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DR. D.L.N. MURTI RAO ORATION

THE FORGOTTEN MILLIONS

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ABSTRACT

Millions of chronic mentally sick are living in this country without proper care. Human rights of most of these patients both for treatment and for leading a life of dignity have been seriously abrogated. This oration discusses the extent of the problem & reviews the work done in this area in India and abroad. Major emphasis is to develop a programme for destigmatization of mental illness and to develop suitable models of care for chronic mentally sick keeping the realities of Indian situation in mind. The proposed programme emphasises on multi modal care of the mentally sick and involvement of local self government institutions like panchayats & municipal corporations.

Key Words : Chronic, mentally ill, rehabilitation

Chairperson, fellows and members of the Indian Psychiatric Society, Ladies and Gentlemen.

At the outset I must express my gratitude to our society and the members of award committee for bestowing this honour on me.

This oration is being delivered in the memory of late Prof. D.L.N. Murti Rao who was pioneer of psychiatric education in India. He was well-known for his clinical acumen and teaching skills. Destiny intervened and I missed being his student as he left for his heavenly abode on the day I went to join the All India Institute of Mental Health 35 years ago.

This year our country is celebrating 50th year of independence and our society 50th year of its existence. It's time for introspection and to think how far have we come and where we want to go.

Father of the nation Bapu stated " True freedom will only come when there will be no tears in any eye". Have we reached anywhere near his dreams? Have we achieved freedom for the chronic mentally sick?

The title of my oration is " **The Forgotten Millions**" I have chosen this topic due to following reasons :

(a) acute care is being provided reasonably but the chronic patients are being neglected even by the professionals,

(b) enactment of the person with disabilities act, 1995 provides us with a unique opportunity to improve the lot of chronic mentally sick,

(c) WPA's (World Psychiatric Association) initiative regarding removal of stigma of mental illnesses can only be achieved if one can provide adequate care to the chronic mentally sick.

I start this oration by recounting two case histories which have always haunted me.

"Mrs S. was living in my native village in the foothills of Himalayas. She has been left by her husband because of recurrent manic-depressive psychosis. Whenever I used to visit my village, I used to give her some medicines for the same. At that point of time lithium was not available in this country. She had to be treated with antipsychotics and antidepressants. Once I could not visit home for a year or so and when I reached next I enquired about her condition from her brother. He informed me that since the patient was getting repetitive episodes it was impossible for

him to take care of her, so he dressed her in saffron clothes and took her to Rishikesh and left her in deep forest, hoping that either some wild beast would kill her or some saintly people may keep her in their ashram. Since then nothing is known about her.

Another young man around 28 yrs of age was suffering from chronic schizophrenia. The family tried to obtain medical help for few years. As no appreciable benefits could be discerned the family allowed his wife to cohabit with his younger brother. All his property was transferred in the names of other family members. Later the family put him on a south bound train. Since then nothing is known of this patient.

These illustrations graphically reveal the disposal of the chronic mentally ill in this country. Millions of our chronic mentally sick brethren are living in a state of neglect, degradation and deprivation. They are neither getting proper medical treatment, nor humane care and their rights are being systematically abrogated. In this oration I plan to broadly assess the extent of the problem, and review the research data available from India and abroad. I will conclude this talk by focusing at what we can do with the existing resources for the betterment of this large mass of suffering humanity.

What is chronic mental illness ?

Conceptualizing chronic mental illness is not difficult but defining it is a problem as the concept encompasses different forms of mental illnesses with a wide clinical spectrum and altogether different duration criteria for chronicity. Clinically a comprehensive definition seems to be, "a group of patients who have suffered repetitive or continuous episodes of mental illness and are left with certain residual symptoms as well as deficits affecting personal, family and occupational life. Response to treatment in such individuals vary with most being non-responders or partial responders". Researchers have shown that many of these patients can show improvement even after long periods of chronicity.Most chronic mental patients belong to the categories of :

- schizophrenia
- affective disorder
- personality disorders
- organic psychoses including traumatic conditions, epilepsy and dementias
- neurotic disorders especially obsessive compulsive disorder and anxiety disorders.

The focus of this presentation has been limited to schizophrenia and affective disorders, for they constitute a large population of chronic mental sickness and large data is available regarding their long term care.

