Stigma: A Clinical Risk Factor for Psychopathology and Recovery

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Introduction

Mental health is an essential component of a person's capacity to live a fulfilling life, with an ability to form and maintain relationships; to study, work, and pursue leisure interests; to contribute to responsibility-taking; to contribute to the society; and to make day-to-day decisions about education, employment, housing, and other choices. Disturbances to a person's mental well-being can adversely compromise this capacity, leading not only to decrease in functioning at the individual level but also to broader welfare losses for the household, society, and nation. Despite the high prevalence of mental illness, most people do not access by choice, or do not have access to, professional healthcare for mental health problems; hence, psychiatric illnesses frequently remain undiagnosed and untreated. Larger populations do not access mental healthcare by choice as a consequence to the stigma attached to mental health, where talking about it alone is considered taboo.

The key barriers to seeking help are the following: public, perceived, and self-stigmatising attitudes to mental illness; difficulty identifying the symptoms of mental illness; concern about the characteristics of the provider; poor knowledge about mental health services; lack of accessibility (e.g. time, transport, cost); difficulty or an unwillingness to express emotion; and worry about effect on career and other aspects of daily life [1].

The causes of stigma are manyfold, one of which is the undue importance to the label of mental illness in our society. It is not surprising that the majority of patients, when being asked about strategies for stigma coping, recommend keeping mental illness a secret or even avoiding contact with other people [2]. This is more so in girls and females for fear of difficulty in getting married. Also, stigmatising views about mental illness are not limited to uninformed members of the general public; even well-trained professionals from most mental health disciplines, including medicine, have stereotypes about mental illness.

Although such attitudes are not limited to mental illness, the public seems to disapprove of persons with psychiatric disabilities significantly

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A. Shrivastava, A. De Sousa (eds.), *Schizophrenia Treatment Outcomes*,
https://doi.org/10.1007/978-3-030-19847-3_13

more than persons with related conditions such as physical illnesses. Different illnesses arouse different kinds of emotional reactions from people, for example, illnesses like heart disease or cancer arouse a feeling of sympathy, communicable diseases garner a fear of getting infected from the sufferer, and other disfiguring conditions may lead to feelings of disgust. Unfortunately, emotional reaction to mental illness is usually more than all these; it is perceived as something strange, mysterious, or dangerous. Such discrimination is usually based on unfounded irrational misconceptions and stereotypes about mental disorders. Unlike physical disabilities, persons with mental illness are perceived by the public to be in control of their disabilities and responsible for causing them [3].

Stigma and Its Types

Stigma is a Greek word which means "mark" or "tattoo" that was cut or burnt into the skin, to identify criminals, traitors, and slaves as morally polluted and shunned by the public [4]. Stigma can occur in many different forms and most commonly deals with culture, race, gender, body appearance, illness, and disease. Stigma may also be described as a label that associates a person to a set of unwanted characteristics that form a stereotype and is affixed. Once a person gets labelled with stigma, others will assume that is just how things are, and the person will remain stigmatised until the stigmatising attribute is addressed. However, the attributes that society selects differ according to time and place [5].

Stigma may affect the behaviour of concerned persons. They start acting in a way that is not expected of them, which affects their emotions and beliefs. The stigmatised individual/social groups often face prejudice that causes depression leading to identity crisis and low self-esteem [6].

Erving Goffman describes stigma as an "attribute, behaviour, or reputation which is socially discrediting in a particular way". Goffman also defined the meaning of the word "stigma" as a special gap between vital social identity and actual social identity. Goffman's meaning on "vital social identity" relates to the way we represent ourselves with people we don't see, and for his take on "actual social identity", he explains it as the way we deal with people in real life [7]. According to Goffman, there are three types of stigma, which is a discrepancy between actual and virtual social identity that causes us to alter our estimation of others negatively [8].

Goffman divides the individual's relation to a stigma into three categories:

- *The Stigmatised*—those who bear the stigma. The stigmatised are rejected and shunned. They experience discrimination and prejudice and are also associated with negative physical and mental health outcome.
- *The Normal*—those who do not bear the stigma.
- *The Wise*—those among the normal who are accepted by the stigmatised as "wise" to their condition.

A recent study showed empirical support for the existence of the own, the wise, and the normal as separate groups; but the wise appeared in two forms: active wise and passive wise. Active wise encouraged challenging stigmatisation and educating stigmatisers, but passive wise did not [9].

