38

Stigma, Discrimination, Social Exclusion, and Mental Health
A Public Health Perspective

Nicolas Rüscher, Sara Evans-Lacko, Sarah Clement, and Graham Thornicroft

Introduction

People with mental illness face a twofold problem. In addition to experiencing symptoms such as mood swings, hallucinations, or anxiety, they often encounter stigma and discrimination, which can present a greater burden than the illness itself. Mental illness stigma is pervasive in developing and developed countries alike (Thornicroft et al. 2009), and typically leads to social exclusion in various life domains such as personal relationships, work, housing, or access to care. Given that stigma affects all areas of life, it is a major public health concern. There is a rich and growing literature on mental illness stigma in particular (Corrigan 2005; Hinshaw 2007; Thornicroft 2006), and on the concepts of stigma and discrimination in general (Link and Phelan 2001; Major and O’Brien 2005; Nelson 2009). In this chapter, we will first briefly define three domains in which stigma and discrimination can operate: public stigma, self-stigma, and structural discrimination. We will then discuss the daily life consequences of these three types of stigma for people with mental illness. Finally, we will outline some ongoing initiatives, for example from Scotland and New Zealand, meant to reduce stigma and discrimination.

Types of stigma and terminology

Public stigma and discrimination

Public stigma comprises reactions of the general public towards a group based on preconceptions about that group. For example, if members of the public consider people with mental illness dangerous, they will be more likely to avoid individuals with mental illness. Stigma is a broad term that is linked to the seminal work of Erving Goffman, who defined it as a discrediting attribute that reduces the stigmatised person ‘from a whole and usual person to a tainted, discounted one’ (Goffman 1963: 3). Modern social-psychological and sociological conceptualisations of stigma distinguish several interrelated components of stigma (Corrigan 2005; Link and Phelan 2001). First, in order to become the source of stigma, a characteristic, such as skin colour or mental illness, must be used to label individuals. There is no clear boundary between mental illness and mental health, and across cultures perceptions of mental illness and health...
vary. Therefore, the label of ‘mental illness’ is a social construct that changes over time. For example, dissociative states or hallucinations are mostly considered pathological in Western societies, but may be considered normal, for example as part of religious practices, in other societies. Second, stereotypes are associated with the labelled characteristic. Stereotypes are knowledge structures known to most members of a social group. They are often based, however, on ignorance or misinformation, and therefore ignorance is another way of thinking about stereotypes (Thornicroft 2006). Typical stereotypes about people with mental illness are that they are violent and dangerous, are to blame for their condition, cannot live independently, are rebellious free spirits, or have childish perceptions of the world (Wahl 1995). Third, prejudice occurs if members of the public are both familiar with negative stereotypes, and also agree with them, and have negative emotional reactions as a consequence (‘That’s right! All people with mental illness are violent and they all scare me’). Fourth, prejudice leads to discrimination as a behavioural reaction. Anger-related prejudice may lead to withholding help or replacing health care with the criminal justice system. As mentioned above, fear leads to avoidant behaviour. For example, employers often do not want persons with mental illness around them for reasons based on fear, so they do not hire them. As a final component of stigma and discrimination, social, economic, and political power is necessary to effectively discriminate against a stigmatised group.

**Self-stigma**

Self-stigma or internalised stigma refers to the reactions of individuals who belong to a stigmatised group and turn the stigmatising attitudes against themselves (Corrigan 2005). It is a process parallel to public stigma, starting with (negative) self-labelling and stereotypes, and finally affects the behaviour of the stigmatised individuals. Persons with mental illness are usually well aware of negative stereotypes against their group. If they agree with the stereotypes, and apply them to themselves, this results in decreased self-esteem and self-efficacy (‘I have a mental illness and therefore I do not deserve good treatment and am not capable to work’). Self-stigma is associated with shame as an emotional correlate (Rüsch et al. 2006), and with reduced empowerment, seriously undermining the quality of life of people with mental illness, and their subsequent motivation to pursue life goals such as work or independent living.