Extent of problem

The prevalence of schizophrenia varies from 2-3/1000 all over the world. Indian workers have also reported similar rates ranging from 0.9 to 4.3/1000 (Sethi et al., 1967; 1972; Dube, 1970; Elnagar, 1971; Thacore et al., 1975, Verghese et al., 1973; Nandi et al., 1975). Recently incidence of schizophrenia has been studied in India (Raj Kumar, 1995-3/10,000 in urban slums, Sartorious et al., 1986-4.2/ 10,000 in rural areas, Wig et al., 1997-4.4/ 10,000 in rural areas and 3.8/10,000 in urban areas). Based on the above one can easily estimate that there will be approximately 2 million persons suffering from schizophrenia at any given time.Kulhara (1997) estimates that 4,05,000 new cases of schizophrenia are being added every year.

Though the outcome of schizophrenia was observed to be better in developing countries including India than the western countries (Brown et al., 1966; Murphy & Raman, 1971; Kulhara & Wig, 1978; ICMR, 1988; Jablensky et al.,1992; Thara et al., 1994) yet nearly 40 to 60% patients of schizophrenia do have some impairments.

Affective disorders are now conceptualized as chronic illnesses and the earlier notion of a better prognosis is being replaced with the acceptance of the fact that very few patients of

affective disorder have a single episode and majority have relapsing course and 10-20% have chronic course (Stephens, 1978; Keller, 1982; Keller et al., 1984). Overall lifetime prevalence for major depression has been found to be around 5% (ECA study).

Indian researchers showed that the prevalence rates of depression in general population vary from 1.5 to 37.74/1000 (Sethi et al., 1972; Nandi et al., 1975)

The prevalence rates of MDP are reported to be 1.3/1000 (Dube, 1970) and 16.9/1000 (Bhide,1982), Venkoba Rao and Nammalvar (1977) followed up 109 patients for 3-13 yrs and showed that only 28% had single episode and chronicity was observed in 11 patients. The foregoing clearly reveals that number of chronic affective disorders would also be very large in the general population.

Most of the western researchers have been preoccupied with the hospitalized mentally sick as in most of these countries every chronic mentally sick had a chance to get admitted.While in India with the availability of one bed/32,500 population (Radhashankar, 1991) there are very little chances for chronic mentally ill to gain admission. Therefore the focus of care of chronic mentally ill in India will be on patients living in the community. This situation has its advantages and disadvantages. The advantages are that many of these patients will not have deleterious effect of prolonged hospitalization. Secondly, their community and family contacts may be still viable. The disadvantage is that they are scattered all over this vast country and may be living in different states of neglect.

Clinical characteristics of chronic mentally sick : Large number of researchers have studied chronic schizophrenia for its cognitive, behavioural and symptomatological characteristics. Similar extensive work on affective disorders is lacking. Most early researches emphasized on chronicity in schizophrenia and few went to the extent to state that if a patient improves than the diagnosis of schizophrenia should be reviewed. Harding (1995) while reviewing long term course of schizophrenia strongly refuted the concept of permanent chronicity. Citing his own studies (Vermont longitudinal study) and ten other recent studies where schizophrenic patients were followed for 2-3 decades he concluded that there is a wide heterogenity in outcome of schizophrenia. He stated that patients are likely to improve even after 20-30 years of chronicity. Schizophrenic patients show a continuous developmental effort due to which many would improve. Ciompi (1980) demonstrated that 33% of their patients were restored to social functioning after an average period of 37 years. Huber et al. (1980), Harding et al. (1987) & Ogawa et al. (1987) showed similar improvement rate. APA, 1989 predicted that after 10-20 yrs of hospitalization 60% would socially recover.

The above very clearly illustrates that the hopeless attitude of the psychiatrist largely based on short term outcome studies needs to change. The improvement in chronic mentally sick is largely dependent on the doctor's optimism and his relationship with the patient. One public education pamphlet in India on schizophrenia compares it with cancer which is likely to produce negative attitude in patients, relatives and doctors.

Vaillant (1975) stated that " prognosis and diagnosis are two different dimensions of psychosis".

Harding and Strauss (1984) stated that, "the longitudinal picture of course reveals nonlinear patterns and trends.The individual has been documented as an active, developing person in interaction with his or her environment. These, important modifiers reshape the course of illness and the persons life in which schizophrenia is but a part."

