CH-20

Community Care of the Mentally Ill

By
Dr. R.L. Kapur
Consultant
Community Health Cell,
No.367, Srinivasa Nilaya, Jakkasandra, I Main, I Block, Koramangala, Bangalore 560 034

Introduction - The burden of mental disorder:

The term mental disorder covers a wide range of conditions which share in common an experience of psychological distress and social dysfunctioning, either by the affected person, or those around him, or both. On one end are syndromes, which are definitely due to neurochemical imbalances or structural changes in the nervous system. Schizophrenia, Bipolar mood disorders, Dementias and certain categories of mental retardation come under this category. There is sufficient evidence that at least 2% of the population, whether in the industrialized nations or in the developing countries, whether in urban or in rural conditions, suffer from the effect of these illnesses. While a number can be treated or managed with appropriate medication, at least one third end up with chronic disability needing financial and social support for their existence.

At the other end are conditions, which reflect a break down of vulnerable persons in response to environmental stresses. Anxiety, depression, vague somatic symptoms are examples in this category. It is estimated that 8-10% of population suffers from these conditions. Poverty and hunger are perhaps the biggest stressors. So is being a woman, or a member of lower castes, in hierarchical societies like India. Increasing urbanisation and dislocation, which are directly related to economic development programmes in poor countries, are other social stressors. There are enough research studies linking these factors with mental ill health, well summarised by Patel (forthcoming). There is also evidence that suicide rates, which are arguably the clearest indicators of mental stress, are high in India and constantly rising (Shah 1996).

Closely related to these stress related psychological disorders are conditions like alcohol and substance abuse which are the resultants of a complex interaction between stress related demand, government promoted supply (in case of alcohol which brings excise revenue) and criminal promotion (for other drugs, which are banned). Here, psychopathology merges with socio-pathology.

The rates of alcohol consumption and alcohol addiction of course vary across the country and the rates of alcohol dependence vary from 1-15% (ICMR-CAR-CMH 1990) to 15-20% (Bang and Bang 1990). According to one report, the rates of alcohol consumption are rising by 15% per annum (Chakravarti and Rathnamani 1995).

According to a World Bank report, 8.1 of the DALYS -- a DALY being the disability adjusted life years, which is a measure of burden produced by specific disease -- are lost due to mental disorder. This burden seems to be equal to, if not more than, that produced by diseases like tuberculosis, cancer and heart disease. Another 34% of the DALYS are lost due to such physical diseases where behaviour related factors play a part e.g. heart disease, lung cancer and sexually transmitted diseases.

The care of the mentally ill:

There was no tradition of institutional treatment for mental disorder before allopathic medicine entered India with the Europeans. The first mention of a mental asylum is in the records of Bombay Presidency 1745-46 (Weiss 1983). The number of mental hospitals was nineteen at the time of Independence. It has currently risen to 45 with a bed occupancy of 21,147 (Central Bureau of Health Intelligence 1992). The conditions in these hospitals is, on the average, very poor. Except for a few, which can be counted on the fingers of the hand, most institutions are poorly staffed, poorly resourced and poorly motivated. The food, clothing and living conditions are abysmal. As recently as 1999 a workshop was held in NIMHANS, in Bangalore, to address the problems of these institutions and to issue some recommendations (NIMHANS Report 2000).

Early in the 1960s and 70s it was beginning to be realised that long term institutional care of all the needy mentally ill was neither possible nor desirable. The answer was de-institutionalisation and community care. The following paragraphs describe the story of how the experiments in community care of the mentally ill have proceeded, along with discussion of issues, which still need to be tackled.

Community care of the mentally ill:

Fifty years ago, if someone had talked of community based programmes for mental health care, he would have been considered over ambitious. At that time, the best we could hope for was compassionate custodial care within the four walls of a mental asylum. These ill people were left there, often for life, by their relatives and community, who would then forget about them. It says a lot for the progress made over the years, even in our country, that we talk not only of treating mentally ill patients in their own surroundings, but also of involving the community in preventing as well as in promoting mental health.

