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A DESCRIPTIVE STUDY TO ASSESS SOCIAL FUNCTIONING AND INTERNALIZED STIGMA AMONG PATIENTS WITH MENTAL ILLNESS WITH A VIEW TO PREPARE GUIDELINES ON HEALTHY LIVING IN SELECTED HOSPITALS OF JALANDHAR, PUNJAB

[1*]Sujata Thakur and [2]Baljinder Kaur

[1] Student of M.sc Nursing II year in MHR DAV Institute of Nursing, Jalandhar, Punjab
[2]Associate Professor, MHR DAV Institute of Nursing, Jalandhar

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Corresponding author

ABSTRACT

A quantitative research approach and descriptive research design was used and research setting comprised of Civil Hospital, Jalandhar, Punjab and Ashoka Neuro Psychiatric Hospital & De-addiction Centre, Jalandhar, Punjab. The study sample comprised of 60 patients with mental illness. Purposive sampling technique was adopted to select sample. Self structured rating scale containing 24 items and self structured likert scale containing 30 items was used to evaluate the social functioning and internalized stigma respectively among patients with mental illness. Results depicts that mean social functioning score among patients with mental illness was 28.20 and mean internalized stigma score among patients with mental illness was 47.38. Hence, it was inferred that patients with mental illness had average social functioning and moderate internalized stigma.

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INTRODUCTION

"Reshape yourself through the power of your will …"

Bhagavad Gita.

Mental illness is not a rare phenomena; it is common to all countries and causes immense suffering to those who live with the illness, to the family members as well as to the community at large. It constitutes one of the major global burdens of disease. Mental illness is any disease or condition that influences the way a person thinks, feels, behaves, and/or relates to others and to his or her surroundings. Although the symptoms of mental illness can range from mild to severe and are different depending on the type of mental illness, a person with an untreated mental illness often is unable to cope with life's daily routines and demands. (Alem A, 2000).

Many people with serious mental illness are challenged doubly. On one hand, they struggle with the symptoms and disabilities that result from the disease. On the other, they are challenged by the stereotypes and prejudice that result from misconceptions about mental illness. As a result of both, people with mental illness are robbed of the opportunities that define a quality life: good jobs, safe housing, satisfactory healthcare, and affiliation with a diverse group of people. (Corrigan and Watson, 2002). Mental illness does not discriminate. It can affect people of any age, income or educational level, and cultural background. Although mental illness affects both males and females, certain conditions such as eating disorders tend to occur more often in females, and other disorders such as attention deficit hyperactivity disorder (ADHD) more commonly occur in children. What makes it worse; people with mental illness are one of the most stigmatized groups of people throughout the world. Scholars in the field of stigma used the analogy of „double edged sword"

or „double headed snake "to describe the two fold challenges of people with mental illness i.e. the struggle with the symptoms and disabilities on the one hand and the widespread stigma towards their illness on the other. The public attitude towards mental illness is often discriminatory and largely based on wrong, exaggerated and biased portrayals of Medias about people with mental illness. This stereotypical and discriminatory attitudes often manifests itself in the form of internalized or self-stigma, a condition in which people with mental illness begin to internalize stigmatizing and stereotyping beliefs about themselves and starts to act accordingly. (Thornicroft, G 2006)

Need of the study

Mental illness is a global public health concern. According to the World Health Organization, one out of four (25%) persons is affected with some kind of mental illness. The prevalence of mental disorders is higher in developed countries, but the global burden of untreated mental disease is higher in developing nations. Eighty percent (80%) of the population suffering with mental illness lives in low-and middle-income (LAMI) countries .The presence of mental illness does not affects only the individual and his personal, social, educational and occupational life, but it also makes his entire family to suffer from negative consequences. (Lakhan R, Ekundayo O, 2015).[12]

