



The Stigma of Epilepsy and its Impact

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Negative connotations of epilepsy have a long if varied history. In this short contribution I shall address: (1) the extent to which this diagnosis or 'label' continues to elicit feelings of shame and to provoke discrimination, and (2) how best to understand the relative importance of (1) for the quality of life of people with epilepsy. It is an account that I initially brought with me to share with conference participants in Melbourne and then Brisbane in the autumn of 2010, but also one that has been modified as a result of the numerous conversations I enjoyed with hosts, colleagues, people with epilepsy, and advocates.

In a book published over 20 years ago (Scambler, 1989), I advanced what I called a 'hidden distress model of epilepsy'. Perhaps oddly, it is a model that still seems to capture something of the experience of living with epilepsy, notwithstanding the sheer heterogeneity of symptoms that comprise epilepsy and of pathologies of which it is a manifestation. At the core of the hidden distress model was the unexpected 'finding' that a sense of personal shame and anticipation of rejection ('felt stigma') trumps actual instances of discrimination ('enacted stigma') as far as epilepsy's impact on quality of life over the life-course is concerned. This warrants a few sentences of elaboration. When adults are informed they have epilepsy, it seems they often become defensive: they fear the worst. It is a label they see as threatening to their wellbeing, whether at the hands

of partners or employers or via those casual interactions that somehow or other make for a contented life. Children have none of these reservation of course, but they can and frequently are 'coached' towards felt stigma ('don't use the word 'epilepsy' at school', 'your granny doesn't like the word', 'no need to tell your boss', 'why invite trouble?') (Schneider & Conrad, (1993)). This defensive orientation discourages openness. The word 'epilepsy', even the fact of turns, blackouts, seizures, remain personal or family secrets. One product of this secrecy is a low rate of enacted stigma: how can people discriminate if they are not 'in the know'? So this is the route to felt stigma's toxicity. Moreover Jacoby (2002) has shown that felt stigma – and the hidden distress model – retain their salience even when people with epilepsy are in remission or have a low rate of seizure frequency. Labeling, and self-labeling, can disrupt people's lives more than the symptoms that get the whole process underway.

In October 2010 in Melbourne, I shared a platform at the Asian and Oceanic Epilepsy Congress with an Australian sporting superstar, Wally Lewis (2009), whose exploits were unknown to me (I follow rugby union), but whose renown became clear to me as all eyes fastened on him. He recounted his personal experiences with great eloquence, and they too seemed consistent with the hidden distress model. Accommodating seizures towards the tail end of his playing career, he kept his own counsel, reasoning that any indication of 'weakness' could tell against him one way or another. On retiring from the game, and now in receipt of a diagnosis of epilepsy, he again opted for secrecy in his new job as a television sports presenter. Felt stigma seemed to underpin this resolute preference for non-disclosure: he feared the worst, dismissal, should

his 'secret' leak out. When the scenario he most dreaded – a seizure on live TV – occurred, like many in my own sample, he was surprised and relieved to find those around him empathic and supportive rather than aggressively defensive. Given his public profile, Wally Lewis' willingness to share this 'experiential' rather than 'scientific' knowledge is powerful indeed.

As a sociologist it would perhaps be understandable if I limited myself to a discussion of how social phenomena – like stigma – can impact negatively on the biographies of people with epileptic seizures. After all, this is where any expertise I possess begins and ends. But I want to take cognizance of the fact that biological and psychological mechanisms are active at the same time as social mechanisms (and 'biological' and 'psychological' are of course forms of shorthand, since multiple subdivisions are possible). For any given individual, epilepsy-related quality of life depends on a variable mix of the biological, psychological and social. Epilepsy is a symptom not a condition. If the underlying pathology is severe, with seizures but one manifestation, then epilepsy per se might be quite unimportant for quality of life. In the absence of overwhelming pathology, psychological factors like personality or locus of control might be critical. If the epilepsy is mild, then psychological or social factors are likely to be key. I have suggested that if any generalization is possible, biological mechanisms typically matter, psychological mechanisms condition people's coping, and social mechanisms provide what can be critical contexts (Scambler et al, 2010).

