3. Stigmatization in the long-term treatment of psychotic disorders

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Summary

Stigma is linked to negative prejudices without examining whether there is any justification for such behaviour. Over time, various efforts have been made to reduce prejudice toward people with mental illness. Yet, the World Health Organization (WHO) World Health Report still describes stigma as one of the greatest obstacles to the treatment of mental illness. While schizophrenia, among other mental illnesses, is the most stigmatized even to the point that some want the name of the illness to be hidden or changed, patients with bipolar illness may also be exposed to stigma. The degree of stigmatization has been found to be positively associated with the severity of the mental disorder, and stigma is carried out not only by patients but also by their families in correlation with the severity. Tragically, people with mental illness themselves are as negative in their opinions about mental illness as is the general public, and concerns about stigma adversely affect self-esteem and adaptive social functioning. There are many programmes worldwide for the fight against stigmatization, and there is clear recognition of the fact that stigma can only be successfully eliminated if the programme becomes a normal part of health service rather than of campaigns of limited duration.

3.1. Introduction

It is written that "And God said, Let us make man in our image" in the Bible (Genesis 1:26). In 1996, Pope John II and the pontifical council convened an international conference with the title, "In the image and likeness of God: always?" and asked the question, "Are mentally ill people also created in the image of God?" in order to draw attention to the terrible situation in which people with mental disorders find themselves—despised, discriminated against, and abused in many ways, as if their illness rendered them no longer made in the image of God. Everybody seemed to agree that the answer to this papal question was "yes", but there was no explanation of the reasons for stigmatization and how they arose (Sartorius 2005). The main dilemma of a psychiatrist is to reconcile the task of bringing the public's attention to the needs of people with mental illness and the task of preventing their stigmatization because of such illnesses. Stigma, unfortunately being attached to mental illness, is not only a consequence of mental illness but also a risk factor for mental and physical disease and a direct cause of disability or handicap (Foti 2005). The word "stigma" is of Greek origin and means "to pierce, to make a hole". The word was also used, however, to mean branding a criminal with a hot iron as a mark of infamy so that others could avoid people with the mark. In more recent years, stigma has been linked to certain diagnoses such as tuberculosis, leprosy, cancer, and mental illness. Stigma is associated with negative prejudices reflecting the readiness of people to act negatively towards the object of the prejudice without examining whether there is any justification for such behaviour. Over time, various efforts have been made to reduce prejudice toward people with mental illness. Despite these attempts, stigma, discrimination, and misconceptions about mental illness continue to be pervasive (Corrigan 2002). Although stigma and its consequences vary among different population groups defined by gender, age, ethnic origin, etc., it affects all people with mental illness or impairment, their families, the mental health professionals who treat them, and institutions where they are treated. Many people including medical professionals (even psychiatrists), politicians, the media, social organizations (even religious institutions), people affected by the illness, and families contribute to a different degree and often unconsciously to stigmatization of those with mental illness. Stigma's effects are surprisingly most pernicious when they are least consciously manifested (Foti 2005). In the year 2001 the World Health Organization (WHO) World Health Report accepted stigma as one of the greatest obstacles to the treatment of mental illness

3.2. Stigmatization and schizophrenia

Of the mental illnesses, schizophrenia is among the most stigmatized, even to the point that many want the name of the illness to be hidden or changed. In 2002, the Japanese Society of Psychiatry and Neurology and the national family organization, Zenkaren, succeeded in changing the name of schizophrenia in order to diminish its stigmatizing effect. This decision is a good example that reveals the tendency of the general public and even health professionals to hold a stereotyped image of those with schizophrenia. The stigma that attaches to schizophrenia extends beyond the individual with the illness to encompass everything and everyone associated with them; it even includes the medications and other treatments that maybe used to control symptoms (Sartorius and Schultz, 2005). This stigmatization of schizophrenia is common among almost every country in the world. Emil Kreapelin recognized the importance of this issue and travelled to Java in 1904, motivated by his wish to study the existence and manifestation of dementia praecox in a population of distinctly different origin and culture from his own European experience (Karno, 1993). Since then, undoubtedly because of his great contribution, schizophrenia has been the mental illness of special attraction to psychiatrists, not only because of the course and treatment of the illness, but also because of the stigmatization process in a transcultural setting. Although there are core symptoms of the illness, as defined by ICD and DSM criteria or by special definitions such as in Schneider's first rank symptoms, schizophrenia in the clinical or social course varies by national setting, and its course is more benign in some nations (Jablensky, 1975).

