

Original Article

Tranquilizing Stigma: Identifying Advocacy Interventions Based on Subjective Experiences of Stigma among People with Schizophrenia

Abstract

Background/Objectives: Research on stigma interventions focuses on general public attitudes and overlooks patients' subjective experiences of everyday stigma arising from significant others. Mental health advocacy has rapidly progressed in western countries, but still continues to be in its early stages in low- and middle-income countries. With this background we looked for possible sources/areas to formulate anti-stigma interventions based on the individual subjective experiences of stigma. **Methods:** Stigma experiences were assessed by conducting interviews with 200 patients suffering from schizophrenia attending psychiatric services in urban and rural settings. Using ATLAS.ti the narratives were analyzed qualitatively and a final analytical web was created to make associations. Using thematic content analysis we identified themes that could possibly have implications for anti-stigma interventions. **Results:** Five different areas were identified based on the objectives: Interventions to target key stakeholders such as family members, service providers, nongovernmental organizations/voluntary organizations and people with schizophrenia itself are identified. Interventions could target media personnel, administrators and planners and mental health professionals too. **Conclusions:** As observed from the results, stigma has multifaceted origins and consequences; and hence interventions too need to occur at these multiple levels with concerted co-ordination.

Key Words: Advocacy, India, interventions, schizophrenia, socio-cultural, stigma

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Introduction

Stigma is often considered as the hidden obstacle to care-seeking among people with mental illness. The World Health Report, in 2001, stated that about 450 million people suffer from mental illnesses all over the world, but only a fraction of them procure any form of treatment. Stigma, prejudice and discrimination were the barriers that stood between the suffering and possible treatment.^[1] People suffering from severe mental illness, especially schizophrenia, also endure effects of stigma, discrimination and the negative consequences as a result of the illness.^[2-4] Stigma associated with schizophrenia in particular hampers an individual's access to proper health care, medication compliance, securing a job and the overall life's chances of a fruitful and fulfilling life.^[5]

A large number of public education campaigns were conducted worldwide by professionals and organizations, especially from high-income countries, to mitigate stigma, improve awareness and promote human rights.

For example, "open the doors," an ongoing program in 20 participating countries was an initiative of the World Psychiatric Association in 1996 to increase awareness about schizophrenia, to improve public attitudes towards individuals with schizophrenia and their families and to eliminate discrimination and prejudice through action.^[5] The Royal College of Psychiatrists launched "changing minds," a campaign to raise public awareness, dispel myths and stereotypes about mental illness through mass communication.^[6] "Like minds, like mine" is another public education program funded by the Ministry of Health, New Zealand. It was initiated in 1997 and is an ongoing program that aims to reduce stigma and discrimination with support from national administrators, nongovernmental organizations (NGO's) and agencies.^[7] National campaigns by SANE Australia^[8] and the National Alliance for the Mentally Ill^[9] are other noteworthy initiatives. Few studies have addressed specific groups among the population such as school students^[10,11] and police officers,^[12] and have found encouraging results. Thus, most stigma interventions focus on general public attitudes, and campaigns are delivered to improve public attitudes or improve their awareness.

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Literature reviews of intervention trials advocate direct social contact with people with mental illness for individual interventions, social marketing for the population level^[13] as well as education based interventions for promoting awareness about mental illness and propagate attitudinal change.^[14] Such interventions are limited in India and other low- and middle-income countries (LAMIC) and assessments about their effectiveness are notably sparse.^[15]

From an Indian socio-cultural perspective, understanding stigma is complex, as the general literacy levels are low and specifically, there is poor awareness about mental illness. The stigma experiences are intricate and are complicated by the socio-cultural myths and beliefs of a vastly heterogeneous population.^[16,17] The only noteworthy intervention study was by Das *et al.* who used a randomized controlled approach and compared the effects of a structured educational program for relatives of people with schizophrenia with another group that did not receive the intervention. Those who completed the educational intervention showed a reduction in causal attributions to black magic and beliefs that visiting a place of worship would cure the disease, compared to those who did not receive the intervention.^[18]

The World Health Organization (WHO) states that advocacy for mental health in the West has progressed, but is still in its infancy in India and other LAMIC.^[19] Thus, we undertook this study to identify and formulate anti-stigma interventions, based on individuals' subjective experience of stigma, whilst being wary of the obligation for advocacy. Direct views of people with schizophrenia are closely analyzed for possible interventions.

Methodology

Sample

We chose 200 out-patients for this study. 100 lived in urban areas and visited the out-patient services of the six adult psychiatry units of the National Institute of Mental Health and Neurosciences (NIMHANS), Bangalore, India. Another 100 lived in rural areas, 51 of whom attended the NIMHANS out-patient facility and 49 who sought services at the six outreach centers located in the rural community. We adopted a purposive sampling by choosing out-patients rather than in-patients as the former were exposed to everyday life situations and community reactions and were most likely to contribute to the study in terms of relevance and depth. We included participants from the rural environment of India, and thus, covered the complete range of situations relevant to the study topic. Individuals who were asymptomatic for at least 6 months were chosen for the study as symptoms were considered to hinder with stigma assessments. Patient case-records, information from the accompanying persons and a mental status examination by the treating psychiatrist were obtained for diagnostic

clarification. Further details of the methods have been described in previous publications.^[16,17] The study was approved by the Ethics Committee of NIMHANS.

