GUS BAKER A WINNER OF THE 2000 AWARD FOR DISTINGUISHED CONTRIBUTIONS TO PROFESSIONAL PSYCHOLOGY

Why I study… epilepsy

I SUSPECT, like most of my peers, I really was not sure which area of clinical psychology I wanted to practise when I had completed my training: although I certainly knew what areas I didn't want to work in! I had already decided, as a result of my earlier forays into clinical-based research, that an opportunity to combine research with clinical practice was going to be a major factor in my decision. So when an eminent neurologist (with an expertise in epilepsy) approached me looking for a 'user-friendly' psychologist who could provide a clinical service and conduct research at the same time, I jumped at the offer. Admittedly, my knowledge of epilepsy at the time was severely limited.

More that a decade later I still find myself working in the field of epilepsy and enjoying it! There are still a number of important questions related to the management of epilepsy that still need to be addressed, and which have direct relevance for psychology. In my own research, for example, I have been attempting to understand how epilepsy impacts on the individual, and what are the most important predictors of a positive adjustment. The multidisciplinary research team I work with has also been investigating the most appropriate antiepileptic drug treatment and the effects of surgical treatment of epilepsy. I will draw upon this research here to highlight why I believe psychology has a significant role to play in the management of epilepsy, and why I still want to be an active researcher in the field.

Addressing the question of successful or unsuccessful acceptance of illness is relatively complex. It relies on understanding of the interaction between the physical presence of a condition and the patient's subjective perception and interpretation of that condition within a social and cultural context. Previous research has identified a number of factors predictive of psychosocial adjustment, including clinical features (age of onset, seizure type, seizure frequency, seizure severity) and demographic features (age, sex, occupational status and marital status) (Baker *et al.*, 1996; Hermann & Whitman, 1986; Jacoby *et al.*, 1996). While this research has been important in improving our understanding, it has not addressed specifically the process of acceptance of illness in people with epilepsy; nor has it explicitly identified factors that are significant in that process. It is important not only to identify with some precision those factors that play a significant role in the adjustment process, but also to look at ways we can influence their impact, and so ameliorate the deleterious effects that epilepsy can have on individual lives. The first stage of this research has been to identify the impact of epilepsy in a variety of groups, including those whose epilepsy is intractable, well controlled, or newly diagnosed.

A common theme across the groups that we have studied is that as a chronic condition epilepsy is characterised by clinical uncertainty. A person with epilepsy faces uncertainty over the diagnosis of his condition, over whether and when seizures will occur, over the nature of the seizures and how best they can be controlled, and over whether they will ultimately remit. The unpredictability of the nature and course of epilepsy is a key factor in the psychosocial handicaps it engenders for people who develop it.

Epilepsy is also characterised by loss of control. For many people with the condition, seizures may occur at any time and under any circumstances with little or no warning. The constant threat of a sudden unpredictable loss of control has been thought to be a fundamental facet of the condition.

Another centrally defining aspect of epilepsy is its stigmatising nature. For centuries and across continents epilepsy has been a condition with extremely negative connotations; even now the label of 'epilepsy' is one rejected by many people who develop seizures. To fully understand the nature of stigma it is important, however, to differentiate between perceived and enacted stigma (Scambler, 1983). Perceived stigma refers to an individual's perception of being stigmatised, while enacted stigma refers to actual episodes of discrimination.

Beliefs about the unpredictability of their condition coupled with fears of stigma and discrimination appear to render affected individuals susceptible to psychopathology. Evidence from the research conducted by our team and that of others confirms that epilepsy is associated with increased levels of psychological and psychiatric morbidity, including anxiety and depression, low self-esteem and a reduced sense of mastery.

Undoubtedly, this increased morbidity can be attributed to psychosocial variables including lack of social support and, importantly, stigma. Such variables may also explain the social withdrawal and isolation that is commonly reported among people with epilepsy, often as the product of anxiety about the hostile reactions of others if a seizure occurs in public. This fear can lead to self-denial of opportunities that can in turn result in a whole host of problems with personal relationships. These problems are reflected in the lower rates of marriage and fertility documented in people with epilepsy compared with the general population.

Psychosocial variables may also partially explain both under-employment and unemployment (the latter shown to be twice as common in people with epilepsy) and lowered rates of academic achievement. Interestingly, the results of a European-wide study showed that there were significant variations across countries for levels of perceived stigma, highlighting the importance of providing a cultural perspective for this concept. These results show that ameliorating the negative impact of epilepsy will require interventions at the level of the individual, family and society.

