



Clinical Consequences of Stigma (Suicide, Non-Compliance and Rehospitalisation)

KEYWORDS

Amresh Shrivastava

Department of Psychiatry, Elgin Early Intervention Program for Psychosis, The University of Western Ontario, Ontario, Canada

Nilesh Shah

Professor and Head, Department of Psychiatry, Lokmanya Tilak Municipal Medical College, Mumbai

Avinash De Sousa

Research Officer, Department of Psychiatry, Lokmanya Tilak Municipal Medical College, Mumbai

Sushma Sonavane

Addl. Professor, Department of Psychiatry, Lokmanya Tilak Municipal Medical College, Mumbai.

ABSTRACT *Stigma and discrimination continue to be a reality in the lives of people suffering from mental illness, particularly schizophrenia, and prove to be some of the greatest barriers to access care, continue to remain under care, and regain a normal lifestyle and health. Research advances have defined stigma, assessed its implications and have even examined intervention strategies for dealing with stigma. The delay in treatment due to stigma causes potential complications like suicide, violence, harm to others and deterioration in capacity to look after one's physical health. These are preventable clinical complications. In order to deal with the impact of stigma on an individual basis, it needs to be [1] assessed during routine clinical examination, [2] assessed for quantification in order to obtain measurable objective deliverables, and [3] examined if treatment can reduce stigma and its impact on individuals. We are of the opinion that stigma has several domains: personal, social, cultural, illness-related, treatment-related, and environmental. Each of these domains has several factors, which may or may not contribute to the degree of stigma affecting a given individual. Components of these domains can be used to design a tool, which can then be standardized and validated in controlled studies. Quantifying stigma in terms of its impact and consequences requires attention to four different components: 1) events of discrimination that have taken place, 2) the real-life experience, 3) the patients' perception of this discrimination, and 4) how has the patient coped to live with discrimination. A reasonable quantification of stigma would be to measure the consequences and its perception in an individual. We hypothesize that the efficacy of an intervention can be successfully measured by comparing it before and after treatment. Longer durations of illness, and particularly treatment, were associated with fewer consequences of stigma and discrimination. Higher levels of consequences related to stigma and discrimination were found to relate to a greater likelihood of non-compliance and to a greater risk for suicide. By assessing and quantifying stigma in this way, there is a better chance of these consequences being reduced and addressed*

INTRODUCTION

Experience of stigma is universal. [1] It is defined as an identifying mark of shame or discredit. It also refers to negatively perceived defining characteristics which is associated with discrimination. It continues to be a reality in lives of people suffering from mental illness [2]. Research in field of stigma has made remarkable contribution which shows that stigma is greatest barrier to regain normal life. Conceptualization of stigma has evolved over years yet it is typically referred to a tie characteristic of individual that leads to a negative valued social identity. The individuals experiencing mental health related issues have a high propensity to avoid seeking help for fear of social stigma and discrimination. Stigma therefore is a significant clinical risk factor which is often associated with suicide, violence and lack of self care. It therefore should be thought of as a clinical condition, and be treated accordingly.

Implication of stigma, despite the discrimination and prejudice, is that of a 'hope'. Stigma not only exists in mental disorders but also in physical disorders e.g. in leprosy and tuberculosis in olden days. It wasn't known then that these conditions could be treated; otherwise, stigma could be reduced, making a qualitative difference to lives of these patients. It was generally understood that stigma arises from social attitude, and personal perceptions and answers to reduce stigma were sought in changing societal opinion and attitude of people. However, the fact is contrary to this belief. It was seen that reduction of stigma happened when scientists found answers to difficult conditions [3]. Stigma existed because these conditions were not treatable e.g. stigma against leprosy did not reduce until a successful treatment

was invented. Further, stigma for complicated and resistant leprosy did not reduce because these patients had disabling condition like loss of figure and toes, and were confined to the four walls of sanatoriums in a number of countries [4].

They were completely isolated from people and did not see light outside their reclusive world. The same happened with tuberculosis and HIV-AIDS. It was an almost universal practice not to keep a person with tuberculosis in the house and to send them to sanatorium when effective treatment was not available. Therefore, stigma is neither a social condition alone, and neither does it arise only from social factors. These are in fact consequences of illnesses which are difficult to treat, leading to severe burden on families, causing disability and dysfunction, and above all becoming a cause for disruption for a family [5]. A fresh look at the concept and theme of stigma elucidates that a common denominator amongst all stigmatized mental and physical disorders is state of ineffective and intractable treatment. Stigma increases as illnesses become severe and florid. It decreases in response to treatment. Thus the question to be examined is whether there is a relationship between stigma and absence of effective treatment; though it does not mean that prejudice, attitude, societal neglect and discrimination do not contribute to cause stigma and its consequences. Stigma perhaps is due to the combination of clinical and social factors including lack of effective treatment [6]. In this paper we will discuss lessons from a few of our studies which are having a common explorative - stigma. We are of the opinion that stigma delays treatment seeking, worsens course and outcome, reduces compliance and increases the risk of relapse, causing further disability,

discrimination and isolation, even in persons who have accessed mental health services.