Instrument

A semi-structured instrument was used to assess stigma and discriminatory experiences. This instrument was previously administered to over 1000 patients and caregivers to assess stigma as part of the Indian initiative of the World Psychiatric Association program to reduce stigma and discrimination because of schizophrenia.^[20] The final version of the questionnaire was based on a factor analysis of this instrument.^[16] For this particular qualitative study, the responses to open-ended questions were used in the final analyses. Open-ended, semi-structured questions allowed participants to elaborate on their experiences of stigma which the researcher suitably probed: (a) "Has your life changed after you have had the illness?" (b) "Are there things that you experience which others without the illness do not?" (c) "How do you cope with your illness?" (d) "Many people with similar illness experience shame, ridicule, and discrimination. Have you also experienced any of these?" The interviews were conducted with persons who spoke Kannada, Tamil and English as the interviewer was fluent with these languages. The researcher transcribed the interviews to English, which were later back-translated to the local languages to look for accuracy. More details about the instrument are described in detail elsewhere.^[17]

Analyses

We adopted a thematic analysis of the data using the framework approach.^[21] The narrative data was read several times to identify new emerging themes. For a more natural and objective analyses, the narrative quotes were coded into constructs using ATLAS.ti, qualitative data analysis software.^[22] A few quotes had more than one implication for intervention. For example, the quote "My wife scolds me at home saying I do nothing at home. But I can't work much; I can only do small tasks" were coded under constructs, "family members" and "persons with mental illness" as in this case one can intervene with the family member and at the individual level. In the example given above, the response was accounted for in both categories: "Family members" and "persons with mental illness," and so on. The constructs emphasized possible roles for interventions to mitigate stigma based on the subjective experiences of stigma, and were modified based on the aims of the study, topics raised by the participants and observations that recurred in the data. Using ATLAS.ti's network we also created nodes and networks from the derived codes, and in an iterative process, the relations between nodes were linked. Using ATLAS.ti's network manager function, a final analytical web was created for viewing. This helped in making associations and analyses.

Results

The analyses yielded five different categories as specified below. The focus of the study was from an intervention perspective and accordingly the categories that emerged were: (a) Empowering persons with schizophrenia (PWS); (b) family member as a partner; (c) modifying the facet of service providers; (d) mental health professionals to envisage beyond hospital-based care; and (e) NGO's: A crucial link for a basic model of care, in that order of frequency. More categories emerged from the analyses and these are represented in a final analytical web [Figure 1]. These categories were identified as the groups who required group-specific interventions.

Empowering persons with schizophrenia

PWS described being teased, ridiculed and being labeled for life. Experiences of status loss, discrimination, anticipated discrimination and the dilemma of whether to conceal ones illness or to reveal it were also common. Suffering from the label more than the illness with distressing emotional responses was common. Many more unanswered questions that left individuals clueless were also observed.

A 35-year-old man describes how the effects of labeling left a permanent psychological scar that is difficult to erase: "People say 'He's mad, leave him alone, it's no point telling him anything, he's useless'. It is difficult to say how the stigma can be reduced, as once you have a mental illness you are labeled forever."

The illness experience and the aftermath of the realization of being diagnosed with schizophrenia can leave individuals overwhelmed. Once a person develops insight into his illness he is often surrounded by many questions for which he is desperately seeking answers. These are often questions about the illness, about facing people in society, about the meaning of madness and many, many more unanswered questions. A 25-year-old man yearning for answers to the baffling array of questions that he asks

himself after being diagnosed with schizophrenia: "Why did I have to get this mental illness? How can I live with such an illness in the society? What if people call me mad? What if people get to know that I have a mental illness?"

Schizophrenia affects individuals' self-confidence often leaves them devastated. Besides, experiences of social discrimination leaves them anticipating more discriminatory experiences. A 30-year-old lady describing her experience of being discriminated and compares a mental disability with physical disability: "After this illness I have lost interest in life and lost my self-confidence. It is unnecessary to tell others that I have a problem. People do not take the initiative to talk to me on their own. Only if I talk, they talk; they don't have the courtesy to call back. Compared to other physical disabilities, people with a mental illness are the most disadvantaged because the mind is very powerful (like a storm) and it is difficult to stop a storm."

A serendipitous discovery of this study was the individuals concealing the illness from others as a coping mechanism. Many individuals used this as a coping mechanism, be it from relatives, friends or in their job applications while applying for work. A 28-year-old lady describes her experiences of being secretive about her illness and why she chose to do so: "I feel as though I can't do anything with my life. For the first 3 months of taking treatment, I wasn't going out to meet people, for the fear of people knowing about my illness. Nobody knows about my illness. I feel the moment they get to know they might look upon me unfairly. When people ask me what is wrong with me, I tell them I have insomnia."

