

Developing an applied research agenda into the social effects of living with epilepsy

The Epilepsy Foundation of Victoria (EFV), Australia

Key Points

- The need is overdue in Australia and South-East Asia to frame meaningful research responses to the WHO's statement of 2001: "...all over the world the social consequences of epilepsy are often more difficult to overcome than the seizures themselves." (WHO, 2001, 1);
- The Epilepsy Foundation of Victoria's research agenda has a dual focus on the stigmatization of epilepsy and issues of living with epilepsy. This is built firmly on the consideration that the agenda is designed primarily in order to produce research that can improve the lives of people living with epilepsy;
- Emerging findings:
 - ⊕ Australian adjusted prevalence for individuals with active epilepsy = 8.8 per 1000;
 - ⊕ Prevalence of individuals with active epilepsy and their immediate family members = 27.7 per 1000;
 - ⊕ Australians with active epilepsy are unemployed at twice the rate of the rest of the population;
 - ⊕ Less than one third of Australians with active epilepsy are employed full time compared to 43% for other Australians;
 - ⊕ After adjusting for other factors, the odds of an Australian with active epilepsy being completely out of the workforce were 3.4 times higher than for other Australians.



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In 2006 the Epilepsy Foundation of Victoria initiated a research plan that will provide much needed evidence based findings on the realities of living with the social consequences of epilepsy. While Australia enjoys excellent medical research and practice into epilepsy, associated work into issues of living with the condition are severely underdeveloped. Six years after the World Health Organisation launched the "Out of the Shadows" campaign, Australia has made only partial progress towards meeting this research challenge.

Dual research focus

Epilepsy is a stigmatised chronic illness that often results in reduced life chances in the areas of education, employment and social status. The nature and the effects of such social exclusion form the twin focus of EFV's research agenda.

1. Stigmatisation

1.1 The issues:

Stigma is a pervasive influence on disease and responses of nations, communities, families, and individuals to illness. Too little research has been done in recent years to better

understand the pathogenesis and implications of stigma, **how beliefs are generated, perpetuated, and translated into behaviours, and the cost of stigma to individuals, families, communities, and nations.** The sense that legislation and education against stigma is sufficient may explain the shortage of interest in research in this field. (Keutsch et al., 2006, 525-527 emphasis added)

The literature charting the effects of stigma on people living with epilepsy or other chronic illnesses is largely based outside Australia (for example: Gray, 1993; Hopper, 1981; Jacoby, 1994; Lawless et al., 1996; MacDonald, 1988; Nijhof, 1995; Voysey, 1975).

In comparison, much less research has been directed towards questions around the levels, mechanisms and nature of illness-related stigmatisation itself. These studies have tended to be small-scale (sub-national) and designed around stigmatisations of single conditions such as autism (Gray, 2002), epilepsy (Jacoby et al., 2004; 2005), HIV/AIDS (Lawless et al., 1996; Parker and Aggleton, 2003) and Parkinson's disease (Nijhof, 1995), or else comparisons of general and specific group attitudes towards a small number of conditions such as combinations of cancer, AIDS, heart disease and diabetes (Hayes and Vaughan, 2002; Katz et al., 1987; Schulte, 2002; Walkey et al., 1999).

While there are several national and sub-national studies (not including Australia) of public knowledge of and attitudes about epilepsy based on the first such study in the USA by Caveness and Gallup and using their same set of questions (Caveness and Gallup, 1980; Canger and Cornaggia, 1985; Hills and MacKenzie, 2002, Jensen and Dam, 1992; Mirnics et al., 2001), the data are limited by a restricted range of questions that concentrate on knowledge and behavioural intent indicators. Nevertheless, they provide some interesting associations between levels of knowledge about epilepsy and demographic variables. Results from an Austrian study (Spatt et al., 2005) are largely consistent with the others listed above. Spatt et al. found that being male, of low socioeconomic background, having little knowledge about epilepsy and no personal acquaintance with someone with epilepsy were independent predictors of unfavorable attitudes towards epilepsy.

1.2 Stigmatisation: the research agenda

EFV will initiate research into Australian's knowledge of and attitudes towards epilepsy. To date there has been no Australian study of the contours or mechanisms of epilepsy stigma. We do not currently know what levels of epilepsy knowledge exist in either the general population or specific significant populations such as employers, teachers and work colleagues. EFV has submitted a module of questions on these issues to the Australian Survey of Social Attitudes (AuSSA) administered by the Australian National University. This is a regular cross sectional survey generalisable to the Australian population. The next survey will take place in 2007 and should EFV's questions be included this will give the first reliable and valid data on the constituents of stigmatization together with data on differences between demographic and other groups.

Additional surveys focusing on particular aspects of stigmatisation are planned in 2007 and 2008.

