Case Series

Lives without Roots: Institutionalized Homeless Women with Chronic Mental Illness

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ABSTRACT

The spiral phenomenon of homelessness and mental ill-health are major growing epidemic in both developed and developing countries. Viewing from a socio-economic-political dimension, homelessness and mental ill-health cause detrimental effects on the individuals' lives as well as the nation-building process. The condition of women seems to be complex, as the gender perspectives are often described in terms of patriarchy and powerlessness. The bi-directionality of mental illness and homelessness creates a vicious cycle, and many women seem to end up in shelter care homes. The scenario of homeless women with chronic mental illness reflects the lack of community-based rehabilitation efforts and gender-sensitive policy level initiatives.

Key words: *Chronic mental illness, homelessness, institutionalization*

INTRODUCTION

Home is regarded as a meaningful concept which is enriched with the ideas of love, care, affection, and security. Globally, the number of the homeless population is estimated to be between 100 million to 1 billion.[1] Homelessness and mental illness are considered to be public health issues of vital concern. The Universal Declaration of Human Rights has stressed the importance of housing and health needs of a person.[2] In India, *homeless people* have been defined as those who do not reside in census houses; a *census house* is defined as a structure with a roof.[3] There are 1.8 million homeless people in India.[4] It is estimated that 20–25% of a nation's homeless population suffers from some form of severe and persistent mental illness.[5]

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Homelessness and mental illness are inextricably linked, and each contributes to the existence of the other. It is a bidirectional phenomenon, and it forces the victims to be in a vicious circle from which an escape seems to be very difficult. The composition of the homeless population is diverse, and it constitutes the wandering population, people residing in streets, those living in unsuitable and unstable conditions, and also the institutionalized population.

In mental health settings, some clients are forced to undergo long-term psychiatric hospitalization in closed wards due to financial issues, familial rejection, stigma, and discrimination; reintegrating them back to

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home was always a big challenge for the mental health professionals. Due to the lack of community-based rehabilitation (CBR) facilities, most of these patients finally end up in governmental or non-governmental shelter care homes, where the institutional setup caters to their basic needs. There is a clear-cut gender difference in bringing the patient back to the home/community:[6] In Indian scenario, a man is always treated as an asset wherein families try to accommodate men even though with the difficulties, and the wife or parents will act as a source of support to them. However, for the women, the situation is entirely different. The widow is abandoned; the divorced one is consistently blamed; the single one is frequently questioned about the illness; and the married women are always shuttled between the family of origin and the family of procreation. A study conducted by the Schizophrenia Research Foundation, Chennai had highlighted the condition of separated/divorced mentally ill women and the hardships encountered by them throughout the life. The study found that most of the separated women stayed in their parental homes and care was provided by their aging parents; out of 75 mentally ill women, legal separation had occurred only in 16 cases.[7]

Women's mental health is considered to be the least prioritized subject matter in many countries.[8] The gender stereotypes in patriarchal Indian society bounded with discriminations, restrictions, and instructions toward women, further worsened the condition of women. Women's mental health is strongly associated with their status in society; it benefits from equality and suffers from discrimination.[9]

HIDDEN HOMELESSNESS AND WOMEN'S SCENARIO

In a country like India, it is not acceptable as a social norm for women to wander around the streets. Hence, the homeless women are invisible, and in case of those who with mental illness had wandered for a period, the family rarely accept them back to the home, and after psychiatric hospitalization, they usually end up being isolated by family and significant others. Women of this nature are placed in non-psychiatric shelter care homes and are institutionalized in different settings for the rest of their lives.

GENDER CONSIDERATIONS IN MENTAL ILL HEALTH AND AFTERCARE

A range of studies indicates that women are disproportionately affected by mental health problems in comparison to men and that their vulnerability to mental illness is closely associated with biological factors, marital status, education, work, and roles in society.[10,11] While all homeless women face multiple forms of violence, abuse, and discrimination, within this, women with mental illness are regarded as one of the most vulnerable groups in this regard.[12] Factors like productivity (less income/job opportunity for women), legislation regarding house ownership, social sanction for remarriage of spouses of mentally ill women, drug compliance issues, and stigma make women more vulnerable to homelessness. Women have been facing denial of economic resources, lack of education and legal and health services, poor physical and mental nurturance, exhaustion from overwork, and abuse of all forms across their lifespan. The stress level associated with the gender role of women is high in comparison with the male gender.[13,14]

There are gender differences in the acceptance and owing of the responsibility of aftercare by the families. Women are more likely to experience rejection, stigmatization, denial of care, and poor access to appropriate healthcare facilities. The impact of mental illness also holds gender bias. women are required to be the primary carers if their husbands are mentally ill; it was their own families that were responsible for women's care if they were to become ill.[6] This scenario often leads to homelessness. Many women with chronic mental illness stay outside treatment settings as a result of unequipped mental health settings which fail to provide long-term care facilities and CBR. Factors such as poverty, deprivation, illiteracy, stigma, lack of community resources, domestic violence, family rejection, abandonment, and death of primary caregivers lead to homelessness in women with mental illness.[4,6]

