

Stigma in psychiatry

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‘It was difficult to make the decision to be public about having a severe psychiatric illness . . . but privacy and reticence can kill. The problem with mental illness is that so many who have it—especially those in a position to change public attitudes, such as doctors, lawyers, politicians, and military officers—are reluctant to risk talking about mental illness, or seeking help for it. They are understandably frightened about professional and personal reprisals¹’.

The above comment is from Kay Redfield Jamison, and few people are better placed to talk about the devastating consequences of mental illness: she is both a professor of psychiatry and a long-term sufferer from bipolar disorder. The stigma and discrimination experienced by service users is something that impacts on everyone. One in four of us will personally experience mental illness². We are all likely to have to deal with mental illness at some time, whether in family members, work colleagues or ourselves. The difficulties of living with psychiatric distress are magnified by the experience of rejection which is the consequence of stigma. In this paper I discuss the nature and causes of stigma, the consequences of this discrimination and what we can do about it.

WHAT IS STIGMA?

The word stigma referred originally to a mark or brand on Greek slaves, clearly separating them from free men. Although the marks of crucifixion appearing on Christian saints’ hands and feet are called stigmata, in common usage the word signifies a disgrace or defect.

In his 1963 book³, Goffman defines stigma as ‘a trait which is deeply discrediting’. He makes clear that stigmatization is an interactive social process, but some interpret his work as indicating that the blame lies with the person carrying the stigma. More recent authors have used the term stigma in a wider sense—for example, to refer to the reaction of other people, or even to include the attitude and behaviour of both the victim and the perpetrator. For proper communication it is important for researchers to define which concept of stigma they are working with. I

shall use Scambler’s terms, developed in work on epilepsy⁵—felt stigma and enacted stigma. Felt stigma (internal stigma or self-stigmatization) refers to the shame and expectation of discrimination that prevents people from talking about their experiences and stops them seeking help. Enacted stigma (external stigma, discrimination) refers to the experience of unfair treatment by others. Felt stigma can be as damaging as enacted stigma since it leads to withdrawal and restriction of social support.

Many psychiatric disorders can be hidden once the person has recovered. This allows people to pass as normal so long as no one finds out. Goffman³ describes this state as ‘discreditable’, whereas people with conditions that cannot be hidden are ‘discredited’. People with a discreditable condition—e.g. bipolar disorder in remission—must decide how much to tell and to whom. By careful information management they can minimize social rejection and enacted stigma. Those who live with a discrediting condition—such as schizophrenia with tardive dyskinesia—will have difficulties with information management and are at higher risk of experiencing enacted stigma.

The concept of stigma has been challenged from two closely allied directions. First, there is the postmodernist trend to contest the dominance of the medical model, with its inherent health/disease dichotomy. ‘One man when posed the question “what would you do if someone called you a nutter?” replied on video: “I’d thank them for noticing. I am different. I’m proud of my differences—they’re part of me⁶.”’

The second challenge is a pragmatic one from service user groups and activists. They wish to move away from the narrow stigma model, which tends to blame the user, towards a human rights and discrimination model⁶. Use of the term discrimination focuses on the unfair attitudes and actions of the perpetrators and society rather than on faults in the service user. The discrimination paradigm links discrimination against service users to sexism and racism, and hence gives ideas for action—for instance, by rendering discrimination illegal, and shaming or boycotting companies that practise it.

Many people hold negative stereotypes of those with a mental illness. Stereotypes are not intrinsically a bad thing; they are an efficient way of structuring knowledge. The difficulties arise when people act on rigid, negative stereotypes in a discriminatory way⁷. Stereotypes can come

from media depictions. Philo in 1996⁸ found that 66% of items about mental illness on UK television focused on violence; media images of violence could override personal experience of pleasant interactions with service users. Negative media reporting increases people's mental distress. One half of the people in a MIND survey⁹ reported that media coverage had had a negative effect on their mental health.

THE PROCESS OF STIGMATIZATION

Some commentators adopt the extreme position that there is no stigma attached to mental illness at all. Proponents of this view—e.g. Crocetti, Spiro and Siassi¹⁰ in 1974—argue that the perceived discrimination against ex-patients is unreal and a sign of misinterpretations due to continuing psychopathology. This notion has been little heard since the rise of the service user movement. Scheff¹¹, writing in the late 1960s, promulgated labelling theory. Scheff proposed that the label 'schizophrenic' activates stereotypes of mental illness learned in childhood (from friends, family and the media) and we respond accordingly, whether patient, family member or professional. The label affects how we respond to and treat the patient and how the patients themselves feel and act.

