MANAGED BY JOURNAL OF PSYCHOLOGICAL MEDICINE AND RESEARCH ISSN: 0253-7176

INDIAN JOURNAL OF Vol 41 • Issue 5 • September/October 2019 • www.ijpm.info

PSYCHOLOGICAL MEDICINE

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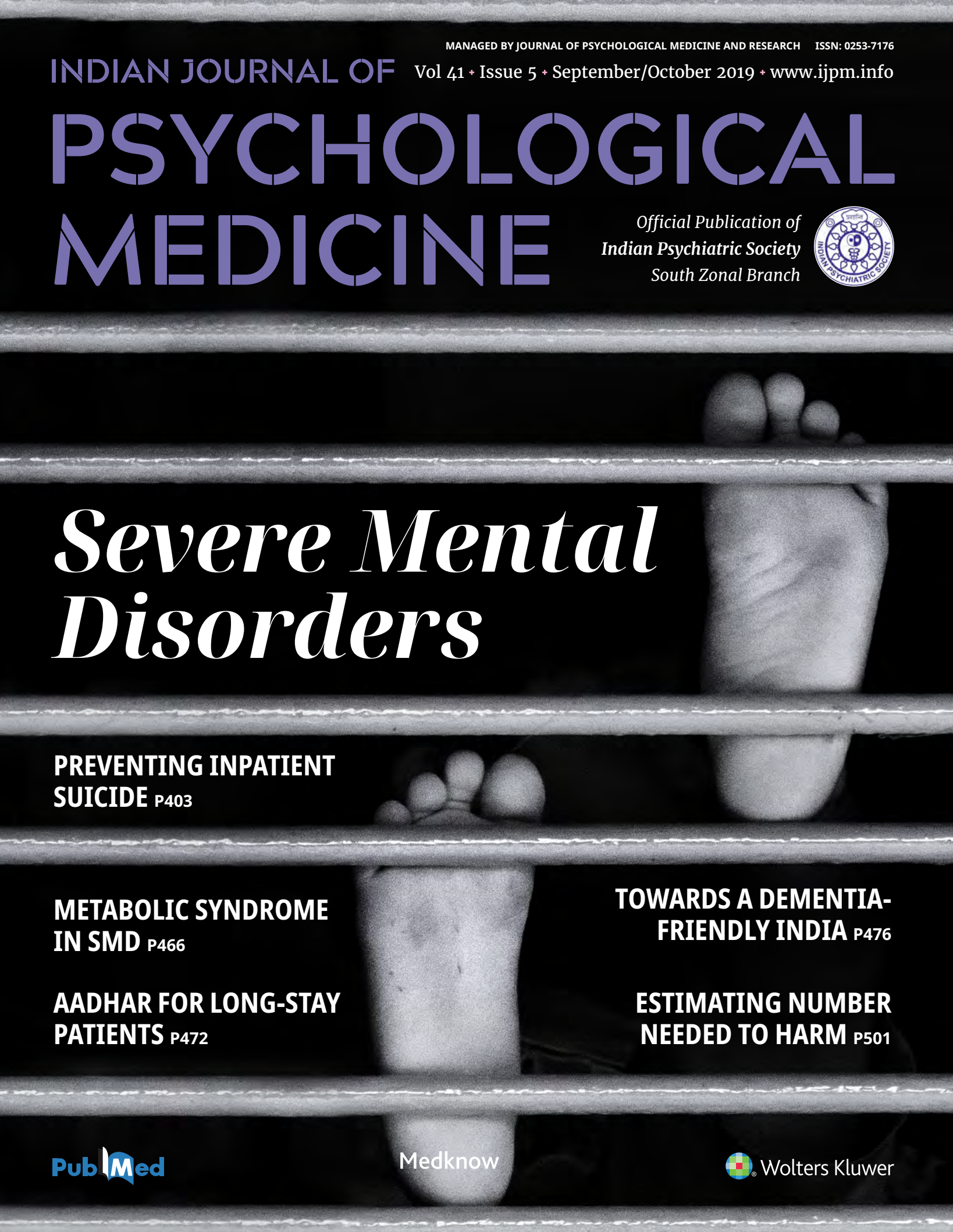

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INDIAN JOURNAL OF

PSYCHOLOGICAL MEDICINE

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Indian Psychiatric Society
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Indian Journal of Psychological Medicine (ISSN: Print-0253-7176, Online - 0975-1564) was started in 1978. It is a peer-reviewed journal published by Indian Psychiatric Society, South Zonal Branch. Dr. Abraham Verghese, then Professor of Psychiatry at Christian Medical college, Vellore, was the first editor. The journal publishes articles on psychiatry, psychology and allied disciplines. It is published bimonthly in January, March, May, July, September and November.

Abstracting and indexing information

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Published by
Wolters Kluwer India Private Limited
A-202, 2nd Floor, The Qube,
C.T.S. No.1498A/2 Village Marol, Andheri (East),
Mumbai - 400 059, India.
Phone: 91-22-66491818
Website: www.medknow.com

Printed at
Nikeda Art Prints Pvt. Ltd.,
Bhandup (W), Mumbai - 400078, India.

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Volume 41 | Issue 5 | September-October 2019
(Volume 9 | Issue 5 as per RNI Registration no. MAHENG/2011/38799)

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Review Article

Suicide Prevention Strategies for General Hospital and Psychiatric Inpatients: A Narrative Review

Karthick Navin, Pooja Patnaik Kuppili[1], Vikas Menon, Shivanand Kattimani

ABSTRACT

Background: In-patient (IP) suicides contribute a small but significant proportion of overall suicides. Despite this, suicide prevention strategies focusing on the general hospital IP population remain relatively underresearched. This paper is intended to provide an overview of various proposed suicide prevention approaches in the general hospital, including psychiatric IP, settings, and their evidence base. **Methodology:** Electronic searches of MEDLINE through PubMed, ScienceDirect, and Google Scholar databases were performed to identify potentially relevant articles from inception till January 2019. The generated abstracts were systematically screened for their eligibility to be included in the review. Included articles were grouped under five broad themes: environmental modification, staff education, pharmacotherapy, psychotherapy, and brain stimulation. Data extraction was done using a structured proforma. **Results:** Environmental modifications and educating the health care professionals appear to be the most promising strategies to reduce suicide-related mortality among IPs. Among pharmacological methods, ketamine has shown initial promise in reducing suicidal ideations. Follow-up data are lacking for most of the described methods. Limited but positive evidence exists for cognitive therapies focusing on the immediate postadmission period and brain stimulation techniques, and it warrants further replication. **Conclusion:** There is a striking paucity of original research on IP suicide prevention. Given the ethical and methodological issues in carrying out studies with IP suicide as the primary outcome, there is a need to focus on intermediate suicide outcome measures, such as knowledge, attitude, and skills among staff handlers of suicidal patients.

Key words: *In-patient suicide, psychiatry, review, suicide, suicide prevention*

Suicide in the in-patient (IP) setting is considered as a "sentinel event," an event though not a fallout of the natural course of the illness but nevertheless causes harm to the patient.[1] It is often considered to be preventable and is associated with serious outcomes. Oehmichen and Staak defined IP suicide in a psychiatric setting as "suicide of a patient during IP

Access this article online	
Website: www.ijpm.info	Quick Response Code
DOI: 10.4103/IJPSYM.IJPSYM_169_19	

How to cite this article: Navin K, Kuppili PP, Menon V, Kattimani S. Suicide prevention strategies for general hospital and psychiatric inpatients: A narrative review. Indian J Psychol Med 2019;41:403-12.

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Received: 03rd April, 2019, **Accepted:** 18th June, 2019

treatment, both inside and outside the hospital setting, e.g. during a leave, an outing, a trial discharge, or a stay in another hospital with concurrent IP psychiatric treatment."[2] Large-scale data about IP suicides are mainly from western countries. Hanging is the most common method of IP suicide.[3,4] However, in a study from the West, jumping from altitude was the most common method.[1]

National Violent Death Reporting System and Joint Commission's Sentinel Event records that out of suicides over a period of 1 year (2004–2005), 75% happened during psychiatric IP treatment, and 48.5–64.9 IP suicides occurred annually. A 10-year retrospective chart review from forensic medicine records noted that nearly three-quarters of IP suicides within the hospital were carried out by incomplete hanging and the other common means were jumping from altitude and poisoning.[5]

IP suicides comprised 2.5% of all suicides in the United Kingdom (UK), and the incidence was found to be about 1.24/1000 IP discharges.[6] In Finland, the incidence of IP suicides was found to be about 3 per 1000 admissions over an 11-year period as per a retrospective chart review carried out at a general hospital psychiatric IP setting.[7] These data are comparable to older data on incidence rates from Europe.[8] In Taiwan, the standardized IP suicide mortality ratio was found to be 8.25, which was higher compared to the rates for the general population.[9]

Several factors have been found to be closely related to IP suicide. Among Taiwanese IPs, younger females and older males had a higher risk of suicide attempts and suicide-related mortality, respectively.[10,11] History of suicide attempt/deliberate self-harm, family history of suicide, mood disorder, schizophrenia, ideas of hopelessness, guilt, and current suicidal ideation have been identified as risk factors for IP suicides.[12] A qualitative study noted that having a psychiatric illness, perceived serious illness, incurring high medical expenses, poor social support, and unsafe IP environment were the themes associated with a high risk of suicide.[13]

The risk of suicide was found to be the highest immediately following admission as well as immediately after discharge. It was found to be inversely related to the length of stay. IP suicides outside the hospital were commonly found to occur during a leave of absence or transfer to another hospital.[8] Further, IP suicides have been found to be secondary to inadequate staffing/resources as well as an increased number of patients with severe mental illnesses.[14]

Given the evidence, the period of IP care is clearly associated with a high risk of suicide. Consequently, suicide prevention among IPs assumes significance both from an individual as well as public health standpoints. Thereby, it is necessary to synthesize evidence base for interventions aimed at preventing IP suicides to guide clinicians and researchers alike. With this background, this narrative review attempts to provide a comprehensive overview of major methods of suicide prevention among general hospital IP population.

METHODOLOGY

Search Strategy and study selection

Electronic searches of MEDLINE through PubMed, Google scholar, and ScienceDirect databases were carried out from inception till January 2019. Search terms included combinations of following medical subject headings or free text terms: "suicide prevention," "IP suicide," "nursing staff," "education," "intervention," "cognitive therapy," "environment," "prevention," "risk reduction," "psychotropic medication," "pharmacological," and "psychosocial intervention". Since there was no definition available for IP suicide in the medical/surgical setting, IP suicide in this review has been defined as "suicide of a patient during IP treatment occurring in a psychiatric or medical/surgical setting" based on the definition by Oehmichen and Staak.[2] Inclusion criteria were articles published in peer-reviewed English language journals.

The search was carried out independently by two authors. The final articles to be included in the review were decided by discussion and consensus among the authors.

The initial search yielded 880 articles. Further, the references in these articles and abstracts were screened manually to identify potentially relevant articles. Conference proceedings were not included in the review. The study selection is depicted in Figure 1.

Data extraction

Upon literature search, we observed that the existing literature could be categorized into the following five broad categories: environmental modification, staff education, pharmacological interventions, psychological interventions, and brain stimulation. Hence, the results are being presented under these headings. In the case of original articles, data extraction was done using a structured proforma and included details of the name of the author, year of publication, type of intervention, and chief outcome [Table 1].

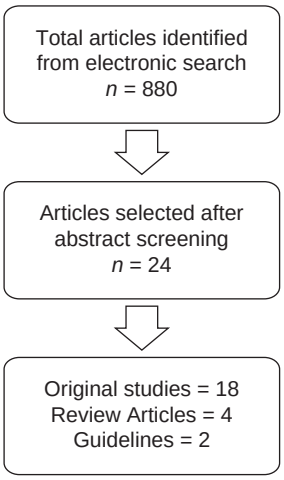

Figure 1: Study selection process

RESULTS

A total of 24 articles were obtained, out of which 18 were original studies conducted in an IP setting. There were four reviews and two guideline/recommendation documents. The preventive measures are elaborated below.

Environmental modification

Often, risk factors associated with the physical environment are neglected because these do not usually find a place in the routine medical education curriculum.[15] Measures of environmental modification can be categorized into two groups - (i) environment-specific and (ii) patient-specific precautions.

Environment-specific precautions

A few studies have demonstrated positive outcomes following environmental modification strategies in the hospital setting [Table 1]. In 2007, the Department of Veteran Affairs, USA developed a checklist termed Mental Health Environment of Care Checklist (MHEOCC). This checklist was developed by a multidisciplinary team of mental health care professionals, engineers, and architects. The final checklist contained 114 items after a comprehensive review by the team. Main components included environmental modifications in the psychiatric intervention rooms and hospital restrooms, such as minimizing fixtures, avoiding ligature points, and reducing breakable and pointed objects. The detailed description and other guidelines regarding the MHEOCC are provided at www.patientsafety.va.gov/professionals/onthejob/mentalhealth.asp. Following its implementation in veteran hospitals, sustained reductions in suicide rates were noted.[16,17] One study reported that installing a metal rail in the windows significantly reduced the rate of a jump.[18]

Patient-specific precautions

No original studies have systematically evaluated the effect of patient-specific precautions on suicidal behaviors. However, patient-specific precautions recommended include routine room searches, planned observations or supervisions, and supervised medication administration. Methods of supervision described ranged from continuous one-to-one supervision to supervising every 15–30 min as well as restricting the movement of patients.[19] Hospital staff such as nursing and housekeeping personnel need to be trained to ensure the safety of cleaning fluids, medicine carts, etc. Further, visitors must be screened for potentially lethal objects such as ropes and bags.[15]

Four levels of supervision, matched to the level of risk, have been described in the literature. Level 1 refers to general observation, wherein the patient's location must be known to the nursing staff at all times. Level 2 refers to intermittent observation. Here, the patient must be checked every 15 min. Level 3 is defined as within eyesight. Level 4 is for those at the highest risk of self-harm, and nursing staff is supposed to be available at "arm's length."[20,21] However, there is no literature available on the outcomes associated with each of these methods of supervision in the hospital setting.

Staff education

Relationship between the hospital staff and patient is one of the modifiable links which might promote patient wellbeing. Studies have highlighted the inadequacy of and the need to improve skills in handling suicidal patients.[22] Lack of skills in caring for suicidal patients, a negative attitude of the staff, and low staffing are some of the staff-related barriers to suicide prevention.[23,24] Educating the hospital nursing staff can help in preventing IP suicides by increasing their knowledge, attitude, and confidence levels in handling suicidal patients.[23,25]

Several reports on staff education programs for IP suicides are available.[23,25-29] Components of the education programs included classes on IP suicide prevention, training activities for mental health staffs, poster campaign on IP suicide prevention, and skills training as a part of the Skills Training on Risk Management (STORM) project. The STORM training package included modules on assessment, crisis management, problem-solving, and crisis intervention.[27] Except for one Belgian study,[29] all other available studies reported positive change in attitude and knowledge. However, there have been no studies assessing the effect of staff education programs on the rate of IP suicides.

Negative change in the attitude toward prevention of suicide can happen in staff following an in-hospital suicide. This can lead to disruption in coping and

Table 1: Summary of presented studies

Author	Sample/study characteristics	Intervention	Chief findings
Environmental modification			
Watts *et al*. (2012)[16]	IPs at VA hospital	Implementation of MHEOCC in 2007	Reduction in suicide rates from 2.64/100 000 IP mental health admissions before 2007 to 0.87/100 000 admissions during implementation period (2008-2011)
Watts *et al*. (2017)[17]	IPs at VA hospital	Implementation of MHEOCC during 2007-2010	Suicide rate decreased from 4.2/100,000 admissions prior to implementation to 0.74/100,000 admissions in continuation period 2011-2015
Mohl *et al*. (2012)[18]	General hospital in a high-rise building	Installing metal rails to prevent jumps	Reduction in jumps from 10/119,269 patients in 114 months prior to installation to 2/104,435 during the 78 months following installation
Staff education			
van Landschoot *et al*. (2017)[29]	1171 staff in emergency and psychiatry department	Poster campaign offering information on identifying and responding to high risk patients was displayed for four weeks	No significant change in attitude was noted at four weeks compared to baseline Higher knowledge scores at baseline was considered as the possible reason
Manister *et al*. (2017)[25]	577 nursing staffs	One-hour class on IP suicide prevention which was repeated 40 times	Significant improvement in knowledge and confidence in handling IP suicidal behaviour was found four weeks after the class
Inga-Lill Ramberg *et al*. (2016)[23]	500 mental health staff: Psychiatrists, doctors under training, nursing staff, contact persons, psychologists, physical therapist, occupational therapist	Mandatory suicide prevention training activities	Significant improvement was noted in attitudes towards prevention of suicide and clarity and confidence regarding the role of participants in suicidal IPs
Gask *et al*. (2006)[27]	458 community mental health workers, IP mental health staffs, crisis service staffs	STORM	Positive changes in attitudes and confidence was noted but previous evidence of skill acquisition was not replicated immediately after and 4-month post training compared to baseline
Appleby *et al*. (2000)[26]	359 health personnel belonging to primary care, accident and emergency departments and mental health services	STORM	Feasibility of conducting such an intervention was demonstrated. After six months of intervention, significant improvement in terms of skills pertinent to assessment and management of suicide risk was noted. It was projected that the intervention could be cost effective by reducing suicide rate by 2-5% and preventing ≤99,747 per suicide and gain of ≤3391 per life year
Morris *et al*. (1999)[28]	33 Non-psychiatrically trained staff (health and voluntary workers)	Eight hours of interview skills training	Confidence and skills for problem solving, future coping, and provision of immediate support improved significantly at one month after training.
Pharmacological intervention			
Modestin *et al*. (2005)[43]	Chart review of 94 IP records	Clozapine for at least six weeks	Rate of suicidal behaviour reduced from 28% in pre-clozapine period to 3% during clozapine period and 18% in post-clozapine period
Ballard *et al*. (2015)[44]	133 IPs were assessed at 60 min before and at 40,80,120,230 min and 1, 2 and 3 days after infusion	Single subanesthetic dose of ketamine was administered intravenously over 40 min.	Ketamine infusion was associated with significant reductions in suicidal ideation compared to placebo, when controlling for the effects of ketamine on depression
Psychological Intervention			
Ghahramanlou-Holloway *et al*. (2018)[46]	24 IPs admitted with recent suicidal crisis. Randomized to PACT + EUC or EUC alone, 12 in each group	PACT - Six sessions lasting 60-90 min over the course of 3 days	Significant reduction in depression, hopelessness and suicide ideation noted in patients receiving PACT compared to control group
LaCroix *et al*. (2018)[47]	36 IPs admitted following a recent suicidal attempt due to trauma-related diagnoses. Randomized to PACT + EUC or EUC alone	PACT - Six sessions lasting 60-90 min	Clinically significant change in depression and hopelessness was noted, but not for suicidal ideation.
Ellis *et al*. (2015)[52]	52 IPs from a psychiatric hospital who reported some form of suicidality within weeks of admission. Study groups were CAMS-based therapy vs TAU. Nonrandomized comparison study	CAMS based individual therapy	Significant reduction in suicidal ideation and cognition as measured prior to discharge compared to baseline, typical IP stay in the setting being 4-8 weeks

Contd...

Table 1: Contd...

Author	Sample/study characteristics	Intervention	Chief findings
Brain stimulation			
George *et al*. (2014)[53]	42 IPs, with suicidal ideations being the reason for IP care. Randomized to each group, 20 in rTMS and 21 in sham group.	High dose left prefrontal rTMS for 30 min three times for 3 days	Significant improvement in suicidal ideations was noted over 3 days.
Patel *et al*. (2006)[52]	Records of 30 mentally ill IP who were treated with ECT, were examined	ECT with bilateral frontotemporal electrode placement; 5-10 sessions at a frequency of three per week	Significant improvement was noted in suicide and depression scale items of Brief Psychiatric rating Scale-24
Kellner *et al*. (2005)[54]	131 patients expressing suicidal intent	ECT with bitemporal electrode placement	Suicidal intent scores on the item 3 of Hamilton Depression Scale 24 item, decreased from 3-4 to 0 in 80.9% of patients by the end of three weeks (nine ECT sessions)
Sharma (1999)[55]	45 IP records were examined for the use of ECT	Both unilateral and bilateral ECTs were given	Failed to demonstrate that ECT had prevented IP suicide

VA – United States Department of Veterans Affairs; MHEOCC – Mental Health Environment of Care Checklist; STORM – Skills Training on Risk Management; PACT – Post Admission Cognitive Therapy; CAMS – Collaborative and Management of Suicidality; TAU – Treatment as Usual; EUC – Enhanced Usual Care; IP-In-patient; USA – United States of America; UK -United Kingdom

distress. Appropriate assistance should be offered to such personnel in order to regain their confidence.[30,31]

Pharmacotherapy

Positive evidence exists for antipsychotics, lithium, antidepressants, and ketamine in reducing general suicidal behavior. Antipsychotics such as olanzapine and risperidone and antidepressants have shown efficacy for a reduction in suicidal behavior.[32-34] Of these agents, the highest amount of evidence exists for clozapine and lithium.[35-42] However, there are only two studies, one each on clozapine and ketamine, demonstrating their efficacy in reducing suicidal ideation/behavior in the IP setting[43,44] [Table 1].

Psychotherapies

Interventions such as cognitive behavior therapy (CBT) and collaborative assessment and management of suicidality (CAMS) have been reported to reduce IP suicides [Table 1].

i) CBT for suicidal patients:
   The efficacy of CBT in reducing suicidal ideation as well as suicidal behavior in adults and adolescents is well demonstrated.[45,46] With respect to cognitive and behavioral therapies for IP suicides, very few trials could be identified. Postadmission cognitive therapy (PACT) is a model of CBT designed for adults hospitalized following a recent self-harm or suicidal attempt.[47] It consists of six sessions divided into three phases. The first phase focuses on building up a therapeutic alliance, delivering psychoeducation, and framing a cognitive conceptualization of the suicide attempt. The second phase deals with improving coping strategies and problem-solving skills and instilling hope. The third phase comprises relapse prevention and developing a safety plan. We identified two trials that evaluated PACT for the prevention of suicidal behavior in the postadmission acute phase.[48,49] Both the trials reported significant reductions in depression, hopelessness, and posttraumatic stress disorder scores. But, only one of them reported a significant reduction in suicidal ideas.[48] Though this intervention appears promising, it clearly requires further replication
ii) The CAMS is a therapeutic framework that involves active collaboration between the patient and the therapist, using a problem-focused suicide-specific approach.[50] It uses a multipurpose assessment, treatment planning, tracking, and outcome tool called the Suicide Status Form (SSF). SSF assess five central suicide markers, such as psychological pain, stress, agitation, hopelessness, and self-hate.[51] Studies using the CAMS framework among suicidal IPs show significant improvement in suicidal ideation and cognition when compared to treatment as usual group.[52]

Brain stimulation

Repetitive transcranial magnetic stimulation (rTMS) is an emerging biological therapy with growing evidence in reduction of suicidal behavior in IP setting.

A randomized controlled trial showed a rapid decline in suicidal ideation scores following administration of rTMS for 3 days, among IPs admitted due to suicidal ideation or attempt.[53] However, this study was primarily conducted to evaluate the feasibility and safety of rTMS in patients with acute suicidal risk, and therefore, these efficacy results must be considered as preliminary. Adequately powered studies are required to confirm the efficacy of rTMS in mitigating IP suicide risk.

Two retrospective studies and one secondary analysis of a multisite study have assessed the efficacy of electroconvulsive therapy (ECT) on expressed suicidal intent. One of the two retrospective studies[54] on ECT showed improvement in the expressed suicidal intent, whereas the other study did not report any positive findings.[55] Another study, which was a part of consortium for research in ECT project, showed a significant reduction in expressed suicidal intent in a depressed patient by the end of nine ECT sessions over a period of 3 weeks.[56] Both the positive studies did not use specific instruments for suicidal intent but instead analyzed items relevant to suicide intent from other scales.

DISCUSSION

Among various strategies for prevention of IP suicides, it is evident that there is a greater focus on staff education. However, a key challenge with the existing literature is that few papers have studied "direct" markers of suicide prevention, such as a decrease in suicidal behaviors.

Staff education

Staff education measures have included components of psychoeducation and crisis intervention.[25-27] Though the majority of the studies have demonstrated improvement in knowledge, attitude, and confidence of the health professionals after the intervention, there are several issues to be considered. Improvement in attitude and knowledge might not directly translate into an acquisition of skills. Changes in the benefits to users (decrease of suicidal behavior), type of organizational practice, and the behavior of the participants, which are among the highest levels of the outcome of training, have not been assessed. Another challenge is the sustainability and long-term effects of the intervention and lack of support and coordination from the organization, which might limit the translation of the effects of the intervention in clinical practice.[57] Demonstrating the cost-effectiveness of the intervention could also pave the way for better implementation at the organizational level. However, only one study has reported the projective estimates of implementation of suicide prevention education program.[26] Hence, there is a pressing need for more cost-effectiveness studies, apart from providing hard statistics of a decrease in subsequent suicidal behavior. It is also important to interpret the study findings considering the methodological caveats, such as the effect of prior experience with suicidal patients on staff attitude and unaddressed attrition of participants. Further, in some of the studies, the components of "suicide prevention training" provided to staff were not elaborated.[23] There have been no studies on staff education exclusively from the IP setting. There is a need for qualitative studies to assess the perspective of patients as well as health personnel on barriers for formulating effective staff education programs.

Environmental precautions

As of now, the environmental precautions are guided by recommendations from the Western world given for community as well as hospitals alike. There are three studies on environmental modification, especially on environment-specific precautions, which have demonstrated decreased suicidal behaviors. Given the argument that the physical barrier could have merely encouraged the patients to postpone their suicidal plans until discharge, doubts exist about the durability of these approaches on suicide prevention. Notably, there have been no studies reporting cost-effectiveness of such interventions. It is important to note that the recommendations given for environmental modifications in various reviews are not based on original studies conducted in a hospital setting and are rather extrapolated from preventive measures recommended in the community setting.

Patient-related precautions

There have been no original studies on patient-related precautions such as supervision. This is closely associated with issues such as poor staffing as well as sociocultural and ethical issues involved in managing the patient in the least restrictive setting. With regard to observation/supervision, the most important, and often neglected, part is observation with due respect, freedom, and privacy to the patient, which improves patient self-confidence and the overall therapeutic relationship.[58] Apart from focusing on safety from a psychiatrist's point of view, patient's perspectives on suicide prevention also merit an equal place to design strategies with optimal efficacy and uptake. It has been found that three components - connection (comprising of meeting a caring person, being reassured, and feeling acknowledged as a fellow human), protection (being offered protection and support), and control (developing insight, being ready for discharge, and better ways of coping with the symptoms) were vital, considering the patients' experience of safety in IP setting.[59]

Pharmacotherapy, psychotherapy, and others

Majority of the studies that showed evidence for the efficacy of clozapine and lithium have been conducted in the outpatient setting and the benefits accrued over a period of months to years.[60] Hence, the evidence for acute antisuicidal effects of these agents is not clear.

In this regard, ketamine seems to be a promising agent. Ketamine has been shown to have a rapid antidepressant effect in cases of unipolar as well as bipolar depression in numerous randomized controlled studies.[61-63] Meta-analyses demonstrate the rapid

effect of intravenous ketamine in reducing suicidal ideation.[1,64] However, the quality of the evidence was found to be very low.

Though there is only a single study reporting the efficacy of ketamine on suicidal ideation in an IP setting, there are six studies including both outpatients and IPs that demonstrated a positive effect of ketamine on suicidal ideation. The onset of action of ketamine was found to occur within 24 h and to last up to about 1 week to 10 days in studies conducted on patients from both outpatient and IP settings.[65-67] Crucially, there is a paucity of literature on the long-term effects of ketamine on suicidality on both IP and outpatient populations.

The effect of ketamine on suicidal ideation is purported to be independent of the antidepressant action. There are few studies which have assessed the acute antidepressant role of ketamine in IP setting.[68] However, the effect on suicidal ideation was not reported. Hence, there is a need for studies reporting on antisuicidal effects independent of antidepressant action. Overall, there is a lack of clarity on the extent to which the antisuicidal role of ketamine extends beyond its acute effect on decreasing suicidal ideation. Further, the use of ketamine is compounded by drug-specific issues, such as abuse potential, need for repetitive dosing, and durability of action. Clearly, there is a need for more long-term studies to confirm the efficacy and sustainability of ketamine on outcomes of interest.

The role of psychological interventions is also emerging. CBT and dialectical behavioral therapy are among the most researched psychotherapies for reduction of suicidal cognition or behavior.[69,70] There are limited studies conducted in the IP setting in comparison to the vast evidence base of CBT in suicide prevention among outpatients.[71,72] Certain methodological issues are present in the existing studies, such as the differing nature of comparator, not assessing suicidal ideation directly as well as feasibility issues in delivering the intervention at the organizational level.

There is a need for more studies to delineate the role of rTMS in preventing suicidal behavior. ECT is another intervention which has been recommended for a reduction of suicide risk.[73,74] Despite an acute reduction of suicidal intent in ECT-treated IPs,[54,56] these findings are limited by methodological shortcomings, such as retrospective and quasi-experimental designs, failure to use specific scales for relevant suicide constructs, and problems of statistical power with secondary analysis. Further, the stigma associated with ECT and current practice of reserving ECT for the treatment-resistant patients and as a last resort prevent it from being considered as an early treatment option for suicide risk.[75,76]

At whom should be these preventive measures directed?

This is the next logical question and becomes especially pertinent in low-resource settings. Ideally, the preventive measures must be directed to all patients with a high risk of suicide such as those with a history of suicide attempts, recent psychosocial stressors, family history of suicide, psychosis (particularly commanding type of auditory hallucinations) or a mood disorder, and concurrent active suicidal ideation. The most important question would be to enquire about current suicidal ideation.[77] A number of easy to use questionnaires are available for screening patients with high suicide risk.[78] It is important that preventive efforts must start right at the first contact. To achieve this, all medical as well as paramedical personnel must be sensitized toward effective triage, timely referral, and liaison with mental health professionals.

Unaddressed challenges and future directions

There are many unaddressed issues related to IP suicide which needs to be addressed. One of them is the role of psychoeducation of patients and caregivers in IP suicides. Though from anecdotal evidence we know that psychoeducation plays a vital role, further studies are needed to strengthen the evidence of psychoeducation in the prevention of IP suicide. Another crucial factor is the illness-specific factors leading to IP suicide. There is no research on specific strategies for suicide prevention customized for each psychiatric illness. However, lithium and clozapine were reported to decrease suicides among patients with mood disorders and schizophrenia, respectively. Apart from these factors, there is a tremendous need for developing consultation liaison psychiatry services, especially in medical–surgical IP settings for management as well as sensitizing and training of health personnel. In addition, the administration should play an active role in encouraging multidisciplinary liaison across the departments for timely intervention.

When it comes to designing studies on IP suicide prevention, having suicide as a primary outcome becomes a key component but may involve ethical issues. Risk of suicide in the "placebo arm" or the unknown risks with the newly designed intervention are some key ethical considerations. Hence, studies on intermediate outcome measures, such as knowledge, attitude, and skills in handling suicidal patients and psychometric properties of instruments measuring them should be encouraged and focused upon. Evidence from such studies may help us to design and implement more effective strategies to counter IP suicides.

CONCLUSION

Maximum evidence exists for environmental modifications and staff education approaches with regard to IP suicide prevention. There is limited original literature on the role of various suicide prevention strategies in decreasing IP suicidal behaviors. Rather than relying on evidence extrapolated from the community- or outpatient-based studies, there is a need for more studies, with rigorous methodology, from IP settings. Further emphasis must be laid on developing sustainable and cost-effective yet ethical and socioculturally acceptable preventive strategies.

Financial support and sponsorship
Nil.

Conflicts of interest
There are no conflicts of interest.

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Original Article

Perspectives about Illness, Attitudes, and Caregiving Experiences among Siblings of Persons with Schizophrenia: A Qualitative Analysis

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ABSTRACT

Background: Siblings of persons diagnosed with schizophrenia (SPS) are one among the major sources of support for persons with schizophrenia. There is a dearth of psychosocial literature on SPS in India. This qualitative study explored the perspectives about the illness, attitudes, and caregiving experiences of SPS. **Materials and Methods:** Qualitative audio-recorded interviews were conducted with 15 SPS, purposively selected from a tertiary mental health hospital of Southern India. A general inductive approach was adopted to analyze the qualitative data. **Results:** Four broad themes were identified from qualitative data analysis. (1) SPS described several explanatory models of mental illness in terms of causal attributions and treatment care. (2) They had expressed emotion toward their ill siblings, such as criticality, hostility, and emotional over-involvement. (3) They experienced objective and subjective burden while caring for their ill sibling. In spite of all these, (4) they were part of their ill siblings' care in terms of ensuring regular follow-ups and drug adherence and supported their livelihood. They coped up with adaptive as well as maladaptive strategies. **Conclusion:** SPS provide significant support to their affected siblings. However, they do have non-biomedical models of mental illness and negative attitudes toward patients and experience burden. Hence, psychosocial interventions may help SPS while caregiving for their affected siblings.

Key words: *Experiences, explanatory models, expressed emotion, siblings, Schizophrenia*

Key messages: *Siblings of persons with Schizophrenia (SPS) play an important role in the treatment and recovery of their ill siblings. This qualitative study revealed that SPS has non-biomedical models of mental illness and negative attitudes toward their ill siblings, and they experience burden. Personalized interventions are required to address the issues.*

Access this article online	
Website: www.ijpm.info	Quick Response Code
DOI: 10.4103/IJPSYM.IJPSYM_318_19	

How to cite this article: Amaresha AC, Venkatasubramanian G, Muralidhar D. Perspectives about illness, attitudes, and caregiving experiences among siblings of persons with schizophrenia: A qualitative analysis. Indian J Psychol Med 2019;41:413-9.

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Received: 31st July, 2019, **Accepted:** 14th August, 2019

The functional impairment caused by schizophrenia[1-3] affects the whole family of persons with schizophrenia.[4,5] More often, the patients in India live with their family members as compared with the patients of western countries.[6-8] Hence, family members in India are highly involved in caregiving activities.[6-8] Also, the family caregivers are more engaged in treatment-related decision making of their patients.[9] These factors expose family members to several challenges from the onset of the illness until the patient's recovery.

Previous studies from India and western countries have reported that caregivers sometimes have supernatural beliefs about mental illness; they attribute illness to social causes and seek non-formal treatment from faith healers.[10-12] Such illness perspectives with stigmatizing attitudes about mental illness among caregivers may result in a prolonged duration of untreated illness,[13-15] which could cause a burden for the family caregivers.[14] Also, they experience emotional problems and are reported to have unmet needs, which have a major impact on their well-being.[16,17]

The existing literature predominantly highlights the illness beliefs and experiences of parents[12,18-20] and spouses of patients diagnosed with schizophrenia.[12,19-21] There has been a growing interest in research with siblings of persons diagnosed with schizophrenia (SPS). Studies have found that they also experience psychosocial consequences of illness, such as poor mental health, poor relationships with their ill siblings, burden, maladaptive coping, and stigma.[22-24] However, the available studies on SPS are from developed countries and have predominantly reported the outcomes of sisters of persons with schizophrenia. There is a paucity of studies from India and from the Asian subcontinent exploring the SPS' illness perspectives, attitudes, and caregiving experiences.

Persons diagnosed with schizophrenia need long-term family support in their recovery.[25] However, India has a lack of government-supported aftercare homes for persons with mental illness. Worries may arise when the parents are aged and there are no other family members to look after the patients[6] In view of this, understanding their issues will help us in designing and providing specific interventions to SPS. Hence, this study aimed to explore the SPS' perspectives about their affected sibling's illness and caregiving experiences.

MATERIALS AND METHODS

Ethical statement

The Human Ethics Committee of National Institute of Mental Health and Neurosciences (NIMHANS), Bengaluru, India, has approved the study related protocol. Written informed consents were obtained from all the participants prior to the interviews.

