ORIGINAL ARTICLE

Discrimination in health care against people with mental illness

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Abstract

This paper discusses factors associated with low rates of help-seeking and poorer quality of physical healthcare among people with mental illnesses. Evidence is reviewed on the associations between low rates of mental health literacy, negative attitudes towards people with mental illness, and reluctance to seek help by people who consider that they may have a mental disorder. People with mental illness often report encountering negative attitudes among mental health staff about their prognosis, associated in part with ‘physician bias’. ‘Diagnostic overshadowing’ appears to be common in general health care settings, meaning the misattribution of physical illness signs and symptoms to concurrent mental disorders, leading to underdiagnosis and mistreatment of the physical conditions.

Keywords: Stigma, discrimination, help-seeking, healthcare access, mental health

Introduction

Sandra came to England from Ghana 30 years ago as a young woman, and between raising her children took courses in Chartered Accounting. Suddenly, at the age of 51, she developed the features of a psychotic illness. She began to give credit to odd beliefs, for example she felt that when she crossed the road that cars swerved to try to run her over. She was admitted to a psychiatric ward in a general hospital, but her behaviour was seen as loud, unpredictable and aggressive. So she was transferred to an intensive care unit at a psychiatric hospital. On one occasion she was forcibly injected with medication. Now she is almost fully recovered from the symptoms of the mental illness, nevertheless she is adamant that this episode has irreversibly changed her life.

Other people treat her differently now, “My friends make me feel like a weakling”. She used to be a central figure in her local community, and was heavily involved, for example, in organizing her church and the annual carnival. Although she tries hard to minimize the impact of being unwell, she admits that it has damaged her. “I used to be very influential in the local community, I was chair of the Education Committee, but I discovered that they don’t involve me so much any more. I keep myself to myself more than before. I used to be a very outgoing person, now I’m more withdrawn from society. I’m no longer the person I used to be. I used to be someone who had leadership qualities. I’ve lost confidence. I don’t want to be the centre of attention any more. I shy away from getting too involved. I used to socialize in my community, then they would be looking at me in a funny way, and for a couple of them, it’s like you don’t exist any more.”

On the other hand, Sandra has mixed feelings about the effect of her illness on her family life. She feels her family were “tremendously supportive”
when she was unwell. Especially as they had previously taken her for granted, “It was as if I was the big pillar that would never fall.” But she did fall. Against the grain, her children began to clean up at home and take their share of domestic responsibilities. When she came home they advised her to “take it easy, and avoid too much stress”. At first she was pleased to slow down, but later on she felt over-protected by her husband and children.

A central dilemma for Sandra, while she is urged not to ‘over-do it’, is to know what level of stress would be too much. In fact she feels caught, as the only way to find this out would be to do too much and become unwell again. Her other choice is to push herself too little, and then to feel that she was under-achieving for the rest of her life. She doesn’t talk about this with her family, or about whether it is helpful to discuss her difficulties. “My family don’t want me talk about my mental problems very much. I think it helps to talk about it here in this country, but they don’t think so.”

Before going into hospital Sandra had been working full time. “My boss was very supportive and when I got my job back, he suggested that I agree to reduce my working hours from 5 working days to 3 working days. After a short while I wished that it would go back to normal, but he said the funding for my project was reduced.” Now she continues to work part-time, but she doesn’t know whether the reason given by her manager is genuine, or if it indicates some degree of discrimination.

Sandra thinks that the main reason for her rapid recovery was her strong religious belief. While she was in hospital she prayed often, and on her discharge she decided to tell her congregation about her experiences. “I gave a kind of testimony in my church when I came out of my illness.” In retrospect she now doubts that this was a good idea. “Sometimes I do get the feeling that they treat me differently, that people who used to come to you and chat; now they look away.” This is connected to ideas that are common among her community of people from Ghana. “In Africa, in Ghana, I would not talk about it because of the stigma. There’s nothing you can say that convinces people that you’re a normal person. You are no longer a credible person.”

Sandra’s strongest feelings are reserved for her treatment by health staff. Although she says that the community psychiatric nurses who visited her at home later were ‘brilliant people’, this was overshadowed by more negative experiences. When she was transferred to the intensive care (locked) ward she was forcibly injected with medication. Although these events happened over a year ago she is still very distressed when remembering this episode. “There were between six and eight staff members, I’m not sure, I can’t remember too much I didn’t have a very clear vision. I saw people surrounding me, holding me by the hand, holding me by the legs. I don’t think it was something they had to do. There was no talking. They would have helped better if they had more understanding and more talking… more respect. I felt really bad. While I was in hospital I tried to complain but I don’t know if anybody was listening. It was a nightmare.”