In the 1970s, WHO conducted a major international collaborative study on schizophrenia. The study demonstrated that schizophrenia did not vary in incidence among the US, UK, India, Colombia, Nigeria, Denmark, Czechoslovakia, the then-USSR, and China. They did find, however, that the course and outcome of schizophrenia were better in developing than in developed countries, as has also been confirmed by some other studies (Sartorius et al, 1996; WHO, 2001). The frequency of stressful events or family members' attitudes did not explain the difference. It is possible that the different forms and levels of stigmatization in Third World countries create the difference, but that has not been systematically examined. Clearly, people with mental illness are highly stigmatized in the West. In developing countries, certain forms of mental illness have been well tolerated, possibly because of popular beliefs about their causation (e.g., that a curse has been put on someone by enemies). In recent years, the situation has been changed in these countries, in part

because of increased urbanization and the influence of mass media and in part because of the breakdown of the traditional family structure, which had allowed care for an ill member in the large households. However, the authors of a WHO follow-up study of schizophrenia suggest that one of the factors contributing to a good outcome in schizophrenia in Cali, Columbia, was the high level of tolerance of relatives and friends for symptoms of mental disorder, which is a factor that can help the readjustment to life and work in the community after the acute phase of the illness (Foti, 2005).

3.3. Axes of stigmatization

Research over the past four decades has compellingly demonstrated that individuals diagnosed as having mental illness are socially stigmatized or discriminated against in several dimensions by key individuals in their communities. For example, studies have found that employers, families of patients, mental health workers, and prospective landlords all endorsed devaluing statements about or discriminated against mentally ill individuals (Link, 1987). The degree of stigmatization has been found to be positively associated with the manifest severity of the mental disorder; however, even persons who have minimal signs of mental illness, that is, those who appear "troubled", may be stereotyped and rejected. Link and colleagues have argued that because people with mental illness internalize the devaluing and discriminatory attitudes of society at large, they anticipate discrimination or rejection by others and develop coping strategies, such as secrecy about their illness or withdrawal from social interaction, in an effort to avoid the rejection. Some investigators also state that to avoid discrimination and rejection, patients with mental illness may limit their social interactions, including with their family members (Matorin, 2002). This limiting, however, further contributes to the array of stigmatized behaviours such patients' exhibit.

Stigma applies not only to patients but also to their families. Often, when a relative is identified as having schizophrenia, the families themselves feel that they are not accepted by their extended family and friends. The fear that schizophrenia or any mental illness in general, makes people aggressive and violent isolates the family even more. Some interesting research was conducted by Polat and her colleagues (2000) in Turkey with the relatives of schizophrenic and bipolar patients. They examined perceptions of and reactions to stigma among parents and spouses of the patients with schizophrenia and bipolar disorder and found that in both groups most family members did not perceive themselves as being avoided by others or as having problems

in the neighbourhood because of their relatives' illness. Despite this, 63% of schizophrenics' relatives and 56% of bipolar relatives were more likely to conceal the illness and not tell anybody other than close family members. Fifty-two percent of the relatives of schizophrenics and 33% of the relatives of bipolar patients felt that "the illness might be their fault". Parents tended to conceal the illness more than the spouses and were worried more because "people would blame them for the patient's problems". The level of family stigma and the negative response of other people directly correlated with the number of hospitalizations. The study group showed that most of the families disguise their relative's illness at least to some degree because of the fear of stigmatization and rejection. They also stated that in Turkey, stigmatization is not only the problem of patients with schizophrenia and their relatives but also of patients with other psychiatric diagnoses.