Individuals reported that being called names and being ridiculed were common experiences. Most of them had strong emotional responses to the same, especially anger. A 37-year-old lady speaks of her suffering and how she copes with it: "People at work call me 'half,' 'mental'. I get angry but I don't react much. People don't assign me responsibility. At times I feel I shouldn't have got this illness. I pray to the Lord daily that my children shouldn't get this illness. I feel I can't maintain relationships and people may think otherwise of me, so I find it difficult at my place of work. I think being mentally ill means a lot of suffering and they suffer more from the label than the illness."

The family as a partner

Individuals with the illness described experiences of discrimination within the family. They perceived interference with chances of other family members getting married; they were excluded from decision making process in the family and blamed the PWS for everything. Sometimes they were told that getting married will lead to improvement or recovery from illness.

A 24-year-old man describes his anguish of discrimination and being excluded from major decision making in the

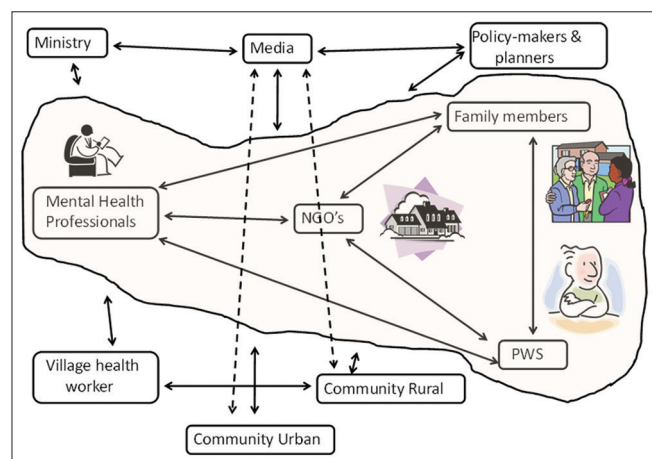


Figure 1: Basic model (within shaded area) in constant co-operation with other stakeholders

family: "My mother tells me to be active as my illness may interfere with the process of my sister's marriage. If there is anything important to be discussed, my family members say 'What's the point in discussing with him; it is no use telling him.'"

A 28-year-old lady describes how her father blames her for everything, taking advantage of her illness: "My father tells me that I am ill and that I won't get better and blames me a lot. People also take advantage of me and blame me for things I haven't done."

Myths about marriage and illness were common within family members. Poor working knowledge and understanding about the illness was pervasive among the close family members who were primary caregivers of the patient. A 36-year-old unmarried lady describes that educating family members, especially elders in the family has a role in reducing the stigma: "I have become very forgetful. I don't get along freely with others, because I can't speak with a group of people. When people get to know that I have a mental illness, they tell me to get married and that I'll get better. The best way to reduce the stigma is by educating the family members (especially the elders in the family)."

Modifying the facet of service providers

Service providers need to address various aspects of individuals' experiences. This study was conducted in a large tertiary care center that was providing services to the mentally ill for several decades and the stigma associated with the service provider's name itself was quoted as a barrier for help seeking. Illness related problems that needed special attention from the service provider were also expressed.

Stigma associated with the name of the service provider was significant, especially if mental health care services were being providing for a very long time. Of the various solutions to reduce stigma, improving functioning of the patients was one of them; a 40-year-old man says: "People say 'He can't work, just leave him alone. He goes to NIMHANS, he's mad.' The best way to reduce this stigma is by improving the functioning of the patients and by ignoring others' comments."

Giving importance to functioning was repeatedly touched upon, as a 45-year-old gentleman suggested that finer aspects of his work needed improvement: "I am a goldsmith and many of my customers don't come to my outlet anymore, thinking I am mentally ill and doubt my capability. I too feel in my work, the finishing and the finer aspects of my work has suffered."

It is easy for people to realize where one is being treated, especially if the service provider is a reputed one, such as a large tertiary care center that offers treatment for people with mental illness. As a result people cope by

concealing their illness in anticipation of being discovered; a 38-year-old lady says: "I avoid telling people about my illness, as I am getting treated at NIMHANS, and hence, people might talk ill of me or make fun of me."

Importance of getting back to work and earn a living was described as an essential part of the treatment and recovery. Importance to employment, employability and the need to stand up and support oneself was highlighted by a 42-year-old man in order to maintain self-esteem in society: "Earlier I could work with interest. Now, I can't do that. I don't feel like leaving my house because I feel people may point out that I am not working. I can't earn; I'm too tired and weak. People say that I'm useless and good for nothing. I could not cope with the machinery and its speed and had to quit my job."

Mental health professionals to envisage beyond hospital-based care

Mental health professionals need to proactively collaborate with rehabilitation centers and consider options as needed. Psychiatrists, in particular while prescribing medications need to address side-effects while prescribing psychotropic medication. Suggestions to promote interactions between the public at large and recovered patients should be considered in the near future to mitigate stigma, especially in rural areas.

The side-effects of psychotropic medications can perpetuate the existing stigma associated with schizophrenia; interfere with functioning and treatment adherence. A 37-year-old man who has problems with medication: "The medications make me feel weak and lazy."

