

Schedule of Factors Influencing Access to Psychiatric Treatment in Persons with Schizophrenia: Validity and Pilot Testing

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ABSTRACT

Background: A substantial proportion of patients with severe mental disorders remain untreated in India. Qualitative research has highlighted the complex interplay of multiple factors that preclude schizophrenia patients in rural Indian settings from accessing treatment. **Aims:** (a) To establish the face and content validities of an interview schedule titled “Schedule of Factors Influencing Access (SOFIAC) to Psychiatric Treatment in Persons with Schizophrenia,” which comprehensively assesses the factors that prevent schizophrenia patients from accessing psychiatric treatment. (b) To assess the feasibility of its administration. **Materials and Methods:** SOFIAC contains 15 items. This schedule involves three phases of interviewing patients and family members. This was given to 12 experts. They used Likert scales (1=not at all satisfactory to 5=very much satisfactory) to rate each item of the schedule. In addition, the experts rated (the same way as above) the following five dimensions of the schedule (as a whole) separately: A (comprehensiveness of the factors), B (scoring system), C (interviewing method), D (general instructions given to the raters), E (overall schedule). Later on, 10 persons with schizophrenia were interviewed with SOFIAC to test the feasibility of administration. **Results:** Thirteen items were rated as either satisfactory (score=4) or very much satisfactory (score=5) by all 12 experts; remaining two were rated as 4 or 5 by 11 experts. Regarding comprehensiveness of the factors, scoring methods and general instructions given to the interviewers, all provided scores >4; regarding the method of interviewing, 11 provided the score of >4; with regard to overall interview schedule, all experts provided scores >4. Pilot testing revealed that it took 60 min to administer SOFIAC. **Conclusion:** SOFIAC has satisfactory face and content validities. It is also feasible to administer SOFIAC.


Key words: Access to psychiatric care, content validity, face validity, interview schedule, rural community

INTRODUCTION

Substantial proportions of schizophrenia patients remain

untreated in the developing countries.^[1] However, the reason for this phenomenon is not well-understood even in the developed countries.^[2] Most Indian studies have used check-lists^[3-5] to assess the reasons for not accessing psychiatric treatment.

Since the problem of remaining untreated is a complex one, use of prepared check-lists and interviewer-directed questionnaires are poorly suited to understand the issue comprehensively: They may fail to capture many patient/family related factors. Further, these checklists/interviews are not standardized. Comprehensive,

Access this article online	
Website: www.ijpm.info	Quick Response Code 
DOI: 10.4103/0253-7176.122226	

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qualitative studies are ideally suited to understand these issues. We have developed a comprehensive tool to assess barriers to access treatment in patients with schizophrenia (Schedule of Factors Influencing Access (SOFIAC) to Psychiatric Treatment in Patients with Schizophrenia). This paper establishes the face and content validities of SOFIAC.

MATERIALS AND METHODS

SOFIAC covers the following factors: Patient's/family member's knowledge and attitude towards the illness and treatment; patients'/family members' attitude towards the need for treatment; lack of insight and active non-cooperation from the patient; family support; family issues/dynamics; family's tolerance and acceptance of illness and related disability; family's resilience towards patient's symptoms and disability; community's attitude and beliefs; community's acceptance and support for the patient; stigma; financial problems; distance and transport-related factors; gender of the patient; age of the patient and medical (other than psychiatric) illness/condition of the patient. In addition to the above mentioned factors, the schedule covers all other factors that the patient/family member may bring in. SOFIAC is a semi-structured instrument. Administration involves the following three phases of interviewing. Phase-1: The interviewer introduces the purpose of the interview and starts by inviting responses about factors responsible for not seeking treatment. Examples of this open-ended approach would be: "please tell me about the reasons or difficulties you faced in seeking treatment for your relative's mental illness from a doctor", "Please tell me about those reasons and/or the difficulties that you faced." The interviewer notes down the factors for further inquiry without interrupting the flow of conversation. If the respondent stops after listing a few, encourage him/her to think about more factors by saying, "anything else?", "go on", etc. Phase-2: The interviewer seeks details regarding each of the factors raised by the patient/caregivers during phase-1. "You told me that ... is a reason/difficulty. Could you please elaborate on this issue? How did it prevent you from seeking treatment? Phase-3: Here the interviewer asks questions about the factors that are present in SOFIAC that are not covered during phase-1 and 2. The authors have provided few sample questions for each SOFIAC factor. To the extent possible, these questions have been framed in such a way so as to reflect natural conversation (without using any technical words). The interviewer is encouraged to use these questions. However, he/she is free to use his/her own style to ensure good quality information. If patients/family members start narrating their experience regarding a different unrelated factor, it is suggested not to interrupt them, but to score that factor first and then proceed

