

**Epilepsy and Stigma:
an update and critical review of recent literature**

Ann Jacoby, BA (Hons), PhD

**Division of Public Health
University of Liverpool, UK**

Corresponding author:

Professor Ann Jacoby
Division of Public Health
Whelan Building
The Quadrangle
Brownlow Hill
Liverpool
L69 3GB
UK
Telephone: 0151 794 5602
Facsimile: 0151 7945588
Email: ajacoby@liv.ac.uk

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Abstract:

In this paper, the concept of illness-related stigma and its relevance to consideration of the psychosocial impact of epilepsy is discussed; an overview is provided of the recent literature on epilepsy-related stigma, as it relates both to the stigma experience of people with epilepsy themselves and the beliefs and attitudes held by other key target groups; limitations of these and previous studies are considered and some advances in knowledge arising from them are highlighted; finally, some suggestions are made about possible areas for further investigation.

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Introduction

Stigma is a well-rehearsed concept in the literature on psychosocial aspects of epilepsy. Epilepsy-related stigma is frequently cited as a potentially reducible cause of psychosocial distress; and many studies have documented the negative beliefs and attitudes held by different general publics worldwide that lead to the experience of stigma among those affected by this condition. In this paper, I will first briefly discuss the concept of illness-related stigma and its relevance to consideration of the psychosocial impact of epilepsy; I will then provide an overview of the recent literature on epilepsy-related stigma; finally, I will consider some advances and limitations of existing research and suggest some possible areas for further investigation.

The concept of illness-related stigma

Goffman [1] proposed that people are stigmatised when they possess an attribute that is undesirable and so 'deeply discrediting'. He identified three broad categories of stigma: the tribal stigmas of race and religion, blemishes of individual character, and what he referred to as the 'abominations' of the body, which would include conditions of ill-health such as epilepsy. Whichever of the three categories applies, Goffman argued that those who are stigmatised are seen by others as 'not quite human' and so legitimate targets for stigmatisation and social exclusion. Stigmatisation is often triggered by a 'public crisis' [2], which, in the case of epilepsy, be a seizure in a public place. Social exclusion and status loss are the end result of a *process* wherein, because of their possession of an 'undesired difference', individuals are denied access to the benefits of belonging to the dominant group [3] and so disempowered [4].

It has been argued that the basis for stigmatisation is the biologically-based need to live in effective groups, so that individuals seen as violating group norms and threatening group functioning, will become the subjects of stigma [5]. In relation to Goffman's category of 'abominations of the body', wherein chronic illnesses such as epilepsy can be subsumed, Reidpath et al [6] extend this argument by suggesting that societal members unable to engage in the process of 'reciprocal exchange' for reasons of ill health are judged as of low social value and so stigmatised. These authors further argue that in order to simplify the task of identifying good and poor 'reciprocators', societies stigmatise whole categories of people seen as having poor social value, rather than individuals. Thus, simply belonging to a chronic illness category will automatically be accompanied by a loss in social value, even where - as is often the case for people with epilepsy - the course of the illness is benign and the accompanying functional loss minimal.

Whereas some conditions of being invoke stigmas are clearly culturally dependent [7], others appear to be universally stigmatising, suggesting they represent some kind of tangible or symbolic danger [8]. Epilepsy occupies a somewhat uneasy place in relation to this divide, most commonly, but not universally, stigmatising across both time and place [9]. Potential explanations of its *almost* universality as stigma revolve around the total loss of control that occurs during seizures, which therefore represent a kind of reversion to the primitive [10] and violate cultural norms around social interaction [11]. Of course, such explanations rest upon the powerful stereotype wherein all seizures are represented as generalised and all epilepsy as chronic and incapacitating. Nonetheless, their relevance is supported by research showing that this stereotype continues to carry considerable resonance for many lay audiences, as will be highlighted below [12].

