Stigma as a Barrier in Treatment Seeking for Mental Disorders in India

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Abstract: *Stigma against mental illnesses is considered as an important factor for increased gap in treatment of mental disorders. The result of National Mental Health Survey indicates a huge burden of mental health problems. Nearly, 150 million Indians need mental health care services but less than 30 million are seeking care. India spends only 0.05% of their GDP on mental health as compared to 15-18% in other countries despite increasing mental health crisis in India. Mental health is a huge contributor to economic burden of non-communicable diseases. A negative attitude is seen in society towards people who are on psychotropic medications or who are consulting psychiatrist for one or another mental health issues. Patients are continuously fighting with their own mental health condition and on the other side, face many challenges due to mental health stigma. Even mental health professionals and the psychiatric nursing staff are also the targets of mental health stigma. Despite the increasing awareness regarding mental health, increasing postgraduate seats in psychiatry, new mental health care act, stigma in society remains the same. Either the individual does not reach the hospital for treatment of mental illness or face many issues regarding their job security, housing, violation of rights, inhumane behavior etc. So, there is need to tackle these emerging issues by various methods such as education, awareness and training among general health practitioners, targeting media, involvement of Non-governmental organizations and strict legislative measures and implementation of new mental health care act, 2017 in India to combat the treatment gap and to handle the mental health crisis in India.*

Keywords: Mental health stigma, mental health care act, Media, Negative attitudes, treatment seeking, mental disorders

1. Introduction

Stigma and discrimination are identified as main obstacles in the integration of people with mental illness in society. (1) Stigma is described as discrediting, devaluing, and shaming of a person because of characteristics they possess. Stigma is more commonly experienced in mental illnesses than physical diseases. It also act as a risk factor which lead to negative mental health outcomes such as social isolation, feeling of rejection, marginalization, and discrimination of patients. (2) It affects patient's treatment course, their families or relatives, along with professionals who work in mental healthcare settings.(3)visiting a mental health professional for treatment of mental illness is still considered as a taboo in Indian society. Globally, 20% of young people experience mental disorders. In India, only 7.3% of its 365 million youth report such problems due to fear of stigma and fewer access the treatment. One-third of young people display poor knowledge of mental health problems and negative attitudes towards people with mental health problems and one in five had actual/intended stigmatizing behavior.(4)it creates a huge treatment gap for mental illnesses in India. Mental illness accounts for 14% of all disability adjusted life years (DALYs) lost worldwide and is one of the major contributors to the global burden of disease.(5)Recently conducted National Mental Health Survey (NMHS) reported the prevalence of 13.7% lifetime and 10.6% current mental morbidity.(6) Results of the survey also points toward a huge gap in treatment seeking. Nearly, 150 million Indians need mental health care services but less than 30 million are seeking care. While compared to other countries who spends about 5 to 18% of their GDP on mental health, whereas India spends only 0.05%. Mental health is an important contributor to economic burden among non-communicable diseases. (7)

Due to continuously increasing burden of mental illnesses in India, there is strong need to address the issues affecting treatment seeking in individuals with mental health problems and try to reduce these barriers. Public stigma is one of these issues which play an important role in the underreporting of mental disorders.(4)

Qualitative analysis revealed that depressive symptoms were perceived as socially disadvantageous as these may affect marriage and social status.(8) People with serious mental illness face double challenges. On one hand, they fight with their symptoms and disabilities due to disease and on the other hand, they face stereotypes and prejudice due to misconceptions about mental illnesses in society. Due to this, they are deprived of the opportunities such as good jobs, safe housing, quality healthcare, and social connection with people. (9) Psychiatric illness causes deterioration in functioning such as difficulty in processing of information, decision- making, expression of emotions, being assertive, and responding to environmental stimulus. These deficits result in poor self- care, unemployment, issues in interpersonal relationships, and overall self-image.(10)

Sandhya et al. assessed the attitudes of 87 nursing students towards mentally ill in terms of shame and stigma towards mental illness by using a cross sectional design. The study results found that highest mean score were obtained in the subscale of reflected shame with respect to the family followed by external shame with respect to the community with mean scores of 7.6 and 6.6 respectively.(11) Attitudes and beliefs of individuals about mental illness are shaped by personal knowledge about mental illness, knowing and interacting with someone living with mental illness, and cultural stereotypes. Few cultural beliefs perceive mental illness as supernatural phenomena and consider them as a result of wrath or denial of spirit or deities.(12)People with mental disorders remain untreated for long time due to these cultural beliefs, and family members often take them to religious/faith healers/astrologers for their treatment rather than visiting to a mental health specialist. Currently, only 10% of people with mental disorders are receiving evidence

based interventions. It results in under-utilization of mental health services by the community.(13)

Sushrat et al. showed that rural Indians have a more stigmatizing attitude towards severe mental illness as compared to urban Indians.(8,13)There is strong need to improve mental health literacy in the community to get rid of these false beliefs regarding mental illness.

