

# Understanding needs of stakeholders and outcomes desired from a home-based intervention program for “difficult to treat” schizophrenia and related disorders: A qualitative study

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## ABSTRACT

**Background:** We aimed to understand the needs of service users – families and patients with schizophrenia and related disorders, and mental health professionals (MHPs) and expectations from a home-based psychosocial intervention program in Indian setting.

**Materials and Methods:** We conducted four focus group discussions (FGDs) with families, patients with schizophrenia and related disorders and MHPs. Two FGDs were conducted with families and one each with the patients and MHPs. Participants in families and MHP group were asked about their primary concerns in caring for the patients, perceived needs of patients and the areas that can be targeted through a home-based psychosocial intervention program. All FGDs were audio-recorded and verbatim transcribed. Content analysis of the data was done to obtain a final list of needs and expected outcomes from a psychosocial intervention supported by families.

**Results:** Six key priority needs were identified for intervention: medication adherence, activities of daily living, promoting physical health, engagement in meaningful work, building of social and support networks and information about all aspects of illness. Priority outcomes identified by MHPs were mostly clinical like symptom reduction, fewer rehospitalisation while families and patients focused more on psychosocial outcomes, such as improvement of wellbeing, having relationships, engagement in meaningful activities, better organization of the day, increased self-respect, reduced stress, lesser interference, and critical comments. All groups suggested that book or mobile app or video could be used.

**Conclusion:** This qualitative study shows that while both clinicians and service users consider recovery from schizophrenia and related disorders to be important, they differ on what they prioritise.

**Key words:** Difficult-to-treat schizophrenia, home-based care, India, psychosocial intervention

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## INTRODUCTION

Schizophrenia and related disorders have significant impairment in socio-occupational engagement.<sup>[1]</sup> “Difficult-to-treat” patients with schizophrenia include treatment-resistant patients as well as those who fail to show desired response to therapy or have a poor compliance or poor engagement with treatment.<sup>[2]</sup> Provision of anti-psychotic medication is not sufficient to address the complex social, economic, and health needs of the affected individuals. Antipsychotics have most effect on positive symptoms, with less effect in improving functioning or negative symptoms. Therefore, it is important to combine anti-psychotic medication with psychosocial interventions for the treatment of schizophrenia and related disorders with focus on recovery.<sup>[3]</sup>

Community care helps in reducing stigma besides improving functional, financial, and cognitive aspects.<sup>[4]</sup> Hospital-based psychosocial interventions, unlike home-based interventions may be limited by logistics (frequent visits) and treatment costs (travel cost, cost of resources). Home-based interventions, on the other hand, are convenient, inexpensive, and enable treatment for a longer duration.<sup>[5]</sup> Home-based care has shown a positive outcome in terms of feasibility, reduced rates of re-hospitalization as well as overall improvement in illness severity. Home-based care has especially been proposed for low-resource settings.<sup>[6,7]</sup> However, the implementation of the community-based psychosocial interventions in low- and middle-income countries (LMICs) has often been uncertain, probably because extrapolation of techniques from western countries may not work in LMICs.<sup>[8,9]</sup> Psychosocial interventions that are based on the needs identified by stakeholders can help in improving symptoms and disability associated with these disorders.<sup>[10-12]</sup>

In India, almost 90% of persons with schizophrenia and related disorders stay at home with families.<sup>[13,14]</sup> Although most family members willingly take on the role of care provider, they often lack evidence-based knowledge about the nature of the illness, and illness-related behaviors. Discrepancies have also been noted in terms of the needs and recovery perceived by patient *viz-a-viz* caregiver.<sup>[9]</sup> Literature suggests that the structured interventions that target areas such as supporting family, psycho-education, setting up of self-help groups, and provisioning for basic needs, can reduce the disability in patients.<sup>[10,15]</sup> Involvement of families in the development of effective psychosocial interventions is important as families are more familiar with the actual needs of the patient as compared to the MHP.<sup>[15]</sup> They also lack support from the mental health professionals (MHPs).<sup>[16,17]</sup> It is, thus, important that MHPs work in collaboration with the caregivers for the treatment of mental illnesses like schizophrenia.