with the previous factor. General scoring instructions: Following are the guidelines: (0) No influence: This factor did not have any influence. (1) Some influence: This factor has had some influence. There is reason to believe that though this factor has played some role, other factors have been more influential relative to this. (2) Significant influence: This factor has played a significant role. This may be a key factor that has caused the patient/family not to seek psychiatric treatment. However, there is reason to believe that if all other factors were conducive, then despite this factor, patient/family would have sought treatment. (3) Profound influence: This factor is the single most important cause for the patient remaining untreated. There is reason to believe that the patient/family would not have sought treatment even when all other factors were conducive. The influence of this factor may make the assessment of other factors difficult as it has an overarching effect on all other causes. Thus, this scoring has to be used after careful consideration of all other factors. It is expected that the use of this score would be very uncommon.

In general, scoring should be done after interviewing the primary caregiver/s. It is advisable to interview patients too wherever they are able to cooperate for a meaningful interview. Interviewing takes about 60 min. In phases 2 and 3, the interviewer keeps anchor points in mind to determine the exact scoring of factors.

Face and content validity

This schedule was given to 12 experts to establish its face and content validities. They used Likert scales 1 (Not at all satisfactory), 2 (somewhat unsatisfactory), 3 (neutral), 4 (satisfactory), 5 (very satisfactory) to rate each item of the schedule. In addition, the experts rated (the same way as above) the following five dimensions of the schedule (as a whole) separately: A (comprehensiveness of the factors), B (scoring system), C (interviewing method), D (general instructions given to the raters), E (overall schedule). The experts were requested to provide specific comments including suggestions to improvise if they rated 1 (Not at all satisfactory), 2 (somewhat unsatisfactory) or 3 (neutral).

RESULTS

Face and content validity

We sought opinions of 12 experts: 8 faculties from the Department of Psychiatry and 4 faculties from the Department of Psychiatric Social Work at the National Institute of Mental Health and Neuro Sciences, Bangalore. They had a mean 16.67 (SD=1.02) years of post-qualification experience of working with schizophrenia patients and their families.

With regard to individual items of SOFIAC, 13 were rated as either satisfactory (score=4) or very much satisfactory (score=5) by all twelve experts; remaining two got a score of <4 from 11 experts. Regarding comprehensiveness of the factors, scoring methods, general instructions given to the interviewers, all experts provided scores >4; regarding the method of interviewing, 11 experts provided the score of >4; with regard to overall interview schedule, all experts provided scores >4.

Feasibility of administering SOFIAC

For this purpose, the first author pilot tested it by administering on 10 consecutive never treated persons with schizophrenia (and their family members). Mean (SD) age of patients was 38.2 (34.5) years and mean (SD) duration of illness was 83.5 (54.0) months. Average time taken to administer the entire schedule was 60 min. Gender had no influence on treatment seeking in any patient. No factor had a profound influence on treatment seeking. Good family support, family issues and dynamics, family's resilience towards patients' illnesses and disabilities, community's attitude and beliefs towards mental illnesses and community acceptance and support were among the common factors responsible for not seeking treatment. For each patient/family, there were more than one factors, which had either some or significant influence on treatment seeking. Details regarding this are provided in Table 1.

DISCUSSION

A comprehensive tool that assesses barriers to access psychiatric is an important need. This study establishes the face and content validity and feasibility of administering one such tool that may fulfil this void. SOFIAC has been developed using

well established qualitative methodology. Feedback from the experts regarding various dimensions of this tool further adds to its validity. Pilot testing revealed not only its feasibility but also its comprehensiveness; in the sense that no new factor emerged even after interviewing ten patients. Some scoring guidelines are as follows: It should be scored after interviewing the primary caregiver/s. It is advisable to interview the patients too wherever, they are able to cooperate for meaningful interview. There are 3 phases of the interview, which would need about 60 min. In phases 2 and 3, the interviewer keeps the anchor points in mind to determine the exact score regarding the influence of each of these factors. In this schedule, the term "psychiatric treatment" is used to mean allopathic care provided by a qualified professional, including psychiatrist. Other forms of treatment are not considered as psychiatric treatment insofar as this schedule is concerned. Patients/families may refer to many problems unrelated to accessing psychiatric treatment. The interviewer should listen to these and cross-check whether these influenced their decision to access psychiatric treatment. Each patient/family may have a unique set of reasons for not seeking treatment. In this background, the "total" score will not have any meaning. It is expected that the interviewer has information regarding the patient's/family's basic socio-demographic details, including age, sex, marital status, occupation, other members in his/her household, symptoms and duration of the psychiatric illness, etc., before using this schedule. These should be kept in mind while interviewing. Additionally, pilot testing has established the feasibility of administering the schedule.