The major public health implications of stigma and social exclusion have only recently begun to be recognised [13-15]. However, it is now known that stigma constitutes a potential risk factor both for physical diseases [16,17] and for mental health problems [18-20]. Possible mechanisms for the effects of stigma on health are likely to be both direct and indirect [15]: direct, because the stigmatised individuals may be exposed to less health-promoting environments and be less able to access high-quality health care; indirect, because 'identify threat mechanisms' may mean stigmatised persons experience negative physiological and psychological threat responses that lead to impaired health. Both direct and indirect effects of stigma are likely relevant to epilepsy, since the well-documented treatment gap [21] is at least in part a product of stigma; and the stress associated with having a condition viewed as highly stigmatising may ultimately have the effect of increasing seizure activity [22]. The finding that subjective experiences of stigma may be as health-threatening as objective acts of discrimination and social exclusion [23,24] is important in light of theoretical work on epilepsy-related stigma which highlights the distinction between *felt* and *enacted* stigma [25,26]. In recently reported studies, 'felt' stigma has been declared by as many as 50% of people with epilepsy [27,28], suggesting it is a major difficulty.

The last point to be made by way of introduction to the issue of epilepsy and stigma is that it is insufficient to consider it from a single viewpoint since stigma operates at multiple levels. A taxonomy of levels is proposed by Muhlbauer [29] as the internalised (ie. the actions and reactions of the person possessing the stigma), the interpersonal (ie, the actions and reactions of significant others), and the institutional (the societal position taken towards a particular form of stigma, as embodied in its laws and statutes). It follows that stigma can only be properly understood and acted upon when each of these different levels is attended to [30].

What does recent literature tell us about epilepsy stigma?

In this section, recently published papers (published during 2007) are discussed and critically reviewed. For a review of papers published prior to this, the reader is referred to the papers by Jacoby and Austin [30] and Jacoby et al [31]. The papers selected for discussion here are subdivided below into those which focus of the experience of stigma among people with epilepsy (in Muhlbaue's taxonomy, internalised stigma) and those which deal with the expressed attitudes of others (Muhlbaue's 'interpersonal' stigma). Muhlbaue's last level, the institutional, is rarely the subject of research, despite that interventions aimed at the first two levels are unlikely to be successful unless supported by changes at this third.

Recent studies of the stigma experience of people with epilepsy

Studies of the life experience of people with epilepsy across both developed and developing worlds consistently document quality of life impairments, including higher than expected rates of unemployment, lower income levels, lower levels of education, reduced rates of marriage and poorer self-reported health and well-being. The extent to which stigma contributes to these impairments is often assumed rather than proven; and the role it plays as a contributor to quality of life receives varying levels of support. Nonetheless, epilepsy-related stigma and its relationship to other outcomes continue to be a major focus for research.

In the developed world setting, Funderburk et al [32] explored the relationship between felt stigma and mental health outcomes in a group of little under 200 children with epilepsy aged between 9 and 14 years. The children's perception of stigma was measured using the Child Stigma Scale [33], which included items relating to the attitudes and reactions of their peers and to the issue of disclosure. Significant correlations were found between stigma and self-concept and between stigma and behaviour problems, though not between stigma and social competence. The effects of stigma were, however, mediated by professed attitudes to epilepsy (as measured using another previously validated scale [34]), suggesting an overlapping conceptual base for both.

A study in the UK [35] reported on the issue of epilepsy and identity in a minority ethnic group, people of Pakistani origin, living in the north of England; and provides some interesting qualitative data on their experience of stigma and discrimination. The authors note that in this community the issue of marriage was 'central to the experience of stigma and prejudice' often long before the affected person had reached marriageable age; as was that of employment. Fear of encountering negative attitudes among their community led people with epilepsy to restrict their social activities and so become socially isolated. However, stigma consciousness operated at a family, as well as an individual level, meaning that families were sometimes experienced as 'a place of refuge from a hostile world outside' but sometimes as 'places where people experienced some of the most hurtful stigmatisation.' And Rhodes et al note that despite their protagonists' familiarity with the Western biomedical model, a clear tension

existed between this, religious interpretations of epilepsy and a belief system that situated epilepsy as contagious (see also Ismail et al [36]) and a form of mental illness.

