Clinical risk of stigma and discrimination of mental illnesses: Need for objective assessment and quantification

Amresh Shrivastava1,2,3, Yves Bureau2,3, Nitika Rewari3, Megan Johnston4
1Department of Psychiatry, 2University of Western Ontario, 3Lawson Health Research Institute, London Health Sciences Centre, London, 4Department of Psychology, University of Toronto, Toronto, Ontario, Canada

ABSTRACT

Stigma and discrimination continue to be a reality in the lives of people suffering from mental illness, particularly schizophrenia, and prove to be one of the greatest barriers to regaining a normal lifestyle and health. Research advances have defined stigma and assessed its implications and have even examined intervention strategies for dealing with stigma. We are of the opinion that stigma is a potential clinical risk factor. It 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. 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 (i) assessed during routine clinical examination, (ii) assessed for quantification in order to obtain measurable objective deliverables, and (iii) examined if treatment can reduce stigma and its impact on individuals. New and innovative anti-stigma programs are required that are clinically driven in order to see the change in life of an individual by removing potential risks. The basic requirement for dealing with an individual’s stigma perception/experience is its proper assessment for origin and impact in both a qualitative and quantitative manner. We further argue that quantification would allow for regular assessment and offer more effective intervention for patients. It will also be helpful in identifying modifiable social factors to enhance quality of care planning for management in hospitals and communities. The objective of quantification is to facilitate developing an approach to bring the assessment of stigma into clinical work and formulating customized strategies to deal with stigma at the patient level. It would be expected that the assessment of stigma would become a part of routine clinical assessment to identify barriers to outcome. This article discusses the need for quantification of patients’ experiences of mental illness stigma.

Key words: Mental illness, quantification, risk factor, schizophrenia, stigma

Mental illnesses are conspicuous by their universal presence in all geopolitical regions and cultures. It has been shown that stigma plays a significant role in accessing treatment, continuing treatment, being compliant, and reaching favorable outcomes and level of functioning; which continues far beyond recovery of a patient.

Address for correspondence: Dr. Amresh Shrivastava, Prevention and Early Intervention of Psychosis Programme, Regional Mental Health Care, 467 Sunset Drive, St. Thomas, Ontario-N5P 3V9, Canada. E-mail: dr.amresh@gmail.com

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a specific measure can make objective and perceptible difference in patients overall quality of life (QoL). The need for a paradigm shift has been felt and proposed for future research as well.[3]

At this juncture the question arises that, what would be the specific and strategic intervention that can bring change in a patient’s life? There is evidence that lack of access to and availability of early intervention and treatment is linked with increased stigma. It is also clear that majority of patients feel that making treatment available can make huge difference in dealing with consequences of stigma. In one of our studies in Mumbai, India; 81% respondents felt that providing appropriate treatment is the most effective method to deal with stigma and discrimination. These findings open up new opportunities for examining methods of dealing with stigma at an individual level.[4] The response needs to be appropriate and proportionate to the nature and degree of stigma in an individual.

**CLINICAL RISK**

Stigma is a risk factor for negative mental health outcomes, particularly in schizophrenia and related psychosis. It causes delay in seeking treatment and continuing treatment. This in turn increases suicide attempts and violence, which further isolates these patients.[5,6] Stigma can prolong the duration of untreated illness and perpetuates neurotoxic effects of psychosis, leading to disability.[7] Research shows that early intervention in psychosis is not only neuroprotective but has the potential to arrest or at least delay deterioration and relapse.[7] It also facilitates good outcome and QoL. Thus, an important goal for ensuring effective interventions as early as possible is identifying and reducing stigma. Unfortunately, the clinical impact of stigma remains a low priority in research.[8,9]

One of the key requirements for success of early intervention programs is to formulate anti-stigma measures. The lack of awareness alone is not responsible for keeping patients away from treatment, but it is the fear of being labeled as mentally ill. Families know that mental illness is an ‘illness’, but prejudice and shame interferes not only in seeking treatment but also continuing with it.[10-12] Undoubtedly, stigma remains a potential ‘risk factor’ for mental illness. It is therefore important to address the issue of stigma at the individual patient level to achieve high retention rates in the program. The response to stigma based upon the current research is lacking in more ways than one, due to several reasons:

1. Biomedical, particularly genetic explanations of serious mental illnesses can increase stigma and reduce optimism about recovery. Having a medical understanding of mental disorders appears to increase stigma and social distance, perhaps because the illness is perceived as fixed and chronic. Absence of an irrefutable argument about reversal or arrest of such brain changes has had a negative impact on attitudes.[6,12-14]
2. There is a tendency among professionals to assume that mental health literacy will automatically increase with increasing advancements in research, leading to stigma reduction, but this kind of a direct correlation does not exist and presents limitations for more innovative experiments besides a possible increase in the risk for the patient
3. Care providers have also shown to sometimes stigmatize persons with mental health problems, which can influence treatment continuation. Their misinterpretation of biological dimension of mental disorders dampens their hope in medical treatment and leads to nonscientific practices and ‘faith healing’ in many cultures.[12]

Contradictory opinions have been expressed for early intervention in relation to stigma. It is well-documented that dealing with stigma can facilitate early intervention and possibly early intervention can in turn reduce stigma. However, early treatment particularly for symptomatic high-risk subjects has been accused of stigmatizing young individuals.[7,13] Also, arguing against the concept of early psychopharmacological interventions in the adolescent population is the fact of the unknown effect of antipsychotics on the developing brain, besides the negative effects of stigma on those adolescents who receive them.[9] Ethical questions from this perspective have also been raised.[15] Such opinions are the best possible examples of the belief that the labeling of mental illness and associated stigma possibly arise or originate from treatment centers. These opinions also put forth the position that professionals can sometimes be part of a system of prejudice. Finally, such opinions appear to be a barrier for bringing the assessment of stigma into clinical practice. Risk assessment forms a core competency in clinical psychiatry.[16] Experiences of mental illness stigma, prejudice, and discrimination can be classified into three possible dimensions: Perceived stigma (how the individual believes they are viewed by society), experienced stigma (instances of discrimination), and self-stigma (internalization of public stigma).[17] Measures used to assess stigma can also be classified into these categories and one study demonstrated that in the past 10 years of stigma research, 79% of studies have used a measure of perceived stigma, 46% of experienced stigma, and 33% of self-stigma.[17] This type of classification system is useful in researchers with a means of selecting a measure of mental illness stigma that is most appropriate to their research goals.

Several dimensions of mental illness have been reported to be directly related to stigma. A study by Staring and colleagues[18] demonstrated that the associations between insight into one’s illness and depression, low QoL, and negative self-esteem were moderated by stigma. Patients
who had good insight and who also did not perceive much stigmatization appeared to be the best off across various outcome parameters, while those with poor insight were found to have problems with service engagement and medication compliance. On the other hand, patients with good insight accompanied by stigmatizing beliefs were at the highest risk of negative self-esteem, low QoL, and depressed mood.[24] This research suggests that attempts to increase patients’ insight to their illness is not enough, perceptions of stigma must also be addressed.

The stigma of being mentally ill and the need for treatment or hospitalization are serious psychological strains.[19] The adverse effects of these social, economic, and societal factors; along with the social stigma of mental illness; constitute a form of ‘structural violence’ that impairs access to psychiatric and social services and amplifies the effects of schizophrenia in the lives of sufferers.[20] The most common patient-reported barriers are the stigma associated with taking medications, adverse drug reactions, forgetfulness, and lack of social support.[21,22] Psychoeducational programs have been proposed to reduce the social stigma and societal intolerance to mental patients. Active family involvement improves compliance and might reduce rehospitalization rates. Stigma also increases the number and duration of hospitalizations in long-term stay facilities.[23] Further, stigma is correlated with beliefs about mental illness. A study by Pyne and colleagues[24] found that younger age, fewer depressive symptoms, lower perceived medication efficacy, greater satisfaction with current mental health, and less concern about mental illness stigma were associated with not believing one was mentally ill.[24]

There is enough evidence to suggest that stigma is a clinical condition; it is related to the phenomenology and symptom constellation of an illness however remains poorly understood, investigated, and treated. To address the issue of stigma in the treatment setting is likely necessary to offer the best possible anti-stigma program at an individual level. In order for this goal to be achieved, it needs to be demonstrated whether or not mental illness stigma can be quantified and that such quantification can help clinicians in dealing with stigma.