In Punjab, One out of eight Punjabis is suffering from mental illness and 80% Punjabis are not getting any access to treatment.This has emerged in the National Mental Health Survey: Punjab (2016-17). A total of 2,895 adult population from four districts - Faridkot, Ludhiana, Moga, Patiala of Punjab were enrolled for the survey, which was completed in six months, August 2015, April 2016. It was found that every 6th Punjabi has suffered from mental illness and every 8th is still suffering. The survey found that in Punjab, the total lifetime prevalence of mental illnesses was 18% (national level: 13.6%) and the current prevalence was 13% (national level: 10.5%). "It means, there are nearly 21.9 lakh people suffering from mental illness in Punjab. Only 20% of them (4.38 lakh) have access to treatment and rest 80% are not getting any treatment," said Dr. BS Chavan, head, psychiatry department, GMCH-32.The survey mentions that treatment gap was 80% for common mental disorders, 57% for severe mental disorders, 81% for alcohol use disorders and 82% for depressive disorders. Nearly 0.5% of the population surveyed people have suicidal risk. (Sethi A, 2017).[13]

During my clinical posting I have seen and observed that people with mental illness do not want to disclose their illness because of stigma. They think that other people will make them feel ashamed because of their mental illness. The patients are having internalized stigma of their mental illness and so they are not interacting much with others and withdraw themselves from society, which critically affects their social functioning. Hence the researcher decided to undertake this study to assess the social functioning and internalized stigma among patients with mental illness.

Objectives of the study

1. To assess social functioning among patients with mental illness.
2. To assess internalized stigma among patients with mental illness.
3. To analyse the association of social functioning among patients with mental illness with their selected socio demographic variables.
4. To analyse the association of internalized stigma among patients with mental illness with their selected socio demographic variables.
5. To prepare and distribute guidelines on healthy living for patients with mental illness.

Delimitations

The study will be limited to:

- 60 patients suffering with mental illness (F20-F39).
- patients above 18years of age.
- patients in recovery phase of mental illness.

Review of Literature

Review of literature is a key step in research process. It makes to the knowledge, insight and general scholarship of the researcher. It is an extensive, exhaustive and systemic examination of publications relevant to the research project.

It consists of following aspects:

- Studies related to social functioning
- Studies related to internalized stigma
- Studies related to attitude towards mental illness

Studies related to social functioning

Deppa C A, Mausbacha B T, Harveyb P D, Bowiec C R, Wolyniecd P S, Thornquistd M H et al (2013) In this cross-sectional study, 164 subjects with bipolar disorder were administered the performance-based Social Skills Performance Assessment (SSPA), rated by an informant on the Specific Level of Functioning (SLOF)–Interpersonal subscale, received clinical ratings of depression and manic symptoms, and performed neurocognitive tests. Impairment in social functioning appears to be common in bipolar disorder objective was to examined performance-based and observer-based ratings of social competence and functioning and assessed the contribution of symptoms and neurocognitive ability to social functioning in bipolar disorder.Mean age of the sample was 47.6 years (SD = 14.1). Subjects were experiencing, on average, mild levels of depression and minimal manic symptoms. A total of 29% exhibited norm referenced impairment on the SSPA, and 64% registered at least one impairment on SLOF items; unemployed subjects had lower SSPA and SLOF ratings A subgroup of outpatients with bipolar disorder has impaired social competence.

Studies related to internalized stigma

James T (2013) conducted a cross sectional survey among 290 patients (18 years or above) with mental illness attending the follow-up outpatient clinics of the government Mental Health Centre and 13 randomly selected mental health integrated primary care clinics in Trivandrum district, Kerala. Study aimed to examine the prevalence and factors associated with high internalized stigma among patients with mental illness and to compare the prevalence between the community based care and psychiatric hospital based care. A pretested

interview schedule and an adapted Malayalam version of Internalized Stigma of Mental illness Inventory (ISMI) were used for data collection. A multivariate model was developed to identify the factors associated with internalized stigma. The prevalence of high internalized stigma in the total sample was 36.2 percent, which was significantly higher among patients from community-based care (42.1 percent) as compared to those from psychiatric hospital-based care (29.7 percent), p=0.028. Treatment in community-based care (OR 1.92, 95 percent CI: 1.07-3.45), unemployment (OR 2.18, 95 percent CI: 1.21-3.92), absence of long-term friendship (OR 2.50, CI: 1.42-4.42), no hope of cure with medication (OR 3.63, CI: 1.66-7.91), no change in job after having mental illness (OR 1.82, CI: 1.04-3.26), family history of mental illness (OR 1.85, CI: 1.05-3.23), presence of other illness (OR 2.13,CI: 1.11-4.17) and number of hospitalizations due to mental illness ≥4 (OR 1.93, CI: 1.05-3.55) were significantly associated with high internalized stigma. The Malayalam version of ISMI had a Cronbach's alpha of 0.90, split half reliability of 0.86, and a construct validity of -0.16, p=0.006.The prevalence of internalized stigma was high.