A study in Indonesia on the stigma-related experiences of nurses and patients revealed the five themes of stigma, out of which, four were patient-related: personal/patients' stigma, public/social stigma, family stigma, and employment stigma and fifth theme was related to stigma toward mental health professionals, categorized as professional stigma.(3)

Types of stigma-
Both public and self stigma is understood in terms of three components- stereotypes, prejudice and discrimination.(14)

Public stigma	Self-stigma
• **Stereotype** -Negative belief about a group (e.g., dangerousness, incompetence, character weakness)	• **Stereotype** -Negative belief about the self (e.g., character weakness, incompetence)
• **Prejudice**-Agreement with negative emotional reaction (e.g., anger, fear)	• **Prejudice** -Agreement with negative emotional reaction (e.g., low self-esteem, low self-efficacy)
• **Discrimination**- e.g., avoidance, withhold employment and housing opportunities, withhold help)	• **Discrimination** -e.g., fails to pursue work and housing opportunity

Apart from these two types of stigma, stigma is also seen at **structural level** such as discriminatory policies, laws, and systems, investment of resources, quality of care standards, organizational culture etc. (15)

Causes of stigma for psychiatric disorders-Various reasons responsible for mental health stigma are described as below-

1) **Violence-**Though mental illnesses contribute to the risk of violence, despite that, the 1-year population-attributable risk (PAR) of violence associated with serious mental illness alone was found to be only 4% in the ECA (Epidemiologic Catchment Area) survey.(10) Violence is more significantly seen in those with co-occurring substance dependence.(16) A study conducted on 104 caregivers in India states that most caregivers of individuals diagnosed with schizophrenia or Bipolar affective disorder experience overall burden of violence. These experiences have adverse impact on the psychological well-being of the caregivers, causing stress, anxiety, and depression in them.(17)

2) **Shame-** Shame is a powerful negative emotion that makes the person to feel inferior, or worthless. A meta analytic review in 2011 of 108 studies examining shame, guilt and depressive symptoms showed that shame had significantly stronger associations with depressive symptoms.(18) Shame hinders in treatment seeking and can lead to worsening of symptoms.(16)

3) **Lack of Knowledge:** Knowledge and attitude in society towards mental illness are poor and neglected as compared to medical illness.(19)Poor knowledge contributes not only to inadequate treatment but also precipitates the stigma and hence reduced access to care, which creates a vicious cycle of despair for the mental illness sufferer.(20)

4) **Negative Attitudes**: Public perceptions and attitudes toward mental illness in community generally emerge from a pre-existing belief system that is based on community's past and present experiences.(21)People have general beliefs that persons with mental illness (PMI) are aggressive, dangerous, violent, unpredictable in their behavior, unable to handle too much responsibility, and more likely to commit offenses or crimes. These misperceptions cause fear and social distance. Social distancing is frequently observed at work, among neighbours, and in marriages.(22) Different causes of negative assumptions about psychiatry include uncertainty, the causation of disorders being poorly understood and most of the conditions are poorly treatable.(23)

5) **Impact of Therapeutics:** The public opinion on psychiatric treatment and facilities has been consistently negative.(24)Psychotropic medications are considered as stigmatizing as some medications can cause unpleasant side effects and personality altering and making people dependent. This lead to non-adherence of treatment and increase the risk of psychotic outbreaks. Newer drugs have fewer side effects and are effective in decreasing the risk of relapse, suicide, and re-hospitalization. High cost of medications and long duration of treatment also play a role. Physical restraints often used in emergency psychiatric treatment also worsen the stigma for patients and influences adherence to medical treatment. There are consistent myths prevalent in society regarding available treatment options despite increasing awareness of mental health illnesses.(16)