2. Living with epilepsy

2.1 The issues:

a. The need for accurate prevalence data

The need for accurate prevalence data is obvious for without this we are dealing with a non-quantified or semi-quantified approximation. It is clear that at the present time there exists no reliable statistic on epilepsy prevalence in Australia and the range of estimates used is a largely a reflection of applying differing overseas experiences. We should also bear in mind that it is not only people with epilepsy who are living with the social consequences of their illness but also their immediate family and/or carers. In calculating or estimating numbers of Australians living with epilepsy, an accurate method is required to take account of both groups.

b. Using existing official statistics/ data sources

Designing and implementing research can be lengthy and costly particularly when the populations studied are national or regional. It is important to ensure that existing official statistics and other available data sources have been exhausted in terms of epilepsy related issues.

c. Quality of life issues

Reidpath et al (2005, 469) discuss the effects of illness-related stigma in terms of at least three dimensions. Firstly, stigmatised groups may suffer direct health consequences from the experience of living with that stigmatisation. Secondly, the fear of experiencing stigma may self-exclude them from employment, healthcare and other opportunities. In this regard, Fife and Wright (2000) claim that that the perceived negative reactions of others are the primary determinant in psychological adjustment to illness. This in turn echoes Scambler's earlier development of the concept of 'felt stigma' in his discussion of epilepsy (Scambler, 1989; Scambler and Hopkins, 1986). Thirdly, actual discrimination by others towards the subject may be experienced (Busza, 2001). In Scambler's terms this relates to 'enacted' stigma (Scambler, 1989).

2.2 Living with epilepsy: the research agenda

2.2.1 Prevalence data and official statistics

EFV has investigated the National Health Survey data collected by the Australian Bureau of Statistics. Based on a national random sample one question in the survey asks respondents if they have epilepsy. This data source appears not to have been used for epilepsy related research. EFV has obtained the data sets for the last four National Health Surveys and has begun analysis of these data. Initial results follow:

Epilepsy Prevalence

Table 1:

Prevalence of epilepsy in Australia by individual and total household members (with denial and unaware correction)

Source	Number PWE	Prevalence % ¹	Rate/Population	Total PWE + people in household ²	Prevalence %	Rate/Population
NHS 2004-5	133 700	0.68%		419 818	2.13%	1/47
NHS 2004-5 'false negative - denial' correction ³	174 543 ⁴	0.89%	1/147	548 065	2.78%	1/36
NHS 2004-5 'false negative - unaware + denial rate' correction ⁵	268 473 ⁶	1.36%	1/73 ⁷	843 005	4.3%	1/23

Source: National Health Survey 2001; 2004-5 – EFV analysis

¹ Total population, Australia in NHS estimates = 19,681,500 (NHS, 2004-5).

² Ratio of PWE to household members based on analysis of NHS 2001 (Brown, EFV), unpublished) = 1:2.14. Total PWE + people in household = Number PWE * 3.14

³ Beran et al. (1985) report the false negative response rate within epilepsy reporting in epidemiological studies as 0.234 [or 23.4% underreporting].

⁴ (133 700/76.6) * 100

⁵ Zielinski et al. (1988) report a false negative rate of 0.268 for cases of epilepsy where the respondent was unaware of the disorder and/or diagnosis.

⁶ (133 700/49.8) * 100

⁷ cf. Banks et al. (1995, 39) give an adjusted rate for Australia: "...as many as one in 50."

Employment

Table 2:

Employment categories by self-reported epilepsy status, Australia 2001 (abridged table showing percentages only)

	Employed full time	Employed part time	Unemployed looking for work	Not in labour force	Total
Does not have epilepsy	43.2%	18.4%	4%	34.5%	100%
Has epilepsy	29.5%	16.7%	9.6%	44.3%	100%

Source: National Health Survey 2001. EFV analysis

Generally fits patterns in European study (RESt, 2000, 1000) where per cent "better employed" for PWE was between 5% (Italy) to 25% (England) less than that for all others.

Table 3:

Logistic regression analysis showing impact of demographic variables on employment status, Australia 2001

Variable	Odds ratio
Self reported epilepsy	3.24**
Female	2.76**
Level of psychological distress (4 cats lo-hi)	1.49**
Age (5 year ordinal bands after 16 years)	1.48**
Location (metro/provincial/remote)	ns
Birthplace	ns

**p<0.01

n=26 862

ns= not significant

Source: National Health Survey 2001, EFV analysis

Logistic regression indicates the relative importance of predictor variables for a categorical dependent variable (employed/not employed) when all others are held constant. Four variables were found to be significant predictors of the likelihood of a person being not employed. In order of predictive power the predictors were: having epilepsy (self-reported); being female; level of psychological distress (measured by the Kessler scale and categorized as 'low', 'moderate', 'medium' and 'high' and age (years). This is

expressed in Table 3 in terms of odds ratios. The odds of a person with self-reported epilepsy being out of employment were 3.42 times higher than for those without self-reported epilepsy. Females were 2.76 times more likely to be outside employment than males. Moving up one category in the four psychological distress categories based on the Kessler scale resulted in that person being 1.49 more likely to be out of employment. For each age band of five years (after 16 yrs.), the odds of not being in employment were increased by 1.48.