In this background, we aimed at developing a home-based psychosocial care program for persons with “difficult-to-treat” schizophrenia (PwS) and related disorders in which delivery of psychosocial interventions would be supported by family members. In the present study, we aimed to understand the needs of PwS and their families and the desired outcomes from a home-based intervention. The study also explored the viewpoints of MHPs regarding home based psychosocial interventions. We additionally explored feasible platforms and techniques that can be used by families and PwS to carry out the interventions at home.

## METHODS

### Settings and participants

This study was conducted at the outpatient department of a tertiary care public-funded general hospital psychiatric unit of a medical school in North India. The target population consisted of family members, PwS, and MHP. The participants were recruited by purposive sampling.

PwS were defined as those who met diagnostic criteria for schizophrenia, persistent delusional disorder, schizo-affective disorder, other and unspecified psychosis on International Classification of Diseases–10,<sup>[18]</sup> with a duration of illness of  $\geq 2$  years, duration of treatment  $\geq 6$  months from our center, having persistent psychopathology (defined as a score of  $\geq 3$  on either of the following items in scale for the assessment of positive symptoms:<sup>[19]</sup> 7, 20, 25, 34; or a score of  $\geq 3$  on either of the following items in scales for the assessment of negative symptoms:<sup>[20]</sup> 8, 13, 17, 22, 25; AND a score  $\geq 4$  on clinical global impressions severity subscale (clinical global impression),<sup>[21]</sup> and could speak and read Hindi or English.

The caregivers (spouse/parent/sibling/offspring) included had to fulfill any three of the following criteria: living with the PwS in the same house, had most frequent contact with the PwS, helped to support the PwS financially, had most frequently participated in the treatment of PwS, and was to be contacted by treatment staff in case of an emergency.<sup>[22]</sup> Caregivers included could be of either gender, aged  $\geq 18$  years, and be able to read and write in English/Hindi. Those who had a history of any psychiatric illness (except nicotine/caffeine dependence) as per mini international neuropsychiatric interview version 7.0,<sup>[23]</sup> or were unwilling to participate, were excluded. MHP group included psychiatrists, clinical psychologists, occupational therapist, and psychiatric nurse; all of whom had  $\geq 3$  years of experience in dealing with PwS. The number of participants in service user group was decided based on the recruitment feasibility while allowing all participants an opportunity to discuss their views and experiences. Data were collected through focus group discussions (FGDs). We conducted two FGDs with families, that were followed by one FGD with the

PwS and one with the MHP. The above-mentioned number was based on the evidence that one FGD per stratum may be sufficient to identify the issues.<sup>[24]</sup>

### Procedure

The FGDs were conducted in group therapy room in the outpatient services. Each participant in the service user groups was met individually and explained the purpose, points of discussion, expected duration of the FGD. Informed consent was taken from all the participants. Primary discussion points in the FGDs with families and PwS focused on their needs, and the target areas for intervention in a home-based psychosocial care program led by families. For the MHP group, the discussion focused on what they considered were the priority needs of families and PwS, and the areas that can be targeted for intervention through this program.

Each FGD lasted between 70 and 120 min. The FGDs were all facilitated by an experienced lead facilitator. The FGDs were conducted in Hindi. All FGDs were audio-recorded and verbatim of the participants was transcribed into written data in Hindi.

Ethical approval was taken from Institute Ethics Committee (IEC 252/05.05.2017).

### Data analysis

The data obtained from the four FGDs were analyzed by thematic analysis.<sup>[25]</sup> Both thematic analysis and content analysis were done to find the themes and identify the needs, concerns, and the desired outcomes. The content was analyzed to explore the needs and expected outcomes, that would further inform the development of interventions. The transcribed data were translated into English. The English data were then analyzed to identify codes and subsequent themes and subthemes. Open coding was done for the transcript of each question raised during FGDs. Based on the open codes, conceptual codes were assigned by the authors. After conceptual coding, a list of needs was made based on the conceptual codes obtained for each question. The needs were then divided into themes and subthemes and ranked according to their frequency of occurrence in the transcript. The needs under each theme across the four FGDs were listed. A final list of themes and needs under each theme was tabulated for analysis and a concept map derived from themes of FGDs with patients and caregivers was prepared [Figure 1].