After leaving hospital she felt physically unwell and consulted her family doctor. “I was feeling really tired and I thought I should see my local GP, and I said “Can you please do a physical examination”, because I wasn’t feeling very well. At the end of the day he said “Have you had any mental problems before?” I was really angry. I was really, really angry with him. Was he trying to say that the reason I was coming to see him was because I had had a mental problem? I left medical clinic that day feeling really, really, really bad.”

Sandra’s mixed feelings about mental health care are common among people with mental illness, who both feel that they have been helped and been misunderstood by psychiatric services. It is a paradox that many mentally ill people do not speak highly of mental health staff, who are specifically trained to treat people with such conditions. The experience of people with mental illness is that they often feel patronised, punished or humiliated by such contact. Indeed service users often rate mental health staff as one of the groups which most stigmatizes mentally ill people (Pinfold, Thornicroft, Huxley, & Farmer, 2005). How is this possible when mental health professionals are especially qualified to understand and offer expert assistance to people with mental health problems?

### Access to mental health care

Most people in the general population (in all the countries where this has been studied) have a mixture of little and wrong information about mental illnesses, alongside wary and cautious attitudes about mentally ill people. It is therefore understandable that they are often slow to recognize developing mental health problems in themselves, in family members or in friends, and are reluctant to seek help for fear of the consequences.

It is only recently that we have begun to understand the power of these barriers to finding treatment and care (Cooper, Corrigan, & Watson, 2003). 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 (Black et al., 2001, Compton, Kaslow, & Walker, 2004; Johannessen 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 eight years for mood disorders, and at least nine 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).

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).

On what basis do people judge where to go for help? A large national survey in Germany described vignettes of people with depression or schizophrenia and asked about how to find help. Revealingly the general public thought that mental health staff are 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, Matschinger, & Riedel-Heller, 1999).

Even under better resourced conditions, 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, Regier, Rae, Manderscheid, & Locke, 1993; Regier et al., 1993; Wang et al., 2005b). Over the last decade the occurrence of mental illnesses each year in the United States has not changed (29.4% between 1990 and 1992, and 30.5% between 2001 and 2003). On the other hand, relatively more people with mental illness were treated, rising over this decade from 20.3% to 32.9%.

It is a paradox that even though two thirds of 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., 2005). Interestingly the idea that conditions which are less stigmatized (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, many people do not seek help or minimize their contact with services in an attempt to avoid being labeled as mentally ill (Corrigan, 2004b; Keating & Robertson, 2004).

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 well-being, 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, Brown-Piper, Kim, & Malone, 2003). 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). In short it is clear that most people of all cultures have relatively little accurate and useful knowledge about mental illness.

Such feelings, at best of ambivalence, and at and 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...
being known as a psychiatric patient

For several decades it has been recognised that having been admitted to a psychiatric hospital can have an adverse effect on a person’s reputation (Goffman, 1963; Goffman 1968; Gove & Fain, 1973). How can we understand such a powerful blemish on a person’s identity? In part this damage is linked to popular views of psychiatrists: Who they are, what they do and what they represent (Bar-Levav, 1976). It is widely believed that psychiatrists use diagnostic labels in a cavalier way (Sartorius, 2002). Similarly it is often believed that psychiatrists tend to use medications rather than psychological treatments, that these drugs have unpleasant or even dangerous side-effects (National Institute for Clinical Excellence (NICE), 2004).

At the same time popular opinion often goes well beyond the facts. We can take mental health medications as an example. A study in Germany tried to understand the reasons why people would accept or reject the psychotropic drugs they had been prescribed, compared with their views about taking drugs for cardiac conditions. The researchers found that psychiatric drugs were generally not well accepted because they were believed to cause more severe side-effects than cardiac drugs. Direct experience of contact with people taking psychiatric medications was limited, and so most people drew on other sources of information, mainly reports in the mass media, which gave an overwhelmingly negative account of mental illness and its treatments (Benkert et al., 1997).

perceptions by service users of healthcare staff

Is it possible that staff trained specifically to treat people with mental illnesses can be seen by service users to be stigmatizing themselves? Strangely enough, the answer seems to be yes (Burti & Mosher, 2003). A survey in South Australia, for example, compared the attitudes of over 250 mental health staff and the general public about the likely outcomes of cases of people with depression and schizophrenia. Professionals were generally more pessimistic about the chances of recovery than the general public, and psychiatrists were less even less optimistic than nurses. In an important observation, the study found that most staff base their attitudes upon their personal experience of treating people with mental disorders (Hugo, 2001).