Setting and participants

The participants for this study were selected from the Schizophrenia Clinic and outpatient and in-patient departments of Psychiatry, NIMHANS, Bengaluru. The SPS were included in this study if they were a biological sibling of a person diagnosed with schizophrenia (DSM-IV); aged between 18 and 60 years; able to speak English, Kannada, or Telugu; not having any mental illness as per M.I.N.I-5.0 International Neuropsychiatric Interview,[26] and found to be not suffering from any medical illness according to a qualified medical professional. In total, 37 subjects were screened for eligibility. Fifteen SPS (Male = 11; Female = 4) who met the inclusion criteria were included in this study. Out of the 15 SPS, 10 were elder siblings, and 5 were younger [Table 1].

Interviews and data collection

To explore the SPS' illness perspectives, attitudes, and caregiver experiences, a semistructured qualitative interview schedule was prepared. This included the sociodemographic profile of the SPS and their ill siblings and open-ended questions. This schedule was face- and content-validated by five mental health professionals who had experience in the field (one psychiatrist, three psychiatric social workers, and one anthropologist) and were not a part of this study. Some of the open-ended questions included were as follows:

Being a brother/sister of a patient, can you describe your experience?
-What is your understanding of your brother's/sister's illness?
How are you managing your sibling and taking care of yourself?
How are you involved in your brother's/sister's care?

With each question, circular questions were asked, and adequate probes were introduced when participants were not expressive to provide rich data. Each audio-recorded interview lasted for 30–45 min.

Data analysis

The qualitative interviews were transcribed and translated into English text. A general inductive approach to qualitative data analysis was adopted.[27] The transcripts were read several times to familiarize with the interview content. The qualitative data were managed and analyzed in QDA Miner Lite Version. 1.4.2 (http://provalisresearch.com/products/qualitative-data-analysis-software/freeware/). During the initial reading of the transcripts, the small text

Table 1: Sociodemographic Profile of Patients and SPS

Sociodemographic profile		Patients Mean±SD, *n* (%)	SPS Mean±SD, *n* (%)
Age in years		30.40±5.42	33±6.72
Gender	Female	3 (20)	4 (26.70)
	Male	12 (80)	11 (73.30)
Sibling status	Elder sibling	-	10 (66.60)
	Younger sibling	-	5 (33.30)
Education (years)		10.26±4.92	11±4.67
Socioeconomic status	Above poverty line family	8 (53.330)	9 (60)
	Below poverty line family	7 (46.66)	6 (40)
Occupational status	Working	3 (20)	14 (93.30)
	Unemployed	12 (80)	1 (6.60)
Marital status	Unmarried	13 (86.70)	6 (40)
	Married	1 (6.70)	9 (60)
	Separated	1 (6.70)	-
Residing together	Yes	-	9 (60)
	No	-	6 (40)
Family type	Joint	-	3 (20)
	Nuclear	-	12 (80)
Caregiver of the patient	No	-	5 (33.30)
	Yes	-	10 (66.70)

SPS=Siblings of persons with schizophrenia; SD=Standard deviation

segments featuring illness perspectives, attitudes, and caregiving experiences of SPS were carefully marked and highlighted, and codes were created. Initial coding was done for five interview transcripts, and the codes were further refined by removing redundant codes, renaming the existing codes, and adding new codes. The coding for the remaining transcripts was completed based on the framework developed from the initial five transcripts. At the analysis of the 14th interview transcript, the codes were saturated, but the coding was completed for all 15 participants. After the coding process, two peer research scholars independently verified the consistency of the codes with the transcripts. The disagreements between the peer research scholars on the codes were resolved with discussion, to reach a consensus. Later, the finalized codes were imported into Microsoft Excel spreadsheet for sorting and grouping. The codes with common features and meaning were grouped and assigned under the overarching themes.

RESULTS

The analysis resulted in the identification of four major themes, such as explanatory models of mental illness, expressed emotion, caregiving experience, and ways of caregiver involvement and coping.

1. Explanatory models of mental illness

Nine out of 15 SPS recalled and described that before consulting mental health professionals, they used to call their affected sibling's illness terms such as "hucchu," "loosu," "paithya" [words for madness in the Kannada language], "thikkalu," and "picchi" [words for madness in the Telugu language]. These terms are highly widespread and commonly discussed among caregivers in southern parts of India.

> "He was behaving very unusually… He was talking to himself and smiling in a way that was totally irrelevant…We thought he has *hucchu* [madness]" (Participant 15, younger brother, 22 years).

> "He was fine during the final year of his bachelor's degree. After the exams, he started reporting that he can hear voices… He started suspecting that people around him are stopping him doing well in exams… We thought he is stressed out due to exams and it will resolve after some time… But it did not… Then we realized it was *picchi* [madness]" (Participant nine, elder brother, 42 years).

Causal attributions about the illness are often influenced by close relatives and community people. Some of the important causal factors reported by SPS were black magic, God's curse, and "gaali" [word for possession of evil spirit in the Telugu language]. One SPS narrated that

> "He was regularly going to work and earning money. Later he used to tell that he is not interested in work… He was complaining a lot about his co-workers. He used to fight with us for no reason… Then we thought that this is because of *vamachara"* [word for "black magic" in the Kannada language] (Participant 14, younger brother, 31 years).

Before consulting the mental health center, SPS made choices with their families on seeking treatment for their ill sibling based on the existing cultural beliefs in the community. It was a ritual for many SPS to visit "Swamis" [religious priests], religious places such as temples, and "Mantravaadis" [black magicians] at some point of the illness trajectory.

> "We did not know where to go initially… Some people told us to take him to temples and perform *poojas* [religious rituals] and some have advised seeking help from black magicians…We visited a few temples…prayed to the God…and even approached *Mantravaadis* [black magicians]… But we lost so much money performing the rituals they suggested" (Participant 12, younger brother, 25 years).

2. Expressed emotion

Expressed emotion (EE) denotes the quality of family interactions or attitude of the family members toward their mentally ill patients that includes the existence of criticality, hostility, and emotional over-involvement. EE is considered to be important indicator of relapse of symptoms of schizophrenia. During the interviews, SPS did exhibit EE toward the patients in the form of criticality and over-involvement.

Owing to a lack of knowledge and increased responsibilities caused predominantly by the negative symptoms or socio-occupational dysfunction, many of the SPS were highly critical toward their patients. Six of them expressed criticality. Some of the SPS reported that

> "Yes, he has an illness… But that doesn't mean that he cannot do anything. He always gives reasons for not doing an activity… It's frustrating sometimes" (Participant four, an elder brother, 34 years).

> "He has improved a lot compared to the earlier times. But still he escapes from work… Being lazy will not help in any way…. There are no days in which we haven't argued on day-to-day issues" (Participant 13, elder brother, 45 years)

Five of the siblings were over-involved in the care, where they were overprotective toward their siblings. SPS were overcautious and anticipated mistakes. Hence, some of the SPS did not allow their ill siblings to perform their daily routines.

> "We know he can manage household finances since he has done Masters in Commerce… But I don't want to take the risk… Though it is an extra responsibility, I would like to take charge of the finances myself." (Participant seven, younger brother, 27 years)

3. Caregiving experience

Eleven of the SPS reported a negative impact of the illness in the form of burden. They experienced both objective as well as the subjective burden due to the severity of the illness and increased responsibilities.

The onset of the illness caused financial burden and increased responsibilities for the SPS, because the patients were having significant socio-occupational dysfunction and were unemployed as reported by the SPS.

> "I'm the only earning member now… If he were not suffering from this illness, he would have joined some work… It would have helped to decrease our financial difficulties" (Participant seven, younger brother, 27 years).

> "My responsibilities are increased now… He is not at all helping us in any-way. He even refuses to fetch water or shop for groceries" (Participant 12, younger brother, 25 years).

SPS reported that their relationship with the ill sibling has worsened due to the negative symptoms. They also reported that their marital relationship was affected because of their involvement in the caregiving. A few SPS reported that caregiving responsibilities such as follow-up visits and consultations significantly interfered with their daily work.

> "He is not like earlier… He doesn't care about my words… His attitude towards us has definitely worsened" (Participant 4, elder brother, 34 years).

> "My husband will not understand the difficulties that my sister is having. Sometimes he stops me from meeting my sister… If I ask for any help with regard to my sister, he won't talk to me for a few days" (Participant eight, elder sister, 36 years).

SPS reported the subjective burden in the form of grief and started avoiding people due to the embarrassment they faced at the initial stages of their siblings' illness [self-stigma].

> "I never thought that my sister would get mental illness… But when we came to know about it, it was upsetting… We were disturbed".
>
> (Participant eight, elder sister, 36 years).

> "He was doubting the people around him, thinking that they are plotting against him… He used to throw

stones at people and pick up quarrels… Neighbours used to complain about him… It was embarrassing and uncomfortable talking to people about his condition… We were deliberately avoiding them [people]".

(Participant four, elder brother, 34 years).

4. Ways of caregiving involvement and coping

Despite all these experiences, a majority of the SPS (12 out of 15) were helping their affected siblings in several ways. Most of them were involved in taking ill siblings for follow-up visits and consultations. In addition, they were the major source of support of their ill siblings' livelihood. Some of them reported that

"Though I'm busy with my work, I take my sister for follow-ups… Every time, I take the opportunity to talk to doctors about treatment-related issues of my sister" (Participant 11, elder brother, 28 years)

"Since my sister is separated from her husband and is currently not working, my older brother and I are taking care of her medical expenses as well as daily needs" (Participant six, younger brother, 29 years)

SPS were involved in other important caregiving activities such as supervising the medications and daily activities, guiding other caregivers in the family about managing the patient, motivating the patients to carry out their daily activities, and spending quality time with the patients. They said the following:

"I'm not staying with my sister, but my parents are there with her… I call once in two days, inquire about her condition, and ensure medication intake… Every weekend, I visit my village and spend some quality time with family… If any emergency comes up, I take leave and go there" (Participant 11, an elder brother, 28 years)

SPS reported about the ways of coping with their ill siblings. It included both adaptive and maladaptive coping strategies. They said that

"Keeping myself busy at work helps me to distract my mind from home until evening" (Participant six, younger brother, 29 years)

"I won't share my problems with anyone… I'm not comfortable sharing them." (Participant 14, younger brother, 31 years)

DISCUSSION

This qualitative study explored the SPS' perspectives about the illness, attitudes, and experiences from the onset of illness to the ongoing treatment. SPS had their own explanatory models about the patients' illness. During the interviews, most of the SPS expressed some negative attitudes toward their ill siblings. They experienced both objective and subjective caregiver burden. Despite all these psychosocial consequences, they were pro-actively engaged in the care of their ill sibling.

In lower-middle-income countries like India, there are several non-medical belief models about mental illness. At the initial stages of illness, SPS in this study had beliefs that mental illness is a result of previous deeds, black magic, or God's curse. Hence, they sought treatment from religious and faith healers. These findings are in tune with previous studies conducted in Southern India with caregivers of mental illness.[28,29] Likewise, some studies have also found the high prevalence of non-medical beliefs among patients as well.[30,31] Some studies had reported similar findings where the persons and their caregivers preferred to seek treatment through these pathways to care before consulting any mental health professionals[30,31] These kinds of non-psychiatric care may delay the access to early psychiatric care and worsen the symptoms of the illness and the functioning of the patients.[32,33]

There is a lack of studies exploring the expressed emotion in SPS. This study has found EE among several SPS. This could be because of the negative symptoms of the patients and the SPS' attributions or beliefs about the illness, which are associated with high EE.[34] Specifically, the controllability attributions are linked with high EE.[35,36] This suggests that if the family members attribute that the symptoms can be controlled by the patient, it will lead to high EE.[35,36] Caregivers EE is one of the major indicators of relapse,[37] and it needs to be addressed with the established interventions.

The results on caregiving experience among SPS are similar to those of previous studies, where SPS experience an objective burden in terms of financial burden; an impact on the relationships with the affected sibling; increased responsibilities and impact on school, work, and recreational activities.[23,38] In addition, studies had reported similar results with regard to subjective caregiving burdens, such as grief, stigma, anxiety, and distress.[23,24] Burden among SPS is associated with factors such as the severity of the symptoms or the illness, disturbances on household routine, and medication non-adherence.[39,40] Further, SPS who attribute that the illness is controllable, feel more burdened than those who feel that their affected siblings cannot control the illness.[39]

Like other caregivers of schizophrenia patients, SPS do involve in and perform many caregiving activities

regardless of the negative effects of the illness. There are differences with regard to the caregiving activities provided by SPS in this study and the western studies. Some of the previous studies from western countries have shown that SPS predominantly provide emotional support to the affected siblings,[23,41] that is, in contrast with our study findings, where SPS were found to be actively involved in patient care. They were providing treatment-related support in terms of accompanying the patients to follow-up consultations and support the patient's livelihood. Additionally, they were providing instrumental support, such as supervising medications and patients' daily activities. This is important in long-term care because the SPS outlive the parents. Also, they can share and reduce the burden experienced by other caregivers in the family.

SPS reported their coping strategies. They used both adaptive and maladaptive strategies such as distraction from the affected siblings by involving in or carrying out their regular work and internalizing their feelings. Similar results were found in previous studies.[24,42] Additionally, previous studies have reported other coping strategies such as getting understanding about the illness by seeking information from professionals, active participation in caregiving, normalizing the situation, maintaining distance, avoidance, grieving, and isolation.[24,43]

This is the first qualitative study exploring the SPS' perspectives of the illness and caregiving experiences in India. SPS are known to be a high-risk group for mental illness.[44] Hence, understanding their perspectives about the illness and the caregiver experiences, such as psychological distress, grief, burden, self-stigma, coping, feelings of guilt, fear of the future of their patients, etc., will help in designing specific interventions for SPS. This, in turn, would encourage SPS to be more active in the treatment process and provide long-term social support to their affected sibling.

The findings of the study should be interpreted cautiously, because it has several limitations such as small sample size and the participants being predominantly brothers and from urban backgrounds. Further, similar studies could be conducted with a large sample size with adequate representation of brothers and sisters. It would be interesting to see the comparison of the results with other caregivers of patients with schizophrenia from different social strata.

In conclusion, SPS do have some non-biomedical perspectives of mental illness. Such perspectives may restrict SPS engagement in the treatment process at least during the early course of the illness. Nevertheless, they provide instrumental support to their affected siblings. They do express some negative attitudes toward the patients and experience both objective and subjective burden. Hence, they may need special attention from the clinicians in terms of understanding their issues and providing need-based psychosocial interventions.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

Financial support and sponsorship

This work was supported by The Wellcome Trust/DBT India Alliance Senior Fellowship Grant (500236/Z/11/Z) to GV. ACA was supported by Wellcome Trust/DBT India Alliance.

Conflicts of interest

There are no conflicts of interest.

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Original Article

Quality of Life in Schizophrenia: What is Important for Persons with Schizophrenia in India?

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ABSTRACT

Background: Quality of life (QOL) is a multidimensional construct and is increasingly recognized as an important outcome measure. Schizophrenia runs a chronic course and is a disabling mental disorder. Assessment of QOL using currently available scales for schizophrenia may not be culturally relevant. **Methods**: In phase one, patients with schizophrenia using psychiatric rehabilitation services, caregivers, and mental health professionals were interviewed qualitatively to identify factors that are important for QOL of patients. In phase two, 40 patients with schizophrenia were recruited consecutively from the outpatient department and asked to rate the importance/relevance of the above items for QOL on a Likert scale. **Results:** Themes that emerged were work, family's understanding about illness, stigma, financial issues, social life, social standing, religion and spirituality, medications, physical health, mental health and symptoms, recreation and leisure, and independent living. Work and family's understanding of illness were considered as moderately or very important by all patients in phase two. **Conclusions**: Work is very important for all patients with schizophrenia for their QOL. The themes derived from this study could guide the development of a scale for QOL that is relevant to the Indian context.

Key words: *Indian context, Quality of life, schizophrenia*

Key messages: *Patient perspectives about factors important for QOL in schizophrenia include multiple domains such as work, family's understanding of their illness, physical health, mental health, stigma, and finances. Factors such as recreation, social life and standing, living independently, religion, and spirituality also seem to be important for patient's quality of life.*

Schizophrenia is a severe mental disorder characterized by three broad categories of symptoms: positive symptoms, negative symptoms, and cognitive symptoms. It generally runs a chronic course with heterogeneous outcomes. Schizophrenia is associated with significant functional impairment, challenges in community living, and burden of disability.[1] In addition to the symptoms and impaired role functioning, schizophrenia affects many other spheres of living, such as interpersonal and socio-occupational domains.[1]

Access this article online	
Website: www.ijpm.info	**Quick Response Code**
DOI: 10.4103/IJPSYM.IJPSYM_71_19	

How to cite this article: Durgoji S, Muliyala KP, Jayarajan D, Chaturvedi SK. Quality of life in Schizophrenia: What is important for persons with Schizophrenia in India?. Indian J Psychol Med 2019;41:420-7.

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Received: 10th February, 2019, **Accepted:** 31th May, 2019

The National Mental Health Survey of India, 2015-16 reported a lifetime prevalence of 1.4% and current prevalence of 0.5% for schizophrenia.[2] Family, social, and work life were significantly affected, leading to disability in these domains in two out of three persons with psychosis in this survey.[2]

The concept of quality of life (QOL) is pertinent to conditions that are chronic in course and when treatment is required for a long period of time.[3] There are many commonalities that schizophrenia shares with other medical disorders that run a chronic course as far as the QOL s concerned. Yet, there are differences such as the effect of psychopathology and symptoms and the side effects of medications on QOL which may be unique to schizophrenia.[4] QOL is now understood to be a multidimensional construct that encompasses both subjective and objective measures.[3] The WHO definition of QOL includes person's physical health, psychological state, level of independence, social relationships, personal beliefs and environment, all of which are shaped by culture and value systems.[5] Culture in this context refers to the unique behavior patterns and lifestyle shared by a group of people which distinguish it from others. Culture may significantly influence symptoms, help-seeking behavior, and the course and outcome of schizophrenia. A study that compared Indian and Swedish patients reported that in a majority of the domains, QOL was the same in both the groups.[6] The Swedish patients were more dissatisfied with social contacts compared with their Indian counterparts. The presence of joint and extended family system and close social ties seen in India may explain this.[6] A qualitative meta-synthesis of QOL studies in mental health problems (that included severe mental disorders) had identified six broad domains: symptoms, autonomy, belongingness, self-perception, activity, hope, and hopelessness.[7] Some domains such as spirituality, religiosity, and the role of the family in a largely collectivistic society in contrast to individualistic societies may be important determinants of QOL in Indian patients.

The information from caregivers has been used as a proxy and surrogate marker of QOL of patients.[8] This becomes important particularly when patients may lack insight. Persons with schizophrenia who did not identify themselves as having an illness have been reported to have a higher QOL.[9] General psychopathology symptoms such as depression and cognition may also influence the QOL in patients with schizophrenia.[10]

Indian studies examining QOL in schizophrenia have used, more often, generic scales such as WHO-QOL BREF, which has been cross-culturally validated.[11-13] Disease-specific scales such as QOL Scale for Schizophrenia have also been used in some studies.[8] To our knowledge, there are no disease-specific scales that have been developed in India for schizophrenia using perspectives of patients with schizophrenia.

METHODS

The aim of the study was to examine what factors significantly affect the QOL in persons with schizophrenia and to quantify the relevance and importance of these factors. The study used mixed methods and was cross-sectional, involving a qualitative phase followed by a quantitative phase. The study was conducted at a tertiary care mental health setting with inpatient units, outpatient clinics, and specialty psychiatric rehabilitation services. Psychiatric Rehabilitation Services of the institute is comprised of a multidisciplinary team. The services provided include day care services, vocational—assessment, training, and placement—services, home-based rehabilitation planning, disability welfare benefits counseling, and community-based rehabilitation. The patients who use the services include both persons with mental illness and persons with developmental disorders.

The institutional ethics committee approved the study, and participants were recruited after obtaining written informed consent.

The qualitative phase involved in-depth interviews of patients with schizophrenia, caregivers of patients with schizophrenia, and mental health professionals with at least 5 years of experience. The interviews of five mental health professionals, three patients, and two caregivers were conducted in English. The remaining interviews that were not in English (either in Kannada or Hindi) were translated to English and subsequently back-translated to the vernacular language to ensure that the data was interpreted for the intended meaning. We included patients who were clinically diagnosed with schizophrenia (ICD-10) utilizing the day care services at the center and able to give a valid interview. Patients with intellectual disability or other disabilities as per the Rights of persons with disability (RPWD) Act, 2016, as comorbidities were excluded. sociodemographic details, clinical global impression-severity (CGI-S) scores, and the positive and negative symptom scale (PANSS) scores were documented. All interviews were audio-recorded and transcribed verbatim. The qualitative analysis involved a deductive content analysis approach as described by Elo and Kyngas.[14] The transcripts were manually coded by two investigators for triangulation, and themes were identified. The data reached saturation with the

inclusion of six patients, six caregivers, and six mental health professionals.

Forty patients with schizophrenia utilizing the various services at the center were asked to rate the importance/relevance of each of these factors for their QOL on a Likert scale, in the quantitative phase.

RESULTS

All the interviews with patients, caregivers, and mental health professionals were carried out by the same interviewer. The interviewer was a resident fellow in Psychiatric Rehabilitation and shared a therapeutic relationship with three patients.

The qualitative phase included six patients with schizophrenia (four males and two females), with a mean age of 38.5 years (SD = 4.18). Of the six, three patients were unemployed, one was married, two belonged to lower socioeconomic stratum, and four were from the middle socioeconomic stratum. Two patients were graduates, three were educated up to high school, and one patient was a postgraduate. The mean duration of illness was 12.6 years (SD = 4.71). The mean CGI-S score was 3 (mildly ill) (SD = 1.15), while the mean PANSS score was 35 (SD = 2.44). All the patients had grade 4/5 insight and were adherent to treatment. Among the caregivers, four were graduates and two were high school educated.

The six caregivers included five males and one female. They were either a parent or spouse of the person with schizophrenia. The mean age of these caregivers was 55 years (SD = 9.33), and the mean duration of their caregiving was 12 years (SD = 4.04). The six mental health professionals interviewed included two psychiatrists, two psychiatric nurses, one psychiatric social worker, and one vocational instructor with more than 10 years of experience in training persons with mental illness. The mean experience of these professionals in their respective fields was 13 years.

The following themes were identified in the in-depth qualitative interviews:

1. **The importance of work:** Work was valued for enhancing self-satisfaction, providing a source of income, building self-esteem, aiding in socializing, and improving social value and standing. The following quote illustrates the importance of work for QOL: "We should be given a job so that we can mix with the people. The job will help us to get a secure place in the society because the job will bring some money. Creative portion of ours can be utilized. The job will also make us useful employees of an organization." Any form of work, and a paid job in particular, was viewed as an integral part of life. Work was also perceived to be a means of distraction from symptoms as well as a mode of engagement to improve QOL: "When you have some job, then you will have some responsibility, you will have some dignity, and you have the income also." A mental health professional stated that having reasonable accommodation at workplace and security from job loss were of significant importance to patients
2. **Stigma** was observed to be an important barrier to perceiving a good QOL. This was noted in the context of socializing, marriage, and work. Self-stigma may play an important role, as exemplified in the following quote from a patient– "It's, like all persons, I should attend functions, festivals, and rituals. I also feel happy about going along with my family, but I feel what people will think about me—that kind of inferiority complex prevents me from going anywhere. I am not able to mingle with people. I feel, what will people ask? What will they say? That will be bothering me from inside." A mental health professional stated that the label of a psychotic illness like schizophrenia might be more stigmatizing than depression. One of the patients described locking herself in a room because she was being labelled "mental" in her locality. The father of a patient with schizophrenia felt that stigma would affect a person's self-confidence and may even lead to a relapse, further worsening the QOL
3. **The role of family members, their acceptance and understanding** of the patient's condition was emphasized recurrently in the interviews. The importance of a caring and concerned family in improving his QOL was iterated by a patient with schizophrenia in the following words—"If I get love from my family, it's more than sufficient. Now, my mother hates me so much. How will others motivate me if my own mother and brother abandon me." Participants—particularly patients—underlined the importance of families' understanding of the mental illness and the importance of families' help and support in getting better symptom control either by reassuring them or by taking them for treatment during periods of relapse or crisis. For a woman with mental illness, having a better QOL meant "settling with her family" and the need to "get love from family"
4. **Mental health and control of positive symptoms** matter to most patients and their caregivers as far as an improved QOL is concerned. A patient with a fair degree of insight into his symptoms spoke about the impact of symptoms on his life—"There are certain voices which keep on mocking at me, teasing me that I'm getting less salary. I feel as if they are trying to phone my relatives. They are also

phoning each other behind my back. Because of this, I am unable to study and concentrate." Father of a lady architect diagnosed with schizophrenia stated that mental health was the most important determinant of a better QOL. Giving the example of his daughter, he observed that—due to symptoms—"she cannot take decisions. She does not know what is good and what is bad… She will never come back to her original position in life… What she has lost is lost." Another caregiver said, "Everything depends on mental health. If your mental health is not good, you cannot enjoy life in any way…f your mental health is good, you will enjoy everything—you will talk correctly and think of yourself and others." A psychiatrist who participated in the study noted that a mental illness like schizophrenia could take away the very "essence of quality in a patient's life." He went on to add that complete deliverance from symptoms would be the ideal scenario, but "recovery they say is a process, and there is no clear endpoint." The father of a person with schizophrenia felt that "experience of happiness" is a fundamental necessity for a good QOL

5. **Medications and their side effects:** A caregiver opined that medications helped in his son's recovery from symptoms after seven years of untreated illness. He reported that "this treatment has given him a new life; his life had become useless… The treatment has restored happiness in his life." Patients also complained about side effects such as tremors and drowsiness as being impediments to enhancing their QOL. For example, a patient observed, "I am taking medications now….and it is making me sedated and lazy, I am not able to walk very fast, I feel tired, and there is no enthusiasm… This should not be there. I think a better life will be a medicine-free life and when I am completely cured.". A mental health professional alluded to the financial costs of treatment in the following words—"The cost of the medication itself can be posing a burden. So, somebody is earning, and spending 20% of their expenditure on medications … This is a significant issue"
6. **The role of physical health and lifestyle:** Physical activities and good physical health, as a factor promoting a better QOL, mattered to many patients and caregivers. This included activities that reduced stress, in addition to the enjoyment involved in activities such as trekking, exercise, and cycling. Physical illnesses that are comorbid with schizophrenia also play an important role in the QOL, as observed by this patient who is on treatment with a second-generation antipsychotic, "The first thing is, diabetes should not be there. What you call 'body mass index' should be normal. In my case, it is more than 35. It means I am obese. I do not do hard work, I cannot walk fast." Staying away from substance use was also viewed as important for a good QOL. Substance use was viewed as a "bad habit," as something censored by religion, as well as something impacting health and family
7. **Finance and money** were noted to be important factors in determining the QOL, from fulfilling basic needs to affording luxuries and more material needs. Factors such as cost of living and financial stability mattered to patients and their caregivers—"In our current life, whatever we earn is not enough for the family. Now everything has become costly. All prices have gone up. For poor people like us, we will not be able to buy anything, what we feel (like doing), we cannot do (are unable to do)." A patient reported—"only when we are financially stable, there is value for us; without money, we cannot do anything. No work can happen. For everything, money is required." Another patient reported, "Nobody can do anything without money… if I look at my future, I should earn money. Otherwise, life becomes very difficult." A caregiver who had three members in his family with mental illness to care for stated, "If you want to buy anything, if you want to purchase ration, you need money for it. We might travel sometimes, we may have to purchase some clothes, we have to cook and have food in house. Without money, we will not get any ration"
8. **The importance of confidantes and companionship:** The value of social relationships for QOL was recurrently emphasized across all three groups. A mental health professional, while summarizing the need for a social life, stated, "Usually, people want to be acknowledged by other people or want to be loved by other people. They want to be in touch with people so that they can share their feelings or share their life. It's no exception for any person with schizophrenia." Having friends or close family members to share feelings and thoughts was observed to be relevant to enhanced QOL. The importance of working on social aspects of rehabilitation during the recovery journey cannot be underemphasized, as illustrated in this quote: "Social relationship is important… When I got affected with schizophrenia, I was between the four walls. I never used to come out. When I started the rehabilitation program in NIMHANS, I started mingling with people of my kind. People had different kinds of illnesses—mental retardation or mental illness. Slowly, I started communicating with mentors over there. When they got confidence in me, they assigned me to different jobs." Marriage was viewed as a social need, a source of support, and as a method of socially and culturally

sanctified companionship. A person diagnosed with schizophrenia, while emphasizing the need for marriage and companionship for his life, stated: "I am single right now. I should be sharing my life with someone. I think of having a partner in life to share things. To talk things. It will make me feel better." The lack of opportunities to marry when mental illness is disclosed or known was viewed as detrimental to this domain of QOL. Sometimes, these are coupled with worries of who will take care of them in the future. For example, a 33-year woman with schizophrenia said, "See, I am already 33. In 2 years, I will be 35 years old. That is the last when girls will get married. Everybody will get old. Then who will look after me? My brother will be there for me only till he gets married. After his wife comes, then what will happen?"

9. **Religion and spirituality:** The patients and caregivers emphasized the role played by the practice of yoga and partaking in religious activities such as praying, sandhya-vandana or meditation, and listening to devotional songs as important for building "inner strength and confidence," fostering recovery, and enhancing the QOL. A psychiatrist commented on the importance of spirituality in the Indian cultural context and how it plays a big role in providing "a sense of meaning, sense of meaning for existence itself." A caregiver who identified himself as a practicing Muslim emphasized the role of prayer both as a religious duty and a source of healing. Another psychiatrist spoke about the importance of spiritual needs and the avenues for fulfilling those needs and listed some examples such as being guided by a temple priest or an elderly spiritual Guru with wisdom and finding "solace" in spiritual or cultural explanations for barriers, to enhance the QOL. Another factor noted was from the Hindu philosophy of Karma—illness as a retribution for "something done in the past." A patient with schizophrenia summed up the importance of this aspect as a domain of QOL, as "We should have trust in God. If we believe, then most of our work will be easy—there will be no obstructions. Even if humans hate us, God will never desert us. That divine strength will do good for us, I feel"
10. **Recreation and leisure:** Playing games, engaging in hobbies such as reading books, watching cinema, attending social gatherings, painting, going to a library, and listening to music were most common examples of recreational and leisure activities valued as important for the QOL. One patient described the advantages of recreation by stating, "I am engaged. There is entertainment. We are going to different places, meeting different people, and seeing different things. It makes me feel happy." Some patients looked at the messages in poems, stories, and songs as aids to motivate them to make small changes in their lives
11. **Independent living:** Living independently, with little reliance on others for daily needs, from personal hygiene to complex activities such as instrumental activities and paid work, was an important need. This theme was closely linked to other themes on the importance of work, social life, and social standing. A caregiver reported the importance of independent living from the perspective of the wellbeing of both the patient and the caregiver in the following way—"He is not capable of looking after himself because of the nature of his illness. He has to be told, for example, when to have a bath, what clothes to wear for what occasion, etc." and "Now she can't take any decisions. We have to be constantly after her and before her sight (supervise her) to look after"
12. **Social standing:** The value of an individual in society is based on achieving certain goals expected for one's age and gender such as meeting societal expectations of roles and responsibilities, working and earning, living independently, contributing to society, and working productively. These were considered important for QOL. We felt that this theme was closely intertwined and linked to several of the themes mentioned before. We deduced this to be a separate theme because the wholesome of a social standing is something that persons who were interviewed aspired and looked forward to. "Recovery", for most patients meant regaining lost positions, lost incomes, lost skills, lost opportunities, and lost dreams. Patients and caregivers spoke about drift in occupations and social standing as very important to their daily lives and deeply impacting their QOL. A patient described this theme as a feeling of being "considered important and needed in society."

The importance of various themes for QOL

In the next phase of the study, the importance or relevance of these themes was rated by 40 patients diagnosed with schizophrenia on a 4-point Likert scale with an additional option of offering no comments. The 40 patients included 15 patients who were utilizing the daycare services, 16 inpatients, and nine outpatients; including 25 males and 15 females. The mean age of this sample was 45 years (SD = 11.86) with a mean duration of illness of 10.5 years (SD = 4.35), mean CGI score of 3 (mildly ill) (SD = 0.84). Thirty of these patients were unemployed, while the remaining were in some or the other form of fulltime or part-time paid employment. Only one of the patients was married and had children. Twenty-five patients belonged to the lower socioeconomic category, while the remaining belonged to the middle class. Table 1 illustrates the rating for all

the 12 domains. Since work was noted to be important for QOL in all the interviews, and it was also rated to be very important for all patients in the second phase, it was further assessed as to the primary reason for the relevance it held—whether as a form of engagement, a way to improve social standing, a source of income, a method to distract from symptoms, or any other reason. Of the respondents, 17 (42.5%) felt it was important as a source of income, 13 (32.5%) felt it was important for keeping themselves engaged, 5 (12.5%) felt work could serve to distract from symptoms, 4 (10%) felt that it was important for social standing and 1 (2.5%) stated that work would keep him happy.

DISCUSSION

There is a lack of an equivalent phrase for "QOL" in Indian languages. Phrases such as "Jeevanada Gunamatta" in Kannada or "Jeevan ki Gunvatta" in Hindi are the closest, but they could also be taken to mean standard of living.[15] Indian translation of QOL may imply good characteristics of life or gunas, the specialty of life or visheshata, how good the life is or uttamata or standard of living.[16] Despite this, during the interviews, we found that the patients and their caregivers were able to understand the construct underlying this phrase and were able to provide perspectives on the various factors that could matter to the patients' QOL.

It is recommended that QOL be measured using tools that are designed using a bottom-up approach, first examining qualitative perspectives of patients and caregivers.[4] Most scales that have been developed have not taken the views of the patients with schizophrenia themselves. The exceptions, however, are the Schizophrenia Quality of Life Scale[17] and the Quality of Life in Schizophrenia (QLiS) questionnaire.[18] The studies that have been conducted in India on QOL in schizophrenia have either used generic scales such as WHO-QOL BREF that has been cross-culturally validated[12] or have used schizophrenia specific scales such as Quality of Life Scale for Schizophrenia that has been developed in the west.[6] There is a need to develop scales that are culturally congruent and relevant. This study is a first step towards designing a QOL tool for schizophrenia that is relevant to our population. We have additionally utilized the perspectives of mental health professionals who came from diverse backgrounds.

Table 1: Importance of different QOL domains for patients with schizophrenia

Domain	Not or mildly important - *n* (%)	Moderately or very important - *n* (%)
Work	-	40 (100%)
Family's understanding	-	40 (100%)
Physical health	2 (5%)	38 (95%)
Mental health and positive symptoms*	4 (10%)	34 (85%)
Independent living*	5 (12.5%)	34 (85%)
Financial issues	7 (17.5%)	33 (82.5%)
Medications	7 (17.5%)	33 (82.5%)
Social standing*	6 (15%)	32 (80%)
Social life*	8 (20%)	31 (77.5%)
Religion and spirituality	9 (22.5%)	31 (77.5%)
Recreation and leisure*	8 (20%)	31 (77.5%)
Stigma*	22 (55%)	16 (40%)

*Remaining patients had no comments. QOL: Quality of life

Many of the themes identified in the qualitative phase are very similar to the factors that have been found to be associated with QOL in developed countries. For example, factors such as stigma related to schizophrenia and mental illnesses, the influence of symptoms and symptom control, drugs and their adverse effects, financial and economic status, social relationships and family have been associated with QOL in schizophrenia.[19] The themes also encompass many domains covered in the WHO definition of QOL in general.

The disadvantage of many of the questionnaires that have been used to examine QOL in schizophrenia is either that they are too lengthy or that they include items borrowed from generic scales of QOL. The items of the disease-specific QOL scale[17] which have been adapted and used in India in patients with schizophrenia do not examine domains such as symptoms, side effects, recreation, leisure, and spirituality. Factors that are assumed to be "clinical"—such as symptoms of the illness and side effects of medications—have been traditionally ignored in QOL scales, but these were subjectively important to our patients.