The Six Dimensions of Stigma

Jones and others added the "six dimensions" and correlated them to Goffman's two types of stigma, discredited and discreditable [10]. There are six dimensions that match these two types of stigma:

1. *Concealable*—extent to which others can see the stigma
2. *Course of the mark*—whether the stigma's prominence increases, decreases, or is terminated
3. *Disruptiveness*—the degree to which the stigma and/or others' reaction to it impedes social interactions
4. *Aesthetics*—the subset of others' reactions to the stigma, comprising reactions that are positive/approving or negative/disapproving but

represent estimations of qualities other than the stigmatised person's inherent worth or dignity
5. *Origin*—whether others think the stigma is present at birth, accidental, or deliberate
6. *Peril*—the danger that others perceive (whether accurately or inaccurately) the stigma poses to them

Stigma in Psychiatric Disorders with a Focus on Schizophrenia

As an underlying condition, stigma prevails across all mental illnesses. However, the severity of stigma increases with severe mental illnesses such as schizophrenia and psychotic disorders. It is difficult to clearly demarcate the difference between the causes and consequences of stigma due to an overlapping phenomenon that exists among the two processes. However, stigma continues to exist as a clinical situation that poses clinical risks along with a bundle of problems that deteriorate the outcome of treatment in schizophrenia [11, 12].

The global state of mental illnesses has battled an extreme form of stigma to reach its current state. From institutionalised mental healthcare to the deinstitutionalised movement and the rehabilitative care model approach, mental health has barely ever been taboo-ridden. While it is not possible that stigma may ever be off the mental health approach, the dynamics and nature of stigma are always changing. Research has shown that there is relatively greater stigma toward severe mental illnesses such as schizophrenia and psychotic disorders [13, 14]. Stigma can have three dimensions: (i) perceived stigma or the way in which an individual believes they are seen by society; (ii) experienced stigma or instances of experience where an individual has faced discrimination/ostracisation; and (iii) self-stigma or when an individual internalises societal public stigma [13]. There is an alternative way to categorise stigma that includes (a) internalised or negative stereotypes and views of permanent flaws accepted by labelled individuals; (b) interpersonal or labelled individuals socially categorised facilitating discrimination; and (c) institutional or labelled individuals excluded by institutional policies and practices [15].

As mentioned, stigma is a clinical condition. It is associated with the symptom constellation and phenomenology of an illness [13]. Stigma is a universal condition. It is one of the leading causes for mental health treatment gap [15]. The burden of mental illnesses climbs above the mere symptom presentations—it is about the first-hand denial of illness severed by stigmatisation of the condition.

Narrowing down the focus on stigma in schizophrenia, there are several aspects that hold a significant value with respect to the treatment outcomes of the illness. There are multiple components of stigma with respect to schizophrenia as an illness: (1) labelling of socially important differences such as hearing voices (hallucinations) or having delusions; (2) linking labelled people with negative stereotypes like saying that people with schizophrenia are violent and unpredictable; (3) categorising people to facilitate social exclusion with labels of "psychotic" or "schizophrenic"; and (4) socioeconomic status loss for and discrimination toward labelled people that includes employment and healthcare inequalities, incarceration, homelessness, and retaliatory violence [16].

There are multiple facets to stigma in schizophrenia that can be understood as the following:

In general, stigma is said to be associated with illnesses that manifest as behavioural disturbances or socially odd behaviours, with schizophrenia being one of the more severe ones as opposed to the less stigmatised perception of somatic complaints.

Following the dimensions of stigma as mentioned above, stigma originates from various sources such the society, general public, infrastructure and resources, policies, familial acceptance, and personal attitudes of an individual. Research shows that a greater share of stigma associated with schizophrenia arises due to societal stigma and least due to self-stigma [13, 15].

Stigma as a condition is seen at all phases of schizophrenia—from onset/prodrome phase of the disorder to illness course, treatment, and

rehabilitation. Research claims that the most stringent effects of stigma are seen during the prodrome and acute phase as the behavioural changes become frank due to socially unacceptable behaviour [13].

The nature of illness of schizophrenia is a debilitating one and is itself stigmatising due to the behavioural oddities (hallucinations, delusions, frank negative symptoms, catatonia) that present as illness symptomatology [17].

