

## HELPING THE CHRONIC SCHIZOPHRENIC AND THEIR FAMILIES IN THE COMMUNITY—INITIAL OBSERVATIONS<sup>1</sup>

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### SUMMARY

There is a growing interest in the problems of mentally ill persons in the community in order to understand and organize services for them. Schizophrenia continues to form the most important problems in the community. The present prospective study involved thirty patients with chronic schizophrenia and their families. The study involved the intensive understanding of the social problems of the patients and families as well as the interventions to manage the problems isolated.

The study revealed the following areas to the source of problems of adjustment : (i) High expectations of the family, (ii) Excessive emotional involvement, (iii) Marital disturbances, (iv) Problems of employment and (v) Problems relating to long term treatment.

The techniques employed in the management were, in addition to long-acting phenothiazines were: (i) periodic and regular home visits, (ii) family financial counselling, (iii) explanation about the illness to enhance treatment acceptance, and (iv) contact with social welfare agencies. The paper is largely descriptive and illustrations of cases are included to highlight the salient aspects of the experience.

Schizophrenia forms an important public health problem. The needs of the chronic schizophrenics have been receiving special attention during the last decade in Europe and North America. As a result, in recent times, there is a growing awareness and acceptance of the need for community care facilities as an alternative to institutional care.

In India, majority of the schizophrenics live in the community. This is chiefly due to the limited mental health facilities and the overcrowding in the existing mental hospitals. It is only in the last few years that the need for community care of these patients has been receiving serious attention (Bhas-karan, 1970).

Three follow-up studies from Chandigarh and Agra (Kulhara, 1974 ; Basit, 1975 ; WHO—IPSS, 1977) have shown that a significant number of schizophrenics remain chronically ill. In addition, studies

from Chandigarh indicate that (i) contrary to the popular belief, the family members of schizophrenics experience significant problems in caring for them (Kulhara and Wig, 1978), (ii) the marital problems are far higher than those in the general population, and (iii) students dealing with the illness often do not complete their studies.

However, all the above studies do not provide details of the needs of the affected families. Additional lacunae exist in the areas and approaches available and suitable for helping them in the Indian situation. This last point is very relevant as even in the welfare states it has been noted that numerous difficulties are described (by families) arising out of the patients' behaviour and deficiencies in the services provided. It was found that "a lack of guidance on the best way to manage disturbed or withdrawn behaviour of the

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patient, support in obtaining the best available help and of really good local accommodation as an alternative to long term hospital residence were the main gaps in the health and social services" (Creer and Wing, 1975).

In view of the limited facilities for the institutional care of chronic schizophrenics, it appears opportune to examine the needs of this group of patients in the Indian situation. Further, the evaluation of the benefits of the different approaches to provide care in the community and the type of facilities that should be organized is another important need. The present report relates to the initial attempt to meet the needs of a group of chronic schizophrenics in the community.

#### *The Setting :*

The study formed a part of the 18 months' work in the "Modcate Clinic" at the Department of Psychiatry, Post-graduate Institute of Medical Education and Research, Chandigarh. The details of the clinical aspects have been presented in details elsewhere (Wig and Srinivasa Murthy, 1979).

The clinic was functioning everyday under the charge of a trained nurse (B. S.), a part-time social worker (S. C.) and the overall supervision of two psychiatrists (N. N. W & R. S. M.). This is a novel experiment in that a psychiatric nurse, following an initial training, was chiefly carrying out the assessment, interviewing of relatives and administering of the drug (Anatensol Decanoate). In addition to the clinic work, she also made home-visits to follow up the patients on four days a week. Further details of the training and the method of work are reported elsewhere (Wig and Srinivasa Murthy, 1979).

Thirty of the chronic schizophrenics of the clinic were evaluated in detail and efforts were made to provide the required help. The method of study was by non-structured interviews and observation of

the patient, family members, and significant others both in the clinic and their homes. The following section deals with (i) the psychosocial problems of the families, (ii) the type of help provided and (iii) the benefits of intervention. The report is largely descriptive and illustrations of cases are included to highlight the salient aspects of the experience.

#### OBSERVATIONS

##### *Psychosocial problems of the families :*

The psychosocial problems of the families in the management of chronic schizophrenics could be classified on the basis of interviews and home observations under the following categories :—

1—*High level of expectation :* Nearly half of the families had high expectations of the patient and the clinic in spite of long duration of illness. Even after the detailed explanation about the nature of illness and treatment, the family members expected a speedy recovery. Consequently, they expressed disappointment and frequently described their dissatisfaction, frustration and anger at the 'insoluble' nature of the problem. For example, one of the patient's father observing the slow improvement discontinued the treatment. The father's explanation was, "Though with drugs his symptoms are in control, yet he has not regained his pre-illness personality, and now I have given him up as a futile case".