The beginnings:

It has become customary, and quite rightly, to begin the story of community psychiatry in India with Dr. Vidya Sagar (Kapur 1971) who, in the late 1950s, started involving family members in the treatment of the mentally ill admitted to the Amritsar Mental Hospital. He did this for purely practical reasons; he had a 900-bedded hospital, which was extremely short of staff. He put up army surplus tents within the precincts of the hospital, and the relatives who brought in new patients were requested to stay on to assist in providing nursing care.

Subsequently, when asked to analyse the impact of his innovation, Dr. Vidya Sagar felt that the exercise achieved much more than he had initially hoped for. First, it reduced the hostility in the minds of the patients of having been abandoned in a strange place.

Secondly, when the family started seeing the patients getting better, it helped to remove the age-old myths about the incurability of mental illness. Finally, by taking group sessions, the relatives learnt the essential principles of mental health and were thus motivated towards improvement in their own ways of life. I was one of those who assisted Dr. Vidya Sagar in this experiment. What I remember most vividly is that many patients actually went back with their families and that the discharge statistics began to rise. All this happened before the era of major tranquillizers.

Tranquillizers:

The entry of anti-psychosomatic drugs in the late 1950s and early 1960s so dramatically controlled the agitation, aggression and withdrawal tendencies of the patients that it became possible to treat the mentally ill in general hospitals. Once again I was a participant in the new revolution, involved as I was in setting up a general hospital psychiatric unit in a medical college hospital during the mid 1960s. What I remember most is the surprise of the other hospital patients that the mentally ill were in fact like other people and responded to medical treatment. Even more interesting was the new sense of confidence in psychiatrists and a visible rise of their status amongst their fellow professionals. More and more graduates started taking up psychiatry as a career. Currently there are about 200 such units in the country (Murthy 1992).

Psychiatric camps:

The next logical step towards involvement of the community was the practice of holding psychiatric camps in remote villages (Kapur et al 1982). The reasons for holding such camps were the difficulty of taking patients to distant hospitals and the cost of travel. However, the main achievements of these camps were the involvement of community leaders and neighbours in the therapeutic process and reducing the stigma of mental illness. When one family was willing to have its sick member treated openly, it was easier for others to follow.

Further advances were the setting up, during the mid 1970s, of the National Institute of Mental Health and Neurological Sciences (NIMHANS) in Bangalore and the Post Graduate Institute of Medical Education and Research (PGIMER) in Chandigarh, where there were programmes to teach doctors and health workers in the primary health centres the skills for early recognition and management of mental illness (Kapur 1979, WIG et al 1981). The reasons for starting such programmes were practical; the country just did not have, nor was likely to have for decades, the necessary specialist staff to deal with all its severely ill psychiatric patients. What these programmes achieved, more than anything else, was the demystification of the phenomenon of mental illness. It was made obvious that a non-specialist doctor or a village health worker could do, after a short period of training, what previously only a highly trained specialist was expected to accomplish.

The success of these programmes was internationally recognized and they were emulated elsewhere both within and outside the country. The demystification process was carried forward at NIMHANS where the community members have been trained to recognize and follow up mentally ill patients (Rao et al 1990). NIMHANS also adopted a district in Karnataka to further develop this programme (NIMHANS Bulletin 1988). Parallel with the rural progress have been the developments in urban settings where general practitioners, school teachers and lay volunteers are being trained to recognize and manage mental

illness (Sham Sunder et al 1978, Kapur.M. 1988). There is still the problem of numbers. With 2% of the population suffering from severe mental disorders a great amount of time, effort and money is needed to spread these programmes across the country. However, this change which has taken just 40 years, has produced an upbeat feeling in the minds of mental health professionals. But the picture is not rosy.

Firstly, it has been discovered that while these training programmes run well in research situations, when tested in unsupervised situation they do not do so well. One study (ICMR 1987) which aimed at testing the impact of training the PHCs then leaving them to detect and treat the patients, showed that in fact the results were poor, both with respect to recognition and management of the patients. The main cause of poor response was poor morale of PHC staff and their preoccupation with other vertical programmes, like family planning.

Secondly, the success of such programmes, in best of conditions, also depends on the support and care which the family can provide. One is not sure whether the families in a situation of fast social change can be depended upon to provide such support.

