AN ETHNOGRAPHY OF FAMILY BURDEN AND COPING STRATEGIES IN CHRONIC SCHIZOPHRENIA

RENU ADDLAKHA

ABSTRACT

There is a growing recognition among mental health professionals of the need for more ethnographic studies on local mental health needs, conceptions, and resources in order to formulate more culturally-informed and effective therapeutic strategies at the health-care planning and policy levels. R.L. Kapur (1992), for instance, underscores the need for detailed family ethnographies on behavioural patterns and intra-familial relationships, especially in the wake of the changes brought on by industrialisation, urbanisation and modernisation in the Indian context. The present paper is a micro-analysis of the ways in which chronic mental illness in a female member is managed by a lower middle-class urban family in Delhi. Through a single case illustration, I argue how a general hospital psychiatry unit may emerge as the only viable option for periodic reprieves for both patients and families in the absence of adequate and acceptable state-sponsored facilities for long-term management of chronicity.

Key words: Family burden, coping strategies, schizophrenia.

General hospital psychiatry is premised on a strategic alliance between the institutions of the family and the hospital. In the context of poor families managing chronic schizophrenia in the home, the services of a general hospital psychiatry unit can preserve patients from total destitution by offering them temporary, but periodic refuge, especially during illness exacerbations. It is important to note that in such cases the principal aim of hospitalisation, i.e., the temporary separation of sick person from society for the purpose of re-socialisation into the norms of health, is relegated to the background. The concern shifts to the procurement of even more basic needs, such as board and lodging. It is in this sense that the general hospital psychiatry ward may emerge as 'a home away from home'.

Readers will be familiar with the range of psychiatric studies in India that have tried to tap the rehabilitative potential of the family system in the long-term management of chronicity in the community (Kazi et al., 1993; Muralidhar and Shariff, 1981; Muralidhar et al., 1987 and Suman et al., 1980). Other studies have focussed on the family as a therapeutic ally in clinical settings (Prasad, 1981; Menon and Shankar, 1993; Shariff et al., 1982a and 1982b). Family ward were set up at NIMHANS (Bhatti et al., 1980; Geeta et al., 1980; Narayanan et al., 1972) and at Vellore (Vergehes, 1971 and 1988). Another significant development at NIMHANS is the home care programme for chronic schizophrenic patients. Recovery was found to be faster and fewer relapses were reported in comparison to hospital care. Follow-up by a trained visiting nurse and continuous counselling ensured a better clinical outcome and social functioning of the patient, in addition to a decrease in family burden (Pai and Nagarajaiah, 1982; Pai and Kapur, 1982). Subsequently, other therapeutic programmes actively engaging the family have been
RENU ADDLAKHA

developed, which have produced good results (Shankar and Menon 1991). While these studies address the patient-hospital-family triad from the providers' perspective, the present paper seeks to reconfigure this theme from the users' perspective.

RESEARCH METHODOLOGY

The data for this study was obtained in the course of fieldwork for doctorate between 1990 and 1992 from the psychiatry unit of a government hospital in Delhi. Tools employed for data collection were direct observation and over half a dozen informal interviews with the patient and others closed to her in the hospital ward, the OPD and the home. Information was obtained on such broad issues as the perception and experience of the disorder, emic categories of explanation, nature of contact with medical care systems (both biomedical and alternative) in addition to the day-to-day coping strategies involved in management of chronic psychiatric disability. In this regard, I wish to make special mention of the sheer wealth of information and insight that patients themselves, irrespective of their psychiatric status, may furnish to an empathic listener. Thus, Sita, the subject of this case study, was my chief and most co-operative informant. Content analysis of the descriptive material highlights both the actual modalities and the experienced burden in the management of chronicity.

