Helping Families of Persons with Mental Illness: Role of Psychiatric Social Work

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Abstract

Families’ ability to adapt positively to a new situation is important to maintain a healthy balance in any difficult situation. It plays a major role in cure and recovery from mental illness. Studies reported that families with severe mental illness often have poor adaptation and functioning. The gross dysfunction in family functioning may be the cause and outcome of mental illness. Families often lack knowledge about the illness and illness management skills. Proper guidance and support from mental health professionals play a significant role in the success of treatment and recovery. The present article will discuss about the strategies for developing better acceptance, providing proper professional support and harvesting resources in the living community to help the families with mentally ill by giving a key focus on the role of Mental Health Social Work.

Keywords: family, mentally ill, adaptation skills, recovery, mental health social work

Introduction

The onset of mental illness in a family member is very traumatic and it is not very easy for people to accept the illness. People are more resistant in accepting mental illness than many other serious illnesses. Stigma, lack of awareness and other socio cultural factors attached to mental illness play a major role in understanding and interpreting mental illness. The onset of mental illness in a member results in a number of changes in the everyday functioning of each member and if the family members lack coping resources, it will result in multiple role dysfunctions. Practitioners should be able to provide services according the felt need of the family and observed by the professionals. Families should be supported for adapting to the difficult situation. Families’ coping skills and resources are important in this context.(¹-⁴)

The recognition of mental illness itself is a difficult task. Most of the time in developing countries the lack of awareness and misinterpretations prevent people from approaching a mental health facility. Stigma and labelling plays a significant role in both developed and developing countries. It is important to help the families in recognising mental illness and initiate treatment as soon as possible. Delay and denial of treatment may lead to irreversible difficulties and disability.(¹, ⁵, ⁶)

Being a very undesirable condition, the families may not be ready to accept the mental illness very easily. They may go in to
bargaining and denial. A good coping style and adaptive pattern are the key for better adaptation to any difficult situation. Studies show that families with mentally ill people often have poor adaptation and functioning. The family dysfunction may be a cause and effect of family’s adaptation style. The family dysfunction often starts with the role dysfunction from the part of the affected person. It will gradually cause a cycle of disturbance and lead to gross dysfunction in other domains as well.\(^\text{7,8}\)

Proper guidance and social support is another area that plays important role in the treatment and recovery. The social support is important in all levels of prevention. It is very important in treatment and recovery also. Chronic mental illnesses like schizophrenia raises lot of difficulty for a person getting back to their normal life. Problems like social breakdown syndrome and social skill deficits make it difficult for them to go back to their previous roles and functions. Stigma and negative attitude of the society and family also plays a serious role. The families with mentally ill also needs various supports systems to cope better. Families often lack knowledge about the illness and management skills. They often get confused about how to deal with specific signs and symptoms. Families with mentally ill person often struggle to meet their various needs. A better acceptance, support and resources in the living community may help in better adaptation to illness and recovery.\(^\text{8-12}\)

### Needs of the Families

Care giving is a complex challenging job and family members often face problems in taking care of the loved one because of various reasons. Most importantly they lack information and skills in managing the person with mental illness. Many often family members fail to discriminate mental illness and its symptoms. Even if they recognize some of the behaviours as odd or abnormal they lack skill in managing them. For example a person with manic disorder may claim that he is very rich and having lot of money and properties. The family members often confront it directly and it may lead to a fight with patient. Poor outcomes, burden and difficulties may affect the mental health of the family members as well. For example a person with schizophrenia may not show any enthusiasm and energy to do activities. Families often feels that they are ill, tired and they need rest. So the family members will not give them (persons with mental illness) any job and responsibilities. This may double the burden of the care giver as because in many situations they may need to play the role of the affected person too in the family. But in reality engaging the affected persons especially like person with schizophrenia may be therapeutic. A structured engagement in day to day activities may help them to recover from their illness and disabilities. The outcomes found to be better when family receive education and training about various aspects of mental illness especially psychoeducation, coping skill training, problem solving and communication skill training.\(^\text{13-16}\)

It is always a trend, especially in developing countries like India to plan for the needy from the practitioners’ perspective. But it will be more logical and complete if we consider the felt need of the families as well. Families of persons with mental illness found to be demanding certain things from the service providers. As an example, a publication of Canadian Mental Health Association reported that the family members of persons with mental illness asking for:

- **Better information and education**
- **Income support to cover expenses and lost income**
- **Peer support** to allow family members an opportunity to share fears and frustrations and to learn coping skills from those with similar experiences.
- **Respite services** to give caregivers a break from their responsibilities.
- **Access to information** about their loved ones care and treatment to enable them to provide the best possible care for their family member.\(^{(15)}\)

**Recommendations for Better Support and Outcomes**
Organizations working with the families of mentally ill persons have given some recommendations to favour better outcome as follow:

1. **Enhancing services and support for families**
   a) There is an increased need for the families to improved access of information, education, counselling and sometimes respite services.
   b) Accurate information to alleviate fears, overcome misconceptions and address concerns.
   c) Education and training in developing successful coping strategies and enhance their contribution to the recovery of their loved one.
   d) Help and assistance in coming to terms with the implications of living with a loved one who has a serious mental health problem.
   e) Support for employment or income generation activities and social recreation programs.\(^{(15)}\)

2. **Active partnership in therapeutic process**
   a) Family members should be active partners in all aspects of care. They must be aware about the illness, diagnosis, prognosis, treatment option etc.
   b) They must be empowered to take proper decisions with right understanding.
   c) They should be aware about the role of pharmacological and non-pharmacological managements with clarity.
   d) They must be trained as a co-therapist while doing psychosocial interventions and adequately trained to deal with patient and symptoms at home to ensure the continuity.\(^{(15)}\)

3. **Encourage families to support mutually**
   a) Families may be motivated for developing a support networks among the families with mentally ill itself. The effectiveness of self-help groups and mutual aid programs are demonstrated better outcomes.
   b) Such programs should also motivated for mental health promotion and enhancing wellbeing of the families along with strategies for alleviating stigma and discrimination.\(^{(11,12,15)}\)

**Role of Mental Health Professionals**
A number of models have developed in various countries and organizations to address the issues of the families of persons with mentally ill. In many countries governmental organizations are supervising such interventions and found to have good results.\(^{(15,18,19)}\) Gaining insights from
previous studies, various models and practical experience the role of mental health professionals in supporting families to recover from mental illness is summarized in the following headings.

**Instilling Hope**
The first and most important aspect to begin with is instilling hope among the relatives and sufferers. There are various types of problems that need to be addressed. Firstly, it is very common among the affected people and relatives expressing no hope of cure and recovery. Secondly, many of them initiate but may not comply with the treatment, which results in multiple relapses and associated complications. Thirdly, some of them may comply with medications but ignore the psycho-social aspects which may hinder the full recovery. Fourthly, some people think that the mental illness (even severe mental illnesses like schizophrenia) can be treated with mere counselling and psycho-therapy. Lastly many of them believe that the recovery means they no more need medications. The important thing to start with is to make the family aware about there are mainly two kinds of recovery. First is symptomatic recovery which means the absence of signs and symptoms of the illness. Second is functional recovery means restoring the psycho-social functioning and wellbeing of the person. Medicine can help in symptomatic recovery but functional recovery in chronic mental illnesses depends on the quality of psycho-social interventions and support. Medicine need to be continued in many types of illnesses especially in chronic illnesses like schizophrenia and bipolar disorders. (18)

**Setting Achievable Goals**
Second important thing is to make the family and patient to have achievable goals or plans. With mental illness people often become hopeless and desperate. The motivational strategies will help the practitioners to encourage the patient and families to work toward some positive goals. It is always good to have a set of goals divided in to immediate and future goals or short term and long term goals. In the short term the goals can be very simple in a way to develop confidence and self-worth in the patient. The goals can set like being independent of self-care and daily activities, taking care of certain family responsibilities such as shopping etc. In the future goal we can keep broader or big goals such as getting job or getting job training or starting self-employment programs. It is always important to remember that the goals should be achievable for the patient and family. (18)

