

Title: Social stigma for adults and children with epilepsy

Ann Jacoby¹ & Joan K. Austin²

¹Division of Public Health, University of Liverpool, UK

²Indiana University School of Nursing, USA

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Address for correspondence:

Ann Jacoby

Division of Public Health

University of Liverpool

Whelan Building, 3rd Floor

The Quadrangle, Brownlow Hill

Liverpool, UK

L69 3GB

Abstract:

For many people with epilepsy, the continuing social reality of their condition is as a stigma. Epilepsy stigma has three different levels; internalized, interpersonal, and institutional. While there have been documented improvements in public attitudes towards epilepsy, the remnants of 'old' ideas about epilepsy continue to inform popular concepts resulting in a difficult social environment for those affected. The social and quality of life problems arising from a diagnosis of epilepsy can represent greater challenges than are warranted by its clinical severity. The relationship between stigma and impaired quality of life is well documented. Tackling the problem of stigma effectively requires that all three of different levels at which it operates are systematically addressed.

Introduction

For many people with epilepsy, the continuing social reality of their condition is as a stigma. Stigma refers to the loss of status that arises from being in possession of an attribute, for example a health condition, that has been culturally defined as 'undesirably different' and so as 'deeply discrediting' (1). A person's perceptions of stigma can result from previous negative experience or from anticipation of future negative experience. It is insufficient only to consider stigma perceptions of those affected by a particular health condition, since stigma operates at different levels, defined by Muhlbauer (2) as the internalized, the interpersonal, and the institutional (Box 1).

Interpersonal aspects of epilepsy stigma: public attitudes

The association of epilepsy to stigma extends far back in time and across many cultures. In ancient and primitive societies, epilepsy was often believed to originate from malignant causes and to be associated with sin or demonic possession. Seizures were often considered bad omens. Theories of epilepsy as contagion and lunacy can also be traced back to antiquity. Even when biomedical explanations for epilepsy replaced these

earlier magical ones, the new paradigm brought its own associations to stigma, with studies linking epilepsy to aggressive or criminal behaviour, abnormal sexual activity, hereditary degeneracy and a specific 'epileptic personality'. These explanations have reinforced negative stereotypes and perpetuate stigma.

Recent studies worldwide have found improvements in public attitudes towards epilepsy, even though levels of knowledge have remained fairly static (3); however, remnants of the 'old' ideas continue to inform popular concepts of epilepsy, resulting in continuing misperceptions and negative attitudes. In Austria, 15% of survey respondents would object to their child marrying a person with epilepsy (4). In the Czech Republic (5) 29% still consider epilepsy to be a form of insanity. In the UK, more than half of 1,600 randomly selected informants agreed that people with epilepsy are treated differently, including social avoidance and exclusion – and they attributed this in part to fears about their unreliability and non-normality (6). Over a fifth agreed that people with epilepsy have more personality problems than those without. The prevalence of such negative attitudes is sufficiently high as to suggest that most people with epilepsy will encounter them fairly routinely.

A US study involving a nationwide random sample of 758 adults found four underlying dimensions that characterized current attitudes about epilepsy (7). First negative stereotypes reflected beliefs that other people hold about people with epilepsy: for example, people with epilepsy are unreliable or should not marry. Second, risk and safety concerns reflected the public's underlying worries about potential harms if a person with epilepsy engages in certain activities. Thirdly, work and role expectations reflected beliefs about the ability of persons with epilepsy to be as successful work and social roles. Fourth, personal fear and social avoidance reflected affective responses such as being nervous around a person with epilepsy or being afraid to be alone with someone with epilepsy. Many (27.3%) believed that there was a high likelihood of death

with every seizure and 66.5% thought they would need to put something in the person's mouth during a seizure. Lower levels of knowledge about epilepsy were associated with higher perceptions of stigma. It is clear that addressing negative attitudes on the part of others must include knowledge-based and emotion-based reactions.

A recent survey of 19,000 USA teenagers indicated many held negative perceptions of people with epilepsy - likely a result of lack of familiarity and knowledge (8). For example, 52% had never heard of epilepsy, 46% were not sure if it was contagious, and 40% were not sure if people with epilepsy were dangerous. Only 31% reported they would consider dating someone with epilepsy and 75% thought teenagers with epilepsy were more likely to be bullied or picked on than their healthy peers. One recent UK study suggested that some social avoidance of teenagers with epilepsy might be related to concerns about not knowing what to do if a seizure should occur. When children and adolescents experience the kind of difficult social environment reflected in these expressed attitudes of peers, internalized stigma would be expected.

Institutional aspects of epilepsy stigma: rules and sanctions

Legal discrimination against people with epilepsy dates back for centuries and has included restrictions on marriage, fertility and immigration, which in some countries have only recently been abandoned. Legal and statutory discrimination still operates across some life domains, even though in many countries epilepsy is now considered as a 'prescribed disability' with legal protections. One obvious area of restriction is employment. In the UK people with epilepsy are barred, by statutory legislation, from admission to the armed forces; and may face restrictions if they opt for careers in teaching, medicine, the police force, fire brigade and prison service. Similarly, worldwide people with epilepsy face driving restrictions ranging from a total ban to the restoration of a license after a fixed period of seizure freedom.

