

LETTERS TO EDITOR

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LESSONS FROM THE ERWADI TRAGEDY FOR MENTAL HEALTH CARE IN INDIA

Sir,

The death of 26 persons with mental illness killed in the tragic fire accident on 6th August 2001 has again focussed the need for organised mental health care in the country. The response of the general population, the administrators, the politicians, the press and the professionals has been one of shock and outrage. The response to the single incident has been manifold. The press has seized the moment to throw light on the larger issues of mentally ill persons. Some of them have written about situations similar to ERWADI in Hyderabad, Ranchi, Ahmedabad, and Patiala. The National Human Rights Commission has called for a Report. The Supreme Court has initiated action on the matter. As a result, it can be expected that there will be many changes not only in Erwadi but also in the different parts of the country. There is need to view the tragedy in the larger perspective of the country situation and a longer time frame.

The inhuman conditions in which persons with mental disorders are cared for were the focus of a NHRC Report (1999) released last year. The observations of the NHRC about the mental hospitals is very similar to the conditions in Erwadi as seen from the following excerpts from the Report. "38% of the hospitals still retain the jail like structure that they had at the time of inception... nine of the hospitals constructed before 1900 have a custodial type of architecture, compared to 4 built during pre-independence and one post-independence... 57% have high walls ... patients are referred to as inmates` and persons in whose care the patients remain through most of the day are referred to as `warders` and their supervisors as overseers` and the different wards are referred to as enclosures`. (p.32)... overcrowding in large hospitals was evident...(p.34).....the overall ratio of cots:

patient is 1:1.4 indicating that floor beds are a common occurrence in many hospitals (p37)..... in hospitals at Varanasi, Indore, Murshadabad and Ahmedabad patients are expected to urinate and defecate into open drain in public view(p38)....many hospitals have problems with running water...., water storage facilities are also poor in 70% of hospitals... lighting is inadequate in 38% of the hospitals.... 89% had closed wards while 51% had exclusively closed wards.... 43% have cells for isolation of patients(p.39)....leaking roofs, overflowing toilets ,eroded floors, broken doors and windows are common sights (p.44)....privacy for patients was present in less than half the hospitals... seclusion rooms were present in 76% hospitals and used in majority of these hospitals... only 14% of the staff felt that their hospital inpatient facility was adequate(p.47)...in most hospitals case file recording was extremely inadequate.....less than half of the hospitals have clinical psychologists and psychiatric social workers...trained psychiatric nurses were present in less than 25% of the hospitals...(p.48)....even routine blood and urine tests were not available in more than 20% of hospitals... 81% of the hospital in-charge reported that their staff position was inadequate(p.54)."This is the situation in 1999, somewhat similar to the situation in the hospitals in Western countries at the end of the 19th Century!

The report notes "the deficiencies in the areas described so far are enough indicators that the rights of the mentally ill are grossly violated in mental hospitals"(p.50). As recommended by the NHRC, there is an urgent and massive need for change in the situation relating to mental hospitals, to become centers of care and treatment rather than be custodial institutions.

The current attempt is to place this bigger picture and identify a variety of areas for intervention.

THE ISSUES

There are FIVE issues that relate to the tragedy, namely (i) the beliefs of the general population; (ii) the reasons for chronicity and

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disability of the mentally ill persons; (iii) the needs of the families (iv) how care should be provided to the persons with mental disorders and (v) state responsibility and regulation of services.

1. BELIEFS OF THE COMMUNITY:

A survey carried out in the mid 1990 s in Trichy with 198 patients attending a psychiatric facility, 45% had sought treatment between 1-15 sessions from either Hindu, Muslim or Christian healers. 49% of the rural patients had sought religious healers care as compared to 39% from the urban areas. The proportion of patients seeing a healer was inversely related to the monthly income. (Campion and Bhugra, 1997). In a recent study (Srinivasan and Thara, 2001) found that the beliefs about the supernatural causation of schizophrenia was seen only in 12%. Family members who had been educated more often named heredity or multiple causes and those with less education more often named supernatural forces as a cause. They conclude that the causal attribution related to the education level and contact with health services. In a similar study in 1999, from Bangalore, Chennai, Delhi, and Mamba, (Srinivasa Murthy et al., 2001) similar observations were reported. Thus it is important to recognise that the belief in non-medical explanations is more a function of education, place of residence, availability of information and access to proper mental health care. The Importance of stigma has been refferred by others (Wig, 1977; Thara & srinivasan, 2000; Weiss et al., 2001)