There is some evidence that the diagnostic label does influence people's attitudes; students were offered vignettes identical except for the person being described as having cancer or schizophrenia. Those with schizophrenia were perceived as less desirable as a friend and less able to function in the community¹². Changing the label changed people's perceptions and expectations.

People tend to think: 'Labels bad, no labels good,' so get rid of labels and there will be no more stigma and discrimination. This is too simple; we cannot just get rid of all labels and psychiatric terminology. A precise language is necessary for clinical communication and for comparison of research results. Certainly people have strong negative expectations of those with conditions such as schizophrenia, but labelling cannot be the whole story. Watch people's reactions to someone shuffling along the street like a stereotypical 'chronic psychiatric patient'. Even though the crowd do not know the specific label, the patient is avoided and socially rejected. We do not all hold the same stereotypes of mental illness, and they are not uniformly negative. Hence we need to take into account what the diagnostic label means to each individual. Addition of a 'perceived dangerousness' scale explained a large part of the variance in people's reaction to a vignette describing schizophrenia¹³.

Another camp would argue that the label is irrelevant; people's rejection of those with a mental illness diagnosis is based purely on their behaviour. Those with a chronic

psychotic illness may have physical signs of their illness, such as poor hygiene, unkempt appearance and abnormal facial movements, that will decrease their social acceptability. However, even in the absence of abnormal behaviour observers' perceptions change when they believe someone has a mental illness. This in turn affects the behaviour of individuals who believe that the observers know about their illness. Those who are completely well, behaving normally and have no remaining outward mark of illness are still treated differently¹⁴.

So we can see that the stigma is not purely due to the person's being labelled or to the person's behaviour. Much of the research in the 1970s was focused on a resolution to the labels/behaviour debate, but this is a false dichotomy: it is not *either* labelling *or* behaviour that leads to enacted stigma but rather a mixture of both. Those with mental illness are discriminated against and suffer as a result. A rights-based approach can cut through the sterile labelling/behaviour debate and focus researcher's energy on how best to intervene and to change attitudes.

ATTITUDES TOWARDS THOSE WITH A MENTAL ILLNESS

Behaviour does not always agree with stated attitudes. Stigmatizing attitudes develop early in childhood and are unchanged over at least eight years¹⁵. The perception of the mentally ill as 'dirty, unintelligent, insincere and worthless' had changed little when retested 23 years later¹⁶. The most negative attitudes seem to be held by older males with less education. Personal experience of those with mental illness may lead to more accepting attitudes although this is not a universal finding.

The general public are reluctant to label anything but the most extreme odd or violent behaviour as mental illness. The tolerance of the public towards service users depends on the closeness of the interaction. To work alongside service users is more acceptable than to have them as a babysitter. Strongly negative and rejecting attitudes towards those who experience mental illness have softened only slightly from the earliest research 50 years ago. In New Zealand¹⁷ five measurements of negative attitudes over the course of 22 years showed little change.

Some research papers refer to 'the mentally ill' as a single category, and this seems to tap into attitudes about those with major psychosis. More recent research has demonstrated that the general public can distinguish between different categories of mental disorder and have differing expectations of people with different disorders. Schizophrenia is linked with chronicity and dangerousness². Alcoholism, drug addiction and eating disorders are seen as the patient's own fault. People with mental illnesses are seen as 'different'—hard to talk with, and unpredictable.

Gender makes no difference to attitudes, nor does personal contact lead to more tolerant attitudes. When the same questionnaire was used in an evangelical Christian group the results were similar¹⁸.

All questionnaire surveys have the drawback that people tend to answer as they 'ought to' rather than saying how they really feel. This social acceptability bias can be partly overcome by behavioural and ecological studies. In the simplest of these a researcher presented himself as 'normal' or as having been mentally ill. The mental illness label led to more negative evaluation of his actions, appearance, pleasantness, etc. This study was replicated with similar results nearly 20 years later¹⁹. The belief that one is stigmatized can alter behaviour, generate anxiety and reduce interaction with others. This was true both for psychology students and for people who had previously been in a mental hospital¹⁴.