Individualized aspects of epilepsy stigma: reactions of people with epilepsy

It is clear that the social problems and repercussions for overall quality of life can be greater challenges than warranted by the seizure severity. First, a diagnosis of epilepsy appears often to be interpreted negatively, leading sometimes to an overwhelming feeling of shame. Once diagnosed, people with epilepsy appear often to operate in expectation of negative reactions and attitudes from others and develop a special “epileptic identity” underpinned by these expectations (9). A distinction can be made between ‘felt’ and ‘enacted’ stigma. Felt stigma refers to the shame of being epileptic and the fear of encountering epilepsy-linked enacted stigma; whereas enacted stigma refers to actual episodes of discrimination. Felt stigma may cause more personal anguish and unhappiness than enacted. Felt stigma may also become a self fulfilling prophecy, in that fear and shame about their epilepsy leads people to conceal it from others and so to deny the opportunity to test whether the enacted stigma and discrimination they expect will, in fact, materialize (9). In one study of people with epilepsy in remission, only 2% could recall any occasion of unfair treatment at work and only 3% thought they had not been successful with a job application because of their epilepsy – yet a third felt their epilepsy made it more difficult for them than for others to gain employment and many admitted they had not disclosed their condition to employers out of fear of discrimination (3).

Family members, particularly parents, emerge as key figures in the process by which people with epilepsy come to acknowledge their ‘undesired difference’. Their reactions to a diagnosis of epilepsy in their child seem to set the stage for the child’s own interpretation of its significance. Where parents’ reactions are negative, the child learns to think about epilepsy as something shameful; where parents’ attitudes are that epilepsy will attract hostile reactions, the child learns that epilepsy is something to keep quiet about. Teachers, healthcare professionals and others may endorse negative attitudes, thus acting as ‘stigma coaches’ for their affected charges. Not surprisingly,

strategies adopted by people with epilepsy for managing stigma include rejection and/or renegotiation of the diagnosis in favour of a more socially benign one; social withdrawal and isolation to avoid public exposure of seizures; and reduction of expectations for the future. Anxiety over other people's potentially negative reactions may also lead to concealment of the condition, 'covering' for seizures; over-protection by significant others leading to increased dependency; and 'disabling talk' (whereby significant others detail to the person affected by epilepsy the restrictions it imposes upon them). It is perhaps not surprising that adults with epilepsy described themselves as less valuable, less adaptable, less dependable, less mature, less stable, less able to cope, less successful and less well-adjusted than people without epilepsy (10). Children and adolescents with epilepsy who experience felt stigma have been shown to have lower self-esteem and increased anxiety and depression.

Prevalence of felt stigma and impact on life success

Felt stigma has been reported by as few as 14% of people with seizures in remission, and as many as 51% of self-help group members, with a clear relationship between felt stigma, seizure frequency and illness trajectory (3). Not all people with epilepsy experience stigma but in those who do felt stigma has been positively associated with learned helplessness, depression and anxiety, impaired physical health status, increased somatic symptoms and other health problems, reduced self-esteem, and reduced life satisfaction. Perceived stigma has been shown to be an important predictor of QOL, accounting for more of the variance in QOL scores than clinical variables. Adults with high felt stigma also may experience greater difficulty with managing treatment regimes and medication adherence.

Prevalence of enacted stigma

The prevalence of enacted stigma has not been systematically documented. Much research has focused on the 'hard end' of enacted stigma, while failing to

document its more subtle aspects. In a recent study in the UK of insurance difficulties encountered by people with epilepsy (one form of enacted stigma), 62% of respondents reported difficulty obtaining insurance coverage and 36% had been refused insurance on grounds of epilepsy. The low employment rates found in many countries among people with epilepsy are almost certainly partly a reflection of enacted stigma. A recent study of UK employers' attitudes towards employing people with epilepsy noted that 21% reported that employing people with epilepsy would be 'a major issue' and 44% that epilepsy was a health condition that would cause them high concern. Epilepsy was commonly reported as likely to lead to work accidents, likely to lead to work absenteeism, likely to make other employees uncomfortable, and likely to increase employers' insurance liability – for which reasons, 76% of employers thought people with epilepsy should disclose their condition, even when they had been seizure-free for two years.

How can we help individuals in the face of epilepsy stigma?

First, we need to recognise and act upon the complexity and variability of the social meaning of epilepsy, both across and within cultures. Second, we need to understand that while not all people with epilepsy embrace the notion of stigma; however, for those who do there is a clear negative impact on their QOL. Third, for those affected by stigma we need to help them develop resilience by providing guidance about legitimate discriminations and practical solutions and support for illegitimate discriminations and stigma. Fourth, we need to address negative coping strategies and challenge negative assumptions in people with epilepsy themselves (both adults and children), their families and their wider social networks, through tested intervention strategies at all the levels at which stigma operates. How can we support people with epilepsy as a collective group? First and foremost, we need to be cognizant that disability, and its associated stigma, is a social, and so a changeable, construction. A

key political role of epilepsy support groups must be to challenge the current social construction of epilepsy as disability and as stigma. We also need to challenge and aim to reduce existing treatment gaps. People with epilepsy deserve well-formulated legislative support such as is embodied in the US Americans with Disabilities Act, the UK Disability Discrimination Act and recent European Union driving regulations. Finally, we need to champion a better resourced research agenda into the social realities of epilepsy, and the ways these can be improved.

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Box 1: Levels of stigma (Muhlbauer, 2002)

- Internalized stigma is felt within the person with the condition and reflects their feelings, thoughts, beliefs and fears about being different.
- Interpersonal stigma occurs in interactions with others both within and external to the family system; and in these interactions the person with the illness is treated differently and negatively because of the health condition.
- Institutionalized stigma reflects indirect expressions of different treatment of persons with an illness as a group in the larger society, e.g. discrimination of persons with epilepsy by policies of an insurance