Stigma experienced by persons diagnosed to have a mental illness – a descriptive study

AM Fernando, AMM Godavitharana, S Pathirana, S Tennakoon, D Ariyasinghe, TN Rajapakse

Abstract

Background
In Sri Lanka, mental illness is often considered an embarrassing topic, which is not openly discussed. The stigma associated with mental illness influences the way people choose to seek help and the use of services.

Aims
To describe the nature of stigma experienced by patients presenting to the adult psychiatry clinic at Teaching Hospital, Peradeniya.

Methods
The stigma scale by King et al. was translated to Sinhala and modified to suit the Sri Lankan context. This modified version was distributed among 100 patients attending the adult psychiatry clinic at T.H. Peradeniya over a consecutive two-month period.

Results
The most commonly endorsed discriminatory items pertaining to stigma were, that the participants felt they could not have a satisfactory married life, and that they felt isolated and talked down to, due to their illness. Almost half said they would avoid telling others about their mental health problems. In contrast, 56.1% reported that they felt that the support from their family has increased due to their mental health problems.

Conclusions
Stigma experienced by persons with mental illness is complex and varied, and a better understanding of this important area would enable improved patient care in Sri Lanka.

Key words: stigma, mental disorders

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Introduction

Stigma has been described as a phenomenon where an individual is deeply discredited due to a given attribute, reducing the bearer from a whole and usual person, to a tainted and discounted one (1, 2). It causes the bearer to be classified by others as undesirable, or as a rejected stereotype. Psychiatric illness is a very commonly stigmatized attribute in most societies; and Sri Lanka is no exception (3).

Stigma is associated with negative attitudes, and discrimination, both at individual and institutional level (4). Commonly reported psychological consequences of stigma include feelings of isolation, anger, depression, fear, anxiety, guilt, embarrassment and avoidance of seeking treatment (5). Stigma is likely to give rise to secrecy regarding the psychiatric illness, and delays in the help-seeking process. Indeed, stigma has been described as one of the main obstacles for provision of care for persons with mental illness (3). Stigma also prevents socialization by patients who are in remission. In Sri Lanka, mental illness is often considered an embarrassing topic, which is not openly discussed. Although common, psychiatric illness in Sri Lanka is often kept secret due to stigma (6). Stigma is influenced by both psychological and social factors, and thus the stigma about mental illness experienced in a South Asian country such as Sri Lanka may differ from the West. In an attempt to assess stigma in the Sri Lankan context, the objective of this study was to explore the nature of stigma experienced by patients with a psychiatric illness, who attended the Psychiatry Clinic, at Teaching Hospital Peradeniya.

Methods

Persons with a diagnosis of psychiatric illness, who were attending the routine follow-up psychiatry clinic at Teaching Hospital Peradeniya, and who were fluent in written and spoken Sinhalese, were considered eligible to participate in the study. A convenience sample of 100 patients attending the follow-up adult psychiatry clinic at T.H. Peradeniya over a consecutive two month period were included in the study. Sample size estimates were calculated using GPower (v.3) (7). Participants were invited to complete the stigma scale by King et al (8). In order to minimize bias, the questionnaire was distributed by a nursing officer, while participants were waiting their
turn to see the doctor in the clinic. Participants were invited to complete the questionnaires anonymously, and it was clearly explained their responses or refusal to participate in the study would not adversely affect their treatment in any way. Those who gave written informed consent were included in the study.

The stigma scale by King et al is a self-administered questionnaire with 28 statements reflecting 3 subscales, namely discrimination, disclosure and positive aspects of stigma (8). Each statement is answered in a Likert scale numbered from 0 to 5, ranging from strongly disagree, disagree, neither agree nor disagree, agree, and strongly agree, in that order. This scale has been used previously for exploration of stigma in Sri Lanka (9, 10).

The scale was translated into Sinhalese separately by two bi-lingual translators, reviewed by two subject experts for clarity, and back translated by two independent translators. The investigators and the bilingual experts then compared the original stigma scale with the English translation to check for any loss of meaning during the translation process. The Sinhalese version of the stigma scale was also reviewed by a group of subject experts, for face validity and cultural appropriateness; during which it was agreed that the scale should be locally adapted by addition of three statements with regards to stigma associated with marriage. This cultural adaptation was done with consent from the author of the original stigma scale. The scale was thereafter pretested among 20 inpatients just prior to discharge from hospital.

Data were analysed using SPSS Version 24. Descriptive statistics, including calculation of frequencies, means, medians and standard deviations were used to explore the level of stigma. For the ease of analysis the ‘strongly disagree’ and ‘disagree’ responses in the Likert scale were considered together as a combined ‘disagree’ response, and the strongly agree and agree responses were similarly combined as well.

### Results

The mean age of the population was 40 years, of whom 64.9% were females (Table 1). Of the participants, 49.5% had been educated up to grade 11 or 12, and 60.3% were unemployed.

The items endorsed by the participants in the discriminatory, disclosure and positive subscales are shown in figures 1-3. The most commonly endorsed discriminatory items due to stigma were, that participants felt they could not have a satisfactory married life due to their psychiatric illness (49.5% median 2, 1.45 SD), and that they felt isolated and talked down to, due to their illness (50.5% median 3, 1.426 SD and 47.3% median 2, 1.359 SD, respectively). Less than 20% reported experiencing any form of discrimination with regards to employment (median 1, 1.139 SD) or education (median 1, 1.269 SD) due to their psychiatric illness.