Stigma is active in real life: simply mentioning that the callers were shortly being discharged from the local psychiatric hospital led to rooms being unavailable for rent, though they were available later when no psychiatric history was mentioned²⁰. Attitudes towards mental illness in non-western cultures have been less frequently explored. These again vary widely. Responses to a vignette of someone with schizophrenia were least stigmatizing in Calcutta and most stigmatizing in Trinidad. White British responses were somewhere in between. In the west, nuclear families seem to be less tolerant of mental illness than extended families. In some societies (e.g. India, Ireland and China) madness is said to be positively valued—at least in theory²¹. An Australian study of five diverse communities of new immigrants indicated that mental illness is viewed as a family problem and not discussed. When help is sought the mental distress is presented in a somatized form. On the positive side, a majority said they had broadened their understanding of mental illness since migrating to Australia; second-generation immigrants expressed less stigmatizing attitudes²².

ATTITUDES OF HEALTH PROFESSIONALS

Service users who are also health professionals report a lot of prejudice from the medical profession. Medical students and doctors agree that psychiatric patients are 'not easy to like', but the more they learn of the subject the less they stigmatize²⁴. Overall the results suggest that medical practitioners hold a range of attitudes towards individuals with a psychiatric diagnosis similar to those held by the general public. Practitioners with the most knowledge about mental illness are generally the least stigmatizing.

CONSEQUENCES OF PSYCHIATRIC STIGMA

UK society has moved a long way from the large Victorian asylums. Effective treatment now allows recovery and reintegration of mentally ill people into society. However, the stigma of mental illness still affects the chances of a service user gaining employment or housing or getting married. Discrimination alters how patients see themselves, their self worth and their future place in the world.

The immediate psychological effects of a psychiatric diagnosis include disbelief, shame, terror, grief, and anger. Social rejection causes diminished self-efficacy, which leads to social withdrawal. Service users may come to accept others' low expectations of them and give up trying. Hopelessness and lack of prospects are a factor in the high suicide rate of people with severe mental health difficulties.

The label of mental illness makes job-seeking more difficult. Schizophrenia alone costs the UK £1.7 billion a year in lost production²⁵. When people with severe mental illness were encouraged and supported in gaining employment, their hospital admission rates fell and their overall mental health improved. Some National Health Service trusts are introducing policies to support employment for their own staff and to decrease employment discrimination; people returning to work after a major mental illness actually have lower sickness absence rates than average²⁶.

Half of those responding to MIND's 1996 survey²⁷ felt that they had been discriminated against by medical services, partly because the mental illness masked physical illness. Service users, reported in a large survey for the Mental Health Foundation, considered their general practitioners insensitive, dismissive and overly reliant on medication as treatment²⁸. Perhaps lack of adequate healthcare contributes to the high mortality in schizophrenia in the UK, where the standardized mortality ratio is 2.5 times the average²⁹. Mental health service users and user organizations have long been voicing dissatisfaction with the psychiatric system and advocating user-led alternatives. They are the experts by experience and are a valuable resource in planning better services.

Health professionals conceal mental illness in themselves and in their families. Denial of illness delays treatment and must play a part in the high suicide rate amongst medical students and young doctors. People living with mental illness are often not seen as credible witnesses and prosecutions are commonly dropped because of fear that, when their mental history comes out in court, they will not be believed³⁰.

Local people's views on those with mental illness drive the many NIMBY (not in my backyard) campaigns, which have been seen up and down the UK and across the world. Two-thirds of mental health service providers have experienced NIMBY campaigns²⁷. These range from protest

meetings and letter-writing campaigns up to open violence. NIMBY campaigns are based on false fears: in a survey of residents near new group homes in the USA³¹ there was no effect on property values, distressing incidents or crime.

Families of those with severe mental illness also experience a 'courtesy stigma' leading half of them to hide their relative's hospital admission from others³². The stigma experienced directly by those living with mental illness also affects mental health services and workers to some degree. We should not forget that in Nazi Germany some staff were exterminated along with patients³³. Mental health services and research are relatively underfunded worldwide³⁴. This contributes to recruitment and retention difficulties.

A POSITIVE SIDE TO PSYCHOSIS?