Setting up more rehabilitation centers was suggested as a way to reduce stigma. Besides this, promoting contact with recovered and well functioning patients was also suggested to reduce stigmatization. As mentioned by a 27-year-old engineering graduate, love and compassionate care are probably the most important ingredients to reduce stigma: "The best way to decrease stigma and discrimination by others is by having more rehabilitation centers, promoting more contact of patients who are well with those without the illness, more of love and compassion."

Attitudes among rural folk are often rigid and difficult to change or modify; thus, giving examples of cured or recovered individuals that could induce change in their attitudes were suggested. A 30-year-old lady from a rural village suggested that: "People's attitudes towards the mentally ill can be improved, especially in the rural areas by giving examples of cured people that is, promoting contact with patients doing well."

Nongovernmental organizations: A crucial link for a basic model of care

Several activities were identified for NGO's based on the individuals responses. For example, facilitating partnership

between consumers, families and NGO's; initiating dialogues with prospective employers/agencies; education, creating awareness and demystifying misconceptions; collaborations and co-ordination with media, mental health professionals and other associated stakeholders are some of the activities that were identified.

One of the key tasks of rehabilitation agencies and NGO's is to facilitate consumers' functioning. A major concern for most individuals is the complexities involved in getting back to work. A 23-year-old lady shares her concern: "I cannot work like before. I am not able to do my household chores like before. People at my home ask me why I don't go to work. They ask me from where and who is going to get food for me."

Being ridiculed at the work place was also a common experience among the individuals. NGO's must sensitize employers at specific workplaces to ensure zero discrimination. A 42-year-old man employed at a factory narrates his experience: "The workers tease me by calling me a madman at the factory where I work. If I speak to them they scold me to keep quiet and pay little importance to what I say."

Suggestions to improve public attitude towards people with mental illness included screening educational films, but it was also suggested that these programs need to be enduring with a long term vision. A 39-year-old man suggests "to improve the attitudes of the people towards mental illness, educational films can be shown. But they have to be repeated constantly to be effective."

Respondents opined that promoting interactions with recovered individuals and educating them about treatment can result in improved public attitudes. A 21-year-old young man suggests: "When I fall sick with fever, people attribute

it to my mental illness. Public attitudes can be improved by enhancing contact of the public with the mentally ill and educate them regarding treatment and relapse."

Discussion

We identified key stakeholders and reflected on specific interventions that can be envisaged for them. PWS need assistance with illness related stigma and need an explanation about their unanswered questions; family members should be involved as a partner in the process of treatment and recovery; service providers need to pay attention to functional recovery and engage in useful collaborations with agencies; mental health professionals should pay attention to care beyond just hospital based treatment; and finally NGO's should play a crucial role in bringing together the consumer, the families and mental health professionals and strengthen partnerships to foster growth of the individual and integration back to society. Table 1 summarizes the possible interventions and discusses the feasibility of these interventions.

Empowering persons with schizophrenia

An individual with schizophrenia is labeled forever as having a serious mental disorder, which may render him socially different due to public prejudice. In all likelihood, once labeled, the person suffers more from the consequence of being labeled despite recovery from the symptoms of the illness. Accordingly, some cope with it by concealing their illness from all spheres of their lives. Similarly, there are a host of issues pertaining to how the individual reacts, perceives and ultimately copes with the illness: Status loss, discrimination and anticipated discrimination, to conceal or not to conceal illness, communication, social skills, questions about the illness itself, emotional responses such as anger, depression and hopelessness are some of the

Table 1: Stakeholder groups and possible interventions for them

Stakeholder/target group identified	Possible intervention for stakeholder group	Feasibility
PWS	Attempting to address their unanswered questions Addressing individuals to cope with illness related stigma	Challenging but possible to address these queries. Parallel need for stepping up essential human resources
Family member	Educating family and making them a partner in the process of recovery May entail multiple inputs from various stakeholders e.g., NGO	Possible, but entails increase in care-providers. Requires specific inputs to family members and wide collaboration
Service providers	Addressing functional recovery Collaborate with employment agencies Suggest alternatives for jobs	Possible. Set up facilities that address specific functional deficits. Collaboration with agencies after sensitizing them
Mental health professionals	Address drug related side-effect Promoting contact with recovered patients Collaboration with rehabilitation centers/NGO's	Possible. Need to look beyond medication treatment. Collaborative and a multi-disciplinary approach is the need of the hour
NGO	Facilitating partnership between consumers-families-professionals Education, creating awareness and demystifying misconceptions Collaborate with other associated stakeholders	Possible, but such agencies are few in number. Establish new partners with similar interests. Increased collaboration with existing NGO's

NGOs: Non - governmental organizations, PWS: Persons with schizophrenia

innumerable unanswered questions. Our sample focused on individuals recovered from their symptoms for at least 6 months and were stable at the time of interview, thus, their needs differed from those in the acute phase, or those still symptomatic or resistant to treatment. Once they have recovered, it is crucial to address these issues at the individual level. Few studies have actually looked at these issues and tried to address them. There are a large number of rehabilitation facilities and programs around the world that may be catering to these needs at the individual level in the process of rehabilitating PWS.