## RESULTS

Thirteen family members participated in the two FGDs ( $n = 7$  and  $6$ , respectively). Ten were males and three were females with age range between 24–72 years. The family members were mostly parents (7), siblings (2), spouses (2), and children (2). All these participants had at

least 2 years of experience of caring for PwS. Five members participated in the FGD for PwS. Four were males and one was female with age range between 23 and 55 years. Eight MHPs participated in the FGD. This group consisted of psychiatrists (5), psychologist (1), and occupational therapist (1), psychiatric nurse (1).

### Perspective of family members of persons with “difficult-to-treat” schizophrenia and related disorders

The family members’ core need was for the patient and themselves to become self-sufficient in all respects. Table 1 presents the themes and subthemes identified in the two FGDs with the family members.

#### Medication adherence

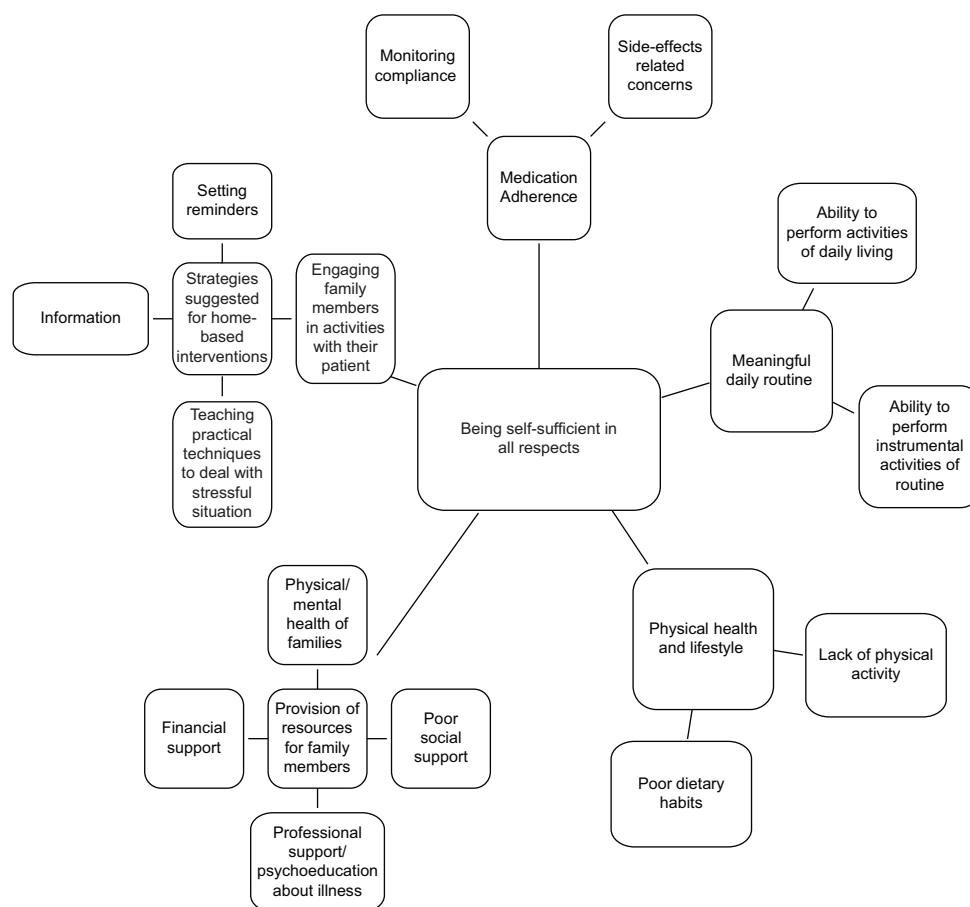
Families recognized how relapses impacted the family members and their relationships with each other as well with the patient. Father of a young male patient discussed on being asked about issues with medication intake, “*whenever he has stopped medicine/changed dose on his own, he has gotten worse;*” Father of a young female patient mentioned, “*she stops talking with us and both of us don’t know how to get her to talk to us*”. The themes that emerged were related to reasons for nonadherence, problems in ensuring the medication adherence and techniques used by families. Families said that even when the PwS was compliant, they kept a close watch on their medicine intake. Suggested strategies included reminders for medicines through the intervention program and reinforcing the benefits of medication compliance by psychoeducation.

#### Involvement in productive/gainful activities

Participants in the families group talked about the need for productive activities for PwS to improve their self-esteem. Mother of a female patient in her thirties (who had completed her graduation before becoming ill) stated, “*We know she can do much more than just sitting at home(..) We want her to start working (...) it will build her self-esteem*”. It was frequently reported by many family members about their patient being “bright” students or being productively employed before falling ill and not engaging in any meaningful activity (paid/unpaid) after falling ill despite improvement in psychotic symptoms.