**Psychoeducation**
The first two steps discussed already will help patients and families for being hopeful and realistic about the recovery. The next step is educating the family about the illness. The family should be educated specifically to the illness they are facing. Educating theoretically or technically may not help the families. Professionals should spend time with patient and families and tell them what is abnormal in the person and how to deal with it. The causes and prognosis of the illness specific to the person should be explained. For example the course of illness will be entirely different for a person who started treatment for schizophrenia in very early stage with no family history compared to another person with same diagnosis who started treatment after ten years of illness with a strong family history of illness. In a country like India the explanatory models influenced by socio-cultural factors are very common. The education should also give enough importance to alleviate the myths and misconceptions about illness and treatment. The family should be made aware and educated about the medications the patient is on, its logic, side effects and precautions. The common medications used in psychiatry have side effects. But many of
them are manageable. For example common side effects of antipsychotic medications are weight gain. It can be easily manageable with proper diet supervision and exercises. The educational strategies should also be focused on developing resilience against stigma and labelling. The family has to be aware about the negative impact of stigma and the benefits of being positive. The factors like proper awareness, clarification on myths and misconceptions, generalization and hope with treatment are found to be associated with lowering stigma.\(^{(1,5,6,16,18,19)}\)

**Give an Appropriate Model of Illness**

Another important area of discussion is to give an appropriate explanation of illness to the affected families. In spite of rectifying the misconceptions, the family will be still in loss by thinking why me/ my son/daughter….? The bio-psychosocial model will be appropriate for this. The model gives importance to a combination of different set of forces from various domains including biological, psychological and social or environmental. This model will also help the families to give adequate importance to deal with family dynamics for the better recovery. Facilitating specialized training to deal with stress may be beneficial to the families as a whole.\(^{(20,21)}\)

**Building Social Support**

Any kind of relationship that is positively enriching and mutually rewarding may be called as social support. Building and enhancing social support is very important for families with mental illness. Man is a social animal and we cannot live in isolation. Mental illness often makes people disengaged from others. It could be due to the fear and stigma associated with the mental illness that society may keep distance from the mentally ill person and his family. Second, the family and patient themselves may stay away from the mainstream society due to fear of stigma and labelling. The third issue is the inability of the patient to socialize because of the illness and disability. The social connections and skills to lead a normal social life is important for all human beings. The illness and its consequences often lead to decreased ability in social and personal context for many individuals. There may be problems in establishing and maintaining interpersonal relationships, communication skills, vocational skills, recreational skills and problem solving skills. Deficits in maintaining personal care, managing day to day activities, future planning etc., may also get affected. All these problems along with stigma and labelling may force the person and family to live in isolation from the main stream of the society. In the absence of a proper social and personal life, recovery cannot be complete.

The deficits in many areas are the result of illness itself or because of the person’s inability to adapt to the new situations. For example when a persona affected by psychosis for a long period of time, there will be many changes in his family and social life. During the active phase of illness he/she may not able to take care of the responsibilities properly. So such roles will be taken up by other members such as spouse or children. They also lose the job and income. Once they become free from the symptoms the realization will come that they lost many things. Family need proper professional guidance to bring back the person to functional life. To restore the proper wellbeing the family need positive support from the community as well. Strategies like generating awareness about mental illness, alleviating fears may help the person with mental illness and their family to develop favourable relationships. It is also very much advisable to start a self-help group or supportive group with people having similar problems and the well-wishers.\(^{(18,22-25)}\)
Avoid Substances
The outcome of the treatment will be complicated when there is an involvement of substance use or dependence. Individuals have various logics for taking substances, like for party, for sleep, alleviating tension and stress etc. Few substances have social sanction in certain communities such as alcoholic beverages, various forms of cannabis and nicotine. The family members often consider that occasional intake of substances in some mild quantities is not a problem. Studies have demonstrated that substances in any from and quantity may complicate the prognosis and treatment response. It is always good that the entire family keep away from the substances rather than insisting the patient alone to be away from the same. Family together can develop an alternative network and behaviour to bring better out comes. Mental health professionals can help families in this regard very effectively.\(^{18}\)

