIDS.²³⁻²⁵ Weiss and Ramakrishna at the National Institutes of Health’s conference on stigma and global health suggested the use of social marketing campaigns aimed at public education for both members of the public and those with disabling conditions.²⁴ While this approach is aimed to reduce misconceptions and misapprehensions and thereby reduce stigma, results using such an approach to reduce the stigma associated with HIV/AIDS have been mixed. Interventions appeared to make gains in public knowledge in the short-term, but attempts to make long-term changes in attitudes and inaccurate beliefs do not appear to be as successful.²⁶

Being familiar with epilepsy may be an important first step in reducing stigma. In the large U.K. study about the public’s knowledge and attitudes about epilepsy, respondents who were familiar with a PWE more often identified signs and causes of seizures and knew that epilepsy could be successfully treated.⁷ Those having fewer educational qualifications expressed more negative attitudes.

While research aimed to reduce the stigma of epilepsy is limited, there is some evidence to suggest its partial success. For

instance, school children in Grade five (n=783) in Ontario, Canada were randomized to receive or not to receive a 30-minute educational program about epilepsy. The intervention and control group completed a baseline and outcome questionnaire one month later. The intervention group demonstrated improved knowledge and slightly better attitudes toward those with epilepsy.²⁶ However, the long-term effects of such an intervention are unknown as is the validity for other age groups.

Group educational programs for PWE themselves may also limit the effect of stigma. Randomized studies have documented that there is enhanced knowledge, self-esteem, and increased coping with felt and perceived stigma. For example, Ried and colleagues^{27,28} have created a psycho-educational program for PWE and their families covering five content areas: medical aspects, healthy lifestyle behaviors, family and peer relationships, self-esteem, and stress management techniques. Sessions were one hour long and met weekly for six weeks. Improvements were documented in all areas.²⁷ By inference, those with better knowledge would be expected to deal with stigma more readily, although this specific issue was not addressed.

Personal Interventions

A European study randomized 242 PWE aged 16-80 years from 22 epilepsy centers to an intervention or a control group.²⁸ The intervention group (n=113) received the Modular Service Package Epilepsy that addressed nine content areas: epidemiology, basic knowledge, living with epilepsy, diagnostics, therapy, self-control, prognosis, psychosocial aspects, and network epilepsy. The control group (n=129) completed similar baseline and follow-up generic and epilepsy-specific questionnaires at six months. There was no change in the SF-36 (general health related quality of life) and self-esteem items. However, there was an increase in knowledge and coping skills, and fewer participants reported seizures in the intervention group. It seems likely that these improvements might diminish the effects of stigma.

CONCLUSION

Stigma is highly associated with incomplete seizure control and poor psychosocial outcomes for PWE (e.g., depression, anxiety, social isolation). The PWE have reported that stigma is one of their most significant challenges.^{15,29} Interventions for individuals with epilepsy in a clinical setting are of unproven benefit to overcome stigma. However, increasing knowledge about epilepsy and interventions to improve self-esteem seem likely to be helpful. Misconceptions about epilepsy continue and programs aimed at increasing knowledge and reducing negative public attitudes need to be enhanced. An atmosphere of understanding within educational and industrial settings and the health care system may help PWE feel sufficiently comfortable to disclose their diagnosis to others, which in turn may contribute to increased public understanding.

Future Directions

Clearly more research is needed to understand the origins of stigma for people with epilepsy and how to decrease its impact. Education at many levels of society including the public,

workplaces, schools, health care and recreational settings is needed. People with epilepsy need to learn about their disorder to explain it appropriately. They also must be able to recognize and deal with stigma when it appears in their personal lives. All of these goals are enormous, but the individual physician can probably help a great deal by considering issues about stigma as they approach each person with epilepsy.

ACKNOWLEDGEMENTS

The authors thank Jeannette McGlone for her comments and suggestions on an earlier version of the manuscript. N.F. Bandstra was supported by a Nova Scotia Health Research Foundation Student Research Award and an honorary Killam Predoctoral Scholarship.

