Original article

Development of Jaipur Stigma Questionnaire: A culturally relevant tool to assess stigma in contemporary Indian context

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Abstract

***Background**: The stigma attached to mental illness is a universal phenomenon, though its experiences may differ locally. Little work has been done to study the understanding of stigma amongst Indian psychiatrists and after a thorough review of literature, it was felt that there is a need to develop a stigma questionnaire suitable for Indian context. **Aim:** The objectives were to (a) study the understanding of stigma for severe mental illness among psychiatrists, (b) study various aspects of stigma for severe mental illness, and (c) prepare a culturally and contemporarily suitable stigma questionnaire. **Method:** Sixty psychiatrists from North India were requested to frame at least five questions to tap stigma, of which fifteen responded. Using ten questions with maximum consensus, a tentative stigma questionnaire was prepared. In a pilot study, attendants of 30 mentally-ill patients were administered Camberwell Family Interview and tentatively-prepared stigma questionnaire to see the relevance of themes. Keeping these results in mind, the study tool, Jaipur Stigma questionnaire (JSQ), was prepared. JSQ was applied on a matched group of 30 attendants of mentally-ill patients and comparison done with other questionnaires on ease of administration, themes and potential to tap stigma. **Results:** The JSQ was easier to administer, included more themes and tapped stigma efficiently. Many themes not felt to be important by the collegiate of psychiatrists were subsequently found to be relevant. Segregation of mentally ill and shame for consultation appear to be fading themes. **Conclusion:** The study has made an attempt to develop a new stigma questionnaire which is relevant for Indian setting and is reflective of contemporary themes of stigma.*

***Keywords:** Stigma, questionnaire, mental illness, India*

Introduction

Stigma is a complex phenomenon that defies a lucid and comprehensible definition. The word *stigma* was originally derived from a Greek word meaning a scar burnt into the body of a slave. Stigma can be defined in terms of the co-occurrence of its components: labeling, stereotyping, separation, status loss and

discrimination. A proposed schema to show the pathway of stigma is as follows: stereotype-prejudice-discrimination, where stereotype represents collectively agreed upon notions about certain group of people**,** prejudice is an (usually) emotional reaction in persons who agree with the stereotype, and discrimination is the behavioral counterpart or acting on the prejudice.[1]

Many people with serious mental illness are challenged doubly, with the symptoms and disabilities resulting from disease and at the same time, by the stereotypes and prejudice resulting from misconceptions about mental illness.The people with mental illness are robbed of the opportunities that define a quality life: good jobs, safe housing, satisfactory health care, and affiliation with a diverse group of people.[1]

Stigma of mental illness is experienced in many ways; the important ones reported in literature are related to the following:[2-9]

(a) Violence and dangerousness, (b) Employment, (c) Heredity, (d) Marriage, (e) Presentation in media, (f) Responsibility, (g) Access to satisfactory care, (h) Avoidance, (i) Segregation, (j) Coercivetreatment, (k) Shame for consultation, (l) Chronicity of illness, (m) Self stigma i.e. guilt and shame, and (n) Labeling.

Stigma is universal, but its experiences are local.[10] Stigma in non-western societies require a more clinical anthropological approach: in depth pictures of behavior, its effect on social identity and function, as well as the symbolic interpretation.[11] Islamic and Christian societies express and report stigma differently.[12] The emphasis on morality and interpersonal obligations and duties is integral to Chinese society and a strong organic somatopsychic integration dominated the tradition and a strict separation of mental illnesses from physical ones was never strongly manifest.[13] In ancient India, it is likely that spiritual person, as well as lay folk and Ayurvedic practitioners handled much of the psychiatric patients. While there are suggestions that positive attitudes like compassion and tolerance were social responses to the mentally ill, evidence also points to frank discrediting and stigma.

A previous study [14] compared the stigma felt by attendants in Bangalore and London and found that in Bangalore, the main concerns in the sample were related to marriage (lowering their own chances of entering a good marriage, but were also concerned with decreasing the chances in one of their relatives). In contrast, marriage was of no concern in the London sample. It was also found that self-perceived stigma was much higher in the London sample than in the Bangalore sample.[14] The stigma attached to mental illness is pervasive, affecting patients as well as families across generations. It is often the main obstacle to provision of the mental health care and interfere with the rehabilitation of mentally ill persons.