Previous studies that examined the QOL in schizophrenia in Indian patients have provided, compared with the developed world, explanations that are sociocultural in nature to explain the differences in QOL. The explanations provided have included the presence of joint families in India, sharing of income among family members, availability of social support from extended families, lack of emphasis on education, and low priority given to recreation and leisure.[6,8,20] These may, however, be changing, following the trends of social changes that have happened in India over the last two decades.[21]

Our study indicates that factors such as work, physical and mental health, independent living, and recreation and leisure seem to be moderately to very important to our patients' QOL. Furthermore, work seemed to be very important for the QOL for all the 40 patients in

this sample, for purposes of providing a source of income and to be engaged in some form of activity. Religion and spirituality emerged as a recurrent theme in the qualitative phase and were found to be very important for 57.5% of the patients. A previous study from north India had found that religiosity and spirituality affect the QOL in patients with schizophrenia.[22] Spiritual aspects need to be, therefore, considered when evaluating the QOL in schizophrenia.

In contrast to a life-threatening condition such as cancer wherein factors such as peace of mind and spirituality were considered most important,[23] in this study involving patients with schizophrenia from the same culture, more material aspects such as work and family's understanding were considered very important.

There is a now a greater emphasis on making services recovery oriented. Recovery, in this context, is not mere amelioration of symptoms but has a very unique personal meaning encompassing various other factors that matter in the process, such as livelihood, education, social life, spirituality, and companionship.[24] The focus of service delivery will have to include all factors that are important for the QOL of patients with schizophrenia. In the background of the importance given to work in this study sample, and also in the context of it being closely related to other themes identified, such as financial status and social standing, there is an important need to focus on providing vocational rehabilitation services to patients with schizophrenia. In India, there is a dearth of such services that comprehensively provide rehabilitative care.

The trustworthiness of this study is enhanced by the following: three groups of key informants were interviewed to triangulate the data; two investigators coded the data and analyzed it. Additionally, in the second phase, respondents from the same setting validated the findings of the qualitative phase. This was a tertiary care hospital-based study; hence, the generalizability of the findings to other settings may be limited. Other factors that limit generalizability were that two-thirds of the patients and caregivers in the first phase were graduates, and the study included patients who had been referred for specialty rehabilitation related services. Therefore, their attitudes towards work may have been different than those of a community-based or general hospital-based sample.

CONCLUSIONS

The patient perspectives about QOL in schizophrenia in our sample include multiple domains such as livelihood, family, physical health, mental health, stigma, and finances. Factors such as recreation, social life and standing, living independently, religion, and spirituality also seem to be important for our patient's QOL. Work was very important for all the patients in the second phase of the study. This study could guide the development of a scale for QOL that is relevant to our population with schizophrenia. The study also highlights the imminent need to develop recovery-oriented services that include vocational rehabilitation services, as work seems to be very important for our patients' QOL.

Financial support and sponsorship
Nil.

Conflicts of interest
There are no conflicts of interest.

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Original Article

Mobile Phones as a Medium of Mental Health Care Service Delivery: Perspectives and Barriers among Patients with Severe Mental Illness

Gopika Sreejith, Vikas Menon[1]

ABSTRACT

Background: The use of mobile phone technology to support various components of health care delivery (often referred to as mHealth) is on the rise. Little systematic information, however, is available on user felt needs and barriers to mHealth approaches among people with severe mental illness (SMI). Our objectives were to elicit user needs, preferences, and barriers to using mobile phones for health care service delivery among people with SMI. **Materials and Methods:** A cross-sectional study was carried out among 75 subjects with SMI between August 2017 and October 2017. All patients had a minimum illness duration of two years or more and a Global Assessment of Functioning score of less than 70. Information on user perspectives was elicited using a 10-item structured questionnaire, to assess mobile phone usage patterns, felt needs, barriers, and preferences, developed for use in patients with SMI. **Results:** Majority of the patients reported using mobile phones and were favorably disposed to mHealth approaches. Voice calls (n = 47, 62.7%) were the most preferred mode of service delivery. The most preferred service frequency was twice-weekly (n = 31, 41.3%), followed by once-weekly (n = 22, 29.3%). Majority (n = 47, 62.7%) reported no barriers to mobile phone usage, whereas 14 (18.6%) perceived a lack of necessity of mobile phones as a service delivery medium. Reminders about medication and appointments through mobile phones (n = 35, 46.6%) were the most felt needs, followed by crisis helplines (n = 27, 36.0%) and information about mental health services (n = 22, 29.3%). **Conclusion:** These findings support the use of mHealth approaches in resource-constrained settings and provide specific inputs to refine the modalities of mHealth service delivery.

Key words: *Bipolar disorders, mHealth, mobile phone, psychiatry, schizophrenia, telemedicine*

Key messages: *Mobile phone based approaches can be used to facilitate mental health care service delivery for patients with severe mental illness in our country. Twice-weekly voice calls appear to be the most preferred frequency and mode of service delivery, whereas reminders about medication and appointments were the most common felt need in this population.*

Access this article online	
Website: www.ijpm.info	**Quick Response Code**
DOI: 10.4103/IJPSYM.IJPSYM_333_18	

How to cite this article: Sreejith G, Menon V. Mobile phones as a medium of mental health care service delivery: Perspectives and barriers among patients with severe mental illness. Indian J Psychol Med 2019;41:428-33.

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Received: 07th August, 2018, **Accepted:** 21st July, 2019

Inequitable access to professional mental health services is a major issue in low- and middle-income countries like India.[1,2] Consequently, a significant percentage of people who are in need of treatment may not receive it. This is often referred to as the treatment gap in mental health disorders,[3] which can be attributed, partly, to ineffective service delivery or utilization. Remote health technology has been rightly positioned as a low-cost, low-burden, sustainable method to address this unmet need.[4,5] Increasing mobile phone penetration rates in India and the rest of the world[6,7] offer a valuable opportunity to harness the power of technology to improve care delivery. More specifically, this medium offers us valuable opportunities to scale up service delivery, provide real-time health outcomes data, and even deliver real-time interventions in the natural environment of the patient, otherwise referred to as "ecological momentary interventions."[8-10]

Based on this premise, several trials using mobile phone based interventions for enhanced management of a range of chronic health conditions, including mental disorders, have emerged from different parts of the globe. Such approaches are commonly referred to as "mHealth,"[11] where the focus is on leveraging mobile technology to support various aspects of health care delivery. In the last decade or so, the evidence base for mHealth approaches in improving adherence, providing psychotherapy services as well as data diagnostics, is rapidly increasing.[12-14] However, there is relatively less data on user preferences and barriers to such approaches.

For optimal success, it is essential to elicit user perspectives and service delivery preferences before the implementation of mobile phone based interventions. This will help in planning interventions that have maximal uptake, continued service usage, and enhanced user satisfaction, ultimately improving clinical outcomes. The barriers to and perspectives on utilizing mobile phones for mental health services may, presumably, differ across cultures and ethnic groups. For instance, it has been shown that patients in South Asian cultures find such approaches to be less stigmatizing.[15] To the best of our knowledge, only one previous study, restricted to centers from North India, has previously assessed barriers and perspectives to mHealth approaches among people with severe mental illness (SMI).[16]

Against this background, we carried out the present study with three objectives: first, to elicit patient perspectives and preferences and to understand their felt needs regarding the utilization of mobile phone technology for health care services delivery; second, to assess mobile phone usage patterns among people with SMI; and third, to assess the barriers to using mobile phones among people with SMI. We restricted our study only to patients with SMI as they are likely to be the most underserved group and, therefore, the most likely to benefit from such approaches than say, people with common mental disorders.

MATERIALS AND METHODS

Setting and design

This was a cross-sectional study carried out in the Psychiatry outpatient department of a teaching-cum-tertiary care center, between August 2017 and October 2017. The hospital, which is attached to a centrally funded autonomous university, is located in an urban area of the union territory of Puducherry, India. Being a centrally funded institution offering heavily subsidized treatment, it draws a significant percentage of clients from the neighboring districts of the state of Tamil Nadu and a smaller proportion from other Indian states. The hospital has all the specialty and super-specialty departments functioning out of a single campus. Most of the service users are patients who belong to the low-income bracket.

All cases presenting to the outpatient walk-in clinic were first screened by a senior resident (qualified psychiatrist) and subsequently, given an appointment for detailed evaluation. On this day, after a detailed history taking and physical examination, a diagnosis and management plan were formulated. All psychiatric diagnoses were made as per the International Classification of Diseases—10 (ICD-10).[17] Patients with a diagnosis of bipolar disorder were asked to follow up in the Mood Disorders Clinic, and those with schizophrenia were assigned to the Psychotic Disorders Clinic. Allotted patients attended their respective clinics once in three weeks for their drug refills.

Subjects and methods

Participants were selected by convenient sampling from the Psychiatry outpatient department. We screened all patients who were on regular follow-up in both the clinics so that every patient had an equal chance of being recruited, and we did not resort to advertisements within or outside the clinic. Only clinically stable patients (who had no changes made to their medication schedule in the last one year) were selected for the study. Screening and recruitment were done by a single investigator and verified by a consultant psychiatrist. The inclusion criteria were outpatients ($n = 75$) in the age group 18–65 years, fulfilling the criteria for SMI as per Ruggeri *et al*.,[18] which include two criteria:

1. Duration of treatment of two years or more, and
2. dysfunction, as measured by a Global Assessment of Functioning (GAF) Scale[19] score of 70 or less.

Apart from documented intellectual subnormality, there were no other exclusion criteria. The Mini International Neuropsychiatric Interview (MINI)[20] version 5.0 was used to confirm the diagnosis in all recruited patients. Sample size (n = 75) was determined based on twin considerations: study site sample from a previous similar paper[16] as well as the time period available for the study. No formal assessment of mental health care capacity was undertaken because we reasoned that selecting clinically stable patients would give us a fair chance of eliciting desired responses.

Those patients fulfilling the above inclusion and exclusion criteria were recruited after taking written informed consent in the vernacular. Separate consents were sought from both the patient as well as the attendant. Basic sociodemographic data were collected by administering a semistructured pro forma.

Subsequently, questionnaire to assess mobile phone usage patterns, perspectives, and barriers in people with SMI[16] was used to collect major outcome data. This is a nine-item questionnaire specifically developed by Indian authors for use in people with SMI that elicits information about usage patterns, ownership details, felt needs, and barriers to mobile phone usage for service delivery. The questionnaire was developed by authors after going through similar instruments from other countries[21] and adapted for use in Indian conditions. Hence, it was thought to be a culturally appropriate tool for the present study and was utilized as such. Face and content validity checks were carried out at our center by running the questionnaire through three faculty experts. Based on their opinion, we included one additional question on the preferred frequency of health service delivery as it would be of relevance to planning future mobile phone based services. This was not covered in the original questionnaire. For certain questions, such as preferred services to be delivered and barriers to using mobile phones, patients were asked to tick as many options as they felt applicable to them. This, we hoped, would give a truer picture of the many barriers that may be operating in a single patient.

The entire process of data collection took about 10–15 min per patient. The study protocol had prior approval from the Institute Ethics Committee for Human Studies.

Data analysis

Baseline sociodemographic and clinical variables of recruited patients were represented as mean with standard deviation or frequencies and percentages for continuous and categorical data, respectively. For results on the main questionnaire, descriptive data using simple frequency distributions were used to describe mobile phone ownership, usage patterns, and barriers to accessing services.

RESULTS

A total of 75 patients participated in the study, of whom 37 (49.3%) had a diagnosis of bipolar disorder, and 38 (50.7%) were diagnosed with schizophrenia.

The mean (±SD) age of the sample was 38.01(±11.3) years. There were 37 males and 38 females. Majority were married (n = 42, 56.0%), were unemployed (n = 50, 66.7%), had studied only till primary school (n = 30, 40.0%), and had a per capita monthly income of less than 1500 Indian rupees (n = 70, 93.3%), i.e., lower and lower-middle-class as per "modified BG Prasad classification."[22] Majority were from nuclear families (n = 46, 61.3%). A slender majority of subjects hailed from urban or semiurban areas (n = 38, 50.7%) as opposed to rural areas (n = 37, 49.3%).

Only 10.7% (n = 8) of respondents did not use mobile phones. Of the remaining, nearly equal numbers reported having a mobile phone registered in their name (n = 34, 45.3%) or using a phone registered in a family member's name (n = 33, 44.0%). Two-third of the sample (n = 50, 66.7%) used only simple cell phone handsets, whereas 22.7% (n = 17) reported having a smartphone.

A good majority (n = 63, 84.0%) used prepaid phone connections, whereas only one respondent used a postpaid connection. More than half the sample (n = 41, 54.7%) preferred to use only the talk function on their phones, whereas texting (n = 13, 17.3%) and surfing the net (n = 13, 17.3%) were less widely used functions.

More than three-quarters of the sample (n = 57, 76.0%) reported using their phones daily, whereas eight subjects (10.7%) were using it only on a weekly basis. One person (1.3%) reported monthly usage, and another person (1.3%) was using his phone on a twice-weekly basis.

Reminders about hospital appointments and medication were the most preferred service through mobile phone mediums (n = 35, 46.6%). The distribution of mobile phone based services preferred is shown in Table 1.

Majority of the sample preferred voice calls (n = 47, 62.7%) as their preferred service delivery medium over text messages (n = 14, 18.7%) and email (n = 1, 1.3%). Thirteen subjects (17.3%) expressed their disinterest to receive service delivery through the mobile phone medium. Among the remaining who were not averse to

the idea, 31 subjects (50%) preferred to receive services on a twice-weekly basis, making it the most popularly preferred frequency of service delivery. The distribution of the preferred frequency of service delivery is shown in Table 2.

The signal strength was reported as excellent by majority (n = 38, 50.7%) of patients followed by good (n = 23, 30.7%) and poor (n = 7, 9.3%). Seven patients did not respond to this question. With regard to reported barriers to using mobile phones, 47 patients (62.7%) did not mention any barriers. Lack of perceived necessity to own a cell phone was the single largest barrier reported (n = 10, 13.3%). The distribution of other reported barriers is shown in Table 3.

DISCUSSION

The present study showed that most mental health service users with clinically stable SMI were using mobile phones, were favorably disposed to the idea of using mobile phones for health care service delivery, and reported no barriers to mobile phone usage for this purpose. However, most of them used only basic handsets with prepaid connections. Prepaid connections refer to a plan wherein the users pay a certain amount of credit in advance of availing mobile services, whereas in postpaid, the billing and payment occur after availing the services. If there is no credit balance on the connection, the service provider suspends prepaid account services until the user credits money and recharges the account. This implies that there can be periods of temporary discontinuity in services in a prepaid plan, and this may adversely impact the continuity of mHealth-based care delivery. Most people belonging to the low socioeconomic strata in India find the prepaid plan to be more convenient as they are unlikely to run up huge bills, due to prior knowledge of amount credited. Hence, this finding may be a reflection of our sample demographics. The fact that signal strength was reported to be good or excellent in their locality by an overwhelming majority of our sample has favorable implications for the planning of services, such as crisis helplines, which require good and timely connectivity.

Table 1: Preferred services to be delivered via mobile phones

Preferred services	*n* (%)
Reminders about appointments and medications	35 (46.6%)
Helpline for emergency services	27 (36.0%)
Information about mental health services	22 (29.3%)
Regular check-ins with providers	15 (20%)
Not interested	13 (17.3%)
Telephonic follow-up in stable patients	11 (14.6%)

Values expressed as frequency (%); total responses may exceed sample size (n=75) as some have given multiple responses

Table 2: Preferred frequency of delivery services through mobile phones

Preferred service delivery frequency	*n* (%)
Twice weekly	31 (41.3%)
Once weekly	22 (29.3%)
Disinterested	13 (17.3%)
Once a month	4 (5.3%)
No response	3 (4.0%)
Daily	2 (2.7%)

Values expressed as frequency (%)

Table 3: Barriers to using mobile phones

Barriers	*n* (%)
No barriers reported	47 (62.6%)
Lack of perceived necessity	14 (18.6%)
Lack of interest	7 (9.3%)
Do not know to use	7 (9.3%)
Affordability	2 (2.6%)

Values expressed as frequency (%); total responses may exceed sample size (n=75) as some have given multiple responses

More pertinently, voice calls were endorsed over text messages for service delivery, and users preferred twice-weekly frequency of services. Reminders about medications and appointments and emergency helplines were the most sought-after service provisions. While these findings support the usage of basic mobile phone functions such as voice calls and one-way texting for select services, it also tells us that the populace is not ready for more sophisticated interventions, including interactive texting and smartphone "app" based service delivery. This calls for a graded and incremental approach to incorporating technology, in general, for mental health service delivery in our setting.

Only one previous study, from North India,[16] has assessed mental health user needs and perspectives on mobile phone based service delivery. The types of phone (nonsmartphone) and mobile phone usage rates were largely similar to our study. The same authors also found that voice calls were the preferred mode of service delivery, similar to our findings. This is also supported by findings from nonpsychiatric populations.[23] However, Chandra *et al*., in a study on women from urban settings, noted that the respondents preferred text messages over voice calls.[24]

Notably, no literature is available from India on the preferred frequency of mHealth service delivery among mental health service users. Our study has bridged this knowledge gap by adding information that service users prefer a twice-weekly service frequency. Furthermore, in our study, reminders about appointments and medications emerged as the most pressing need,

followed by helplines, and this is at variance with what was noted in the North Indian study.[16]

These results have important implications for research translation. For instance, forgetfulness has been shown to be a major barrier to medication adherence,[25] and therefore, daily reminders may make theoretical sense. Emerging evidence,[26-28] however, has suggested that people are more likely to view daily reminders as spamming and suggest that twice-weekly reminders may confer advantages both in terms of clinical effects and patient retention. This, juxtaposed with our study findings, suggests a definite need to examine the comparative efficacy of twice-weekly versus daily reminders on target outcomes such as medication adherence in people with mental illness.

There are some limitations to the present study. This study was conducted wholly among patients with SMI attending a tertiary hospital, and the results may not necessarily generalize to other settings and common mental disorders. The questionnaire was presented in a multiple-choice format, and this limits the amount of information that can be captured as opposed to say open-ended questions or focus group discussions. However, we did include response options such as "others" for certain questions, to capture answers not included in the preprinted response categories and allowed multiple responses for questions wherever applicable, to elicit maximum information. No formal validity or pilot testing of the questionnaire was undertaken prior to using it. As the percentage of nonmobile phone users was small, we could not compare the groups meaningfully for differences. The cross-sectional study design also precludes conclusions about whether user felt needs and preferences might change with time and initiation to mHealth approaches.

The strengths of the study include studying the treatment needs and preferences among a population where mHealth approaches may have greater relevance due to a high treatment gap. We have used a prevalidated questionnaire but modified it with an additional question to elicit preferred service frequency among people with SMI about which there is no information thus far in our population. The study results are, therefore, expected to inform the planning and implementation of mHealth strategies that have maximum chances of success.

In conclusion, the study shows that mobile phones are a feasible and acceptable medium for service delivery and may be considered to overcome various health care challenges among patients with SMI. Majority of the patients desired to receive reminders about medications and appointments through twice-weekly voice calls. No barriers to ownership were reported by most patients. However, a sizeable minority declined the need for mHealth service delivery, and health care providers must think of other strategies to take care delivery to the doorstep of such individuals.

Financial support and sponsorship

The study received financial support from the Indian Council of Medical Research (ICMR) through their Short-Term Studentship (STS) Scheme (Project no. 2017-02319).

Conflicts of interest

There are no conflicts of interest.

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Original Article

Sexual Dysfunction in Drug-Naïve or Drug-Free Male Patients with Psychosis: Prevalence and Risk Factors

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ABSTRACT

Background: There is a growing body of literature on the high prevalence of sexual dysfunction in patients with psychotic disorders. However, most studies have focused on medication-related sexual side effects. **Material and Methods:** Consecutive males with a diagnosis of acute psychosis or schizophrenia who were either drug-naïve or drug-free for six months were recruited to the study after obtaining informed consent. Sociodemographic and clinical data, psychopathology (using Positive and Negative Syndrome Scale), and sexual functioning (using The International Index of Erectile Functioning and DSM-IV TR criteria) were assessed. Bivariate and multivariate statistics were obtained. **Results:** One hundred males were recruited. The overall prevalence of sexual dysfunction by DSM IV-TR criteria in this population was 17%. The factors that were associated with sexual dysfunction were older age and later age of onset of illness. The rate was higher on excluding those who said that they were not sexually active (25%). **Conclusions:** Sexual dysfunction may be found in patients with psychotic disorders even prior to commencing antipsychotic medications. It is possible that this is contributed to by several factors including the disease process. Assessment of sexual function in these patients will help in early identification and appropriate management.

Key words: *Schizophrenia, sexual dysfunction—prevalence and nature, sexual dysfunction—risk factors*

Key messages: *Impaired sexual functioning may be present prior to initiation of treatment in patients with psychotic disorders. Sexual dysfunction in these patients may be contributed to by the disease process and should be differentiated from sexual side effects due to prolactin-increasing properties of the antipsychotic medication. A detailed assessment of sexual functioning at the onset of treatment may be beneficial.*

The prevalence of sexual dysfunction in men with schizophrenia and other psychotic disorders has been reported to be as high as 80%.[1-3] Despite this being higher than that seen in the general population, which is about 20%,[4] this area has not been adequately researched. As the onset of schizophrenia most often coincides with the reproductive period of a person, sexual dysfunction can significantly affect the quality of life in

Access this article online	
Website: www.ijpm.info	**Quick Response Code**
DOI: 10.4103/IJPSYM.IJPSYM_1_19	

How to cite this article: Ravichandran D, Gopalakrishnan R, Kuruvilla A, Jacob KS. Sexual dysfunction in drug-naïve or drug-free male patients with psychosis: Prevalence and risk factors. Indian J Psychol Med 2019;41:434-9.

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Received: 09th January, 2019, **Accepted:** 16th May, 2019

these patients.[5-7] It has also been reported to contribute to medication non-adherence.[8] As the majority of patients with psychosis do not spontaneously report their sexual difficulties, the magnitude of the problem is often underestimated. However, it is a challenging problem for the clinicians.

Sexual difficulties among patients with schizophrenia are commonly attributed to the side effects of antipsychotic medications.[9] Other etiological factors that have been implicated include impairment in social and personal relationships, negative symptoms of the illness, and comorbid substance use.[5,10,11] There is also increasing evidence to suggest that sexual dysfunction in schizophrenia may be an intrinsic part of the illness, either during its development or as sequelae.[6,12]

Studies on the prevalence of sexual difficulties among drug-naïve patients with psychosis are scarce with a reported prevalence of 30–60%.[2,3,12] This study aimed to assess the prevalence, nature, and risk factors of sexual dysfunction in drug-naïve or drug-free male patients with psychosis using standardized diagnostic criteria and assessment tools in contrast to previous reports. To the best of our knowledge, there have been no published studies from India which have looked at this topic.

MATERIAL AND METHODS

Study design

This study employed a cross-sectional design.

Study setting and site

The study was carried out in a tertiary care psychiatric hospital which provides short-term care for patients with a range of psychiatric diagnoses. Patients were recruited over a period of 12 months from December 2012 to November 2013. Participants were interviewed at the initial presentation to the hospital when in a drug-naïve state or when off antipsychotic medications for at least six months. All patients received treatment as usual.

Subjects

Consecutive male outpatients and inpatients who were Tamil speakers aged between 18 and 60 years, who satisfied International Classification of Diseases - 10 (ICD-10) research diagnostic criteria for acute and transient psychotic disorder or schizophrenia were invited to take part in the study. Those with a history of antipsychotic exposure within the previous 6 months; with severe language, hearing or cognitive impairment; with a diagnosis of primary mood disorder, substance use disorder or organic disorders; with comorbid medical or surgical disorders or concomitant use of other medications which affect sexual functioning; and those who were unable to participate in the interview due to the severity of psychosis were excluded. The details of the study were explained and written informed consent was obtained from the patient and his caregiver. The Institutional Review Board and Ethics Committee approved the study protocol (IRB Min. No. 7940 dated 02.08.2012).

Variables assessed

Sexual functioning of all subjects who consented to take part in the study was assessed using the Tamil version of the International Index of Erectile Function scale (IIEF)[13] and diagnoses were made in accordance to DSM IV-TR criteria for male sexual dysfunctions. The severity of illness was assessed using the Positive and Negative Syndrome Scale (PANSS).[14] Sociodemographic data and clinical variables were recorded in a specially designed proforma. Serum testosterone (early morning fasting sample) and serum sex hormone binding globulin levels were tested, and free testosterone indices were calculated. All assessments were carried out by the first author (DR).

Sample size calculation

The sample size was determined using EpiInfo (Version 6.0; 1993). The calculations were based on the following assumptions: Estimated prevalence of sexual dysfunction in drug naïve men with psychosis 50%, confidence interval 95%, margin of error of estimate 10%, power 80%.[12] The sample size thus obtained was 100.

Data analysis

Mean, standard deviation, and range were employed to describe continuous variables, while frequency distributions were obtained for polychotomous variables. The Chi-square test and Student's t-test were used to assess the significance of the associations for categorical and continuous variables respectively. Spearman's correlation coefficient was employed to study the correlation between continuous variables. Multivariate logistic regression analysis was carried out using factors found significant on univariate analysis. SPSS for Windows (version 16.0.1) was employed for the analysis of data.

RESULTS

One hundred and eight patients who fulfilled the inclusion criteria were invited to take part in the study. Eight patients refused consent, and hence the sample consisted of 100 patients.

Sociodemographic and clinical characteristics are summarized in Table 1. The majority of the patients

Table 1: Socio-demographic and clinical characteristics of the patients

Sociodemographic and clinical characteristics (*n*=100)	Mean (SD)	Frequency (percentage)
Age in years	31.09 (8.43)	-
Religion - Hindu	-	88 (88)
Occupation of the patient - Employed	-	75 (75)
Occupation of the spouse - Employed (*n*=39)	-	21 (54)
Residence - Rural	-	92 (92)
Literacy - Read and write	-	22 (22)
Marital status - Single	-	58 (58)
Duration of marriage in years (*n*=40)	11.61 (7.95)	-
Age of the spouse in years (*n*=39)	31.56 (6.49)	-
Years of schooling	9.51 (4.49)	-
Family's monthly income (INR)	6113 (8303.69)	-
Patient's monthly income (INR)	1785 (4370.47)	-
Debt - Yes	-	69 (69)
No. of sexual partners (*n*=45) - Single sexual partner	-	41 (91)
Separate bedroom - Yes	-	49 (49)
Diagnosis - schizophrenia	-	87 (87)
Age of onset of illness in years	28.27 (7.59)	-
The total duration of illness in months	33.19 (49.41)	-
Weight (kg)	55.29 (9.48)	-
BMI	19.90 (3.32)	-
PANSS		
Positive scale score	24.78 (6.69)	-
Negative scale score	28.51 (7.17)	
General psychopathology score	53.93 (10.15)	
Depression/anxiety factor score	9.37 (4.17)	
Total score	107.22 (19.36)	
Sexual activity in the last one month - present	-	48 (48)
IIEF		
Erectile function	14.44 (12.14)	-
Orgasmic function	4.62 (4.87)	-
Sexual desire	5.67 (2.09)	-
Intercourse satisfaction	4.56 (5.18)	-
Overall satisfaction	6 (2.20)	-
Testosterone level (ng/dL)	431.68 (210.16)	-
Serum sex hormone binding globulin (nmol/L)	38.94 (18.09)	
Free testosterone index (%)	43.78 (24.34)	

Reliable information regarding age of the spouse and occupation of the spouse were not provided by three patients and hence these patients were excluded, resulting in an 'n' of 39. Similarly, two patients did not provide information on duration of marriage, resulting in an 'n' of 40. INR – Indian Rupees; BMI - Body Mass Index; PANSS - Positive and Negative Syndrome Scale; IIEF - International Index of Erectile Function

were single, employed, and with financial debt. Of those who were married, the majority had been married prior to the onset of the illness. Most patients were diagnosed to have schizophrenia, with a mean age of onset of illness of 28.27 years (sd – 7.59 years) and mean duration of illness of 33.19 months (sd – 49.41 months). A minority of patients reported the use of tobacco or alcohol. Nineteen percent of the study subjects had low testosterone levels (less than 290 ng/Dl in males below 50 years, less than 212 ng/Dl in those above 50 years), and 42% had a baseline low free testosterone index (normal range: 33.8%–106%).

Sexual activity

Totally, 52% of the participants said that they had not been sexually active in the past month. Such lack of sexual activity was significantly associated with higher negative symptom ($t = 3.72$, $df = 98$, $P < 0.001$), general psychopathology ($t = 3.72$, $df = 98$, $P < 0.001$), total PANSS scores ($t = 3.94$, $df = 98$, $P < 0.001$), and single marital status ($\chi^2 = 10.11$, $P = 0.001$). Testosterone levels in the normal range ($\chi^2 = 4.42$, $df = 1$, $P = 0{,}036$, higher body mass index ($t = -3.08$, $df = 98$, $P = 0.003$) and older age ($t = -2.24$, $df = 98$, $P = 0.027$) were associated with being sexually active in the past month.

Sexual dysfunction

17% of the participants reported sexual dysfunction based on the DSM-IV TR criteria. The most common sexual dysfunction was hypoactive sexual desire disorder. Premature ejaculation, male erectile disorder, and orgasmic dysfunction were also reported [Table 2]. IIEF was administered to all participants. Two patients qualified for erectile dysfunction based on the IIEF score and four satisfied DSM-IV-TR criteria.

DSM-IV TR[15] stipulates that in order to make a diagnosis of sexual dysfunction, sexual difficulties should cause significant distress to the individual. On excluding the distress criterion, the overall prevalence of sexual dysfunction increased to 70%, the majority of which were hypoactive sexual desire disorders.

Risk factors associated with sexual dysfunction

Sexual dysfunction of any type was associated with increasing age, later age of onset of illness, married status, presence of financial debt, and higher PANSS depression/anxiety factor [Table 3]. There was no association between sexual dysfunction and the severity of illness or serum testosterone levels. Similarly, there was no correlation between serum testosterone levels and IIEF erectile function scores among those patients who reported to be sexually active.

PANSS negative score had a weak correlation with IIEF subscales of erectile function ($\rho = -0.428, P < 0.001$), orgasmic function ($\rho = -0.373$, $P < 0.001$), sexual desire ($\rho = -0.333$, $P = 0.001$) and intercourse satisfaction ($\rho = -0.353, P < 0.001$). Similarly, PANSS general psychopathology score correlated with erectile function ($\rho = -0.373$, $P < 0.001$), orgasmic function ($\rho = -0.297$, $P = 0.003$), sexual desire ($\rho = -0.301$, $P = 0.002$) and intercourse satisfaction ($\rho = -0.340$, $P = 0.001$). PANSS total score correlated with erectile function ($\rho = -0.401$, $P < 0.001$), orgasmic function ($\rho = -0.343$, $P < 0.001$), sexual desire ($\rho = -0.311$, $P = 0.001$) and intercourse satisfaction ($\rho = -0.346$, $P < 0.001$).

Presence of financial debt (OR = 0.16, CI = 0.03-0.81, $P = 0.027$) and PANSS depression/anxiety factor (OR = 1.17, CI = 1.02-1.34, $P = 0.022$) remained statistically significant on logistic regression when adjusted for age.

Table 2: Prevalence of sexual dysfunction

Type of sexual dysfunction	Prevalence	
	DSM-IV TR criteria (*n*=100)	DSM-IV TR criteria and sexually active (*n*=48)
Hypoactive Sexual Desire Disorder		
Overall	14 (14%)	18.8%
Single	4 (6.9%)	
Married	10 (23.8%)	
Premature Ejaculation		
Overall	5 (5%)	10.4%
Single	-	
Married	5 (11.9%)	
Male Erectile Disorder		
Overall	4 (4%)	
Single	2 (3.4%)	8.3%
Married	2 (4.8%)	
Orgasmic Dysfunction		
Overall	1 (1%)	
Single	1 (1.7%)	2.1%
Married	-	
Prevalence		
Overall	17 (17%)	25%
Single	5 (8.6%)	
Married	12 (28.6%)	

None of the patients fulfilled criteria for sexual aversion or sexual pain disorder. Marital status: Single n=58, Married n=42

DISCUSSION

This study attempted to document the prevalence and characteristics of sexual dysfunction in drug-naïve patients with psychosis, in contrast to most other

Table 3: Factors associated with sexual dysfunction in drug-naïve patients with psychosis - bivariate and multivariate statistics

Socio-demographic and clinical characteristics	Sexual dysfunction		Bi-variate statistics			Multivariate statistics[$] (Adjusted for age)	
	Present (*n*=17)	Absent (*n*=83)	df	t/χ^2	*P*	Odds ratio (CI)	*P*
Age in years (sd)	35.18 (8.23)	30.25 (8.27)	98	-2.24	0.028*	-	-
Marital status							
Single	5	53	1	6.87	0.009*#	0.31 (0.07-1.31)	0.112
Ever married	12	30					
Financial debt							
Yes	15	54	1	3.54	0.084*#	0.16* (0.03-0.81)	0.027*
No	2	29					
Number of sexual partners	0.94 (0.9)	0.45 (0.67)	98	-2.62	0.01*	-	-
Age of onset in years (sd)	33.47 (8.38)	27.2 (7.01)	98	-3.25	0.002*	1.20 (0.99-1.46)	0.062
PANSS - positive score (sd)	24.29 (6.05)	24.88 (6.84)	98	0.33	0.744	-	-
PANSS - negative score (sd)	27.06 (7.4)	28.81 (7.14)	98	0.92	0.363	-	-
PANSS - general psychopathology score (sd)	55.59 (10.33)	53.59 (10.14)	98	0.74	0.462	-	-
PANSS - depression/anxiety factor (sd)	11.24 (4.48)	8.99 (4.02)	98	-2.06	0.042*	1.17 (1.02-1.34)	0.022*
PANSS - total score (sd)	106.94 (20.03)	107.28 (19.34)	98	-0.07	0.948	-	-

PANSS – Positive and Negative Syndrome Scale; *t*=*t* value on Independent *t*-test; χ^2=Pearson Chi-Square value; df – Degree of freedom. The following variables were not significantly related to the presence of sexual dysfunction: years of schooling, place of residence, number of people living in the household, separate bedroom, substance use, duration of illness, serum testosterone level and BMI. [$]Logistic regression adjusted for age. [#]Fisher's exact test *P*. *$P<0.05$

studies that have focused primarily on the prevalence of sexual dysfunction and the effect of medications on sexual functioning.[5,9]

The overall prevalence of sexual dysfunction in this hospital sample was 17%, which increased to 25% on including only those patients who were sexually active. These rates are lower than the prevalence reported in the general population in this region.[4] The EUFEST trial in patients with first-episode schizophrenia reported decreased libido in 30.8%, erectile dysfunction in 17.7% and orgasmic dysfunction in 15%, while Sabry *et al*. reported a prevalence of 64% in their report on 50 drug naïve men with psychosis from Egypt.[2,3] The varying prevalence rates can be explained by the differences in sample selection and assessment criteria.[15-17] In contrast to this study which used the DSM-IV TR diagnostic criteria, previous studies used questionnaires to assess sexual functioning. The mechanical use of assessment instruments may have resulted in higher rates, as these often do not take into account the distress and broader personal and social context that are necessary for a contextual diagnosis of sexual dysfunction.[18] One could also attempt to explain the lower prevalence rates as secondary to the severity of psychopathology;[19] however, there was no statistically significant difference between the two groups based on PANSS positive symptom score in this investigation. Another possible explanation is that partners are more concerned about positive psychotic symptoms and poor occupational and social functioning, and consequently, do not regard sexual dysfunction as a priority, resulting in the under-reporting of it as a problem.

The DSM IV-TR includes distress related to sexual dysfunction as a criterion for diagnosis. Those who did report distress were those who had a lower negative symptom score. This may suggest that patients with significant deficits related to the illness may be less concerned about the sexual difficulties.[5,6] The presence of reduced sexual desire and negative symptoms may explain the lack of distress.

Age was found to be an independent risk factor for sexual dysfunction, and this has been well documented in several other studies as well.[20] Sexual dysfunction and related distress were found to be significantly associated with a later age of onset of illness and married status. While an early onset of the psychotic illness may interfere with the sexual maturation of an individual, later onset of illness following a period of normal sexual functioning may result in greater distress. Many of the single males in the sample were not sexually active. Possible explanations for this could be the fact that the cultural milieu in India does not encourage premarital sex, in addition to which patients with psychosis may not have the social sophistication or resources required for a romantic relationship to progress to a sexual relationship. Such patients may consequently be unaware of their sexual difficulties and therefore report less distress.

