Original Research Article

Internalized stigma and quality of life among recipients of a rural community mental health program in southern Karnataka, India: a cross sectional study

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ABSTRACT

Background: In the field of mental health the role of adherence to medications is an important concept. One of the important reasons to be non-adherent to medications is the presence of stigma among mentally ill patients. The objectives of this study were to measure stigma to mental illness and quality of life among the enrolled patients in a community mental health program.
Methods: A cross-sectional study was conducted among 300 persons registered under a rural mental health program selected by consecutive sampling. A questionnaire capturing information on socio-demography, stigma using Internalized stigma of mental illness (ISMI), and quality of life using WHO-BREF QOL questionnaire was used.
Results: In study 8 (2.7%) of the study, subjects were suffering from moderate stigma. Factors like gender, type of family, and marital status were significantly associated with total stigma. Quality of life domains was also positively associated with education, occupation, marital status, and socioeconomic status.
Conclusions: The study showed minimal existence of stigma and lower mean scores in quality-of-life domains.

Keywords: Quality of life, Mentally ill persons, Rural mental health program, Stigma

INTRODUCTION

Health involves mental health which plays a major part in general well-being and health. World Health Organization (WHO) estimated that globally 450 million people suffer from mental disorders.[1] The overall weighted prevalence for any mental morbidity was 13.7% lifetime and 10.6% current mental morbidity according to a survey conducted in 2015-16.[2] One of the risk factors that can lead to non-adherence in any disease is the Stigma of the patient.[3] Stigma is the loss of status and discrimination triggered by negative stereotypes about people labeled as having a mental illness. Stigma impedes recovery by eroding individuals' social status, social network, and self-esteem, all of which contribute to poor outcomes, including unemployment, isolation, delayed treatment-seeking, treatment-refractory symptoms, prolonged course, and avoidable hospitalizations.[4] The occurrence of non-adherence and stigma can further deteriorate the condition of the patient. It can lead to relapses, dependence, complications, and toxicity. The absence of stigma and increased adherence promotes secondary prevention, promotion of treatment interventions, and economic benefits.[5]

The mental health disorders itself produces stigma for both the patient and the family which in turn reduces the ability of the subject to look after their own status leading to non-adherence to treatment in terms of stopping medication. Thus the interaction of stigma and non-adherence leads to reduced wellbeing and quality of life

which is assessed and proved in many studies.[6-9] This study was done to assess the internalized stigma to mental illness and quality of life among the mentally ill patients.

METHODS

This was a cross-sectional study among those persons above 18 years enrolled in the rural community mental health program, done for one year from February 2015 to January 2016. The rural community mental health programme (The Maanasi Project) of the institution, St John's medical college Bangalore is in operation since November 2002 and about 1500 patients are enrolled in the clinic who spread out to about 180 villages in surrounding districts (Bangalore Urban and Rural, Kolar and also from Hosur and Krishnagiri districts of Tamil Nadu). As a part of this project, a weekly clinic is conducted on Fridays (fixed day). Patients are offered consultations and medications at concessional or for free of cost depending on their socio-economic status. Further the trained health workers of the project follow-up the patients at their homes on non-clinic days. A list of enrolled patients in the rural mental health program till August 2014 was prepared from the Register maintained under the project. All enrolled patients with at least one follow-up visit to the clinic after initial registrations were included in the study. Those patients who were severely sick, unable to comprehend and answer the questions, and those who were not present in the house after two visits were excluded from the study. The sample size was calculated based on the study done to assess stigma in South India which was 21.5%.[10] A total sample size of 300 was considered based on the confidence level of 95%, absolute precision of 5%, and 5% non-response rate. The study was started after the approval of the Institutional ethics committee and subjects were selected by convenient sampling. After obtaining the informed consent, they were interviewed separately in privacy of their home, in a language understandable to the subjects using a pre-structured and pre-tested questionnaire by the primary investigator. The questionnaire contained; bio-socio-demographic details; socioeconomic status assessed using standard of living index (SLI) scale. Internalized stigma of mental illness scale.[12] ISMI is a 29-item questionnaire measuring self-stigma among persons with psychiatric disorders which is validated in Indian settings.[13,14] The mean value of the total stigma and domains are categorized into minimal (<2), mild (2-2.5), moderate (2.5-3), and severe (>3) according to review of the literature.[15] Quality of life of patients was assessed using the WHO QOL BREF tool.[16] The descriptive data were analyzed using frequencies, mean, median, and standard deviation. Tests of association were performed using appropriate tests like Fischer's exact test, independent t test, One-way Anova test and Pearson's correlation for the bivariate analysis. Variables which were found statistically significant in bivariate analysis were considered for linear regression to expose the definitive predictor factors. The significance level for all statistical analyses was set at 0.05. We analyzed the data using SPSS version 16 software.