Studies related to attitude towards mental illness

Kumar R (2013) the survey was conducted in month of March-May 2012 in selected rural and urban community of district Amritsar, Punjab India, to assess attitude of rural and urban community people towards mental illness .A cross sectional survey was carried out among randomly selected rural and urban community people (N=200). Data were collected through face to face interview, using a structured rating scale. Data was analyzed and interpreted by using descriptive and inferential statistics. Findings revealed that the urban community subjects" shows more positive attitude than rural people to the statements i.e. If mental health facility is set up in my street or community, I will move out"(x^2=29.81,P<0.000), "It is not appropriate for a person with mental illness to get married (x^2=12.795, P<0.012), "People with mentally ill should not have children" (x^2=29.091, P<0.000), 'There is no future for people with mental illness' (x^2=30.877,P<0.000, 'Corporations and the community should offer jobs to people with mental illness' (x^2=19.293, p<0.001),'It is harder for those who have illness to receive the same pay for the same job'(x^2=61.668, P=0.001).The study findings suggest that there is a need to improve the knowledge of community people regarding mental disorders and its related aspects. The government initiatives should also strengthen to disseminate the informations related to mental health and mental illness for better utilization of mental health services.

Description of tool

The tool consists of three parts:

Part-I: - This part includes socio-demographic variables of the participant. Socio-demographic variables include age in years, gender, religion, education, occupation, income per month, marital status, type of illness, duration of illness and number of previous treatments.

Part-II: - This part includes rating scale to assess social functioning among patients with mental illness. It includes 24 items. This scale had 10 negative items (1, 12, 13, 16, 17, 18, 20, 21, 22 and 23) and 14 positive items (2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 14, 15, 19 and 24). The responses to the items were categorized into three: always, sometimes, never. The positive items were scored 2, 1, 0 for always, sometimes, never respectively. The negative items were reversely scored. The maximum possible score of the tool was 48 and minimum score was 0. A total score of 44-48 indicates very high social functioning, 35-43 indicates high social functioning, 25-34 indicates average social functioning and up to 24 indicates low social functioning.

Part-III: - This part includes likert scale to assess internalized stigma among patients with mental illness. It includes 30 items. This scale had 21 negative items (1, 2, 3, 4, 5, 6, 8, 9, 11, 12, 13, 14, 17, 18, 21, 22, 23, 26, 28, 29 and 30) and 9 positive items (7, 10, 15, 16, 19, 20, 24, 25 and 27). The responses to the items were categorized into four: strongly agree, agree, disagree, and strongly disagree. The positive items were scored 3, 2, 1 and 0 for strongly agree, agree, disagree, and strongly disagree respectively. The negative items were reversely scored. The maximum possible score of the tool was 90 and minimum score was 0. A total score of 0-45 indicates mild internalized stigma, 46-72 indicates moderate internalized stigma and 73 and above indicates severe internalized stigma.

Content validity

Validity of the tool was confirmed by expert's opinion regarding the relevance of items. The tool was circulated among experts from the field of Psychiatry, Psychiatric Nursing and Psychology. According to their valuable suggestions modifications were made in the tool. A language expert translated the modified tool into Punjabi. Validity of the guidelines was confirmed by experts.

Pilot study

After obtaining formal approval from the Senior Medical Officer, Jalandhar the pilot study was conducted at Civil Hospital in month of January 2017 to ensure the reliability of the tool and feasibility of the study. 10 patients with mental illness (F20-F39) were chosen by purposive sampling technique. Purpose of the study was explained to the subjects, and they were assured about anonymity and confidentiality of the information provided by them and verbal consent was taken from those who were willing to participate in the study. Structured interview technique was adopted to collect the data from patients. The sample selected for pilot study was excluded in the actual study. The pre testing of the self-structured rating scale and likert scale was done to check the clarity of the items, their feasibility, reliability and practicability. All the items in the tool were clear to the subjects. The collected data was analyzed by using descriptive and inferential statistics. The study was found feasible. This plan of data collection was finalized for the main study as the investigator didn't face any major problem while conducting the pilot study.