Thus, there exists tremendous scope for an individualized, tailor-made therapy for PWS. Social skills training (SST) was useful in preventing relapses and improving adjusting among in-patients,^[23,24] however generalizability of these skills to “real-life settings” was uncertain. SST addressed only minimal areas of functioning than the more obvious and pressing needs of individuals with schizophrenia. In this regard, a randomized trial comparing personal therapy with family therapy, combined personal and family therapy and supportive therapy for schizophrenia^[25,26] showed that personal therapy was more effective than the other therapies in preventing relapse and maintaining compliance among individuals living with their families, than among individuals living away from family. However, among patients living away from family, personal therapy was more effective than supportive therapy in improving work performance and relationships outside of home. Personal therapy provided personal and social adjustment through management of affect dysregulation, which was considered to precede a relapse. It also offered psycho education about nature and treatment of schizophrenia, supportive therapy, a phased plan for resuming expected roles and skills training techniques from SST. The overall package was delivered in a phased manner depending on the phase the individual was at postdischarge. In another study of predictors of cognitive stress appraisal, the findings supported that interventions targeted to reduce stigma should aim at variables such as rejection sensitivity, self-belief that people with mental illness are of low regard and cognitive appraisal of perceiving stigma related harm to be more than one’s coping resources.^[27] The authors suggest addressing these variables, as they predominantly afflicted individuals. In contrast, Shih^[28] explains that traditional literature focused more on how stigma negatively impacted individuals, whereas there are several examples of individuals with a stigmatized identity overcoming this barrier and prospering in society. The author reviewed various psychological processes involved in such individuals and suggests that these positive qualities could be imbibed by individuals facing adverse stigmatizing identity. She also suggested that individuals viewed the process of overcoming stigma as empowering than an exhaustive process of coping with it. Less attention is paid to stigma intervention research concerning the subjective experiences of stigma

by the individual suffering from schizophrenia. It is thus the need of the hour to conceive and develop an integrated, individualized, tailor-made therapy for PWS. Just as specific type of individual therapies exist, such as Interpersonal and Social Rhythms Therapy for bipolar disorders, one can envisage the need for similar therapy for people with schizophrenia, though the needs of individuals with these two conditions may differ considerably.

The family as a partner

Stigma and discrimination of a PWS exists within the family too. They manifest in various ways, such as exclusion from decision making and shunning them from important matters, labeling by other members of the family and being perceived as the reason for reducing the chances of their siblings getting married. In India, the family is an important source of support and is closely united,^[29] and as a result, the caregivers of people suffering from schizophrenia are usually the family members themselves. However, the stigma of having one member in the family with schizophrenia extends to the other family members, and is termed as “courtesy stigma.”^[30] In a study on needs assessment, it was found that caregivers of people with schizophrenia needed more awareness about schizophrenia, required inputs on rehabilitation,^[31,32] wanted help on managing difficult behavior and information about the socio-vocational aspects of the person with the illness.^[33] Another study asked primary caregivers what outcomes or benefits they expected from treatment.^[34] Symptom control, reduced side-effects, and cognitive ability were clinical domains that were mentioned, whereas among the functional domains, activity, social functioning, education/employment, independent functioning were the outcomes expected by the primary caregivers. Barring a few select hospitals, institutes and rehabilitation services that provide the much needed inputs to the families in India, most clinicians, due to lack of time, may not routinely use the family psycho education modules in their clinical practice, despite the well-documented efficacy of these programs.^[35,36] There is thus a need in India, for more care providers who are willing to offer these services to these families, a need to train more mental health professionals on dealing with families, and now in the era of the internet it is essential to have dedicated websites for families or caregivers of people with schizophrenia which are interesting, possibly interactive and most importantly informative.

Involving the family member as a partner in the process of recovery is probably a key step in the overall recovery of an individual with schizophrenia and in reducing the impact of stigma on the family member. The WHO recommends empowering them with a sense of control, authority and power along with the consumer.^[19] One way of achieving this is to educate and train them about schizophrenia and the treatment and services that are available. The

families themselves can form caregiver groups, create a strong, local, self-help advocacy and garner support from various organizations, for example, NGOs working in the sector. In Slovakia, the tetralogue model involved four stakeholders to reduce stigma and discrimination and to integrate people with mental illness back to society: The consumers, their relatives, the professionals and the public. Of these four groups, the first step was to involve the families and form associations. This led to further trialogue with professionals and later included the public.^[37] With this approach it was observed that professionals found their task smoother when the responsibility of caring for the PWS was shared, than when it was delivered in the usual approach of the therapist as the sole prescriber of medicines. A successful example from India is The Association for the Mentally Disabled (AMEND), an NGO that was initiated in 1992. Through its advocacy activities families are provided awareness about mental illness and its treatment, and families are backed by education and empowerment.^[38] A spinoff initiative of AMEND is Action for Mental Illness (ACMI), which is now involved in litigations representing the rights of the mentally ill in addition to its advocacy activities. ACMI campaigns for regional and national laws to be made uniform with the United Nations Convention on the Rights of Persons with Disabilities and also holds legal aid workshops for families of people with mental and psychosocial disabilities. This is in consonance with the “right to exercise legal capacity and the right to personal autonomy and safety of people with mental illness.”^[39] For example, individuals could consult their caregivers (usually the family members) and decide the place and type of treatment delivered to them, or individuals and their families arrange for practices and safety measures to prohibit restraint and treatment without free and informed consent.^[40] The successful example of these NGO’s highlights the need for families and users to connect themselves with NGO’s for a fruitful partnership of education, empowerment and privilege.