This ‘physician bias’ is understandable, as doctors will tend to draw upon their own clinical experience when advising patients. In many specialist mental health services the service users who recover quickly are discharged from care, and so, over time, doctors
will tend to accumulate most of their clinical experience in trying to treat patients who do not fully recover, or who recover and then relapse again. They simply do not keep in touch with those who recover and stay well.

Perhaps an extreme version of this process applies to forensic psychiatrists whose working life consists of assessing and treating mentally ill offenders, often people who have committed serious crimes. As a consequence such psychiatrists tend to be even more cautious and pessimistic about therapeutic outcomes than general psychiatrists (Lau, 2003). Interestingly, in recent years a number of studies of schizophrenia have been published which indicate that the long-term outlook for this condition is considerably better than used to be believed (Ciompi 1988; Harding, Brooks, Ashikaga, Strauss, & Breier, 1987a, 1987b). A more charitable view of this issue is that mental health staff often feel a strong personal responsibility for doing everything that they can to prevent a relapse of mental illness for the people they treat, and so they are reluctant to encourage service users to take on potentially stressful activities, for example full-time work, in case the person’s condition deteriorates (Murray & Steffen, 1999).

People with some particular mental disorders are less favoured by psychiatric staff, especially people with a diagnosis of a ‘personality disorder’. Paradoxically, although service users with such a diagnosis claim to be especially rejected by healthcare staff, there are few investigations of stigma against people with a personality disorder (Camp, Finlay, & Lyons, 2002; Lequesne & Hersh, 2004; Markham, 2005; Nehls, 1998). These studies do suggest that people with this diagnosis are felt by staff to be difficult, less deserving of care, manipulative, attention-seeking, annoying, and in control of their suicidal urges (Lewis & Appleby, 1988). The diagnosis is therefore interpreted by some mental health staff as pejorative (Gallop, Lancee, & Garfinkel, 1989), and one that does not to arouse their empathy (Fraser & Gallop, 1993).

Other diagnostic groups also appear to be less popular with health staff. Chronic fatigue syndrome is bitterly contested in terms of its status as a physical, psychiatric or psycho-somatic condition, and arouses controversy about its causation and treatment. People who have been given or assumed this diagnosis often describe experiences of rejection by both general and mental health staff (Asbring & Narvanen, 2002; Davidson, 2005; Jason, Taylor, Plioplys, Stepnek, & Shlaes, 2002; MacLean & Wessely, 1994).

“All of the worst experiences I have had have been in psychiatric hospitals. I recognize the need to be kept safe but often I have felt that my rights and dignity have been stripped away. Being intimately searched again and again and constantly followed whilst under ‘close observation’ just leaves me feeling singled out and perceived as little more than a nuisance (“there’s to be no trouble on my shift”). I have seen, unofficially, my hospital notes and there is more than one occasion when nurses have actually lied to cover their own backs after I have self-harmed. After I have self-harmed, just when I feel at my most vulnerable, I have encountered a wall of silence as if talking about it will only encourage me to do it again. This is without the stigma attached to self-harm by many of my fellow patients. I have heard many comments along the lines of “Oh she’s cut again. Why doesn’t she just do it properly and kill herself.” Sandra.

If anything, service users report that some family physicians/general practitioners are even more often stigmatizing than psychiatrists in responding unsympathetically to people with mental illnesses (Broadhead, 1994; Hodges, Inch, & Silver, 2001; Schlosberg, 1993). A series of focus groups in England asked service users about their experiences of stigma and about who should receive targeted educational sessions to reduce discrimination. The group most often mentioned (by about two-thirds of service users) was family doctors, closely followed by school children, employers and police (Pinfold et al., 2003a, 2003b). This view is justified by the findings of a national survey in Australia which showed that family doctors and psychiatrists had more pessimistic views about the outcomes for mental illnesses than psychologists and the general public (Jorm, Korten, Jacomb, Christensen, & Henderson, 1999). The attitudes of psychiatric nurses were similar to those of psychiatrists, except that nurses were generally more positive about alternative and complementary approaches to treatment, such as vitamins, minerals and naturopathy (Caldwell & Jorm, 2000, 2001).