As part of a large programme of work which also examined knowledge and attitudes of members of key community groups (see below), Birbeck et al [37] examined the social and economic impact of epilepsy and the issue of stigma in one African country, Zambia. Adult informants with epilepsy were matched for age and sex with informants with other non-stigmatising medical conditions; and all completed questionnaires addressing issues of economic status, personal safety and 'felt' stigma. People with epilepsy had significantly higher stigma scores and substantially poorer social and economic status as measured across a broad range of indicators, supporting the 'long-held supposition that people with epilepsy in developing regions carry a heavy burden of stigma.' A study in another developing world region, India, highlighted both the enormous potential impact of epilepsy stigma on marriageability [38] and the relevance of Mulhbauers's third level of stigma, since at the time of the study Indian law categorising epilepsy as grounds for divorce had only recently been repealed. Santosh and colleagues [38] interviewed 85 women with epilepsy, over half of whom reported having concealed their condition from their spouse at the time of marriage and over 90% of whom believed that societal discrimination was particularly pronounced towards women with epilepsy.

Based on their study in another African country, Cameroon, Allotey and Reidpath [39] present a convincing argument that what lies behind the stigma of epilepsy is the affected person's reduced ability to perform normal social roles - and hence a reduction in their perceived social value. Certainly, their informants with epilepsy, like those in many other studies, reported experiencing stigma and social exclusion across such major life domains as marriage, education and employment; and their recognition of the stigma potential of their condition was acute. However, the daily life restrictions they faced were as much the product of their internalisation of a 'chronically ill' identity and accompanying adoption of the 'sick role'. Allotey and Reidpath note that this identity was reinforced both by healthcare workers whose counsel was to avoid all forms of strenuous exercise; and by informal carers whose beliefs about epilepsy translated into often major restrictions on their daily activities. In the work of our own group [40], similar themes emerged even though from within a very different cultural context. In our studies in China and Vietnam, we found that despite operating from highly 'embodied' and so relatively non-stigmatising explanatory disease paradigms, informants saw epilepsy as enormously socially disruptive; and though levels of stigma and social exclusion were in part attributable to knowledge gaps and misunderstandings, other highly pragmatic factors were also at play, in as much as those with epilepsy were seen as unable to fulfil their normal social roles and obligations adequately; and hence a 'bad bet' in relation to, for example, marriage and employment.

Recent studies of public attitudes to epilepsy

In relation to the interpersonal aspects of stigma, recent studies worldwide have provided further evidence that while there have been significant improvements in public attitudes towards epilepsy, 'old' ideas about its causes and consequences continue to inform popular concepts, resulting in continuing misperceptions and negative attitudes [31]. The studies of the attitudes of members of the general public discussed here originate from Brazil, Canada, Laos, Pakistan, Turkey and Zambia. In the first of these countries, a programme of work addressed attitudes held by members of the public [41,42], teachers [43] and secondary school students [44]. To undertake this programme, a new scale was developed and validated aimed at identifying 'the perception of epilepsy stigma by a subject.' Though the authors are to be commended for their desire to produce a culturally-specific and psychometrically more sensitive scale than those previously available, scrutiny of the items that make up this scale raises some questions about its theoretical base, since many appear to tap into the concept of epilepsy impact rather than epilepsy stigma (despite that the two are not synonymous). Thus respondents are asked, for example, to comment on difficulties people with epilepsy may have in daily life and whether people with epilepsy feel worried, dependent, fearful and so on. In the general public survey, involving a large (n=1850), randomly selected, metropolitan sample, epilepsy was seen as generating significant levels of prejudice in the context of a number of life domains: employment (by 64%), social relationships (by 47%) and education (by 36%); while social prejudice was seen as less of a problem in relation to marriage (21% thought significant prejudice existed in this domain) and family relationships. In addition to these individual item responses, overall scores on the stigma scale were calculated and shown to vary significantly by gender, educational and socioeconomic group.