Homelessness and mental illness cause a lot of distress when experienced independently, and in combination, they can make devastating results.[4] Mental illness is one of the main factors for homelessness among women. The women with chronic mental illness reach governmental or non-governmental shelter care homes due to various psychosocial factors and the social support from the familial level get gradually weak. Also, some women become homeless due to diverse reasons and then are taken under reception order to a mental health setting and finally placed in the shelter care homes. The struggle of women seems to be high, and the suffering of this segment is underrepresented both in research and policy level initiatives. The current research explores complex psychosocial circumstances leading to homelessness among women with chronic mental illness placed in shelter care homes.

SETTING, METHOD, AND ETHICAL CLEARANCE

The study received ethical clearance from the

Institutional Ethics Committee, Behavioural Science Division, National Institute of Mental Health and Neuro Sciences, Bengaluru. By utilizing case study method, the effort has been made to explore the circumstances wherein women with chronic mental illness turned in to the verge of homelessness and the conditions which resulted in the loss of familial support and engagement in their life.

CASE STUDIES

Case 1

Mrs K, 37-year-old married lady, a resident of Karnataka, educated up to Pre University Course with a history of working as a Junior Assistant, diagnosed with bipolar affective disorder, has been on treatment for 3 years. The patient had undergone severe psychosocial stressors in the form of the husband's extramarital affair and domestic violence issues. The client, after being separated from her husband, was living alone in a rented house. After her mother's death, she never received any support from her siblings. Due to repeated psychosocial stressors, medication compliance became an issue, and her symptoms got exacerbated which created a lot of stigma and discrimination in the community. A distant relative got her admitted to a tertiary psychiatry care closed ward for better inpatient care. Once she recovered from the illness, the multidisciplinary team made repeated efforts to reintegrate the client back to the family. Both the family of origin and procreation were not willing to take up the responsibility of taking care of the client in view of stigma and financial burden. Later, she was placed in a government shelter care home which provides care and protection to women in distress. She has currently completed 3 years in the shelter care home, and none of her family members ever visited her in this period. Her illness is in remission, she is on regular maintenance medications and is still living with a hope that family members will come and take her back.

Case 2

Mrs P, a 54-year-old woman, widow, belongs to the poor socio-economic background of rural Karnataka. She was brought to NIMHANS by her daughter, in view of wandering behavior. Reportedly, the client stayed alone in the village, isolated from the mainstream society. She has been diagnosed with paranoid schizophrenia. She was admitted to the closed ward in view of financial difficulties and the inability of the daughter to take care of the client due to poor support from her husband and in-laws. After around 3 months of treatment with an antipsychotic at a tertiary care hospital, the client was recovered enough to be placed in the community along with her family. Client's daughter expressed her inability to take care of the responsibility due to financial difficulties, lack of support from her family of procreation, the absence of other siblings to take care of the client, lack of social support from relatives, and significant stigma in the community. Due to the absence of family support, after the multiple collateral contacts and networking with the organizations, the client has been placed in a non-governmental shelter care home. Over the last 1 year, she has been living with the hope that her daughter will come and take her back home.

Case 3

Ms S, a 32-year-old, unmarried lady, who had studied up to Pre University Course and belongs to the lower socio-economic status, from rural Karnataka, has paranoid schizophrenia. She has been on treatment for 6 years and has also had closed ward admissions multiple times in the past due to symptoms exacerbation as a result of non-compliance to medications. She had undergone significant psychosocial stressors from the childhood, in the form of domestic violence and unstable living conditions. After the onset of the psychiatric problem, the family abandoned the client in the psychiatric ward, and currently there is no contact between the family and the client. Multiple placements in non-governmental organizations from the multidisciplinary team were unsuccessful, primarily due to administrative issues with regard to keeping the client with mental illness in non-psychiatric residential care, absconding tendency, and her difficulty in adjusting with new environments. She was sent back to the tertiary hospital from these organizations, and she stayed in a closed ward for a long duration due to lack of rehabilitation options in the community. The client is currently placed in a government shelter care home in Bengaluru. She has recovered from her illness and is currently coming to OPD for regular follow up. In the present scenario, even though she is in full remission from the psychiatric illness, she has decided to stay in government destitute home as she does not have a job and place to stay in the community. The client knows that nobody from the family would come and take her back home.