3.4. Stigmatization of bipolar illness

Most studies of the stigma associated with mental illness have focused on patients with schizophrenia or chronic mental illness; however, as the study above indicated, there are signs that patients with bipolar illness may also be exposed to stigma (Fadden, 1987). Results from a mental illness awareness survey done in 1999 showed that a significant gap exists between people's perceptions and awareness of mental illness, and in particular, of bipolar disorder. The Opinion Research Corporation survey done by telephone interviews conducted among 1008 adults residing in the US, conducted on behalf of the National Alliance for the Mentally Ill (NAMI) and the National Depressive and Manic-Depressive Association (NDMDA), found that 67% of those surveyed were unable to accurately describe manic-depressive illness. Only 33% correctly characterized manic-depressive illness as wide swings in emotion or mood. Thirty-three percent incorrectly believed that manic-depressive illness is a more serious form of depression, and only 43% were able to identify symptoms of mania. Social stigma dictates many people's attitudes toward mental illness: 44% agreed that people with manic-depressive illness are often violent, and another 25% thought that people who have mood disorders or manic-depressive illness are different from other people. Twenty-one percent of those surveyed said they would feel uncomfortable being in the presence of a manic-depressive person. Many believed that mental illness is a personal failure, not a disease: Nineteen percent of those surveyed felt that individuals with depression or bipolar disorder are personally responsible for the development of their own illness. Forty-six percent of those surveyed said they

know someone who exhibits signs of manic-depressive illness. When asked if they have ever approached such a person offering help, 40% said no. Ninety-three percent of respondents agreed that manic-depressive illness is a medical condition requiring professional treatment. Yet, only 35% would consult a mental health professional if they were to be ill themselves or if they knew someone else experiencing symptoms of mania or depression. This survey is available at www.nami.org (2005).

Although the majority of respondents (54%) accurately stated that manic-depressive illness most often occurs in the teens and 20s, this age group was the least likely to seek help. An overwhelming 81% of those aged 18–24 said that if they were experiencing symptoms of manic-depression, they would try to solve the problem themselves rather than consulting someone about symptoms. Forty-two percent of those aged 25–34 would avoid asking for help because they wouldn't want to admit there was a problem. Twenty-five percent believed manic-depressive illness can be self-controlled. An overwhelming 81% agreed that people suffering manic-depressive illness are often misdiagnosed. When asked about treatment options for manic-depressive illness, 56% mentioned medication, 53% said consultation with a therapist, psychologist, or psychiatrist, and 21% noted group therapy. The results of this survey clearly indicate the need to increase the awareness of the general public about bipolar disorder. The general public is uncertain about the symptoms of the disease and sees patients as potentially violent or "different" from other people. Although respondents believed that manic-depressive disorder is a disease that should be treated medically, they were reluctant to seek help in cases in which they experienced the symptoms of the illness.

The experience of patients with manic-depression confirms the results of this survey. The World Federation for Mental Health (WFMH) announced results of a global bipolar disorder consumer survey (Sartorius and Schultz, 2005) of 687 patients, conducted across Canada, Germany, Greece, Italy, Spain, the United Kingdom, and the United States, at the World Congress of Biological Psychiatry in 2005. The survey revealed that almost half (47%) of all people with bipolar disorder—or "consumers" as they prefer to be called—feel that their disease has had a highly negative impact on their quality of life. Furthermore, more than a third (35%) of respondents stated they have been discriminated against as a result of their condition, usually within the context of everyday social relationships. The survey also revealed that 26% of respondents never tell people they have bipolar disorder. Fear of social stigma is a key reason why people do not share this information with others. Seventy

percent of people with bipolar disorder who were surveyed believe that the public does not understand their illness and that ignorance may be causing the stigma that many feel.