The psychiatrist is the apex of the care-pyramid of the mentally ill. The attitude, understanding and interventions (in relation to mental illness) done by the psychiatrist have an amplified and cascading effect on all those involved in the care of the mentally ill. It has been widely reported that psychiatrists may have a stigmatizing attitude.[15,16] These attitudes of psychiatrists have far more devastating effects on their patients than either medication or the mental health act. [17,18] Major changes have taken place in psychiatry in the recent past, including de-institutionalization of mentally ill and National Mental Health Programme. The psychiatrist must also keep abreast with the changing attitudes and circumstances in the society and should continuously challenge their own knowledge, understanding and prejudices associated with mental illness.[15,16]

Stigma is a dynamic process and probably its themes will keep changing with the development of science and effectiveness of treatment. There was a time when leprosy and tuberculosis had tremendous stigma as incurable diseases. In today's era, effective treatment of these conditions has resulted in a dramatic reduction of the stigma.

The authors reviewed the existing literature in search of a tool which effectively and comprehensively evaluates stigma in the present scenario and found that either the tools were outdated or were not suitable for the population of the region. It was found that Camberwell Family Interview (CFI)[19] was closest to the desired questionnaire. However, even CFI did not contain certain themes (local myths, guilt, shame, social distance etc) relevant to the regional culture. With this background, the authors aimed to study the understanding and attitude of Indian psychiatrists in relation to stigma towards severe mental illness and subsequently prepare a questionnaire to evaluate stigma for severe mental illness, which was culturally and contemporarily suitable for the population of the region.

The objectives were to (a) study the understanding of stigma for severe mental illness among psychiatrists, (b) study various aspects of stigma for severe mental illness, and (c) prepare a culturally and contemporarily suitable tool to assess the various aspects and severity of stigma associated with mental illnesses.

Materials and Method

The study design was approved by the institutional review board. Informed consent was taken from all participants of the study.

A gathering of 60 psychiatrists of the north Indian region was approached and requested to frame at least five questions which could be used to interview the attendants of the severely mentally ill to tap different aspects of stigma for severe mental illnesses. Of total, 15 psychiatrists responded. The responses of these psychiatrists were analyzed to see which themes were not touched upon and which themes were felt to be more relevant. A frequency table was prepared to see the consensus on themes of stigma for severe mental illnesses. Ten questions with maximum consensus were collected and a tentative stigma questionnaire (TSQ) was prepared.

In a pilot study, the attendants of 30 consecutive mentally ill patients who visited the psychiatry OPD and were literate, physically and mentally healthy were administered two questionnaires, Camberwell Family Interview (CFI) and the tentatively-prepared stigma questionnaire (TSQ). Their responses were noted and all the 20 questions were analyzed individually and were studied to see what percentage of population shows stigma in each dimension. This was done to see if themes represented in the questionnaire were locally relevant or not and also to see if locally prepared questionnaire held any advantage on its western counterpart.

Keeping the results of the pilot study in mind, a culturally and contemporarily suitable tool, Jaipur Stigma Questionnaire(JSQ), was prepared to elicit stigma for severe mental illness and their sufferers.

While preparing the tool, the authors tried to include the following features:

(a) Should be regionally, culturally and contemporarily suitable
(b) Should be easy to use - easy language with limited things asked per question
(c) Should be simple enough to be used by all mental health professionals
(d) Should take less time to administer
(e) Should cover all major themes
(f) Should serve as a reminder to mental health professionals on issues needing consideration to improve quality of life of the patient and his family

(g) Should be thought provoking and should encourage change in attitude of the family members as well.

Instead of using a "agree- disagree" likert scale, the authors felt that tracking the progression of an idea to stereotypy , stereotypy to prejudice and prejudice to discrimination will be more useful and relevant

The tool so prepared, JSQ, was applied on another 30 literate, physically and mentally healthy attendants of severely mentally ill, the group was matched for socio-demographic factors and for the diagnosis of their patients with the group used in the pilot study. The results are being presented and discussed below.

Results

The themes of stigma identified by the collegiate of psychiatrist in decreasing order of frequency are shown in Table 1. Certain themes like labeling, coercive treatment related, responsibility related, access to satisfactory care related, presentation in media related , heredity related and violence and dangerousness related etc. were not felt to be important issues by the collegiate of psychiatrists.

Table 1: Themes of stigma touched upon by the psychiatrists

Themes	Frequency
Treatment and consultation related	20
Shame	13
Employment related	8
Social distance	6
Guilt	4
Knowledge related	4
Marriage-related	3
Avoidance/ rejection	2
Segregation	1
Chronicity	1

The analysis of contents of different questionnaires (CFI, TSQ,JSQ) was done and the number of questions devoted to each theme of stigma have been shown in Table 2. On applying all three questionnaires viz. CFI, TSQ and JSQ, the theme-wise response of interviewees are shown in Table 3.