6) **Attitude towards Mental health professionals:** Sartorius et al. investigated the way psychiatrists and psychiatry are viewed by different groups. In opinion of general public, psychiatrists are considered as low-status doctors who use too many psychotropic medications. The media presents psychiatry as a specialty without training, representing psychiatrists as madmen, healers, or even charlatans.(16) Their knowledge, expertise and duration of training is underestimated. Negative attitude is also observed even in medical profession among doctors of other specialities. Medical students often do not view psychiatry as an intellectually challenging career choice and see it as a profession with low job satisfaction and limited fulfillment.(24)Most often, patients present as a comorbid condition of other disorders ormissed or inappropriately managed by fellow doctors.(25)

7) **Role of media:** Media has an important responsibility to give accurate information about an illness or procedure or efficacy of treatment. But unfortunately, in case of mental illnesses, media contribute to stigma through the exaggerated, inaccurate, and comical portrayal of persons with psychiatric disorders as well as provide incorrect

information about mental illness. In the absence of actual experience with people with mental illness, individuals rely on the media for their perceptions of those who have mental illnesses.(26)

Media analysis of film and print have identified three patterns in people with mental illnesses which are as follow-

- They are considered homicidal/violent/murderous who need to be feared/avoided
- They have childlike perceptions of the world that should be marveled
- They are responsible for their illness because they have weak character
  Media is also responsible for the negative attitudes of the general population toward the use of electroconvulsive therapy (ECT) for persons with psychiatric disorders. ECT is perceived as cruel and painful procedure by the society which causes brain damage, and is used as a punishment for persons with mental disorder who are violent or uncooperative. But, this is not the case. The efficacy of ECT is well known scientifically in unmanageable or treatment resistant cases.
- Reporting of celebrity suicide is also a concern. Repetitive reporting in a glorifying or sensationalize way can influence the vulnerable and suicidal people. The reporting should be cautious, factual and mourning.

Consequences of stigma on quality care of patients with mental illness: Key themes observed are as mentioned below(15)-

- Delays in help-seeking
- Discontinuation of treatment
- Suboptimal therapeutic relationships
- Patient safety concerns
- Lack of understanding by family, friends, and co-workers
- Poor quality mental and physical care
- Fewer opportunities for work, school or social activities
- Bullying, physical violence or harassment
- Health insurance that doesn't adequately cover your mental illness treatment
- Feeling excluded from decisions
- Receiving threats of coercive treatment
- Being given insufficient information about one's condition or treatment options
- Being treated in a paternalistic or demeaning manner
- Being spoken to or about using stigmatizing language.

Stigmatization also has inward-facing impacts on medical professionals own willingness to seek help or disclose a mental health problem. Despite knowing their treatable medical condition, they rely on self-treatment, have low peer support, fear judgment from co-workers if disclosure does occur and increased tendency of suicide is observed.

Steps to remove barriers to access and care through stigma reduction-
Targeting mental health stigma is a cost-effective way to reduce the risk of relapse and poor outcome in mentally ill patients who have chronic exposure to stigmatising

environments.(2) It can improve their quality of life and can decrease the treatment gap.

1) **Get treatment-** Treatment can reduce symptoms that interfere with your work and personal life.
2) **Don't isolate yourself-** If you have a mental illness, you may be reluctant to tell anyone about it. Your family and friends can offer you support if they know about your mental illness. Reach out to people you trust for the compassion, support and understanding you need.
3) **Education**- Educating people about mental illnesses can breakdown the stigma by modifying negative stereotypes and replacing them with true and factual information.(16,24)Education and contact, both had positive effects on reducing stigma for person with a mental illness and serve as an important tool to reduce stigma. (27, 28)
   a) Various educational strategies are mentioned below-
   - Public service announcements
   - Books and brochures
   - Films/videos/websites and other audio-visual resources
   - Use of symptomatic vignettes for public education to improve young people's understanding of mental health problems.
   - Awareness campaigns integrated with educational institutions and content should be relevant to culture and age-appropriate social roles.(4)
4) **Role of health organizations-**Collaboration of public and private sectors is must to ensure mental health services utilization and to reduce treatment gap.They should take lead roles in tackling the problem. Community-based health workers also play an important rolein their communities. They must be trained in identifying the key symptoms or warning signs of mental disorders, to make appropriate referrals, and to communicate, despite of limited literacy and resource constraints.(13)
5) **Demonstrating recovery-** Showing how the patient recovered from a mental illness and showing ways in which healthcare providers play an impactful role in that process helps in alleviating the stigma and motivate other patients and families to seek help for mental illness.(15)
6) **Social contact-** Social contact with the mentally ill person is considered a powerful tool to understand their behaviors and reduce stigma. It refers to hearing from patients and their family members who are trained to speak about their experiences of illness and recovery, both in the community as well as with professionals during their training.(13,15,16) Patrick et al. also shows the similar findings.(27,28)
7) **Take help of Media**- Media act as a powerful tool to change the image of psychiatry and mentally ill persons and help in change the public opinion about them.(24) Good, accurate and balanced reporting help the community in understanding the experience of mental illness and encourage help-seeking behavior.
   - **Humanise the mental illness**- Feature stories about people with a mental illness and emphasize the impact of mental illness on family members, friends, and carers.