There was no association between sexual dysfunction and serum testosterone levels. The lower testosterone levels frequently reported in patients with schizophrenia are most often secondary to antipsychotic medication-related hyperprolactinemia. Negative symptoms are known to be associated with poor functioning in all aspects of life: sexual functioning also appears to be affected, as evidenced by the correlation between negative symptom and IIEF scores in exploratory analysis.

The study adds to the sparse literature on the subject. Its advantages include the use of standard tools for the assessment of sexual dysfunction and psychosis, enrollment of consecutive subjects, the relatively large sample size, and the use of biological parameters and multivariate statistics. Information from the partner provided a useful supplement to patient information; however, it was not possible in patients who were unmarried or living alone. While more objective measurements of sexual functioning to improve reliability would be ideal, these would be time-consuming, resource intensive, and fraught with ethical problems. While the sociodemographic and clinical factors described above were found to be associated with sexual dysfunction, the cross-sectional nature of this study does not allow us to comment on the direction of the relationship. Sexuality is a complex interplay of biological and psychosocial factors, and different kinds of stress are known to have an adverse impact on sexual functioning.

CONCLUSIONS

Impaired sexual functioning is evident prior to initiation of treatment in patients with psychotic disorders. This may suggest that sexual dysfunction in these patients may be contributed to by the disease process and should be differentiated from dysfunction secondary to the prolactin-increasing properties of the antipsychotic medications. A detailed assessment of sexual functioning at the onset of treatment will help in establishing the multidirectional relationships between psychopathology, antipsychotic medication side effects and sexuality, which can improve both psychiatric and sexological treatment.

Financial support and sponsorship
This study was funded by Fluid Research Grant No. 22X921 from Christian Medical College, Vellore.

Conflicts of interest

There are no conflicts of interest.

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Original Article

Perception about Marriage among Caregivers of Patients with Schizophrenia and Bipolar Disorder

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ABSTRACT

Background: Marriage has a complex relationship with mental illness. The marriage of a person with mental illness (PMI) is a controversial issue with varied opinions. There is a dearth of studies exploring perception about marriage among caregivers of patients with severe mental disorders. **Materials and Methods:** Thirty caregivers were interviewed in depth using a semi-structured interview schedule. Quantitative data were analyzed using MS Excel, while qualitative data were interpreted based on Colaizzi's framework. **Results:** About half (53%) of the caregivers believed that PMI should marry, and 46% of caregivers believed that marriage could worsen the mental illness of their patient. The qualitative analysis showed that factors that affect the decision among caregivers to get their mentally ill wards married include shovelling off the stigma of keeping the unmarried ward at home and to have somebody to take care of the unmarried ward after their death. Many caregivers believe that marriage and/or sexual intercourse can be a cure/treatment for various mental disorders. **Conclusion:** Caregivers of patients with severe mental illness have many misconceptions about the association of marriage and outcome of mental illnesses.

Key words: *Caregiver, marriage, mental illness*

Key messages: *Slightly more than half of the family caregivers of patients with severe mental illnesses believe that people with severe mental illnesses should get married. Family caregivers of patients with severe mental illnesses have many misconceptions about the association of marriage and mental illness.*

Marriage is a consensual and contractual relationship recognized by law.[1] According to historical perspective, marriage exists in one form or another in every culture, ensures social agreement to a physical union between man and woman, and acts as a building block for the family.[2] Besides the physical union, marriage is also associated with multiple emotional, social, and occupational demands.[1]

Marriage is an important institution in human society and particularly so in eastern countries. In India, it is

Access this article online	
Website: www.ijpm.info	Quick Response Code
DOI: 10.4103/IJPSYM.IJPSYM_18_19	

How to cite this article: Kumar P, Sharma N, Ghai S, Grover S. Perception about marriage among caregivers of patients with schizophrenia and bipolar disorder. Indian J Psychol Med 2019;41:440-7.

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Received: 12th January, 2019, **Accepted:** 16th June, 2019

almost compulsory for every individual to marry and "settle down" and is considered an important event of life which affects the social position of a person. In Indian society, being unmarried after a certain age is considered a stigma.[3]

Marriage has a complex relationship with mental health. Marriage is considered as an opportunity for growth and development in all spheres of life. It can provide social support and security for some people; at the same time, it can also act as a stressor and precipitate mental illness or crisis in vulnerable individuals.[4] The relationship gets even more complex when it is about the marriage of a person with mental illness (PMI). Data suggest that PMIs have higher rates of separation and divorce.[5] Chronic mental illnesses such as schizophrenia and bipolar affective disorder (BPAD) possibly reduce the abilities required for marital adjustment and increase the chances of marital disharmony.[6] However, for some, marriage can be a source of social support.[1]

Although marriage is a well-established norm in Indian society, when it comes to the marriage of a PMI, it is often associated with stigma and scepticism. Looking at the marriage of a PMI from the human rights perspective, it should not be in any way different from the marriage of any other individual. However, when one takes into account the various factors associated with the marriage of PMI, issues such as the risk of relapse, inability to carry out the responsibility, stigma attached to getting married to a PMI, and high probability of marital discord, the issue of marriage of PMI turns controversial. There are also cultural beliefs which suggest that marriage can be therapeutic for people with mental illness, and according to the prevalent myths, marriage is at times considered a cure for mental illnesses.[7]

While the public at large can be prejudiced about the marriage of a mentally ill individual, PMI and their family members may perceive the entire situation altogether with a different perspective. However, data with regard to the perception of the caregivers about the marriage of a PMI are grossly lacking. This study, thus, aimed to explore the perception of caregivers of patients with severe mental illness about the marriage of persons with severe mental illness.

MATERIALS AND METHODS

Setting

This study was carried out in the Department of Psychiatry of a tertiary care hospital in north India. The department provides extensive mental health services at both inpatient and outpatient basis. The study was approved by the Institute Ethics Committee, and all the participants were recruited after obtaining written informed consent.

The study followed a cross-sectional design, in which all the participants were evaluated only once. The study sample was selected using purposive sampling.

To be included in the study, the caregivers required to have a family member diagnosed with either schizophrenia or BPAD by a qualified psychiatrist using the ICD-10 criteria,[8] who was aged >18 years and unmarried. To be included in the study, the caregivers were required to be biologically related to the patients and responsible for making the decision regarding the marriage of their relative with mental illness.

The selection of the study participants was done by the treating consultant who referred the patient to the researcher after briefing about the purpose of the study. The researcher further detailed them on the study objectives and obtained the written informed consent.

Research tool

Data were collected using an interview schedule which had guiding questions for further interview. The items on the interview schedule aimed to assess various aspects of the marriage of a PMI from a caregiver's perspective. The questions were formulated in such a way that there was a chance for expansion into various thoughts and views. The interview schedule was designed by a group of experts working in the area of mental health and aware of the prevalent cultural norms about marriage in the society. The schedule comprised a total of 24 questions. Each question aimed to explore distinct aspects of marriage and mental illness. Certain questions posed a generalized query, like "Should people with mental illness get married? If yes, why? If no, why?" Other questions were personalized to the family member of a PMI, like "What do you think about the marriage of your son/daughter/brother/sister?" The schedule was developed with an intention to get an in-depth understanding of the caregiver's perception. Thus, questions included exploration of the perception of association of marriage of PMI and relationship of marriage with cure, recovery, worsening, and the onset of mental illness. The issue of disclosing the mental illness to the family of the prospective partner was also evaluated. In addition, some of the questions evaluated the general understanding of the caregivers about mental illnesses and their expectations from treatment. Some of the questions used to assess these aspects included "According to you, what is the cause of your patient's mental illness?" and "Do you think anything else besides medications can help in the management of your patient's illness?"

The face validity of the interview schedule was established by seeking the opinions of experts in the fields of psychiatry, clinical psychology, psychiatric nursing, and psychiatric social work.

Procedure

The researcher had an initial rapport building session with the caregiver, and this was followed by an in-depth interview. The interviews were conducted on a one-to-one basis. The interview room provided a conducive environment and privacy. The time spent on each interview varied from half an hour to one hour, depending on the length of the responses given by the caregiver. While some caregivers gave elaborate responses, others preferred to be brief in their responses. All the interviews were audio-taped and transcribed within 24 h. Initially, the script was prepared in Hindi, and then, it was translated into English by experts who were fluent in both the languages. To ensure the trustworthiness of transcripts, these were double-checked by a bilingual translator who was competent in both Hindi and English.

Data analysis

The quantitative data were analyzed in the form of mean, standard deviation, frequency, and percentages. The qualitative data were interpreted by following the steps described by Colaizzi[9] and included reading and re-reading of participant's description to acquire feeling for their experience and making sense of their account. The first step of the analysis included reading each transcript several times to gain an understanding of the whole content. During the second stage of the analysis, the significant statements or verbatim were extracted and written on separate sheets, with corresponding participant code. After extracting the significant statements, two researchers (PK and NS) independently assessed the themes first and later cross-checked with each other and reached a consensus. In the third step of the analysis, the meanings for each significant statement were extracted and coded under categories. Then, both the researchers compared these formulated meanings and reached a consensus about including the descriptions/items. The whole statements and their meanings were checked by an expert researcher (SG, fourth author) who ensured that the correct process was followed and that the meanings of the statements were consistent. In the next step, the formulated meanings were categorized as clusters of the theme. Both researchers compared their clusters of themes and checked the accuracy of the overall thematic map. To establish the trustworthiness of the study findings, peer review of the emerging ideas was done through discussions with the study supervisors (SG and SG) and an independent researcher.

RESULTS

Table 1 depicts the sociodemographic profile of the caregivers. Most of them were the parents of PMI.

Perception about marriage and mental illness

Based on the responses to the in-depth interview, some quantitative findings were generated [Table 2]. About 53% of the caregivers felt that people with mental illness should get married, and 26.7% of the caregivers felt that marriage could be a cure for mental illness of their ill relative. About 30% the caregivers felt that marriage could help in improving the mental illness of their patient and 46.7% of the caregivers felt that marriage could worsen mental illness of their patient. In terms of searching for an alliance, 90% of the caregivers reported that they had never looked for an alliance for

Table 1: Sociodemographic profile of caregivers of mentally ill patients (*n*=30)

Parameters	Caregivers *n*=30 Mean (SD)/frequency (%)
Gender	
Male	18 (60)
Female	12 (40)
Age (years)	49.2 (12.3) (range: 21-67)
Age (years)	
15-30	2 (6.7)
31-45	7 (23.3)
46-60	13 (43.3)
61-75	8 (26.7)
Educational status	
Primary	6 (20)
Matric	7 (23.3)
10+2/diploma	7 (23.3)
Graduate	4 (13.3)
Master/professional	6 (20)
Occupation	
Professional	4 (13.3)
Skilled worker	4 (13.3)
Unskilled worker	1 (3.3)
Unemployed	11 (36.7)
Clerical/shop owner/farmer	6 (20)
Retired pensioner	4 (13.3)
Per capita income (Rs.)	
≤15,000	27 (90)
15,001-30,000	2 (6.7)
≥30,001	1 (3.3)
Per capita income (Rs.) (mean and SD)	8016.66 (10914.62) (range: 500-55,000)
Marital status	
Married	26 (86.7)
Unmarried	4 (13.3)
Relationship with the patient	
Father	10 (33.3)
Mother	13 (43.3)
Siblings	6 (20)
Other	1 (3.3)
Presence of medical morbidity	
Yes	11 (36.7)
No	19 (63.3)

SD–Standard deviation

Table 2: Frequency distribution of themes of responses on semi-structured interview

Items	Frequency (%)			
	Yes	No	Depends on situation	No idea
Should people with mental illness get married?	16 (53.3)	3 (10)	11 (36.7)	-
Can marriage be a cure for mental illness of your patient?	8 (26.7)	5 (16.7)	7 (23.3)	10 (33.3)
Can marriage help in improving mental illness of your patient?	9 (30)	5 (16.7)	8 (26.7)	8 (26.7)
Can marriage worsen mental illness of your patient?	14 (46.7)	5 (16.7)	6 (16.7)	5 (16.7)
Do you know any person whose mental illness improved after marriage?	8 (26.7)	22 (73.3)	-	-
Do you know any mentally ill person whose mental illness started after marriage?	7 (23.3)	23 (76.7)	-	-
Do you know any mentally ill person whose mental illness worsened after marriage?	4 (13.3)	26 (86.7)	-	-
Did you ever look for a match for the marriage of your patient?	3 (10)	27 (90)	-	-
Did you ever discuss the issue of marriage of your patient with your doctor?	5 (16.7)	25 (83.3)	-	-
Suppose you are looking for a match for one of your other child or a relative and you are told that the prospective match which you selected has a mental illness, would you agree for the marriage?	4 (13.3)	19 (63.3)	7 (23.3)	-
Do you think one purpose of getting married is to fulfill the sexual desire?	16 (53.3)	4 (13.3)	-	10 (33.3)
Can fulfillment of sexual desire in wedlock or outside the wedlock improve mental illness of your patients?	12 (40)	8 (26.7)	-	10 (33.3)
Will your patient be able to take responsibilities of his/her family after marriage?	22 (73.3)	6 (20)	-	2 (6.7)
Did the doctor tell you about the name of your patient's illness?	22 (73.3)	8 (26.7)	-	-
Have the doctor told you about the prognosis of your patient's mental illness?	18 (60)	12 (40)	-	-
Have the doctor told you about the duration of your patient's treatment?	25 (83.3)	5 (16.7)	-	-

their mentally ill ward. Surprisingly, only 16% of the caregivers ever discussed the issue of marriage of their mentally ill ward with their treating doctor. Around 53% of the caregivers believed that one purpose of getting married is to fulfil the sexual desire and 40% of the caregivers believed that fulfilment of sexual desire within or outside the wedlock could improve the mental illness of their patients. About 73% of the caregivers were optimistic about their patient's ability to take up the responsibilities of the family after marriage.

Qualitative responses

When the caregivers were asked "should people with mental illness marry?"53% gave a response in assertion, while 10% responded contrary to this. About one-third (36%) of the caregivers were not sure about the same and responded that the issue would depend on the situation. On further enquiry, those who had responded in affirmation elaborated that "marriage can improve mental illness and that marriage is important to shovel off the stigma of keeping an unmarried ward at home, especially a female. Parents of males with mental illness reported that there would be someone to care for a patient after the death of the parents, that marriage is an important part of life, and that it is a rule of society and an age-old norm." Some of the caregivers reported, "Getting their child married is a desire and responsibility of every parent—Hence, irrespective of mental illness, all the parents should be allowed to fulfil their desire and responsibility." The 10% of caregivers who reported that a patient with mental illness should not marry felt that "marriage and related discord can worsen mental illness and lead to relapse." One of them also cited the risk of hereditary transmission as one of the reasons for not getting their mentally ill relative married. One-third of the caregivers felt that there cannot be one clear-cut answer to the question and elaborated that the decision of marriage of mentally ill persons is contingent upon various factors such as the patient's ability to earn or care for self ($n = 2$), severity of mental illness (as the patients with illness of less severity can consider marriage ($n = 8$), and the patient's own willingness for marriage ($n = 1$). The other factors to be considered were the risk of relapse and hope for recovery with treatment/medication.

When asked specifically about the marriage of their own ward/relative, about one-fourth of caregivers ($n = 7$) were considering getting their mentally ill relative married only after recovery. Six of the caregivers wished that their ward should get married, but only after some improvement, if not complete recovery. Another group of caregivers felt that they would consider getting their ward married only after he or she becomes self-dependent, gets a job, or attains the ability to rear children ($n = 3$). A caregiver of a female patient expressed that "doing household work would be enough to make their child eligible for marriage." A father showed ambivalence with regard to the marriage of his mentally ill son, "I'm not sure whether to get him married or not—There is always a risk due to the episodic nature of the mental illness." One of the caregiver was even ready to compromise in terms of getting their patient married with a partner from low socioeconomic status. One of the caregivers also reported that they have not been able to take any decision regarding the marriage of their relative, owing to which they have started avoiding social gatherings and functions.

When asked "can marriage cure mental illness of your ward/relative?" one-fourth of the caregivers expressed that marriage can be a cure for mental illness of their relative with mental illness. Those who felt so believed that marriage could cure mental illness through a reduction in mental stress and a diversion of mind. On the other hand, a few caregivers (n = 5) felt that marriage could not cure mental illness. One of the parents stated that "the concept that marriage improves mental illness is an outdated one. Understanding about mental illness has increased over the years." A caregiver clearly reported that "marriage is not a medication" and that "It is a misconception in the society that an illness like schizophrenia is curable by any available means."

On enquiry about "can marriage improve mental illness of your ward/relative?" 30% of the caregivers felt that marriage could lead to an improvement in the mental illness of their patient. Furthermore, some of them elaborated that the improvement is likely to occur through a reduction in stress through communication with the partner. One of the caregivers quoted a real-life practical example, mentioning a patient who recovered after marriage, had children, and was leading a comfortable life. Another caregiver described that "after marriage, the routine of the life gets organized, which helps in the recovery of the mental illness." Four caregivers felt that marriage could not improve mental illness, as marriage is not a medication for it, and three caregivers felt that there is no relation between marriage and mental illness. Six caregivers felt that improvement in mental illness after marriage depends on marital adjustment, marital understanding, and love with the partner. One of the caregivers said "If the mentally ill person is treated with love, there is a likelihood of improvement, and if the potential partner understands the patient's nature, then the illness can improve." A few caregivers stated that improvement in mental illness after marriage would be dependent on the cause of the illness and the medication compliance after the marriage. While most of the caregivers attributed the outcome of marriage to factors related to a potential partner, one of them attributed it to the patient's mental makeup and desire as well as his or her ability to maintain discipline in day-to-day life activities. Another caregiver reported that the outcome of marriage would depend on medication compliance after marriage and not on marriage *per se*.

When asked "Can marriage worsen mental illness of your patient?" about half (47%) of the caregivers agreed that marriage could worsen mental illness of their patient. They felt that marriage is a stressful phase of life for a normal person as well. Two caregivers felt that worsening of mental illness is also possible if information about their patient being suffering from a mental illness is concealed from the other party. Lack of cordial relation with the partner, lack of adjustment with the partner, and conflict and quarrel with the partner can cause worsening. Some of the caregivers believed that marriage could not worsen mental illness, as other family members will also be available for care for a PMI. Some of the caregivers felt that the impact of marriage on the outcome of mental illness is contingent upon certain factors such as the presence of a mutual understanding between the partners and medication compliance. One of the caregivers felt that the worsening of mental illness can also depend on the patient's ability to carry out his or her responsibilities.

In terms of looking for a match, when enquired "did you ever look for a match for the marriage of your ill relative?" the majority (90%) of caregivers revealed they never did so, taking into account the patient's poor will power and inability to take independent decisions. While one of the caregivers was not mentally prepared for the marriage of the ward, a few others felt they would consider marriage of their mentally ill ward after the marriage of other children. Some of the caregivers expressed that they were waiting for their child to attain appropriate age for marriage, while others felt they would consider marriage after the child completes education. One of the caregivers mentioned that they would consider their ward's choice in his or her marriage. A small fraction of caregivers (10%) had looked for a match for their mentally ill ward. They too expressed doubts about the sustainability of marriage. The caregivers were even ready to compromise on the economic background of the prospective partner.

When given a hypothetical situation, "Suppose you are looking for a match for one of your other child or a relative (who does not have mental illness) and you are told that the prospective match which you have selected has a mental illness, would you agree for the marriage?" only 13.3% of caregivers agreed that they would go ahead for such an alliance, and about two-third disagreed to get their children married to a PMI. However, on further probing, one of the caregivers agreed that they would go ahead with such an alliance, provided everything is revealed about the mental illness by the other party. Some of the caregivers said that marriage with a mentally ill person would pose an additional burden. They felt that marriage with a mentally ill person could lead to problems. Two of the caregivers asked "Why should a normal person marry a mentally ill person?" Another caregiver expressed that "getting their child married with a mentally ill person means putting their own child in turmoil." It was also felt by one of the caregivers that "everyone expects a suitable match, PMI do not make a proper

match." About one-fourth of the caregivers gave a situation-based response regarding the marriage of their normal ward with a PMI. Three caregivers expressed that they would agree if there is a scope of improvement in the mental illness in the future. Another group of caregivers told that if the disease is serious, they would not agree. Three caregivers responded that if the patient is stable with medication or gets cured, they would agree. A few of the caregivers also felt that if the person is self-dependent, can manage the family, and can adjust with the spouse, they would agree.

When the caregivers were asked about the purpose behind getting their ward married, the most commonly expressed purpose was to have one's own family, which was reported by 10 caregivers. The other commonly reported purpose of marriage was family proliferation, taking forward the family name, and completion of the family cycle. The other caregivers cited fulfillment of parental responsibility as the purpose of marriage. "Companionship" was also cited as one of the purposes by a caregiver. A few caregivers also felt that marriage is important to obtain some moral and social support.

When the caregivers were asked whether the purpose of marriage is to fulfill the sexual desire, more than half (53.3%) expressed that this was true, and on further elaboration, the most common theme was "sex is a part of marriage; however, the purpose of getting married is not to fulfill the sexual desire only." However, other caregivers answered the question in a negative way.

When an attempt was made to understand the relationship of marriage with sexual intercourse and the caregivers were asked "Can the fulfillment of sexual desire in a wedlock or outside the wedlock improve the mental illness of your patients?" a majority of the caregivers (60%) agreed that fulfillment of the sexual desire of a PMI could lead to an improvement in mental illness. A smaller fraction of caregivers felt that sexual intercourse will provide momentary diversion and can aid in recovery. A few caregivers felt that mental illness could improve by mutual cordial communication and not by fulfillment of sexual desire. One caregiver felt that sexual relationships could act as a diversion but not a treatment. One of them said "medications are the only form of treatment." Some of the caregivers were ambivalent and verbalized that sexual intercourse may or may not improve mental illness. A caregiver expressed that "sex cannot be a cure for mental illness—if it had been so, married people would not have mental illness, but this is not true."

When asked if their patient/ward will be able to take responsibilities of his or her family after marriage, three-fourths (73%) of caregivers were optimistic about it. Nine caregivers felt that since their ward is able to perform household works, he or she has the ability to take responsibilities of his or her family after marriage. Two caregivers also felt that because the patient is already engaged in other family responsibilities and is performing well outside, there are chances that he or she shall be able to take responsibilities of his or her family after marriage. One of the caregivers felt that his ward was not abusing any drugs nor had any other bad habits, so he will be able to take up the responsibilities. Two other caregivers were optimistic, yet they felt that the real picture would be revealed only after marriage.

When asked whether they discussed the issue of marriage of their patient with their doctor, only a minority ($n = 5$) told that they had discussed it with the treating psychiatrist. Two caregivers said that the doctor suggested revealing about mental illness to the other party. Another common advice offered by the doctor was not to hurry for marriage. One of them explained that the doctor advised to marry the patient only after he or she becomes independent.

DISCUSSION

Marriage is one of the important social institutions which provides an opportunity to both the partners to satisfy their physical, psychological, social, cultural, and economic needs. It also permits an opportunity for the couple to establish a stable relationship with each other to form a family.[2] In a country like India, marriage is a social institution of extreme importance. However, the issue turns controversial when it comes to the marriage of a PMI. There is a great deal of stigma associated with mental illness *per se*, which makes the marriage of a PMI an issue.[10,11] Treating mental health professionals are often asked about the possibility of getting their mentally ill child married, and there are no clear-cut answers. Furthermore, many a time, mental health professionals encounter situations where they find that patient has been married, despite parents being explained the pros and cons of the same on the course of mental illness.

The general public has a preconceived negative notion about mental illnesses,[10,12] which influences the marriage decision and prospects. Although the general public has a negative view about the marriage of mentally ill subjects, little is known about what their caregivers, who actually decide about the marriage of the mentally ill relatives, think. Although some studies have evaluated the impact of mental illness on marriage and vice versa,[13] little is known about what the parents/caregivers of patients with mental illness think about the marriage of mental illness. This study attempted to explore the beliefs of caregivers of patients with mental

illnesses regarding the marriage of PMI in general and the marriage of their own mentally ill family member. The basic question addressed in the study was, "Should a PMI marry?" As there are no previous studies on this topic, it is not possible to compare the findings of this study with the existing literature. In view of this, an attempt is made to discuss the findings in the context of the existing sociocultural norms and what can be done by the mental health professionals to change the behavior and attitude of caregivers toward the marriage of PMI.

This study reveals that in general, parents/caregivers of patients with mental illness are inclined to get their child/relative married. This is possibly fuelled by the existing social structure with respect to marriage and presence of other beliefs which suggest that marriage and/or sexual intercourse can lead to improvement/cure of mental illness.[3,14] This is despite the fact that the relatives/parents are aware that marriage can worsen mental illness. This study also reflects that it is not just the social norm of getting married that influences the parental decision of getting their children with mental illness married. Other social factors such as having someone to care for the patient after their death and their desire to get their children married also influences the decision of marriage. Furthermore, the decision for marriage is also influenced by the belief of the parents/relatives that PMI will be able to take responsibility for the family after marriage.

This study also reflects that most of the parents/relatives do not discuss the issue of marriage with the treating psychiatrists. This possibly also shows the apathy of the treating psychiatrists toward this social issue or possibly reflects their presumption that they will not be able to do anything about such issues. Accordingly, it can be said that psychiatrists should be proactive in discussing the issue of marriage with the caregivers and explain the pros and cons of the same. During psychoeducation about the illness, the mental health professionals should devote sufficient time to discuss the issue of marriage and clear the myths in the minds of the parents/caregivers. The caregivers should be clearly explained about the association of worsening/relapse of mental illness with different stressors arising as part of the wedlock. In addition, mental health professionals should also explain the caregivers as to how supportive relationships can prevent relapse and improve the overall outcome of mental illness. This could possibly help the caregivers to take an informed decision. The mental health professionals must also inform them about the legal status of the marriage of a PMI and about the consequences of not informing the family of the partner about mental illness prior to marriage, especially if the illness is of serious nature.

In general, it is believed that most people in the society consider mental illness as a disqualification for marriage and would not consent to marriage if told directly about the presence of mental illness in the other party. The finding of this study supports this general belief. This study also reveals that although the parents want their relatives with mental illness to get married, they are not prepared to accept a match of a PMI for their children/relatives who do not have a mental illness. This finding shows the double standards being followed in the society and stigma attached to mental illness. Accordingly, if it is desired that the attitude of society changes toward the marriage of people with mental illnesses, there is a need to reduce the stigma associated with mental illness. Furthermore, there is a need to amend the laws related to the marriage of PMI in the country. According to the Hindu Marriage Act, marriage can be annulled if any of the party is not capable of giving a valid consent for marriage as a result of unsoundness of mind, or even though capable of giving consent should not be suffering from a mental illness of such a nature or extent that makes them unfit for marriage and procreation of children and should not be suffering from recurrent attacks of insanity. Some of the authors have argued that with the advancements in treatment of mental illnesses, there is a need to amend the law.[15] This will possibly reduce the stigma associated with the marriage of PMI.

This study has certain limitations. It is known that attitude toward mental illness and marriage differs across different regions of the country. Accordingly, the findings of this study must be interpreted in light of the same. As most of the patients were on treatment for long, it is quite possible that the attitude and belief about marriage could have been altered by the encounter with mental health professionals. The demographic factors such as the educational and social status of caregivers also can play a major role in the formation of beliefs and attitude, which was not studied in the present investigation. Thus, it is recommended that future studies must attempt to overcome these limitations.

CONCLUSIONS

The present study suggests that a significant proportion of caregivers of patients with severe mental illnesses have many misconceptions about the association of marriage and the outcome of severe mental disorders. Accordingly, the clinicians should always discuss the issue of marriage with the caregivers and try to clarify the misconceptions about the association of mental illness and marriage.

Financial support and sponsorship
Nil.

Conflicts of interest

There are no conflicts of interest.

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Original Article

Marital Problems among Partners of Patients with Bipolar Affective Disorder

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ABSTRACT

Background: Partners of patients with bipolar affective disorder (BPAD) have problems with their marital life. Identification of these problems is important to develop strategies to solve them for improving quality of life. **Aims:** To identify marital distress and problem areas in their marital life among the partners of patients with BPAD. **Materials and Methods:** A cross-sectional descriptive design was used to collect data from 125 participants, 59 males and 66 females, who were partners of patients with BPAD. The study was done in outpatient clinics of Community Mental Health Clinics of District Mental Health Program. Tools used for data collection included a semi-structured interview schedule to collect socio-personal data of partners of patients with BPAD and clinical data of the patient, Couple Satisfaction Index (CSI), and Problem Areas Questionnaire (PAQ). Purposive sampling technique was used. **Results:** Majority of the participants (male - 55.9%, female -54.5%) expressed marital distress on CSI. Handling family finances and career/job decisions were the most problematic areas for male participants, whereas household tasks, handling finances, and career/job decisions were the most problematic areas for female participants. **Conclusion:** A significant proportion of spouses of BPAD patients have marital distress in important areas of life, with a potential for long-term consequences in their lives.

Key words: *Bipolar affective disorder, marital problems, partners*
Key messages: *Marital problems in partners of patients with bipolar disorder is a significant clinical issue deserving attention.*

Bipolar affective disorder (BPAD) can damage relationships and impair various aspects of an individual's life. Marriage may be stressful for vulnerable people, which may lead to the development of mental health problems.[1] Cyclical mood swings may create major changes in the life of individuals, including their marital life. Partners of patients with BPAD face various problems, of which marital problems is an important one.[2] A high proportion of patients with BPAD get married when compared with those suffering from schizophrenia.[3] But, patients with mental disorders have higher rates of marital discord, separation, and divorce.[4] BPAD often starts early in life. Patients who get married often suffer from many

Access this article online	
Website: www.ijpm.info	**Quick Response Code**
DOI: 10.4103/IJPSYM.IJPSYM_409_18	

How to cite this article: Drisya P, Bindumol K, Saleem TK, Narayan D. Marital problems among partners of patients with bipolar affective disorder. Indian J Psychol Med 2019;41:448-54.

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Received: 13th October, 2018, **Accepted:** 11th April, 2019

negative consequences in their marital life due to the illness, and there are high rates of divorce/separation among BPAD patients.[3]

Studies have reported a deteriorating marital process in which an initial concern and caring by the spouse is eventually replaced by resentment and impatient reactions, leading to further complications. Marital problems and conflicts may be common in families in which one of the members is suffering from BPAD.[5] Specific marital problems like sexual dysfunction among patients receiving various psychotropic medications have been reported to be high.[6] Poorer marital adjustment among patients with BPAD and their spouses have been reported earlier.[3]

It is important to understand the marital and sexual adjustments of patients with various mental illnesses and their spouses. Health care providers have a responsibility in identifying these problems. Lack of a warm and comfortable relationship may put great stress on the partner, which may interfere with providing care and support for the patient.

Aims

The study aimed at identifying marital distress and problems areas in their marital life among partners of patients with BPAD. In addition to the primary objective, gender-wise comparison was done and association of these variables with marital distress was analyzed for variables such as age, education, occupation, religion, and type of marriage of the partners, and clinical variables of the patient such as the presence of physical illness, medication, present clinical condition and duration of treatment

MATERIALS AND METHODS

A quantitative descriptive survey approach was used. Twenty-two mental health clinics coming under the District Mental Health Programme (DMHP) were selected as the setting for the study. The partners of patients with BPAD constituted the study population.

The sample consisted of 125 participants accompanying their partners with BPAD attending the community clinics. The sample size was calculated based on previous literature on depression and marital satisfaction, offsetting for variability.[7] Purposive sampling technique was used. Permission for the study was granted by the Institutional Ethics Committee and Scientific Review Committee of the institution. Informed consent was obtained from each participant before data collection.

Tools included a semi-structured interview schedule to collect socio-personal data of partners of patients with BPAD and clinical data of the patient. The CSI[8] was used to identify whether the partners of patients with BPAD reported marital satisfaction or marital distress. This study used the16-item format (CSI- 16), which is available in the public domain. The maximum score possible for CSI-16 is 81, and the minimum score is zero. A score of less than 51.5 indicates marital distress, and a score above this indicate marital satisfaction or couple satisfaction.[9] CSI scales are demonstrated to have strong psychometric properties.[8] The scale was translated to Malayalam and language validity was established by sending the tool to an expert panel of seven members from the field of mental health after the forward and backward translation procedure.

The Problem Areas Questionnaire (PAQ) was used to identify the marital problem areas where the partners of patients with BPAD report dissatisfaction about their spouses' behavior.[10] The tool is available in the public domain for academic use. PAQ lists areas in which couples are often dissatisfied or have disagreements about other's behavior. This scale has 14 items with seven ratings. It is used to identify the problem areas and also to identify the most problematic area from a list of 14 problems. For the purpose of analysis of each item, this study adopted a scoring ranging from 1 to 7. An open space was given at the end of the rating scale for mentioning any other related problem, to which none of the participants responded. PAQ scale was also translated to Malayalam and language validity was established.

Data collection

Data collection was done by the first author during the months of February and March 2017. A pilot study was conducted in a sample of 10, and necessary modifications were made. The investigator went through the written records of each patient attending the clinic, and available details were collected. Patients diagnosed with BPAD as per ICD-10 criteria for mental and behavioral disorders[11] by the treating psychiatrist were selected. Spouses of the patients who accompanied their partner to the clinic were selected, based on the inclusion criteria. Partners who were the primary caregivers and staying with the patient at least for the last six months were included. Partners with known mental illness and significant physical problems were excluded. Using the semi-structured interview and record review, the demographic data of the partners and clinical data of the patients were collected. After providing sufficient instructions, the CSI and PAQ were given to the participants, which were completed by them. Data collection from a participant took approximately 20 minutes, and on

an average, four to six participants were evaluated in a day. The data collected from 125 participants were tabulated, analyzed and interpreted using descriptive and inferential statistics using SPSS 11th version for Windows.

RESULTS

Among the 125 participants, 47.2% (n = 59) were males and 52.8% (n = 66) were females. Also, 35.6% of male participants belonged to age group 51-60, and 31.8% of female participants belonged to the age group 41-50. Similarly, 44.1% of male participants and 45% of female participants had attained secondary school education. Majority of male participants (62.7%, n = 37) were manual laborers, whereas two-thirds of the female participants were unemployed. Most of the participants had a monthly income of less than 2500 rupees, and almost all of them belonged to nuclear families. Majority of the participants belonged to the Hindu religion, had a rural domicile, and were in an arranged marriage. Five female participants did not have any children [Table 1].

For male participants, the mean age at the time of marriage was 28.68 (±6.8) years and for female participants, it was 21.89 (±4.47) years. Mean age at onset of BPAD in male patients was 32.29 (±11.45) years and in female patients, it was 34.23 (±13.97) years. The mean duration of illness in male patients was 20.39 (±11.48) years and in female patients, it was 20.86 (±11.92) years. The mean duration of treatment in male patients was 20.37 (±11.54) years and in female patients was 20.38 (±12.37) years.