Table 2: Table showing analysis of contents of different questionnaires: Number of questions on each theme

Theme	CFI	TSQ	Study tool JSQ
Social Distance	2	2	2
Shame for consultation	0	1	1
Rejection /employment	0	1	2
Discrimination/labelling	6	0	1
Guilt	0	1	1
False belief	0	1	1
Violence	0	0	1
Shame	1	2	1
Marriage	0	1	1
Segregation	1	1	2
Heredity	0	0	1
Presentation in media	0	0	1
Responsibility for illness	0	0	1
Chronicity of illness	0	0	1
Coercive treatment	0	0	1
Access to satisfactory care	0	0	1

CFI: Camberwell family interview; TSQ: Tentatively-prepared Stigma questionnaire; JSQ: Jaipur Stigma Questionnaire

Some noteworthy findings were:

- Social distance, guilt and labelling appeared to be important issues in the regional context
- Themes like segregation of mentally ill from the society and shame for consultation seemed to be fading as concerns in the regional context.
- Themes related to Labeling, Coercive treatment, Responsibility, Access to

satisfactory care, Presentation in media, Heredity and Violence and dangerousness were not addressed by the collegiate of psychiatrists, but the authors subsequently found these themes to be relevant in the regional context.

Table 3: Theme-wise response of attendants: comparison of different questionnaires

Theme	CFI	TSQ	Study tool JSQ
Social distance/ Segregation	22	6	26
Shame for consultation	–	1	9
Rejection /employment	18	0	22
Discrimination /labelling	22	–	18
Guilt	–	18	30
False belief	–	1	30
Violence	–	–	27
Shame	20	18	30
Marriage	–	15	27
Heredity	–	–	24
Presentation in media	–	–	21
Responsibility for illness	–	–	24
Chronicity of illness	–	–	24
Coercive treatment	–	–	27
Access to satisfactory physical health care	–	–	24

CFI: Camberwell family interview; TSQ: Tentatively-prepared Stigma questionnaire; JSQ: Jaipur Stigma Questionnaire

The study tool, JSQ, was easier to administer (observed by comparing the no. of times the interviewer was asked to repeat/explain the question) and took lesser time. The questionnaire takes 4-9 min to apply and the examiner was interrupted on an average 3 times. (compared to 15 min and 9 interruptions for CFI, 9 min and 5 interruptions for TSQ). The JSQ had the advantage of identifying whether the given idea was impacting at the level of stereotypy, prejudice or possible discrimination. A break up of the results on the above mentioned basis are shown in Table 4.

Discussion

The present study has attempted to develop a stigma questionnaire, Jaipur Stigma Qquestionnaire (JSQ), which is relevant for Indian setting and is reflective of contemporary themes of stigma. The stigma of mental illness is, in many ways, the most important handicap faced by the people with mental disorders and is the most important challenge confronting the contem-

Table 4: Study tool (Jaipur Stigma Questionnaire): Break-up of results

Theme	No impact	Stereotypy	Prejudice	Possible discrimination
Social distance /Segregation	4	11	3	12
Shame for consultation	21	9	0	0
Rejection /employment	8	10	0	12
Discrimination /labelling	12	11	0	7
Guilt	0	12	0	12
False belief	0	12	0	12
Violence	3	12	3	12
Shame	0	3	9	18
Marriage	3	0	0	27
Heredity	6	7	2	15
Presentation in media	6	5	4	12
Responsibility for illness	6	15	0	9
Chronicity of illness	0	12	0	12
Coercive treatment	4	5	6	15
Access to satisfactory physical health care	6	3	12	9

porary psychiatric services. The themes of stigma of mental illnesses vary from region to region. An understanding of the themes of stigma which are prevalent in a region is necessary for providing better aftercare to psychiatric patients and to bridge the gap between needs and services.

With advancement in treatment options, the themes for stigma are changing. For example, shame for consultation and segregation of mentally ill are fading themes and guilt, social distance and labeling are presenting as the more pressing problems. It is essential for the mental health professionals in general and psychiatrists in particular to continuously update themselves about the stigma themes impacting their patients.