A study of the general public in Laos [45] also employed a questionnaire developed de novo. It consisted of 108 items and nine open questions covering knowledge and beliefs about epilepsy, presumed causes and possible treatment options, management of epilepsy and seizures, and social attitudes towards epilepsy. The study involved interviews with 83 people with epilepsy, 83 family members and 166 age/sex-matched villagers living in one province in Laos. Stigmatising attitudes were frequently reported – so, for example, two-thirds in all groups would object to their children marrying a person with epilepsy; and between a third and two-thirds would object to people with epilepsy sharing meals with them. The strength of this study lies in its exploration of wrong beliefs about epilepsy likely to contribute to these negative attitudes and, by extension, the identification of potential foci for future interventions aimed at education and attitude change – thus, the authors report that between 25% and 42% of informants thought epilepsy had supernatural origins, between 38% and 57% thought it was contagious, and between 14% and 44% thought contact with saliva was a possible mode of transition.

Two other studies reporting on general public attitudes in resource-poor countries are that by Shafiq et al [46] in Pakistan and that by Demirci et al [47] in Turkey. In the first of these, face-to-face interviews were conducted with just under 500 adults, using questions 'most frequently identified' via a search of the current literature. The majority of informants considered epilepsy as non-infectious and treatable; and thought people with epilepsy could be educated and perform usual activities of daily living - despite which the majority did not want a child of theirs to marry a person with epilepsy, and around a third thought people with epilepsy could not contribute usefully to society and should be isolated from others. In the second, Demirci and colleagues also drew their question set from previous studies, in this case with the explicit intention of making comparisons. As in all the other studies reported here (and many previously reported), commonly held attitudes were that people with epilepsy represent poor marriage partners and poor employees.

Studies focussing on particular population subgroups include those by Chomba and et al [48] and Fernandes et al [43]. The former examined knowledge, attitudes and beliefs of healthcare workers in Zambia as part of a series of studies which also involved the attitudes of teachers [49], clerics [50] and police officers [51] and reported that: higher levels of knowledge were more common in those who had received more formalised training and had graduated more recently; and were associated with greater social tolerance. Almost all workers recognised that epilepsy was non-contagious, required long-term treatment and that good treatments were available; though only two-thirds recognised epilepsy as a disorder of the brain. Similarly, Fernandes et al found that a formal educational programme could increase knowledge and improve attitudes among school-teachers towards their pupils with epilepsy. Despite these encouraging findings, the possibility that such influential others could act as what has been referred to as 'stigma coaches' persists – for example in both studies around 20% of workers took the view that people with epilepsy could not or should not marry.

All the studies of public attitudes so far described involve direct questioning of informants about their attitudes towards people with epilepsy and so risked the possibility of being subject to the phenomenon of social desirability (though there is some evidence that this may be less of a problem for the mail surveys than for the interview-based ones [52]). A study carried out in Canada [53] attempted to circumvent this problem by tapping into stereotypes about epilepsy indirectly, using a series of vignettes. The study involved both members of the general public and specific subgroups including medical and law students and physicians, and explored whether people with epilepsy are seen as more violent than other people. This study repeated one done two decades earlier and found, somewhat alarmingly, that responses were fairly stable over this 20-year period and those changes that had occurred suggested beliefs about the capacity of people with epilepsy to be violent had, if anything, worsened. In 2006, when the second-wave data were collected, at least 40% of the questions were incorrectly answered and physicians were the only group whose overall scores

improved. The authors note that negative stereotypes were more commonly reported in their study than in many other previous ones conducted in the Western world; and suggest that their own findings are likely less prone to bias because of the vignette approach. This being the case, the logical conclusion is that despite previous reports of declining levels of stigma, a considerable amount of work remains to be done to disabuse those living there of the negative beliefs they hold about the condition.

Conclusion: Where next in epilepsy stigma research?