I will now focus more on social mechanisms, or contexts. One neglected possibility, less rare than we might think, is that epilepsy can impact negatively on quality of life in the

absence of biological mechanisms. How can this be? It can occur when epilepsy is misdiagnosed. The conferment of the diagnostic label by a state-licensed authority like a physician turns a person-cum-patient into 'an epileptic', as it were, like it or not. By the same token, the presence of the requisite mechanisms need not lead to medical, social and self-labeling if a physician is not consulted or there is a failure to diagnose: what is lost here in terms of antiepileptic treatment might be compensated for by the lack of a potentially stigmatizing label and status.

There are a number of ways in which social mechanisms are relevant to the study of epilepsy and to epilepsy-related quality of life. First, the medical diagnosis of epilepsy is itself more recent than many imagine; and the phenomena sheltering under this diagnostic umbrella, and their division into types and sub-types, continues to be re-assessed. The evolution of diagnostic categories and their modes of application, in other words, are themselves worthy of sociological investigation. Science and medicine in both pure and applied forms are 'social constructed', that is, products of particular times, places and configurations, as are all branches of knowledge. To state this is not of course to denigrate them in any way, as is sometimes suspected.

A second sociological focus is aetiology. Just how might social mechanisms contribute to those pathologies of which epilepsy is a manifestation? It is apparent, for example, that those from low-income families are more likely than those from high-income families to suffer accidents in the home, neighbourhood and workplace (perhaps a function of deprivation); and that men are more likely to have accidents than women (perhaps a function of differences in patterns of behaviour). It is likely therefore that epilepsy, along with most other conditions/symptoms, is to be disproportionately found in specific social segments or groupings.

Behaviour around symptoms is a third area of enquiry. Why is it that some people report and seek help for seizures while others do not? Interestingly, it might be extrapolated from the sociology of health, illness and help-seeking behaviour that people from lower-income families and men are prone to be 'poor' help-seekers. Help-seeking

does not always imply professional or medical help however. The anthropologist Kleinman (1982) writes of 'local health care systems', distinguishing between 'popular', 'folk' and 'professional' sectors. It is easy in developed societies like Australia and the UK to exaggerate the salience of the professional sector. We know little about the ways in which people handle their symptoms in the 'privacy' of their personal or close-knit family or other networks, or with the engagement of complementary or alternative practitioners.

A fourth dynamic is that between physician/healer and patient/client. It is known that attributes of these relationships can have a direct bearing on the effectiveness or otherwise of treatments and on quality of life. Over 20 years ago I suggested that 'good quality medical care' implied more than efficient tests, diagnosis and seizure management. I referred to the need for 'co-participation in care', affording patient autonomy; for an 'open agenda' during consultations, allowing patients to ask questions and raise their own concerns; for a holistic rather than biomedical orientation to care; and for physicians and other health workers to be trained in counseling. I stressed that if physicians protested that they simply did not have time to respond to such criteria, then this may be reasonable, but that nobody should conflate 'the best one can do in the circumstances in which one finds oneself' with 'good quality care'.

A fifth focus is on coping, a focus that underpinned my own early studies. The hidden distress model of epilepsy belongs here. There is in fact now a considerable literature on the pros and cons of day-to-day living with chronic conditions (or symptoms), including a range of studies on the impact of enacted and felt stigma on the biographies of people with epilepsy.


Finally, sociology might contribute more than it has so far to the investigation of how stigma, invoking norms of shame, has come to take its present forms. An emphasis on coping suggests we are dealing with a 'personal tragedy' when epilepsy is diagnosed. Disability theorists and activists have insisted instead that norms of shame constitute a form of oppression. So why is it that epilepsy remains stigmatizing (and 'dis-abling') in countries like Australia and the UK?

To what extent are norms of shame embedded in deep social structures that are resistant to purposive change?

These six foci add up to an extensive research programme, and one which, although well underway, requires deepening as well as extending. A great deal more money is spent on studying biological and even psychological mechanisms in relation to epilepsy than their social equivalents. Nor does what we know so far translate easily into interventions to reduce stigma. I have suggested elsewhere, however, that a reasonable starting point is a recognition that felt stigma is a key component of the disadvantages that can accrue to people with epilepsy. Adopting Bourdieu's (1977) idea of habitus (i.e. a socially acquired mind-set that predisposes us to think and behave in certain ways), it is important to discourage people with epilepsy from adopting an 'epilepsy habitus'. Adoption of an 'epilepsy habitus' would seem to preclude what I have recently called 'project stigma'. This denotes to a refusal to accept enacted stigma without falling prey to felt stigma: it is the kind of 'fighting back' epitomized in the activities of Wally Lewis and many, many others.

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