Family and the care of the chronically ill:

In the 1960s a programme was stared in the USA and subsequently in other western countries to treat mentally ill patients outside mental hospitals. This programme was started, not because there was a shortage of mental hospitals but because of the new knowledge, which showed that long-term hospital stays could lead to chronicity. The programme involved the setting up of half-way homes, hostels and, most importantly, the treatment of patients in their own family settings through follow up visits by nurses and social workers. It was soon discovered that even rich western nations did not have sufficient funds to run the half-way homes and the domiciliary services. Above all, the family was just not willing to keep the patient. The result was that the patients were coming back to the hospitals through a kind of revolving door situation and if the re-admission policy was strict, they became homeless and roamed the streets. As recently as 1985, I saw disturbed psychiatric patients walking about in parks around Harvard University. I also read reports of patients who were violent on the streets and some who died of exposure. My first reaction was self-congratulatory. " Are we not so much better off in India where the family is willing to look after its own?" This reaction was short-lived because I soon discovered that a western family was not so much unwilling, as unable to do the caring. With the nuclear family being the norm, all able bodied people going to work and children going to school, who would look after the patients during the day or even at night, following a hard day.

Family care in India:

The tide is turning in India as well. There is an increasing migration to the cities, a gradual diminution of family size and fewer people available to stay at home to look after patients. Is it likely, even in India, that people will continue to look after the mentally sick when other pressures increase? The process of social change is going to become faster with the new economic philosophy. I am afraid that family support is not going to be as easily available in the future and if the community is interested in the welfare of the mentally ill, it will have to think of other means.

The writing is already on the wall. Wherever half-way homes for the chronic mental patients are available, they are running full and have long waiting lists. This, in spite of the fact that most places charge amounts which are more than the annual incomes of average Indian families. As I worry about this, I am appalled that almost all the mental hospitals of the country are vying with each other to give up their asylum function; the shorter the stay of the patient in the hospital, the more modern and scientific they are supposed to be. The space and services, which were reserved for chronic patients in the old fashioned hospitals, are dwindling away rapidly.

Just as 20 years ago, when we started innovative programmes for the treatment of the mentally ill, we must now start developing innovative programmes for the care of the chronic mentally ill patients. Before accelerating social change forces the family to deposit its chronic patient on the road, we must start planning for a roof over his or her head and arrange food, clothing and some recreation, to put some meaning into his life. This is too big a task to be left to the private sector. In spite of all the effort in the last 10 years, there are only about 250 places for chronic mental patients in private establishments. The funds required for even the minimal care of non-productive chronic mental patients are massive. The government will have to shoulder the responsibility and the planning process should start immediately. It is in this context that the giving up of the asylum function by the mental hospitals, which possess a lot of space as well as a fair number of nursing aides, seems so irresponsible.

Common mental disorders:

Epidemiologists will claim that while the prevalence rate of psychoses is 1% that of neuroses is 8% t 10%. This is perhaps true but if we include conditions such as substance abuse and personality disorders of various kinds in this category, the percentage will be even higher. It is also true that at least one-third of the patients who go to non-psychiatrists, suffer from psychological rather than physical illness. However, these conditions are not diseases in the usual sense of the term but an expression of their inability to cope with the difficulties of life. Most of these patients require psychotheraphy and social intervention rather than medicines or surgery. Unfortunately, there has been an increasing 'medicalization' of distress. The average doctor has neither the time nor the basic skills to deal with the stress, which has made the patient seek his help, and finds it convenient to prescribe tranquillizers. These, of course, work only temporarily and if used for a long time lead to dependence and abuse. What the patient needs is help in developing sensible coping strategies.

There was a time when society offered different kinds of support measures to the stressed, in the form of family elders, village mantarwadis (sorcerers) and temples. Stories from folklore and mythology were used to rouse a person to a meaningful existence in the face of life's trials. There were clear-cut values to live by. Social change has diluted these values and the stories which were effective before, now appear to be naïve and irrelevant. The situation is much worse in urban slums where the sense of alienation is even greater and social support less. What kind of community effort is needed to devise new social values and supportive links? Tranquillizers are not the answer and what we need urgently is an effective community education programme to fight the excessive use of these drugs. We must also focus on the drug company-general practitioner axis and counter the pressure that the companies exert to prescribe their medicines, a pressure which is in the form of subtle and not so subtle inducements.