- **Offer hope to persons with mental disorders** - Highlight stories about the successful management of mental illness by interviewing recovered patients and their caregivers.
- Emphasize the importance of **early recognition and treatment** of mental illness.
- Tell the **warning signs and factual information** regarding mental illnesses by interviewing psychiatrists or mental health professionals.
- **Language and stereotypes** used for patients with psychiatric disorders on social media should be addressed.(26)

  These subtle changes can help people to change their attitudes and breaks the negative stereotypes prevalent in Indian society.

8) **Stigma self-management:** Self-management encourages mentally ill patients to get better and to find new motivations.(16) **Adult Mental Health Practice Support Program**in British Columbia teaches self-management cognitive behavioural tools to physicians and other frontline healthcare providers for patients with mild to moderate depression and anxiety. (15) Mental health self-care options are very limited in India. Few **support groups** are available for patients with depression, anxiety, suicidal ideations, schizophrenia, bipolar disorder, substance use disorders such as alcohol or opioid use disorders. Some local and national groups, such as the National Alliance on Mental Illness (NAMI), offer help to reduce stigma by educating people with mental illness, their families and the general public. Some state and federal agencies and programs, focus on vocational rehabilitation and offer support for people with mental illness. Support groups help the individual by reducing social isolation, increase individual engagement, prevent social disintegration, teach family members to recognize the early signs of major depression and other psychiatric disorders with serious suicidal risk and also provide efficient care following discharge by mental health professionals.

9) **Legislative Reform and Advocacy**–
   a) **United Nations Convention** on the Rights of Persons with Disabilities provide protections against coercion and forced treatment and guide governments and institutions to provide economic, social, and health support to remove barriers to the social participation of mentally ill people.(16)
   b) **Advocacy** is important because it guide to direct changes in legislation and policy, as well as the development of services. It involves various strategies, such as-
      - Awareness raising
      - Disseminating information
      - Education
      - Training
      - Counselling
      - Defending the disadvantaged
   c) **India's national mental health policy** and new **mental health care act passed in April 2017** targets reduction of stigma and non-discrimination and protects the rights of person with mental illness.(4) The new act removed few stigmatizing terms and definitions. The provision of **Advance Directive** allows the mentally ill individual to take his treatment decisions that how that individual should be treated in mental health crisis.(29) The mentally ill person can also appoint a **Nominated Representative** that would be bound to take care of his treatment and his health during the crisis situation. It also decriminalises the suicide.(6)New act also includes the punishment for the offenders or for those who violates the rights of person with mental illness.

10) **Anti-stigma training**- It makes people aware of how the certain beliefs and behaviours contributes to stigmatizing experiences. Healthcare providers also hold pessimistic views about the reality and likelihood of recovery, which is experienced as a source of stigma and a barrier to recovery for people seeking help for mental illnesses. Research with healthcare providers in Canada indicates that the level of stigma regarding their own willingness to disclose and/or seek help for a mental illness is consistently higher than their level of stigma for other dimensions such as negative attitudes and preference for social distance.

11) **Training of undergraduates**- The style of teaching of undergraduates should be changed to improve understanding about mental illnesses and the branch psychiatry. Direct patient contact and effectiveness of psychiatric interventions can improve attitudes of undergraduates and enhance psychiatry branch as a career choice. (24)

2. Conclusion

There is strong need to understand the ongoing mental health crisis in India and to take preventive measures against these issues. Lack of education and negative cultural beliefs about the causation of mental illnesses and their treatment which should be targeted at the root level. There are many lacuna in implementation of legislative measures, deficiency in allocation of resources and inadequate expenditure on mental health. The target of this study was to know the stigma as an important mediating barrier in help seeking regarding mental health issues.

Author Contributions
All authors participated in all stages of the article, including literature review, writing and approval of the final version.

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