Perceived social norms are a crucial contributor to an individual's social distance with those who suffer from a mental illness. Lack of awareness and low levels of education/literacy are reasons that lead to negative stereotypes and prejudiced attitude of the society. People generally have misperceptions that individuals suffering from schizophrenia are violent and sabotaging. Public attitudes and public prejudice are the chief causes of stigma around schizophrenia.

Individuals who have had no contact with mental illness before are also potential sources of stigma.

Attitudes of family members toward schizophrenia determine the stigma that an individual faces in the closest circle of interpersonal relationships and influence the quality and quantity of care/support they receive and the recovery process from the illness [18].

Poor resources, inadequate national mental health policies and programmes, and lack of mental healthcare are institutional deficiencies that encourage stigma to sustain.

The greatest devitalising effect of stigma is observed as delayed intervention or poor early intervention as individuals deny treatment, prolong to harbour stigmatised views of the public and self, and thus, lose on the quality of life that could persist with intervention at an earlier stage. This further accentuates stigma in the treatment process, which not just involves delayed treatment but also noncompliance of medication, wearisome recovery, and overall treatment dropout, which increases the stigma. Public prejudice may also impact treatment where the individual may absolutely deny treatment or end treatment prematurely.

Stigma also emanates among primary healthcare and mental healthcare professionals, in their attitudes toward the patients in the treatment phase of schizophrenia, which may aggravate the stigmatised outlook to schizophrenia among the general community.

Stigma around schizophrenia is also an outcome of work environment and colleagues'/coworker attitudes who are reported to make fun and outgroup those with schizophrenia. It is an unpleasant situation that further increases self-stigma in suffering individuals.

Criminalisation of mental illnesses is another institutionalised source of stigma that involves growing intolerance of forensic issues and general human rights issues [13].

Poverty is another stigmatising factor that deters effective mental health treatment and social inclusion. The association is stronger in lower- and middle-income countries. There are increased social stressors as a resultant of poverty and various other factors, such as impoverished nutritional state and poor affordability.

Media representations such as those in movies, radio broadcasts, and other media are also reported to be stigmatising, especially for illnesses such as schizophrenia [15].This instigates further taboo related with illnesses in the society.

Stigma is also medication-induced, where side effects of drugs may cause discomfort to the individual and lead to internalisation of stigma. Frequent hospitalisations are also one of the reasons for stigmatisation and early and repetitive relapse.

Research has shown that being a female and being young as a patient of schizophrenia led to relatively higher stigma than in the counterparts [17].

Low self-esteem, low mood, depression, self-isolation, and post-hospitalisation suicide are common after the treatment of schizophrenia and bear a link with the attached stigma.

The consequences of stigma, though not very distinguishable, are exhausting. It can be life-threatening and humiliating, can deprive an individual of their basic needs, marginalises them and leads to poorer psychosocial support and low self-esteem which affects interpersonal relationships and marriage prospects, and can lead to ostracisation from the society. These consequences of stigma are seen across the duration of illness, from the onset to the course and treatment of illness. The nature, determinants, and conse-

quences of stigma vary with socio-demography and cultures.

Stigma and Recovery: An Indian Perspective

Stigma has been shown to lead to complete social devaluation of a person who suffers from psychiatric disorders [19]. This discrimination leads to disadvantages in many aspects of life including personal relationships, education, social life, and work. Psychiatric patients may lose self-esteem and harbour feelings of shame, social withdrawal, guilt, and a sense of alienation after experiencing stigma [20]. Many patients with psychiatric disorders feel that they may be treated in a discriminatory way and hence hide their illness or refrain from taking up opportunities for treatment and recovery.

Across nations, the meaning, society attitudes, and outcome of stigma differ, even when we find stigmatisation to be a powerful and most likely response to illness and disability [21]. A large body of stigma and mental health research has been done in the West, and there is a dearth of research to understand the experience of stigma and how it may be burdensome in the Indian context [22].

Studies on stigma in India started over 30 years ago, but recent research has reported severe levels of stigmatising attitudes toward patients with mental illness among community members and healthcare workers [23]. The effects of stigma on seeking help, treatment compliance, and recovery have been shown to be high. A study reported that patients with psychiatric problems were ridiculed, avoided, or looked down upon by society. They were also starved or given stale food, kept home bound, chained, tied up, and beaten or hit with stones. They were subject to ridicule, insults, and lack of respect from family members [24]. Male psychiatric patients experienced stigma with regard to employment, work place, and earning, while female patients experience the same in relation to marriage, childbirth, and purely out of their belonging to the female gender [25].