Negative attitudes can develop early. The findings of studies with medical students in several countries are far from reassuring (Mino, Yasuda, Kanazawa, & Inoue, 2000; Mino, Yasuda, Tsuda, & Shimodera, 2001; Mukherjee, Fialho, Wijetunge, Checinski, & Surgenor, 2002; Rodrigues, 1992). In Croatia, for example, trainee doctors have been found to have stigmatizing attitudes to mental illness, largely based upon fear and ignorance (Filipic et al., 2003). As we saw earlier, contact with people with mental illness is also linked with more favourable attitudes among medical students (Arikan & Uysal, 1999; Arikan, Uysal, & Cetin, 1999), nursing (Llerena, Caceres, & Penas-Lledo, 2002), or occupational therapy students (Lyons & Ziviani, 1995) although enduring and positive changes in such attitudes may be difficult to achieve (Arkar & Eker, 1997; Roth,
Antony, Kerr, & Downie, 2000; Sadow, Ryder, & Webster, 2002; Sivakumar, Wilkinson, Toone, & Greer, 1986).

Medical students also had clear preferences for particular categories of patients, and were less sympathetic toward those whom they believed to be undeserving of treatment because they were responsible for their condition, for example people with eating disorders (Fleming & Szmukler, 1992; Wiese, Wilson, Jones, & Neises, 1992). One effect of these inaccurate and negative views by medical students about people with mental illness is that relatively few choose psychiatry as a career. There is evidence that psychiatry is attracting fewer medical graduates, with associated shortages of qualified doctors in some economically developed countries (Sierles & Taylor, 1995). As a result there is a ‘brain drain’ of psychiatrists from less economically developed countries who move to richer countries, leaving their own countries even further depleted of staff (Chikara & Manley, 1991).

The core issue of dehumanization that occurs time and again in service users’ accounts is of: Being spoken to as if they were children; being excluded from important decisions; and staff assuming the lack of capacity to be responsible for their own lives (Corrigan, 2005). Further recurrent themes from the perspective of service users are being given insufficient information about their condition and treatment options, and feeling that behind many encounters with psychiatric staff is the usually unspoken threat of coercive treatment (Chamberlin, 1979, 2005; Szmukler & Appelbaum, 2001; Ucok, Polat, Sartorius, Erkoc, & Atakli, 2004).

“The worst I have come across is medical people. I suffer badly from stomach problems. I have always had a sensitive stomach, i.e. stomach ulcers, bleeding stomach, and IBS (irritable bowel syndrome). But when I try to get help from my doctor, they say “Oh it’s your depression”, or my phobia. I’m far from stupid and I’m well aware of the difference between IBS pain and what symptoms I get because of my phobia. I’ve even been told I’m anorexic and in denial. From the time doctors are aware of my mental problems, they talk at me, instead of to me, like I haven’t a mind of my own.” Eva.

The parts of the general health system that seems to be most despised by many people with mental illness are the casualty (emergency room, accident and emergency) departments (Mazeh, Melamed, & Barak, 2003). The same themes occur repeatedly in service users’ accounts. The first issue is that people who attend after harming themselves very often feel deliberately punished by staff.

“This is very damaging. If you have to attend A&E (Accident and Emergency Department) after an incident of DSH (deliberate self harm) and have been made to feel worthless, a waste of time, etc. Consider what message this sends out. DSH is all about transferring the emotional into the physical. You feel SO bad about yourself that you cut yourself to the bone to feel alive, YOU burn yourself until you can smell your skin burning and your arm twitching. Why? You don’t understand the pain that you are going through. You cannot talk to anyone about it because they don’t understand. You get stuck in a spiral of despair, which as the years go on gets deeper and deeper.