Despite revolutionary advances in treatment of mental disorders, outcome of these disorders have not crossed the threshold where people do not remain threatened by recurrence of illness. E.g. Evidence suggests that a good outcome of schizophrenia obtained by early intervention seldom sustains after 5 years. Long-term outcome of schizophrenia continues to be poor and relates to personal and social disability [7]. It is necessary to understand the complex relationship of stigma with clinical psychiatry. Stigma is one of the most challenging areas at present; however optimism remains. A successful program for treatment needs to demonstrate change in a patient's life and the center for care needs to shift from hospital to communities.

THE PATIENT LEVEL

Though the patient is the victim of stigma, it is not clearly known whether stigma originates from his experience of prejudice and discrimination or from his opinion of mental illnesses. It is difficult for the patient to have an objective viewpoint in an environment suffering from lack of awareness and education regarding mental disorder. In one of our studies, we attempted to assess the patient's perception of schizophrenia regarding stigma and discrimination. The main objective of this study was to find out determinants and the nature of stigma. We used a guided, self-rated, semi structured proforma, which was developed by a national working group for the World Psychiatric Association's steering committee for its landmark study 'open the doors'. [7] In a 100-patient study (selected from the outpatient department of a psychiatric hospital in Mumbai, India) with mean age of 39.2 years, 74% were male. The results indicated that stigma was perceived to be highest in family 81%, social context 37%, and personal life 69%. A whopping 97% believed that stigma was caused by lack of awareness about schizophrenia. Participants reported that second common cause of stigma was the illness itself (73%), followed by lowered self-esteem (69%). Participants felt they were avoided due to their illness (61%), discriminated in family (50%) and at work (42%). About half of the patients had heard offensive comments about mental illness. Interestingly, a very high number of subjects felt hopeful that stigma could be dealt with. According to them, a relapse prevention program [88%], complete treatment [85%], better treatment provisions and rehabilitation [81%], early identification and educating the community [77%] would be the most effective measures for reducing stigma. We concluded that more treatment facilities, modern and comprehensive treatment and education for patients and communities should be developed. [8]

Nowadays, patients and relatives are well informed of their rights and advocacy groups are making great contributions in care of the mentally ill. Patients are asking questions that are impossible to refuse or delay. They are asking for treatments, access to care, support and services. [9] Further, they are asking respect of their civil rights. Findings of this study support the argument for early and easily available care. It must be realized that illness, attitude and prejudice alone are not marginalizing the mentally ill; it is the callous governments, insensitive philanthropy, discriminatory volunteerism and ignorance of funding organizations that are abating the poor outcome with delayed or no treatment. That is where stigma begins.

Relatives of the patients are key caregivers. Burden of care has been extensively researched, though the burden of care is caused by emotional and physical insolvent and caregiving. Not only do relatives suffer due to severity of illness and lack of services, they are also affected by stigma which significantly interferes in them accomplishing their roles. Patient's relatives also experience discrimination, and are also one of the causes of discrimination towards the patient. It is a paradoxical situation for a caregiver to have a stigmatized view-

point about the illness and still be responsible for managing medication, compliance and hospital visits. They can neither hate nor love.

We conducted a study in Mumbai India to examine the 'Relative's perception' of stigma. Our viewpoint was that relatives should at least be able to recognize circumstances of potential risk for suicide, violence and deteriorating self-care whilst being responsible for caregiving. Their ability to identify depends on their knowledge, attitude and involvement in the care of these patients. [10] A relative with high degree of stigma is less likely to pay attention, prevent risky situations and make arrangements for effective intervention. Dealing with stigma of the relatives, imparting knowledge and changing attitude thus becomes part of a patient-centric comprehensive care. Relatives' perception of stigma is therefore an important component of anti-stigma intervention. [11].

In our study of 300 family members of patients, responses were classified into five categories: 1 origin and nature, 2 impacts and experience, 3 anti-stigma interventions, 4 opinion regarding mental illness and 5 hopes for treatment and the future outcome. The study found that caregiver's emotional involvement [64.8%] in treatment was seen as an important measure to reduce stigma. Responses of patients' relatives clearly bring out their opinion when they suggest anti-stigma measures as a potential treatment component. The study exemplifies what the relative believed in whilst dealing with stigma. In their opinion, it is important to focus on factors that may become a barrier. They believe that targeting the lack of awareness and bringing about a change in attitude of people, professionals including psychiatrists and other mental health professionals, support workers and caregivers is the mandatory next step. Delaying treatment not only increases risk of noncompliance and poor outcome, but also leads to chronicity, social impairment, poor response to treatment and frequent hospitalization.