The schizophrenic patients have been shown to have cognitive deficits mainly in the form of poor attention, memory and abstraction (Wallace, 1993). It has also been demonstrated that the rehabilitative potential varies directly with the amount of

cognitive deficit (Wallace,1993; Rund, 1994). Most of these patients will also show some negative and positive symptoms which may be further complicated by depression and difficulty in personal, social and occupational adjustments. Many researchers conceptualize some of the negative symptoms as coping strategies (Ciompi, 1980; Hoffman, 1995). The importance of this observation is that these negative symptoms could improve with improvement in positive symptoms and negative symptoms may not be considered permanent or secondary to neurophysiological deficits.

The schizophrenic withdrawal may be an attempt of the patient to avoid disturbing hallucinations and delusional experiences.

Coping strategies have also been studied in India by Kumar et al . (1989), Kumar and Srinivasan (1992) & Raghuram (1993).

The schizophrenic patients thus are involved in a struggle in negotiating between the world as others know it and the world of their own inner reality (Hartfield, 1989).

Persons with chronic affective disorders due to repetitive episodes of the illness have to undergo multiple disruptions and according to one estimate person who had first episode at the age of 20 years is likely to spend 14 years of their adult life in illness episodes.

Those having bipolar disorders have much more disruption in their personal, occupational and family life. Quite often such patients loose their job, develop marital difficulty and slide down the socioeconomic ladder. If chronic depression or chronic mania persists then life becomes much more stressful due to which quite a few commit suicide and others are admitted in institutions for long term care.

MANAGEMENT STRATEGIES

Pharmacotherapy : Last few decades have very clearly demonstrated the effectiveness of pharmacological treatment both for affective disorders and schizophrenia. Two points which have been emphasized in the literature are :
(i) early and prompt treatment can reduce chronicity,
(ii) continuous treatment is required for most relapsing patients and the treatment may be required life-long (Schultz, 1995).

However these research insights have not been put into practice and there is a dire need for rational drug treatment.

In schizophrenia the new focus on atypical antipsychotics in schizophrenia has revolutionised the management. Most patients who were earlier treated with traditional antipsychotics suffered from extra pyramidal symptoms. Troublesome side effects like akathisias led to large scale drug non-compliance. Secondary negative symptoms and depression were also attributed to these drugs. Though long term efficacy of the atypical antipsychotics is not yet fully established but the expectations are that these drugs would control the symptoms with minimal untoward effects. The rational drug treatment for schizophrenia should include minimal effective doses, with once a day prescription and energetic management of side effects to make the drugs more acceptable, tolerable and effective.

Pharmacological management of recurrent affective disorders both unipolar or bipolar, is much more unsystematic than schizophrenia. Most patients are being treated with antidepressants or antimanic agents repetitively in each episode for inadequate duration and often in inadequate dosage resulting in rapid cycling, drug refractoriness and chronicity. It has been shown that recurrent depression leads to sensitization and may induce permanent biological changes which can be prevented by proper prophylaxis (Post, 1995). It is therefore recommended to use mood stabilisers for bipolar patients and long term antidepressants or mood stabilisers for unipolar patients.

Such research findings some how do not reach the average practitioner. It is imperative that pharmacological strategies should be such that repetitive episodes could be avoided.

Psychosocial management : Psychosocial management of chronic mental sickness varies from country to country and has changed with time. Beck (1811) opined that best place for such patients is in asylums. "Moral treatment consists in removing such patients from their residence to some proper asylums and for this a calm retreat in the community is preferred, for it is found that continuance at home aggravates the disease, as the improper association of ideas can not be destroyed. It will also be proper to forbid their returning home too soon. Hospitals are the only places where insane persons can be at once humanely and properly controlled". Since this observation of Beck, the scene in mental health care has completely changed and there is a strong movement towards community care and rehabilitation. Based on well documented research there is a mood of sceptic optimism regarding community care of chronic mentally sick.

Italian government took a comprehensive policy decision for closure of mental hospitals in 1978. Assessing the success of commmunity care strategies in Italy, Sarceno & Frattura (1990) have observed that it has been quite successful in the north of country while less so in the central part and miserable in the south which largely depended on the availabilty of personnel and infrastructure facilities indicating that the community care of the mentally ill requires carefull planning and sufficient resources.

Four years follow up of chronic mentally ill in Denmark (Eikelman and Reker, 1991) showed that 50% were living in sheltered community, 25% on their own and 10% have returned to the hospital for long term care. Very few patients were able to get job in open market but vast majority could work under sheltered condition. Lang et al. (1997) followed up patients who were inpatient in mental hospital for atleast 5 years found that 59% had again become inpatient and 23% had been living in supported accomodation.