When the present clinical condition of the patients was analyzed, 67.8% (n = 40) of males and 59.1% (39) of the female patients were in remission as per their clinical records. Manic episode was present in 16.9% (n = 10) of the male patients and 30.3% (n = 20) of the female patients. Similarly, depressive episode was present in 15.3% (n = 9) and 10.6% (n = 7) of male and female patients respectively. Any of the physical illnesses such as diabetes, hypertension or thyroid dysfunction was present in 42.4% of males and 50% of females. It was found that 84.7% of the male participants and 51.5% of female participants had onset of BPAD after marriage. Sodium

Table 1: Sample characteristics

Characteristics	Category	Male (n=59)		Female (n=66)	
		F/Mean	%/S.D.	F/Mean	%/S.D.
Age	21-30	1	1.7	2	3
	31-40	2	3.4	16	24.2
	41-50	9	15.3	21	31.8
	51-60	21	35.6	19	28.8
	>60	26	44	8	12.2
Education	No formal education	4	6.8	1	1.5
	Primary education	25	42.4	30	45.5
	Secondary education	26	44.1	30	45.5
	Degree/professional	4	6.8	5	6.6
Occupation	Unemployed	19	32.2	44	66.6
	Manual labor	37	62.7	20	30.3
	Government job	3	5.1	2	3.0
Religion	Hindu	40	67.8	41	62.1
	Muslim	5	8.5	20	30.3
	Christian	14	23.7	5	7.6
Type of family	Nuclear family	57	96.6	62	93.9
	Joint family	2	3.4	4	6.1
Monthly Income	<2500	45	76.3	46	69.7
	2501-5000	6	10.2	13	19.7
	5001-1000	3	5.1	4	6.1
	>10000	5	8.5	3	4.5
Place of residence	Rural	49	83.1	59	89.4
	Urban	10	16.9	7	10.6
Type of marriage	Selection by self	5	8.5	1	1.5
	Arranged by family members	49	83.1	60	90.9
	Arranged after selection by self	5	8.5	5	7.6
Number of children	0	0	0	5	7.6
	1	7	11.9	11	16.7
	2	25	42.4	31	47.0
	3 or more	27	45.8	19	28.8

SD: Standard deviation

valproate was the current medication in 49.15% (n = 29) of male patients and in 33.33% (n = 22) of the female patients. Benzodiazepines (m = 38.98%, n = 23; f = 48.48%, n = 32), haloperidol (m = 27.12%, n = 163; f = 21.21%, n = 14), chlorpromazine (m = 30.51%, n = 18; f = 18.18%, n = 12), sertraline (m = 22.03%, n = 13; f = 10.61%, n = 7) lithium (m = 20.34%, n = 12; f = 21.21%, n = 14), risperidone (m = 20.34%, n = 12; f = 24.24%, n = 16) and trihexyphenidyl (m = 42.38%, n = 25; f = 33.24%, n = 20) were the other drugs received by the patients. A few patients received olanzapine, clozapine, imipramine, amitriptyline and quetiapine.

On CSI, marital distress (score <51.5) was reported by 55.9% of the male participants and 54.5% of the female participants [Table 2]. In total, 55.2% of the participants reported marital distress. Comparison of mean scores of male (52.69, ±13.19) and female (50.59 ± 15.60) participants showed no significant difference between the groups (P = 0.42) [Table 3].

The relationship between marital distress and selected variables were tested using appropriate statistical tests for the whole sample (n = 125), as there was no gender difference on CSI. There was no significant relationship between marital distress and socio-personal variables such as education, occupation, religion, type of marriage, and clinical variables of the patient such as the presence of physical illness, medication, and duration of treatment. Notably, there was no significant difference between the mean age of participants (P =0.48) who had marital distress (n = 69, 52.48 ± 11.94) and those who had no marital distress (n = 56,53.98 ± 12.01). Similarly, the association between the present clinical condition and CSI was analyzed using one-way ANOVA (n = 125). It was found that participants whose partners were in remission (n = 79, 53.96 ± 14.49) had a significantly higher mean score (P =0.045) in comparison to participants whose partners were in a manic (n = 30, 46.53 ± 14.77) or depressive episode (n = 16, 49.31 ± 11.67).

The Figure 1 shows mean scores for items of the PAQ by male participants (n = 59). Handling family finances (mean = 4.79); career/job decisions (mean = 4.20); aims, goals, priorities, major decisions in life (mean = 3.94); recreation and leisure time (mean = 3.94); and sex relations (mean = 3.70) were the important problem areas reported by male participants. Drugs or alcohol (mean = 2.04) and religion (mean = 2.68) were the PAQ items for which male participants scored the lowest.

The mean scores of item-wise analysis of the response of female participants on the PAQ are shown in Figure 1. Household tasks (mean = 4.56), handling family finances (mean = 4.39), career/job decisions (mean = 4.26), recreation-leisure time together (mean = 4.22), and sex relations (mean = 4.07) were the important problem areas. Item such as children or parenting (mean = 3.97); aims, goals, priorities, major decisions in life (mean = 3.92); and drugs or alcohol (mean = 3.75) also scored high. Comparison of mean scores of PAQ between male (53.37 ± 13.21) and female (49.17 ± 15.43) participants showed no significant difference between the groups (P = 0.11) [Table 3].

Table 2: Distribution of participants based on marital problems

Characteristics	Male (n=59)		Female (n=66)		Total (%)
	Frequency	Percentage	Frequency	Percentage	
Marital distress (<51.5)	33	55.9	36	54.5	55.2
Marital satisfaction (>51.5)	26	44.1	30	45.5	44.8

Table 3: Comparison of male and female participants on CSI and PAQ mean scores

Characteristics	Male (n=59) Mean (S.D.)	Female (n=66) Mean (S.D.)	t	P
CSI	52.69 (±13.19)	50.59 (±15.60)	0.81	0.42
PAQ	53.37 (±13.21)	49.17 (±15.43)	1.63	0.11

CSI: Couple Satisfaction Index; PAQ: Problem Areas Questionnaire

DISCUSSION

Results were organized separately for male and female participants as their problems may be different. But, a meta-analysis on gender differences in marital satisfaction for nonclinical, community-based samples had indicated no significant gender differences between couples.[12] Findings of our study are presented here separately for males and females as, unlike the general population, the context of a psychiatric clinical condition in one of the partners may give insights for direction of future research. Distribution of sociodemographic variables in this study is comparable to the findings of other studies on the topic.[13]

According to similar studies done elsewhere, men and women were generally comparable in their symptom presentation, age of onset of BPAD, and in the total number of mood episodes, but differed in the type of episode at onset and comorbidity patterns.[14] A study on age at onset and affective temperaments in a Norwegian sample of patients with BPAD showed that the mean age of onset of BPAD was 28 years.[15] Findings consistent with this have been seen in our study as well.

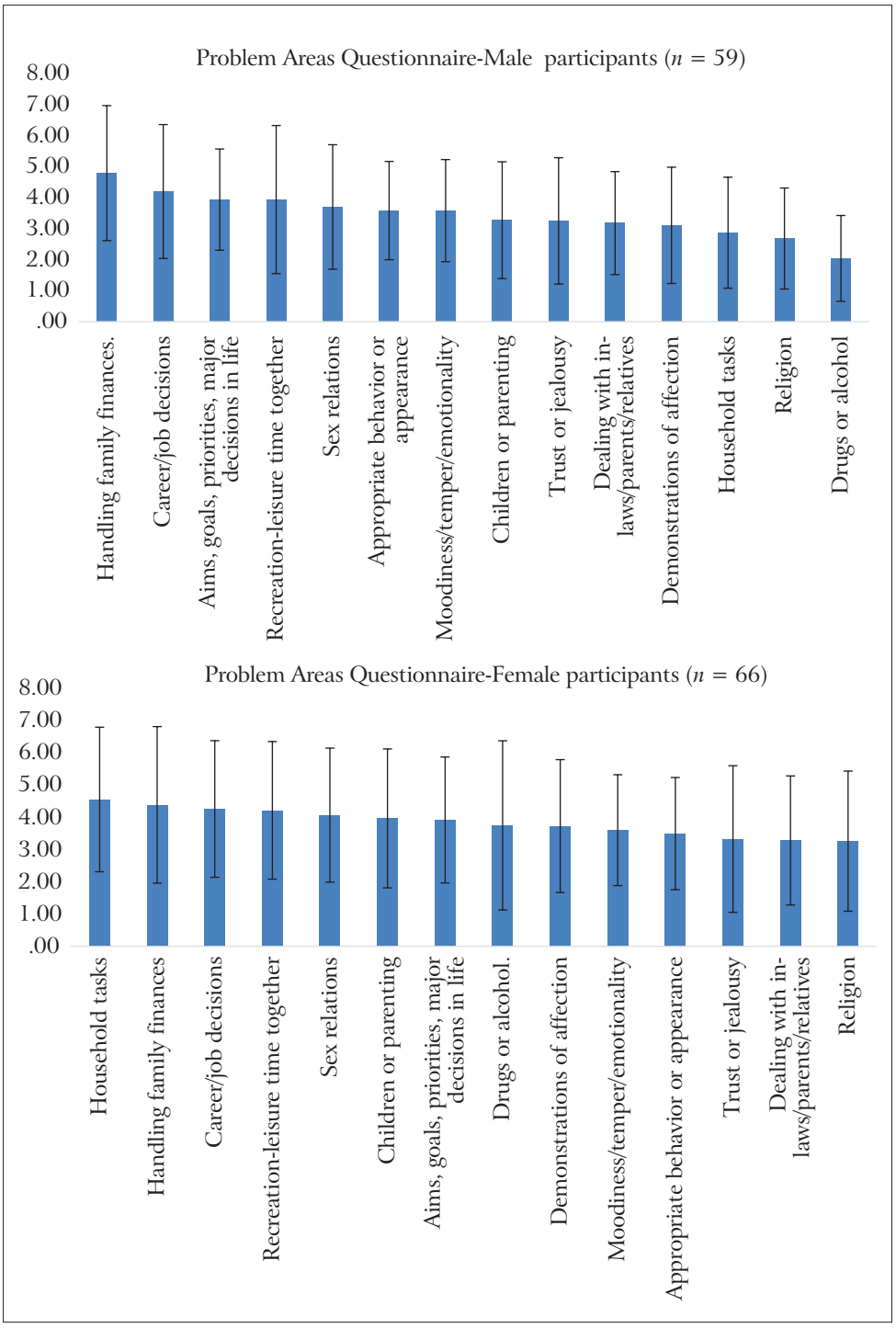

Figure 1: Problem Areas Questionnaire

The most important finding of our study is that 55.9% of the male participants, and 54.5% of the female participants reported marital distress. Comparison of mean scores of male and female participants showed no significant difference between them, which shows men and women have similar degrees of problems. Association between marital problems and depression has been reported earlier.[16] Another study which examined the caregiver burden and psychological distress among spouses of BPAD patients had reported a high level of psychological distress.[17] A similar study compared marital satisfaction between patients with schizophrenia and BPAD, in remission, and reported that marital dissatisfaction was greatest among patients with schizophrenia (96%).[18] Considering the high divorce rate among patients with BPAD, it is

important to uncover information related to the marital relationship in patients and spouses individually.[19] As this study had limited scope of describing the extent of marital distress among spouses of patients with BPAD, future studies are recommended.

Management of BPAD involves a prolonged period of medication and attention to psychosocial issues for patients and their families. Economic burden among these patients is a result of treatment costs, indirect costs arising from mortality, and indirect costs related to morbidity and lost productivity.[20] In our study, both male and female participants reported handling family finances as an important problem in their marital life. For improved long-term outcome, it is particularly important to support their families in economic terms through social security means.

Return to employment and family life are basic needs during remission in patients with BPAD.[21] Occupation, finance, and other daily events were some of the problems articulated by the BPAD in a qualitative study.[22] Our study found career/job decisions, major decisions in life, and recreation-leisure time together as problem areas in their marital life. Family support is an important contributor to patient well-being and a better prognosis.[23] Female participants of our study reported household tasks as the most problematic area for them. It reflects the subjective burden in primary caregivers, particularly female partners of patients with BPAD.

The mental illness in the partner affects the social life and leisure activities of the caregiver. Despite their burden, relatives do not complain much.[24] Our study also found that recreation-leisure activities is an important problem area for male and female participants. In a study that assessed the burden and marital and sexual satisfaction in the partners of patients with BPAD, participants reported reduced sexual satisfaction, which is consistent with the present study where sexual relations was one of the problem areas for both male and female participants.[13] Consistent results by another study reported that quality of 'current sexual satisfaction' was significantly lower among the spouses of BPAD patients.[25]

Limitations

Findings of the study may not be generalizable, considering the smaller sample size and use of purposive sampling technique. Similarly, this study did not look into the association of symptom severity of patients with couple satisfaction, which was an important variable. Effect of medicines on sexual functions was not within the scope of our study. But, a significant number of participants in this study were receiving sodium valproate, which is known to cause sexual dysfunction.[26] Although this study did not find any significant association between co-morbid physical illness of the patient and marital satisfaction, it is well-documented that the physical health of partners affects couple dissatisfaction.[27] Despite these limitations, the study has clinical implications.

CONCLUSION

Partners of patients with BPAD experience various problems related to their marital life. Distress in the partner affects the quality of their relationship with the patient and adversely affects their prognosis.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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Original Article

Stigma and its Correlates among Caregivers of Patients with Bipolar Disorder

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ABSTRACT

Background: Stigma associated with mental illness is multifaceted, and it extends to even those who take care of the afflicted persons. Research shows that stigma has maximal impact on patients who have schizophrenia and their caregivers, but information pertaining to caregivers of patients with bipolar disorder is minimal. Accordingly, this study aimed to evaluate stigma and its correlates among caregivers of patients with bipolar disorder. **Methodology:** This cross-sectional study conducted at a tertiary care hospital purposively enrolled 103 caregivers of patients with bipolar disorder-I. The caregivers were assessed on the stigma scale for caregivers of people with mental illness (CPMI) and the Explanatory Model Interview Catalogue (EMIC) stigma scale. **Results:** The majority of caregivers attributed the illness of the patient to stress (54.4%), chemical imbalance (48.5%), or heredity (29.1%), while nearly one-fourth believed it to be the will of God. The mean weighted scores on various domains of CPMI were comparable [affective domain = 2.24 (standard deviation (SD) = 0.51); cognitive domain = 2.25 (SD = 0.54) and behavioral domain = 2.23 (SD = 0.55)]. The mean score on EMIC was 28.00 (SD = 14.57). Caregivers with low income reported higher stigma in affective and cognitive domains. Also, lesser time spent with the patient correlated with higher stigma in the affective domain. Furthermore, poor functioning of the patient was associated with high caregiver stigma in cognitive and behavioral domains. **Conclusion:** Caregivers of patients with bipolar disorder experience significant affiliate and courtesy stigma, and higher stigma is associated with lower income of the caregivers and lesser time spent in caregiving.

Key words: *Bipolar disorder, caregiver, correlates, stigma*

Key messages: *Caregivers of patients with bipolar disorder experience significant affiliate stigma. Experience of higher affiliate stigma among the caregivers is associated with poor functioning of the patient.*

Stigma is conceptualized as "an attribute that is deeply discrediting" and reduces the bearer "from a whole and usual person to a tainted, discounted one."[1] Stigma associated with mental illnesses is not limited to patients but it also extends to their caregivers. Studies from the different parts of the globe suggest

Access this article online	
Website: www.ijpm.info	**Quick Response Code**
DOI: 10.4103/IJPSYM.IJPSYM_24_19	

How to cite this article: Grover S, Aneja J, Hazari N, Chakrabarti S, Avasthi A. Stigma and its correlates among caregivers of patients with bipolar disorder. Indian J Psychol Med 2019;41:455-61.

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Received: 19th January, 2019, **Accepted:** 16th June, 2019

that caregivers of patients with severe mental disorders such as schizophrenia experience significant stigma.[2-5]

The stigma faced by the caregivers due to their association with a mentally ill individual is referred to as "associative stigma" or "courtesy stigma."[1,6] Besides this, caregivers can stigmatize themselves (the equivalent of self-stigma in patients themselves), which is known as "affiliate stigma" and is understood as a personal affliction of caregivers by the public stigma that is prevalent in the society.[7] Affiliate stigma is considered to have three components, namely, affective (e.g., feeling of unhappiness), cognitive (e.g., thoughts of helplessness), and consequent behavior (avoidance, alienation, etc.).

Previous research on stigma in caregivers of mentally ill persons suggests that more than half of them suffer from some kind of stigma.[8] Furthermore, the stigma faced by the caregivers of patients with a severe mental disorder is associated with significant psychological distress in caregivers.[9] They also believe that the society devaluates people with mental illnesses and their families, and thus, many a time, caregivers are reluctant to reveal themselves as caregivers of persons with mental illnesses.[10]

In terms of correlates of stigma, available literature suggests that parents of persons with mental illnesses who report higher stigma often conceal hospitalization of the patient. Furthermore, higher stigma was reported by those who do not stay with the patient, by those who have a higher education level, and when the patient was a female.[2] Although a good amount of research is available for stigma in schizophrenia and its impact on the patients and their caregivers, limited information is available for caregivers of patients with bipolar disorder (BD).

As a part of the Systematic Treatment Enhancement Program for Bipolar Disorder (STEP-BD) study, the authors assessed stigma in caregivers of individuals with BD. Stigma was high in Hispanic caregivers of unwell patients with BD-I (vs. BD-II), those with low social support, and those having few social interactions.[11] Similarly, among caregivers of well patients, stigma was more in an adult child of the patient, those educated to college level, those with few social interactions, and those caring for a female patient with BD.[11] Other studies suggest higher perception of stigma by carers, in turn, predicts more depressive symptoms, avoidance, and social withdrawal in them.[12] In a recent multicentric study from India, caregiver stigma was measured using stigma scale for caregivers of people with mental illness (CPMI), and highest level of stigma was reported by the caregivers of patients with schizophrenia, followed by BD, and the level of stigma was the least in those with recurrent depressive disorder (RDD).[13] In addition, the score was also highest for various components of CPMI, namely, affective, behavioral, and cognitive, for the caregivers of patients with schizophrenia. Interestingly, the caregivers of patient with schizophrenia had lowest General Health Questionnaire scores, and the proportion of those having a psychological morbidity was significantly lower among the caregivers of patients with schizophrenia when compared with the caregivers of patients with BD or RDD.

Notwithstanding the current research on various perspectives of caregiving in mental illness from India, minimal exploration has been done on stigma experienced by the caregivers of patients with BD and its correlates. With the aim of filling this gap, this study aimed to evaluate stigma and its correlates among caregivers of patients with BD.

METHODOLOGY

This was a cross-sectional study, conducted at the Outpatient Department of Psychiatry services at a tertiary care hospital that caters to major part of north India. The study was approved by the Institute Ethics Committee, and the recruitment of patients and caregivers was done after obtaining written informed consent. Using a purposive sampling method, 103 caregivers of patients suffering from BD-I as per the Diagnostic and Statistical Manual, fourth revision, age 18–65 years, and currently in clinical remission were chosen. The caregivers were included only if they were >18 years of age, did not suffer from any psychiatric or chronic physical illness (other than nicotine dependence), and could read and/or understand Hindi. They were also required to be living with and intimately involved in the care of the patient.

The following self-report questionnaires were filled by the caregivers:

Stigma scale for CPMI:[7] It measures the caregiver's internalization of stigma or affiliate stigma in three domains, namely, cognitive, affective, and behavioral domains. Each item of the scale is rated on a 4-point Likert scale from strongly disagree (1) to strongly agree (4). The mean scores are obtained for each domain from the scores obtained on various items included in the particular domain. The scale has a Cronbach's alpha value of 0.95, which reflects excellent internal consistency. Weighted mean scores of each component were calculated to compare the severity of each component. We used the Hindi translated version of

this tool, which has been used in an earlier study from our center[5] and was also used in a multicentric study evaluating stigma in caregivers of patients with severe mental disorders.[13]

Explanatory Model Interview Catalogue (EMIC) stigma scale:[14] It assesses anticipated or perceived stigma in the caregivers. It is a self-report scale which has 15 questions, with four answering options, with a higher score indicating higher perceived stigma.

In addition to these self-report questionnaires, the caregivers were evaluated for their etiological attribution of the illness of the patient. This was done by a semi-structured instrument.

The patients were evaluated on the following scales:

Hamilton Depression Rating Scale (HDRS):[15] The 17-item HDRS was used to evaluate depression in the patients. A cut-off score of 7 was used to define remission.

Young Mania Rating Scale (YMRS):[16] This 11-item scale was used to evaluate the remission of manic illness. A score of <7 was used to define remission in this study.

Global Assessment of Functioning scale (GAF):[17] The GAF scale was used to rate the impact of BD on the patients' functioning. This scale measures how the patients are doing in the domains of psychological, social, and occupational functioning and covers the aspects of positive mental health and severe psychopathology. It is a very simple scale to use and has good reliability and validity.

Data analysis

Data were analyzed using the Statistical Package for the Social Science Version 14 (SPSS for Windows, Version 14.0. SPSS Inc., Chicago, IL, USA). Descriptive analysis was used for continuous and categorical variables. The relationship of stigma with other variables was studied using Pearson's product moment correlation, Student's *t*-test, and Chi-square test.

RESULTS

Sociodemographic profile

Demographic details of the patients are shown in Table 1. The mean age of the patients was 40.83 [standard deviation (SD) =11.56] years, and the mean duration of formal education was 10.63 (SD = 3.98) years. The majority of the patients were married (82.7%) and had a monthly income in excess of 7,000 Indian rupees (INR) (76.7%). Slightly more than half of the patients were unemployed (55.3%), belonged to joint or extended family setup (53.8%), and were from a rural background (52.9%).

Male (57.3%) caregivers outnumbered female caregivers. The mean age of the caregivers was 43.41 (SD = 12.43) years, and the mean duration of formal education of caregivers was 10.59 (SD = 4.14) years. The majority (74.7%) of the caregivers had a monthly income of more than 7,000 INR. There was a nearly equal distribution of caregivers who were on paid employment and those who were not on paid employment. In terms of relationship with patients, nearly half of the caregivers were spouses (54.4%), and this was followed by parents (22.4%). The mean duration of being in the caregiver role was 10.12 (SD = 7.89) years and the mean duration of face-to-face time spent in caregiving was 0.42 (SD = 1.72) hours per day. Caregivers had accompanied the patient for more than 90% of the hospital visits in the past 6 months.

The clinical details of the patients are shown in Table 2. The mean age of onset of illness was 29.63 (SD = 10.18) years, and the mean duration of illness was 131.79 (SD = 98.57) months. The mean duration of remission at the time of assessment was 11.16 (SD = 13.0) months. The mean number of depressive episodes experienced by the patients was 2.61 (SD = 2.55), while that for mania was 3.95 (SD = 3.73) and the mean HDRS and YMRS scores at the time of assessment were 0.75 (SD = 1.44) and 0.29 (SD = 0.92), respectively. The mean number of lifetime episodes was 7.25 (SD = 5.98), and the current GAF score at the time of assessment was 78.21 (SD = 0.36).

No comorbid psychiatric and physical illness were seen in 98 (95.1%) and 95 (92.2%) caregivers, respectively. Alcohol dependence was seen in three patients, three patients also had comorbid tobacco dependence, and opioid dependence syndrome currently in remission was present in one patient. Hypothyroidism was present in three patients, and one each had diabetes mellitus, both hypertension and diabetes mellitus, obesity, epilepsy, and vitiligo.

Attribution of illness (etiological models) by the caregivers

The majority of the caregivers reported the etiology of the illness of the patient to be related to stress (54.4%), chemical imbalance (48.5%), or heredity (29.1%) [Table 3]. Overall, a biological etiological model was attributed by more than three-fourths of the caregivers. Nearly one-fourth of the caregivers (25.2%) attributed the illness to the will of God (25.2%).

Table 1: Sociodemographic profile of the patients (*n*=103) and their caregivers (*n*=103)

Variable	Patients *n* (%)/mean (SD)	Caregivers *n* (%)/mean (SD)
Gender		
Male	61 (58.7)	59 (57.3)
Female	42 (40.4)	44 (42.7)
Marital status		
Single	18 (17.3)	16 (15.5)
Married	86 (82.7)	87 (84.5)
Education		
Up to matriculation	53 (51.5)	53 (51.5)
More than matriculation	50 (48.5)	50 (48.5)
Employment status		
Not working	57 (55.3)	52 (50.5)
Working	46 (44.7)	51 (49.9)
Monthly income (in INR)		
Up to 7000	24 (23.3)	26 (25.3)
More than 7000	79 (76.7)	77 (74.7)
Type of family		
Nuclear	47 (45.2)	47 (45.2)
Joint/extended	56 (53.8)	56 (53.8)
Locality		
Rural	55 (52.9)	55 (52.9)
Urban	48 (46.2)	48 (46.2)
Relation with patient		
Parents	NA	23 (22.4%)
Siblings		11 (10.7%)
Children		13 (12.6%)
Spouse		56 (54.4%)
Mean age (years)	40.83 (11.56)	43.41 (12.43)
Mean years of education	10.63 (3.98)	10.59 (4.14)
Mean duration of being the primary caregiver (years)	-	10.12 (7.89)
Time spent by the caregiver with the patient in a day (h)	-	0.42 (1.72)
Percentage of visits in the last 6 months in which caregiver accompanied the patient	-	91.21 (14.78)

SD: Standard deviation

Table 2: Clinical details of patients

Variable	Mean (standard deviation)	Range	Median
Age at onset of illness (years)	29.63 (10.18)	13-58	30.0
Total duration of illness (months)	131.79 (98.57)	12-456	108.0
Duration of remission (months)	11.16 (13.00)	2-72	6.0
Number of episodes of depression in past	2.61 (2.55)	0-18	2.0
Mean duration of depressive episodes in months	2.47 (1.86)	0-9	2.0
Current HDRS score	0.75 (1.44)	0-6	0
No. of episodes of mania in past	3.95 (3.73)	0-20	3
Mean duration of manic episodes in months	2.53 (1.37)	0-9	3
Current YMRS score	0.29 (0.92)	0-5	0
Number of episodes of hypomania in past	0.60 (2.24)	0-20	0
Mean duration of hypomanic episodes in months	0.14 (0.37)	0-2	0
No. of episodes with mixed features	0.08 (0.34)	0-2	0
Mean duration of mixed episodes in months	0.05 (0.36)	0-3	0
Total number of lifetime episodes	7.25 (5.98)	2-41	5.2
Total number of episodes with psychotic symptoms	2.00 (3.53)	0-18	5
Percentage of episodes with psychotic symptoms	26.41 (28.00)	0-100	20
Total no. of hospitalization	0.38 (0.75)	0-3	0
Mean GAF score	78.21 (10.36)	40-92	80

HDRS: Hamilton Depression Rating Scale; YMRS: Young Mania Rating Scale; GAF: Global Assessment of Functioning Scale

Caregiver's stigma

On CPMI, the mean total (weighted) score was 2.24 (SD = 0.51). In terms of CPMI domains, the mean weighted score was equal for affective (mean 2.25; SD = 0.49) and cognitive (mean 2.25; SD = 0.54) domains, and the mean score for the behavioral domain (mean 2.23; SD = 0.55) was slightly less than the other two domains [Table 4]. Nearly two-thirds of

the caregivers disagreed or strongly disagreed on almost all the items of CPMI, and the rest agreed on most of the items. On the EMIC scale, the mean score was 28.00 (SD = 14.57).

Correlates of caregiver's stigma

The caregivers who had lesser income and who spent lesser time with the patient reported higher stigma in the affective domain of CPMI (Pearson's correlation coefficient -0.237; $P = 0.016$*), as well as had a higher total CPMI score (Pearson's correlation coefficient -0.197; $P = 0.046$*). In addition, higher stigma on the cognitive domain of CPMI was reported by caregivers having lower monthly income (Pearson's correlation coefficient -0.200; $P = 0.043$*) [Table 5]. None of the other sociodemographic variables of caregivers (namely, the age, education, duration of being a caregiver, accompanying the patient during follow-up in past six months, supervising medication, etc.) had a significant correlation with any of the domains of CPMI and total EMIC scores.

The poor functioning level of the patient (as indicated by lower GAF score) was associated with higher caregiver stigma in the cognitive (Pearson's correlation coefficient -0.206; $P = 0.036$*) and behavioral domains (Pearson's correlation coefficient -0.202; $P = 0.041$*) of CPMI and a high total score (Pearson's correlation coefficient -0.199; $P = 0.044$*) as well [Table 5]. However, no correlation was observed with patients' attributes such as age of the patient, gender, duration of illness, duration of remission, number of episodes in the past, scores on HDRS and YMRS, number of follow-ups in the past 3 months, or total number of hospitalizations.

Table 3: Etiological explanations reported by the caregivers

Etiology	*n* (%)
Stress	56 (54.4%)
Chemical imbalance	50 (48.5%)
Heredity	30 (29.1%)
Ghosts	6 (5.8%)
Spirit intrusion (*Upari Kasar*)	9 (8.7%)
Divine wrath (*Devi Devta Prakop*)	6 (7.8%)
Planetary influences (*Grah Nakchatra*)	14 (13.6%)
Sorcery/witchcraft (*Jaadu tona*)	9 (8.7%)
Evil spirits (*Buri atma*)	8 (7.8%)
Bad deeds in past life (*Karma*)	14 (13.6%)
Punishment by God	12 (11.7%)
God's will	26 (25.2%)
Breaching the taboos of God	8 (7.8%)
Number of caregivers with at least one supernatural etiology (i.e., reported at least one of the causes as listed from 4-13)	45 (43.7%)
Number of caregivers with at least one biological etiological model (i.e., reported at least one of the causes as listed from 1-3)	79 (76.7%)

Table 4: Caregivers' stigma as per CPMI scale and Explanatory Model Interview Catalogue

Item	Mean (SD)
CPMI-affective component	2.25 (0.49)
CPMI-cognitive component	2.25 (0.54)
CPMI-behavioral component	2.23 (0.55)
Total CPMI score	2.24 (0.51)
Total EMIC score	28.00 (14.57)

CPMI: Caregivers of People with Mental Illness; SD: Standard deviation; EMIC: Explanatory Model Interview Catalogue

Relationship of etiological models of illness by caregivers with their sociodemographical and stigma-related variables

Depending on the presence or absence of at least one supernatural or magicoreligious etiological model, the caregivers were divided into two groups (45 with a supernatural or magicoreligious etiological model and 58 with none). It was seen that such a belief was more if the caregiver was a female ($P = 0.002$), educated less than matriculation ($P < 0.001$), or was unemployed ($P < 0.01$). However, the two groups did not differ on the various measures of anticipated or affiliate stigma.

DISCUSSION

Recently, the stigma associated with mental illnesses has received significant attention.[18-22] However, the research is still scarce with respect to family stigma or affiliate stigma and perceived stigma among the caregivers of patients with BD. This provided the impetus to conduct this study.

Caregiver's stigma

In this study, nearly one-third of the caregivers of patients with BD "agreed" or "strongly agreed" on statements endorsing courtesy/affiliate stigma. With respect to anticipated/perceived stigma as assessed on

Table 5: Correlation of caregiver's stigma with sociodemographic/clinical variables of caregivers and patients

Variable	Affective component	Cognitive component	Behavioral component	Total CPMI score
Relationship with caregiver variables				
Caregiver income	−0.237* (0.016)	−0.200* (0.043)	-0.148 (0.135)	−0.197* (0.046)
Hours of time/day	−0.263** (0.007)	-0.169 (0.088)	-0.156 (0.116)	−0.198* (0.045)
Relationship with patient variables				
GAF score	-0.168 (0.091)	−0.206*(0.036)	−0.202*(0.041)	−0.199*(0.044)

*$p<0.05$; **$p<0.01$. CPMI: Caregivers of People with Mental Illness; GAF: Global Assessment of Functioning Scale

the EMIC scale for caregivers, 60% of the caregivers endorsed stigma. A higher proportion of caregivers of patients who were single (82%) reported difficulties in getting married due to caring for a person with BD in the family. This finding is in keeping with the cultural and general public attitudes in the Indian society, where the marital alliance is solemnized after an intense screening, and mental illness adversely affects the marriage prospects of the sufferer and siblings.[23] When compared to a recently published study from the same center,[5] which involved caregivers of patients with schizophrenia, the mean scores on affective (2.25 vs. 2.3), cognitive (2.25 vs. 1.9), behavioral domains (2.23 vs. 1.8), and total CPMI (2.24 vs. 2.1) score were slightly higher in the index study. The multicentric study from India, which also used the same scale, reported the highest level of stigma among the caregivers of patients with schizophrenia, followed by BD and least in those with RDD.[13] A study[24] from China also reported the highest affiliate stigma for the caregivers of patients who have schizophrenia, when compared with caregivers of patients with BD. When one attempts to understand the finding of this study and the existing literature, it is evident that the issue is not yet settled with respect to the hierarchy of stigma experienced by the caregivers of various severe mental disorders. It can be said that the caregivers of patients with BD also appear to experience a comparable level of stigma as that reported by caregivers of patients with schizophrenia.

Correlates of caregiver's stigma

In the STEP-BD study, patient characteristics, namely, an early age of onset of illness; a greater number of hospitalizations; suffering from a more severe type of illness; and caregiver attributes of high burden, depressed mood, and low social support, were associated with higher caregiver stigma. On the other hand, in the same study, caregivers of well patients who were females, more educated, and had fewer social interactions reported higher perceived stigma.[11] In this study, caregivers who earned less and spent less time with the patient reported higher affiliate stigma. None of the patient's sociodemographic and clinical variables were associated with perceived stigma in their caregivers. We did not find any association of relationship of caregiver with the patient and perception of stigma. However, in previous research, higher stigma has been reported by an adult child of patient[11] or parents.[24]

In this study, higher stigma in the affective domain (of CPMI) was seen among the caregivers who spent less time with the patient. This finding possibly suggests that caregivers who are less bonded to patients report higher stigma. However, it is also possible that caregivers who experienced more stigma avoided the patient and resultantly spent less time with the patient.

Among the patient variables, stigma had a significant correlation with the level of functioning of the patients, with caregivers of patients with better functioning reporting lower stigma. This finding suggests that clinicians managing patients with BD should not limit themselves to achieving clinical remission only but also address the functioning, as better functioning can possibly lead to lower caregiver burden and resultant stigma.

This study has certain limitations. The assessment of stigma was limited to a single cross-sectional evaluation and a relatively small sample size. The study recruited patients and caregivers attending a tertiary care hospital and patients who were clinically stable. There was a lack of a control group in the study. We did not evaluate other psychological variables such as expressed emotions, coping, and psychological morbidity among the caregivers. Future studies must attempt to overcome these limitations.

To conclude, this study suggests that caregivers of patients with BD suffer from high affiliate and courtesy stigma, which is comparable to that reported by caregivers of patients with schizophrenia. Hence, there is an urgent need to address stigma among the caregivers of patients with BD. Measures such as proper psychoeducation of the patient and their caregivers, access to various social welfare schemes, rehabilitation of the patient, and public awareness programs to mitigate stigma among the patients and the caregivers may help reduce stigma related to BD.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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Original Article

Change in Attitude among Nursing Undergraduate Students Following One-Month Exposure in a Mental Healthcare Setting

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ABSTRACT

Background: Attitude of treating professionals plays an important role in the treatment of mental illnesses. Nursing professionals are an important part of the mental health care team. As a part of their nursing coursework, nursing students are posted in a mental health setting. It is important to assess the impact of such postings on their attitudes. **Materials and Methods:** A total of 235 undergraduate nursing students posted in a mental healthcare setting for one month participated in the study. Their attitude towards mental illness and psychiatry was assessed before and after the posting, using Personal data sheet, Attitude Scale of Mental Illness (ASMI), and Attitude towards Psychiatry Scale (ATP). **Results:** At pre-assessment, the nursing students had a negative attitude on all dimensions of ASMI except benevolence, and positive attitude on all the six domains of ATP. At post-assessment, attitude improved significantly on pessimistic prediction dimension of ASMI, and they were able to maintain their positive attitude on ATP. **Conclusions:** One-month posting had a weak positive impact on attitude towards mental illness and no detrimental impact on attitude towards psychiatry. There is a need for better efforts to increase the impact of training on attitude towards mental illness.

Key words: *Attitude, mental health, mental illness, nursing, undergraduate*

Key messages: *Among the health professionals, there should be no place of negative attitude while managing people with mental illness and especially the nursing professionals. However, the current method of clinical teaching-training have minimal alleviating effect on their attitudes and hence requires a significant revamp.*

Nursing professionals are the backbone of any treating team.[1] They have the maximum amount of direct contact with the patients and their caregivers. Their role is receiving due consideration in the current healthcare scenario in India.[1] Attitude and behaviour are directly or indirectly related to each other.[2] Attitude sets the stage for how people interact with and treat objects. In

Access this article online	
Website: www.ijpm.info	**Quick Response Code**
DOI: 10.4103/IJPSYM.IJPSYM_342_18	

How to cite this article: Grover N, Jameel S, Dhiman V. Change in attitude among nursing undergraduate students following one-month exposure in a mental healthcare setting. Indian J Psychol Med 2019;41:462-5.