Modifying the facet of service providers

Stigma is probably linked to service providers themselves, especially large mental hospitals, big tertiary care centers and institutes offering specialist care for the mentally ill for years on end. Service providers may unintentionally create a barrier for themselves and to others from the community seeking help, despite the good intention and credibility of providing specialist services to the community. A study in Hong Kong alluded to this concern and examined the personal experience and structural framework of treatment-related stigma among Chinese patients with schizophrenia. The structural stigma refers to the stigmatizing experiences of patients even if the service providers do not have a conscious motive to discriminate. In this study, 44% of patients with schizophrenia expressed unfavorable experiences during hospitalization, such as, negative staff attitudes, overuse of physical/chemical

restraints, insufficient information/grievance systems, and restricted rights.^[41] An integrated model of community-based care for vulnerable persons with severe mental disorders, INCENSE program [Figure 2], is being conducted in two mental hospitals in India - the Lokopriya Gopinath Bordoloi Regional Institute of Mental Health at Tezpur and Regional Mental Hospital, Pune. This program is in its pilot phase and is designed to respond to the challenges in developing a range of services for individuals with severe mental illness and to overcome the entry and exit barriers that may exist.^[42] The aims and objectives of the program are outlined in Figure 2. The study could also be regarded as an initiative towards testing the feasibility of the movement of deinstitutionalization. This step is a positive move to address complex needs of persons with severe mental illness, though India is still a long way away from initiating this process since community-based services are still sparse. Several activities should predate the initiation of this process.^[43]

The WHO advocates that community mental health services are associated with high levels of user acceptability, reduced stigma and lesser likelihood of human rights violation.^[43] An evaluation of a community-based rehabilitation program for chronic schizophrenia was conducted in Barwani district of Madhya Pradesh in India, an impoverished region with scant resources.^[44] The community-based rehabilitation program was remarkably better in reducing disability compared to standard out-patient care and demonstrated similar reductions in longitudinal follow-up.^[45] This model inspired an ongoing randomized-controlled trial (COPSI trial) comparing community-based rehabilitation model with standard out-patient care.^[46] The collaborative community-based care was modestly more effective than standard out-patient care and was recommended as an initial service especially in rural settings that are scarce in resources.^[47] Nested within the COPSI trial was another mixed-method study that appraised the experiences of stigma and discrimination faced by people with schizophrenia. The preliminary qualitative analyses of

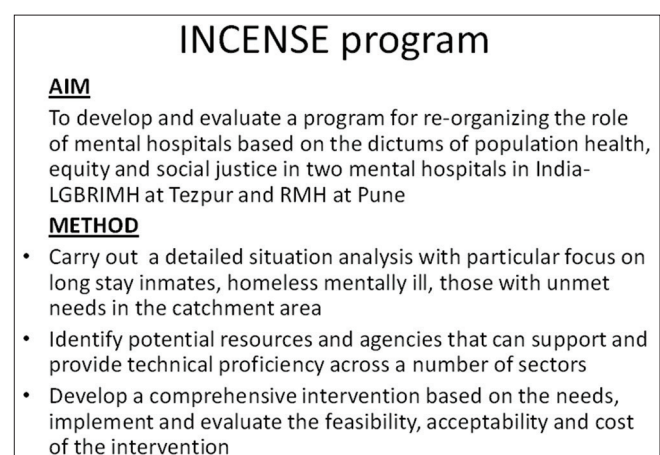


Figure 2: Aim and objective of the INCENSE program

narratives conveyed promising developments with regard to the community-based rehabilitation.^[48,49] Service providers need to give a thought about addressing functioning of patients apart from providing usual care. Catering to finer aspects of work functioning, addressing cognitive deficits, providing alternate solutions to jobs and a greater need to collaborate with employment agencies were some of the specific concerns that featured in our analyses. Well established interventions are available for various other aspects of functioning such as, social skills training, social cognitive training, cognitive remediation and cognitive behavior therapy.^[50] Service providers should impart interventions based on the socio-cultural and individual needs, though many such interventions may be available at one's disposal. To address these concerns, Balaji *et al.* (2012) conducted in-depth analyses of what outcomes were desired by PWS and their primary caregivers. This study was part of the formative phase of the COPSI trial,^[46] which was alluded to earlier. The study concluded that interventions must target functional outcomes such as employment, education, social functioning, fulfilling ones roles, self care and managing their illness without medication, besides focusing on clinical outcomes alone.