A HOME AWAY FROM HOME

Sita is a forty year old Punjabi women with a diagnosis of chronic schizophrenia spanning the past fifteen years. Her illness history is punctuated by several acute exacerbations. A resident of Delhi, she has been hospitalised several times in the psychiatry ward of the major government general hospitals in the city, in addition to a three months stay at the Shahdara Mental Hospital. The case sheet revealed that she had dropped out of school in the tenth standard.

Her elder sister told me that Sita was married about fifteen years ago to a man thirteen years older than her. He is also reported to be psychiatrically disturbed. The couple have three daughters aged thirteen, nine and five years respectively. The other members of her affinal joint family household are, her widowed mother-in-law two married brothers-in-law and their families. They reside in the Khari Baoli area of central Delhi.

In addition to the patient, my other informants were her two younger married sisters. The elder, Pratibha, is a primary school teacher living with her husband and two sons in Paschim Vihar, a residential suburb in west Delhi. Sita's other sister, Bimla, is a nurse in another government hospital in Delhi. She also has two children. Sita's eldest daughter Gita, who was her mother's attendant in the ward, was also very communicative.

My first encounter with Sita was on a hot June afternoon, a day after her admission into the ward. She presented herself at that time as a short, stocky, dark-skinned woman dressed in an old and rather unclean nightgown. Her gray hair was dishevelled, and her clothes were soaking wet. Pratibha, who had accompanied her to the hospital, told me that Sita had started throwing buckets of water over herself ten to fifteen times during the course of the day. She said :

This is what she has been doing for the past few days. She is also eating a lot and talking nonsense all the time.

After a few days in the ward on psychotropic medication, Sita was calmer and more amenable to communication. She told me of her own accord:

I got this illness when I was in tenth class. I drank too much coca cola. My throat began to hurt and then I got sick. Since then, I have been taking 'largetil' and 'magectil'.

This unvarying, albeit incoherent etiologic explanation for the onset of her suffering, was accompanied by such physical complaints as a sinking feeling in heart, constipation and general bodily discomfort. During her stay in the ward, she was obsessed by the idea that she had high blood pressure.
Whenever she saw any doctor, she would rush up to him imploring him to take her blood pressure saying, "My blood pressure has gone up ('pressure' badh gaya hai)."

In the course of a conversation with Pratibha, some of the family's management strategies were delineated. Upon my asking her whether anyone from Sita's conjugal home had come to see her since her current admission into the ward, Pratibha explained in the course of an interview:

Pratibha : When she has an attack, she either comes to my house or to Bimla's. Then we bring her to hospital.

Renu : But when she is alright, then does she stay at Khari Baoli?

P : Off and on. Last year, she stayed for six months with our brother in Orissa. They neither look after her nor her children at Khari Baoli. We also have to take care of the children.

R : That must be a great burden on you. How do you manage?

P : Yes, it is very difficult. I myself have two sons and Bimla's husband died a few years ago. Just food, clothing and school fees for one more person makes so much of a difference. But she is our elder sister, if we don't look after her, then who will, Gita stays with me and the other daughter Pooja is in Orissa. Her husband has kept the youngest daughter with him.

R : Is this a permanent arrangement?

P : No, nothing is permanent. Pooja was staying with Bimla before she went to Orissa. If they had been boys instead of girls, then they would have kept them at Khari Baoli. After Anju, the youngest daughter was born, we got Sita sterilised, because they would never have thought of it themselves.

R : And where does Sita stay when she is not in Khari Baoli?

P : Sometimes here, sometimes there. She was in Orissa for a year. When she stays either with me or my sister, our brother sends some money for her every month. It has been going on like this for many years. There is also the hospital. Invariably, she becomes ill once a year. Then, she has to be hospitalised for a month or so.

In addition to providing sustenance to Sita, especially during periods of relapse, her siblings (and by extension their conjugal families) are also engaged in the more arduous and long-term task of bringing up her children. Their responsibilities include the provision of basic needs, such as food, shelter and medical treatment for Sita, and the upkeep of her three daughters. This even involves, on the part of Sita's sisters, reproductive decision-making on her behalf. The hospital emerges as a convenient and necessary resort in this carefully worked-out, ongoing family-based system of management and care.