THE SERVICES LEVEL

Of all consequences of stigma, the worst is the delay in treatment; unfortunately it is also the first sign that a patient has high stigma and has been avoiding treatment for long time. Service availability does not correlate with reduced duration of illness amongst patients who approach the hospital. Prolonged duration of illness and untreated illness are known from regions with a wide network of services. If stigma is one of the factors that delay treatment-seeking and continuation, then specific measures to reduce stigma in a variety of mental illnesses may prove to be of a great value for achieving better outcomes. [12, 13] For the patient, reduction of social barriers due to prejudice will allow for better social integration into society. However, integrating anti-stigma interventions and developing opting strategies in routine clinical practice remains a challenge. There is little doubt that services for mental health treatments are required for everyone. These illnesses need to be treated at the earliest; they require a range of services. [14]

It is ironical that availability of care is not necessarily accessed. There are number of barriers between availability of services and their utilization by the patients. Once again these foremost barrier remains stigma and lack of awareness [15]. We studied the pattern of service utilization in a community mental health center, which had round the clock contact with people by a helpline for suicide prevention. In the city of Mumbai, helpline service is primarily a part of local community health service networks with number of hospitals, voluntary agencies, and community psychiatric facilities including psychiatrists in private practice so that a patient calling from far of catchment area can be referred to an appropriate place.

The study showed that of more than 15,000 telephone calls during a 5-year period, 2,500 patients accessed care at community mental health services. These were patients

in 3 groups, 1: with suicidal ideas and without any mental illness, 2: patients with suicidal ideas with previous contact with mental health services. 3: patients with suicidal ideas with psychiatric illness contacting for the first time. Of 1,015 patients who agreed to psychiatric consultation 82% had a psychiatric illness, and 18% had no psychiatric diagnosis. 37.7% were first contact patients. Of the group diagnosed with non-affective psychosis, 39.5% were first contact early psychosis and 60.5% had a history of treatment for schizophrenia. This study highlights that even after contacting the services only 15% of patients agreed to attend the community mental health center for further evaluation. Only a quarter of patients assessed by psychiatrists opted for a follow-up, only 20% of subjects starting on psychotherapy completed 8 sessions of therapy. Overall we found that only a small percentage of patients utilize the services and complete the treatment requirements. There is a high rate of dropout at the level of 1: completing the referrals, 2: following up the treatment, and 3: completing the course of psychotherapy. However an important positive side of our observation is that a number of first contact patients with a shorter duration of illness approach for treatment. This finding is the silver lining for increasing access to early intervention programs.

Availability of services is important and its lack creates stigma. On a wider canvas stigma is understandably high because less than 10% of the mentally ill have access to care and not more than 10% receive mental health services. Provisions of mental health education, newer courses and opportunities to attract the best brains to fill the gap of human resources are missing. We argue that establishing programs of early intervention shall go a long way in reducing stigma.

Hospitalization and non compliance

Compliance is key to success of treatment. There may over simplistic answers: that the patient does not want to take medication due personal choice, felt-need, poor acceptance of side effects, etc. However it is well known that non-compliance is an intrinsic part of the illness. The cognitive dysfunction is related to lack of insight which leads to non-compliance. Perhaps patients who are highly compliant are a different subgroup, possibly due to their cognitive status. Stigma delays treatment. Thus acute symptoms develop due to stigma causing treatment to be delayed further, which in turn leads to stigma. Patients who have low stigma are more compliant.

Research suggests that the stigma of mental illness can impair treatment utilization in two ways: a) through perceived public stigma, individuals with mental illness may seek to avoid the public label and stigmatization of mental illness by choosing not to seek treatment or to discontinue treatment prematurely; and, b) through internalized stigma, individuals with mental illness may seek to avoid the negative feelings of shame and guilt by choosing not to seek treatment. It has been found that self-stigma is one of the contributing factors in undermining treatment adherence. Individuals with schizophrenia often endorse a feeling of self-disregard and incompetence. It may be possible that their self-stigmatized thoughts might, therefore, reduce their motivation and thus readiness for seeking therapy.