REFERENCES

1. Tellez-Zenteno JF, Pondal-Sordo M, Matijevic S, Wiebe S. National and regional prevalence of self-reported epilepsy in Canada. *Epilepsia*. 2004;45:1623-9.
2. Wiebe S, Bellhouse DR, Fallahay C, Eliasziw M. Burden of epilepsy: the Ontario Health Survey. *Can J Neurol Sci*. 1999; 26:263-70.
3. Kale R. Bringing epilepsy out of the shadows: wide treatment gap needs to be reduced. *BMJ*. 1997;315:2-3.
4. Goffman E. *Stigma: notes on the management of spoiled identity*. New York: Simon & Schuster; 1986.
5. Epilepsy Foundation [http://www.epilepsyfoundation.org/]. Landover, MD: The Epilepsy Foundation; [cited 2007 Dec 28]. Available from: <http://www.epilepsyfoundation.org/epilepsysusa/news/stigmarecipe.cfm>.
6. Austin JK, Shafer PO, Deering JB. Epilepsy familiarity, knowledge, and perceptions of stigma: report from a survey of adolescents in the general population. *Epilepsy Behav*. 2002;3:368-75.
7. Jacoby A, Gorry J, Gamble C, Baker GA. Public knowledge, private grief: a study of public attitudes to epilepsy in the United Kingdom and implications for stigma. *Epilepsia*. 2004;45: 1405-15.
8. Harrison R, West P. Images of a grand mal. *New Soc*. 1977;40: 762-82.
9. Scambler G. *Epilepsy*. London: Tavistock; 1989.
10. Reis R. Epilepsy and self-identity among the Dutch. *Med Anthropol*. 2001;19:355-82.
11. Caveness WF, Gallup Jr GH. A survey of public attitudes toward epilepsy in 1979 with an indication of trends over the past thirty years. *Epilepsia*. 1980;21:509-18.
12. Fisher RS, Vickrey BG, Gibson P, Hermann B, Penovich P, Scherer A, et al. The impact of epilepsy from the patient's perspective I. Descriptions and subjective perceptions. *Epilepsy Res*. 2000;41: 39-51.
13. Paschal AM, Hawley SR, St. Romain T, Liow K, Molgaard CA, Sly J, et al. Epilepsy patients' perceptions about stigma, education, and awareness: preliminary responses based on a community participatory approach. *Epilepsy Behav*. 2007;11:329-37.
14. Link BG, Phelan JC. On stigma and its public health implications. 2001, [cited 2007 Dec 28]. Available from: www.stigmaconference.nih.gov/LinkPaper.htm.
15. Jacoby A. Felt versus enacted stigma: a concept revisited. Evidence from a study of people with epilepsy in remission. *Soc Sci Med*. 1994;38:269-74.
16. Collins TBK, Camfield PR, Camfield CS, Lee K. People with epilepsy are often perceived as violent. *Epilepsy Behav*. 2007; 10:69-76.
17. Camfield P, Camfield C. Long-term prognosis for symptomatic (secondarily) generalized epilepsies: a population-based study. *Epilepsia*. 2007;48:1128-32.
18. Jacoby A, Baker GA, Steen N, Potts P, Chadwick DW. The clinical course of epilepsy and its psychosocial correlates: findings from a U.K. community study. *Epilepsia*. 1996;37:148-61.

19. Moore PM, Baker GA. The neuropsychological and emotional consequences of living with intractable temporal lobe epilepsy: implications for clinical management. *Seizure*. 2002;11:224-30.
20. Wirrell EC, Camfield CS, Camfield PR, Dooley JM, Gordon KE, Smith B. Long-term psychosocial outcome in typical absence epilepsy. Sometimes a wolf in sheep's clothing. *Arch Pediatr Adol Med*. 1997;151:152-8.
21. Kanner AM. Depression in epilepsy: prevalence, clinical semiology, pathogenic mechanisms, and treatment. *Biol Psychiatry*. 2003;54:388-98.
22. Baker GA, Brooks J, Buck D, Jacoby A. The stigma of epilepsy: a European perspective. *Epilepsia*. 1999;41:98-104.
23. Birbeck G. Interventions to reduce epilepsy-associated stigma. *Psychol Health Med*. 2006;11:364-6.
24. Weiss MG, Ramakrishna J. Stigma interventions and research for international health. *Lancet*. 2006;367:536-8.
25. Brown L, Macintyre K, Trujillo L. Interventions to reduce HIV/AIDS stigma: what have we learned? *AIDS Educ Prev*. 2003;15:49-69.
26. Martiniuk ALC, Speechley KN, Secco M, Campbell MK, Donner A. Evaluation of an epilepsy education program for Grade 5 students: a cluster randomized trial. *Epilepsy Behav*. 2007;10:604-10.
27. Ried S, Specht U, Thorbecke R, Goecke K, Wohlfarth R. MOSES: an educational program for patients with epilepsy and their relatives. *Epilepsia*. 2001;42 Suppl 3:76-80.
28. May TW, Pfäfflin M. The efficacy of an educational treatment program for patients with epilepsy (MOSES): results of a controlled, randomized study. *Epilepsia*. 2002;43:539-49.
29. Jacoby A, Austin JK. Social stigma for adults and children with epilepsy. *Epilepsia*. 2007;48 Suppl 9:6-9.