It is now generally accepted that 70–80 per cent of people who develop epilepsy will become seizure-free while maintained on antiepileptic medication

shortly after initiation of treatment (Sander, 1993). Until recently the choice of antiepileptic drugs was fairly limited, but a number of drugs have been marketed recently including vigabatrin, lamotrigine, topirimate and gabapentin; others such as tiagabine and levetiracetam are still in phased development. The drug prescribed depends largely on the type of epilepsy, the aim being to control seizures with the simplest drug regime and the fewest side-effects. Though there may be little difference in the efficacies of these drugs in controlling seizures, there are critical differences in their tolerability and cost.

Another way in which these drugs may be different is in relation to their side-effects. To investigate this issue, my colleagues and I are conducting a multi-centred pragmatic randomised clinical trial comparing standard versus new antiepileptic drug treatment in newly diagnosed patients, using a prescribed battery of neuropsychological and psychological measures. This study will be the largest study of its kind and will allow us to have a better understanding of the impact of drug treatment on the day-to-day lives of people with epilepsy. It should also allow researchers to document patient perspectives on the costs and benefits of these drugs, which will help decide which drug for which individual.

While the mainstay of treatment for epilepsy is pharmacological, for a small but significant proportion of patients with intractable epilepsy a surgical option may be appropriate. A number of different surgical procedures are now available, including partial removal of the amygdala and hippocampus, removal of a significant amount of the temporal lobe, partial separation of the two hemispheres, and removal of a significant amount of one hemisphere of the brain. About 20 per cent of patients with difficult-to-control seizures will prove suitable candidates for epilepsy surgery; pooled studies of the outcome for those operated on show that around 70 per cent will become seizure-free (Engel, 1993).

This radical clinical improvement in condition is not always accompanied by immediate psychosocial improvements, as a number of previous studies have shown. This is probably because of the difficulties inherent in adjusting to becoming seizure-free, after a significant period of time with very frequent and unpredictable seizures. Following surgery, both the patient's expectations and those of his or her family are often that they will now be able to reject the sick role and lead a normal and fulfilling life. However, these goals are often unattainable in the short term. Rehabilitating patients who have undergone surgery requires the input of a multidisciplinary team, including psychology, whose aim should be to help the individual and their family to set realistic goals and make a positive adjustment to their new status. As part of our research programme we have been trying to identify the quality-of-life changes associated with the effects of surgery in both the short and long term. There are also implications with regard to more subtle changes that occur as a result of surgical resection (particularly removal of the amygdala) on emotional recognition and memory performance. My colleagues and I are currently pursuing this line of investigation.

Of course, if you study the psychological consequences of epilepsy it is inevitable that you will be drawn into studying the phenomenon of non-epileptic attack disorders (seizures that resemble epilepsy but do not have an organic basis and are more than likely to have a psychological origin). My colleagues and I have established a programme of research investigating factors important in the development and maintenance of this complex condition.

Epilepsy by its nature is a fascinating topic. Why a condition characterised clinically as an abnormal discharge of electrical activity of the brain should result in such elevated rates of psychological and social problems is more than worthy of investigation. For the last 10 years I have had the luxury of being able to devote myself to addressing this problem, and I know that with recent radical developments in epilepsy from both clinical and basic science I can expect to be kept busy over at least the next 10 years.

References

Baker, G. A., Jacoby, A., & Chadwick, D. W. (1996). The associations of psychopathy and epilepsy: A community study. *Epilepsy Research, 1*, 29–39.

Engel, J., Jr. (Ed.). (1993). *Surgical treatment of the epilepsies* (2nd edn). New York: Ravens Press.

Hermann, B. P., & Whitman, S. (1986). Psychopathology in epilepsy: A multietiological model. In S. Whitman & B. P. Hermann (Eds.), *Psychopathology in epilepsy: Social dimensions*. Oxford: Oxford University Press.

Jacoby, A., Baker, G. A., Steen, N., Potts, P., & Chadwick, D. W. (1996). The clinical course of epilepsy and its psychological correlates: Findings from a UK community study. *Epilepsia, 37*, 148–161.

Sander, J. W. A. S. (1993). Some aspects of the prognosis in the epilepsies: A review. *Epilepsia, 34*, 1007–1016.

Scambler, G. (1983). *Being epileptic: Sociology of a stigmatising condition*. Unpublished PhD thesis, University of London.

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