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Received: 17th August, 2018, **Accepted:** 07th January, 2019

the management of mental illnesses, the attitude of the treating professionals towards mental illness and towards psychiatry plays an important role. The attitude of the nurse is crucial in the treatment of mental illness. Since attitude once developed during training can remain stable over the years,[3] research needs to focus on the attitude of the nursing students. Efforts have been made to assess the attitude of nursing students toward mental illness and psychiatry.[4-7] Researchers have reported nursing students' having a negative attitude and have suggested that there is an urgent need to evolve innovative teaching strategies to improve their attitude. Efforts have also been made to assess the impact of teaching strategies,[8] brief educational intervention[9] and four weeks' mental health placement[10] on the attitude of nursing students in different countries. However, there is a need for more research assessing the impact of these interventions and clinical postings on the attitude of nursing students. In India, undergraduate nursing students have one month posting in a mental health setting as part of their course curriculum. But there is a dearth of studies assessing the impact of the posting on their attitude. In view of the above, the present study aimed to assess the impact of the one month posting on the attitude of nursing students. The specific objectives were to assess the change in the attitude of undergraduate nursing students (a) towards mental illness and (b) towards psychiatry following one-month posting in a mental healthcare setting.

MATERIALS AND METHODS

The sample of the study consisted of undergraduate (second and third year) nursing students posted for one month as a part of their course in a tertiary care academic institution at institute of human behaviour and allied sciences (IHBAS) Delhi in India. The study duration was from January to August 2016. All the students posted during the data collection period were invited to participate. Written informed consent was obtained from all participants. The quantitative pre-post assessment design was used. The pre-assessment was carried out at the first week of their posting and post-assessment was carried out in the last week of the posting, in about 25-30 minutes, in a group setting. The study protocol was approved by the Departmental committee, Master of Philosophy (M.Phil.) committee and Ethics committee of the Institute. The following tools were used:

Personal data sheet

A personal data sheet to collect various socio-demographic details.

Attitude Scale of Mental Illness

Attitude Scale of Mental Illness (ASMI) consists of 34 items and is a modified version of the questionnaire, 'Opinions about Mental Illness in the Chinese Community' (OMICC).[11] It is a self-report measure of attitude in which each item consists of a five-point Likert scale from 1 to 5 (1 = strongly disagree; 5 = strongly agree). ASMI items are categorised into six conceptual factors as Separatism, Stereotyping, Restrictiveness, Benevolence, Pessimistic prediction, and Stigmatization. High scores on benevolence and low scores on the other five dimensions indicate a better and favorable attitude, whereas the reverse indicates an unfavorable and negative attitude.

Attitude towards Psychiatry

Attitude towards psychiatry (ATP) is a self-report measure of attitude consisting of 29-items rated on a 4-point Likert scale from "strongly agree," to "strongly disagree".[12] The scale examines the attitudes towards psychiatry in six areas: overall merits of psychiatry, efficacy, role definition and functioning of psychiatrists, possible abuse and social criticism, career and personal reward, and specific institute factors. A higher score indicates a positive attitude in that domain.

Components of one-month exposure

The students were given orientation and posted in various wards on rotation. They got the opportunity to see almost all kinds of psychiatric illnesses during their posting. They were allowed to interact with the patients under supervision. They had to observe the history taking process and assessment of mental status examination. Theoretical knowledge was provided through classes taken by different mental health professionals of the institute, where the emphasis was on the clinical feature of mental illnesses and treatment approaches. They were required to submit five case reports in which they have taken the detailed history from the patient. The students also participated in various activities and festival celebration held in the institute during their posting period.

Statistical analysis

Data were analyzed with the Statistical Package for Social Sciences (SPSS) version 16 at the pre-assessment levels, independent sample *t*-test was administered to see the impact of different socio-demographic variables on the attitude. Paired *t*-test was used for finding levels of significance among the scores of scales at pre- and post-assessment stages, and Bonferroni correction was applied here. The effect sizes are reported using Cohen's d.

RESULTS

A total number of 262 students participated in the study at pre-assessment. At the post-assessment, only 235 students could participate, due to the absence of

27 students on the days of the assessment. Data from a total of 235 students were put for statistical analysis.

Sample characteristics

Age range of the participants was 18–25 years with mean age (±SD) of 20.38 (±1.47) years. The sample was dominated by unmarried female students (n = 223, 91.6%). The majority were Hindus (n = 157, 69.1%), followed by Sikhs (n = 72, 28.6%). Number of participants from the rural background were more as compared to the urban background (n = 139 and 96, 58.4% and 41.6%, respectively). There were an almost equal number of second (n = 115) and third (n = 118) year students.

At the pre-assessment levels, t-test reported no significant difference between the attitude of rural (n = 139) and urban (n = 96) background participants. However, religion did show a significant difference; with Sikhs (n = 72) having better attitude towards mental illness and towards psychiatry in comparison to Hindus (n = 157) on the "stigmatization" domain of ASMI (t = 4.95, P = 0.002, Cohen's d = 0.20) and "career and personal reward" domain of ATP (t = 4.95, P < 0.001, Cohen's d = 0.48) respectively. Third-year students (n = 118), as compared to second-year students (n = 115), were found to have a better attitude to mental illness on stigmatization domain of ASMI (t = 3.07, P = 0.002, Cohen's d = 0.41) and better attitude to psychiatry as well on career and personal reward domain of ATP (t = 2.56, P = 0.000, Cohen's d = 0.91). The significance level was used at P <.004, after Bonferroni correction.

Attitude towards mental illness

The mean scores of students' attitude towards mental illness on ASMI at the pre-exposure level were on the higher side in all the areas [Table 1]. A within-group comparison was carried out between pre- and post-exposure assessment using paired sample t-test. To overcome the possibility of false positive results due to multiple hypothesis testing, Bonferroni correction[13] was done and a stringent criterion of significance level, P < 0.008 was used. As shown in the Table 1, there was a significant difference between means on the pessimistic prediction dimension (t = 2.90, P =0.004, Cohen's d = 0.23). There was no statistically significant difference between mean scores on other domains of ASMI.

Attitude towards Psychiatry

On the ATP scale, the scores were on the higher side at the pre-exposure assessment [Table 1]. The comparison between pre- and post-exposure assessments showed statistically significant difference at the significance level P < 0.008, following Bonferroni correction, on efficacy domain (n = 235, t = 4.95, P = <0.001, Cohen's d = 0.41), and on possible abuse and social criticism domain (n = 235, t = 2.74, P < 0.007, Cohen's d = 0.23). There was no statistically significant difference between the mean scores on other domains of ATP.

DISCUSSION

Unmarried Hindu females dominated the sample, and this finding is not surprising in view of the perception of the nursing profession as "female predominant job,"[14] leading to more girls joining a nursing course.

Attitude to mental illness

At the pre-assessment, the group held a negative attitude in all the areas, except on the benevolence scale. Similar finding of negative attitude has been reported by other researchers.[4-6] On benevolence scale, the students had a positive attitude of paternalistic and sympathetic view towards the persons with mental illness. The results at the post-assessment showed that there is a significant increase in the optimism about the treatment of mental illness and the future growth of persons with mental illness

Table 1: Pre- and post-assessment findings from ASMI and ATP

Domains	Pre-assessment scores mean±SD	Post-assessment scores mean±SD	Range	Mean difference	*t*-score	*P*
ASMI						
Separatism	27.74±4.93	26.95±5.61	16-43	0.78	2.16	0.031
Stereotyping	12.25±2.63	12.20±2.74	4-19	0.00	0.00	1.00
Restrictiveness	10.00±2.84	9.85±2.41	2-19	0.15	0.75	0.449
Benevolence	27.93±3.60	28.22±3.44	13-39	0.29	1.18	0.238
Pessimistic prediction	12.55±2.72	11.90±2.87	5-19	0.65	2.90	0.004*
Stigmatization	8.29±2.44	8.47±2.55	4-18	0.17	0.93	0.349
ATP						
Overall merit to psychiatry	10.09±1.43	9.91±1.34	5-12	0.18	1.62	0.105
Efficacy	10.58±1.37	9.94±1.77	5-12	0.64	4.95	0.001#
Role definition and functioning	20.00 ± 6.87	19.35±2.35	12-117	1.01	2.21	0.028
Possible abuse and social criticism	5.25±1.89	5.64±1.24	2-26	−.38	2.74	0.007#
Career and personal reward	22.71±4.40	22.91±4.77	13-32	−.20	0.54	0.586
Specific medical school factor	19.11±2.63	18.93±2.89	10-24	0.17	0.86	0.388

Significant at *$P \leq 0.004$ and #$P \leq 0.008$, ASMI – Attitude towards mental illness, ATP – Attitude towards Psychiatry, SD – Standard deviation

(pessimistic prediction dimension). However, negative attitude in the sense of keeping persons with mental illness at a safe distance (separatism domain), threat perception (restrictiveness domain), sharing of stereotypical attitudes with society (stereotype domain) and discrimination in terms of disgracefulness of the person with mental illness (stigmatization domain) remained unchanged.

The findings showed only a weak positive impact of the posting on the attitude towards mental illness. It is an area of concern, and concentrated efforts are needed in this direction to bring positive change in nursing student's attitude because they are the future service providers. A very similar study in Australia had shown a more positive outcome than the present study following four weeks' clinical placement in a mental health setting.[10]

Attitude towards Psychiatry

At pre-assessment, the students had a positive attitude on all the six domains of attitude towards psychiatry. Similar findings were reported by another study.[7] On a comparison of pre- and post-assessment scores, the more important domain of "possible abuse and social criticism" showed changes in positive direction, which indicated that the one-month direct exposure strengthened their belief that mental health professionals work with integrity and ethics. The positive and high scores on this domain are always desirable. The group's belief in the efficacy of psychiatrists had come down (efficacy domain). There were no significant differences observed in other domains of ATP scale, indicating that the group was able to maintain its positive attitude towards psychiatry after the one-month exposure period.

The present study has some limitations. The assessment in a group setting can influence attitude because of the "feel" that others are present, even though the physical interference was taken care of and clarifications were provided by the researcher only. The assessment was done in the mental health setting itself, and it could have led to an obligation on the part of students to give positive ratings on attitude to psychiatry. However, in order to reduce the possibility of any bias, the researchers had time and again reminded about and emphasized the ethical considerations to the participants. A bigger sample size and a control group could have provided more strength to the findings. A long-term follow-up assessment, to see any late impact on attitude change, could be of interest in future research. However, given the scope and feasibilities of the present study, it was impossible to overcome these limitations.

To conclude, the findings on the attitude to mental illness bring out a significant concern. The results reveal a negative attitude among the nursing student population. More importantly, it does not show significant changes post-exposure to month-long posting, which indicates the need for modifications in the training. The silver lining is their positive attitude towards the field of psychiatry and mental health professionals and the fact that positive attitude remains intact after exposure to the mental health setting. Our findings underline the suggestions provided by other researchers that innovative teaching strategies are needed to improve the attitude of future nursing professionals.

Financial support and sponsorship
Nil.

Conflicts of interest
There are no conflicts of interest.

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Viewpoint

Role of Integrated and Multidisciplinary Approach in Combating Metabolic Syndrome in Patients with Severe Mental Illness

Metabolic Syndrome (MS) is a constellation of cardio-metabolic risk factors such as increased waist circumference, hyperglycemia, hypertension, hypertriglyceridemia, and decreased high density lipoprotein (HDL) levels, associated with significant morbidity as well as mortality.[1,2] The prevalence of MS in the general population globally was found to range 20–25%,[3] whereas the pooled prevalence of MS in patients with severe mental illnesses (SMI) was found to be 32.6%.[4] Hence, the presence of MS in patients with SMI could lead to greater disability, considering both MS and SMI being significant contributors to the global burden of disease.[5]

Patients with SMI could be at higher risk of developing MS due to a myriad of reasons. First, an unhealthy lifestyle in the form of sedentary life with less physical activity, intake of carbohydrate- and lipid-rich diet, and substance use could contribute to the development of MS.[6] Second, psychotropic medications, especially second-generation antipsychotics such as clozapine and olanzapine, notoriously increase the risk of MS.[4] Third, by virtue of SMI, the patients could have limited access to medical care and poor health seeking behavior.[7] Thereby, there is an urgent need to address these barriers and combat MS in terms of effective prevention as well as treatment.

Acknowledging these barriers, it is necessary to focus on strategies which can encourage patients to seek medical help, such as sensitizing staff and caregivers, improving knowledge and attitude of the staff, as well as reduction of psychiatric symptoms in the patient.[8] Serial physical monitoring; appropriate selection of drugs; lifestyle modifications, including adequate physical activity, properly balanced diet and cessation of use of substance; and psychoeducation are the various components which need to be incorporated in combating MS.[7,9,10]

At the baseline, in all patients with SMI, proper history must be taken, including past and family history of cardiovascular or metabolic disease and details of substance use, diet and activity. Comprehensive evaluation in the form of complete physical examination, including blood pressure, body mass index and waist circumference, and laboratory investigations such as fasting blood glucose and lipid profile must be done. Psychoeducation about lifestyle modifications should be meticulously done. At week six, it is recommended to review the choice of antipsychotics in patients with a weight gain of more than 7%. Review of physical and laboratory examination and continuing psychoeducation is recommended at weeks 6, 12, and 52. Further physical and laboratory evaluation must be done annually if these were normal until the end of 1 year. In case of any abnormality, the patient must be referred to a physician.[11]

Though an intense monitoring system is recommended, the proportion of patients with SMI being monitored for MS has been found to be low in outpatient as well as community settings.[12,13] Hence, there is a definite need for addressing the unmet physical needs of patients of SMI, keeping in view the time and resources needed for such intense monitoring and the limited number of psychiatrists.[10,14,15]

An integrated and multidisciplinary approach could go a long way in addressing MS in patients with SMI. The concept of integration of mental health care with primary or community care involving nurses and paramedical health professionals is garnering attention in recent times, with parallels drawn between mental illness and physical noncommunicable diseases.[16] In the context of MS, multidisciplinary approach has been defined as interdisciplinary coordination between medicine, endocrinology, psychiatry, psychology, nutritional medicine, and surgery.[17]

American Psychiatric Association also advocates proper coordination between psychiatrists and primary care providers.[18] Further, care managers such as nurses can play a pivotal role in maintaining communication and providing health education.[19] With this background, the current article attempts to provide a viewpoint about the multidisciplinary and integrated approach in addressing components of MS in patients with SMI receiving psychotropic medication.

Studies in a hospital setting

A large body of evidence in the form of numerous reviews, including systematic reviews and meta-analyses, exists which report feasibility and efficacy of such multidisciplinary and integrated approaches in reducing components of MS in person with SMI.[20-25] These interventions were delivered by psychiatrists, nurses, dieticians, psychologists, and counselors, alone or in liaison across the interventions.[20-25] The interventions delivered can be classified into weight management/physical activity approaches,[20-25] dietary approaches,[20,22,25] psychoeducational approaches,[22] cognitive behavioral therapy approach[21,23,25] and a holistic approach called "wellness program."[26]

Dietary/nutritional approach involved providing education about promoting a healthy diet, discouraging maladaptive food practices, and emphasizing appropriate dietary intake, calorie restriction, and healthy diet.[20,22,25] Weight management involved physical activity through exercise or yoga and modification of dietary habits.[20-25] Psychoeducation encompassed providing information to the patients about the illness, medication, need for lifestyle modifications, cessation of substance, and need for relapse prevention.[22] The wellness program was a holistic approach involving monitoring of physical health, exercise, nutritional counselling, advice for cessation of substance use, and an emphasis on improving quality of life.[26]

The earliest systematic review, dating back to 2003, found that behavioral interventions by diet and (or) exercise could lead to only smaller reduction of weight in patients with schizophrenia on antipsychotics, with at least 5% weight loss being demonstrated in only three of sixteen studies.[20]

In 2008, a meta-analysis of 10 randomized controlled trials (RCT) demonstrated the feasibility and efficacy of nonpharmacological interventions (behavioral, cognitive behavioral, nutritional) in producing a significant reduction of antipsychotic-induced weight gain. There was no significant difference between the results of the nonpharmacological interventions by type or type of delivery.[21]

In 2012, a narrative review of 42 studies of interventions for MS in schizophrenia noted that comprehensive interventions including nutritional, physical activity, psychoeducational components had better outcomes in weight reduction compared to nutritional advice alone. The authors also highlighted the role of nurses in delivering these interventions.[22]

A meta-analysis of seventeen studies assessing the effect of nonpharmacological interventions (behavioral, nutritional, or cognitive behavioral interventions) in schizophrenia found a significant reduction in weight, body mass index, waist circumference, fasting blood glucose, total cholesterol, low density lipoprotein, and triglycerides across the studies. However, no acute, as well as long-term effects were noted in HDL or systolic blood pressure. Significant improvement in body mass index (BMI) failed to persist after 12 months of intervention. Another interesting finding was that this improvement was significantly better in the outpatient setting compared to the inpatient setting. No significant difference was noted between various types of nonpharmacological interventions.[23]

In 2015, a systematic review and meta-analysis of 20 studies assessing the effect of exercise in patients with schizophrenia found that moderate to vigorous exercise was associated with a significantly greater reduction in psychiatric symptoms and waist circumference and improvement in the quality of life. However, no significant reduction in BMI was noted. The study also noted that aerobic form of exercise had significantly better outcomes.[24]

A recent systematic review of eleven studies, conducted in 2018, found that in patients with schizophrenia, interventions providing exercise, dietary advice, and education, singly or in combination, led to a significant reduction in weight, BMI, waist circumference, and blood glucose. The study also highlighted the role played by the dietician, nurse, and clinical psychologists in providing the interventions.[25]

The studies[20-26] are summarized in Table 1.

There is minimal literature on interventions from the lower and middle-income group setting. There is a single published study from India assessing the role of psychoeducation on MS. A psychoeducational intervention program comprised of psychoeducation about SMI, side effects of medication, risk of metabolic abnormalities, role of healthy diet, exercise and weight control measures. Fifty percent of the patients (who had MS at baseline) who were followed up after 6 months did not qualify for MS.[27]

Studies in the community setting

Limited studies exist on integrated models of care in the community setting. There is only one RCT, which assessed the efficacy of integrated medical care for patients with SMI compared to usual care at a community care center. Integrated medical care was derived from a nurse practitioner and nurse care

manager. Nursing case managers promoted advocacy and communication with physicians and provided health education, and this was compared to treatment as usual. The integrated medical care approach was associated with significantly higher utilization of services, better quality of care, as well as significant reduction of cardiovascular risk factors at the end of 12 months.[28] The outpatient psychosis clinic managed at community level by nurses (psychiatric and assistant) and occupational therapists, under liaison with mental health professional and physician, is an existing successful model in monitoring and management of MS in Sweden.[29]

Role of health professionals in screening for MS

In contrast to the abundant literature on interventions, there is limited literature on the role of health professionals in screening for MS. A dramatic increase in the frequency of monitoring the BMI (from 2% to 67%), waist circumference (from <1% to 68%) and sending referrals to the general physician (from 0 to 37) was noted after employing a nurse practitioner in an acute inpatient unit in Australia.[30] A single educational intervention session to the nurses was found to result in increased reporting of waist circumference by almost 40–50% of the case files in Australia.[31]

The feasibility of nurses or pharmacist administering a metabolic screen checklist for components of MS was demonstrated as a part of "Point of care metabolic screening program" in an outpatient setting in the United States of America. The checklist consisted of height, weight, BMI, waist and hip circumference, blood glucose, blood pressure, personal history of substance use, diet, activity, past as well as family history of diabetes mellitus or hypertension and current treatment, and would provide recommendations to the treating psychiatrist.[32] There is a tremendous need for training nurses regarding MS, as a survey revealed that the proportion of nurses who did not know that low HDL and elevated blood pressure are risk factors of MS were about one third and one fourth respectively.[33] Further, it is also disappointing to know that a significant proportion of the mental health nurses in the United Kingdom did not receive training in physical health needs of the patient and expressed ambiguity about their role in managing physical needs.[34]

Methodological issues

It is important to interpret the existing study findings in the background of their methodological limitations. Majority of the studies included in the reviews were poorly powered, had a lower sample size, and a shorter duration of assessment.[23,25] Even the RCT lacked proper elaboration of randomization, concealment, and imputation analysis.[21,25,35] The method of delivery of the intervention was not clearly elaborated in some of the studies.[25] Due to heterogeneity in the study methodology, a quantitative analysis could not be conducted in many of the reviews.[24,36] The generalizability of some of the studies was compromised due to the limited representation of ethnic groups.[36]

Newer strategies: The way forward

There is an immense need for RCT of rigorous methodology to generate further evidence for nonpharmacological interventions. More studies assessing an integrated model of care involving active liaison between mental health professionals, physicians, nurses and allied health professionals, especially from the community setting, are needed as the only published study dates back to 2010. More studies assessing components of MS as outcome parameters are required.

Further, there is a tremendous need for studies from the lower and middle-income group (LAMIC) setting as the majority of the studies were from higher income countries. The interventions adopted in the developed countries might need to be customized to the needs of the LAMIC in the background of the varying working profile of health professionals.

Quality improvement intervention (QI) program could be a feasible intervention for better screening of MS by sensitization and training of health professionals as well as the development of a template for the screening of MS. Training residents about using MS screening bundle template (assessing BMI, blood pressure, fasting glucose and lipid profile) was found to result in about 3.5- to 10-fold increased rate of screening of MS.[37]

"Metabolic Clinics" could be a one-stop avenue for meeting the physical health needs of the persons with SMI, where the psychiatrist can work in close liaison with a physician, psychologist, nurse, dietician, occupational therapist, and social worker. Establishing community mental health clinics (CMCH) with integrated mental health care and medical care could help in better accessibility and availability of services. Cost analysis of a model CMCH at the United States of America was carried out, and it was found to be highly cost-effective with a mean of 74$ being spent on each patient annually.[38] Further training of the undergraduates in such clinics at the hospital as well as community level can help in sensitizing them to the physical health issues of persons with SMI.

Table 1: Summary of reviews assessing the multidisciplinary and integrated treatment approaches in combating metabolic syndrome in patients with severe mental illness

Author	Study methodology	Chief findings
Faulkner *et al*. 2003[20]	A systematic review of 16 studies was carried out assessing the effectiveness of interventions to control body weight in patients with schizophrenia There were eight studies with pharmacological interventions (*n*=311) There were eight studies with behavioral and dietary interventions (*n*=142)	-A small reduction of weight (less than five percent of body weight at baseline) was achieved in five studies employing pharmacological interventions and all the studies with behavioral interventions -A multimodal intervention involving diet, dietary counselling and exercise had the greatest effect size of 2.52.
Papanastasiou, 2012[22]	A narrative review of interventions improving physical health and decreasing cardiovascular risk factors of MS in subjects with severe mental illness was done There were 44 studies with pharmacological interventions There were 42 studies with behavioral interventions There were nine studies with both pharmacological and behavioral interventions	-Wellbeing programmes incorporating health check-up, exercise and dietary advice, cognitive behavioral therapy, nutritional education, weight management (exercise+dietary modification), psychoeducation were the various behavioral interventions studied -Wellbeing programs were found to improve physical health -Restricted consumption of calories alone or with nutritional education and behavioral techniques were found to control weight gain across several studies.
Caemmer *et al*. 2012[23]	Meta-analyses of seventeen RCTs was carried out assessing the effectiveness of non-pharmacological interventions to control weight gain by antipsychotics as well as metabolic abnormalities (*n*=810)	Compared to treatment as usual, non-pharmacological interventions had significantly: -Greater weight loss (-3.12 kgs; 95% CI: -4.03- -2.21; *P*<0.0001) -Decrease of BMI (-0.94 kg/m^2; 95% CI: -1.45- -0.43; *P*=0.0003), weight circumference, total cholesterol, LDL, TG -No significant difference was noted with respect to HDL and Systolic blood pressure -Significant changes in weight and BMI were noted only in studies with outpatients -No significant difference was noted between individual versus group approach and CBT versus dietary counselling
Firth *et al*. 2015[24]	Systematic review and meta-analyses of twenty RCTs was carried out assessing the effectiveness of exercise interventions on physical and mental health in patients with nonaffective psychosis (*n*=659)	-No significant improvement was found in BMI in subjects receiving exercise intervention -Significant improvement was noted in waist circumference as well as cardiovascular fitness -Moderate-vigorous exercise of about 90 min per week was found to significantly improve psychiatric symptoms
Guruswamy *et al*. 2018[25]	A systematic review of eleven RCTs was carried out assessing the effectiveness of exercise, educational and dietary interventions on risk factors of MS in patients with Schizophrenia (*n*=614)	-Modest weight loss was noted with adjunctive interventions with a duration of less than three months and as well as more than four months compared to treatment as usual -Significant reduction of weight, BMI, waist circumference, blood glucose were noted across studies -The feasibility of the interventions being carried out by nurses, dieticians was also demonstrated

BMI: Body Mass Index, CBT: Cognitive behavioural therapy, CI: Confidence interval, H: High density lipoprotein, LDL: Low density lipoprotein, MS: Metabolic Syndrome, N: Sample size, RCT: Randomised controlled trials, TG: Triglycerides

CONCLUSION

There is positive evidence for an integrated and multidisciplinary approach in the management of MS in the form of weight management/physical activity approaches, dietary approaches, psychoeducational approaches, and/or cognitive behavioral therapy approach, delivered through psychiatrists, nurses, dieticians, psychologists, and counsellors, alone or in liaison. Hence, there is a need for sensitizing all the health personnel to the physical health issues of persons with SMI.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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Access this article online

Website: www.ijpm.info

DOI: 10.4103/IJPSYM.IJPSYM_48_19

Quick Response Code

How to cite this article: Kuppili PP, Nebhinani N. Role of integrated and multidisciplinary approach in combating metabolic syndrome in patients with severe mental illness. Indian J Psychol Med 2019;41:466-71.

Facilitating Aadhaar and Voting for Long-Stay Patients: Experience from a Tertiary Care Center

Globally, 23% of persons with mental illness who are admitted to mental hospitals for treatment stay there for more than one year.[1] Such patients are in a state of "handicaptivity"[2] and are left with little options other than accepting the security of a hospital, due to lack of better available alternatives. This population has been termed by some experts as "unwanted patients."[3]

THE LIFE OF A LONG-STAY PATIENT

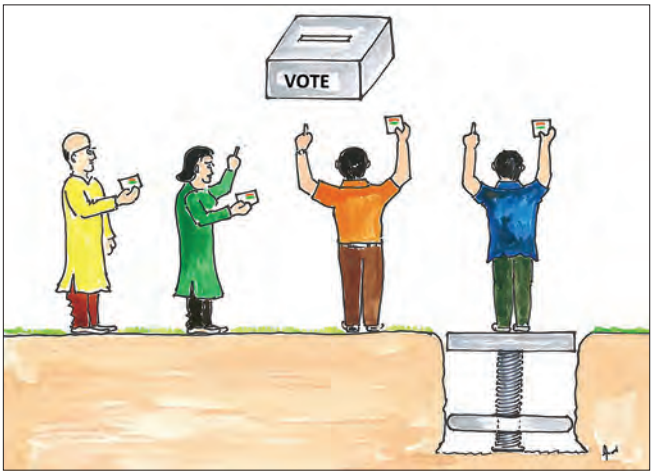
Like most mental hospitals across India, National Institute of Mental health and Neurosciences (NIMHANS), Bengaluru has long-stay patients who are in the hospital ward for many years because they do not have a family or a place to go back to. This is in spite efforts to place them in agencies and homes outside the hospital. In many instances, the hospital has made multiple attempts to trace the families of these patients, albeit unsuccessfully.

Each of them has a story that they narrate about how they got here and how the wards have gradually become their home. For most of these patients, hope does not lie in big things but in the very small gestures, they receive. Most find happiness in fulfilling small needs like having something special to eat or some old ornaments to wear.

Many of them spend their time in activities in the wards and at vocational sections at daycare facility of psychiatric rehabilitation services, to keep themselves engaged. Patients who attend the psychiatric rehabilitation services get incentives for the work they carry out. Some of the patients are very old and are assisted by the nursing staff and the hospital attenders in activities of daily living.

THE IMPETUS FOR AADHAAR ENROLLMENT FOR LONG-STAY PATIENTS

In a study on long-stay, female patients attending the daycare services at NIMHANS, most common rehabilitation need expressed by the patients, the nursing staff, the vocational instructors, and the treating team was more monetary incentives to enable patients to have food of their choice occasionally and to buy items for personal care and hygiene.[4]



Hospital authorities were sensitized about the study findings, and the incentive was increased from Rs 60/month to Rs 700/month in March 2015.[4] The nursing staff in the ward maintains a register of money received, and it is used to procure food or personal care items as per the preference of the patients.

Other options for ensuring remuneration are to facilitate employment opportunities (within or outside the hospital) or pension if the patient fulfills criteria for benchmark disability. Both require proof of identity and address. Enrolment in Aadhaar would solve the issue.

AADHAAR FOR LONG-STAY PATIENTS

Aadhaar, an identity document, is a 12-digit random number issued by the Unique Identity Authority of India (UIDAI) to the residents of India on satisfying the verification process.[5] Any individual, irrespective of age and gender, who is a resident of India, may voluntarily enroll to obtain Aadhaar. During the enrolment process, which is free of cost, minimal demographic and biometric information has to be provided by the person willing to enroll. Aadhaar serves both as proofs of identity and address. The first Aadhaar card

of the country was issued on 29th September 2010.[6] Most long-stay patients were admitted to the hospital before the Aadhaar era began. Aadhaar enrolment for a long-stay patient could serve as proofs of identity and address and facilitate other steps such as disability certification, voter card enrollment, and opening a bank account.

DILEMMA IN PROVIDING HOSPITAL ADDRESS FOR AADHAAR

Although it is ideal to get an Aadhaar card in their home address, there are logistic difficulties for a hospital to verify the home address the patient remembers and getting an address proof document for that address. The patient may have left home long back (several decades in some cases), may be from a different state, or may not remember the address. The address may no longer exist, or no family member is alive at the last known address.

In such a situation, it appeared pragmatic to get the hospital address as address proof. It does not mean that the patient will stay at the hospital forever. When the circumstances arise, the address can be changed to the place where the patient can be discharged to.

THE PROCEDURE FOLLOWED FOR AADHAAR ENROLLMENT FOR LONG-STAY PATIENTS

After being appraised about the issues, Institute authorities accorded permission to provide the hospital address as address proof for enrolment in Aadhaar. The process of enrolment of decertified (i.e. not under reception order as per the Mental Health Act, 1987) long-stay patients was initiated toward the end of 2016. UIDAI authorities in Bengaluru were contacted. The Institute authorities issued a letter containing the name, age, sex, latest photo, and hospital address/contact details in the format desired by UIDAI. For patients whose date of birth was not known, first January was given as date and month of birth, and the year was calculated from the age recorded in the case file.

Owing to logistic difficulties in transporting long-stay patients to the Aadhaar enrolment center, UIDAI authorities kindly consented to enroll these patients at the hospital premises itself. On 6th April 2017, biometric verification for Aadhaar enrolment was done in the ward for 21 long-stay patients. Patients were oriented about the procedure and made comfortable prior to and during Aadhaar enrolment. The enrolment number was used to follow-up with UIDAI portal, and e-Aadhaar was downloaded when it was available. The copy was given to the nursing staff in the ward for filing in the case records.

VOTING RIGHTS OF A LONG-STAY PATIENT

According to the World Health Organization Community Based Rehabilitation (CBR) Matrix, political participation is one of the sub-components of empowerment needs of persons with disabilities.[7]

In India, the following are relevant clauses pertaining to voting by a person with mental illness:

1. Representation of People Act 1951 (Chapter IV, Section 62(2)): It states that "No person shall vote at an election in any constituency if he is subject to any of the disqualifications referred to in section 16 of the Representation of the People Act, 1950 (43 of 1950)"[8]
2. The Representation of the People Act, 1950 (Section 16 (1b): One reason for disqualification for registration in an electoral roll is if "he is of unsound mind and stands so declared by a competent court."[9]

A diagnosis of mental illness is neither necessary nor sufficient for a finding of unsound mind.[10] United Nations Convention on Rights of Persons with Disabilities (UNCRPD) also states that persons with mental illness cannot be denied right and opportunity to vote.[11] Legally, persons with mental illness can, unless declared to be of unsound mind by a competent court, exercise their constitutional right to vote. This holds true for a long-stay patient as well.

THE PROCEDURE FOLLOWED FOR FACILITATING VOTING FOR LONG-STAY PATIENTS

After obtaining the Institute's permission, the process of getting voter cards was initiated in April 2018 for Karnataka assembly elections scheduled on 12th May 2018. Among patients enrolled in Aadhaar with hospital address, only five were in a position to vote. Some patients did not have the capacity to understand "voting," and one person had been declared to be of "unsound mind" by the court. Out of the five patients, only three (two females and one male) expressed an interest and were in a position to vote. None of them had voted in the past. The duration of hospital stay was 4, 10, and 19 years, respectively.

The online application was filled for enrolment as a voter and submitted with supporting documents (Aadhaar, which served as both proofs of identity and

address). House number was a mandatory column to be filled while applying for voter card. The ward number was given as house number. In spite follow-up, voter cards had not come till 11th May evening. The issue was brought to the attention of Chief Electoral Officer by an official email on 11th May after the working hours. The election officials swiftly responded to the email. Voter ID and polling station details were shared by email.

The patients were sensitized about the voting process. One among them would speak well only to a particular therapist, and that therapist sensitized him. They were accompanied to the polling booth on 12th May 2018. The polling booth officials and the general public were very helpful and permitted the patients to skip the queue and vote. When the voter cards came (after the elections), the three patients were thrilled to see a laminated card with their photo. The voter cards are in safe custody.

All the three patients voted for the second time in Lok Sabha elections in 18th April 2019, for which government officials themselves arranged a car for transporting the patients to the polling booth.[12]

CHALLENGES FACED

As this was a unique initiative done for the first time in a government institute, it took time to clarify the procedure, obtain the necessary permissions, contact the key personnel for Aadhaar and voter cards, gather the documents in the prescribed format, facilitate the paperwork, follow-up on the progress, and coordinate with the stakeholders to take it to the logical conclusion.

During the process, concerns were raised about the ability of the patients to understand the political situation to cast their vote, privacy concerns of using the hospital address, and about "utility" of the entire exercise. While approaching the three patients for voting for the second time, there were doubts if the novelty of voting would have worn-off and if they would be interested in voting again. However, the patients were keen and excited to vote again.

FACILITATORS

The permission of the Institute, enthusiasm of the long-stay patients, encouragement from our colleagues, and the support of the election officials and the general public kept us going. The three votes cast on 12th May 2018 are "a small step," which can and needs to be replicated across the country. After the NIMHANS initiative, voting was facilitated for more than 150 long-stay patients at the Institute of Mental health, Chennai on 18th April 2019.[13] With such initiatives, hospitals are acknowledging the person in every "patient" and empowering them in sync with the recent rights-based legislations.

THE WAY FORWARD

A lively and dedicated endeavor to rehabilitate this population both inside and outside the hospital needs to be attempted.[14] Clarity and affirmative action are also needed for certifying long-stay patients for disability, facilitating access to disability pension, and credit to their own bank accounts opened by the hospital.

National Human Rights Commission has advised that hospital authorities may find some jobs for the fully recovered patients on nominal remunerations within the hospital, to rehabilitate them.[15]

The Mental Healthcare Act, 2017[16] states that "long term care for patients in mental health establishments shall be used only in exceptional circumstances, for as short a duration as possible, and only as a last resort when appropriate community-based treatment has been tried and shown to have failed" (Clause 18 (5c)). It also affirms that long-stay patients have a right to community living in their family home or in less restrictive community-based establishments, including half-way homes and group homes. Enrolment in Aadhaar and getting voter card are steps toward facilitating social inclusiveness and community reintegration. Further, it is important to develop services such as supported housing, supported education, and supported employment to cater to their complex needs.[4]

CONCLUSION

Persons with mental illness need to be able to exercise their rights as citizens of the country, including their right to vote. It is the duty and responsibility of mental health professionals to facilitate appropriate opportunities for the "voiceless" population.