2. CHRINICITY AND DISABILITY:

The groups of patients in Erwadi and many patients in mental hospitals are there because of long-standing illness and their inability to care for themselves. This often gives the impression that mental illnesses are incurable and life long. This is not true, especially when the illness is diagnosed early in the illness and provided proper treatment. schizophrenia, often associated with chronicity, is seen as only one short episode with complete recovery in nearly third of the ill persons. Only about 10% need long term care. Further, studies from a number of centers in India have

shown that the disability was less in those receiving treatment. Factors contributing to chronicity and disability are (i) delay in seeking treatment, (ii) irregularity and incomplete treatment, (iii) lack of support from family and (iv) inadequate rehabilitation support. All of these are areas suitable for intervention by public health measures. For the large majority of the mentally ill person's life long illness or disability is totally avoidable. The groups of patients reaching mental hospitals, the religious places for custodial care are either due to neglected care or for social reasons like elderly parents and non-existence of caring relatives. This is not to deny that due to illness and social reasons there will be a proportion of the ill persons who will need support in protected places. This number is small. India has about 30000 psychiatric beds. As we know more than half of the beds in the mental hospitals are for care of long term patients. Even if we were to consider that the average stay is about one month, we have about 180 000-bed months. A very conservative estimate of people requiring hospital care, at sometime, would be not less than 2 per thousand, which means for the 1 billion population there is need for 2 million bed months are needed. The available 180 000-bed months for acute inpatient care is less than 10%. This is assuming that all the stay is short duration. Thus it would be appropriate to say that the inpatient care is available to about 10% of the very ill persons. Majority of the persons with illness are living in the community and receiving support mainly from the families.

3. FAMILY SUPPORT:

The majority of the mentally ill live with the families in India. Families have been a part of the care program for a long time. In the last 50 years, efforts have been taken to involve them in care during the period of hospitalisation, educational programs for the family members have been organised, partnership between professionals and families have been formed and self-help groups of families have come up in a number of cities. In a way the current primary carers of the mentally ill are the families. What the families need is support

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to carry on doing what they feel they want to for their ill family members, with support from the professionals and the state. As pointed out above (under 2) the numbers not cared for and sent to institutions is less than 1 in 10. It is important to not blame the families for leaving their responsibility. They are doing an excellent job of their responsibility. They need recognition and support to carry on providing the care.

4. CARE FOR THE MENTALLY ILL PERSONS:

The developments in the 20th century have changed dramatically the concepts of mental health care as a result of new knowledge about mental disorders, treatment choices and a better understanding of prevention of mental disorders and promotion of mental health. Overall, there has been a shift from mental illness to mental health. In the field of mental health care, since the World War II, supported by development of specific therapeutic advances, care of the mentally ill in non-institutional settings has been the focus of attention. This approach referred to as 'community psychiatry'. This approach is practiced both in the developed and developing countries.

During the last 50 years, in India, the place of mental health as part of the general health has significantly changed. From a situation of no organised mental health care at the time of Independence, currently, mental health issues are actively seen as part of the public agenda in the various forms. Some of the examples are (i) the formulation of the National Mental Health Programme (Govt. of India, 1982), (ii) integration of mental health with primary health care at the district levels, (Govt. of India, 2000) (iii) the adoption of Mental Health Act, in 1987, and Persons with Disabilities Act in 1995, (iv) Supreme Court judgements about mental hospitals (v) voluntary agencies initiatives in the areas of self-help groups, rehabilitation, drug dependence and suicide prevention and (vi) wide media coverage of mental health issues (DATE on radio in 1992, Mindwatch on TV in 1997) (vii) the NHRC Report on the quality of care in the mental hospitals (NHRC, 1999), (ix) the proposed allotment of Rs.220 crores for mental health during the 10 Five year Plan. The overall

effect has been the movement to recognise mental health as an important issue in the community and services to move beyond mental hospital care to care in the community. Mental health professionals in India have viewed community mental health as not only care in the community but also care utilising the community resources, in other words care by the community.

The NATIONAL HEALTH POLICY (NHP) (1983) refers to mental health care as follows: "Special well coordinated programmes should be launched to provide mental health care as well as medical care and also the physical and social rehabilitation of those who are mentally retarded, deaf, dumb, blind, physically disabled, inform and the aged". The National Mental Health Programme was formulated in 1982 (Government of India, 1982) with the following objectives of (i) to ensure availability and accessibility of minimum mental health care for all in the foreseeable future, particularly to the most vulnerable and underprivileged of the population; (ii) to encourage application of mental health knowledge in general health care and in social development and (iii) to promote community participation in mental health services development and to stimulate effort towards self-help in the community. The specific approaches utilised for the implementation of the NMHP are:

1. Diffusion of mental health skills to the periphery of the health service system.
2. Appropriate appointment of tasks in mental health care.
3. Equitable and balanced territorial distribution of resources
4. Integration of basic mental health care with general health services
5. Linkage to community development.