Case 4

Ms B, 23-year-old, unmarried woman, educated up to Pre University Course, belonging to lower socio-economic status from rural Karnataka, who had earlier worked as a tailor in a garment factory, got admitted along with her 20-year-old sister Ms P at a tertiary care psychiatric hospital. Both were brought by the police as per the reception order from the court of the Additional Civil Judge as they were wandering in the village, showing abusive and inappropriate behaviors toward the public. Seeing this, the villagers lodged a complaint at a local police station, and the sisters got admitted through

reception order. Ms B was diagnosed with psychosis NOS, and Ms P was a known case of intellectual developmental disorder and has been undergoing treatment for behavioral problems in the same hospital. Both the clients had undergone significant trauma, neglect, and abuse in the childhood. They had lost both the parents 13 years back and were raised by a maternal aunty. Losing parents in the childhood itself was the first traumatic life experience for them. Secondly, there had been persisted financial crisis in the family due to which Ms B needed to go for a job at a young age, and there was an incident of financial cheating by the house contractor which was one of the most stressful incidents for the client as she lost all her savings in that. The client developed psychiatric problems following this incident, and she stopped going for work. The support from other extended family members was very poor, and none of them was willing to take the clients back after they were adequately treated in the hospital. The cousin who accompanied the police officials at the time of admission refused to take them back. The neighbors and villagers also did not want the sisters to stay in their village as they were very abusive and assaultive towards them. The sisters were abandoned in the hospital. Multidisciplinary team members made several attempts to contact extended family members to reintegrate them to the community. Considering multiple factors – homelessness, inadequate primary and secondary social support, stigma, social ostracism and discrimination in the community, absence of mental health facilities in their place, and the lack of family members to supervise their medications and bring them for regular follow up – the clients were placed in a government home by the multidisciplinary team of the hospital. Both are eagerly waiting, thinking that their cousin would come and take them back to their home someday.

Case 5

Ms M, a 56-year-old woman, educated up to 10th standard, born in Kerala, brought up in Karnataka state and belonging to poor socio-economic status, is diagnosed with paranoid schizophrenia. She has been having psychiatric problems since 1997 and had received multiple closed ward admissions in the past at a tertiary care hospital. She has a widowed elderly mother and a sister who used to bring her for follow-up. Gradually, when the illness progressed, and symptoms started to get worse, the family started to detach from the client. Family members requested the consultation team for the long-term placement for the client, in view of significant financial difficulty and caregiver burden. For the last 12 years, no family member came to see her. She expressed her feeling and pain saying "*I am living only for meeting death.*"

PSYCHIATRIC SOCIAL WORK INTERVENTION-BACK TO HOME

Family support and having a healthy home environment are vital factors in the recovery journey of a mentally ill person. Losing that support and being forced to remain under a roof which does not have any emotional aspects a home brings to a person, is one of the hardest reality and the most painful experience for a client. In most of the cases, family members directly communicate to the consultation team about their inability to accommodate the patient due to stigma, discrimination, financial issues, and the death of the caregiver. Placing women in a shelter care home is the last option, and the strategies followed to send the patient back home are given in Figure 1 (Psychiatric Social Work Intervention strategies).

DISCUSSION

The above exploration of five case studies clearly indicates the complexity of the spiral phenomenon of mental illness and homelessness. The familial, individual, economic, societal, and cultural factors clearly contribute to this phenomenon. The extent of rejection and abandonment, the real hardships, the dearth of family support, and denial of rights are largely visible among these women with mental illness. Reintegration either with family or community becomes a challenging task for the service providers in the absence of structural and functional facilities for the implementation of community-based programs. There is a clear absence of governmental community-based psychiatric facilities, halfway homes, sheltered workshops, and transit home facilities, lack of income-generating employment

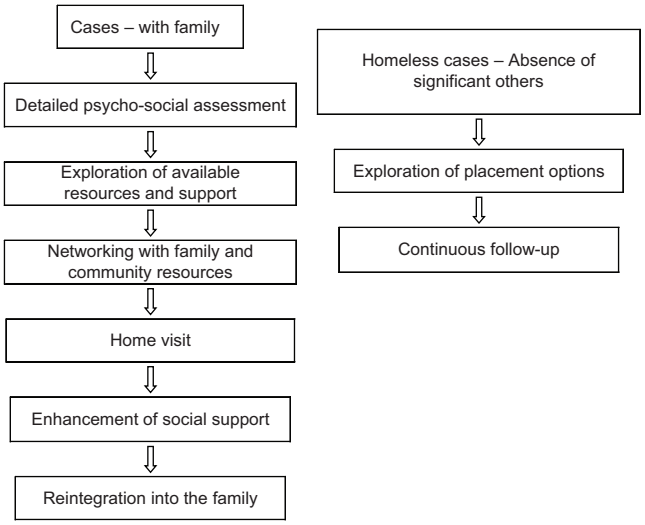

Figure 1: Psychiatric Social Work Intervention strategies

programs, housing, and policies to protect the rights of homeless mentally ill women in the country.[10] Women with mental illness undergo a repeated cycle of institutionalization either in the mental health setting or non-psychiatric shelter care homes. To break this cycle of institutionalization among these abandoned mentally ill women, there is a need for gender-sensitive care, programs and policy in caring for women with mental illness.