Other common complaints were about the patient's residual symptoms such as social withdrawal, underactivity, lack of conversation, neglect of personal appearance, etc. A patient's mother complained, "I wish he could talk a little more and not be so lazy and depressed". As regards the household work, the family members expected the patient to work as adequately as before, and like any other family member. They were upset by their failure to encourage the patient to sustain interest in any hobby and activity. For example, a patient's mother remarked, "Prior to her illness, she

was very efficient in her work, but now she spends hours together doing absolutely nothing”.

2—*Excessive emotional involvement* : Nearly 40 per cent of the family members were either overprotective or critical of the patient. This thwarted the progress and made them more dependent. The parents did not understand the limitations and potentialities of the patient. In one family due to the father's over protectiveness, the patient (28 years old) was not able to regain her self-confidence and continued to manipulate her parents for minor needs. The father remarked, “She is still a child, we fulfil all her demands, otherwise she throws a temper-tantrum”. Another example is of a family where the father was confident of the patient's full recovery who was ill for 5 years. But, on the other hand, the mother rejected the patient by commenting, “He has lost all his sense and I have no hope in regard to his improvement”. We observed that in this family contradictory messages were being passed on to the patient.

Over protective attitude was also shown by not allowing the patients to go out alone or to make decisions and by overlooking their inactivity. The parents were doing certain household work which could be performed by the patient and thus blocking the opportunities of taking initiative and being active. One good example is of a daughter who was playing the role of a mother in the house, with the result the patient (the mother) was pushed to the background and was not given any opportunity to take up simple responsibilities or household tasks at home.

3—*Problems related to long term treatment* : Some of the families were finding it difficult to continue treatment due to reasons such as (i) patients refused oral drugs, (ii) lack of understanding of the illness, the importance of medication was over-looked, (iii) the fear of social stigma hampered regular visits to the clinic, (iv) the plan

to get the patient married led to discontinuation of medication and (v) physical distance discouraged them to maintain regular follow-up.

4—*Lack of understanding of patient's residual symptoms* : Relatives complained about the patient's withdrawal from social contact. Some patients did not go out. Others by their behaviour prevented the family members from having friends at home. Many relatives were upset by their failure to encourage the patient to sustain interest in any hobby or activity. Patient's lack of conversation was another very frequent complaint. For example, a patient's mother commented, “I wish he could talk a bit more”. They also expressed their annoyance about patient's slowness, clumsiness and neglect of personal hygiene. Some patients used to be “moody” which made the relatives worried and annoyed. Some of them commented, “We don't give him any cause of worry but still he looks so sad”. Others felt that the effects on their own health had been severe. For example, a mother stated, “Thinking about her illness, I remain under a great tension and anxiety”.

5—*Problems related to marriage* : In the group of patients about half of the couples were having marital problems of one form or the other. These were due to the nature of symptoms like violent or aggressive behaviour, social withdrawal, sexual problems and inability to play the role of a husband or wife. One of the newly married spouses commented, “I feel very upset because for the first time I was facing a mentally ill person”. Another stated, “I had many dreams and hopes of a young bride but due to my husband's illness it seems as if the world has come to an end”.

In addition, it was observed that due to the marital problems after marriage, some of the spouses had left the patient for a few months and stayed with their parents. But later on seeing the improvement in the patient's condition with treatment, and also

with support from the parents and the doctors the spouses were able to adjust to living with the patients and support them.

Ten per cent of the group were divorced or separated due to mental illness. These patients were found to be ill before marriage which led to a quick divorce due to lack of tolerance and acceptance from the other part.

5—*Unmarried patients* : About 40 per cent patients were single due to illness and unemployment which was a source of worry to the family members. The parents were also apprehensive about the possibility of a relapse after marriage and the consequences. Social stigma also limited the opportunities for a marriage. For example, one of the mothers remarked, "Before we start some negotiations, one of our relatives or neighbours having strained relations with us would inform the other party". A father stated, "If my daughter recovers completely, then we would think of marriage, otherwise due to her illness she might get divorced. All men want perfect wives". Majority of the family members were worried (especially in regard to the female patients) about their future rehabilitation. The problem was stated in the remark made by an elderly father whose daughter was ill for 4 years. "Now we are here to look after her, but what happens when we are no more?" The constant preoccupation of the families appeared to be to get their daughters somehow married in spite of their age and chronic illness. Moreover, many parents believed that marriage would cure mental illness. This was contrary to the advice given in the clinic.