When I asked Sita how she felt about being looked after by her siblings, especially during her illness, she replied in a quiet tone voice:

If they were not there, who would look after us? My children and I would die. Our bhabhi always fights about me. When I was in Orissa, I lived in the servant quarters. She told my brother, 'I won't keep this madwoman in my house'. I cooked my own food on the stove. In Pratibha's house, they also fight when I go. At least there is no such problem when I am here in the ward. Then, Gita only has to miss school to be with me.

But when I asked her, on the day of her discharge from the ward, where she wanted to go, she said solemnly, "Khari Baoli".

Renu : But you say that your husband beats you?

Sita : So let him beat me!

Bimla, who had come to collect her, told me that Sita would stay with her for the time being.

Renu : And after that, where will she go?

Bimla : We will see. Pratibha and I have been thinking of finding her some job as an ayah. She can do that sort of work. When she is alright, earn a little money and keep herself occupied. The trouble is that after some time she falls ill again.

Sita (interrupted): He does not allow me to take the medicines. He sits in the temple the whole day, he forgets things and he beats me.

B : Yes, her husband is also 'mental'.

R : Was he also like that at the time of marriage?

B : Yes, they were both of 'weak mind'.
RENU ADDLAKHA

Otherwise, who else would have married her?
But her in-laws should look after her as they look
after him.

Although most members of Sita's conjugal family, including her husband, do not provide either financial or emotional support, her own children come to function as her caregivers, especially when she is hospitalised. Gita looked after her mother in the ward with great solicitude. In addition to reporting on her mother's condition to the doctors, she cleaned her utensils, ensured that she kept herself clean, and patiently bore with her frequent outbursts of temper. She did not seem to mind the burden imposed on her by this role reversal with her mother. On the contrary, she told me cheerfully:

“She has always been like this. Even when she is not ill, she doesn't do much work. When she is sleeping or talking with some other patients, I try to study because I have to give a 'compartment', when school reopens.

A sense of alienation is expressed by Sita's longing for a space of her own. Deprived of a normal home with her husband and children, she often expressed the wish, "I want to build my own house." It seems that the closest that she could get to the fulfilment of this wish, in her circumstances, was coming to the ward. Like several other patients, Sita sought refuge in the hospital from her domestic woes. I saw her one day, towards the end of my fieldwork, in the OPD with Pratibha and her youngest daughter. She begged the doctors with tears in her eyes to be admitted into the ward, saying, "Don't send me home. I am very sick. I have nowhere to go. They are tired of me."

When Pratibha was asked what had happened, she shook her head saying:

I don't know. She came from Khari Baoli and was looking 'puzzled'. So I brought her here. I also think she needs to be admitted. Can Anju be with her in the ward? Gita has to study for her exams.

The poignancy of the family's plight is revealed by the fact that they had brought the five-year old girl to fulfil the hospital requirement for ward admission, namely the presence of an attendant for each patient provided or paid for by the family.

CONCLUSION

The analysis of this narrative highlights the crucial role of the natal family in the care and management of a chronic mentally disturbed woman and in the rearing of her children. This continuous support, even after her marriage (when a woman in the Indian context is considered to be largely socially and morally the responsibility of her affinal family), is not as uncommon under the given circumstances as it might at first appear. Similarly, paining up the handicapped in the arranged matrimonial system is another management technique employed by families of both the physically and mentally disabled. Although her siblings, despite adverse circumstances of their own lives, provide Sita and her daughters sustenance and care, underlying economics strains are evident. This in turn creates interpersonal tension. One indicator of this is the patient's frequent relapses. Secondly, the conscious seeking out of the hospital by both the patient and her family shows the differential appropriation of the biomedical space, more as a welfare than as a therapeutic space.