**Structural discrimination**

Discrimination does not only result from individual attitudes or intentions. Societal rules and regulations may systematically disadvantage people with mental illness, something which is referred to as structural discrimination. Examples include legislation, funding decisions about research and mental health services, or health insurance policies that exclude people with mental illness from insurance coverage. For example, when making decisions about health insurance coverage, an insurance employee may discriminate against applicants with schizophrenia unintentionally, just by following the insurance company’s rules of handling applications.

**Consequences of stigma**

**Public stigma, discrimination, and social exclusion**

Stigma and discrimination can lead to social exclusion of people with mental illness. People with mental illness indicate that discrimination most typically occurs in relationships with friends
and families, in intimate relationships, and at work or school (Thornicroft et al. 2009). Unfortunately, recent evidence suggests that the stigma of mental illness may have increased rather than decreased over the last decades in Western countries (Angermeyer and Matschinger 2005; Phelan et al. 2000).

In terms of global patterns, we know very little about levels of public stigma across different countries. In a recent survey of over 700 people with schizophrenia in 27 countries (Thornicroft et al. 2009), nearly half of the participants reported being discriminated against in making or keeping friends, and in contact with family members. Over a quarter experienced discrimination finding or keeping a job, as well as in intimate relationships or contact with their neighbours. Rates of anticipated discrimination were even higher. These data underline the pervasiveness of mental illness stigma and the potential for experiencing multiple threats in different areas of life. Rates of experienced and anticipated discrimination were similar across countries, suggesting that stigma and discrimination are a global phenomenon.

The results of assessing stigma in Africa, Asia, the Americas, in Islamic countries of North Africa and the Near East, and in Europe have produced generally consistent findings (Sartorius and Schulze 2005). First, there are few countries, societies, or cultures in which people with mental illness are considered to have the same value as people who do not have mental illness, as shown, for example, in lower rates of financial investment in mental health services. Second, the quality of information that we have is relatively poor, with few comparative studies having been conducted between countries or over time. Third, there are clear links between popular understandings of mental illness, and whether or not people in mental distress seek help or feel able to disclose their problems. The core experiences of shame (to oneself or to one’s family) and blame (from others) are common, although they vary to some extent between cultures. Where comparisons with other conditions, such as physical illnesses, have been made, mental illnesses are usually more stigmatised. Finally, the behavioural consequences of stigma (rejection and avoidance) by others to the stigmatised individual appear to be universal phenomena (Sartorius and Schulze 2005).

**Self-stigma: secrecy, withdrawal, avoidance of treatment**

Many people with mental illness try to avoid the negative consequences of labelling, stigma, and discrimination by keeping their mental illness a secret. Unlike many other stigmatised characteristics such as ethnicity, mental illness is usually not visible. Depending on the severity and course of their disorder, people with mental illness can therefore often decide whether or not to disclose, and secrecy is a common reaction to the threat of stigma. As noted above, discrimination is anticipated so widely that it may lead to social withdrawal when persons with mental illness avoid other people who are perceived to be potentially stigmatising. While these coping reactions may help to avoid some experiences of discrimination, unfortunately they are also associated with negative outcomes, such as demoralisation and unemployment (Link et al. 1991; Rüsch et al. 2009b).

A second common consequence of secrecy and label avoidance is that individuals with mental illness may opt not to seek care because they fear being labelled as a consequence of entering treatment. There is mounting evidence that high levels of perceived stigma and low resilience to stigma (Rüsch et al. 2009a) are associated with low levels of care-seeking. Stigma, therefore, contributes to poor treatment participation worldwide (Schomerus and Angermeyer 2008; Thornicroft 2008), which is a major public health concern (Wang et al. 2007). Stigma-related barriers to treatment-seeking are a burden that compounds the effects of mental health services that are often of poor quality or even entirely absent.
Structural discrimination: consequences for funding and other policies

Discrimination is not necessarily deliberate (Corrigan et al. 2004). Legal or cultural rules and regulations can profoundly disadvantage minorities, intentionally or unintentionally. One example of structural discrimination is legislation that restricts the rights of people with mental illness in areas such as voting or parenting (Corrigan et al. 2005). It is important to note here that some restrictions may be justified because of an individual’s current psychiatric symptoms or disabilities, and therefore do not necessarily constitute discrimination. For example, it can be appropriate and necessary to preclude a person with a current and serious thought disorder from driving buses. However, a mental illness per se does not justify the restriction of rights if no current disability is present that specifically impairs performance of the activity in question.