<table>
<thead>
<tr>
<th>Variables</th>
<th>N = 100 (%)</th>
<th>Occupation</th>
<th>N = 100 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age range, years</strong></td>
<td></td>
<td>Employed</td>
<td>26 (29.5%)</td>
</tr>
<tr>
<td>18-39</td>
<td>47 (47.5%)</td>
<td>Unemployed</td>
<td>53 (60.3%)</td>
</tr>
<tr>
<td>40-59</td>
<td>46 (46.5%)</td>
<td>Studying</td>
<td>3 (3.3%)</td>
</tr>
<tr>
<td>&gt;60</td>
<td>6 (6.1%)</td>
<td>Retired</td>
<td>3 (3.3%)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td>Diagnosis</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>34 (35.1%)</td>
<td>Bipolar affective disorder</td>
<td>27 (32.1%)</td>
</tr>
<tr>
<td>Female</td>
<td>63 (64.9%)</td>
<td>Depression</td>
<td>35 (41.7%)</td>
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<tr>
<td></td>
<td></td>
<td>Schizophrenia</td>
<td>16 (19%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Delusional Disorder</td>
<td>2 (2.4%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Anxiety disorders and obsessive compulsive disorder</td>
<td>4 (4.8%)</td>
</tr>
<tr>
<td><strong>Level of education</strong></td>
<td></td>
<td>Marital Status</td>
<td></td>
</tr>
<tr>
<td>Not attended school</td>
<td>1 (1%)</td>
<td>Married</td>
<td>55 (53.4%)</td>
</tr>
<tr>
<td>Grade 1-5</td>
<td>2 (2.1%)</td>
<td>Unmarried</td>
<td>39 (37.9%)</td>
</tr>
<tr>
<td>Grade 6-10</td>
<td>33 (34%)</td>
<td>Separated/ Divorced</td>
<td>4 (3.9%)</td>
</tr>
<tr>
<td>Grade 11-12</td>
<td>48 (49.5%)</td>
<td>Widow/ Widower</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>Graduate/undergraduate</td>
<td>4 (4.1%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vocational training</td>
<td>9 (9.3%)</td>
<td></td>
<td></td>
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</tbody>
</table>
Figure 1. Endorsement of items on the discrimination subscale:

Figure 2. Endorsement of items on the disclosure subscale:

Figure 3. Endorsement of items on the positive subscale:
Almost half said they would avoid telling others about their mental health problems (47.1% median 2, 1.214SD), and that they were scared about how others would react if they found out (44.8% median 2, 1.286SD). Interestingly, over half of the participants said they would reveal about their mental illness to a spouse (median 1, 1.33SD), although about 30% said they would not do so.

A large majority (over 70% median 3, 1.25 SD) endorsed the statement “I would have had better chances in my life if I had no mental health problems”. However, 56.1% (median 3, 1.338 SD) also reported that they felt that the support from their family had increased due to their mental health problems; and over half also stated that they themselves had become more understanding, due to their experience of mental illness.

Discussion

A majority of the participants in this study had experienced several aspects of stigma, related to issues around discrimination, and disclosure, due to mental illness. This is keeping with previous findings by Fernando et al., who reported a significant stigma experienced by patients with psychiatric illness in Sri Lanka, as well as their carers (9, 10). Interestingly, in our study, the most common discrimination reported was with regards to interpersonal and social issues; for example discrimination with regards to marriage, feeling isolated, and being ‘talked down to’. Previous studies from Sri Lanka too have found that stigma associated with mental illness is associated with concerns of reduced chances of getting married, not only for the person concerned, but for their family members as well (3, 11). The stigma regarding psychiatric illness seems inherently linked not only to the person concerned, but to the view of the person’s family by society (3). This may reflect importance of family and inter-personal relationships in Sri Lanka, and the collectivistic nature of our socio-cultural background (12).

Only a small number of participants reported experiencing discrimination in education or employment. This is in contrast to previous Sri Lankan studies, that have reported discrimination against employment as being one of the most frequently endorsed items with regards to stigma. The female gender bias in our sample (64.9% female) may have influenced this finding in our study – perhaps the majority females in the study placed less emphasis on issues related to employment, compared to males.

The fact that over 70% of participants declared that they would have had a better life if not for their mental illness, reflects the significant negative impact experienced by patients with psychiatric illness in this country. On a more positive note however, a majority of our study participants also stated that support from their families have increased after they fell ill. Similarly, data from India also suggests that despite the high stigma around psychiatric illness and marriage, the proportion of marriage in Indian patients were higher than that of their counterparts in developed nations. However, cultural factors may also have influenced this finding (13). The positive attitudes from the family reported by our patients, maybe a strength which could be further supported and enhanced.

Limitations

Since the stigma scale was administered in Sinhalese only, those who were not fluent in spoken and written Sinhalese could not be included in the study, and this is a limitation. The stigma scale by King et al., which was used for this study, has not been formally validated for use in Sri Lanka, although every effort was made to minimize bias by translation, back-translation, and local adaptation with expert review. Given the limited sample size, we were not able to explore associations between variables such socio-demographic characteristics, diagnosis and duration of illness, and level of stigma.

Conclusions

Stigma experienced by persons with mental illness is complex and varied. The results of this study suggest that in Sri Lanka it is experienced significantly in the context of interpersonal and social issues, such as marriage. Stigma related to psychiatric illness in Sri Lanka has been shown to impact negatively on help seeking behaviour and the course of treatment (9). Thus, addressing stigma related to psychiatric illness in this country, is of paramount importance. Education, and contact with persons who have had psychiatric illness and recovered, have been shown as effective methods of combatting stigma, internationally (14). Research is needed to explore the efficacy of such measures in the Sri Lankan cultural context. Ways in which local cultural attributions of mental illness, such as how beliefs about ‘evil spirits’ or ‘bad time’ influences stigma, is also worth exploring in future research. A better understanding of this important area would enable improved care and better quality of life of persons with psychiatric illness in Sri Lanka.

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Disclosure statement

None declared
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References