Mental health professionals to envisage beyond hospital-based care

Mental health professionals must take the lead in mitigating stigma by thinking beyond routine hospital-based care and treatment using medications alone. There are several reasons why psychiatrists must take leadership in allaying stigma. Iatrogenic stigma^[51] is the term used to describe how mental health professionals themselves (specifically psychiatrists) can account for stigma. Psychiatrists need to pay attention to the casual use of diagnostic labels when communicating with nonprofessionals. Within the discipline it is necessary to use diagnostic labels for our own communication and understanding. Other health professionals may get prejudiced when they hear about the label and their decisions may be biased by prejudicial attitudes. Not using labels at all is not the solution to stop stigmatization, instead we need to exercise caution in our daily use of diagnostic labels by understanding the power of diagnosis and the process of labeling. The propensity of some medicines to cause certain side-effects (especially extra-pyramidal symptoms) can act as a "marker" for the illness. These side-effects may be regarded as a type of structural stigma.^[41] Some governments in LAMIC support the use of such medication as they are inexpensive. Instead, the professional body should pledge for availability of better and safer drugs such as, atypical anti-psychotics and selective serotonin reuptake inhibitors at all primary health care levels and possibly prevent unnecessary side-effects and stigmatization through side-effects. Invariably, the use of typical anti-psychotics is probably inevitable if symptom reduction is the prime requisite, at the cost of unwanted side-effects.

As discussed in the section earlier, PWS have multiple issues that need to be addressed, and often due to lack of time and human resources they do not get the attention, leaving them unsatisfied with the treatment. Mental health professionals need to actively collaborate with rehabilitation centers and facilities offering care that may improve functioning of patients. The treatment should also address functioning of PWS besides clinical outcome alone. It is understandable, that in a busy clinic, due to scarcity of human resources a practitioner may just have time to prescribe and dispense medication, in which case he can refer such persons who require additional inputs to improve functioning to centers where rehabilitation facilities are available, if it is not available at the same center. Psychosocial rehabilitation and collaborations with other support systems are components of a service user-driven rehabilitation plan and improves a service user's ability to live independently in the community, which is in adherence to Article 25 of the Convention on the Rights of Persons with Disabilities (CRPD) – "right to enjoyment of the highest attainable standards of physical and mental health."^[39,40]

Inadequate access to basic mental health services was one of the concerns among the common human rights violations experienced by service users in the global report published in Lancet.^[52] As is the case in most LAMIC, the problem of accessibility and affordability of mental health care has received little consideration,^[53] that consumers are forced to visit large psychiatric institutes^[54] which are often associated with gross human rights violation.^[52] While planning services for the mentally ill, mental health professionals should ensure sufficient workforce (psychiatrists, psychologists, psychiatric social workers, psychiatric nurses and primary care doctors) to provide services to the vast number of people who are still untreated in the community. Enough evidence is available to train primary care doctors in simple skills of detection and treatment of common psychiatric conditions; and these conditions are amenable to medical and psychological intervention.^[46,55-59] On that account mental health professionals should devote a significant proportion of their time in training, supervision and monitoring of human resources, apart from clinical care and/or research.

Nongovernmental organizations: A crucial link for a basic model of care

The NGO sector is comparable to that of a linchpin that binds other stakeholders - a link between the service provider and the consumers (with their families). The successful tetralogue model of Slovenia consisted of four stakeholders, namely the consumers, their relatives, mental health professionals and the public. Even this model could not have reached out to the public without the formation of their own self-help group.^[37] That is precisely the role we suggest to NGO's: Providing support through empowerment, education and privilege. We thus

propose that for successful integration of a PWS back to society one must have the support of their family, the service provider (or mental health professional) and a link to an NGO. We propose that a PWS should be a part of this basic sub-unit/sub-system [Figure 3] for better recovery and integration. Based on our study aim, we identify key domains where the NGO sector can provide support. These areas are not restricted to, but include, (a) rehabilitation services, including day care services and half way homes, (b) promote awareness about mental illness to the families and the public at large, (c) collaborate with employment agencies and provide supported employment, (d) provide legal information and support the rights of the mentally ill, and (e) collaborate with various other agencies/stakeholders such as media, policy makers and planners, the ministry and the public at large. However, this model is likely to succeed in situations where NGO's are established and where partnerships between the stakeholders are evolving.

As far as awareness is concerned NGO's can go a long way in promoting awareness about mental illnesses. They could target various groups and provide appropriate messages. For example, they could arrange for talks about various aspects of mental illness to the family members, they could organize an awareness program for the general public, talk to the media about a key topic on mental illness and so on. The Schizophrenia Research Foundation, Chennai, is an NGO initiating awareness campaigns related to schizophrenia, through various types of mass media programs. Information about their efforts with the mass media in providing awareness about mental illness is available on their website (www.scarfindia.org). Article eight of the CRPD asserts that awareness campaigns are necessary to promote a greater understanding of the capability, talent, and accomplishment of people with disability.^[54] Such interventions are markedly limited in India and other LAMIC and assessments about their effectiveness are negligible.^[15] In 2008, the Indian Law Society in Pune, India, in partnership with WHO, introduced the International Diploma in Mental Health Law and Human Rights and a PhD program in Human Rights

Law and Policy in collaboration with VU University, Amsterdam, Netherlands (<http://cmhlp.org/>). This is a successfully growing program that prepares national stakeholders (and the general public) with the competence needed to support human rights and mobilize remedial measures at the national level. Examples of successful initiatives by Indian NGO's with regards to legislation and rights of the mentally ill include the efforts of ACMI. ACMI succeeded in obtaining income tax rebate for persons with mental illness and their family in association with other NGOs in the country.^[38] A recent initiative of ACMI is their lobbying for the existing mental health laws in India to be uniform with the CRPD, besides conducting regular legal literacy forums for families of people with psychosocial disabilities.

