

# Stigma and discrimination limit access to mental health care

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**Abstract.** This editorial provides an overview of how far access to mental health care is limited by perceptions of stigma and anticipated discrimination. Globally over 70% of young people and adults with mental illness receive no treatment from healthcare staff. The rates of non-treatment are far higher in low income countries. Evidence from some descriptive studies and epidemiological surveys suggest that potent factors increasing the likelihood of treatment avoidance, or long delays before presenting for care include: (i) lack of knowledge about the features and treatability of mental illnesses; (ii) ignorance about how to access assessment and treatment; (iii) prejudice against people who have mental illness, and (iv) expectations of discrimination against people who have a diagnosis of mental illness. The associations between low rates of help seeking, and stigma and discrimination are as yet poorly understood and require more careful characterisation and analysis, providing the platform for more effective action to ensure that a greater proportion of people with mental illness are effectively treated in future.

## MOST PEOPLE WITH MENTAL ILLNESS ARE NOT TREATED

Although each year approaching 30% of the population worldwide has some form of mental illness, at least two thirds receive no treatment. This under-treatment occurs even in countries with the best resources (Kohn *et al.*, 2004a; Thornicroft, 2007). In the USA, for example, 31% of the population are affected by mental illness every year, but 67% of these individuals are not treated (Kessler *et al.*, 2005a). Moreover, in Europe mental illness affects 27% of people every year, 74% of whom receive no treatment (Wittchen & Jacobi, 2005). The proportions of people with mental illness who are treated in low and medium resource countries (LAMIC) are far less, for example a recent worldwide survey found that the proportion of respondents receiving mental health care over 12 months was as low as 1.6% in Nigeria, and that in most of the 17 countries studied only a minority of people with severe disorder received treatment (Wang *et al.*, 2007).

A WHO overview of 37 studies across the world, for example, found that the proportion of people untreated for particular conditions is: schizophrenia 32.2%; depres-

sion 56.3%; dysthymia 56.0%; bipolar disorder 50.2%; panic disorder, 55.9%; generalised anxiety disorder 57.5%; and obsessive compulsive disorder 57.3%; alcohol abuse and dependence 78.1% (Kohn *et al.*, 2004b; World Health Organisation, 2005; Wittchen & Jacobi, 2005). Indeed one particular study of depressed people in St Petersburg only 3% were treated (Simon *et al.*, 2004b), both because of the low level of coverage of services, and because of demand limiting factors such as the need for out-of-pocket payments to afford treatment.

Two factors which contribute towards this degree of neglect are (i) the reluctance of many people to seek help for mental illness related problems because of their anticipation of stigma should they be diagnosed, and (ii) the reluctance of many people who do have a diagnosis of mental illness to advocate for better mental health care for fear of shame and rejection if they disclose their condition (Kohn *et al.*, 2004a).

## STIGMA: A COMBINATION OF IGNORANCE, PREJUDICE AND DISCRIMINATION

Stigma is a word which has evaded clear, operational definition (Keusch *et al.*, 2006; Link & Phelan, 2006; Jamison, 2006; Jacoby *et al.*, 2005). It can be considered as an amalgamation of three related problems: a lack of knowledge (ignorance and misinformation), negative attitudes (prejudice), and excluding or avoiding behaviours (discrimination) (Thornicroft, 2006b; Corrigan, 2005; Sartorius & Schulze, 2005; Thornicroft *et al.*, 2007; Thornicroft, 2006a). The combination of these three elements has a powerful force for social exclusion