Mental health funding is another example of structural discrimination. A German study found that the public had a strong preference to cut funding for mental rather than physical illnesses, thus facilitating structural discrimination (Schomerus et al. 2007). Underfunding of mental health services is a global problem. According to the World Health Organization (WHO), mental illnesses cause about 12 per cent of all illness-related disability (Disability Adjusted Life Years); however only about 2 per cent of overall health care budgets are allocated for mental health services, indicating a dramatic lack of resources (Saxena et al. 2007). This is reflected in the view of service users in Hong Kong, who saw poor quality and accessibility of mental health services as a major source of structural discrimination (Lee et al. 2006). However, there is a scarcity of research on international aspects of structural discrimination, especially for developing countries.

Interventions to reduce stigma and discrimination

We now discuss strategies and some ongoing initiatives to fight the three main types of stigma and discrimination: public, self-stigma, and structural discrimination.

Public stigma

Three main strategies have been used to reduce public stigma: protest, education, and contact (Corrigan and Penn 1999). Protest, by stigmatised individuals or members of the public who support them, is often applied against stigmatising public statements, such as media reports and advertisements. Many protest interventions, for example against stigmatising advertisements or soap operas, have successfully suppressed negative public statements, and for this purpose they are clearly very useful (Wahl 1995). However, it has been argued (Corrigan and Penn 1999) that protest is not effective for improving attitudes towards people with mental illness. Education interventions aim to diminish stigma by replacing myths and negative stereotypes with facts, and have reduced stigmatising attitudes among members of the public. However, research on educational campaigns suggests that behaviour changes are often not evaluated, and the degree of change achieved is both limited and may fade quickly. The third strategy is personal contact with persons with mental illness. In a number of interventions in secondary schools, education and personal contact have been combined (Pinfield et al. 2003). Contact appears to be the more efficacious part of the intervention. Factors that create an advantageous environment for interpersonal contact and stigma reduction include equal status among participants, a cooperative interaction, and institutional support for the contact initiative.
For both education and contact, the content of anti-stigma programmes matters. Biogenetic models of mental illness are often highlighted because viewing mental illness as a biological, mainly inherited problem, may reduce shame and blame associated with it. Evidence supports this optimistic expectation (i.e. that a biogenetic causal model of mental illness will reduce stigma) in terms of reduced blame. However, focusing on biogenetic factors may increase the perception that people with mental illness are fundamentally different, and thus biogenetic interpretations have been associated with increased social distance, perceptions of mental illness as more persistent, serious, and dangerous, and with more pessimistic views about treatment outcomes (Phelan et al. 2006). Therefore, a message of mental illness as being ‘genetic’ or ‘neurological’ may be overly simplistic and unhelpful for reducing stigma.

Anti-stigma initiatives can take place nationally, as well as locally. National campaigns often adopt a social marketing approach, whereas local initiatives usually focus on target groups. An example of a large multifaceted national campaign is ‘Time To Change’ in England (Henderson and Thornicroft 2009). It combines mass-media advertising and local initiatives. The latter try to facilitate social contact between members of the general public and mental health service users, as well as target specific groups such as medical students and teachers. The programme is evaluated by public surveys assessing knowledge, attitudes, and behaviour, and by measuring the amount of experienced discrimination reported by people with mental illness. Similar initiatives in other countries, for example ‘See Me’ in Scotland (Dunion and Gordon 2005), ‘Like Minds, Like Mine’ in New Zealand (Vaughan and Hansen 2004), or the World Psychiatric Association anti-stigma initiative (Sartorius and Schulze 2005) in, among many other countries, Japan, Brazil, Egypt, have reported positive outcomes.