One significant limitation of the schedule is that we were not able to interview all patients. Though we intended to get perspectives of both patients and

Table 1: Results of the pilot testing

Factor	No influence	Some influence	Significant influence	Profound influence
Knowledge and attitude of patient/family members	None	2 (20)	8 (80)	None
Family members/patients' attitude towards the need for treatment	None	3 (30)	7 (70)	None
Lack of insight and active non co-operation from the patient	1 (10)	2 (20)	7 (70)	None
Good family support	1 (10)	8 (80)	1 (10)	None
Family issues and dynamics	3 (30)	6 (60)	1 (10)	None
Family's acceptance of patients' illnesses and disabilities	5 (50)	5 (50)	None	None
Family's resilience towards patients' illnesses and disabilities	4 (40)	6 (60)	None	None
Community attitudes and beliefs towards mental illnesses	3 (30)	7 (70)	None	None
Community's acceptance and support for the patient	4 (40)	6 (60)	None	None
Stigma related to severe mental disorders	4 (40)	5 (50)	1 (10)	None
Financial problems	3 (30)	5 (50)	2 (20)	None
Distance and transport related factors	1 (10)	1 (10)	8 (80)	None
Gender related factors	10 (100)	None	None	None
Age of the patient	9 (90)	1 (10)	None	None
Medical diseases other than psychiatric disorders	9 (90)	1 (10)	None	None

family members, it was not possible as patients were too ill to cooperate for valid interviews. However, in our country, only a miniscule proportion of patients with schizophrenia-in which lack of insight is a defining feature of the illness- seek treatment on their own; a vast majority of them are brought for treatment by their family members. Another limitation was that we were able to interview only such patients who were living with their family members. There were many patients in the community who have no families. The tool does not capture perspectives from such patients. Ethical issues related to consent precluded us from recruiting them.

Finally, one item of the schedule has been detailed in the Appendix 1. Full copy of the schedule may be obtained after writing to the corresponding author.

CONCLUSION

SOFIAc fulfills an important need in schizophrenia research in our country. The tool comprehensively assesses barriers to access psychiatric care for patients with schizophrenia (and their families) in rural communities. The schedule taps many more factors than a check-list does and shows which factor is more important and which is less in each individual. Doing this may help in prioritizing the public health interventions.

APPENDIX 1

Lack of insight and active non-cooperation from the patient

The patient may have actively opposed any attempt to get him/her treated including religious methods. The patient would either become aggressive or would actively resist when family members attempt to take him/her for treatment. In some instances, patient would do something to embarrass the family members or even try to hurt him/herself when attempts were made to initiate treatment.

0. No influence

This factor has not at all influenced non-access. Some situations that fit in this description are: (a) patient is highly motivated to take treatment; (b) the patient is not motivated to take treatment but has never shown any resistance for efforts to treat him/her with alternative methods of treatment; (c) the caregivers have not at all attempted to initiate treatment.

1. Some influence

The patient has shown some resistance in getting him treated. However, there is reason to believe

ACKNOWLEDGMENT

The researchers would like to thank Accredited Social Health Activists (ASHA) workers, health workers, and Primary health doctors in Turuvekere community, which helped in the identification of patients in the community.

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How to cite this article: Reddy KS, Thirthalli J, Kumar CN, Reddy NK, Renukadevi NR, Rawat VS, *et al.* Schedule of factors influencing access to psychiatric treatment in persons with schizophrenia: Validity and pilot testing. *Indian J Psychol Med* 2013;35:364-7.

Source of Support: This work was conducted with the help of research grants to Dr. Jagadisha Thirthalli from the Government of Karnataka and to Dr. C. Naveen Kumar from the American Psychiatric Association as part of "Young Minds in Psychiatry" award (year 2009), **Conflict of Interest:** None.

that this could be easily overcome by appropriate efforts. For instance, despite his/her active refusal to cooperate, the family has been able to access treatment.

2. Moderate influence

This factor has played a key role in influencing treatment non-access. However, this has happened because of its combination with other factors. If other factors were conducive, then the patient could have been treated despite this factor. E.g., (a) had the treatment center been nearer; (b) if there was help from other sources like other family members/neighbors; (c) if the family believed that treatment would help, etc.

3. Profound influence

This factor has been the single most important cause in patient not having accessed psychiatric treatment. The family would have made attempts to take him/her for treatment, but because this reason alone, they were unsuccessful in their efforts.