#### Daily routine/activities of daily living

The participants discussed the importance of managing everyday tasks such as hygiene, simple household tasks, leisure, and social activities. Lack of daily schedule impacted both the patient and families, as families had to spend more time and effort in assisting the patient in carrying out these activities. “*he would not do anything unless prompted to (...) we can’t go out as we feel worried*”. Subthemes that emerged were related to the difficulties experienced by patients in carrying out activities of daily living.



**Figure 1:** Concept map derived from themes of FGDs with patients and caregivers

### *Taking care of physical health and lifestyle*

Weight gain was a major concern by majority family members. Family members talked about the issues such as lack of physical activity, erratic eating schedule, and side effects of psychotropics. Participants said that issues such as diabetes, hypertension in their patients further increased their burden of care. *“it is difficult to take care of his psychiatric illness, diabetes (...) it demands most of our energy. Affording both the psychiatric and diabetes medicines becomes hard”*.

### *Deprivation of resources amongst families*

Participants in both the family groups talked about their personal concerns, stress, and needs that often get overlooked in the process of caregiving. Father of a middle-aged male who and his wife were themselves suffering from multiple medical ailments reported, *“We have not been able to get my tests done as we keep forgetting about them.”* Father of another young patient reported not being able to sustain the financial burden of handling medication, commuting, admissions, with a sole source of income being their pension. Some old parents expressed the need for long-term care alternatives and social support, for their own emotional needs and for providing care to their ward. *“After us, I don’t expect my other son to look after him”, “(..) we*

*hope to find something like a support in form of a group of people who are like us”*.

### *Strategies for home-based psychosocial interventions*

Family members expressed keenness to become a part of home-based psychosocial interventions under the guidance of MHPs. *“We are taking care of the patient on day-to-day basis. Psychiatrist or a psychologist can provide professional guidance;” “Short motivating movies through which patients can learn how to communicate with others. With the help of videos, they can be trained to make new friends.”* They reported that information and important activities that need to be carried out can be compiled in books or provided as mobile app, which may help them take care of their patients at home, making them self-reliant. The participants said that information about schizophrenia and how to deal with difficult situations at home would empower them in caring for their ward. *“It would help me know how much I can push him to do something (...)”*.

### **Perspective of persons with “difficult-to-treat” schizophrenia and related disorders**

Patients, similar to family members, also expressed the need to be self-sufficient. Table 2 presents the themes identified from FGD with PWS.