Thorncroft et al. (1991) studied patients transferred from a large mental hospital in London to a rehabilitation unit. There was no difference in symptoms in two groups but transferred patients had a better social outcome and behaviour.

Most long-term researchers on chronic mentally sick have come to the conclusion that there is a core group of patients who still require hospital care inspite of the availability of comprehensive community care. Lawrence et al. (1991) while comparing admission rates in 3 different hospitals concluded that there is a bed rock of illnesses which will always need inpatient care however comprehensive the community resources are.

Lelliott et al. (1994) conducted a national audit of new long-term psychiatric patients in United Kingdom and showed that younger new long-stay patients (18-34 yrs of age) were predominantly suffering from schizophrenia, were single and had history of serious violence or dangerous behaviour. The older new long-stay patients (age 55-60 yrs) were predominantly married women with diagnosis of affective disorders or dementia with poor personal and social functions.

The foregoing very clearly emphasize the fact that some patients would always require prolonged hospital care and early claims of closure of all the mental hospitals may not be practically feasible.

Wasylenki et al. (1989) identified following components of care required for schizophrenic patients :

- medical-psychiatric services - which include family physicians, a comprehensive biopsychosocial approach to psychiatric care, and a variety of hospitalization options,

- community housing, a critical and often overlooked environmental component of rehabilitation planning,

- a variety of systematized, psychosocial interventions : these include social therapeutic clubs, social network therapy, and self help groups, all of which attempt to address the severe social deficits associated with chronic

schizophrenia. In addition specific attention must be paid to vocational and educational issues and financial services,

- interagency coordination and advocacy, to ensure that all individuals with long-term mental disabilities receive appropriate treatment and rehabilitation.

Family management : Family management has been comprehensively studied in chronic schizophrenics and follow up studies clearly show the superiority of drugs and family intervention to drugs alone (Leff et al., 1982; 1989; Faloon et al., 1982; Mc-Creadie et al., 1991). Essential components of family intervention include psychoeducation, problem-solving, improving communication, dealing with emotional issues, reducing contact and reducing expectations.

Though these interventions require more time yet these are cost-effective when all the direct (Tarrier et al., 1991) and indirect (Cardin et al., 1986) costs of chronic mental illness, its treatment and disabilities are included.

Family and the illness : As there are very few mental hospital beds available in the country, 90-95% of all chronic mentally sick are being cared or uncared by their families. In earlier times family was conceived as pathogenic. Now the emphasis is on the interaction within the family and between the family and patient. Western researchers have emphasized the role of expressed emotions and overinvolvement as the key issues in the relapse (Brown et al., 1966; Leff et al., 1989; Vaughan & Leff, 1976; Vaughan et al., 1992). Similar findings have been replicated by Indian researchers. Suman et al. (1980) have studied psychosocial problems of family and concluded that following problems are frequently seen :

- high level of expectations
- excessive emotional involvement
- problems related to long-term treatment
- lack of understanding of patients residual symptoms and
- problems related to marriage and rehabilitation.

Most Indian families continue to harbour hope of full recovery, expect cure by marriage and are unable to come to term with deficits which may lead to lower category of employment. Mental illness is considered shameful for the family which has to be hidden. Indians can go to any extent to hide the mental illness in the family and would like to marry the mentally ill at earliest opportunity.

Family burden has been defined as effect of the patient on the family (Goldberg and Huxley, 1980). Various aspects of the burden on the family have been studied - financial burden (Hoeing and Hamilton, 1966; 1969; Pai & Kapoor, 1981), social discrimination (Claussen and Yarrow, 1955), restriction of social and leisure activity (Grad and Sainsbury, 1968), effect on health of others (Brown et al., 1966). Family burden has been studies in India by Pai & Kapoor (1981), Gautam and Nijhawan (1984) Rangarao (1988), Mubarak Ali and Bhatti (1988) & Gopinath & Chaturvedi (1992). These studies indicated that poor self care, inactivity and slowness were more distressing to family than violence.