Most people experiencing a major mental disorder are distressed by it, and on recovery want to get back to normal and forget their odd and difficult experiences; but being psychotic is not always a negative experience. Peter Chadwick, a psychology lecturer with a diagnosis of schizophrenia, argues that psychosis brings forth talents in creativity, social sensitivity and awareness³⁵. A service user workshop on 'positive aspects of madness'⁶ found 'spiritual understanding and joy, the ability to write fiction professionally, an enhanced sensitivity to others, increased empathy and improved skills as a mental health worker' as some of the positive sides of psychosis.

TACKLING STIGMA

The benefits to individuals and families of tackling stigma include a reversal of the negative effects of discrimination listed above. It is likely that people would present for treatment sooner and comply better if psychiatric services were less stigmatized and stigmatizing. Services that are perceived as less stigmatizing have a lower drop-out and default rate³⁶. Anecdotal evidence suggests that the stigma of mental illness affects the recruitment and retention of staff. Anti-stigma work can be a positive experience for those involved. Society would benefit from greater social cohesion, and financially by rehabilitating people back into paid employment.

Mental health discrimination stems from structures in society and from individuals' attitudes and behaviours; both individuals and structures need to be changed by legal reform, public education and protest, and grass-roots activity. Public education and protest can be international, national or locally based. Current international projects include that of the World Psychiatric Association global programme to fight the stigma and discrimination that arise from schizophrenia³⁷. This programme is being piloted in several countries with promising early results. World Mental Health Day is celebrated in more than a hundred

countries annually, with many different public education events. In 1992 Norway held a mass-media campaign that resulted in sizeable shifts in knowledge and attitudes³⁸. Perhaps this helped create the positive reaction which greeted the Norwegian Prime Minister when, in 1998, he took time off with depression.

In the UK the Government is developing policies to promote inclusion of people with mental illness in all areas of society—through, for example, the Disability Rights Commission (DRC), Lifelong Learning and Health Action Zones. The DRC and the Disability Discrimination Act 1995 will establish acceptable practice by employers. The DRC has taken on several cases concerning discrimination on grounds of mental illness³⁹. However, the UK Government's actions are not all benign. The recent white paper on reforms of the Mental Health Act links 'dangerous severe personality disorder' with a diagnosable mental illness. This will tend to reinforce the link between madness and violence, which is rarely justified.

The Royal College of Psychiatrists (UK) is currently running a 5-year campaign 'Changing Minds, every family in the land'. The aim is to reduce the stigma of mental illness through activities such as road shows, local events and a cinema trailer. Clearly, the media, particularly television, are a major source of people's information and images on mental health⁴⁰. Written and telephoned objections to stigmatizing portrayals can lead to change in the advertisements, articles or programmes. The Royal College of Psychiatrists has a network of Divisional Public Education Officers whose role is to support the local media in presenting accurate information on mental health, writing articles, being a contact point for journalists, writing to complain about discrimination and supporting others in protesting. MIND (a service user group) in the UK has 'Respect', a campaign to challenge stigmatizing coverage and place positive pieces in the press. Provision of accurate information that contradicts stereotypes should help change false beliefs; the difficulty lies in getting the information to the target audience.

WHAT CAN INDIVIDUALS DO ABOUT STIGMA?

All of us, especially medical professionals, need to consider our own attitudes and awareness. The recognition that anyone will break down if stress is high enough should help free us from an 'us and them' attitude. Reading about people's own experience of mental illness can promote understanding; examples include a successful actress⁴¹ and a prize-winning author⁴². The willingness of these service users to take the risk of being honest about their experiences has encouraged others to speak out.

For mental health practitioners, enabling service users to influence service development is another strong anti-stigma

move. Collaboration with stigmatized people on projects has had major impacts on attitudes in other arenas of discrimination. Anti-discrimination work may mean writing an appropriate reference for someone who has had treatment, or supporting a service user through an industrial tribunal. A cognitive behaviour therapy approach can help individuals to overcome felt stigma and cope better with discrimination, but we should avoid giving the impression that the stigma is their fault.

We should stand up against mental health discrimination wherever it is encountered. This means challenging people who use disrespectful language or tell a 'nutter on the bus' joke. It means being willing to befriend and work with someone who has a history of mental illness. Most of all it means being honest about our own experiences.

'Madness... is not irredeemably awful but mixed: at times tragic, wasteful, frustrating, boring, life denying; at other times extraordinary in the ways that contribute both to users' lives and to those around them'⁶. People who have experienced mental illness suffer as much from other people's responses and expectations as from the symptoms of the illness itself. Change is needed and change can be achieved.

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