

# Challenges and Barrier to Community Rehabilitation of patients after a long-term stay in a Psychiatric Hospital in Northern India

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## ABSTRACT

For patients suffering from mental illnesses, an access to mental health care facilities remains a challenge. But in today's scenario, it has become even more difficult to de-institutionalize patients admitted in these health care facilities for a long period. The mental health care providers face multiple challenges in mobilizing the community to help rehabilitate these patients. Barriers in discharging these patients are very complex and involve many social factors. Patients who are suffering from mental illnesses are not given the needed care and do not get the opportunity to become the part of the 'mainstream' society. Now it's high time that we address the impediments in rehabilitation of these patients. This requires a liaison between the medical sector and other sectors like the social and welfare sector.

**Keywords:** patient with mental illness, Community rehabilitation, long-term stay of patients with mental illness, social welfare sector, state mental hospital.

## INTRODUCTION

A number of patients with mental illnesses remain hospitalized for years in psychiatric facilities of our country.<sup>[1]</sup> One such hospital in northern part of India is currently home to several such patients. Only a few of these patients truly require this long stay in the institution due to resistant illness that does not respond to treatment.<sup>[2]</sup>

Majority of the patients continue to remain confined in the institute as they do not have any alternative. NIMHANS/National Commission for Women (NCW) in the year 2016 suggested that these patients after being treated should not be kept in restricted environment and should be either handed over to families or be sent to less restrictive institutes like halfway homes.<sup>[3]</sup>

Rehabilitation of these persons suffering from mental illnesses is currently considered the duty of state run mental health care institutes, which are functioning as part of the health sector whereas practically, the role of health sector is minimal, and the social and welfare sector needs to step in and take up greater responsibility as the programs regarding community rehabilitation and reintegration of persons with mental illness in the society is the mandate of the Department of Social Justice and Empowerment.

## **BARRIERS AND CHALLENGES TO COMMUNITY REHABILITATION OF PATIENTS AFTER A LONG STAY IN ONE OF THE PSYCHIATRIC HOSPITAL RUN BY THE STATE**

The institute faces numerous issues when it tries to rehabilitate its patients. There are multiple social, financial and logistical barriers that prevent the discharge of the patients immediately after their symptoms resolve and unnecessarily prolong their stay in the institute. Here we discuss some of the commonly faced problems.

### **A) Social Factors:**

I. Lack of knowledge about mental illnesses: The public is generally unaware of the symptoms of mental disorders and the patients are usually taken to faith healers for years before a doctor is finally approached. By this time the patient's illness has flared up so much that treatment becomes difficult and disability increases. When these patients are finally admitted they take a long time to recover and residual symptoms persist making it difficult for them to function independently. This increases the caregiver's burden and the family often becomes reluctant to accept them back.

II. Stigma: The history of being treated as a patient in a psychiatric hospital is stigmatizing. The patient and his kin often face rejection from the society. A patient, who is discharged from a mental health institute after a very long stay, is often looked down upon. He/she may be considered dangerous by his/her relatives and neighbors, especially if the patient tends to get violent during the active phase of the illness. The family members too may turn into a laughingstock and be ousted from the society. This too makes family members reluctant to accept these patients back. There have been multiple incidents of family members abandoning the patients at the institute and never coming back to meet them.

### **B) Patient factors:**

I. Some patients are not able to give any information about their family and do not remember their address and phone numbers. These include patients who have been suffering from chronic psychiatric illnesses that have never been treated and end up in an autistic state or patients who have left their homes a long time back and are thus unable to recall any information.

II. There are patients that belong to faraway places and do not speak English, Hindi or any of the local languages making it difficult for them to communicate.

### **C) Legal and Policy related factors**

I. At times patients are admitted under reception order under the mental health care act 2017. Mostly the orders state that the patient is to be admitted in a Psychiatric hospital under section 102 of mental health care act, 2017 but there is no instruction for the family members. The family refuses to stay with the patient and refuses to take them back after they stabilize. At times the patients are brought by the police and no details of the family or place of residence is attached and it becomes very difficult for the hospital administration to trace the family. Thus, despite not requiring any indoor care the patients are forced to remain confined to the hospital.

II. Sometimes the hospital stay also gets prolonged as even if the patient's address and families are traced, they are unable to come to fetch the patient due to monetary reasons. Here, especially if the patient belongs to a faraway place, the hospital authority finds it difficult to re-unite the patient with the family.

III. All patients may not have skills to help them live alone and earn their own livelihood. The institute lacks the needed staff and equipment to teach these patients skills that can help them fend for themselves and they continue to remain dependent on others. The prolonged stay and the illness further increase their disability and more the time spent in the institute, the more lethargic the patients become.