Most distressing concern of the family of chronic schizophrenic is their fear of the future. Most parents worry as to what would happen to their sick child after them which is more so for girls. Many even go to the extent of requesting the psychiatrist " could she not die?" To cite an example - a 75 year old man suffering from prostatic cancer has a chronic schizophrenic daughter who has been divorced by her husband. His biggest worry is who will look after his daughter after his death. Though he has sons yet he is sure that they are not going to care for their sister. It brings into focus the myth that the Indian families can care for the chronic mentally sick. Clinical experience indicates that parents and the female spouse of chronic mentally sick do care for them while others try to get rid of them as fast as possible. Exception to this rule are definitely there.

Inspite of all such problems many Indian workers have lauded the role of family in the management of chronic mental sickness. The movement started with Dr. Vidyasagar at Amritsar who involved the families in the treatment of patients admitted in mental hospitals. In our setup families are usually an integral part of management of chronic mentally sick.

Social skill training : This highly structured form of psychotherapy usually given in groups is based on behavioural and learning theories and has been widely researched and practised for the treatment of social disabilities in chronic mental illness particularly schizophrenia (Benton & Schroeder, 1990; Hogarty et al., 1991; Backer et al., 1986 & Wallace et al., 1980). User friendly modules of social skill training have been devised and it has been found that it is effective in making chronic mentally ill to learn basic conversation skills (Bellack & Mueser, 1993) and also skills related to sexual behaviour (Lukoff et al., 1986), job finding (Jacobs, 1988; Kramer & Beidel, 1982) or medication management (Eckman et al., 1990)., The problem with this type of training is not of effectiveness but of sustenance of effect as most of such interventions have been of short term which may lead to loss of gains over a period of time.

Case management : Case managers are proponents of continuity of care. Continuity of care means that the patient should continue to receive orderly, uninterrupted service from diverse elements of service delivery systems. However even in the west this continuity of care seems to be inadequate. Stein (1992) emphasized on the current scene " non system of mental health care which involves interventions and programmes which are uncoordinated, non-collaborated and often in competition with each other". However Test (1984) has observed that assertive forms of clinical care management are effective in coordinating care, minimizing relapse and recidivism and maintaining community tenure.

In United Kingdom a concept of core-care giver has been evolved. The core care giver is responsible for total care of the patient. Identifying one mental health professional for long term care of each patient seems an important development in the area of continuity of care.

Vocational rehabilitation : Hospital based vocational programmes increase institutional dependency (Bond & Boyer, 1988) and are now regarded as ineffective. Similarly sheltered workshops have a disadvantage that these fail to increase person's self-esteem and competence, though these may be used as transitional phase preceding full vocational rehabilitation strategy (Jacobs, 1988), but for some seriously compromised patients it may be the only option available.

In India the concept of psychosocial rehabilitation is in it's infancy. However there have been number of efforts from various centres in the country. Most comprehensive efforts have been made by Schizophrenia Research Foundation, Chennai founded by Dr. M. Sarda Menon. Many other institutions and some non governmental organisations are also active in this field.

The Schizophrenia Research Foundation has evolved an intervention schedule, the result of which have been presented only in terms of general inferences (Radhashankar & Sarda Menon, 1993).

Nagaswami et al. (1995) indicated that 50% of chronic schizophrenic's families wanted economic assistance. Most families demand for total cure and making their patient fit for competitive employment (Radhashankar & Sarda Menon, 1991).

Reasons for the neglect of chronic mentally sick : One of the main reasons for the neglect of the mentally ill is the problem of stigma associated with mental illness (Wig, 1997). For destigmatization to be successful we must first focus on what causes stigma.

Most stigmatising illnesses were

tuberculosis, leprosy, and sexually transmitted diseases and the reasons for their stigmatization were - (a) the illnesses were considered chronic and incurable, (b) they could be dangerous because they could infect the healthy around them, (c) they were acquired due to bad deeds of the individual, (d) such individuals were not expected to hold any position of responsibility.

The stigma of tuberculosis has completely disappeared and to a large extent that of leprosy too. The reason behind this destigmatisation is development of prompt treatment, reduction of threat of infections to their healthy neighbours and scientific elaboration of the etiology.

If we think similarly about mental illness, the cause of stigmatisation of mental illness seem to be the following.

The general population believes that (a) mental illnesses are chronic and incurable, (b) mentally ill are impulsive and dangerous as they can produce physical harm to people around them. Institutions where mentally ill are treated further this belief. The patients are kept behind high walls to protect the society from them, (c) mental illness is caused by "bad blood" in the family or due to "bad deeds" in this life or past, (d) mentally ill can not be given positions of responsibility as they are unreliable and incompetent. Most government services bar mentally sick from seeking employment. If a person develops mental illness during service many organizations have a provision of terminating their services, (e) mentally ill are unfit to marry or remain married. Hiding the fact of mental illness at the time of marriage is considered enough ground to nullify marriage.