The WPA launched a global initiative against stigma under the leadership of Norman Sartorius in 1996.[20] In the past, a lot of work to study stigma was also done in India.[21,22] However, the tools used to study stigma in these studies are not suitable for our region because of one or more of the following reasons:

1. Concept of stigma is dynamic and changing.
2. They are not suited to the special needs of the region.
3. They are not suited for use by non-psychiatrist mental health professionals.
4. They are either not comprehensive or too long and complex to be used in a limited period of time.

In order to fill this vacuum, an effort has been made to develop a suitable tool which is being presented for wider use (Appendix 1).

The newly developed tool, JSQ, has the following features:

- It is in Hindi language
- It has 14 statements which touch upon various themes of stigma
- Each questions has four options to choose from, which if translated to English, are as follows: (a) Neither I feel this way nor the society does, (b) I don't feel this way but the society does, (c) Sometimes I feel this way, and (d) I totally agree with the statement.
- It has the advantage of identifying whether the given idea is impacting at the level of stereotypy, prejudice or possible discrimination. e.g. the selection of first option shows that there is neither stereotypy nor prejudice, second option shows that there is stereotypy but no prejudice, third option shows prejudice and fourth option shows probable discrimination.

To conclude, stigma is a dynamic process and probably its themes will keep changing with the development of science and effectiveness of treatment. The available tools to assess stigma are either outdated or not suitable for the local population. Certain culture-specific themes e.g. local myths, guilt, shame, social distance etc may be more relevant to the given region and not covered by the western questionnaires. The study makes an attempt to develop a new stigma questionnaire which is relevant for Indian setting and is reflective of contemporary themes of stigma.

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Appendix 1: New study tool: Jaipur Stigma Questionnaire

निर्दश –

नीचे दिये गए कथन पढिए तथा निम्नलिखित विकल्प मे से आपको जो सबसे सही लगे उसका चयन कीजिए

विकल्प –

(1) न मैं ऐसा मानता हूँ ओर न ही समाज ऐसा मानता है ।
(2) मैं तो ऐसा नहीं मानता पर समाज मानता है ।
(3) कभी – कभी मुझे ऐसा लगता है ।
(4) मैं इस बात से पूरी तरह सहमत हूँ ।

कथन –

1. गम्भीर रूप से बीमार मानसिक रोगी को समाज/ परिवार के साथ नहीं रखा जाना चाहिए क्योंकि वह आक्रामक हो सकता है ।
   (1) (2) (3) (4)
2. गम्भीर रूप से बीमार मानसिक रोगी को उपचार के उपरान्त भी नियमित कार्य पर नहीं रखा जा सकता ।
   (1) (2) (3) (4)
3. एक मानसिक रोगी के बच्चों मे भी मानसिक रोग हो सकता है ।
   (1) (2) (3) (4)
4. गम्भीर रूप से बीमार मानसिक रोगी को फिल्म अथवा टी वी सीरियल में उचित रूप से दर्शाया जाता है ।
   (1) (2) (3) (4)
5. गम्भीर रूप से बीमार मानसिक रोगी अपने व्यवहार को नियंत्रित कर सकता है ।
   (1) (2) (3) (4)
6. गम्भीर रूप से बीमार मानसिक रोगी सामान्य जिंदगी नहीं जी पायेगा ।
   (1) (2) (3) (4)
7. गम्भीर रूप से बीमार मानसिक रोगी को अलग रखकर जबरदस्ती उपचार देना सही है ।
   (1) (2) (3) (4)
8. मानसिक रोग इस जन्म या पूर्व जन्म के पापों का फल है ।
   (1) (2) (3) (4)
9. उपचार के बाद भी वह गम्भीर रूप से बीमार मानसिक रोगी की शादी नहीं की जानी चाहिये।
   (1) (2) (3) (4)
10. मानसिक रोगी की शारीरिक बीमारी को भी मनोरोग का लक्षण समझ कर टाल दिया जाता है ।
    (1) (2) (3) (4)
11. मानोचिकित्सक से राय लेना या मनोचिकित्सालय जाना शर्मनाक है ।
    (1) (2) (3) (4)
12. गम्भीर रूप से बीमार मानसिक रोगी को पागल / सरका कह कर बुलाया जा सकता है ।
    (1) (2) (3) (4)
13. मुझे अक्सर शर्म आती है जब लोग कहते है कि इसके परिवार में मनोरोगी है ।
    (1) (2) (3) (4)
14. मरीज के लिये यह ही बेहतर होगा कि हम उसे अपने हाल पर छोड़ दें ।
    (1) (2) (3) (4)