IV. The only way to shift these patients to a less restrictive environment is to send them to institutions like halfway homes. The capacity of the state-run halfway homes is not enough to accommodate so many patients. Thus, these patients continue to remain in the hospital even though keeping them confined is a breach of their rights.

V. Lack of treatment options at doorsteps: As all the health care providers are not trained to handle psychiatric patients and only a small number of psychiatrists are serving in the state, the families often struggling with financial constraints, find it difficult to bring the patients for regular follow-ups to distant centers. These patients often remain in the active phase of the illness and due to this their disability increases further leading to a prolonged hospital stay when they are finally admitted.

## **DISCUSSION**

### **WHAT IS THE WAY OUT?**

Treating the symptoms of a patient suffering from mental illness may become meaningless if there is no way to rehabilitate him/her into the society. It is high time that these patients get an opportunity to become a part of the community and be allowed to contribute to the society. In our country, the care of patients with mental illnesses is mostly done by the family. All the needs of the patients like shelter, clothes, food, emotional needs, financial needs, medical care and rehabilitation are fulfilled by the family members.<sup>[4]</sup> There is involvement of family members in every decision regarding the patient's discharge from a mental hospital, regular follow up with mental health professional, adherence to medicine, decisions regarding educating them, searching for employment, etc. In case there is no family, or if the family is not willing to take care of the patient all these decisions need to be taken by other agencies, such as the government or some non-government organizations, to facilitate community rehabilitation and reintegration of patients with mental illness. So far, only the medical

sector has been dealing with these patients directly and hence the responsibility of rehabilitating these patients has been falling on it. It is not possible for the medical department alone to achieve this and there is a need for multiple sectors to come together to achieve this feat.

### **ROLE OF THE MEDICAL SECTOR**

I. Vocational Training: Apart from the treatment being provide at the hospitals, the medical sector should take steps to establish vocational training courses at the centers that admit the patients for long periods. The long stay at the hospital can be utilized by teaching skills that can later help the patient get jobs and earn money. The model used by jails can be followed where the inmates are sent out to work every day. The patients who are stuck in the hospital only because of financial reasons can benefit from this model as they can earn enough money in a few months to sustain themselves outside. Following the jail model the administration can consider establishing small scale industries in the campus where the patients can manufacture goods and later these can be sold in the market. The department can also come up with job opportunities inside the hospital campus where the services of the stable patients can be utilized, and they can be remunerated for these services.

II. The department should strengthen its centers and focus on training all medical practitioners in psychiatry. This can help in providing follow-up services close to the patients' homes and increase the chances of adherence and prevent re-hospitalizations and cut down the expenditure.<sup>[6]</sup>

III. Regular IEC activities should be organized to spread awareness about mental illnesses so that patients receive early treatment and care, and disability can be prevented.

IV. The department should appoint psychiatric social workers to deal with social issues faced by these patients. They can efficiently manage family and social issues that the patients face and can also help in the rehabilitation of the patients.

They can search for appropriate job opportunities for these patients and can also help in psychoeducation of the community.

### **ROLE OF THE SOCIAL AND JUSTICE WELFARE SECTOR: -**

I. As per MHCA 2017, it is the duty of the social and welfare sector to nominate a representative to take important decisions for a person with mental illness for a family member or nominated representative is not available.

II. It is in the hands of this department to set up more halfway homes in the state to cater to the patients with mental illnesses who do not have any family support and cannot earn for themselves.

III. Social security benefit like disability pension/ sahara yojna will help in the community rehabilitation of these patients, as family member are often not able to bear the financial burden of the patient's treatment.<sup>[5]</sup> The sector can utilize resources for comprehensive post discharge care of these patients to avoid re-hospitalization.

IV. Incentives can be considered for families that accept these patients and take good care of them.

V. The department can help in monitoring the home environment of these patients and protect the patients from falling prey to domestic violence and abuse.

### **ROLE OF NON-GOVERNMENTAL ORGANIZATIONS**

I. As there is only a small number of halfway homes in the state and their capacity is not enough to accommodate all the patients that need their services, there is need to come up with new institutes with the help of various non-government organizations.

II. The different non-government organizations can also contribute to provide vocational training to the patients that can help them learn skills which later help them earn a living.

III. They can help in generating job opportunities for these patients and employ them with their NGOs.

### **COMMUNITY PARTICIPATION IN REHABILITATION**

Non acceptance by the community is a major barrier and challenge in rehabilitation of the patients staying for a long time in a mental hospital. The stigma attached and all the misconceptions related to mental illnesses need to be allayed by awareness programs using IEC, social media, newspapers, TV, internet, etc. The local bodies like panchayats and municipalities can help organize campaigns at community centers and educational institutions to spread awareness. Once the perception of the community is changed, the community can help in early identification and treatment of individuals with mental illnesses and can also help in their rehabilitation. They can help generate employment for these patients and create a pressure on family members to accept them back.