**Table 1: Perspective of family members of persons with "difficult to treat" schizophrenia and related disorders**

| Main themes  | Subthemes   | Codes   | Number of times themes were coded  |   |
|--|---|---|--|---|
| Medication adherence   | Monitoring compliance                               | Patient needs close monitoring by the family member   | 12   |   |
|  |   | Patients skip the prescribed dosage   | 5  |   |
|  |   | Need to know how to ensure medication adherence   | 8  |   |
|  | Side-effects related concerns                       | Patient refuses to take medicine  | 6  |   |
|  |   | Concern about the side effects of medicine  | 6  |   |
|  |   | Setting a reminder  | 5  |   |
|  | Strategies  | Discussing the importance of medicines  | 3  |   |
|  |   | Activities of daily living  | Difficulty in maintaining hygiene  | 6 |
|  |   |   | Should be able to perform daily tasks (taking medicine, taking care of hygiene and health) independently | 6 |
| Meaningful daily routine   | Instrumental activities of routine                  | Lack of social interactions   | 4  |   |
|  |   | Lack of interest in leisure activities  | 7  |   |
|  |   | Need to engage in productive (and paid) work outside home   | 8  |   |
|  |   | Engagement in household activities  | 4  |   |
|  | Strategies  | Setting a reminder  | 3  |   |
|  |   | Engagement in the activity with the patient   | 4  |   |
|  |   | Involvement of family members in training of these skills   | 4  |   |
|  |   | Weight gain   | 7  |   |
|  | Physical health                                     | Ill   | Not engaging in any productive physical activity (paid/unpaid)   | 6 |
|  |   |   | Difficulty in management of physical illness   | 5 |
|  |   |   | Impact of erratic meals and eating schedule on physical health   | 5 |
|  |   | Poor dietary habits and lifestyle   | Impact of smoking  | 6 |
| Healthy behaviors incorporated for the entire family                       |   |   | 3  |   |
| Health issues of other family members (other than the patient) get ignored |   |   | 5  |   |
| Lack of resources for family members                                       | Poor physical/mental health                         | Health issues of other family members (other than the patient) get ignored  | 8  |   |
|  |   | Subjugation of needs of family members other than the patient   | 4  |   |
|  |   | Stress - About future of family member with schizophrenia   | 10   |   |
|  | Poor social support                                 | Change in routine and needs to suit the patient   | 5  |   |
|  |   | Limited social support/feeling isolated or lonely   | 6  |   |
|  |   | Reduced interactions with relatives/friends   | 6  |   |
|  | Poor professional support/information about illness | Stigma  | 5  |   |
|  |   | Lack of access to professional help   | 7  |   |
|  |   | Lack of professional/scientific information related to caring for schizophrenia                                   | 4  |   |
|  | Poor financial resources                            | Financial issues (limited financial sources, high expenditure)  | 3  |   |
|  |   | Limited time and resources to take care of self   | 4  |   |
|  |   | To give equal time to other family members  | 4  |   |
|  | Self-care strategies for families                   | Set some time aside (daily, weekly, or monthly) for yourself  | Not to feel guilty about spending time on self-care  | 4 |
|  |   |   | Learn communication skills   | 5 |
|  |   |   | Learn more about the illness   | 3 |
| Practical techniques   |   | Be a part of network of other families going through the same difficulty  | 4  |   |
|  |   | For management of stressful situations/problem behaviors  | 5  |   |
|  |   | Provide psychological techniques on how to deal with problems (like violence, medication refusal)                 | 7  |   |
| Strategies for home-based psychosocial interventions                       | Information   | Provide information about illness (causes, course, warning signs, relapse, treatment plan, duration of treatment) | 6  |   |
|  |   | Platform for delivery of psychosocial intervention  | 6  |   |
|  | Books   | Books   | 6  |   |
|  |   | Mobile based program/apps   | 7  |   |
| Videos   | Text based/mobile messages                          | 3   |  |   |
|  | Videos  | 4   |  |   |

**Medication adherence**

Some participants discussed how medications helped them in various ways especially in the alleviation of symptoms. "Since I started taking medicines, I don't feel scared (...) the voices don't disturb me". However, very few patients acknowledged the presence of psychotic

symptoms and reported taking medicines to reduce their stress or depression. While majority acknowledged their medications being supervised by their caregivers, a young patient reported, "I take my medicine myself, I don't need my parents to look after this...I have already given them a lot of trouble."

**Table 2: Perspective of persons with “difficult to treat” schizophrenia and related disorders**

| Main themes  | Subthemes   | Codes   | Number of times themes were coded                 |
|--|---|---|---|
| Medication adherence                               | Monitoring medicine compliance                                | Close monitoring by the family member   | 3   |
|  |   | Forgets/skips the prescribed dosage   | 4   |
|  |   | Refuses to take medicine as they do not feel the need   | 3   |
|  |   | Need to know how to ensure medication adherence   | 3   |
| Meaningful daily routine                           | Side-effects related concerns                                 | Concern about the side effects of medicine  | 5   |
|  |   | Setting a reminder  | 3   |
|  | Strategies  | Difficulty in maintaining hygiene   | 4   |
|  |   | Lack of productive/meaningful activities  | 3   |
|  | Instrumental activities of daily living                       | Lack of interest in leisure activities  | 3   |
|  |   | Lack of social interactions   | 3   |
|  |   | Engagement in productive (and paid) work outside home   | 2   |
|  |   | Engagement in household activities  | 1   |
| Strategies   | Gentle reminder   | 4   |   |
|  | Engagement of family members in the activity with the patient | 2   |   |
| Physical health                                    | Poor physical health  | Weight gain   | 3   |
|  |   | Lack of physical activity   | 3   |
|  |   | Management of physical illness  | 2   |
|  |   | Erratic meals and eating schedule on physical health  | 3   |
| Lack of resources                                  | Poor dietary habits and lifestyle                             | Smoking   | 1   |
|  |   | Healthy behaviors incorporated for the entire family  | 2   |
|  | Strategies  | Poor social support   | Limited social support/feeling isolated or lonely |
| Poor financial support                             |   | Future of patient after death/in absence of primary caregiving family member                                      | 5   |
|  | Strategies for home-based psychosocial interventions          | Poor financial support  | Stigma  |
| Unemployment                                       |   |   | 4   |
| Practical techniques for management                |   | High expenditure on medicines, commuting, food, etc.  | 1   |
|  |   | For management of stressful situations/problem behaviors  | 4   |
| Psychoeducation                                    |   | Provide psychological techniques on how to deal with problems (like voices, anxiety)                              | 4   |
|  |   | Provide information about illness (causes, course, warning signs, relapse, treatment plan, duration of treatment) | 3   |
| Platform for delivery of psychosocial intervention | Books   | 2   |   |
|  | Mobile-based program/apps                                     | 2   |   |
|  | Videos  | 1   |   |