During the last few years, the District Mental Health Programme (DMHP) has been launched at the national level. This was the outcome of the meeting of the Central Council of Health in 1995, and the recommendation of the Workshop of all the health administrators held in February 1996 at Bangalore. The DMHP was launched in 1996-1997 in four districts, one each in Andhra Pradesh, Assam, Rajasthan, and Tamil Nadu, with a grant assistance of 22.5 lakhs each. A budgetary

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allocation of Rs.28.00 crores has been made during the Ninth Five-Year Plan period for the National Mental Health Programme. The current programme envisages:

" a community based approach to the problem, which includes (i) training of the mental health team at the identified nodal institutes within the State; (ii) increase awareness in the care necessity about mental health problems; (iii) provide services for early detection and treatment of mental illness in the community itself with both OPD and indoor treatment and follow-up of discharged cases and (iv) provide valuable data and experience at the level of community in the state and Center for future planning, improvement in service and research. GOI, 2000).

The DMHP was extended to 7 districts in 1997-1998, five districts in 1998 and six districts in 1999-2000. Currently the programme is under implementation in 22 districts in 20 states. It is proposed to be extended to 100 districts in the 10th Plan period.

The area of REHABILITATION for the patients with various forms of disabilities due to mental disorders is making beginnings in the country. Centers of day care, half-way homes and long-stay facilities are coming up gradually, especially in the big cities. Two masters program for training rehabilitation personnel at Richmond Fellowship Bangalore and at the Father Muller Hospital, Mangalore has been started. However, there is gross shortage of these facilities leading to greater burden on the families and further deterioration of the ill persons.

5. STATE RESPONSIBILITY: The Mental Health Act 1987 places the responsibility for planning and monitoring on the state. It has also structures to carry out the functions. Unfortunately, not all states have formed the State level mental Health Authority and initiated the process of planning of state health services, licensing of the hospitals and related matters. The full implementation of the provision of MHA 1987 would go a long way to meet the needs of the mentally ill persons. In the country, there is greater growth of private sector psychiatry than the public sector investment in

mental health care. For the rural population, for the poor, the marginalised groups the state has the main responsibility to organise care.

AGENDA FOR FUTURE

India is one of the countries to develop many innovative approaches to mental health care. This leadership should be maintained in the coming years. The advances in the understanding of human behavior and mental disorders justify the optimism of developing meaningful and realistic mental health programs. It is mandatory to bring the fruits of science to the total population of India. The barriers of lack of awareness of the general population, the occurrence of chronicity and disability, the burden of families providing care, the lack of institutional infrastructure can be addressed by following measures.

1. The wide variations across the states of India demands that plans are developed for each of the states and union territories, besides a national plan and program. There is a need for a central and state level mental health departments in the health ministries.
2. All the psychiatric care facilities should be upgraded in terms of trained personnel, treatment and rehabilitation facilities, living arrangements and community outreach activities. All the medical colleges should have independent departments of psychiatry to ensure adequate undergraduate training in psychiatry. The current amount of training in psychiatry to medical students should be increased.
3. All districts in the country should have full mental health teams, as part of the district hospitals and the district health office. There should be at least a 10 bed separate psychiatry ward in each district hospital. Integration of mental health with primary health care should be achieved to facilitate early identification of patients, regular treatment and reintegration into the community. This can be achieved by training of all the primary health care personnel, provision of essential drugs at all the health facilities, inclusion of mental health in the regular health information system. All general hospitals should have separate psychiatry wards.

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4. All the Mass media should be utilised fully for public education about mental disorders. This effort of public mental health education should be a continuous effort for the next few years.

5. Support from the government for the families of the mentally ill persons in terms of community based services, respite care, and help in acute emergencies, financial support for care, formation of self-help groups should be provided. The full implementation of the Persons with Disabilities Act 1995 and the facilities that are available to physically handicapped (reservation for employment, social benefits, travel facility etc) should be available to the persons with mental disorders.

6. Special schemes to support the voluntary agencies to take initiatives towards treatment and rehabilitation of mentally ill should be initiated. The involvement of education, labor and welfare in the developing mental health programs is valuable.

7. Planned mental health manpower development by increasing the centers of training and creating opportunities for employment of the trained professionals should be made. Research on issues central to the understanding and treatment of mental disorders should receive support from the Indian Council of Medical Research.

The very unfortunate tragedy at Erwadi throwing the spotlight on the needs of the persons with mental disorders could be utilised to bring the best of the available new knowledge so that the ill individuals and their families can receive the support needed towards a better quality of life. The road is long and calls for continuous effort but it is never too late to start. If not overnight, we can bring about changes over time and prevent tragedies like that at Erwadi.

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