Personal view

Epilepsy and prejudice

D C TAYLOR

University Department of Psychiatry, Manchester

“It is not good to have respect of persons
in judgment.” Proverbs xxiv, 23.

In his massive study of social behaviour, ‘Social being’, the philosopher and social psychologist Rom Harré declares, in a throwaway line, that the whole of man’s social behaviour is directed at the maintenance and management of his self esteem.¹ Social life, according to Goffman,² can be seen as a series of negotiations in which the self is presented to its best advantage, despite its many defects, to secure and maintain the best possible level of social support. Social support in its turn is crucial to the maintenance of health. Totman summarised work that shows how being separated from one’s appropriate social reference group and being required to learn new sets of social rules lead to ill health.³ Prejudice is a social Exocet missile, a long range destroyer of esteem. Without reference to the quality of local social skirmishes, prejudice annihilates one particular group of protagonists.

Prejudice has changed from meaning either a prejudgment or one made on the basis of inadequate evidence.⁴ It now means ascribing to another person or group attributes of such overwhelming importance that they override their individual characteristics.⁵ The validity, the ‘truth’, of the discriminating characteristic is irrelevant and the precise characteristics of the outgroup may be quite hard to identify at times. It is enough to be ‘not us’. ‘The mere fact of division into groups’ wrote Tajfel ‘is enough to trigger discriminatory behaviour’.⁶ Thus posing the question ‘Are the more stupid people sitting on the right side of this room?’ to an audience creates a climate in which it becomes necessary to know from whose perspective the room is to be viewed rather than one that rejects a nonsensical, ridiculous question. It is the possibility of producing such spurious and divisive questions that has led to anxiety about ‘labelling’ in medicine, especially in the psychological and social aspects of medicine.

Tajfel’s hypothesis that divisiveness inheres in categorisation was shown in experiments with perfectly normal secondary school children. An entirely spurious but apparently normal physiological difference was the basis of their grouping. In subsequent scoring tasks the children allocated marks, worth money, differentially dependent upon whether the recipient was or was not a member of the same ludicrous ‘grouping’ as the scorer.⁶ Since, as will be argued, categorisation and labelling are also absolutely necessary to thinking,⁷ it is clear that a conscious effort has to be made to keep labels uncorrupted as far as possible. But labels like ‘epileptic’ are handed on encrusted with the accretion of ages. Many of the papers written about epilepsy and prejudice imply that the prejudice against epileptics is wrongly conceived, ignorant, or irrational and that if more people realised that people with epilepsy were not necessarily mentally retarded or insane matters would improve. Irrationality is not the basis for my regarding negative views about people with epilepsy as prejudiced, in the same way that I would not regard proving myself non-Jewish an appropriate defence against anti-Semitism.

Prejudice is not an attribute of some rather nasty people out there in the world. It is a universal characteristic originating in the categorising process that underpins thinking. Labels are discriminatory, as Tajfel found, because that is the purpose of labels. It follows that there must be positive as well as negative prejudice. Doctors benefit from being accorded attributes that they might not have (such as a doctorate!) and so are certain treatments and medicines (the placebo response). More important is to consider what causes certain phenomena to be attributed negative and others positive characteristics. Why would epilepsy be so pervasively negatively regarded?

The moral and ethical problems and some of the characteristics of stigma are revealed in the case of Sharon.

Sharon was aged 15 when she was referred to us because it was thought unlikely that her attacks were epileptic and because of her disagreeable behaviour. She came from a chaotic and angry family in which her temper tantrums, her 'fits of temper', had been a lifelong method of coping. In recent months she had been 'found on the floor in a pub' where, in fact, she had been drinking and where, on another occasion, she had 'laughed herself to the floor'. In explaining her absence from school to the school doctor, mention of these attacks led to detailed enquiries about their possible nature. Auras were enquired into and auras of taste and smell were agreed to. A neurological opinion was sought, an electroencephalogram 'focus' appeared, and phenytoin was prescribed. The tablets were promptly used in a suicidal gesture. The family ignored the gesture but the girl told the neurologist that she thought she was going mad. It was not possible to discover any unequivocal evidence of epilepsy.

Is it more prejudicial to call this girl epileptic than not to do so? Is there any need for any one component of her sickness to be explained by another? As I see it, the moral aspects of sickness are forced forward into prominence as the 'disease' component recedes⁸ and in a chronic, sporadic, arcane disorder moral concerns can come to dominate the whole management. Prejudicial responses in health care professionals may determine very important aspects of policy in such cases.

In his chapter in 'Introduction à la psychologie sociale' Tajfel writes, 'In the case of strong negative evaluation of a category it is very important that an individual who is a member of it should not be 'missed', with the attendant danger of his assignment, by mistake, to a positive valued category . . . errors of assignment in a negative valued category will be in the direction of overinclusion.'⁹ Think of what constituted 'a communist' under McCarthyism. Sharon *might* be an epileptic. Woodland fungi 'might' be poisonous so they are left alone on the whole.

Sharon's predicament becomes like that of the child accused of sorcery reported by Levi Strauss.¹⁰ 'How can an innocent person accused of sorcery prove his innocence if the accusation is unanimous—since the magical situation is a consensual phenomenon'—that is, magic only exists by agreement. Whether such consensual beliefs about magic, or the parental state of Manchester United supporters, are sustained depends upon the level of social development of the group deriving the belief and the personal development of individuals within that group. In the stage of Piagetian egocentrism through

which we all pass (or to some extent remain) we are unable to conceive of a situation from a point of view other than our own either in terms of moral or cognitive development, and actions may follow from infantile projections foisted on to the outgroup. 'We got the boot in first!' The ingredients for change in reducing prejudicial responses induced in these ways are through personal growth, social development, and knowledge. Knowledgeable botanists will feast on the chanterelles that others scorn.

Turning to the specific case of epilepsy, consider first the curious nature of its stigma. Suddenly and without warning the individual suffers an astonishing loss of control and of developmental skills. The epileptic attack is the quintessence of the paroxysmal behaviours.¹¹ How might this propensity to sudden loss of status be negotiated? Perhaps in a way akin to premonitory grieving, by making declarations in word and deed between the attacks which, though of themselves stigmatising, do prepare those concerned against the catastrophe. Perhaps this might be achieved by social deference or perhaps by aggressive assertiveness. There is no doubt that the import of the epileptic attack is through its occasional association with madness, deterioration, and death. Such associations need only intermittent reinforcement. Chance and Russell regarded such 'protean displays' as epileptic seizures as a form of allaesthetic behaviour, a behaviour that produces behavioural effects on other animals.¹² It is difficult to imagine what biological advantage derived from the terrifying display of tonic-clonic epilepsy, but the residue is that at least half the mothers who witness a febrile convulsion fear momentarily that their child is dying. Doctors should respond to the needs that seizures create.

In many social surveys in the West over the years since the second world war there is evidence of changes, at least of what it is regarded as permissible to say about people with epilepsy, which might become the basis of real changes of attitude and behaviour. But prejudicial responses will only diminish with real education and with social development. We have to persuade ourselves, as an effort of will, that our old, deep, prejudice needs to be controlled. Doctors spend their whole training learning to take decisions on the basis of incomplete evidence, which is in itself a prejudiced response! They also have to learn, though it is less systematically taught, to tolerate uncertainty.

"Judge not according to appearance but judge righteous judgment." John vii, 24.

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Correspondence to Professor D C Taylor, University Department of Psychiatry, Jesson House (R M C H), Manchester Road, Pendlebury, Manchester M27 1FG, England.