Another self-administered survey was done in 11 EU countries on bipolar patients. The impact of the stigma in bipolar patients' lives was found to range between 34% and 98%. The condition was found to have a negative impact on work, interpersonal, and leisure activities (Morselli, 2005). The concerns about stigma were shown to have effects on social adaptation among persons with a diagnosis of bipolar affective disorder, also in a study consisting of 264 persons with bipolar I, bipolar II, or schizoaffective disorder. Patients were evaluated with clinical scales and a measure of perceived stigma. People who had concerns about stigma showed significantly more impairment on the social adjustment scale. Concerns about stigma predicted a higher avoidance of social interactions with people outside the family and psychological isolation (Deborah, 2001).

3.5. Self-stigmatization in the course of illness

Tragically, people with mental illness themselves accept the stereotype of their own condition. A number of studies have shown that mental patients are as negative in their opinions about mental illness as is the general public. Some reports, indeed, indicate that mentally ill patients more strongly reject those with mental illness than do family members or hospital staff. The perception of stigma by people with psychosis is associated with enduring negative effects on their self-esteem, well-being, mental status, work status, and income (Link, 1987). Self-stigmatization, which is not taken into consideration as often as other forms of stigmatization, may be of particular importance in illnesses with an episodic course, such as mood disorders and cycloid psychoses. Studies of self-stigmatization have been few, and the results concerning factors associated with such stigma are controversial (Ashdown, 1993; O'Graddy, 1996). In a study from Taiwan using the Self-Stigma Assessment Scale, the authors evaluated 247 outpatients with depressive disorders to determine their levels of self-stigmatization. Twenty-five percent of the patients had high levels of self-stigma, and patients who had more severe depression and less education had higher levels of self-stigma (Struening, 2001).

Concerns about stigma adversely affect the recovery of people with mental illness. These concerns affect self-esteem and adaptive social functioning out-

side the family and influence the willingness of outpatients to take the medications that their psychiatrists prescribe for them. Adherence is affected by "the complex interplay of illness features, personal values, interpersonal supports, and environmental conditions", and successful interventions must address these issues in their behavioural complexity (Heinssen, 2002). Therefore, non-compliance or non-adherence to prescribed medicine because of fear of stigmatization is a significant problem in the long-term treatment of mental disorders. Self-stigmatization has a special and deep impact in mood disorders specifically. The findings of the studies reported here suggest that clinicians need to be aware that concerns about stigma may reduce adherence to the medications they prescribe or may delay recovery of self-esteem and adaptive social functioning, even under conditions of optimal psychopharmacologic response.

When thinking about stigma, psychiatrists and mental health workers usually think about personal stigma, the prejudicial attitudes and discriminatory behaviour concerning an individual with mental illness. Sociologists, unlike psychiatrists or psychologists, are more concerned with structural stigma, a term used to describe the situation in which an institution, contributes to stigmatization, e.g., by broadcasting stigmatizing messages. In a study conducted by Corrigan et al. (2002), the investigators surveyed 3353 newspaper stories and found that 39% of all stories focused on dangerousness and violence in mental illness.

The recognition of the adverse impact of stigma is only a first step toward curing the problem. Among the necessary ingredients in the fight against stigma are continuing efforts to provide the public with a more accurate and less prejudiced view of mental illness and to work with people with mental illness in developing strategies for coping with stigma that do not lead them to avoid social and treatment settings. Making the public aware that mental illness is a treatable biological illness similar to other more accepted medical conditions—for example, diabetes mellitus or hypertension—is also a useful technique for a mental health service to use in reducing stigma. The experiences of people with bipolar patients may provide important clues for starting points in anti-stigma campaigns. Patients have vast and valuable knowledge about many topics; for example, how to explain gaps in one's resume, how to obtain medical care without being labelled a "psychiatric patient", how to explain one's depression to family members who oppose the use of medications and insist that one is simply "not trying hard enough", how to manage side-effects such as tremor and weight gain that are difficult to conceal, and how to cope