RESULTS

The mean age of the population was 46.57±15.48 years. The youngest was 18 and the oldest was 92 years respectively. In the study, the maximum number of subjects 183(61%) belonged to the age group of 35-60 years. The majority of study subjects 238 (79.33%) are females. The sociodemographic profile in detail is described in (Table 1).

Table 1: Sociodemographic profile of the subjects.

Categories		N	%
Age (years)	≤19	9	3
	20-34	52	17.33
	35-60	183	61
	>60	56	18.67
Education	No Formal education	152	50.7
	School education	125	41.7
	PUC (11th & 12th)	15	5
	Collegiate education	8	2.6
Occupation	Daily wager	53	17.7
	Agriculture	27	9.0
	Business	16	5.3
	House wife	117	39.0
	Not employed	87	29.0
Marital status	Unmarried	29	9.7
	Married	227	75.7
	Widow	36	12.0
	Widower	4	1.3
	Separated	4	1.3
Religion	Hindu	286	95.3
	Muslim	14	4.7
Type of family	Nuclear	157	52.3
	Joint	138	46.0
	Extended	5	1.7

Majority 226 (75.3%) of the subjects belonged to middle socioeconomic status according to the Standard of Living Index. More than half of the subjects 178 (59.33%) were diagnosed with mood affective disorders (Table 2). In the study, moderate and severe self-stigmatization is experienced by 8 (2.7%), and mild and minimal self-stigmatization by 292 (95.3%) of participants. (Table 3) The association between means of stigma domains and gender of the population showed a significant association between alienation domain, discrimination domain, stereotype endorsement and social withdrawal domain to the gender of the population, i.e., females were having more stigmas in the domains of alienation, discrimination, stereotype endorsement, and social withdrawal respectively (Independent 't' test, p<0.05). There is a significant association between all the domains and total stigma to the family type of the population (One-way ANOVA test, p<0.05). There are more stigmas among subjects who reside in the extended family.

Table 2: ICD-10 classification of mental disease in the study population (n=300).

Classification of disease based on ICD-10	N	%
F10-F19 Mental and behavioural disorders due to psychoactive substance use	4	1.33
F20-F29 Schizophrenia, schizotypal and delusional disorders	8	2.67
F30-F39 Mood (affective) disorders	178	59.33
F40-F48 Neurotic, stress-related and somatoform disorders	43	14.33
F60-F69 Disorders of adult personality and behaviour	2	0.67
F70-F79 Mental retardation	5	1.67
F90-F98 Behavioural and emotional disorders with onset usually occurring in childhood and adolescence	3	1
G20 43-40 Diseases of the nervous system	46	15.3
Illness not classified in any of the above specificities like post traumatic stress disorders	11	3.67

The subjects are classified based on ICD-10.

There is a significant association between total stigma, discrimination domain, and social withdrawal domain to marital status, i.e. more amount of stigma is experienced by a widow and separated subjects (One-way ANOVA test, $p<0.05$). The multiple linear regressions of the variables (marital status and type of family) with total stigma showed that marital status is more significantly associated with stigma. The total stigma mean score is below 60 score in unmarried and married categories compared to above 60 score in widowed and separated categories. If a change happens in marital status, the average score of stigma increases by 0.3 scores and is statistically significant ($p<0.05$).

In the study, most of the people 204(68%) believed their overall quality of life is satisfactory, i.e. neither poor nor good. In the study majority of people, 201 (67%) perceived their health quality as neither satisfactory nor dissatisfied. The mean ±SD domains were 52.25±13.00, 51.81±13.12, 38.59±13.64 and 46.71±14.39 for physical, psychological, social relationship and environment domains respectively. The association between QOL domains and age of the population showed, the subjects belonging to age group of 20-34 years were experiencing increased quality of life in physical, psychological and social relationship domain. Also, subjects belonging to 35-60 years were experiencing increase quality of life in environment domain.

Table 3: Categories of domains of stigma (n=300).

Variables	Minimal stigma, N (%)	Mild stigma, N (%)	Moderate stigma, N (%)	Severe stigma, N (%)
ISMI total	277 (92.3)	15 (5)	8 (2.7)	0
ISMI Alienation	284 (94.7)	7 (2.3)	8 (2.7)	1 (0.3)
ISMI stereotype endorsement	288 (96)	12 (4)	0	0
ISMI Discrimination	281 (93.7)	9 (3)	10 (3.3)	0
ISMI social withdrawal	282 (94)	10 (3.3)	8 (2.7)	0
ISMI stigma resistance	292 (97.3)	6 (2)	2 (0.7)	0

Stigma domains are classified based on categories and expressed as frequency (%)

Table 4: Multiple linear regression of QOL and its associated factors.