Acknowledgments

Ms. Amrita Roy (PhD scholar in Mental Health Rehabilitation), Dr. Rashmi (Fellow in Psychiatric Rehabilitation), Ms. Lydia (M.Phil Psychiatric Social Work Trainee) and Dr. Manjushree (Junior Resident in Psychiatry) for facilitating voting of long-stay patients in 2018 and 2019 elections.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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Access this article online	
Website: www.ijpm.info	**Quick Response Code**
DOI: 10.4103/IJPSYM.IJPSYM_235_19	

How to cite this article: Sivakumar T, James JW. Facilitating Aadhaar and voting for long-stay patients: Experience from a tertiary care center. Indian J Psychol Med 2019;41:472-5.

Towards a Dementia-Friendly India

India is the second most populous country in the world and is home to 1.2 billion people.[1] Of this, 8.6% or 104 million are 60 years old or over. Furthermore, with increasing life expectancy in a developing country like India, this figure is anticipated to grow higher. Prevalence rates of dementia in India have been found to vary greatly between studies, ranging from 1% to 10%. This is in part due to the diversity of the populations studied and the methodological differences between studies. Prevalence rates are higher in studies which used instruments appropriate for populations with low awareness of dementia and where relatives are less likely to report symptoms even in the presence of objective evidence.[2] Added to this the fact that the prevalence of dementia doubles every five years after the age of 65. Taking all the above into account, it is estimated that there are about 4.1 million people with dementia in India[3] and this is expected to double by 2030 and treble by 2050.[4]

"Dementia is a syndrome usually chronic, characterized by a progressive, global deterioration in intellect including memory, learning, orientation, language, comprehension and judgement due to disease of the brain."[5] Dementia is a disease mostly of the old, though young people can get affected as well. Alzheimer's disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia account for 80% of all dementias, with Alzheimer's type being the most common.[4] As dementias are degenerative brain diseases, it is not possible to alter the course of the disorder, but treatments can delay the progression of the disease and ameliorate its behavioural and psychological symptoms, and psychosocial interventions can support those with dementia and their carers.

Dementia adversely affects not only the individual (ill health, disability, impaired quality of life and reduced life expectancy) but also his/her family (significant carer burden and poor quality of life) and society (economic and social costs), and is a significant cause of disability in late - life. The World Health Organisation's (WHO) Global Burden of Disease Report[6] calculated the proportionate contribution of different chronic diseases to the total chronic disease burden among people aged 60 years and over, expressed in terms of both Years Lived with Disability (YLD) and Years of Life Lost (YLL), and found dementia to be a major contributor. The 10/66 dementia study,[4] among other things, also looked at the care needs of people with dementia and found that, in India, between 50 and 70% of those with dementia needed care, and most of these needed 'much care.' It also noted that between 40% and 72% of primary caregivers (usually family members) reported high levels of psychological morbidity. In addition to the individual disability and carer burden, the social and economic costs borne by the wider society are also huge, some hard to quantify.

A rough estimate in 2010[4] pegged the total societal cost of dementia for India to be US$ 3.415 billion (INR 147 billion); with its 56% (INR 88.9 billion) being the informal care costs and 29% being direct medical costs (INR 46.8 billion). Rao and Bharath[7] estimated the annual household cost of caring for a person with dementia in India, depending on the severity of the disease, to range from INR 45,600 to INR 2, 02,450 in urban areas and INR 20,300 to INR 66,025 in rural areas. Costs increased with increasing severity of the disease.

In this article, we emphasize the need to view dementia as a public health problem, and elaborate on public health-based prevention models[8] gaining popularity in dementia Primary prevention though refers to efforts to prevent the disease; in neurodegenerative conditions like dementia the aim may be to delay the onset of symptoms. Secondary prevention targets delay in the progression of symptoms and covers screening, early identification and treatment. Tertiary prevention focuses on reducing the disability and its impact on the family. We aim to approach the public health prevention model using pragmatic strategies relevant to Indian situation. Synthesizing the current evidence available in this field, we then propose a model for delivering dementia care services in India.

PREVENTION STRATEGIES

Minimising risk

With no major breakthroughs imminent in the medical treatment of dementia, primary prevention strategies are crucial. There are seven potentially modifiable risk factors that have been shown to be associated with Alzheimer's disease, and hence these are ideal targets for primary prevention: diabetes, midlife

hypertension, midlife obesity, physical inactivity, depression, smoking, and low educational attainment. It was proposed that relative reductions of 10% per decade in the prevalence of each of the above seven risk factors could reduce the prevalence of Alzheimer's disease by 8.3% worldwide in 2050 and that the incidence of Alzheimer's disease can be reduced through improved access to education and the use of effective methods targeted at reducing the prevalence of vascular risk factors and depression.[9] Multimodal interventions that include more than one behavioural or lifestyle intervention (physical, mental, cognitive, diet, etc.) may have a greater likelihood of influencing neurobiological mechanisms underlying cognitive decline than any one activity alone.[10] The WHO[11] proposed linking dementia with other programmes, policies, and campaigns on Non-Communicable Diseases (NCD) risk reduction and health promotion across relevant sectors. In a country like India, when there are competing needs for the scarce resources available, demands should be realistic and pragmatic. It is clear that inter-sectorial collaboration is the best way forward in addressing the complex challenges associated with dementia care and organising services. Although strengthening health and social care systems will form the backbone of many of the components described above, and because policy decisions are essential for sustainable regional or national strategies, successful small scale collaborations can be forged at local levels. Mental health professionals (psychologists, social workers, and psychiatrists) have a crucial role in facilitating such collaborative models at regional, state and national organisational levels. Vehicles such as the National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS) can be used to include dementia piggyback on to other NCDs. NPCDCS, launched in 2010 in 100 districts across 21 states, focuses on health promotion, early diagnosis, management and referral besides strengthening the infrastructure and capacity building.[12]

Awareness raising

There are two essential aspects in identifying people with dementia: the general public should be aware of dementia and its symptoms, and be ready to seek appropriate help and when an individual approaches a professional, he/she too should be aware and competent to make a correct diagnosis of dementia. This emphasises the importance of awareness creation among the public and skills development among various professional groups. Actions in this regard could include finding ways to make opinion-leaders, media, and celebrities to talk more about dementia and organising ongoing dementia awareness programmes. Awareness programmes should be contextual and culture specific. Cultural practices and beliefs play a major role in shaping attitudes and behaviours. From understanding dementia as a disease process as against a part of normal ageing and recognising symptoms of dementia, would enable and break barriers to seek help and support by families affected by dementia. Stigma and discrimination against people with dementia occur at various levels. Even health professionals can be perceived as unhelpful and dismissive. Advocacy is important to increase awareness in the political sphere, which should be collaborative and include families, health care professionals, non-governmental organisations (NGO), social service, etc., The campaigns should be structured and long term. Risk reduction strategies should be an inevitable component of awareness programmes. A dementia-friendly community approach, which aims at building a society where people with dementia have a good quality of life, is the way forward.[13]

Early diagnosis

Early identification and diagnosis of dementia and providing support to the person and his/her carer/s are essential to ensure a good quality of life. However, the treatment gap (the difference between number of people with the condition who need care and the number of people who receive care) for dementia in India is about 90%.[14] Acquisition of skills to suspect and identify people with dementia is important for all professionals likely to come in contact with the elderly people. This includes nurses, doctors, social workers, occupational therapists, physiotherapists, etc., and a range of non-healthcare professionals. Lack of a medical cure and the worrisome impact the diagnostic label can have on the patient and the relatives are reasons for low rates of diagnoses by medical professionals. However, often, the families are relieved to realise that their relative suffers from a medical condition and that they are not being 'purposefully difficult.' A medical diagnosis often allays several other anxieties and often shifts attitudes positively.

In addition to people presenting specifically with memory/cognitive problems, screening for memory problems among elderly people in other settings such as medical and surgical outpatient clinics and those admitted in hospital wards will help identify more people with dementia. Periodic screening for cognitive problems among the elderly people in the community can be conducted by primary health centres in collaboration with local NGOs. Cognitive screening may also be combined with various other health intervention programmes in the community as part of the NCD strategy. Community workers should have the basic knowledge to offer appropriate advice regarding

dementia and there ought to be pathways in place to ensure an appropriate and timely response.

Memory clinics

The core functions of such clinics/services are to assess people with suspected memory difficulties, make a diagnosis, and come up with a treatment plan. They should also be equipped to treat comorbid conditions and to offer a range of medical and psychosocial interventions to patients and their caregivers. Some such clinics also offer inpatient stay and take on non-medical work in this field such as running awareness-raising campaigns and training programs. Such clinics can be located in general hospitals or community centres and need to have multi-disciplinary input from doctors (neurologists, psychiatrists, geriatricians, etc.), nurses and social workers, depending on the available resources.[15]

Services for those with dementia and their carers

Once a diagnosis is made, patients and their carers will need a range of help and treatment/support services. They need information about the condition and skills to manage the situation. It becomes difficult to deal with the challenges of dementia without appropriate knowledge and skills.

There should be an identified source where they can turn to. This could be the local health centre, a local NGO or a local self-government body. Information is plentiful in some areas and languages but rather scarce in others. Social work institutes, preventive medicine departments and so on are best positioned to translate, adapt and provide such information in collaboration with specialists. Community-level health workers should be able to train the family caregivers to deal with the daily stresses of dementia care. Most people would want to try cognitive enhancers, which should be considered after providing information about the moderate effectiveness of these agents in improving the condition.

In early stages of illness, many relatives find that day centres (where people with dementia are cared for during working hours) are effective alternatives to leaving them home on their own and provide breaks for caregivers who have other responsibilities as well. These centres offer leisure activities and cognitive stimulation. Day centres which provide free or subsidised places should be available locally or regionally. As dementia is a progressive condition and as symptoms get worse, caregiving demands go high, and the distress levels tend to escalate. In India, the primary caregivers are often women and elderly partners. National Mental Health Policy[16] acknowledges that the unmet needs of elderly caregivers have a negative impact on their lives as well as the lives of those for whom they provide care. Dias *et al*.[17] showed that home-based support for caregivers of persons with dementia, which uses locally available, low-cost human resources, is feasible and acceptable, results in significant improvements in caregiver mental health and lessens the burden of caring.

The advanced stage of the condition requires palliative care approaches. Community-level palliative care teams[18,19] may have transferable skills to care for patients with dementia. Where it is no longer possible to look after those with dementia in their own homes, they will need to be admitted to care homes. Nursing homes with qualified and skilled staff members with a safe, stimulating environment are important in such centres. Although there are some private agencies that provide such care, albeit few and far between, the government sector needs to step up too. Though precise official data are not available, it is estimated that there are only 20-day care centres and 30 full-time residential centres that cater to the needs of people with dementia across India and they are mostly concentrated around major cities.[20]

Families caring for those with dementia will also benefit from support in the care of their loved ones. Those who can afford may utilise paid caregivers but those who cannot, rely on informal support from relatives, friends and the wider community. One needs to be innovative in mobilising community support – examples include volunteers, senior citizen groups or local networks of people small or big. There is no 'one-size fits all' approach as there are cultural, social and attitudinal factors associated with this type of help-seeking and provision.

The specific role of community workers is important, and the inclusion of members of the local community in a semi-formal network of care is one way forward. The idea is to create a network of community members to provide psychosocial support in strengthening mental health services at the primary care level.

Care of people with dementia also comes under the new Mental Healthcare Act 2017.[21] It is considered to be a progressive and revolutionary piece of legislation intended to provide mental healthcare and services for persons with mental illness and to protect, promote and fulfil the rights of such persons. It has several positive aspects[22] and measures such as opportunities to make advance directives (AD), nominated representatives, regulating all facilities that provide psychiatric care irrespective of systems of medicine practiced or nature of service provider, and setting up systems to ensure due process when personal liberties are restricted. These

are hoped to bring about significant changes in the care of patients with dementia as well. However, there seem to be several ambiguities and gaps which need to be reviewed to bring it in line with the principles followed in other countries but adapted to local situations.

A national dementia plan and more research

Dementia should be acknowledged not only as a national public health priority but also as a social care priority. A national dementia plan with allocated funds to see it through has to be in place. The key components of an effective dementia plan include: making dementia a national priority, increasing awareness about dementia, improving early identification and treatment, developing home care and community support, building carer support packages, developing comprehensive dementia care models, and increasing funding for dementia research. As the needs of people with dementia are multiple and varied, and because they fluctuate over time, it would be impossible for a single professional or agency to address all their needs. This is what calls for partnership between families, government agencies and voluntary sector organisations.[23]

Research in dementia from India is either small-scale independent studies or studies that are part of international research collaborations. Whether regional variation of dementia rates shown in some studies is related to a lower prevalence of certain risk factors or higher prevalence of certain protective factors need to be explored further.[24] We need answers to questions such as what interventions do families find useful? How can effective interventions be delivered in low resource settings within existing infrastructure? And what would ease the burden of caregivers of people with dementia? Long term research plans are needed to address the complex challenges associated with dementia.[25] Intersectoral collaborations between government departments (e.g., health and family welfare and social justice), NGOs, community workers, academicians, and researchers are the way forward.

Proposed model for delivering dementia care services: Seven core strategies

Dementia India Report[4] proposes a model for effective dementia care based on seven core strategies focusing on awareness creation, demanding services for people with dementia; capacity building of health care teams; providing affordable treatment; effective long-term care through community-based programmes and residential, respite and day care facilities; and developing legal services and training services. These strategies echo the propositions by international organisations. Alzheimer's Disease International (ADI)[26] emphasises that national dementia plans are the single most powerful tool to transform national dementia care and support, but India does not have one yet. ADI identified ten areas that should feature in any future National Dementia Plan, which are: improve awareness and education, improve early diagnosis and treatment, improve support available at home, strengthen support available to family caregivers, improve residential/institutional care, better integrate care pathways and the coordination of care, improve training for healthcare professionals, monitor progress, commitment to research, and recognise the role of innovative technologies.

Although there have been no significant national level programmes focusing on dementia, there are a few good models of practice which could easily be replicated in other parts of the country. A classic example is Kerala State Initiative on Dementia. Taking cognizance of dementia as a major public health problem affecting the community, Kerala became the first state to launch a state-wide dementia initiative in 2014. Kerala State Initiative on Dementia used a public-private partnership model linking various government departments with Alzheimer's and Related Disorders Society of India (ARDSI). It has several components including creating dementia awareness among all sections of the society, equipping health personnel and professional caregivers with knowledge and skills for dementia care, establishing memory clinics for diagnosis and care of people with dementia, opening care homes and day-care centres in all districts for dementia patients, and so on.[27]

To upscale such innovative ideas to the national level in the form of a national plan, commitment from the government is essential. Multidisciplinary models and collaborative working with other health and social care professionals is the way forward. Caregiver support should be provided not only using formal systems but informal system as well, utilising local community resources, with all stakeholders included. There should be more emphasis on chronic health problems, NCDs, and long-term care. The focus should be on improving the quality of life.

CONCLUSION

Dementia not only affects the health, and quality of life of the individual but also has huge impact on the psychological and emotional well-being of the caregiver in addition to the socio-economic burden of the family and society at large. Furthermore, with the number of people who have dementia in India expected to double from the current 4.1 million by 2030 and treble by

2050, there is no denying that it is a significant public health issue. Given this, public health-based prevention strategies need to be in place – i.e. prevention at primary (intervention strategies prior to the onset of dementia), secondary (interventions covering screening, early identification and treatment), and tertiary (treatments for the chronic condition, including psychosocial and rehabilitation needs of the individual and the carer) levels. Recognising dementia as a priority health and social care issue by the policymakers, specific government funding allocation, active engagement of voluntary organisations, strong patient advocacy movements including networking, media attention and utilising existing local community level initiatives and infrastructure are the crucial drivers in building a dementia-friendly India.

Financial support and sponsorship
Nil.

Conflicts of interest
There are no conflicts of interest.

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Access this article online

Website: www.ijpm.info

DOI: 10.4103/IJPSYM.IJPSYM_25_19

Quick Response Code

How to cite this article: Kumar CT, George S, Kallivayalil RA. Towards a dementia-friendly India. Indian J Psychol Med 2019;41:476-81.

Income Generation Programs and Real-World Functioning of Persons with Schizophrenia: Experience from the Thirthahalli Cohort

Low rate of employment is an important contributor to disability associated with schizophrenia.[1] In India, a large proportion of persons with schizophrenia do not receive vocational rehabilitation services concordant with standards of good clinical practice,[2] but the course and outcome have been consistently shown to be better than in developed countries.[3-5] It is possible that in communities, other factors may be operating that may be inherently rehabilitative in nature. For instance, in India, there are income generating programs that are successfully operating in rural communities. Here, we report the role of these programs in vocational rehabilitation of a rural cohort of persons with schizophrenia and present the audit of 50 patients (out of 256) who had utilized these programs.

SETTINGS AND METHODS

Sample for this study was schizophrenia patients under the Community Intervention in Psychotic Disorders (CoInPsyD) program in Thirthahalli taluk. Details of the program are mentioned elsewhere.[6] Almost all schizophrenia patients of the entire taluk are being identified, treated, and followed-up for the past 12 years. Vocational rehabilitation inputs are limited to the provision of common-sense counseling and guiding patients towards existent employment/vocational avenues. Data for the paper was extracted by reviewing case files and by informal interviews at follow-up. Of the 380 patients in the cohort, 256 were interviewed (Death: 37, Migration: 25, Change of diagnosis: 12, Refusal of consent: 12, Not able to contact: 38). Fifty patients had utilized the below-described programs and were productively employed. The CoInPsyD project was approved by the Institutional Ethics Committee. Written informed consent was obtained from all patients/family members.

1. Income generation Programs:

a. **Mahatma Gandhi National Rural Employment Guarantee Act (MNREGA):** It provides for the enhancement of livelihood security for below the poverty line households in rural areas of the country by providing at least 100 days of guaranteed wage employment (unskilled manual work) in every financial year. The tasks are executed by gram panchayats, and local developmental works are given priority.[7]

b. **Sri Kshetra Dharmasthala Rural Development Program (SKDRDP):** Its objective is "inclusive rural development." Participants are active in self-help groups (SHGs, 5--6 members) that are income generating. Each day of the week, one member of each group would go to any of the other members' home and work, for example, in farming. The person is remunerated for the work. Some part of this income is saved. There is an arrangement to give small loans as well from the capital (and interest) accrued.[8]

c. **Self-help groups:** There are three of them including (a) Sthree Shakti SHG, (b) Navodaya Grama Vikas Charitable Trust, and (c) Caste-based SHGs. The first one is supported by the state government (loans at subsidized rates for individuals) while the other two are not. The basic format of these SHGs is that from a shared common pool, the needy get loans, which is paid back after the need is fulfilled. The aim is to empower rural women and make them self-reliant. Fifteen to 20 women members from below poverty line families, landless laborers, scheduled castes/tribes, Anganwadi teachers, etc., form the SHGs. SHGs also offer self-employment training and marketing guidance.

d. **Primary agricultural and credit cooperative society:** This is akin to a bank and is run by the government through gram panchayats. The operation is similar to that of the SHGs mentioned above.

A notable point is that these agencies cater to the entire community and not specifically to those with psychiatric illnesses. Furthermore, though programs (c) and (d) are not directly income-generating, families utilize the financial resources from these projects in order to gainfully employ their wards. Patients will actively contribute by lending themselves to agricultural work.

RESULTS

The mean age of the sample was 39 years, with more females (58%) than males (42%). More than three-fourths of the 50 patients were married (78%), and most of the patients belonged to the lower or lower-middle socioeconomic status (94%). The mean duration of remission was 6.3 years, with the mean time taken to work after remission being 2.1 years. Table 1 summarizes the findings.

Patients had responded well to medications and evidently were asymptomatic for long periods of time. Other anecdotal observations about this patient group included that they had low levels of adverse effects, excellent medication adherence, less negative symptoms, good pre-morbid functioning, and relatively well-preserved personalities. One-third of the patients were using more than one organization/program for employment. There was no significant correlation between patient's severity of illness or duration of illness and their salary or regularity of attending work.

DISCUSSION

This report shows that about one-fifth of the patients in this cohort were gainfully employed, utilizing income-generating resources available locally. A substantial proportion of others in the cohort were meaningfully occupied through other means as exemplified by our previous report from the same cohort.[6] This report assessed work functioning at

Table 1: Sociodemographic and occupational details

Sociodemographic and clinical variables	Findings
Sociodemographic Details	
Age	
[Mean (SD)]	39.0 years (10)
Gender	
Male	21 (42%)
Female	29 (58%)
Marital Status	
Married	78%
Single/separated	22%
Socioeconomic Status	
Lower	58%
Lower Middle	36%
Upper Middle	6%
Mean years of education [Mean (SD)]	6.3 (2.1)
PANSS Positive symptoms score Baseline [Mean (SD)]	15 (1.8)
PANSS Negative symptoms score Baseline [Mean (SD)]	28 (2.1)
Mean duration of illness [Mean (SD)]	139 months (61.0)
Mean duration of remission [Mean (SD)]	6.3 years (2.1)
Time taken to start work after remission [Mean (SD)]	2.1 years (1.2)
Asymptomatic for [Mean (SD)]	6.3 (2.1) years Median=7 years Range: 1-10 year
Occupational Details	
Program Utilized	21 (12 males; 09 females)
MNREGA*	26 (13 males; 13 females)
SKDRDP	21 (03 males; 18 females)
SHGs	Mean: 5,600
Average monthly income (INR)	Median: 5,000
Regularity at work	Range: 1,500 to 10,000 Regular: 41 Irregular: 9
Any complaints from the employer	Nil
Is the patient satisfied with the work performance?	Yes (n=50)
Is the family satisfied with the work performance?	Yes (n=50)
Is the patient satisfied with the salary?	No (n=50)
Future plans	All 50 plan to continue working.

*Numbers do not add up to 50 as some patients were using more than one organization/program for employment. INR=Indian National Rupees, MNREGA=Mahatma Gandhi National Rural Employment Guarantee Act, SHGs=Self Help Groups, SKDRDP=Shree Kshetra Dharmasthala Rural Development Program

the end of 4 (mean) years of follow-up (baseline time differed for every patient differed as and when they got recruited to the cohort. The assessments for the purpose of the above report were done during the year 2011). It showed that there was a significant drop in the scores of "work" domain of the Indian Disability Evaluation and Assessment Scale (IDEAS): The score was 2.2 (SD = 1.6) at baseline and 1.1 (1.2) at follow-up [$t = -9.1$; $P = 0.001$]. The mean total IDEAS score decreased to 1.4 (1.9) from baseline total score of 6.6 (4.8).

Specialized human resources were not necessary to do this kind of rehabilitation work,.[5,9] A medical social worker trained in rehabilitation coordinated this work. He guided patients/families towards employing their ward/s by giving information about various avenues available and the possible ways of contacting the agencies. This method is especially relevant in countries such as India where human resources are meager and specialized interventions are neither affordable nor accessible. Some patients would stop work in between---gently nudging them towards restarting work often resulted in success. However, as noted in our previous papers, rehabilitation work is fraught with many barriers in patients with negative symptoms, inadequate symptomatic recovery, absent/poor insight, or poor treatment adherence. These patients, in particular, require multidisciplinary inputs in more specialized settings and do not yield themselves for the public health strategy of managing schizophrenia.[6,9,10]

Accredited Social Health Activists (ASHAs) and Village Rehabilitation Workers (VRWs) are potential ground-level workforce for rehabilitation, if they are provided training in psychiatric (including vocational) rehabilitation and continual support. These could be simplified so as to integrate this rehabilitation work with their routine responsibilities. This is in keeping with the philosophy of "community-based rehabilitation" promulgated by the World Health Organization as well.[11]

Therefore, income generation programs---governmental and non-governmental---that are locally available can be utilized as livelihood opportunities for patients and their families by appropriate guidance from community level workers for rehabilitation.

Often, families themselves took the initiative of employing the patient based on their clinical status. This asset in Indian culture needs to be harnessed by providing all possible support from stake holder agencies. The laws and policies of the land need to align with the needs of the families, besides protecting and supporting patient rights.

The programs were clearly helping in generating additional income for the patients/families; yet, there was dissatisfaction with financial gain. This is understandable, given the gap between requirements and income generated. The mean income as reported was Rs. 5,600/month; this has assisted the families/households in generating additional income but obviously was not satisfying enough for the patients or families. This reflects the scenario prevalent in the lower and middle-income countries in general. Aspiration for more income, although present, did not bother them too much, as denoted by the satisfaction with the quality of life that emerged out of vocational functioning. Similar findings have reported previously as well.[1,5] Obviously, more qualitative research in these aspects will give us more information on this interesting discrepancy.

An anecdotal finding was an experience of very little stigma from employers by patients. The realization that patients' work-performance is similar to that of normal people could be one reason for lesser stigma.

The limitations of the study are lack of *a priori* hypothesis; anecdotal observations without systematic measures to evaluate adherence, adverse effects and burden; and retrospectively extracted data.

Financial support and sponsorship
Nil.

Conflicts of interest
There are no conflicts of interest.

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Access this article online

Website: www.ijpm.info

DOI: 10.4103/IJPSYM.IJPSYM_151_19

Quick Response Code

How to cite this article: Ravilla S, Muliyala KP, Channaveerachari NK, Suresha KK, Udupi A, Thirthalli J. Income generation programs and real-world functioning of persons with schizophrenia: Experience from the Thirthahalli cohort. Indian J Psychol Med 2019;41:482-5.

Clozapine-Related Constipation: A Retrospective Study

To the Editor,

As per the Rome III Expert Consensus, functional constipation is considered to be present if the patient experiences change in bowel movements, with an inability to pass stools less than three times per week despite adequate intake.[1] The prevalence of constipation in patients who are on clozapine is three times that of patients taking other antipsychotics.[2] A recent meta-analysis suggests that constipation is one of the most common side-effects (prevalence rate: 31.2%; CI: 25.6–37.4) of clozapine and that the prevalence of clozapine-associated constipation is influenced by factors like whether the constipation was assessed as a primary, secondary, or a nonspecific outcome of the study, with higher rates reported in studies which evaluated the same as a primary or secondary outcome.[2] Available evidence also suggests that constipation is related to the dose of clozapine, with doses higher than 300 mg/day being more frequently associated with constipation.[2]

There is limited data on the association of clozapine with constipation from India and other Asian countries. If one looks at the dietary pattern, it is expected that patients from Indian subcontinent should have a low prevalence of constipation. However, when one looks at the cultural aspect, with respect to preoccupation with bowel movements, it can be said that Indians get very much distressed about alteration in bowel movements and possibly report the same early.[3-5] If one goes by a strict definition of constipation, in many of these cases, a patient may not fulfill the standard definition of constipation, but may still be distressed.[2] One recent study from India investigated the prevalence and predictors of clozapine-related constipation and reported a prevalence of 56%, with the median time to onset of constipation as 60 days and the median dose of clozapine to develop constipation to be 300 mg/day.[6] Keeping this in mind, this retrospective study evaluated the data of inpatients who were started on clozapine during the period of 2010 to 2016, with the aim to evaluate the dose of clozapine-associated with the development of constipation and time to the development of constipation. The study was approved by the Ethics Committee of the Institute.

In our set up (a tertiary health care centre in North India), we maintain a clozapine registry for all patients started on clozapine. Besides the relevant socio-demographic and clinical data, data with respect to the efficacy of clozapine and various side effects of clozapine is also maintained. When the patient is started on clozapine, especially in the inpatient setting, doses at which each side effect develop is captured.

For this study, data of 53 patients with treatment-resistant schizophrenia who were started on clozapine as inpatients was extracted. The mean age of the patients was 33.3 (SD: 12.26) years with two third (66%) of them being males. The mean duration of illness at starting clozapine was 10.96 (SD: 7.70) years.

In terms of the dose of clozapine associated with the development of constipation, the mean dose was 147.87 (SD: 66.94) mg/day, with a median dose of 150 mg/day and a range of 25-300 mg/day. The mean duration to onset of constipation was 19.56 (SD: 9.45) days, with a median of 20 days and a range of 6-38 days.

The most common strategy utilized to manage clozapine-associated constipation included the use of high fiber diet (N = 36; 67.9%), followed by use of bulk laxatives (Isabgul husk –N = 8; 15.1%) and a combination of liquid paraffin and magnesium hydroxide (Cremaffin- N = 6; 11.3%). Using these strategies, constipation could be effectively managed, and the dose of clozapine could be increased further in all the cases to the level required for a therapeutic response.

The findings of the present study suggest that our patients who received clozapine developed constipation on much lower doses than that reported in some of the earlier studies[7-11] and this side effect is often encountered during the initial phase of the treatment. Our findings are not in concurrence with the previous Indian study, which reported constipation with a median dose of 300 mg/day, and the time to onset of constipation being 60 days.[5] Although the previous study from India used rating scales to define constipation, which was not done in the present study, the findings of the earlier studies do not fit into the clinical experience with day to day encounter with patients from India.

Our findings must be understood in the background of the fact that Indians are very much pre-occupied with their bowel functions and get very distressed if they experience constipation. In view of this, some of the researchers and clinicians have proposed different median normal stool frequency and stool form to define constipation in Indian population[3,4,12,13] when compared with Western population. This suggests that, in the Indian context, constipation as a side effect of clozapine should not be defined as per the standard Western definitions. Accordingly, there is a need to relook at the prevalence of constipation and its association with the dose of clozapine by using a definition of constipation which has been accepted and standardized in the Indian context.

The present study has limitations in the form of small sample size, retrospective study design, not evaluating the information on stool consistency, and inclusion of inpatients only. The study was limited to patients for whom data was available in terms of the dose of clozapine at which constipation developed and the time of development of constipation. Accordingly, this study does not provide information on the prevalence of constipation with clozapine. Further, this study did not specifically evaluate the effectiveness of interventions carried out for the management of constipation.

Financial support and sponsorship
Nil.

Conflicts of interest
There are no conflicts of interest.

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Access this article online

Website: www.ijpm.info

DOI: 10.4103/IJPSYM.IJPSYM_467_18

Quick Response Code

How to cite this article: Grover S, Sahoo S, Hazari N. Clozapine-related constipation: A retrospective study. Indian J Psychol Med 2019;41:485-7.

Steroid-responsive Encephalopathy as a Semblance of Neuroleptic Malignant Syndrome in a Patient with Schizophrenia

Sir,

The exact etiopathogenesis of schizophrenia remains unclear, but the field of psychoneuroimmunology has provided certain plausible immunological underpinnings. Lately, more attention has been paid to autoimmune encephalopathies of both rheumatic origin and those associated with autoimmune encephalitis. In contrast to the rheumatic conditions which mainly present with systemic involvement, autoimmune encephalitis syndrome usually presents with an initial clinical picture that is dominated by headache, mild hyperthermia, and frequent cerebrospinal fluid (CSF) pleocytosis and thus is often treated in line of a bacterial or viral meningoencephalitis. The second stage may be characterized by psychiatric manifestations such as altered mood and behavior, memory changes, anxiety, and insomnia or neurologically a reduced level of consciousness and seizures, with/without other severe symptoms such as autonomic instability, dyskinesias, hypoventilation, and at the end coma may ensue.[1] The frequent occurrence of psychiatric symptoms as an initial presentation of certain autoimmune encephalitis/encephalopathy and findings of autoantibodies in such patients enthused various researchers to explore a possible autoimmune etiology of severe mental illnesses such as schizophrenia. However, the evaluation of various autoantibodies in persons with schizophrenia has remained inconclusive till date.

Although various neuropsychiatric symptoms are the common initial presentation in autoimmune encephalopathies, semblance to the neuroleptic malignant syndrome (NMS) is rarely reported.[2-4] Moreover, it is a very uncommon observation that autoimmune encephalitis, which has usually an acute and progressive course of illness, presents as an episodic mental illness with a long interepisodic interval. Only two case reports of autoimmune encephalitis are available wherein a diagnosis was made after a long history of relapsing psychosis or mood disorder.[5,6] Here, we report a case of steroid-responsive encephalopathy with a semblance of NMS in a patient of episodic schizophrenia.

CASE REPORT

The patient is a 61-year-old male who was diagnosed with schizophrenia 22 years ago. He presented to the accident and emergency department of our institute with complaints of high-grade fever, rigidity, stupor, mutism, autonomic instability, and poor oral intake for the last 15 days. A diagrammatic presentation of the course of illness of the index patient is shown in Figure 1. He was initially managed by the internist, with a possible diagnosis of meningoencephalitis. Apart from the hematological and blood biochemistry, a CSF examination and computed tomography of the head without contrast were done [Table 1]. The psychotropic medications were stopped, and he was empirically treated with intravenous fluids, antihypertensive, antipyretic medications, and a course of intravenous ceftriaxone and prophylactic acyclovir for the next 3 days. However, in view of a minimal response, consultation with psychiatrist and neurologist was done, and the possibility of schizophrenia with NMS was entertained. He was admitted to psychiatry inpatient section for further management. His physical examination showed a thinly built, poorly kempt man with a nasogastric tube and urinary catheter *in situ*. His vitals revealed body temperature of 102°F, systolic/diastolic blood pressure to be 150/90 mmHg, pulse rate of 110/min, and the respiratory rate to be 16/min. His mental status examination (using Kirby's method) showed generalized rigidity of limbs (lead-pipe) as well as torso and minimal efforts to bring the body part in a comfortable position when placed in an awkward position. He remained mute; did not follow commands; had an expressionless face with minimal movements of eyes, reduced blink rate, largely a fixed gaze, and no response to sudden movements toward his eyes or to pain stimuli. The diagnoses of schizophrenia and NMS according to the Diagnostic and Statistical Manual – fifth edition (DSM-5) were made, and a trial of bromocriptine up to 25 mg/day was given for 10 days. Minimal improvement in the form of remission of fever and reduction of creatine phosphokinase levels to normal range was observed. Thereafter, in the next 7 weeks and in due consultation-liaison with the neurologist, adequate trials of intravenous lorazepam up to 8 mg/day in divided doses (weeks 2–3), levodopa 100 and carbidopa 25 mg (weeks 4–5), and finally, bilateral modified electroconvulsive therapy (seven therapy sessions in weeks 5–7) were tried, but they failed to elicit any further response. In view of the persistence of the rest of the symptoms, namely, rigidity, mutism, poor oral intake, minimal response to sensory stimuli, passive negativism, staring and withdrawal (akin to catatonia), and further investigations [Table 1], the differentials of a small vessel disease [Figure 2] and immune-related encephalitis/vasculopathy were entertained. Due to financial constraints, only a limited autoantibody profile was done [Table 1]. The patient showed a dramatic response to intravenous methylprednisolone (1 g/day for 5 days), and he started to communicate, regained nearly normal gait, and accepted oral feeds. The formulation of methylprednisolone was changed to oral prednisolone (40 mg/day) after a week, which is planned to be given for at least 2 months at the same dose. At the end of week 8, the patient regained urinary and fecal continence. Furthermore, symptoms of cognitive decline, as well as executive dysfunction, have been observed clinically, which will be evaluated once he stabilizes.