If we evaluate the above on scientific evidences following conclusions can be drawn :

1) *Mental illnesses are incurable* : Most researchers have shown that 50-60% of mentally ill have reasonably good recovery and another 10-20% can live gainfully in normal community, which is similar to any other chronic physical illness e.g. diabetes, arthritis etc.

2) *Mentally ill are impulsive and dangerous that's why they should be segregated* : It has been very clearly established that majority of mentally ill can be treated in their homes or in general hospitals, they neither need the high walls nor the chains. They seldom harm any one unless provoked.

3) *Mentally ill can not be given position of responsibility* : Most mentally ill act more responsibly than general population. Few may act irresponsibly during acute episode (e.g. manics or delusional schizophrenics).

4) *Mental illness is caused by bad blood or bad deeds* : It has been now scientifically shown that mental illnesses have genetic predisposition. This genetic predisposition only enhances their chances of developing illness, but it does not affect their ability to perform other tasks or their character. There is no evidence that mental illness can be caused by bad deeds.

5) *Some of treatments of mental illness increase the stigma* : Antipsychotic drugs used for treatment of these patients used to make them drowsy and produced extrapyramidal symptoms leading to immobility and odd postures. This increases the stigma of mental illness. By scientific pharmacotherapy most patients can be treated on small dosage which will not produce these unwanted effects. Drugs which do not produce drowsiness or extrapyramidal symptoms will go a long way in relieving the stigma. Treatments like ECT increases the stigma further.

The profession and society should take concrete action to reduce the stigma of mental illness.

(a) The profession should give up the pessimistic view and should be able to instill a sense of hope in the patients and the families. Instead of informing them that they are suffering from a chronic deteriorating illness they could be informed in the following words-

" Yes, you have a serious illness but results from 10 world-wide studies show that you have a

50-50 or better chance of significant improvement and perhaps recovery. It may take quite a long time but we will be here to maximize the return to functioning (Harding, 1995).

(b) Use drugs rationally to minimise unwanted side effects.

(c) There should be active advocacy to remove mental illness as a bar to employment.

(d) Mentally ill should be able to marry and mental illness as a legal bar to marriage should be modified. Though marriage by suppressing the fact of mental illness should be condemned but marriage after full disclosure with a willing partner should be encouraged. The mental health professional should develop balanced views on the question of marriage. Marriage is a fundamental right of every individual.

Stigma of mental illness will only be removed by showing good results of treatment and by publicising such results.

Clifford Beer's book " The mind that found itself" did a lot for the humane care of mentally sick. We now need many more Clifford Beers to help remove the stigma of mental illness.

Stigma being the major cause behind the neglect of mentally ill some other realities in this regard need also to be looked into.

In democratic countries the state will spend money in those areas of health sector which are considered as priority and have high vote-catching potential. State's priorities are infections, malnutritions, heart disease, cancer and family planning. Mentally sick in the absence of any advocacy on their behalf usually are neglected. However mental illness are a major cause of morbidity and mortality. It is time that active advocacy based on scientific principles becomes integral part of our functioning.

Families perceive mental illness as a shameful event and would go to any extent to hide it. Due to this reason the families avoid forming pressure groups for the care of their mentally sick relatives.

Even mental health professionals due to their pessimistic view of outcome and lack of immediate rewards avoid wasting time on chronic mentally sick .Due to which most psychiatrists feel quite relieved when such mentally sick stops coming to them.

Let us face the facts

- Roughly 0.5% to 1% population will have certain disabilities,due to chronic mental illness.

- Barring a few thousand all others are living in community.

- They are occupationally impaired and their family and personal life is in shambles.

- Most of these patients are either maltreated or untreated.

- There are roughly 3,500 psychiatrists and most of them are concentrated in large towns or in big institutions. Most non government psychiatrists are working single handed.

- Almost all major towns have one/two practising psychiatrists yet many cities remain uncovered.

- Only few hundred non medical mental health professionals are available which includes clinical psychologists, psychiatric social workers and psychiatric nurses.

- There are roughly 35,000 hospital beds most of which are in large mental hospitals which are poorly managed and are often occupied by chronic mentally ill.

