Stigma: ignorance, prejudice or discrimination?

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Summary  The term stigma refers to problems of knowledge (ignorance), attitudes (prejudice) and behaviour (discrimination). Most research in this area has been based on attitude surveys, media representations of mental illness and violence, has only focused upon schizophrenia, has excluded direct participation by service users, and has included few intervention studies. However, there is evidence that interventions to improve public knowledge about mental illness can be effective. The main challenge in future is to identify which interventions will produce behaviour change to reduce discrimination against people with mental illness.

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Stigma is a mark or sign of disgrace usually eliciting negative attitudes to its bearer. If attached to a person with a mental disorder it can lead to negative discrimination. It is sometimes but not always related to a lack of knowledge about the condition that led to stigmatisation. There is now a voluminous literature on stigma (Link & Phelan, 2001; Corrigan, 2005), but this has largely been limited to attitude surveys rather than studies establishing an evidence base of effective interventions (Sartorius & Schulze, 2005). Stigma can therefore be seen as an overarching term that contains three elements: problems of knowledge (ignorance), problems of attitudes (prejudice), and problems of behaviour (discrimination).

SHORTCOMINGS OF WORK ON STIGMA

Five key features have limited the usefulness of stigma theories. First, although these processes are undoubtedly complex, academic writings on stigma (which in the field of mental health have almost entirely focused upon schizophrenia) have made relatively few connections with legislation concerning disability rights policy (Sayce, 2000) or clinical practice. For example, legislation such as the Americans with Disabilities Act of 1990 in the USA and the Disability Discrimination Act 1995 in the UK are now being applied to cases involving mental illness (23% of all Disability Discrimination Act cases in the UK). Second, most work on mental illness and stigma has been descriptive, overwhelmingly describing attitude surveys or the portrayal of mental illness by the media. Little is known about effective interventions to reduce stigma. Third, there have been notably few direct contributions to this literature by service users (Chamberlin, 2005). Fourth, there has been an underlying pessimism that stigma is deeply historically rooted and difficult to change. This has been one of the reasons for the reluctance to use the results of research in designing and implementing action plans. Fifth, stigma theories have de-emphasised cultural factors and paid little attention to issues related to human rights and social structures.

Recently there have been early signs of a developing focus upon discrimination. This can be seen as the behavioural consequences of stigma which act to the disadvantage of people who are stigmatised (Sayce, 2000). The importance of discriminatory behaviour has been clear for many years in terms of the personal experiences of service users, in terms of devastating effects upon personal relationships, parenting and childcare, education, training, work and housing (Thornicroft, 2006). Indeed, these voices have said that the rejecting behaviour of others may bring greater disadvantage than the primary condition itself.

IGNORANCE: THE PROBLEM OF KNOWLEDGE

At a time when there is an unprecedented volume of information in the public domain, the level of accurate knowledge about mental illnesses (sometimes called ‘mental health literacy’) is meagre (Crisp et al, 2005). In a population survey in England, for example, most people (55%) believed that the statement ‘someone who cannot be held responsible for his or her own actions’ describes a person who is mentally ill (Department of Health, 2003). Most (63%) thought that fewer than 10% of the population would experience a mental illness at some time in their lives. There is evidence that deliberate interventions to improve public knowledge about depression can be successful, and can reduce the effects of stigmatisation. In a campaign in Australia to increase knowledge about depression and its treatment, some states and territories received an intensive, coordinated programme while others did not. In the former, people more often recognised the features of depression, and were more likely to support help-seeking for depression or to accept treatment with counselling and medication (Jorm et al, 2005).

A series of government surveys in England between 1993 and 2003 revealed a mixed picture. On one hand there are some clear improvements: for example, the proportion thinking that people with mental illness can be easily distinguished from ‘normal people’ fell from 30% to 20% (Department of Health, 2003). On the other hand, views became significantly less favourable over this decade for several items: for example, the proportion believing that residents have nothing to fear from people coming into their neighbourhood to obtain mental health services decreased from 70% to 55%. An increase in knowledge about mental illness thus does not necessarily improve either attitudes or behaviour towards people with mental illness.

PREJUDICE: THE PROBLEM OF NEGATIVE ATTITUDES

Although the term ‘prejudice’ is used to refer to many social groups that experience disadvantage, for example minority ethnic groups, it is employed rarely in relation to people with mental illness. The reactions of a host majority to act with prejudice in
DISCRIMINATION: THE PROBLEM OF REJECTING AND AVOIDANT BEHAVIOUR

Attitude and social distance surveys usually ask either students or members of the general public what they would do in imaginary situations or what they think ‘most people’ would do, for example, when faced with a neighbour or work colleague with mental illness. Important lessons have flowed from these findings. This work has emphasised what ‘normal’ people say without exploring the actual experiences of people with mental illness themselves about the behaviour of normal people toward them. Further, it has been assumed that such statements (usually on knowledge, attitudes or behavioural intentions) are congruent with actual behaviour, without assessing such behaviour directly. Such research has generally focused on hypothetical rather than real situations, neglecting emotions and the social context, thus producing very little guidance about interventions that could reduce social rejection. In short, most work on stigma has been beside the point.

CONSEQUENCES FOR ACTION

Experience and evidence gained so far indicates that the time has come to shift the focus of research and action from stigma to discrimination, Thus, instead of asking an employer whether he or she would hire a person with mental illness, we should assess whether he or she actually does. This would allow an evaluation of our interventions by measuring whether and how they change behaviour towards people with mental illness, without necessarily assessing changes of knowledge or feelings. Finally – and most importantly – such a shift of focus would make it possible for people with mental illness to expect to benefit from relevant anti-discrimination policies and laws in their country or jurisdiction, on a basis of parity with people with physical disabilities ( Thornicroft, 2006). In sum, this means sharpening our focus upon human rights, upon injustice and discrimination as actually experienced by people with mental illness, and upon adding to our knowledge about interventions that society should undertake to reduce both stigmatisation and its consequences.

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