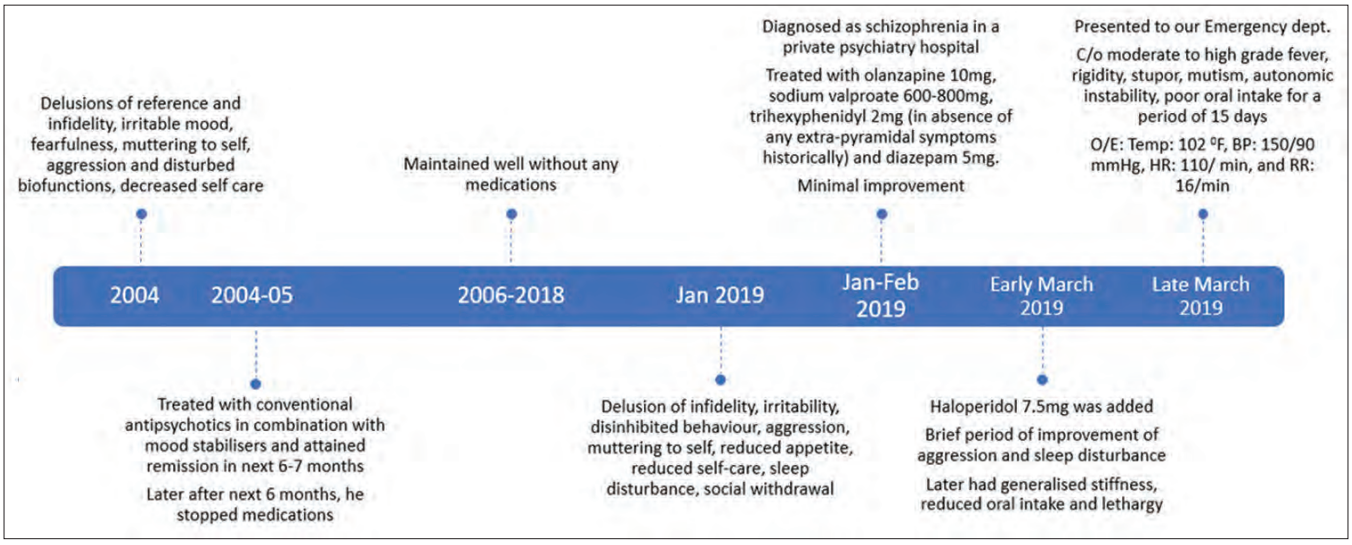

Figure 1: Diagrammatic presentation of the course of illness of patient

Table 1: Physical investigations of the patient during inpatient management

Investigation		Result
Complete hemogram	Hemoglobin (g/dL)	12.0 (day 1), 11.6 (day 5), 9.6 (day 21), 9.0 (day 45), 9.9 (day 56)
	Total leucocyte count (mm^3)	8480 (day 1), 6220 (day 5), 5110 (day 21), 9230 (day 45), 12890 (day 56)
	Differential leucocyte count (neutrophils/ lymphocytes/monocytes/eosinophils in %)	67/24/6/3 (day 1), 62/30/6/0 (day 5), 69/21/7/1 (day 21), 75/11/13/1 (day 45), 87/9/3 (day 56)
	Platelet count (per mm^3)	1,00,000 (day 1), 1,06,000 (day 5), 1,50,000 (day 21), 2,87000 (day 45), 1,97,000 (day 56)
Liver function test	SGOT/PT (U/L)	31/72 (day 1), 34/60 (day 15), 18/27(day 45), 21/17 (day 56)
	Bilirubin (mg/dL) (total/direct/indirect)	0.6/0.12/0.48 (day 1), 0.46/0.02/0.37 (day 15), 0.68/0.15/0.53 (day 45), 0.36/0.08/0.28 (day 56)
	Proteins (g/dL) (total/albumin/globulin)	6.67/2.70/3.96 (day 1), 7.28/2.85/4.43 (day 15), 6.84/2.78/4.06 (day 45), 5.36/2.76/2.60 (day 56)
	Prothrombin (s) time/control time/INR	12.4s/12.1s/1.03
Kidney function tests	Urea/creatinine (mg/dL)	73/1.16 (day 1), 107/1.01 (day 15), 51/0.93 (day 21), 32/0.91 (day 45), 69/0.77 (day 56)
	Serum sodium/potassium (mmol/L)	142/3.97 (day 1), 141/4.52 (day 15), 129/5.11 (day 21), 136/4.55 (day 45), 137/3.70 (day 56)
Urine culture/sensitivity		*Escherichia coli* growth (day 21), *Pseudomonas aeruginosa* growth (day 37), *E. coli* growth (day 56)
CPK-NAC (µg/L)		918 (day 2), 394 (day 5), 261 (day 10)
Thyroid function test		FT3 1.65 pg/mL, FT4 1.10 ng/dL, TSH 8.20 mIU/L
Anti-TPO antibodies		1.83 IU/mL
ESR		107 mm in first hour
VDRL/HIV/HBsAg/HCV ELISA		Non-reactive
Serum homocysteine		9.34 µmol/L
CSF examination	CSF microscopy (WBC/RBC)	Nil/425 cells/mm^3 - hemorrhagic tap (day 2) 05/80 cells/mm^3 - cytospin smears showed occasional lymphonuclear cells (day 45)
	CSF biochemistry (sugar/protein/chloride in mg/dL)	68/35/135 (day 2) 87/33/121 (day 45)
	CSF Culture/Sensitivity	No growth seen (days 2 and 45)
	Special staining (Gram's staining/ZN staining/India Ink staining)	Negative (days 2 and 45)
	Anti-NMDA antibodies	Negative (day 45)
Ultrasonography of abdomen and pelvis		Lithogenic bile with microlithiasis within gall bladder
Neuroimaging	NCCT brain	Features suggested senile atrophy with chronic end vessel ischemic changes (day 7)
	MRI brain and MR-angiography	Small-vessel ischemic changes involving bilateral corona radiata and centrum semi-ovale. Microbleeds involving bilateral basal ganglia and pons-chronic hypertensive microvascular changes. Diffuse cerebra atrophy. Subtle narrowing in bilateral ICA causing < approx. 30% stenosis. (day 40)
EEG		Diffuse slowing observed in frontal and temporal leads
ANA/dsDNA		Negative
RA factor		7.2 IU/mL (normal range=0-20I U/mL)

SGOT – Serum glutamic oxaloacetic transaminase; SGPT – Serum glutamic pyruvic transaminase; CPK-NAC – N-acetyl-cystein activated creatine phosphokinase; anti-TPO – anti-thyroid peroxidase antibodies; ESR – Erythrocyte sedimentation rate; VDRL – Venereal disease research laboratory test; HIV – Human immunodeficiency virus; HBsAg – Hepatitis B surface antigen; HCV – Hepatitis C virus; FT3 – Free triiodothyronine; FT4 – Free thyroxine; TSH – Thyroid stimulating hormone; INR – Internationalized normalized ratio; CSF – Cerebro-spinal fluid; WBC – White blood cell; ICA - Internal carotid artery; RBC – Red blood cell; ZN staining – Ziehl neelsen Staining; NCCT – Non-contrast computed tomography; MRI – Magnetic resonance imaging; NMD – N-methyl-D-aspartate; EEG – Electroencephalography; ANA – anti-nuclear antibodies; dsDNA – anti-double strand DNA antibodies; RA Factor – Rheumatoid Factor

DISCUSSION

Apart from the presence of a long gap between the occurrence of psychotic episodes in the absence of any systemic disease, initially this case appeared to be a typical one. However, the subacute onset of the current episode with a rapid progression within 3 months despite psychopharmacotherapy and progression to treatment-resistant NMS (the yellow and red flags for possible autoimmune encephalitis)[7] along with elevation of erythrocyte sedimentation rate, diffuse slowing of electroencephalogram (EEG) in frontal and temporal regions, and the neuroimaging findings led us to consider an autoimmune etiology.

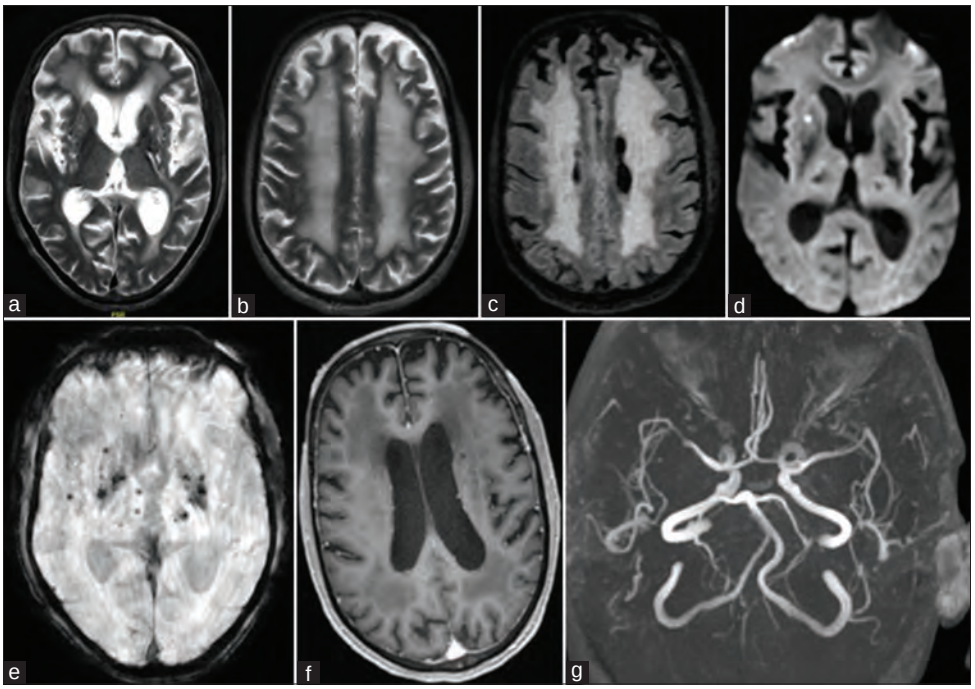

Figure 2: The axial T2 images (a and b) and axial FLAIR image (c) show diffuse confluent periventricular and lobar white matter hyperintensities. Prominent perivascular [Virchow-Robin (VR)] spaces noted at bilateral basal ganglia. The axial diffusion-weighted image (d) shows an acute lacunar infarct at right putamen. The SWAN image (e) shows microhemorrhages at bilateral basal ganglia and thalami. The postcontrast T1MPRAGE (f) and TOF MR (time of flight magnetic resonance) angiogram (g) are unremarkable. The image features are consistent with diffuse small-vessel disease

Furthermore, the absence of systemic manifestations and negative autoantibodies ruled out possible rheumatic encephalitis. Although CSF, EEG, and neuroimaging profile were not conclusive for an autoimmune encephalitis, which may occur due to a range of factors,[8-10] the presence of cerebral small-vessel disease too suggested a primary immune-based vasculitis and encephalitis. The presentation in the index patient remarkably differed from the previously reported cases which had a younger age of onset of illness,[2-6] had a female predominance,[2,3,5,6] and had a seizure or other neurological symptoms at the initial presentation.[2,3,6]

The nonevaluation of a panel of other autoantibodies was a limitation in this case, and a definitive diagnosis based on a brain biopsy was not feasible. The future course of management for this patient would be a course of cyclophosphamide with/without rituximab, evaluation of cognition and executive functions with standard tools, and rehabilitation. To conclude, autoimmune encephalitis forms a close differential diagnosis for various neuropsychiatry syndromes, including, rarely, the NMS and hence, one should suspect an autoimmune pathology in cases of unusual clinical presentation or resistance to traditional treatments.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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Access this article online

Website: www.ijpm.info

DOI: 10.4103/IJPSYM.IJPSYM_307_19

Quick Response Code

How to cite this article: Aneja J, Mahal P, Sudhakar G, Panda S, Tiwari S. Steroid-responsive encephalopathy as a semblance of neuroleptic malignant syndrome in a patient with schizophrenia. Indian J Psychol Med 2019;41:487-91.

Central Pontine/Extrapontine Myelinolysis Presenting with Manic and Catatonic Symptoms

Sir,

Central pontine myelinolysis (CPM) is a neurological disorder associated with demyelinating lesions in the central pons. It is usually caused by electrolytic disorders, especially rapid correction of severe hyponatremia.[1] Systemic disorders such as chronic alcoholism, hepatic failure, severe burns, malignant neoplasms, and hemodialysis also predispose to this condition. It may coexist with extrapontine myelinolysis (EPM), where it involves lesions outside pons, i.e., in caudate and lentiform nuclei, putamen, thalami, cerebellum, hippocampus, and cerebral cortex. It often presents with dysphagia, dysarthria, quadriplegia, encephalopathy, or coma. Such cases may additionally develop tremors, dystonia, cogwheel rigidity, ataxia, mutism, myoclonus, etc. Besides neurological symptoms, CPM may also present with neuropsychiatric symptoms such as personality changes, inappropriate affect, emotional lability, disinhibition, catatonia, psychosis, and delirium, as described in some reports.[2-4] None of the previous reports have suggested an occurrence of prominent manic symptoms followed by catatonia in patients with central pontine/extrapontine myelinolysis (CPEM). We describe a unique case of an elderly man with such a presentation after rapidly corrected hyponatremia.

CASE REPORT

A 72-year-old man was admitted to the cardiothoracic surgery unit floor for aortic valve repair and coronary artery bypass graft. He had history of hypertension and coronary artery disease along with rheumatic aortic stenosis for the last 30 years. He had no psychiatric illness and denied any substance use in the past. During preoperative workup, his serum sodium was found to be low (114 mmol/L), but he was asymptomatic. Serum sodium levels repeated over the next couple of days remained unchanged. During surgery, his serum sodium level decreased to 104 mmol/L. As per intraoperative notes, serum sodium was rapidly corrected with intravenous 3% saline. His serum sodium levels were 134 and 139 mmol/L, respectively, on postoperative days 1 and 2. His postoperative course was uneventful from the cardiac surgery perspective. However, on

day 3, he developed manic symptoms in the form of persistently elated mood, decreased need for sleep, perceived increase in physical energy, loud and excessive speech, authoritativeness, sexual disinhibition, and grandiose and persecutory ideas.

A psychiatric consultation was sought for his behavioral problems. On mental status examination, he was alert and fully oriented and had elated mood, grandiose and persecutory ideas, impaired judgment, and absent insight. He denied any hallucinatory experiences. There were no apparent neurological deficits. Oral haloperidol 2 mg/day was started, and his manic symptoms began to improve within the next 2 days. By postoperative day 6, manic symptoms remitted and he was discharged.

He remained well for the next 2 days, after which his family brought him to the emergency department because of decreased food intake and decreased spontaneous movements. He was found to have dysphagia and dysarthria. On examination, he had rigidity and brisk reflexes in all four limbs, along with staring, posturing, and gegenhalten. Although some of the findings (rigidity, brisk reflexes, dysphagia, dysarthria) could be ascribed to pyramidal/extrapyramidal involvement, motor behaviors such as staring, posturing, and gegenhalten were characteristic of catatonia.

We repeated hemogram, serum chemistry, urine routine/microscopy analysis, and serum creatine phosphokinase levels, none of which showed any abnormality. We also performed magnetic resonance imaging (MRI) brain, which showed [Figure 1] central hyperintensities in the pons, bilateral caudate, and lentiform nuclei, as well as the thalami on axial T2-weighted sequence. Therefore, based on the overall history, examination, and neuroimaging findings, we made a diagnosis of CPEM secondary to rapid correction of hyponatremia. Haloperidol was discontinued. He was admitted to Geriatric Medicine unit, managed conservatively with fluid and nutrition management, and given oral lorazepam 1 mg twice a day for catatonic symptoms. He showed mild improvement in the catatonic symptoms over the next 5 days, was able to walk with assistance, and was able to speak and feed himself. Further lorazepam dose escalation could not be done as his family got him discharged due to logistical issues, with a plan to follow-up in the outpatient clinic. Repeat MRI brain could not be done for the above reason as well.

DISCUSSION

In the present case, neuroleptic malignant syndrome (NMS) was the single most obvious differential considered, based on the history of haloperidol use and occurrence of acute-onset generalized rigidity. NMS is characterized by fever, altered mental status, autonomic instability, rigidity, increased serum creatine phosphokinase (CPK) level, leukocytosis, etc. However, it was ruled out clinically because our patient was afebrile and had clear sensorium, no evidence of autonomic instability, and normal complete blood count and serum CPK level. A diagnosis of CPEM was quite evident, with a typical history of rapid correction of low serum sodium, leading to the occurrence of manic symptoms followed by neurological as well as catatonic symptoms along with the development of characteristic brain changes. We ascribe CPEM as the main cause of manic symptoms and catatonia here, based on other factors such as temporal association, the age of presentation, and no past or significant family history of psychiatric illness. Patient's poor outcome could be attributed to the extremely low serum sodium before it was rapidly corrected.[5]

So far, to the best of our knowledge, there has been only one report of manic symptoms occurring in association with CPEM. According to Goggin *et al.*, a patient initially developed delirium that evolved into mania. In that case, the brain lesions were limited to central pons only.[6] In the present case, catatonia emerged later, which has been described in only a few of the earlier reports.[7,8] It was observed that the patient's neurological and neuropsychiatric symptoms were well correlated with the brain lesions observed in MRI. The patient was found to have demyelination in bilateral caudate, lentiform nuclei, and thalami, which could potentially disrupt striatal and thalamic functioning. Frontal–striatal–thalamic circuit (FST) is implicated in regulating mood, reward processing, action selection, strategic planning, and working memory. Previous studies have shown that alteration in the functioning of the striatal–thalamic circuit is implicated in bipolar disorder.[9] Bipolar disorder is also well associated

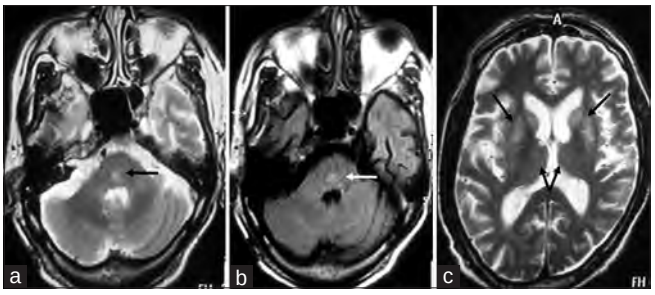

Figure 1: (a-c) There is central hyperintensity in the pons (arrow) on axial T2W (a) and FLAIR (fluid attenuated inversion recovery) (b) MR images of posterior fossa. Axial T2W image at the level of basal ganglia shows hyperintensity in the bilateral caudate and lentiform nuclei, as well as thalami (arrows). Imaging findings in this particular clinical scenario are diagnostic of osmotic demyelination (both central pontine and extrapontine myelinolysis)

with catatonic symptoms[10] seen in our patient. There is a possibility that FST might be involved in the pathophysiology of catatonic symptoms too. We recommend that neuropsychiatric symptoms such as psychotic, mood, or catatonic symptoms developing in the background of rapid correction of low serum sodium should be investigated thoroughly and should not be assumed to be a part of a primary psychiatric disorder. Such rare psychiatric presentations of CPEM could provide insights into the brain areas involved in the occurrence of specific psychiatric symptoms and perhaps, mental disorders.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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Access this article online	
Website: www.ijpm.info	Quick Response Code
DOI: 10.4103/IJPSYM.IJPSYM_58_19	

How to cite this article: Patil V, Gupta R, Singh S, Goyal A, Deb KS. Central pontine/extrapontine myelinolysis presenting with manic and catatonic symptoms. Indian J Psychol Med 2019;41:491-3.

Imaging in Psychogenic Nonepileptic Seizures: An Observational Study

Sir,

Psychogenic nonepileptic seizures (PNES) are characterized by paroxysmal time-limited alterations in motor, sensory, autonomic, or cognitive signs and/or symptoms in the absence of excessive and hypersynchronous brain discharges.[1] It is reported that 5%–10% of outpatients in epilepsy clinics and 20%–40% of patients in epilepsy monitoring units have PNES.[2] Recently, there are reports on associations between PNES and many structural and functional brain abnormalities,[3] suggesting a neurobiological origin for PNES.

We undertook this study to look at the neuroimaging profile of our patients with PNES. This was a cross-sectional analysis of the data collected (from June 2010 to July 2013) for a study on induction techniques in PNES.[4] Demographic data including age, sex, education, occupation, religion, etc.; clinical data including duration of symptoms, use of antiepileptic drugs (AEDs), psychiatric and other comorbidities, coexisting epilepsy, frequency of events, and imaging data were collected after obtaining ethics approval. Imaging results, if available, were reviewed by a neurologist and impression recorded, if required, after discussion with a radiologist. Continuous data were compared using the *t*-test or Mann–Whitney *U* test depending upon normality. Frequencies were compared using Chi-squared tests. All data were analyzed using STATA version 14.2, StataCorp, USA.

Seventy-seven subjects with documented PNES [Video-electroencephalograph (VEEG) review by two epileptologists showing typical event in the absence of EEG changes] were included. The mean age of the participants was 22 years (SD 10.8), and 59 (76%) were women. Forty-six (60%) were on AEDs, but only ten (13%) had coexistent epilepsy. None of the participants reported sexual abuse, and two (2%) had a coexistent psychiatric illness (one psychosis and one anxiety disorder). By self-report, 14 (18%) were employed, 11 (14%) were studying, and the rest 52 (68%) described themselves as unemployed. Twenty-eight (36%) had undergone neuroimaging, of which 25 (93%) had undergone CT scans of the brain while only three had undergone MRI.

In univariate analysis, undergoing neuroimaging was associated with secondary school or higher level of education ($\chi^2 = 3.93$; $P = 0.05$) and lack of suspicion of PNES by referring physician ($\chi^2 = 5.69$; $P = 0.02$). The other factors including age, gender, duration of PNES, coexisting epilepsy, and AED intake appeared to be similar in both the groups.

Out of the 28 subjects imaged, 11 (39%; 95% CI 11%–57%) had abnormalities. The abnormalities observed are given in Table 1. Calcified granuloma(s) was the most common abnormality, seen in five (45%) of the 11 subjects. Both patients with psychiatric comorbidity had abnormal imaging. Only two patients with coexisting epilepsy were imaged, and one of them had abnormality (right frontal calcification). On univariate analysis, those with abnormal imaging were more likely to be men (OR = 5.6; 95% CI 0.8–45.8) and more likely to be on two or more AEDs (OR = 6.2; 95% CI 0.8–77.1) compared with those with normal imaging. Other features like age, duration of PNES, education levels, and coexisting epilepsy were not different between those with imaging abnormalities and those with normal imaging.

Patidar *et al*., in their study on demographic features of subjects with PNES from India, wanted to image all their subjects. However, they reported that only 27 of 50 patients (54%) were imaged.[5] This is, as expected, higher than 36% of subjects who were imaged in our cohort as we only collected imaging data as available at referral. So, we were able to explore the factors that may cause such patients to be more readily imaged. Higher education levels and lesser physician suspicion for PNES were found to be significantly associated with imaging. While we

Table 1: Abnormalities detected on neuroimaging

Patient no.	Age/ sex	Imaging modality	Abnormality
1	13/M	MRI	Bilateral basal ganglia hyperintensity
2	21/M	MRI	Left hippocampal atrophy ?cyst
3	15/F	MRI	Tuberculoma
4	13/F	CT	Suprasellar arachnoid cyst
5	18/M	CT	Asymmetric ventricles, partial agenesis of the corpus callosum
6	60/M	CT	Frontal contusion
7	14/F	CT	Leftpareito-occipital calcification
8	30/M	CT	Asymmetric temporal horns
9	24/M	CT	Multiple calcifications
10	14/F	CT	Multiple calcifications
11	22/F	CT	Right frontal calcification

have no direct evidence to suggest that education will lead greater demand for imaging, there is sufficient evidence from literature in epilepsy and other fields that health-seeking behavior improves with education and lower education is associated with higher treatment gaps.[6,7] Lower physician suspicion for PNES will also understandably lead to increased imaging. Surprisingly, we found no association between frequency of events, coexisting epilepsy, or number of AEDs used with being imaged.

Abnormal structural imaging was seen in 39% (95% CI 11%–57%) in our cohort, with the commonest abnormality being calcified granulomas. This proportion of abnormal findings in structural imaging is similar to the results presented by McSweeney *et al*.[8] who reported a prevalence of 25%–33% but is larger than the 18.5% reported in Indian PNES patients by Patidar *et al*. Possibility of incidental findings may be considered, but the prevalence of such findings on brain MRI have been reported to be around 2%[9] and on CT, 1%–19%.[10] Hence, our higher frequency of 39% cannot be accounted for by incidental findings alone.

The importance of the association between abnormalities on imaging and PNES is unclear, as these abnormal findings may be the cause of PNES, the result of unrelated trauma, a marker of associated conditions, or the result of changes secondary to PNES or therapy of PNES. In addition, in resource-poor settings like India where video EEG evaluation of PNES events is difficult, a lack of video EEG evaluation of PNES events is difficult, a lack of awareness of this relatively frequent presence of imaging abnormalities may result in inappropriate exposure of these patients to AEDs and their toxicity.

We also found that abnormalities in imaging were associated with AED polytherapy and male gender. We are unable to explain why abnormal imaging findings were more likely among men. Myers *et al*. studied gender difference in PNES and reported a significant difference between the genders in the frequency of events, utilization of mental health services, report of sexual trauma, levels of dissociation, and use of avoidance, but they did not comment on neuroimaging.[11] Unfortunately, most studies on PNES neuroimaging have an underrepresentation of men, and the differences between the genders remain unexplored.

The strengths of our study are that all our participants had documented PNES according to International League Against Epilepsy guidelines.[1] The number of subjects in our study is comparable to that in similar studies in the literature. Limitations of our study are that imaging was done according to the discretion of the referring physician, most underwent CT only, and no control group was present.

In conclusion, structural imaging abnormalities are not uncommon in patients with PNES. Further studies are needed to verify if these changes are specific to PNES or due to confounders like epilepsy. Gender differences in PNES also remain to be explored.

Financial support and sponsorship
Nil.

Conflicts of interest
There are no conflicts of interest.

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Access this article online

Website: www.ijpm.info

DOI: 10.4103/IJPSYM.IJPSYM_487_18

Quick Response Code

How to cite this article: Aghoram R, Nair PP. Imaging in psychogenic nonepileptic seizures: An observational study. Indian J Psychol Med 2019;41:494-6.

Comments on "Factors Associated with Treatment Adherence in Children with Attention Deficit Hyperactivity Disorder"

Sir,

Safavi *et al*.[1] identified factors related to treatment adherence in a 'convenience' sample of children with attention deficit/hyperactivity disorder (ADHD). We believe that there are several reasons why their findings should be interpreted with reservations.

Studies may be exploratory (hypothesis generating) or confirmatory (hypothesis testing) in design.[2] Hypothesis-testing studies need to state primary and secondary outcome measures in advance.[3] Safavi *et al*.[1] neither stated a priori outcome measures nor admitted that their study was exploratory. Consequently, readers may not realize that their findings should be interpreted as speculative, not definitive.

Curiously, Safavi *et al*.[1] did not even outline a plan of analysis; rather, they enthusiastically examined the association between every sociodemographic, clinical, and instrumental variable for which they had collected information and adherence, as operationalized by Medication Adherence Report Scale scores. When a large number of statistical associations are indiscriminately tested, the risk of a Type 1 (false positive) error is magnified. This means that some or many of the significant findings reported in the paper[1] may have been false-positive findings, and the average reader would not know that this was so because the authors did not declare that their plan of analysis was exploratory in nature. The absence of a plan of analysis and such testing of all possible associations between variables is, unfortunately, a common failing in scientific studies and publications.

The multivariable regression analysis described by the authors[1] does not address the false-positive risk because no correction of the *P* value is applied in regression, regardless of the number of variables entered into the equation.[4,5] Additionally, given that the variables entered by the authors in their regression were chosen because they were significant or near significant in univariate testing, that some variables remained significant in multivariable testing is hardly surprising and will not mean that the associations identified in the sample are true for the population.

Last but not least, the authors conducted their study in patients who had been on treatment for at least 6 months; that is, in patients for whom a reasonable degree of adherence was established by virtue of retention in follow-up. So, this is an extreme example of a convenience sample and one that is very likely not representative of the population of children with ADHD.

As a take-home recommendation, we suggest that all original studies describe their primary and secondary outcomes if these were set a priori; else, the exploratory nature of the study should be declared in both abstract and text so that readers can interpret the findings with caution.

Financial support and sponsorship
Nil.

Conflicts of interest
There are no conflicts of interest.

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Access this article online

Website: www.ijpm.info

DOI: 10.4103/IJPSYM.IJPSYM_276_19

Quick Response Code

How to cite this article: Andrade C, Harshe D. Comments on "Factors associated with treatment adherence in children with attention deficit hyperactivity disorder". Indian J Psychol Med 2019;41:497-8.

Comments on "Adaptation and Validation of Parental Behavioral Scale for Children with Autism Spectrum Disorders to Kannada"

Sir,

Gayathri and Tiwari[1] studied the psychometric properties of their Kannada translation of a parental behaviour scale for children with autistic spectrum disorders. We wish to express our concerns regarding some of their methods and findings.

First, the authors examined test-retest reliability in a sample of only three parents. This is far too small a sample to allow credible conclusions about the reliability of an instrument. Whereas it could have been challenging for the authors to estimate, in advance, a necessary sample size to identify an unknown value for the reliability, it would have been desirable to recruit a sample of at least 30 parents so as to reasonably represent the population.

Next, the authors reported that the intra-class correlation coefficient (ICC) value for test-retest reliability was 0.993. This is an incredibly high level of agreement and is credible only if the authors were assessing facts that do not change. However, they were assessing the agreement on 50 different items, rated on a 1–5 point scale, at time points that were 15–30 days apart. In such circumstances, such a high value for the ICC seems impossible.

Finally, the authors asked three speech-language pathologists to indicate their agreement/disagreement with each item of the scale and to provide suggestions/modifications. The authors wrongly described this exercise as inter-rater reliability. Inter-rater reliability is actually the agreement between different raters who each use the instrument to assess the same patients at the same point in time.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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Access this article online

Website: www.ijpm.info

DOI: 10.4103/IJPSYM.IJPSYM_338_19

Quick Response Code

How to cite this article: Singh GP, Tekkalaki B, Andrade C. Comments on "Adaptation and validation of parental behavioral scale for children with autism spectrum disorders to Kannada". Indian J Psychol Med 2019;41:498-9.

Authors' responses to the comments on "Adaptation and Validation of Parental Behavioral Scale for Children with Autism Spectrum Disorders to Kannada"

Sir,

Singh *et al*.[1] have questioned about the estimation of test–retest reliability for our article[2] for the adaptation and validation of the Parental Behavioral Scale for children with autism spectrum disorders to Kannada. The author(s) have commented regarding the sample size of the test–retest reliability analysis and suggested to include at least 30 subjects to represent the population. We agree that there are procedures and formulas to estimate the sample size for the test–retest reliability of the sample and a sample of three parents is less. However, the use of intraclass correlation (ICC), as in our study, takes care of the estimation of test–retest reliability in case of small samples (less than 15)[3] to certain extent. The ICC value of test–retest reliability may depend on several factors, including the time between tests. The high level of agreement could have resulted due to a short gap of 15–30 days between the two tests.

Another query was on three speech language pathologists (SLPs) indicating agreement/disagreement of items in the scale, and providing suggestions/modifications, described as interrater reliability. It is the content validation process that was described by measurement of agreement between the SLPs using Kappa test.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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Access this article online

Website: www.ijpm.info

DOI: 10.4103/IJPSYM.IJPSYM_357_19

Quick Response Code

How to cite this article: Gayathri KS, Tiwari S. Authors' responses to the comments on "Adaptation and validation of parental behavioral scale for children with autism spectrum disorders to Kannada". Indian J Psychol Med 2019;41:499-500.

Ultraprocessed Food and Cardiovascular Risk: Estimating the Number Needed to Harm in an Unfamiliar Situation

Chittaranjan Andrade

ABSTRACT

The Number Needed to Harm (NNH) statistic is a measure of effect size. It is defined as the number of patients who need to be treated for one additional patient to experience an adverse outcome. The NNH is conventionally calculated in the context of a randomized controlled trial. This article explains how the NNH can be estimated and understood for a lifestyle behavior in the context of an observational study in which the outcome was described using an uncommon unit. The lifestyle behavior, here, was the intake of ultraprocessed food and the outcome was stated as the number of events per 1000 person-years. The NNH can be estimated from the data provided, expressed in different ways, and converted into a form that is relevant to clinical practice.

Key words: *Cardiovascular disease, measures of effect size, number needed to harm, ultraprocessed food*

Many psychiatric disorders are associated with sedentariness, increased appetite and weight, and metabolic dysregulation; these predispose to cardiovascular disease, type 2 diabetes mellitus, metabolic syndrome, and premature mortality. As a part of an approach towards advocating healthy lifestyle behavior in patients, psychiatrists need to know not merely how much patients eat but what they eat. In this context, trans fat, saturated fat, and added sugars are well-known unhealthy components of food. However, for many reasons, including the promotion of public understanding, current dietary guidance emphasizes the nature of food rather than the contents of the food. As examples, foods encouraged for intake include fruit and vegetables and foods discouraged for intake include processed and ultraprocessed foods.

Ultraprocessed foods are foods or beverages that do not exist in the natural state and that have been prepared through industrial processing. Ultraprocessed foods include bakery and other confectioneries, sweet- and savory-packaged

Access this article online	
Website: www.ijpm.info	Quick Response Code
DOI: 10.4103/IJPSYM.IJPSYM_340_19	

How to cite this article: Andrade C. Ultraprocessed food and cardiovascular risk: Estimating the number needed to harm in an unfamiliar situation. Indian J Psychol Med 2019;41:501-2.

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Received: 10th August, 2019, **Accepted:** 10th August, 2019

snacks, hamburgers and pizzas, carbonated beverages and packaged milk shakes, and others. In this context, Srour *et al*.[1] showed that ultraprocessed food intake is associated with an increased risk of cardiovascular disease events.

The data were drawn from the NutriNet-Santi population-based cohort, France, during 2009-2018. The sample comprised 105,159 mostly middle-aged adults for whom 24-hour dietary intake was assessed on a mean of 5.7 occasions across a median follow-up of 5.2 years. Assessment of the degree of food processing was based on the NOVA classification.[2] Analyses compared persons in the highest (31% by weight) versus lowest (8% by weight) quarters of ultraprocessed food intake, based on percentage by weight of total food intake. Analyses were adjusted for important confounds; incidences were adjusted for age and sex.

Across 518,208 person-years of follow-up, the incidence of overall cardiovascular disease events was found to be 277 versus 242 per 100,000 person-years in subjects with high versus low ultraprocessed food intake. For every 10% increase in ultraprocessed food intake, the risk of cardiovascular disease events increased by 12% (Hazard ratio: 1.12; 95% confidence interval: 1.05-1.20). The findings were similar when coronary disease events and cerebrovascular disease events were separately considered. The findings remained statistically significant after adjusting for markers of nutritional quality, such as intake of sodium, sugar, saturated fat, and dietary fiber. The findings remained significant in a wide range of sensitivity analyses.

In summary, the study[1] found that middle-aged adults whose daily diet was high in ultraprocessed food were at an increased risk of experiencing a coronary or cerebrovascular event across about 5 years of follow-up. An obvious take-home message is that, if we want to reduce our risk of cardiovascular events, we must reduce our intake of ultraprocessed food. However, Srour *et al*.[1] did not provide a number needed to harm (NNH) estimate for the risk. So how can the reader estimate the magnitude of risk from the information provided?

The clue lies in the cardiovascular event incidence data for the highest versus lowest quarters of ultraprocessed food intake; this was 277 versus 242 per 100,000 person-years. How does one convert 100,000 person-years into a clinically meaningful NNH value?

From the data, if the incidence was 277 versus 242 per 100,000 person-years for high versus low intake groups, it means that there were 35 extra cardiovascular events per 100,000 person-years in the high intake group. This is arithmetically equivalent to one extra event per 2857 person-years. Thus, the NNH is 2857 person-years.

How does one interpret an NNH expressed in this manner? One possibility is to say that 2857 persons need to fall into the highest quarter of ultraprocessed food intake for one extra person to experience a cardiovascular event during a year of follow-up. Another possibility is to state that one person needs to fall into the highest quarter of ultraprocessed food intake for 2857 years in order to experience a cardiovascular event. Both are fair interpretations of the NNH.

The NNH can be expressed in yet another manner, and one that is more clinically practical. Cardiovascular risks are commonly reckoned across a 5- or 10-year span. Hence, an NNH of 2857 person-years can be restated as follows: if 285.7 persons have a high intake of ultraprocessed food for 10 years, then one extra person will experience a cardiovascular event. Alternately, as Srour *et al*.[1] had a median follow-up of 5.2 years, one might say that the NNH was 571 (i.e., 285.7 × 2) for a 5-year follow-up.

A more detailed discussion on the numbers needed to treat and harm statistics is available elsewhere.[3]

Parting notes

The authors evaluated ultraprocessed food intake in terms of percentage by weight. Thus, persons drinking sugary beverages would have had higher intake using the percentage by weight measure because the water content would contribute to the numerator, but a lower intake using a percentage by calories measure because water is calorie-neutral. Thus, the use of the percentage by weight method could have pushed water ingesting persons into the high intake group. This could explain the small difference in incidences between high and low intake groups, and hence the large NNH.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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