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(Thornicroft, 2006b). Indeed there is no known country, society or culture in which people with mental illness with a diagnosis are considered to have the same value and to be as acceptable as people who do not have mental illness. Second, the quality of information that we have is relatively poor, with very few comparative studies between countries or over time. Third, there do seem to be clear links between popular understandings of the meaning of a diagnosis of mental illness, if people in mental distress want to seek help, and whether they feel able to disclose their problems (Littlewood, 1998). The core experiences of shame (to oneself and one's family) and blame (from others) are common everywhere stigma has been studied, but to differing extents. Where comparisons with other conditions have been made, then people with a diagnosis of mental illnesses are more, or far more, stigmatised (Lai *et al.*, 2001; 2005), and have been referred to as the 'ultimate stigma' (Falk, 2001). Finally, rejection and avoidance of people with a diagnosis of mental illness appear to be universal phenomenon, and a recent study of terms used by school children to refer to mental illness revealed 250 different words and phrases, none of which are positive (Rose *et al.*, 2007).

#### **LIMITED ACCESS TO MENTAL HEALTH CARE**

It is only relatively recently that the full potency of such barriers to finding treatment and care have been recognised (Cooper *et al.*, 2003; Amaddeo & Jones, 2007). For example studies from several countries have consistently found that even after a family member has developed clear-cut signs of a psychotic disorder, on average it is over a year until the unwell person first receives assessment and treatment (Compton *et al.*, 2004; Johannessen *et al.*, 2001; Black *et al.*, 2001). A survey of almost 10,000 adults in the USA has added more detail to this picture. The results showed that the majority of people with mental disorders eventually contact treatment services, but they often wait a long time before doing so: with average delays before seeking help of 8 years for mood disorders, and at least 9 years for anxiety disorders. People who wait longer than average before receiving care are more likely to be young, old, male, poorly educated, or a member of a racial/ethnic minority (Wang *et al.*, 2005a; Morgan & Fearon, 2007).

Where do people go to try to find help? The detailed US survey just mentioned also asked this question and produced some surprising answers. Only about a third (41%) of people who had experienced mental illness in the previous year had received any treatment: 12% from

a psychiatrist, 16% from a non-psychiatric mental health specialist, 23% treated by a general medical practitioner, 8% from a social services professional, and 7% from a complementary or alternative medical provider. In terms of treatment adequacy, mental health specialists providing care that was at least reasonable in about half (48%) of the cases they say, while in primary care only 13% of people treated received care that was adequate. Unmet needs were greater for the poor: older people, minority ethnic groups, those with low incomes or without insurance, and residents of rural areas (Wang *et al.*, 2005b). The study concluded that 'most people with mental disorders in the United States remain either untreated or poorly treated.' (Wang *et al.*, 2005b)

It is mistaken to think that health services are usually the first port of call when people want help for mental illness. In the national survey referred to above, a quarter of people who sought help first went to a member of the clergy. This pattern seems to be remarkably stable and applied to 31% in the 1950s and to 24% in the 1990s. Indeed more people first went to a faith leader for help than went to a psychiatrist (17%), or to a general medical practitioners (17%) (Wang *et al.*, 2003).

How do people judge where to go for help? A large national survey in Germany described vignettes of people depression or schizophrenia and asked about how to find help. Revealingly the general public thought that mental health staff is useful for treating people with schizophrenia, but not for depression. The reason for this is that most people felt that schizophrenia was caused by biological or uncontrollable influences, while they understood depression to be a consequence of 'social disintegration' (including unemployment, drug or alcohol misuse, marital discord, family distress or social isolation) so that people with depression were more often recommended to seek help and social support from a friend or confidant (Angermeyer *et al.*, 1999).

This may go some way to explain why depression is essentially untreated in some countries. An international study of depression found that 0% of people with depression in St. Petersburg received evidence-based treatment in primary care, and only 3% were referred on to specialist mental health care at all (Simon *et al.*, 2004a). But the major barrier to care in that Russian site was money: an inability to afford treatment costs was the main barrier to care for 75% of the depressed Russian patients studied.