Role of the mass media:

The media can obviously play a big role in the management of mental illness but unfortunately what one often sees behind an exercise is an attempt to titillate and shock at the cost of someone else's emotional pain. Education about mental health is a task of great responsibility and, before anything else, media persons who undertake this should themselves learn about the complexity of the human mind and the multifactorial nature of emotional disorders. What is required is a sacred partnership between professions and media persons, each giving and receiving an accurate feedback on this sensitive issue.

Promotion of mental health:

The promotion of mental health is too important a matter to be left to mental health professionals alone. There is a lot in our spiritual heritage as well as in textbooks of psychology which shows that faith and a life style compassionate to others can increase our stress tolerance. There is also evidence that consistent parenting and a schooling which provides meaningful challenges, without oppressing the child, can prevent the occurrence of mental disorders in later years (Kellam 19994). These principles strike at the very root of the civilization, which we see today -- a civilization, which is built on the edifice of greed and competition of power. Will this civilization destroy itself? We can see the difficulties involved when plans to cut down the depiction of sex and violence on the cinema and television screens meet with resistance, even when there is fairly conclusive evidence that symbolic violence of this kind promotes real life violence (Newson 1994). Good wishes and education programmes are not enough; we need firm political action.

REFERENCES

1. Bang AT, Bang RA. Community participation in research and action against alcoholism. *World Health Forum* 12, 104-109
2. Central Bureau of Health Intelligence. *Health Information of India*. 1992 D.G.H.S. Government of India, New Delhi
3. Chakravarti S, Rathanami L . Invasion of the foreign spirit. *India Today* 1995, May 15:175-177.
4. ICMR . *Collaborative study of severe mental morbidity*. Indian Council of Medical Research and Department of Science and Technology. 1987
5. Kapur M. Decentralization of the mental health care. *Health of the Millions* 1988;14.
6. Kapur RL. Priority in mental health workshop on priorities in developing countries. *Indian J. Psychiatry* 1971;13:175-82.
7. Kapur RL., Chandrashekhar CR, Shamsundar C, Isaac Mohan K, Parthasarathy R, Shetty S, Extension of mental health services through psychiatric camps: A new approach. *Indian J. Psychiatry* 1982;24:237-41.
8. Kapur RL. Community therapy. *Bull NIMHANS* 1979.
9. Kapur RL. Mental health care in rural India: A study of existing patterns and their implications for future policy. *Br J. Psychiatry* 1975;127:286-93
10. Kellam SG. The course and malleability of aggressive behaviour from early first grade to middle school: Results of a development epidemiologically based preventive trial. *J. Child Psychol Psychiatry* 1994;35:259-81
11. Newson E. Video violence and the protection of children. The *Psychologist* 1994 June
12. *NIMHANS publication*. Minimum standards of care in mental hospitals: Recommendations and Report :2000
13. Patel V (forthcoming) *Poverty, inequality health in developing and mental countries*: Oxford Press.
14. Rao M, Chadrashekhar CR, Parthasarathy R, Srinivasa Murthy R. Community participation in mental health through village leaders: An initial observation. *Swasth Hind* 1990;34:45-6
15. Shamsundar C, Kapur RL, Sundaram UK, Pai s, Nagarathna GN. Involvement of the general practitioners in urban mental health care. *J. Indian Med Assoc* 1978;71:310-13
16. Shah G, Suicide Prevention in India. In Global Trends in Suicide Prevention: *Toward the Development of National Strategies for Suicide Prevention* (eds RF Ramsay & BL Tanney) Tata Institute of Social Sciences 1996;233-252
17. Weiss M, Desai A, Jadhav S, Behre P, Gupta L. Paper presented at conference on permanence and change in Asian Health Care at the annual meeting of the American Anthrolpological Association, Washington D.C., December 1985.
18. Wig NN, Srinivasa Murthy R, Harding TW. A model for rural psychiatric services: The Raipur Rani Experience. *Indian J. Psychiatry* 1981;23:275-90.
19. Wing JK. Institutionalism in mental hospitals. *Br J, Soc. Clin. Psychol.* 1962;1:38-51
20. World Bank Report: *Investing in Health*: 1993. Oxford University Press, New York.