2.2.2 The issue of self-reporting

Self-reporting of epilepsy (for example, ticking the box or selecting the answer alternative from a list provided by an interviewer as in the case of some of the above examples) runs into general and specific validity issues. The general issues are to do with reporting bias involving respondent's ideas of social desirability i.e. not wanting to appear 'different' or 'unworthy'. This has been debated in relation to questions about at-risk behaviours to unpopular attitudes and everything in-between. Chronic illness reporting would certainly be included here.

Specific issues involve the possibility of the stigma associated with epilepsy causing underreporting and the possibility that people with various levels of controlled epilepsy might not report it as a condition they any longer/presently have (that is, a confusion between the symptoms and the underlying condition). All of these factors could tend to cause underreporting.

Ultimately these problems can only be overcome by asking more detailed survey questions.

An interesting US study (in light of this discussion) compared (cross-checked) the answers given in a telephone survey of three common health conditions to the respondent's medical records in order to gauge the nature of self-reporting (Martin et al., 2000). The respondents were asked if a doctor or health professional had ever told them that they had diabetes, hypertension and/or hypercholesterolemia and their answers checked against their own medical records. 83% diagnosed with hypertension reported that they had been told they had hypertension. The figures were 73% for diabetes and 59% for hypercholesterolemia (n=599). Even though the authors conclude that 'self-reports are reasonably accurate for certain chronic conditions', it seems clear that a level of only 59% for hypercholesterolemia means that this survey would have underreported that condition by 41% and that if this was caused by any perception of stigma attached relative to diabetes and hypertension, then the levels attached to epilepsy will likely be much greater.

2.3 Quality of Life Issues

2.3.1 Researching the impact of epilepsy. A project undertaken by the Epilepsy Foundation of Victoria and the Chronic Illness Alliance. Funded by the William Buckland Foundation, Australia.

This project is being conducted by the Chronic Illness Alliance on behalf of the Epilepsy Foundation of Victoria. Workshops and interviews are being conducted across the state with people with epilepsy, their families and carers to explore what aspects of their condition people with epilepsy consider to have the greatest impact on their lives. People are being asked to identify those issues they would most like the new research program at EFV to address.

Following a qualitative analysis the results of these workshops and interviews will be used by EFV to provide a consumer and carer-focussed context for its applied research program and to inform the program of services to people with epilepsy offered by EFV.

Starting in early 2006, workshops and interviews have so far been conducted with a number of groups, including young adults, people from regional Victoria and people

from metropolitan Melbourne. Contact has been made with organizations working with young offenders, with culturally and linguistically diverse (CALD) communities and with indigenous communities to better understand the impact of living with epilepsy in these contexts.

While data-gathering continues, themes have emerged. People with epilepsy, their families and carers consider:

- Lack of public awareness about epilepsy generally places burdens on them. Many people would like to see public awareness campaigns explaining; epilepsy and addressing community prejudices against people with epilepsy;
- Loss of independence associated with epilepsy is burdensome. Not being able to drive, being unemployed or relying on family members is all part of the broader issue of being dependent. Some people consider that community ignorance contributes to this loss of independence, by reducing access to employment, educational opportunities and community participation;
- Lack of information about treatment and support programs makes living with epilepsy more difficult;
- Many people with epilepsy live with the constant stress of uncertainty. Uncertainty may relate to seizure control, to disclosure or to feeling safe in public places. It is doubtful there are many other conditions where such uncertainty about daily life is experienced on a daily basis.

In addition to these themes, the project has also identified that people with epilepsy, their family and carers value being consulted. While people with other conditions such as diabetes, asthma, cancers are often consulted about the services they receive across the full spectrum of the health and welfare system, this happens rarely in the treatment and care of epilepsy. Additionally the project has identified that people with epilepsy, especially in regional Victoria, value being able to meet and spend time with other people with epilepsy. They seek out opportunities to attend weekend camps and value support groups.

This project will be completed at the beginning of 2007.

2.3.2 Creating a research register of participants

The construction of a sampling frame of people living with epilepsy in Victoria has commenced and numbered 355 at the end of October 2006. This is a voluntary sample and will provide the basis for a series of research projects into quality of life issues. The possibility of longitudinal research is also being considered in conjunction with this database which would provide a unique opportunity to study the social effects of living with epilepsy over time.

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