Many studies have shown that stigmatising reactions were often expressed by family members and neighbours [26]. In a study that had 76 women with schizophrenia whose marriages had broken, qualitative methods were used to assess and gather information about stigma. The majority were abandoned by their husbands and very few received financial support, while others experienced beating, domestic violence, emotional torture, and neglect. Many felt themselves a burden to their own parents and received hostility from family members and their spouse [27].

There are few studies on the determinants of subjective experiences of stigma in India, and very little qualitative research is available. Indian research on stigma in mental illness across diverse income groups is poor and yields no conclusive evidence [28]. The nature of the mental illness, symptoms, diagnosis, and aggression or violent behaviour in determining social reactions has been studied [29]. Stigma in India must be understood in transcultural contexts and with what is at stake [30].

Hindu philosophy, in Indian society across different religious groups, holds that doing one's duty in life (living in accordance with "Dharma") is central to a moral life and that living by the ways of conduct described by Dharma (i.e. meeting social role expectations and codes of behaviour) shall lead to purification of mind and, ultimately, Moksha (liberation) [31]. Furthermore, employment holds added importance in India, with minimal state government welfare provisions, and loss of income from mental illness affects families existentially. Many patients in India are sole income generators, and cost-effective treatment with minimal days of loss at work may not always be possible due to the nature of mental illness itself [32]. Unemployment poses huge threats to a man's social status, while remaining unmarried is a huge stigma for women and plays a vital role in recovery from psychiatric illnesses like schizophrenia [33].

Marriage and schizophrenia in Indian society are looked at as a desired outcome, an economic necessity, a social role expectation, and a potential "cure" for the illness [34]. In a recent study, women with schizophrenia and broken marriages perceived the loss of social status associated with a broken marriage as more burdensome than even the stigma associated with their mental illness, affecting long-term recovery and treatment compliance [35].

Mental health professionals are aware of the harmful effect of stigma against mental illness. One of the earliest scales questionnaires developed was culture specific, valid, and reliable, along with the development of socioculturally relevant vignette stories [36, 37]. In an early review on the subject, it was stated that "The general trend of the studies carried out in India indicate that the lay public, including the educated urban groups, are largely uninformed about the various aspects of mental health. The mentally ill are perceived as aggressive, violent, and dangerous. There is a lack of awareness about the available facilities to treat the mentally ill, and a pervasive defeatism exists about the possible outcome after therapy. There is a tendency to maintain social distance from the mentally ill and to reject them" [38].

An early review on stigma mentions that "Mental illness is usually perceived as something strange, mysterious, and also dangerous. It is probably due to the difficulty in communicating with persons having mental illness and a certain unpredictability about their behaviour. Such discrimination is usually based on unfounded irrational misconceptions about mental illness" [39]. The common man has a general concept of mental illness where mental illness is equated with being mad or insane, and this thus affects recovery from illnesses like schizophrenia [40]. Research reports maximum prejudice faced in India faced by patients with schizophrenia [41].

Mental illness has always been reported as something to ridicule, something to laugh at, which is bizarre, disgusting, or frightening. But the current trends point toward the opposite, with media being supportive of mental health and the mentally ill in recent years [42].

Summary of Research Findings on Stigma and Recovery

Reviews on attitudes toward mental illness summarised some recent findings: People are currently better informed about mental illness. The public's ability to label a broader range of behaviour as mental illness has also increased. However, even though mental illness seems to be accepted as an illness like any other, people's feelings about it are not consistently shaped by this cognitive awareness. This shall aid faster recovery in illnesses like schizophrenia [43].

Factors in the patients with schizophrenia and other disorders that influence public attitude include frequency of actual or anticipated behavioural events; extent to which violence is an issue; intensity of the behaviour; visibility in the open community and geographic location; the degree of unpredictability; and the loss of accountability [44].

Increasing age, lower socioeconomic status, and lower educational level are associated with greater intolerance and rejection in patients with schizophrenia. Among the relatives, the lower the socioeconomic class, the greater the feelings of fear and resentment, whereas the higher the socioeconomic class, the greater the feelings of shame and guilt [45].

Even taking into account the inadequacy of delivery of mental healthcare services in many countries, there is still general reluctance in seeking psychiatric care. People would choose friends, family doctor, relatives, or clergymen before resorting to professional psychiatric services. This delays recovery from illnesses like schizophrenia [46].