### *Meaningful daily routine/Need to be engaged in productive work and physical health*

Participants shared that they faced problems in completing routine activities, such as selfcare, household chores, and leisure activities. A patient who experienced half-formed/fleeting ideas of references stated, “I don’t go out for any chores, as I feel people stare at me (...)”, “I don’t feel like getting up early (...) medications affect my concentration and make me lazy”. They expressed need to be engaged in productive work, such as a job or household tasks. Participants expressed that work would bring them respect from others. A man in late thirties reported, “I want to earn money, so I don’t have to ask others”. However, a common issue faced by the patients was either lack of motivation or not willing to do a job below their assumed caliber. For example, a patient who had done B. Tech mentioned, “I don’t want to work in my father’s shop as a helper. I am more qualified, but people don’t give me job as per my qualification.”

### **Lack of resources**

#### *Need for social support/networks*

Participants shared that they felt the need for a friend who they could talk to about their personal feelings. Some

participants discussed about the absence of meaningful interactions with close family members, particularly siblings. A middle-aged patient staying with his younger brother reported, “I feel lonely, more so after I lost my mother (...) both my siblings are busy with their families. I want to have a family of my own someday (...)”

#### *Information/professional help*

PwS wanted to know more about their illness, especially about recovery from schizophrenia, treatment modalities, and its impact on their capacity to work. A young patient asked, “Will it ever go away? (...) till when do I need to take these medicines?” Another female patient was keen on knowing more about the illness and its impact on her life, “Can I work as a teacher after I am fine? Will I be able to handle job stress.”

#### *Experience of stigma*

Both self-stigmatization and stigmatization by others were evident in the discussion. A young male reported, “when I apply for a job, I don’t want to tell anyone that I have schizophrenia”. Another male patient reported, “My brother doesn’t let his daughter come close to me (...) I feel bad about

it". They would experience the need to have a person in their life in whom they could confide and who would be empathetic to their situation.

#### Strategies for home-based psychosocial interventions

PwS expressed that having a program that helps them to learn techniques for the management of issues in their daily life would be useful. A patient-reported, "If there is something like a book or a video that tells how people in similar situation deal with problems of schizophrenia, that would be helpful". They reported that for all issues they face in day-to-day situations, a guide in the form of book or mobile app that answers their queries would be useful.

#### Perspective of MHPs

A focused group discussion with the MHPs was conducted to triangulate the findings from the FGDs done with families and service users. Table 3 presents the findings.

#### Medication adherence

Regular medication was considered important to deal with the symptoms of schizophrenia, prevent relapses and hospitalizations. One of the MHPs reported, "taking medicine on time and right dose is important (...) will ensure relapse prevention and reduce the number of hospitalizations". They reported that ensuring medication adherence may be the first and foremost step in building toward psychosocial rehabilitation as it would make them self-reliant.

#### Psychoeducation

The need for psychoeducation for families and PwS about the nature of schizophrenia, treatment modalities, and management of psychosocial issues that emerge due to illness was emphasized. Many MHPs reported, "They should be aware of how and where they can seek treatment, have knowledge about side-effects and dosage schedule of medications." Many MHPs reported that side effects would be an important reason patients/family members would want to discontinue or reduce the medications.