Even under better resourced countries, it is known that most people with a mental illness in the United States do not seek assistance. An early national survey found that fewer than one third of all mentally ill people received assessment and treatment, although the rate rose to 60%

for people with a diagnosis of schizophrenia (Narrow *et al.*, 1993; Regier *et al.*, 1993; Wang *et al.*, 2005b). It is a paradox that even though two thirds of all adults with a mental illness went untreated, a half of those who did receive treatment did not have a clear-cut mental illness (Kessler *et al.*, 2005b). Interestingly the idea that conditions which are less stigmatised (for example depression compared with schizophrenia) are those which are seen to be more treatable is not supported by the findings of these surveys (Mann & Himelein, 2004). So no single factor is enough to explain complex patterns of help seeking. Nevertheless the weight of evidence does suggest that even when there are no major financial barriers to care, that many people do not seek help or minimize their contact with services in an attempt to avoid being labeled as mentally ill (Corrigan, 2004a).

Particular social groups may have even lower rates of treatment for mental disorders, and this applies in particular to African Americans in the USA or to Black Caribbean groups in the UK (Hines-Martin *et al.*, 2003b). Several American studies suggest that African Americans receive mental health care about half as often as white people (Diala *et al.*, 2000; Snowden, 2001; Snowden, 2003), even though they have higher rates of some mental disorders (Thornicroft *et al.*, 1999; Davis & Ford, 2004). Several important barriers to care can increase the impact of mental illnesses among black communities in Britain and the USA. These factors have been described as: socio-cultural (health beliefs and mistrust of services), systemic (lack of culturally competent practices in mental health services) (Corrigan *et al.*, 2004), economic (lack of health insurance), or individual barriers (denial of mental health problems) (Swanson & Ward, 1995).

The interplay of these factors produces the contradictory situation in which black groups may have higher rates of many mental illnesses, lower rates of general referral and treatment, but higher rates of compulsory treatment and forensic service contact (Keating & Robertson, 2004; National Institute for Mental Health in England, 2003). In the USA patterns of contact with mental health services are in some ways different for black and white people. Black people with a mental illness are more likely to seek help if their families are supportive, and if a family member has had a positive personal experience of mental health care. In one study they did not view mental health on a continuum of wellbeing, but tended to think of themselves as either mentally healthy or mentally ill. Many interviewees said they did not think they were 'crazy', therefore they did not seek mental health services (Hines-Martin *et al.*, 2003a). Also there was little information about mental health services in the

African-American community. Most people interviewed did not learn about available mental health services until their conditions had become severe (Davis & Ford, 2004). There is an important general point here: that most people of all cultures have relatively little accurate and useful knowledge about mental illness.

Such feelings, at best of ambivalence, and at worst of deliberate avoidance of treatment and care for fear of stigma, have been found throughout the world. For instance, a study of Muslim Arab female university students in Jordan, the United Arab Emirates and Israel, for example, found that for most of these women their first resort was to turn to God through prayer during times of psychological distress, rather than to seek help from health or social care agencies (Al-Krenawi *et al.*, 2004). A strong reluctance to be seen as mentally ill appears to be a universal phenomenon.

Even in battle-hardened soldiers stigma is a powerful factor. Over 3000 military staff from US Army or Marine Corps units were anonymously surveyed three to four months after their return from combat duty in Iraq or Afghanistan. They were assessed for depression, anxiety, or post-traumatic stress disorder (PTSD). Most of the unwell soldiers (60-77%) did not seek mental health care, largely related to concerns about possible stigmatisation (Hoge *et al.*, 2004).

Why do so many people try so hard to avoid contacting psychiatric services? People who are starting to have symptoms of mental illness are also members of the general population and share the same pool of information about psychiatric disorders. The following common beliefs are likely to reduce their likelihood of seeking help: that psychiatric treatments are ineffective (Corrigan, 2004b); that others would react with avoidance; or that a person should solve their own problems (Kessler *et al.*, 2001). At the same time strong family encouragement to go for mental health assessment and treatment does often work (Link *et al.*, 1989).