### **LAW AND JUSTICE**

The department of law and justice can play a major role in the rehabilitation of patients suffering from mental illnesses who have living in hospitals for a long period of time.

### **LAW ABOUT LONG STAY PATIENTS**

MHCA 2017 and RPWD clearly defined the right of persons with mental illness and responsibility of the government toward these patients. MHCA clarifies that a person should not stay in mental hospitals due to lack of other alternatives.<sup>[7,8]</sup>

A) Clause 18 of MHCA clarifies that admission in a mental hospital should be the last option that should be exercised only when community-based treatment has been tried and despite this there is no improvement in patient's mental health.

B) Clause 19 of MHCA gives the right to live in community setting and not to be in a mental hospital just because he/ she has no family or the family is not willing to accept him/ her".

C) If a person with mental illness is abandoned by the family members or

society, the state government should provide legal aid and facilitate to exercise his right to live in the community setting with family. Free legal cell advisory should be available to the patients so that they can fight for their rights without facing any financial crisis. Simultaneously, establishment of institutes with less restrictive environment like halfway homes, old age homes, nari niketan etc should be done by the state government.

In the last few years, the judicial system has shaken off the inertia and has started working in the direction of restructuring/reforming of mental hospitals.<sup>[9]</sup>

The need of the hour is to come up with new laws that suggest punitive measures for people who abandon family members suffering from mental illnesses. Punitive measures can include fines, confiscation of property and even imprisonment. Confiscation of the patient's share of the property if he/ she is abandoned by family members may prove effective in decreasing cases of abandonment. The family can also be made to pay for the upkeep of the patient in case they refuse to keep them at home and the patient must be shifted into a halfway home or ashram.

The department of police plays a pivotal role in identifying and bringing persons suffering with mental illness into the treatment loop. Chapter 13 of MHCA states that it is the duty of every police officer to protect persons suffering from mental illnesses. It is the duty of the police to bring the patients who are found wandering, to the police station and to take them back to their residence if they are not found to require any indoor care.

It can also play a pivotal role in addressing complaints of domestic abuse of these patients.

### **INTERDEPARTMENT COORDINATION**

Experts have noticed that care of patients gets hampered due to rigid boundaries

among the different departments.<sup>[9]</sup> Continuous intensive cooperation between different departments is advocated to bring about rehabilitation of patients suffering from mental illnesses.<sup>[10]</sup> The MHCA and RPWD has clearly specified that a representative of social justice and welfare department should be one of the members of the respective state mental health authority<sup>[11]</sup> and there should be a close co-operation between the health and social justice and welfare departments to take care of the patients with mental illnesses. The social justice and welfare department should nominate a representative for patients with poor social support, to coordinate their community rehabilitation.

It is expected that long stay patients be rehabilitated in halfway homes by social justice welfare department and simultaneously the patients require continuous clinical care by mental health professionals. This coordination between the two departments should be strengthened for better care of patients which will help in community rehabilitation of persons suffering from mental illnesses.

District Mental Health Program should be enforced by the state government seriously and regular training sessions should be conducted for the general practitioners and other health care providers because the medical teams in the vicinity can provide better and regular care in government run halfway homes and long stay homes in each district.

### **HOW TO PREVENT NEW LONG STAY ADMISSIONS?**

Homeless persons with mental illnesses should be helped by social justice and welfare department by appointing a nominative representative who will help in rehabilitation after discharge from mental hospital as MHCA 2017 precludes long term hospitalization.<sup>[8]</sup>

Emphasis should be laid on the social justice and welfare department working with the state government and other agencies to expand the 'Deendyal Disabled

Rehabilitation' scheme by constructing at least one halfway home in each district. Community education about stigma related to mental illness is a must, especially in areas where people are superstitious, and family members are reluctant to seek help from mental health professionals and prefer to take the patients to faith healers. Family members need to be counseled regarding mental illnesses so that they can accept the patients after treatment in mental hospitals. They also need to be made aware of the role of regular treatment and follow-up in preventing relapse and reduces the need for re-hospitalization. These psycho-education activities can be carried out at hospitals or through mass media, nukar- nataks and other IEC activities. Female patients who are stable on treatment and are capable of functioning independently, can be rehabilitated through the 'Swadhar Greh' scheme, that provides social and economic security. <sup>[12]</sup>

## CONCLUSION

MHCA 2017, clearly ensures that it is the right of a person with mental illness to live in community with dignity and without any discrimination. Family members of patients need to be counseled about the fact that long admissions in mental hospital is not the only option for treatment. Emotional support from family members, care and support from other agencies like NGOs can help in community rehabilitation of these patients. Creation of more halfway homes, old age homes and Nari Niketans can provide better opportunities and support for community living of patients. Social sector needs to put more effort to liaison with health sector to provide better care for patients. There is a need to provide vocational training and generate job opportunities for these patients.

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