- Treatment being completely voluntary most patient seek treatment on out patient basis and discontinue treatment when active symptoms are controlled or when they do not get adequate response or due to disabling side effects of drugs.

- Most psychiatrists depend on pharmacotherapy. Attempts at psychoeducation and rehabilitation are generally limited to occasional verbal advice.

- Many become homeless or live in their own

house but uncared and their properties are misappropriated by their relatives.

- However there are few centres of excellence doing commendable work in developing research data and models for treatment.

- Most of these groups are active in few cities of south India.

- A new development is taking place. New long term care homes are being opened in many major cities by individuals and N.G.O's. These hospitals/homes are charging large amounts of money for life long care. There is a need for such institutions but their functioning and long term planning need to be carefully monitored so that they may not become places of neglect instead of care.

Human and civil rights of the mentally ill

Human rights of the mentally ill have been systematically eroded. Many mentally ill are put into prison and continue to be there as there is no better place for them. The Supreme Court of India has prohibited this practice (W.P. 237/89). In another order the supreme court banned the practice of chaining the mentally sick. The judicial activism has been able to bring into focus the poor functioning of the hospitals, prolonged incarceration of mentally sick in jails or mental hospitals. However these being human issues court orders alone can not bring about the change. The change has to occur in the attitudes of the community and care givers. Worse is the fate of some of the non hospitalized chronic mentally sick who are kept in chains or behind closed doors in their homes. The profession has to be sensitive to the abrogation of human and civil rights of the mentally sick.

Main rights are : (i) the right to treatment, (ii) the right to refuse treatment, (iii) the right to be treated with dignity, (iv) all other rights of a citizen.

Let us think ahead

I have given an overview of the extent of problem and have sailed through the work done in India and abroad. We also now understand the ground realities existing in our country regarding state's non-participation, poor resources, huge patient load and societal influences. Human misery can not wait. Moments lost due to mental illness can not be regained. There can't be any excuse for not making concerted effort in improving the lot of the mentally ill within the resources available. We may not achieve the ideal but even if minimal improvement can be made one would have reasons to be satisfied. This problem can not be remedied by the mental health profession alone and multi agency involvement is required. Main objectives are :

(i) to provide humane existence, (ii) to provide optimal medical management, (iii) to provide psychosocial rehabilitation.

Available resources are : (i) *state*, (ii) *society*, (iii) *mental hospitals*, (iv) *mental health professionals*, (v) *patients*, (vi) *families*.

State : In most of the western world the health of the individual is state's responsibility and every sick patient has access to treatment and rehabilitation process. Though the Indian constitution provides for basic treatment to all but in practice medical treatment in general and psychiatric treatment in particular is not available to all and is accessible to only privileged few.

Mental health Act, 1987 has become operative but even today majority of states have done very little to implement it.

The recently passed "persons with disabilities (equal opportunities, protection of rights and full participation Act, 1995) is a very important piece of legislation. Strong advocacy for its implementation can bring a ray of hope to the mentally sick.

Central and state government will have to accept their responsibility towards the chronic mentally ill. A new act may be passed to provide for involuntary treatment in domestic setting so that patients could be treated in the

community.

The state should provide more resources for training of the mental health professionals. The state should also earmark funds for the local authorities to care for chronic mentally sick.

Society : This disabilities Act 1995 aims at providing rehabilitation, education and treatment to every disabled person. The responsibility under the Act for implemention rests with the panchayat or the local bodies. The philosophy of the entire programme rests on the premise that each community should provide care for the chronic mentally sick.

1) It should be made mandatory that every local body be it a panchayat, town council or municipal council maintain a register of every chronic mentally disabled. The local population should be encouraged by advertisement in media (Press, radio, T.V.) to enlist their mentally sick with the local area authority.

2) Wandering, homeless, uncared person should be identified by police or some other agency.

A committee consisting of 3 persons one of which should be a doctor/mental health professional should screen each individual for the following - a) presence of chronic mental sickness (as per lay person's criteria), b) is he being cared for regarding accommodation, food, clothes, c) if he needs specialized consultations then how can it be achieved.

3) Each local area authority should organize a local network group which would be responsible for social/occupational support to these individuals and their overall management. Such groups have been successfully used in China.

4) There should be provision for housing for homeless and maltreated individuals in each locality so that they can be provided minimum basic necessities.

5) Legal help committee - They should look after the civil rights of these chronic mentally ill and should ensure that their property is managed in such a way that their best interests are cared for. The provision for this exists in the law but it is seldom exercised.