Stigma may be real or perceived (i.e. fear of stigmatisation by the patient and family). Fear of rejection, self-doubts, concealment, and withdrawal can be far more significant barriers to full social reintegration than the stigma associated with negative public attitudes. This has been reported widely to affect recovery in patients with schizophrenia [47].

There exist more supernatural, religious, moralistic, and magical approaches to illness and behaviour. While they may confer strong stigma in some cultures, they may not in others (e.g. the sufferer may not be blamed for an external cause and the course is expected to be brief). Engaging in these forms of treatment for respite rather than scientific approaches may affect recovery from schizophrenia [48].

Assessment of Stigma

Stigma is an invisible, clinical component of mental health. Several assessment tools have been developed to make an attempt to quantify stigma in order to make it a measurable entity and, thus, address it appropriately. There are various ways to assess stigma in an individual or in a group to understand their attitude and acceptance. Some of them are as follows:

Social Distance One of the most commonly used measures is that of social distance. This assesses a person's willingness to interact with a target person in different types of relationship. It has good to excellent internal reliability and good construct validity. There are two main limitations to its validity—social desirability bias and difference between reported intentions and behavioural responses [49].

Semantic Differential and Related Measures This provides a direct assessment of stereotyping. This also has the limitation of social-desirability bias.

Opinions About Mental Illness (OMI) This scale was developed by Cohen and Struening. OMI has a wide spectrum of coverage of issues, and it also measures changes in attitudes over time [50].

Community Attitudes Toward the Mentally Ill (CAMI) The scale includes 40 items. It measures attitudes toward community mental health treatment facilities [51].

Emotional Reaction to Mental Illness Scale It is developed by Angermeyer and Matschinger. It has three dimensions: aggressive emotions, prosocial reactions, and feelings of anxiety.

A brief self-report scale to measure the stigma related to mental illness is available. The scale measures both felt and enacted stigma and consists of 42 questions. The questionnaire takes 5–10 min to complete. This scale is similar in content to that the Internalised Stigma of Mental Illness scale developed by Ritsher and others [52].

A Stigma Quantification Scale has been developed that can help to identify individuals having severe stigma. It consists of 49 items and 3 subscales: self-experience, illness-related consequences, and coping strategies. Some believe that this scale can also change stigmatisation levels [53].

Assessment of knowledge, attitudes, and emotions regarding stigma is also a way of measurement of stigma itself. Measuring knowledge about mental illnesses is a good predictor of readiness for treatment, compliance, and long-term maintenance in treatment. Knowledge measures are relatively easy to administer and score. Attitudes can be measured using behavioural intention, which can be done by direct observation. Behavioural intentions, which are proximal to the time when the behaviour will occur, are more likely to reflect actual change. Emotional reactions are measured using self-report instruments [54].

Stigma and Its Role in Recovery from Schizophrenia

Stigma cripples the recovery process of an individual suffering from any illness. With the abovementioned factors that contribute to stigma, a vicious cycle gets created that prolongs stigma, further disabling the outcomes of mental illnesses (Fig. 13.1). The outcome of treatment of schizophrenia can be understood from the similar standpoint.

The stigma faced by individuals suffering from schizophrenia is doubled, taken the nature and course of illness. The problems begin right from delayed early intervention due to stigma and continue to rehabilitating individuals after treatment process [55].

To begin with, there is a stigma of the diagnosis itself. Stigma prevents early intervention during the onset of schizophrenia that only promises a debilitating course of the illness with poor psychosocial adjustability. With growing symptoms and lack of awareness (and consequent lack of sensitivity), schizophrenia becomes a matter of targeted discussion, and the individual ends up feeling further stigmatised. Feelings of low mood and sometimes depression are likely consequent.

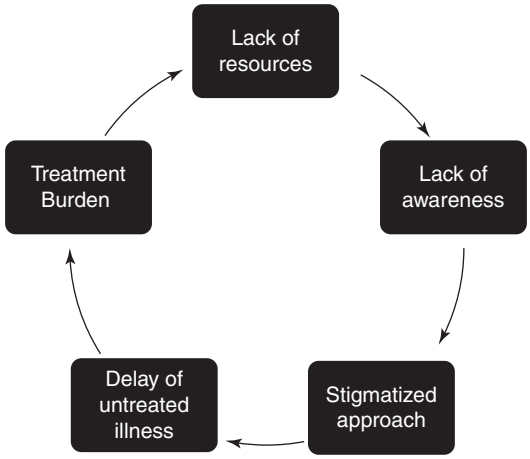

Fig. 13.1 A cycle of events reinforces stigma. (Original figure by co-author Pragya Lodha; used with permission)

Violence and aggression are also likely seen to spurt. The availability of resources, infrastructure, and the policy of provisions also play a crucial role in aiding the illness or further deteriorating its status [56].