**QUANTIFICATION**

The concept of measuring stigma as a quantifiable item is not new. A number of attempts have been made to measure attitudes to mental illness and stigma, most of which have focused on attitudes towards mental illness held by people in the community. Far fewer attempts have been made to measure stigma directly with service users themselves.[8,25]

The need for quantification arises from certain unanswered questions. Firstly, there is a lack of understanding of the various cultural manifestations of stigma. We also do not know the best method to deal with stigma both for individuals and for groups of people. It is also not clear what role stigma plays in mental illness vis-à-vis care and treatment. Stigma is seen in cultures where treatment is available to all; it is therefore not clear whether nonavailability of treatment and care causes stigma or stigma interferes in utilization of care. Perhaps both may be true. While stigma is related to discrimination, individual/family/community coping mechanisms with stigma are not known. We also do not have enough research to inform how clinical manifestation of illness is influenced by the presence of stigma to be able to develop a clinical response to stigma that is actionable and meaningful.

As mentioned previously, the stigma of mental illness has been studied in terms of perceived stigma, experienced stigma, and self-stigma. These three components have been measured using: (a) Survey methods: Administering questionnaires to large number of patients or relatives; (b) administering semi-structured tools to a select group of patients; and (c) structured assessment scales developed and tested with good psychometric properties and test-retest validity. None of the available measurement tools, however, attempt to quantify and measure the presence of stigma, which can guide and help in clinical practices.

Quantification would allow its regular assessment and offer intervention at an individual level. It will also be helpful in identifying missing social and community level support to improve the outcome of mental illnesses.[26] Stigma originates from personal, social, and environmental domains. Once measures of quantification have been validated, it will be possible to quantify stigma at an individual level. The clinical practice of evaluating stigma will be helpful for more individuals coming forward for treatment, continuing to remain in treatment, and follow-up without dropping out.[2,21,22,27] It is well known that a fear of being labeled as ‘mentally ill’ delays treatment initiation.[2,21] Previous research exploring the perceptions of adults diagnosed with schizophrenia has highlighted the importance of understanding stigma not as a unitary experience but as individual experiences in specific contexts.[28,29] The available measurement tools do not take into account the many components of stigma, which have a direct bearing on treatment and outcome.

The outcome of mental disorders is dependent on multiple factors. Factors such as compliance, suicidality, and hospitalization have been proposed as outcome parameters; which make much more sense than purely clinical and social outcomes. Assessment of factors that interfere with outcomes may enhance the quality of care. Current examples of some factors are level of functioning, degree of disability, and QoL. A standard psychiatric assessment not only quantifies level of functioning, degree of disability, and QoL; but also the burden on key relatives.
All these psychosocial functions are subjective experiences but researchers have been able to objectively quantify and provide valuable tools useful in therapeutics. Stigma needs to be quantified in a similar way.

There are major advantages in quantifying stigma from clinical parameters: It simplifies communication, it can determine action and provide meaningful data upon which future research is to be developed, it will set the path for future research to find methods to formulate a customizable strategy to minimize stigma, and it lays a foundation for bringing the assessment of stigma into clinical assessments of patients in psychiatric treatment settings. Quantification can form the basis of evidence-based practice for clinicians providing treatment care plans for patients and will therefore add value, enhance compliance, and develop broad standards of care. Though quantification is not well-studied, arguments for the possibility of quantifying stigma in a patient’s life exists.

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. These measures can test and assess the presence and perception of stigma in an individual’s life. The care plan must be customized for a patient’s needs and take factors related to stigma in rehabilitation, family therapy, and psychotherapy including cognitive remediation and behavioral therapies, into account. Stigma is a personal experience and is not just a socially-felt prejudice. Though stigma is subjective, an objective measure will be a helpful clinical tool. Its assessment as part of routine clinical work and interventions will have to be evidence-based.

This premise is based upon individual as well as community perceptions of stigma. Following the footprints of community research in reducing duration of untreated psychosis using assertive community treatment, awareness, and easy access to treatment; anti-stigma programs can be made more effective in a given community. Living examples of destigmatization will certainly be an incentive for other patients to access care. Quantification will offer an objective measure of social factors that can interfere to reduce effectiveness of treatments. It would be best if pathway of care and treatment plans, both can be designed keeping the idea of dealing with stigma as a central component, irrespective of regions and cultures.

CONCLUSIONS

In summary, while stigma remains one of the most challenging areas of research in present times, optimism remains. We believe stigma is a clinical risk and barrier to outcome and therefore the response to stigma, needs to be individually tailored for clinical practices. A successful program needs to demonstrate change in a patient’s life. Quantification of stigma on clinical parameters is needed for routine practice. This shifts more anti-stigma programs from communities to clinics, which is likely to be helpful for improving the QoL of patients suffering from mental illnesses. Future research in stigma needs to be clinically driven and quantitative to develop standards of care.

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