Data collection procedure

Final data was collected in Ashoka Neuro Psychiatric Hospital and De- addiction Centre and Civil Hospital, Jalandhar from 1st February 2017 to 28th March 2017 after getting administrative approval. Written permission was taken from the higher authorities of selected hospitals. Total 60 patients with mental illness who fulfilled the inclusive criteria were

selected as sample using purposive sampling technique. Self-structured rating scale was used to assess the social functioning and likert scale was used to assess the internalized stigma among patients with mental illness. Data was collected from patients with mental illness who came for follow up visits or those admitted for treatment of mental illness and in recovery phase. Structured interview technique was used to collect information. Time taken to conduct interview sessions for each patient was 40 to 45 minutes. As the patients use to come to the reception (Psychiatric department), researcher use to see his/her diagnose in the treatment card and if the patient was diagnosed according to ICD 10 between F20-F39 then researcher use to select that patient as subject for the present research study. Then the selected patient used to be explained about the study and if willingness from his/her side was obtained then the researcher use to take verbal consent by assuring about anonymity and confidentiality of the information provided by them and use to include that patient as subject for the study. The interview session use to be conducted in the waiting area of the OPD for the outpatients and for the inpatients, in the ward. From the inpatient, only one patient stopped answering in between and refused to continue the interview, therefore that patient was not included in the study. From the outpatient one patient refused to participate in the study, so that patient was not included in the study. All other patients were willing to participate and almost all the patients (approx.90%) become emotional (some even started weeping) during the interview and felt relaxed that at least somebody tried to understand them and their problems. The collected data was then organized for analysis.

Ethical consideration

- Ethical clearance was taken from the ethical committee of MHR DAV Institute of Nursing, Jalandhar.
- Ethical clearance was taken from the higher authorities of the selected hospitals of Jalandhar.
- Verbal consent was taken from the patients before conducting the study.

Plan of data analysis

Analysis and interpretation of data was done according to objectives by using descriptive and inferential statistics. Frequency and percentage distribution were used to analyze the socio-demographic variables of patients. Mean and Mean Percentage were used to assess social functioning and internalized stigma among patients with mental illness. Chi-square test was used to find the association of social functioning and internalized stigma among patients with mental illness with their selected socio demographic variables.

Major Findings

Section I: Analysis of socio demographic variables.

33.33% (20) patients with mental illness were in age group 40-50 years, 68.33% (41) were females, 71.67%(43) belonging to Hindu religion, 55.00% (33) patients with mental illness had education up to 10^{th} standard, 55.00% (33) were non employed/homemaker, 60.00% (36) patients had 5000-10,000 family income per month (in Rupees),73.33% (44) were married, 33.34%(20) were suffering from recurrent depressive episode (F33), 65.00% (39) had duration of illness <5 years and 46.66% (28) had <5 number of previous treatments.

Section II: Assessment of social functioning among patients with mental illness.

Objective 1: To assess social functioning among patients with mental illness.

- Mean social functioning score was 23.20 and mean percentage was 58.75%
- 65.00% (39) patients with mental illness had average social functioning.
- **Section III:** Assessment of internalized stigma among patients with mental illness.
- **Objective 2:** To assess internalized stigma among patients with mental illness.
- Mean internalized stigma score was 47.38 and mean percentage was 52.64%
- 55.00% (33) patients with mental illness had moderate internalized stigma.
- **Section IV:** Association of social functioning with socio demographic variables by using chi square test.
- **Objective 3:** To analyze the association of social functioning among patients with mental illness with their selected socio demographic variables.
- All socio demographic variables were found to be not significant at $p<0.05$ level of significance. This that there is no association of social functioning among patients with mental illness with their selected socio demographic variables.
- **Section V:** Association of internalized stigma with socio demographic variables by using chi square test.
- **Objective 4:** To analyze the association of internalized stigma among patients with mental illness with their selected socio demographic variables.
- Socio demographic variable occupation was found to be statistically significant at $p<0.05$ level. This shows that patients with mental illness doing private job had more internalized stigma.
- Socio demographic variable number of previous treatments was found to be statistically significant at $p<0.05$ level. This shows that patients with less than 5 previous treatments had more internalized stigma.
- Other socio demographic variables were found to be non significant at $p<0.05$ level of significance

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