In summary, there is evidence for the effectiveness of anti-stigma initiatives. On a more cautious note, individual discrimination, structural discrimination, and self-stigma lead to innumerable mechanisms of stigmatisation. If one mechanism of discrimination is blocked or diminished through successful initiatives, other ways to discriminate may emerge (Link and Phelan 2001). Therefore, to substantially reduce discrimination, stigmatising attitudes and behaviours of influential stakeholders need to change fundamentally.

Efforts to reduce self-stigma and to increase empowerment

Before discussing more specific interventions to tackle self-stigma and to increase empowerment, we need to make it clear that we do not see self-stigma as a clinical problem or somehow the fault of the person with mental illness. On the contrary, it is a consequence of unfair public discrimination. However, as long as public stigma continues, many people with mental illness will internalise stigma, and therefore, strategies to reduce self-stigma matter. One way to reduce self-stigma is to discuss and refute negative stereotypes in groups of people with mental illness that are run by professionals or peers, using paradigms of cognitive therapy. Research suggests that to accept stigma as fair and to hold the group of people with mental illness in low regard is associated with more negative reactions to stigma (Rüschi et al. 2009c). Therefore, efforts to reduce self-stigma should enable people with mental illness to reject stigma as unfair and to think better of themselves and their group. Psycho-education and empowerment interventions can facilitate informed choices and shared decision-making. Further, mutual-help/peer-support groups can be a source of support and empowerment, thus decreasing self-stigma. Another approach is to promote active participation in mental illness service provision, either through consumer-operated services, or through using advance statements that give service users more control over their treatment.
Fighting structural discrimination

Improving public attitudes and behaviours is not sufficient to fight stigma, because discrimination can persist in long-lived social and cultural rules and regulations despite the best intentions of individuals. Comprehensive anti-stigma efforts can effect structural discrimination by specifically addressing legislation, mental health care funding, or health insurance policies which disadvantage people with mental illness. Differences between developing and developed countries should be taken into account (Rosen 2006) because structural discrimination, and initiatives to fight it, depend on legal and cultural local factors.

Conclusions

We outlined forms and consequences of mental illness stigma and discrimination and discussed anti-stigma initiatives. There is growing interest in stigma research among service users, clinicians, and researchers, and work from different disciplines such as psychology, sociology, and public health has increased our understanding over the last decades. Still, there is much to be done.

Research in this field would, in our view, benefit from addressing the following topics. First, while surveys of attitudes and intentions have been helpful, it is now time to focus on discriminatory behaviour. Behaviour of, for example, a stigmatising employer, is an outcome that seriously affects people with mental illness. Second, future studies should be more theory-driven instead of merely offering descriptive reports. For example, applying social-psychological models derived from other stigmatised groups to mental illness stigma may be promising (Rüsch et al. 2009b, 2009c). Third, emotional aspects of both stigmatisers (e.g. disgust) and their targets (e.g. shame) have been neglected in previous work (Link et al. 2004). Fourth, future studies should rigorously test the effectiveness of anti-stigma interventions, especially in terms of long-term behaviour change (Thornicroft et al. 2008). Fifth, the voice of service users has been under-represented, and more qualitative and quantitative work is needed to fill this gap (Rose 2001). Sixth, investigations of mental illness stigma have largely neglected the impact of structural discrimination on stigmatised individuals (Corrigan et al. 2004). Finally, to gain a global perspective, we need studies that assess cultural factors and international similarities and differences (Thornicroft et al. 2009).

Future anti-stigma initiatives should take comprehensive steps to address different aspects of stigma and discrimination simultaneously. In particular, they should measure success in terms of reduced discrimination as experienced by people with mental illness, which in our view is the most relevant outcome. This is not an easy task, but recent anti-stigma initiatives provide reason for cautious optimism. Success will depend on the continuing collaboration of many groups in society, involving people with mental illness as well as key stakeholders such as teachers, mental health professionals, faith leaders, employers, police officers, and legislators. Judging from the history of the civil rights movement, a long-term collaborative effort is needed to achieve profound social change and substantially reduce mental illness stigma.

References