It is fair to include not only individual but also systemic factors in trying to understand the puzzle of under-treatment. In the USA the National Depressive and Manic-Depressive Association undertook an investigation to explore why 'there is overwhelming evidence that individuals with depression are being seriously under-treated'. They concluded that the 'reasons for the continuing gap include patient, provider, and health care system factors. Patient-based reasons include: failure to recognize the symptoms, underestimating the severity, limited access, reluctance to see a mental health care specialist due to stigma, noncompliance with treatment, and lack of health insurance. Provider factors include poor profes-

sional school education about depression, limited training in interpersonal skills, stigma, inadequate time to evaluate and treat depression, failure to consider psychotherapeutic approaches, and prescription of inadequate doses of antidepressant medication for inadequate durations. Mental health care systems create barriers to receiving optimal treatment'. (Hirschfeld *et al.*, 1997; Castiello & Magliano, 2007).

*"Two months ago I went to my home village. I went for a coffee at a cafe. Most people there, of those who were aware of my problem, call me "mad". More specifically they said "Here is the lunatic". That incident made me very sad, I quickly finished my coffee and I left". Tom.*

Are people in rural areas better or worse served than those in towns and cities? The evidence here is patchy but a clear outline does tend to emerge. If a person with a mental illness wants to keep personal information confidential, this seems to be more difficult in rural communities. A study in Arkansas, for example, compared over 200 urban and rural residents' views about depression and its treatment. The rural residents with a history of depression labeled people who sought professional help more negatively than their urban counterparts. By the same token, those who labeled depression more negatively were less likely to have sought professional help (Rost *et al.*, 1993).

Similar findings also emerged from a study in Iowa where people living in the most rural environments were more likely to hold stigmatising attitudes toward mental health care than people in towns, and such views strongly predicted willingness to seek care (Hoyt *et al.*, 1997). Perhaps for these reasons, a survey of rural residents in Virginia found that over a third of the population had a diagnosed mental disorder, but only 6% subsequently sought help, and those who did not go for treatment said that they 'felt there was no need' (Fox *et al.*, 1999). Evidence from Tennessee also showed that among people who were mentally unwell, those more likely to seek help were women, younger people and those who had been treated for a mental illness previously (Smith *et al.*, 2004).

*"In my village they don't know that I am living at a group home and that I am on medication. I have told them that I am working at a shop in Athens. My close relatives know it and some of them were more supportive after I got sick than before. In my village I don't want them to know about it because I don't want people to say things about me". Diana.*

There is some evidence that these factors also prevent rural children with mental illness from having access to mental health care. A study of parents in rural areas of North Carolina concluded that although as many as 20% of children had some type of treatable mental illness, only about one-third of them received help from the mental health system (Costello *et al.*, 2001; Angold *et al.*, 2002). The researchers found that one of the main barriers to care was stigma toward the use of the mental health care.

So it seems to be true that stigma about mental illness is no less in many rural areas, and may be even stronger than in towns and cities. In part this may be based upon fears that a rural community will learn details about a period of mental illness, while it is easier in cities to remain anonymous. But relatively little research has been done in rural areas to understand these processes in more detail. This is especially important because there are relatively high rates of suicide among male farmers in many countries (Gregoire, 2002; Hawton *et al.*, 1999; Thomas *et al.*, 2003; Voracek *et al.*, 2003; Notkola *et al.*, 1993; Li *et al.*, 2004; Page & Fragar, 2002; Sundar, 1999).

In summary, this paper shows that stigmatisation against people with mental illness is common wherever it has been studied, and that these processes present formidable barriers both to social inclusion and to proper access to mental health care. As the disabilities associated with mental illness exceed those of most other disorder groups (World Health Organisation, 2001; Saxena *et al.*, 2007), now is the time to: (i) undertake evidence-based interventions to reduce stigma, (ii) increase access to mental health treatment and care, and (iii) to scale up the available services in proportion to the magnitude of the need (Chisholm *et al.*, 2007).

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