with loneliness and isolation from the mainstream culture (Matorin, 2002). Goodwin and Jamison (1990) stated that individuals with manic-depressive illness feel ashamed and humiliated because of their illness, their bizarre and inappropriate behaviour, violence, financial irregularities, and sexual indiscretions. This feeling of shame can lead to self-stigmatization that may follow the patient as a dark and inescapable shadow for many years. As they quote from a bipolar patient: ***"There is a particular kind of pain, elation, loneliness and terror involved in this kind of madness... And always, when will it happen again? Which of my feelings are real? Which of the me is me?"***

3.6. Fight against stigma

The World Psychiatric Association (WPA) Programme to Reduce Stigma and Discrimination because of schizophrenia, which was launched in 1996, has established projects to fight stigma in 20 countries, using a variety of techniques (Sartorius 1997). At each site, the first step was to conduct a local survey of perceived stigma—the experiences of patients and their families since the illness onset. On the basis of these surveys, the local committees selected interventions targeted at some social groups, such as students, workers, and criminal justice personnel. Messages for the target groups as well as the methods to convey them were carefully selected and tested. The project produced an array of useful experiences and suggestions about ways to combat stigma. The programmes continue in clear recognition of the fact that stigma can only be successfully eliminated if the programme becomes a normal part of the health service rather than existing as campaigns of limited duration.

3.7. Conclusions

Three sets of conclusions can be drawn about the stigma of mental illness: (1) Mental illness stigmatizes more than physical illness; (2) stigma and in particular stereotyped ideas about dangerousness and lack of self-responsibility lead to discrimination; and (3) familiarity with people who have a mental illness is among the interventions that can reduce the stigma (Foti, 2005).

Changing attitudes through personal contact and giving accurate information are ways health workers can reduce stigma for people with mental illness, and these approaches increase the chance for a better treatment outcome and their patients' integration into the community. In adopting these avenues,

psychiatrists should not forget that patients and the community are learning a lot in this age of information, that the treatment of people with mental illness has changed considerably, and that patients do not fit the old roles they were previously given. That means, as William Ashdown, president of a non-governmental organization of people with affective disorders, stated: "A new paradigm is emerging because there is a reduction in the attitudes of helplessness; fuelled by internet; contact with others; gaining strength and political power; based on more equal and balanced relationship" (Ashdown, 1993). Physicians must expect that patients know a great deal more about their illness and treatments, and sometimes, they will know more than we do. The challenge for physicians is that they have to learn more to work with patients, because as Fromm-Reichman has stated (1950), our patients could be even more informed than we are, and this should lead us to be braver than them. The increased insistence on achieving recovery or full remission, instead of only response, can be an important contribution to efforts to overcome self-stigmatization. As Bryan L. Court, a bipolar patient, stated, stigma due to the illness is a feeling or sense of disgrace, dishonour, shame, or discredit with the impression of being blemished or stained in an ugly, undesirable way (Court, 1996). "Stigma comes in the form of newspaper articles that misrepresent the truth and movies that make fun of the mentally ill. Nobody wants to be like the characters in the movies or newspapers. For the most part, everyone who is uneducated and unsympathetic to those with bipolar disorder instils a sense of stigma in us. Who takes stigma and puts it in us? We do! Why do we let that happen? We can't change what others think of us, but we don't have to accept and absorb their views of this illness as our own. I can change only the way I think about myself. I can choose to remove the stigma from myself and let the perpetrators keep it… The God I choose to believe in loves me and accepts me unconditionally and I choose to believe what He says about me… And if God says I'm OK, I can love and accept myself without stigma…"

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