The course, nature, and treatment of the illness, medications being taken—and their side effects—can be an additional cause of stigma apart from the society's prejudiced understanding about the illness. Thus, stigma during the treatment phase of the illness is one of the stronger factors when an individual internalises stigma or when the self-stigma strengthens (see Table 13.1). This impacts the potential recovery rate and relapse prevention in the illness of an individual. Going to work during the treatment phase or in the recovery phase is further stigmatised with institutional stigma, self-stigma, and lack of inclusion/acceptance in the workplace and among peers [57].

Anti-stigma Interventions

Stigma is a clinical risk that deters recovery and treatment process in schizophrenia. Being a clinical condition, it must be treated in a similar way in order to make the outcomes in schizophrenia treatment more resilient. There have been both broad-based and specific-focused interventions to address stigma, however, with a spectrum that addresses the problems faced by the patient and the caregivers. There has been a long-standing public health perspective to stigma [13]; however, the present need of the hour is to address stigma from a clinical standpoint in order to target prevention and intervention for stigma.

The following would contribute toward effective anti-stigma interventions, aiding better care and treatment for schizophrenia [58]:

- Psychoeducation to the patient and his/her family to inform about the nature and course of illness, preventions to be taken, and adherence to treatment.
- Psychoeducational programmes must also address sensitivity toward the burden caused to the patient and the caregivers during the course of the illness.
- Effective early intervention can reduce stigma, delay relapse, and ensure a prolonged quality of life.
- One-on-one and face-to-face sessions with the patient are a prime recommendation for higher retention in treatment.
- Increasing public and community awareness to make mental health and mental illnesses a sensitive issue and part of colloquial narration with reduced attached stigma.
- Increasing the overall mental health literacy.
- Imparting the knowledge of mental illness from a biological-psychological-sociological model of understanding vs only a biological explanation.
- Addressing stigma straightforwardly rather than avoiding the topic.
- Encouraging treatment of mental disorders is one of the most progressive and direct ways of attacking stigma.
- People may not choose to speak about their mental health condition, but approaching for treating silently also is a step forward.
- Comorbid conditions of depression and suicidal ideation should be directly addressed as part of the treatment.
- Enhancing access to care, relapse prevention, and early identification are some of the other measures.

Table 13.1 Various causes and consequences of stigma at different phases of schizophrenia

Phase of schizophrenia	Causes of stigma	Consequences
Onset/prodrome	Lack of awareness, lack of education, denial due to interpersonal/societal stigma, stigma of diagnosis	Delayed early intervention
Acute phase	Due to socially unacceptable behaviour and behavioural disturbances, role of media representations	Considered violent and dangerous to society, socially isolated
Treatment phase	Medication induced stigma due to side effects, internalised/self-stigma	Noncompliance, premature termination, early relapse, debilitating condition, suicide, lack of self-care, violence
Rehabilitation phase	Public stereotypes, self-doubt and low self-esteem, self-denigration	People are made fun of especially at work, social isolation, compromised psychosocial abilities, suicide

- Completion of treatment, risk management, relapse prevention, and rehabilitative facilities are one of the stronger markers to deal with stigma attached with outcomes in schizophrenia.
- Improving access to mental healthcare by bridging the treatment gap and providing new and more services.
- Individualised and tailored treatments to best suit the needs of the patients are also a promising intervention.

An integrated approach of public health and clinical practice for addressing the stigma around schizophrenia is an ideal one. Stigma may never be eradicated from the face of mental illness, but we, as a community, can always work toward reducing it and normalising mental illnesses in order to facilitate care.

Conclusion

After an extensive discussion, it is evident that stigma in mental illness leads to adverse outcomes. It is due to stigma that patients with mental illness avoid seeking treatment. This leads to increase in the symptoms and exacerbation, which in turn causes further stigma. As stigma affects the line of treatment, we need more systematic ways to manage stigma and improve the outcome. An evidence-based approach is required to understand what to change and how to make this change possible.

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