Variables	Social relationship B (95% CI)	Physical domain B (95% CI)	Psychological domain B (95% CI)	Environmental domain B (95% CI)
Age (in years)	-0.79 (-3.25 to1.65)	-0.016 (-2.73 to 2.11)	0.001 (-2.51 to 2.56)	0.14 (-2.54 to 2.82)
Education	4.37 (2.07 to 6.67)*	1.79 (1.76 to 5.29)*	2.24 (1.80 to 5.6)*	3.27 (1.75 to 5.79)*
Occupation	-1.27 (-2.32 to -0.21)*	-0.09 (-1.673 to 0.41)	-0.18 (-1.68 to 0.51)	-0.61 (-1.77 to 0.54)
Marital status	1.69 (-0.84 to 4.22)	0.004 (-2.41 to 2.57)	0.016 (-2.26 to 2.97)	0.09 (-2.67 to 2.86)
SLI	6.39 (3.34 to 9.44)*	3.76 (2.68 to 8.70)*	4.11 (2.87 to 9.19)*	6.34 (2.99 to 9.68)*

Analysis was done using multiple linear regressions and significance was set at a p value of 0.05 level. B- Denotes unstandardized coefficient, *indicates p value less than 0.05.

Also, a significant association was there between all the domains and education of the population, i.e., the more

the education the more the quality of life in all domains. There was a significant association between QOL

domains and occupation, i.e., subjects belonging to the occupation of business had more quality in physical, environmental, social relationship and psychological domain. There was a significant association between all domains and marital status, i.e., high quality was experienced in social relationship domain among separated people and among widowers in other domains. There was significant association between SLI and all quality-of-life domains. The high SLI category subjects, i.e., belonging to higher socio-economic status also experienced high quality in all domains. (One way ANOVA test, p<0.05). Multiple linear regression was done with the domains of QOL and significant factors. Education, occupation, and SLI score is significant with the social relationship domain and, Education and SLI score are significant with the physical, psychological and environmental domain of quality of life after regressing the other variables (Table 4). If a one-unit change happens in education, occupation, and SLI, the average score of each domain changes by the corresponding B value and is statistically significant.

DISCUSSION

In this study the mean age of the study population was 46.57±15.48 years. The mean age of the population was similar to community-based study done in Hong Kong which was 45 years. In our study only 44 (14.6%) of the study subjects were single whereas in Hong Kong study were about 47% were single. In this study only 7.6% had PUC or collegiate education which is similar to the study done in Hong Kong and however in a hospital-based study done in Nigeria about 30% had higher than school education. Also the illiterate people comprised about 50% in the study which is more than the national average of about 32% in rural area by census 2011.[17-19]

In this study most of the study subjects (79%) were women which can be due to the fact that most of the common mental disorders (CMDs)-depression, anxiety, and somatic complaints found predominantly in women. Both community-based studies and studies of treatment seekers indicate that women on average have, 2-3 times, at greater risk to develop CMD. Hormonal factors related to the reproductive cycle may play an important role in increasing women's vulnerability to develop depression. Another reason would be the factors associated of being a female gender. These factors include excessive partner alcohol use, sexual, and physical violence by the husband, being widowed or separated, having low autonomy in decision making, and having low levels of support from one's family. Also they are less empowered due to lesser opportunities for education and employment.[20] More than half of the study subjects (52.3%) belonged to nuclear family. The traditional joint families allow for diffusion of burden in families causing to reduce the prevalence of mental illness in the family.

