

Epilepsy, stigma and quality of life

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Abstract

Epilepsy is a psychological and social as well as a biological phenomenon. Just why and how this is the case is discussed in the opening section of this contribution. The rest of the paper is committed to the social in general, and to the stigma often associated with epilepsy in particular. The concluding paragraphs commend a future social research programme, and discuss its salience for stigma reduction programmes.

INTRODUCTION

That epilepsy is at one and the same time a biological, psychological and social intrusion into people's lives may not be entirely apparent. Its anchorage in biological mechanisms, from epilepsy genetics to the pharmacology and surgery of antiepileptic therapies, is evident enough. It is recognized too that biological mechanisms can 'travel upstream' to occasion cognitive impairment, depression or lowered self-esteem. Further upstream, as it were, they may lead to discrimination, reduced job opportunities. Less obvious is the way social mechanisms can 'travel downstream'. The medical diagnosis of epilepsy is itself a social product, as are those biological mechanisms implicated in its aetiology; and they are historically malleable products at that. A misdiagnosis of epilepsy – that is, a diagnosis erroneously made in the absence of any requisite biological mechanisms – nevertheless brings psychological and social costs in its wake: in such circumstances there is a clear sense in which one "has epilepsy" / "is epileptic". Non-diagnosis, for whatever reason, may be accompanied by psychological and/or social gains as well as therapeutic losses. It follows from these few observations that epilepsy's impact on an individual's quality of life is a complex and dynamic issue.

A "HIDDEN DISTRESS MODEL" OF EPILEPSY

In the 1980s, Scambler² developed a 'hidden distress model' of epilepsy that has survived a subsequent generation of social scientific research. This hinges on (1) the concept of *stigma*, and (2) a distinction between *enacted* and *felt stigma*.

Following Goffman³, stigma is understood to denote an "ontological deficit": the infringement is against social norms of identity or being. The person with epilepsy is "imperfect" rather than morally culpable. Enacted stigma refers to actual instances of negative discrimination against people with epilepsy on the grounds of their unacceptable ontological difference, while felt stigma refers to an internalized feeling of shame and, crucially, a fear of encountering enacted stigma.

The hidden distress model can be summarized in three propositions. Firstly, when diagnosed with epilepsy, people develop a "special view of the world" that is predispositional and characterized by felt stigma. While adults often acquire this "mind-set" on or shortly after receipt of the diagnosis, children do so as a result of what Schneider and Conrad⁴ insightfully call "stigma coaching" on the part of "(over-)protective" adults (like parents, doctors, teachers). Secondly, their special view of the world leads people with epilepsy to a first-choice strategy of non-disclosure and concealment. And thirdly, the net effect of this strategy is that felt stigma is typically more disruptive of the lives of people with epilepsy than enacted stigma.

Accumulated studies suggest that while not everybody with epilepsy fits this model, a surprising proportion do, even those with low seizure frequency or in remission. It should be added, however, that studies generally identify a small but neglected minority of people with epilepsy who resist or actively combat what they see and experience as personally unacceptable norms of social unacceptability. Scambler¹ uses the term *project stigma* to catch this generally personal but occasionally social or political resistance.⁵

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FUTURE RESEARCH AND STIGMA REDUCTION PROGRAMMES

There is a need for epilepsy research that is unapologetically interdisciplinary. This is not simply a matter of conducting investigations that incorporate biological, psychological and social *variables*. Variable-oriented, or 'positivistic', methodologies are flawed and outmoded. Mechanisms at these various 'levels' *interact*: they travel upstream and downstream. This has implications for stigma reduction programmes.

Almost all current (Western) stigma reduction programmes for epilepsy are predicated on the salience of *education*, variously directed at lay populaces, physicians and allied health professionals, employers, policy-makers or people with epilepsy themselves. In truth, however, the quality of life of individuals with epilepsy *can be* determined by the underlying pathology (in other words, biological mechanisms); by psychological mechanisms involving personality, locus of control and so on; or by socially-induced contextual happenstance. Moreover the causal contribution of biological, psychological and social mechanisms can vary over time within the individual life-course.

The suggestion in this paper is twofold. Firstly, interventions oriented to stigma reduction might most effectively focus on what in the hidden distress model was termed the "special view of the world", and what hereafter I shall call, with due acknowledgement to Bourdieu⁶, the *epilepsy habitus*. Bourdieu's notion of habitus was created in recognition that 'objective' mechanisms can play a vital and frequently covert or unrecognized role in our 'subjective' sense of what is happening and why. It is in some ways a logical corollary of the hidden distress model that people with epilepsy may be (objectively-induced) to define their situations (subjectively) as to further disadvantage themselves (objectively). Those who find their way/commit to project stigma are a small, under-researched *and critical* grouping. Interventions might optimally target the epilepsy habitus or mind-set.

Secondly, it should not be forgotten, just because it is not so readily addressed, that enacted stigma, or stigmatization, is rooted in the wider society: its anchorage is in "deep" social structures as well as culture. Stigmatization in general tends to the pre-existing "fault-lines" of society. As theorists and researchers on disability have insisted, the ostracism, exclusion, rejection or "othering" of people with long-term illnesses

or disabilities is not just, or even primarily, a personal matter; *but a form of social oppression*. In a very real sense, the problem lies with the *oppressors* not the *oppressed*; and oppression cannot be properly understood in the absence of a grasp of society as a whole. "Othering" is omnipresent across societies and serves multiple functions.

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