Acknowledgments: I am grateful to Professor Veena Das for her insightful comments on earlier drafts of this paper. I also acknowledge with gratitude the helpfulness of the staff of the public hospital, where this study was done. Lastly, I am also grateful to Sita and her family for their co-operation in the construction of this ethnography.

REFERENCES

Bhatti, R.S., Janakiramaiah, N. and Channabasavanna, S.M. (1980) Family psychiatric ward treatment in India. Family Process, 19, 193-200.

Geeta, P.R., Channavasavanna, S.M. & Bhatti, R.S. (1980) The study of efficacy of family ward treatment in hysteria in comparison
with the open ward and the outpatient treatment.

Kapur, R.L. (1992) Family and schizophrenia: Priority areas for intervention research in India. Indian Journal of Psychiatry, 34, 1, 3-7.

Kazi, S.A., Kavitha, M.A. & Shariff, I.A. (1993) Indicators of social support in the families of mentally ill belonging to scheduled castes. Indian Journal of Clinical Psychology, 20, 2, 69-72.

Muralidhar, D. & Shariff, I.A. (1981) Obstacles in the way of readjustment of mental patients in the family. Journal of Rehabilitation in Asia, 21, 4, 37-41.

Muralidhar, D., Narayana Reddy, G.N. & Shariff, I.A. (1987) Rehabilitation potentials in the families of mentally ill. Journal of Medical and Psychiatric Social Work, 1, 1, 21-25.

Narayanan, H.S., Embar, P. & Reddy, G.N.N. (1972) Review of treatment in family ward. Indian Journal of Psychiatry, 14,2,123-126.

Pai, S. & Nagarajaiah (1982) Treatment of schizophrenic patients in their homes through a visiting nurse: Some issues in the nurses’ training. Journal of Nursing Studies, 19, 167-172.

Pai, S. & Kapur, R.L. (1932) Impact of treatment intervention on the relationship between dimensions of clinical psychopathology, social dysfunction and burden on the family of a psychiatric patient. Psychological Medicine, 12, 3, 651-659.

Prasad, R. (1981) Family as a support in crisis situations in clinical settings. Indian Journal of Social Research, 22,3, 279-284.

Sarda Menon, M. & Shankar, R. (1993) Family and professionals working together in the management of schizophrenia. In Mental health in India: Issues and concerns, (Eds.) Mane, P. & Gandevia, K.Y., pp. 261-276. Bombay: Tata institute of Social Sciences.

Shankar, R. & Sarda Menon, M. (1991) Family intervention programme in schizophrenia: The SCARF experience. In: Unit for Family studies, Tata institute of Social Sciences, (Eds.), Research on families with problems in India, Vol. I, pp.128-144. Bombay: Tata Institute of Social Sciences.

Shariff, I. A., Sekar, K., Chamendeswari, S., Muralidhar, D. & Murthy, N.S.N. (1982a) Hospital treatment of the mentally ill with periodic family participation: A boon for better rehabilitation. Journal of Rehabilitation in Asia, 23, 3, 35-39.

Shariff, I.A., Sekar, K., Eswari, S., Muralidhar, D. & Murthy, S. (1982b) Involvement of the families in the treatment of mentally ill in the hospital. Indian Journal of Social Research, 23, 2, 151-154.

Suman, C, Baldev, S.C., Srinivasa, M. & Wig, N.N. (1980) Helping the chronic schizophrenics and their families in the community: Initial observations. Indian Journal of Psychiatry, 22, 1, 97-102.

Verghese, A. (1971) Involvement of families in mental health care. Journal of Christian Medical Association of India, 46, 84-87.

Verghese, A. (1988) Family participation in mental health care: The Vellore experiment. Indian Journal of Psychiatry 30, 2, 117-121.

RENU ADDLAKHA*, Department of Sociology, Delhi School of Economics, University of Delhi, Delhi-110 007.

*Correspondance