#### Meaningful activities of daily living

The participants said that structuring the day would help in the reduction of negative symptoms. For example, "it is not just the paid job or an employment (...) tasks like waking up on time, taking care of their hygiene would be useful activities... structuring of the daily activities would be helpful." According to the MHPs, the first target should not be to gain a paid employment but to engage in a meaningful routine that structures their day.

#### Physical health

Most MHPs expressed that their patients did not just suffer from schizophrenia or related psychotic disorder but a number of other physical problems, such as obesity, diabetes, and hypertension. They believed that the patients need to be treated comprehensively and not just for their psychiatric symptoms. One of them stated,

**Table 3: Perspective of mental health professionals**

| Main themes  | Subthemes  | Codes   | Number of times theme were coded |
|--|--|---|----------------------------------|
| Medication adherence                                 | Monitoring medicine compliance                     | Patient needs close monitoring by the family member   | 8                                |
|  |  | Patients skip the prescribed dosage   | 8                                |
|  |  | Patient refuses to take medicine  | 8                                |
|  | Side-effects related concern                       | Concern about the side effects of medicine  | 8                                |
|  |  | Need to educate how to ensure medication adherence  | 7                                |
|  | Strategies   | Setting a reminder  | 5                                |
| Meaningful daily routine                             | Activities of daily living                         | Discussing the importance of medicines  | 2                                |
|  |  | Difficulty in maintaining hygiene   | 8                                |
|  | Instrumental activities of daily living            | Lack of productive/meaningful activities  | 3                                |
|  |  | Lack of interest in leisure activities  | 3                                |
|  | Strategies   | Lack of social interactions   | 3                                |
|  |  | Setting a reminder  | 5                                |
| Impact of illness on families/lack of resources      | Poor physical/mental health                        | Engagement in the activity with the patient   | 5                                |
|  |  | Health issues of other family members (other than the patient) get ignored  | 5                                |
|  |  | Subjugation of needs of family members other than the patient   | 5                                |
|  | Poor social support                                | Stress - About future of family member with schizophrenia   | 2                                |
|  |  | Limited social support/feeling isolated or lonely   | 3                                |
|  |  | Stigma  | 7                                |
| Strategies for home-based psychosocial interventions | Practical techniques for management                | For management of stressful situations/problem behaviors  | 3                                |
|  |  | Provide psychological techniques on how to deal with problems (like violence, medication refusal)                 | 6                                |
|  | Psychoeducation                                    | Provide information about illness (causes, course, warning signs, relapse, treatment plan, duration of treatment) | 5                                |
|  |  | Booklets  | 4                                |
|  | Platform for delivery of psychosocial intervention | Mobile based program/apps   | 7                                |
|  |  | Text based/mobile messages  | 2                                |
|  |  | Videos  | 2                                |

*“Physical health management is important to take care of metabolic syndrome.”*

#### *Strategies for home-based psychosocial interventions*

MHPs also appreciated the need of a home-based care psychosocial care model in addressing the diverse needs of families and PwS living in low resource settings. *“When the family members have difficulty in bringing the patient to the hospital, they have no knowledge about alternatives about how and where to approach”*; It was suggested that a common modality for providing home-based interventions could be mobile phones or booklets. A member from FGD reported, *“Mobile phone and apps can be helpful for giving new information to the caregivers...they can also connect to other caregivers caring for patients suffering from similar condition”*.

## DISCUSSION

Medication adherence, daily scheduling, promoting physical health, engagement in work, building of social support networks, and psychoeducation were the priority needs identified in the current study. Similar findings on the needs of families and PwS and their expectations from the treatment of schizophrenia have been observed in the previous studies.<sup>[10,15,26,27]</sup> Gandhi *et al.* assessed perspectives of users recovering from schizophrenia in a qualitative study in southern India and observed similar findings. They found different themes as facilitators (e.g., family involvement, adherence to treatment, being engaged in some activity, and basic needs) and barriers (e.g., being alone, medication side effects, and poor social support) to recovery.<sup>[28]</sup> Another study done in southern India using in-depth interviews on 70 patients found some additional needs such as managing difficult behaviors of patients, easy availability of medications, and financial support from state.<sup>[29]</sup>

We also observed convergence between the needs and expectations of families and patients in our study. A few other studies have also reported the overlap between actual needs of PwS and the needs perceived by their family members.<sup>[15,30]</sup> Both the families and PwS reported that interventions in these areas would help them to lead a normal life. Work is an important aspect of recovery and rehabilitation plan for schizophrenia and related disorders. These have been found to be one of the most desired outcomes for PwS as it ensures a normal life.<sup>[31,32]</sup> There are studies, in contrast, which have shown a discrepancy between the needs perceived by patients and their caregivers, such as effectiveness and financial feasibility of community-based care was only acknowledged by the caregivers, and the desire to be understood by caregivers was only identified by the patients.<sup>[9]</sup> The difference in our findings could be attributed to the cultural variations or methodological variations between the two study populations.