7—*Rehabilitation* : Half of the patients needed specific help in rehabilitation in the form of a job or day care facility. It is significant to note that patients staying in joint families and having their own land were being helped by other relatives and their own children. The patients who improved with long term drugs were in a condition to take up jobs. But due to lack

of facilities they remained unemployed. In certain poor families there was a pressing need to employ the patient who could add to the income of the family. During the hospital visits the doctors were requested by the relatives to rehabilitate the recovered patient. As regards day care facility, there were problems in motivating the parents to send the patients to the day care centre. The patients coming from emotion-charged families or where there was lack of stimulation were encouraged to attend the day care centre. To take an example—a female patient (30 years) came from a family where there was an overprotecting father and a rejecting mother. Even with long term treatment, she was unable to show significant improvement. She used to spend hours doing nothing at home. Efforts were made to bring her to day care centres but the parents expressed their problem saying, "I'm a heart patient, my wife is old and moreover she has to look after the house. The patient cannot be sent alone and there is no facility for regular transportation". It was observed that due to physical distance and non-availability of regular transportation, it was difficult for the relatives to make full use of the day care centre.

8—*Intervention* : The following techniques, in addition to the drugs, were used for the management of the problems over a period of 18 months ;

- (i) Regular Home-visits
- (ii) Family counselling
- (iii) Marital counselling
- (iv) Contact with social welfare agencies
- (v) Providing an understanding about the illness.

#### *Home-visits :*

All the families were visited periodically and were given therapeutic help. These home visits became a source of support to the family. Consistent efforts were made to involve the patient in social interaction and specific activities like playing indoor games with the family members, etc. This

became a learning process for the family members. We were able to spend more time with the family at home than in the clinic, and through home-visits good follow-up could be maintained.

#### *Family and Marital Counselling :*

Marital counselling was needed by more than half of the couples. This was chiefly to improve the relationship and to increase the support for the patient. Separate and joint sessions were made to enhance their understanding of the illness. The family members were also given an opportunity to verbalize and discuss their doubts, fears, etc. so that better understanding could lead to the development of the positive attitude towards the patient. It was observed that many of the spouses were not able to discuss their problems with anyone else due to the fear of social stigma, and our intervention provided them a channel to ventilate and to discuss their problems in a more meaningful way.

9—*Explanation about illness :* With the control of symptoms, patients were accepted more easily in the family and this resulted in regularity to treatment and better understanding of the illness. Our main aim was to clear their misconceptions, to answer their questions about mental illness and to advise them on the management of the patient at home. The family members were also explained the importance of treatment with drugs and follow-up. Majority of the families wanted guidelines on the following points :

- (i) How much protection and care to be given to the patients ?
- (ii) What type of job and responsibilities a patient can take up ?
- (iii) How to handle an aggressive or violent patient ?
- (iv) What are the advantages and disadvantages of marriage ?
- (v) What type of rehabilitation for the patient
- (vi) When is hospitalization necessary ?

(vii) How much the patient's behaviour is determined by his illness ?

10—*Contact with social and Welfare agencies :* Though a significant number could have benefitted from help of social and welfare agencies, the help available was limited. Currently, mentally ill do not have any special provision for employment. On the other hand, due to the prevalent social fears and stigma the employers are generally reluctant to employ these individuals. The need for sensitizing the public, employers and welfare agencies is an urgent one. So, often we have taken the patient to the stage of social acceptance without being able to make him socially effective through employment.

#### OUTCOME

The experience of work with this group of patients has provided a valuable insight into the complex nature of needs and limitations for providing help. Our interventions have been of benefit, though much of it cannot be clearly attributed to the socio-psychological intervention (as all of them were on regular drugs). However, some of the areas where clear changes were noted were :

- (i) Half of the families were given marital counselling. They are maintaining well and coming for regular follow up. In one case the marriage break-up was prevented by our intervention.
- (ii) Family counselling showed improvement in the following areas :
  - (a) Better understanding of the patient and his illness.
  - (b) Change of approach in the management of the patient at home.
  - (c) The parents made constructive efforts for the patients in the form of seeking employment and involving the patient in home situation.
  - (d) they became more regular in follow-up.

- (e) the patients requiring the help of motivated, with partial success.

To summarize, this paper highlights some of the psychosocial problems being faced by the chronic schizophrenic patients and their families and reports the efforts made to understand how to handle these problems.

#### IMPLICATIONS

- (1) Chronic schizophrenics in the community form a significant public health problem.
- (2) Family members have multiple needs when living with a chronic schizophrenic.
- (3) The needs should be specifically examined and met to enhance the level of functioning of the patient as well as to decrease emotional problems of the family members.
- (4) The utilization of multidisciplinary team 'reaching out' to the community is helpful to meet some of the complex needs.
- (5) There is greater need for planned services which are responsible, integrated and comprehensive to meet the needs of this ill population.
- (6) The paraprofessional can play a major role in the care of the patients in the community.
- (7) A plea is made for further examina-

tion and evaluation of models to suitably care for this group of patients and their families.

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