Teach Relapse Prevention Strategies
In many developing countries specifically designed programs are available to make the family member skilful in identifying and preventing relapses. First and foremost aspect is to make the family aware about the causes of relapses. Often people believe that if they are taking medications regularly the illness will not recur. Relapse could be due to poor compliance, lack of response to medications, any other illness, change in daily activities, psycho social stresses, change in sleep pattern or sleep deprivation, substance use and so on. The relapses usually start with some minor symptoms or changes. Such symptoms are called as early warning signs. Examples are difficulty in getting asleep or sleep difficulty, change in appetite, feeling tense or nervous, irritability, feeling low, poor concentration, etc. In a little advanced stage the individual may start exhibiting the same symptoms of the illness like in the past such as hearing of voices, withdrawn, tall claims, suspiciousness etc. The family members should be educated in detail about all of these. Clear instructions should be given what they should do in such situations. Many practitioners noticed that it is very useful giving a detailed list of early warning signs to the key care taker to check the relapses.\(^{18,26,27}\)

Life Style
The routine activities and lifestyle also found to have direct and indirect effect on recovery. Circadian rhythm plays a significant role in remission and relapses of various mental illness especially bipolar illnesses. Managing a similar routine every day help individual to fasten the recovery process. Most importantly the sleep pattern needs to be monitored. Family in this regard should be aware and supportive. The feeling that the patient is too tired and should take rest could be counterproductive. Family members in turn can assist the patients in going for a walk in the morning, doing yoga or going to gym or doing any physical exercise, going to temple, mosque or church, playing indoor and outdoor games, in doing house hold chores, gardening etc. At a later stage, they can make the patient more independent and place them in an earning job. Such activities also give indirect benefits as well. i.e., many of the psychiatric drugs results in increased appetite, weight gain, risk of diabetics and increased cholesterol levels. As a result, often the treating practitioner is forced to change the medications even when there are positive results with the same. Imbibing a healthy life style by the patient mitigate the frequent medicine changes and onset of other illnesses.\(^{18,28,29}\)

Role Restructuring
The role dysfunction is very much common among all kind of psychiatric conditions especially in chronic illnesses. It happens in
many ways. The illness is primarily responsible for role dysfunctions as it incapacitate the individual in performing the role adequately. When a member of the family is affected by a severe mental illness there will be a sudden disruption in his role performance. It will then subsequently affect the other family members. It will be more complicated if the person is a key earning member of the family. In such conditions other family members need to compensate for the part of patient along with their own duties. The added responsibility of care giving will again increase the burden. Many often families do not recognize the need and benefit of restructuring the roles by giving an affordable share to the patient. Mental health professionals can make the family aware about these matters and help them to engage the patient in the day to day functioning of the family gradually. (3,4,30)

Enhancing Communication and Problem Solving Skills

It is widely observed in many studies that the families of individuals with mental disorders have poor communication and problem solving skills. (30-33) Communication enhancement and problem solving skill training models developed subsequently are found to be very promising. The problem in communication and negative expressed emotions can be managed effectively by teaching the family healthy communication styles. The starting point is the patient only. The patient in many cases will be a passive member in the family with only having need based communication. Developing a system by including patient as well in the communication system is very important. Families must be educated about it and then helped for developing strategies. There are specially designed manuals available for teaching families about communication and problem solving. (3,4,13,16,30-33)

Be in Touch with the Treating Team

Last and most important aspect to discuss is the need of being in touch with the treating team. In many of the advanced models of practice, a mental health professional usually a social worker/psychologist/ nurse will be appointed as a case manager to ease the relationship with the professional team. In India we have difficulties in affording such services because of the scarcity of qualified professionals. The patient and family should be encouraged to approach the treating team in their difficult situations. The bond between the therapist and client is the key of success in psychosocial interventions. Now in the era of advanced technologies the contact can be maintained through diverse mediums, such as mobile phones, email, whatsapp, etc. A specific time in a day or a specific day and time in week can be given to the families for contacting the treating team when they have queries. (18)

Conclusion

Mental illnesses especially chronic illnesses are very much disabling and distressful to the person affected and for the family. Living with mental illness and living with a person with mental illness are equally difficult. The factors like stigma, labelling, lack of professional support and guidance, socio-cultural influence, lack of affordability and accessibility etc., make the outcomes more complicated. Proper professional support and guidance to the family in various aspects of illness and illness management may help them to deal with the illness in a better way and enhance the process of recovery.

References

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rehabilitation. Schizophr Bull 1992;18 (3).