Stigma and public attitudes to epilepsy are self-evidently popular topics for research and there is a wealth of literature for the interested reader. One difficulty that arises in interpreting findings from these many studies is the lack of consistency with regard to the measures used. To assess levels of felt stigma among people with epilepsy themselves, several authors have employed the 3-item measure developed by Jacoby [26]; to assess public attitudes to epilepsy, authors have commonly employed the question set developed by Caviness and Gallup for their landmark series of US public attitude surveys [54]. The temporal and cross-cultural applicability of both these measures has been assumed rather than demonstrated; so there is some doubt as to their validity in different contexts. Conversely, question sets developed *de novo* have often not been subject to any formal development processes, raising questions about their psychometric robustness; or appear to lack any theoretical base. Research investment in developing and validating appropriate and theoretically informed outcome measures, with common core question sets and add-on culturally specific modules or items, such as has been done in the context of measurement of health-related quality of life, would improve the quality of reported findings and strengthen confidence in their meaningfulness.

The theoretical distinction between felt and enacted stigma is well-supported by reported studies including those reviewed here. However, the question has been raised as to whether the differing clinical realities (and hence differing levels of seizure control) mean that felt stigma will be of much greater concern to people with epilepsy in the developed world, and enacted stigma of greater significance for their developing world counterparts [55]. Future studies aimed at reducing epilepsy stigma could therefore usefully address the relative weight with which these two distinct elements are played out in particular socio-cultural contexts. Elucidation of this point will be important in determining the framing of planned stigma reduction interventions. Likewise, further elucidation of cultural-group or target-group specific beliefs is required in order to mount tightly focussed intervention studies.

A repeated finding across the various studies reviewed here and previously reported in the literature is that particular socio-demographic characteristics – age, gender, socio-economic status, level of education - tend to be associated with more negative attitudes. The issue of familiarity with people with epilepsy is less clear-cut, the conclusion from some studies being

that 'familiarity breeds contempt' and from others that the reverse is true. Future work could helpfully try to explore the reasons why this is so, since much current work on stigma reduction rests on the theoretical position that contact with stigmatised persons will 'normalise' them in the eyes of others and so render attitudes more positive.

Finally, as alluded to above, the stream of studies describing public attitudes to epilepsy and the lived experience of people with epilepsy worldwide point, first to the commonality of daily life domains impacted by epilepsy stigma and discrimination; and second, to the need for the research community to move from simple description towards formal examination of strategies for their reduction. Though formulated for other conditions of ill-health, intervention studies are sadly lacking for epilepsy – we still know little about how to change negative attitudes and experiences in an effective and sustainable fashion. One recently reported US-based study has begun this process through a community participatory approach in which people with epilepsy themselves have identified the elements of misinformation they would prioritise for targeting [56]. Studies such as the ethnographic ones reported by Allotey and Reidpath [39], Jacoby et al [40] and Rhodes et al [35] explore beliefs about epilepsy in depth and take full account of the issue of cultural specificity of such beliefs; and so promise to meaningfully inform future interventions. Such interventions need formal evaluation, to ensure maximum appreciation of aspects of their design and execution that promote or detract from their success at reducing the stigma of epilepsy and improving public attitudes. They also need support at the institutional level, in recognition that changes in attitudes and beliefs are not *de facto* accompanied by changes in behaviour and other behavioural change reinforcements may also be required.

Noteworthy papers:

- Allotey and Reidpath [39]** – presents evidence of epilepsy as ‘an identity of exclusion’ which hinders the ability of those affected to engage with their community at multiple levels; and highlights the need for intervention studies to focus on increasing participation of people with epilepsy.
- Collins et al [53]* – uses specially formulated vignettes to overcome elicitation of socially desirable answers; and documents worryingly high prevalence of perceptions of the *violence potential* of people with epilepsy.
- Funderburk et al [32]* – involves a large sample of children; and clearly defined hypotheses about the nature of relationships between stigma and mental health are defined and tested; makes concrete proposals for possible stigma reduction interventions.
- Jacoby et al [40]** – presents evidence about the ‘embodied’ and relatively non-stigmatising nature of beliefs about epilepsy in a specific cultural context; and emphasises the role of other highly pragmatic factors in creating and sustaining stigma.
- Tran et al [45]* – reports the first study of knowledge of, attitudes to and practices around epilepsy to be conducted in Laos; and explores wrong beliefs about epilepsy likely to contribute to negative attitudes.

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