The society's notion about the mentally ill women as a figure who is a failure to bear the culturally tagged responsibilities of "typical women" again fastened the process of keeping them away from the home context and placing in the shelter care homes. Stigma and discrimination play a major role in this process of homelessness. With inadequate support and strong gender bias, the mentally ill women are rarely accepted into the family and are either abandoned or forced to fend for themselves, resulting in homelessness. Moreover, when women with mental illness leave the family and are missing from home for long duration secondary to wandering behavior due to mental illness, there are moral reasons to experience rejection from the family and community, especially in the Indian context.[15] The provision of rehabilitation for mentally ill women has been, and still is, one of the major challenges.[6] The National Commission for Women, India and NIMHANS collaborative study on addressing concerns of women admitted to psychiatric institutions in India based on 42 mental hospitals revealed that majority of the recovered women patients who are staying in hospitals for >5 years is either brought through reception order or are admitted by the family members in closed ward. These women are abandoned by the family by giving incorrect addresses, language barriers in tracing the families of patients belonging to other states, women with intellectual disability being unable to give their contact details, and family's reluctance to accept recovered patients by stating safety-related issues. To improve the quality of care and living conditions of women with mental illness, the National Commission for Women and NIMHANS collaborative study proposed various institutional, familial, and community level recommendations.[10]

At the institutional level-need having for gender-related care in hospital, making women to aware of their rights, discouraging long stay closed ward admissions to prevent abandonment, having stand protocol for homeless out of state women, and opening of midday homes for recovered women who need a place to stay and get training to start their life on their own. At the family level, to empower them providing accessible and free/subsidized treatment, access to government welfare, in case of gross neglect and abuse, a proactive role, and evaluation and monitoring by the National Commission for Women/State Commission for Women to protect the women with mental illness. At the community level, establishing women's respite/halfway home/rehabilitation facilities, daycare center, shelter for homes for women with mental health needs, training in income-generating skills-based activities in the community through NGOs and linking with Self Help Groups, employment schemes, and other welfare benefits.

THE WAY FORWARD

Considering the mental ill health scenario and the occurrence of homelessness resulting from mental illness, solution for this spiral phenomenon lies in awareness creation, stigma reduction, and application of the multi-sectoral approach to combat the human rights violation in mental health settings. Some interventions and strategies which would facilitate social inclusion and family/community engagement in patient care are listed below.[6]

Daycare centers

One of the important rehabilitation options is daycare centers which provide care and gender-sensitive vocational options to the patients and at the same time involve the family in the patient care. Daycare centers provide services which reduce the burden on the family without losing support for the patient. These models are replicable and can be managed by family members or trained volunteers.

Halfway homes

After psychiatric hospitalization, one has an opportunity to live in a setup which helps them to facilitate gradual reintegration with the family and community. The occurrence of homelessness and lack of family support can be better managed if a halfway home facility is provided to a patient, in a therapeutic community model. For homeless mentally ill women who are vulnerable to physical and sexual abuse, these homes function as safe shelters while also providing vocational training and initiating a process of integration with the family.[6]

Home-based rehabilitation

One of the important aspects of management is home-based care and initiation of rehabilitation efforts by empowering the family members. In the Indian context, there are lack of guidelines in this aspect. The mental health professional must facilitate intervention in this regard and educate the family members by advocating the success stories of families who well-managed patients at home environment irrespective of stigma and discrimination.

Community-based rehabilitation

CBR stresses on helping people with disabilities by establishing community-based programs for social integration, equalization of opportunities, and rehabilitation programs. CBR is widely accepted in view of the shortage of human resources and other related sources. The core components of CBR include the creation of a positive attitude toward people with disability and provision of education and training, long-term care facilities, income generation, and so on.

CONCLUSION

An attempt was made here to highlight some of the dilemmas and difficulties encountered by providing a glimpse into the lives of women with mental illness. There is an urgent need to redefine the lives and living situations of institutionalized abandoned, homeless women with mental illness. The facilitation of recovery starts from the central and integral essence of hope, which is possible only when society starts to accept and become open toward people with mental illness. Mostly, the core reason for family abandonment and rejection seems to be the presence of a high level of stigma and discrimination. Mental health professionals have a very responsible role in creating awareness across the communities and reduction of stigma, involving various stakeholders. There is also an alarming need to bring gender-sensitive policy level initiatives and effective community rehabilitation programs for bringing a positive change in the lives of homeless women with chronic mental illness.

Declaration of patient consent

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

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Conflicts of interest

There are no conflicts of interest.

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