The reasons for this remain obscure. Non-adherence to medication treatment is common but difficult to detect in patients with schizoaffective disorder and schizophrenia, almost half of whom take less than 70% of prescribed doses (Like patients in all areas of medicine, patients with schizoaffective disorder weigh the perceived benefits of medications against perceived disadvantages.) Similarly, re-hospitalization is also closely related to stigma. We examined the pattern of re-hospitalisation in an acute psychiatric setting of a tertiary hospital. Studies have found that repeated hospitalization leads to economic drain, disability, poor outcome, stigma and discrimination. [16] Hospitalization consumes more than 90% of the mental health budget. Identifying the potential

risk factors for repeated hospitalization and the interrelationship between risk factors and patient's vulnerability will help us take appropriate measures to prevent hospitalization and promote care in community. [17] Logistically there are three possible factors that may lead to repeated hospitalization. 1: characteristics of the patient; 2: nature of illness and treatment, 3: systemic issues of service providers and organizations.

We hypothesize that there are specific psychological characteristics in these patients that significantly contribute. A therapeutic approach for dealing with factors like resilience, childhood sex abuse, trauma and stigma can significantly reduce possibility of repeated hospitalization. We studied inpatients with repeated hospitalization on a number of clinical, psychosocial and personal factors. The results show that there are significant patient-related factors e.g. resilience, life events, suicidality and unremitted symptoms correlated to repeated hospitalization. We conclude that individual vulnerability is contributing to environmental factors for repeated hospitalization. Past studies have found that repeated hospitalization leads to economic drain and disability. We are conducting a prospective cross sectional cohort study. Preliminary findings suggest that a significant number of patient related factors, e.g. experience of trauma, chronic suicidality and unremitted symptoms are important causes for non-compliance and re-hospitalisation. The nature of illness and treatment were not significantly involved in rehospitalisation. A preventive strategy needs to address these factors and provide therapeutic measures for dealing with such vulnerabilities. It was interesting to observe that a large number of patients did not report sensitive personal information, which could be of therapeutic significance, e.g. childhood sex abuse. It is argued that this is because of stigmatized attitude of people in general and health professionals towards mental illness as well as negatively perceived factors contributing to mental disorders.

Quantification (for evidence-based intervention)

Experience of stigma needs to be quantified to develop evidence-based intervention, which is required to be carried out in medical clinics. In order to deal with impact of stigma on an individual basis it needs to be assessed during routine clinical examination, assessed for quantification in order to obtain measurable objective deliberates and examined if treatment can reduce stigma. [18, 19] Newer and innovative anti-stigma programs are required that are clinically driven in order to see a change in the life of an individual by removing potential risk. We are of the opinion that stigma has several domains: personal, social, cultural, illness related, treatment related and environment related. Each of these domains has several factors, which may or may not contribute to the degree of stigma affecting a given individual. Components of this domain can be used to design a tool, which can then be standardized and validated in controlled studies. These measures can test and assess the presence and perception of stigma in an individual's life. The care plan for treatment can then be customized and optimized by selecting necessary treatment from a range of psychiatric interventions. Therefore, to quantify stigma in terms of impact and consequences attention should be paid to 4 separate components: 1, events of discrimination that have taken place, 2. Real life experiences, 3, Patient's perception of this discrimination, and 4, How the patient copes with discrimination. A reasonable quantification of stigma would be to measure the experiences of these consequences.

We developed such a tool called stigma quantification scale for burden of stigma for clinical practice. In this tool we tried to quantify: A] Experience of stigma consisting of psychological, social experience, experience of illness and treatment, and coping strategies, B] Quantification of individual's opinion. This is somewhat different from measuring experience as this part is asking what the person thinks about stigma, instead of reporting the amount of stigma. Preliminary findings of our study show that besides correlation to several

demographic factors we observed that the stigma score was positively correlated to non-compliance and suicidality. A series of our studies conducted in India and in Canada show that stigma is a reality and affects both the patients, and the families. Patients are very hopeful that it can be reduced. The best way to reduce stigma according to them is making treatments available, though we also found that only small percentage of patients utilize it. Stigma is a clinical risk; it interferes with treatment and can be quantified. Stigma is related to repeat hospitalization and is directly related to non-compliance and suicidality.

Our findings make forkful arguments for developing services, making people aware of availability of service, treating stigma as an outcome dimension and involving physicians to carry out anti-stigma measures into their clinic considering it as a therapeutic tool. There is much more to be discussed, primarily how stigma remains the single most important fac-

tor for loss of respect for civil rights of mentally ill persons, but this is out of scope of this chapter though. More research is required, however unless we bring the findings of research into clinical practice for people who suffer stigma, pathways and opportunities for reducing the stigma will not be dealt with. Continued stigma is likely to cause severe direct disability and indirect economic implications. Reducing stigma may represent a cost-effective way of reducing the risk of relapse and poor outcome occasioned by chronic exposure to stigmatizing environments. In addition, significant gains in quality of life may result if all patients with schizophrenia routinely receive information about stigma and are taught to use simple strategies to increase resilience vies-a-vies adverse, stigmatizing environments.

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