A unique aspect of our study is an FGD with MHPs. Priority outcomes defined by the MHPs were clinical in nature like symptom reduction, fewer rehospitalizations while families or PwS focused more on psychosocial outcomes, such as improvement of wellbeing, having relationships, engagement in meaningful activities, better organization of the day, increased self-respect, and reduced stress. Studies have indicated that the families and PwS tend to define recovery and the treatment goals differently from the clinicians.<sup>[27,30]</sup> Families expressed the need for receiving reliable information about schizophrenia, treatment options, and how to respond during crisis situation. For PwS, information was important for knowing about their treatment process, recovery, and leading a normal life in the community. Both families and PwS expected information to address the subjective experiences of living with schizophrenia and welfare schemes for persons with schizophrenia. MHPs stressed upon the need of a psychoeducation module for treatment adherence, understanding clinical symptoms, and relapse prevention. These discrepancies show their differences of opinion on how they define recovery.

Families echoed their concern for future of PwS in case their absence. In countries such as India where there is an absence of public social security system and an affordable long-term care system for people with schizophrenia and related disorders, this concern is something that requires attention from public health professionals as well as policymakers.<sup>[33,34]</sup> Despite the stress, families reported that they would want to continue with their role and responsibility as the primary caregiver. They expected an intervention to support them in their role as a caregiver, and not take on the role of a caregiver.

Most participants reported that they would prefer face-to-face format for delivery of interventions. Other platforms suggested were the development of booklets and videos. Various booklets and informational videos have been developed in the past by institutes like NIMHANS, like “Handbook of Psychiatric rehabilitation services,” “Activities of Daily Living” caregivers’ videos on “road to Recovery.”<sup>[35]</sup> It was interesting to note that the participants suggested the use of the mobile app-based platform to deliver the interventions. An exponential increase in mobile phone penetrance in India has been seen with a tele-density of 92.84%.<sup>[36]</sup> The mobile phone ownership amongst PwS has been reported to be around 84%.<sup>[37]</sup> These suggestions must lead a way forward for MHPs to plan home-based psychosocial interventions.

This study helped us understand the priority needs and expectations from a psychosocial intervention, from the diverse perspectives of families, PwS, and MHP. The discrepancies between the expectations of families, PwS, and MHPs for an intervention are important to understand. It is important for clinicians to learn skills to work in



collaboration with the caregivers for better outcomes and utilization of families as the most important and affordable resource in a country like ours. Participants in all three groups agreed that their concerns and needs can be addressed through a home-based psychosocial care program that is designed and implemented through a collaboration among MHP team, families, and PwS. Families and MHPs deliberated on various methods such as printed booklets, mobile-based applications, mobile texting, and short videos for delivering the psychosocial interventions. Regular interaction with the mental health team was stressed upon by participants in all three groups. The findings from this study may be helpful in developing the components of a psychosocial intervention program for improving medication adherence, activity scheduling, lifestyle interventions, and imparting psychoeducation in patients with schizophrenia and related disorders.

The study is one of the few studies to assess the needs of patients, caregivers, as well as expectation of mental health practitioners in a qualitative manner. With the help of stringent selection criteria, we specifically aimed to target patients with schizophrenia having persistent psychopathology and dysfunction, which poses a huge caregiver burden, patient distress, as well as challenge for the MHP. However, this study is limited by small number of participants and FGDs. The data were collected in a single tertiary care center, limiting the generalizability of the findings.

## CONCLUSION

The needs identified by families, PwS, and MHPs, and their expectations from a home-based psychosocial intervention program differ. A psychosocial intervention program that synthesizes the priorities and expectations of all three groups will be successful in bringing the desired outcomes for schizophrenia and related disorders. It is important for MHPs to understand and collaborate with the service users in planning the interventions.

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## Conflicts of interest

There are no conflicts of interest.

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