Table 1 summarizes the target groups identified based on the analyses and lists possible interventions directed to these groups. A few other groups were ascertained besides these target groups, for example, policy makers and planners, the media, the ministry, the health workers and of course the public at large. A detailed discussion of these target groups were not considered here as the themes were based predominantly on subjective experiences of PWS and these themes did not recur as frequently as the others described here. However, a detailed account of the other groups and the action recommended for those groups is available elsewhere.^[60] An analytical web was generated [Figure 1] that appraised all the stakeholders and illustrated the complex synergy that needs to prevail between them. We speculate that a synchronous collaboration is essential for a purposeful and compelling measure to tranquilize stigma. In this complex web of stakeholders/target groups, we incorporated the basic model (consisting of the PWS, family members, mental health professional and the NGO) as a prerequisite.

Conclusion

PWS continue to experience a wide range of stigma and discriminatory experiences in the community in India. We acknowledged their experiences, validated key stakeholders and identified specific goals as anti-stigma interventions. Along these lines, empowering PWS (user), engendering partnership between PWS and their family (carer) thereby reinforcing the user-carer relationship, identifying lacunae in the functioning of service providers, bringing in purposeful care perspective among mental health professionals and entrusting NGO's with greater responsibilities were the primary anti-stigma interventions identified.

The principal strength of the study is that it considered subjective stigma experiences and formulated implications for interventions. Forasmuch direct opinions and views of PWS are examined in devising anti-stigma interventions. Twenty percent of participants of our sample did not receive any type of formal education and these illiterate participants were largely from the rural belt.^[16] None of

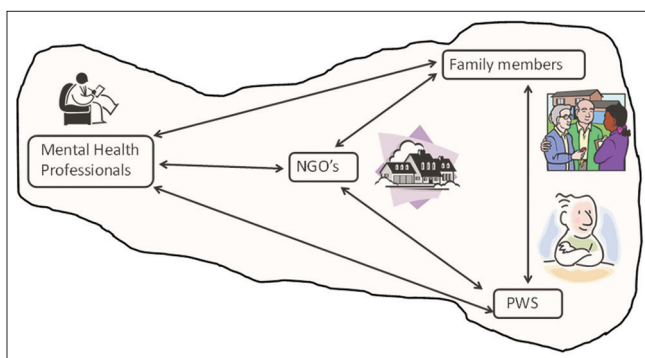


Figure 3: Basic stakeholder unit recommended for successful integration of persons with schizophrenia back into society. Note the key position of the nongovernmental organization

them were involved in any type of advocacy activities pertinent to mental health or human rights issues, and thus their views were unbiased expressions of their experiences of stigma in the community they lived. We hope to prevent human rights violations among PWS considering that explicit opinions of PWS are taken to devise anti-stigma interventions. Stigma and discriminatory experiences in the community and the denial of social, political and economic rights in itself is a rights violation, and accordingly the study discusses rights issues consistent with the CRPD and the quality rights toolkit of the WHO. Other key results that have tremendous implications for intervention is the opportunity for devising a tailor made individual therapy for PWS and in bringing forth the basic model as a prerequisite for successful reintegration of PWS back into society. The study pushes for specific anti-stigma actions for the key stakeholders and recognizes various other stakeholder parties that may have a substantial influence as well, although the basic model gives priority to four of the stakeholders [Figure 3]. On the whole the study encourages advocacy in India, which could apply to other LAMIC countries.

A drawback to the study is that advocacy is yet to take off in India on a large-scale basis, and the mental health NGO sector too, is sparsely distributed in the country. Yet, the study makes promising remarks to inspire and kick-start the advocacy movement. The situation in rural provinces of India are different, as community models of care are not in place implying that the basic model may not really pertain to them and it is essential to target them as a different group. On the other hand, there is great promise for community-based rehabilitation models or community-based care for schizophrenia in the future.

The study pronounces that collaboration among the different stakeholders holds the key for successful advocacy. All concerned stakeholders need to work with others in harmony to develop successful partnerships. It is not surprising that planning anti-stigma interventions also addresses human rights violations. Accordingly, some of the anti-stigma strategies observed in our study, such as promoting awareness about mental illnesses, supporting better training of mental health professionals and improving treatment facilities, recommending rehabilitation for severe mental disorders, fostering the formation of self-help or support organizations for users and carers are also essential strategies to mitigate human rights violations. Consequently, anti-stigma interventions, promoting human rights, mental health literacy and advocacy are all inter-linked and enmeshed with each other, that any one intervention on its own is likely to affect the other. There may have been many more human rights issues in keeping with the CRPD which may not have relevance to our study and hence were not deliberated.

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Conflicts of interest

There are no conflicts of interest.

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