In this study, we found that majority of study subjects (59.3%) were suffering from affective disorders, which is similar to other studies that reported that common mental disorders like depression and anxiety to be more prevalent in the community.[2] In this study, we assessed the stigma of the study subjects using the Internalized Stigma of Mental Illness (ISMI) scale. In this study, we found that the prevalence of moderate total stigma (>2.5 scores) was 2.7%. This is much lower compared to other studies like 70% reported in Egypt, 46.7% in Ethiopia, 40% in Iran, 36% in the USA, 34.1% in India, 22.5 % in Nigeria.[10,22-25] This lower prevalence of stigma among study subjects can be because in this study we studied mentally ill patients who were registered under a rural mental health program and they are contacted by mental health professionals including psychiatrists, general practitioners, and health care workers. In these services, programs are geared to minimize stigma in many ways; such as like weekly clinics, cross consultation with other specialty services, provision of psychiatric medications, counselling services, follow-up sessions, home visits, health education about the mental illness and treatment, role plays to envisage the common myths about mental illnesses and empowerment initiatives. In this study we found gender (female) to be playing a major role in stigma with regards to domains of alienation, stereotype endorsement, and social withdrawal. This observation of ours is consistent with the studies done in Pakistan.[26] This finding is an obvious fact, as in rural India, women are discriminated against than men due to gender-related biases which were reflected in the psychiatric patients also. In our study with regards to marital status and stigma, we found widows and separated subjects (male and female) experienced higher stigma. This observation of ours is in congruence with a study where it was found that mentally ill patients usually would be isolated ending up being separated. Many studies have concluded that a higher rate of mental illness exists among the widowed than their married counterparts.[27,28] In this study we didn't find any association between stigma domains and age, education, occupation and socioeconomic status of the population. However there are studies which showed association between education and perceived stigma which showed that the lower the education higher the level of stigma.[29] The probability of there being no higher stigma in our study population could be because of the constant and sustained community mental health outreach work undertaken by the rural mental health programme of the institution. According to this study the mean±standard deviation of each domain of QOL was as follows; physical domain 52.25±13, psychological domain 51.81±13.12, social relationship 38.59±13.64, Environment domain 46.71±14.39 respectively. The mean scores of domains are lower compared with a study was done in panic disorder patients [30] were quality of life domain scores: physical 57.86±17.56; psychological 56.04±18.31; social 56.25±25.92; and environmental 47.03±16.92 respectively and also with a study done among epileptic patients were the mean scores in the physical, psychological, social, and environmental domains were 55.7, 37.92, 57.75, and 50.56, respectively.[31] This difference can be because the study

population was a mixed population with multiple psychiatric disorders ranging from anxiety disorder, panic disorder, alcohol dependence, depression, epilepsy, schizophrenia, and psychosis. In the mean scores, the score of social domains was much lower compared to the other studies which signify the socially isolated nature of mentally ill persons.

In this study we found that there is a significant association between quality-of-life domains and occupation, i.e., subjects belonging to the occupation of business has more quality in physical, environmental, social relationship, and psychological domain. This result is similar to a study done in south India among epilepsy patients which showed that patients who were not preoccupied with work had a lower level of quality of life.[32] The reason for this finding can be attributed to the fact that mentally ill persons will be having disturbed psychomotor activities contributed to reduced quality of life in all domains. In this study, we found that there is an association between all domains and marital status, i.e. high quality of life is experienced in the social relationship domain among separated people and widowers in other domains. This finding is similar to studies which showed that currently married status leads to a reduced quality of life.[31-33] In this study we found significant association between QOL domains and age categories, i.e., the subjects belonging to age group of 20-34 years are experiencing increased quality of life in physical, psychological and social relationship domain. Also, subjects belonging to 35-60 years are experiencing increase quality of life in environment domain. This result is comparable with studies done showing increasing age shows poorer quality of life. This can be due to the fact that after a particular age a person's life will be influenced by many responsibilities which lead to a decrease in quality of life.[31,32] With increasing age, the stigma in society regarding job opportunities and social life may manifest, and hence the poor QOL.

In this study we found that there is a positive association between all the domains and education of the population, i.e. the more the education the more the quality of life in all domains. This is similar to many studies which showed that higher the education levels higher the quality of life. In this study we found that there is significant association between SLI and all QOL domains.[33,34] The high SLI category subjects, i.e., belonging to higher socio-economic status also experience high quality in all domains. This result is similar to a study which showed that higher the income higher the quality of life.[32]

The reason for this fact can be due to the fact that a person with higher income can be able to avail all the prosperities of life in all aspects, physical, social and environmental. The study showed nil significant relationship among the variables like stigma and QOL. But many studies have showed raised self-stigma reduced the QOL which makes the patient discontinue or interrupt the treatment without doctor's orders.[6-8,35,36]

Limitations

The cross-sectional design of the study might have limited in assessing the change of behaviours over a particular period or due to any events. Assessment of social or applied stigma and categorization based on severity of disease were lacking in the study.

CONCLUSION

In this study we found that prevalence of stigma among the patients was less. Subjects belonging to younger age and higher socioeconomic status were experiencing a higher quality of life.

Recommendations

The health practitioner can simplify the medication regimen for the patient to accommodate multiple medications in their life. The next step can be by imparting appropriate knowledge and enhancing patient education by utilizing a variety of approaches, such as culturally relevant, language-specific patient education materials and literature appropriate for the patient's level of reading. A sincere attempt can be done in modifying the patient's beliefs, through awareness campaigns and health education sessions. Other than the education and advocating strategies, contact strategies which consist of increasing interpersonal contact between members of the public at large and individuals with behavioral health conditions. In our setup, this can be achieved by health workers and link workers like ASHAs and ANMs. The use of peers and policy changes in minimizing stigma also can be tried. Longitudinal and qualitative assessment to collect more granular data about the influence and relation of stigma and quality of life should be done to analyze the trends and perceptions about the concerned issue.

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