Physical health care

“When I took an overdose, I was kept in A&E (emergency room) for the night. The staff were very rude to me, which has stopped me from going back there when I am in a crisis.” Fiona

If staff attitudes are problematic within the mental health services, is the situation any better when people with mental illness also need treatment for physical health problems? If anything, the situation may be even worse. There is strong evidence that people with a diagnosis of a mental illness, for example, have less access to primary health care (Levinson, Druss, Dombrowski, & Rosenheck, 2003), and also receive inferior care for diabetes and heart attacks (Desai, Rosenheck, Druss, & Perlin, 2002; Druss, Bradford, Rosenheck, Druss, 2002; Radford, & Krumholz, 2001), even though rates of physical illness and poor dental health among people with severe mentally illnesses are much higher than in the general population (Jones et al., 2004; McCreadie, 2003; McCreadie et al., 2004; Phelan, Stradins, & Morrison, 2001), with especially high levels of cardio-vascular disease, obesity, diabetes and HIV/AIDS (Rethink, 2005). This combination of high rates of physical illness and low rates of effective treatment leads to the fatal consequences of discrimination and neglect: People with types all mental disorders have an increased risk of premature death (Harris & Barraclough, 1998).

“Whilst I have good experiences in the NHS, it being a microcosm of society, there is fear and prejudice there too. Overworked casualty staff have little energy left to treat self-harm with the sympathy and respect it deserves and often it is just treated with contempt. I have been stitched without anaesthetic which feels like punishment and comments like “You should be letting us treat patients who are really ill” are not uncommon. Treatment like this is dehumanizing and just increases the feeling of being stigmatized.” Sandra.
Your first involvement with psychiatric services is innocent enough. YOU really believe that they will be able to help, but you are still involved in the system years later. Again I question why?” Martina.

The second key theme that emerges about casualty departments is that people going there for help report that they are not treated with respect.

“In my experience it has been mostly health professionals who have been at fault when it comes to treating me with respect and dignity. Some of these are or were within the mental health service, but more often it was other health professionals. My experiences include the following incident. (1) Talking to me in a derogatory manner, as if I was a child or wouldn’t understand. This contrasted with how they spoke to my husband, who sometimes accompanied me to appointments. (2) They would say one thing at one appointment and then something else at the next, as if I would not remember what had been said the first time. (3) Not fully explaining to me what’s going on with my treatment, apparently fearing that I would not be able to cope with the truth. Whilst that was possible, once I did find out the truth, difficulties in coping with it were exacerbated by a deep sense of betrayal. (4) After taking overdoses, overhearing the comments of nurses in A&E or on the ward, and in some cases these comments were said directly to me. They included: “It’s your own fault you’re here” and (most hurtful of all) “Don’t you think we have better things to do, treating people with real problems.” On one occasion, I was so upset by these comments that I pulled out a drip and ran out of hospital” Nadia.

Choosing to stop contact with mental health services

Perhaps not surprisingly, the single biggest factor which leads to stopping contact with mental health services, according to a Danish study, is dissatisfaction with the care received (Tehrani, Krussel, Borg, & Munk-Jorgensen, 1996). When people with mental illness leave treatment before making a full recovery, then their reasons for this may be especially revealing. Generally speaking it is people who are young, poor, single, uninsured, or who have more than one diagnosis who are more likely to stop contact with services (Tehrani et al., 1996), even if they are still unwell when they take their own discharge (Edlund et al., 2002; Killaspy, Banerjee, King, & Lloyd, 2000; Rossi et al., 2002; Young, Grusky, Jordan, & Belin, 2000). Interestingly, dropout rates are higher for people who believe that psychiatric treatments are rarely effective, who are embarrassed to be seen by a mental health professional, or who are prescribed with medication without any psychological treatment (Edlund et al., 2002). Surprisingly little has been written about why people stop attending appointments, from the point of view of service users themselves, either to understand what affects their satisfaction with care, or to find out how stigma and discrimination play a role in these treatment decisions, or to appreciate the mixed feelings many people with mental illness have about their harmful healers (Parkman, Davies, Leese, Phelan, & Thornicroft, 1997; Sirey et al., 1999, 2001a, 2001b).

“I hope to God I never get any serious mental health issues again, because I couldn’t handle being treated like I’m nobody, and have no say in how I’m treated. When I used to go to see my psychiatrist, I’d see people in there, sobbing their hearts out because the council have told them to go away, and treated them like nothing, and they have had to come down to the centre to get their psychiatrist to help them with benefits, and its really horrible to see.” Eva.

Acknowledgement

This is an extract from Shunned: Discrimination against people with mental illness by Graham Thornicroft published by Oxford University Press.

References


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