6) Local area committees need to network with district and state for consultation and guidance.

7) Each local area committee can use innovative ideas for rehabilitating the patients.

8) Specialist consultation could be arranged on contractual basis with private or government psychiatrists available nearby.

Mental hospitals : Existing mental hospitals have to be reorganized.

1. Each mental hospital needs to continue with appropriate number of beds for long term care of patients residing in the vicinity of the hospitals so that these patients can maintain contact with their families.

2. These chronic patients should be provided with sheltered work and the aim should be to send them back into the community only when adequate arrangements have been made rather than pushing them out without proper arrangement in the community.

3. A small portion of the hospitals should continue to operate as acute treatment centre. The acute unit should not keep patients longer than 30-60 days.

4. Remaining facilities of the hospital should be used for training mental health manpower, for sensitizing the community and to be available for consultancy services for a defined geographical area.

Many mental hospitals are forcing recovered patients on the families. Such steps are likely to result in relapse, if the family is not ready to receive the patient. The reservations of the family should be discussed and their cooperation assured. If such is not forthcoming then community resources have to be developed so that the person can be taken care of by the community instead of the family.

Mental health professionals : Only mental health professionals available in this country are the psychiatrists. Other mental health

professionals are very few. Psychiatrists in private practice or public sector are largely overloaded with acute care. They generally provide pharmacotherapy and very little effort is made towards psychosocial problems and rehabilitation. However this needs to change if chronicity is to be avoided and patients are to be rehabilitated. Following have proven to be effective in relapse prevention-

a) Continuous care
b) Pharmacotherapy
c) Family intervention
d) Rehabilitation

a) *Continuous care* : Every patient who consults a mental health agency who is liable to become chronic needs to be ensured continuous care. India being a democratic country no one can be forced to seek treatment. Under these circumstances the psychiatrist needs to get the patient enrolled in central register of the local body, it is the duty of this body to ensure that the patient is treated by some agency of his/her choice. Enactment of community treatment act may facilitate continuous care.

b) *Pharmacotherapy* : Whenever prolonged drug treatment is required the psychiatrist need to provide such drugs which are acceptable and do not produce marked side effects. Cost of the treatment has to be kept as low as possible.

c) *Family intervention* : Family education and intervention should be an ongoing process and not a one time affair. Factors which have been proven to be responsible for chronicity should be reduced. A standardized intervention programme suitable in our conditions should be prepared.

Along with the clinical work each psychiatrist will also need to be involved with the following : (i) consultation with the local authority, (ii) work as catalyst to develop patient's relative group, (iii) participate in community education and (iv) advocacy.

d) *Rehabilitation* : The chronic mentally ill should not be treated as dumb recipients of treatment Their wishes, expectations and psychological needs have to be major determinants in the selection of the type of care they desire. Different levels of needs of patients have to be appreciated. (i) can live independently and work independently- only crisis intervention is required, (ii) can live with family but non productive - appropriate rehabilitation, (iii) severe symptoms and disability precludes family living or no family support available- requires accomodation and specific care.

The family is our most potent resource in the management of chronic mental illness. For many years we have been alienating the families by calling them disease inducers. It is time to make them an important ally and to empower them to manage the chronic mentally ill. Expecting an individual family to care for the chronic mentally sick does not appear to be totally justified. These families should get support of the community and state if one wishes to avoid their complete demoralization. They should also have an assurance that their mentally sick ward will be cared for after they are no longer available.

They will need assistance of the community and other organisations to lessen their burden. In this regard family group of mentally sick can go a long way in providing hope and ameliorating distress.

If the foregoing are pursued energetically there is every hope that vast majority of chronic mentally sick can lead a human life.

Many in the audience might be wondering that these are ideal, impractical dreams but one who does not dream can never initiate change. Not all dreams are achievable but they do provide us direction to strive. Momentary smile on a face could be the best reward one can hope for. The profession must rise above the state of existential depression and must initiate steps for betterment of our chronically ill brethren so that one may be able to perceive a ray of hope at the end of this dark tunnel.

Concluding, I will like to restate that even

with all restraints much can be achieved if we marshal our resources meaningfully. This would be our best tribute to Prof. D.L.N. Murti Rao.

Thank you for your patient hearing. I will be more than satisfied if this oration can initiate a process of change in our attitude towards these forgotten millions.

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