PRESIDENTIAL ADDRESS

Burden of untreated mental disorders; do we have resources to share it?

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At the outset, I express my heart felt gratitude to all the members of North Zone Indian Psychiatric Society for electing me the President of the Indian Psychiatric Society North Zone. With your blessings and guidance, I hope that I will be able to do justice and maintain the dignity of the office of President of the Society.

It was a very difficult task to decide the topic for the Presidential address. Though there were many issues which were important and could have been deliberated but I decided to talk on the burden of untreated mental disorders because large numbers of people suffering from mental disorders are not into treatment and they and their families are suffering day and night and nobody is trying to reach to them. In my talk I would like to discuss the magnitude of problem, burden of untreated mental disorders, available resources and strategies to tackle the problem.

MAGNITUDE OF PROBLEM

Meta-analyses carried out by Reddy and Chandrashekhar[1] and Ganguly[2] have reported that the prevalence of mental disorders in India varies from 58 – 73 per one thousand population. This includes psychosis, affective disorders, anxiety, mental retardation, substance abuse disorders, epilepsy and neurotic disorders. This does not include milder forms of mental disorders who are seeking help from physicians. Thus, there are approximately 65 million people in India who are suffering from various types of mental disorders and need treatment. Recent analysis done by WHO[3] show that neuro-psychiatric conditions had an aggregate point prevalence of about 10% for adults. Large numbers of them have chronic mental disorders including chronic schizophrenia, resistant depression, bipolar affective disorders and substance abuse. The chronic mental illnesses, which is either continuous or repetitive have lead to residual symptoms and deficits which are affecting personal, family and occupational life of these persons. About 20% patients of unipolar depression follow a chronic course with no remission especially when adequate treatment is not available. The recurrence rate for those who recover from first episode is around 35% within 2 years and 60% at 12 years. Around 15-20% of depressive patients end their lives by committing suicide.[4] GBD (WHO 2000) shows that unipolar depression alone is ranked as the fourth leading cause of burden accounting for 11.9% of total YLD Schizophrenia causes a high degree of disability associated with physical and mental conditions, psychosis was ranked as third most disabling condition.[5] Though it has been demonstrated that schizophrenia follow a less severe course in developing countries,[6,7] still about one third have a chronic course with significant deterioration and disability causing severe burden on individual & family.

What are our resources;

a) *Mental Health professionals:* As all of us are aware that we have shortage of mental health professionals including Psychiatrists, Clinical Psychologists, Psychiatry Nurse and

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Psychiatry Social Workers. There are only 44 Institutions in India which are imparting MD Psychiatry training and there are only 130 seats. Large numbers of mental health professionals are also leaving the country as there are large number of vacancies in U.K. and Australia. No efforts are being made to meet the shortage of mental health professionals. In last 25 years, there are only 13 new institutions which have started MD Psychiatry training with a annual output of 39 seats. There are many states which do not have post graduate training facilities. Southern states have more seats than northern states. The institutes imparting training for Clinical Psychologist, Psychiatry Nurse and Psychiatry Social Worker are also very few. There is acute shortage of mental health professionals for the population with specific needs including children, women, elderly, substance use disorders, mentally challenged, autistic and persons with cerebral palsy. The availability of mental health professional for the rural population is almost negligible as majority of the mental health professionals are working in the major cities leading to unequal distribution of resources.

b) *Beds:* There is a acute shortage of beds for the mentally ill persons. Roy[8] has reported that there are only 2.5 beds per one lac population in India. Most of these beds are located in the mental hospitals and are meant for chronic mentally ill persons. The poor qualities of care, inhumane treatment and in adequate infrastructure in the mental hospitals discourage many persons with mental illness from seeking admission into these hospitals. The rest of the beds are located in tertiary care hospitals in bigger cities and there are hardly any psychiatry beds at District hospital and PHC level. The recent attempt by the Govt. of India to improve infrastructure at the District Hospital level through District Mental Health Programme (DMHP) has not been very successful. Most of the psychiatry departments which are involved in the implementation of DMHP are providing only out patient services and for admission patients are referred to territory care hospital where cost of treatment is very high and many patients and their families find the atmosphere highly structured and hostile.

   The beds available in tertiary care hospital are meant only for short stay to tide over the acute phase of illness and these patients are discharged into community where there are no facilities. Patients requiring longer admission beyond one month find admission difficult.

c) *Resource for crisis intervention:* Other than the emergency services available in tertiary hospitals for psychiatric emergencies, there are no other facilities from where the caregivers can seek help in case of crisis. It becomes difficult for the caregivers to bring this person into emergencies at odd hours. The situations like aggression and violence, suicidal attempts, intoxication, side effects of drugs at times become unmanageable and the caregivers feel incapable of handling such situations. The general health care facilities available near to their residence refuse to intervene and advise them to consult their Psychiatrist, who are not available at that time.

d) *Resources for Rehabilitation services:* The services available for the care of mentally ill persons cater to only management of acute symptoms. Majority of the mental hospitals, psychiatry department in the teaching hospitals and psychiatry nursing home, lack facilities for rehabilitation. Large number of mentally ill persons are known to have chronic

course leading to deterioration in social and vocational skills. In the absence of vocational training facilities, these persons remain dependent on their families and continue to suffer due to their disability.

e) *Facilities for protection of human right of mentally ill persons:* Large number of mentally ill persons are subjected to inhumane treatment and are forced to leave an isolated and non-stimulating life. In the recent past many legal provisions have been made to protect the human rights of mentally ill persons,[9,10,11] but majority of the caregivers, mental health professionals and law enforcing agencies are not aware of such provisions and thus the benefit has not been extended to the persons and their families for whom these provisions have been made. Since, in many situations, the close family members are themselves responsible for the abuse of mentally ill persons, there is no one to make complaint about it and even if some one in the neighborhood comes to know about it, he/she doesn't know whom should such a case be reported and thus the suffering goes on.

f) *Budget for Mental Health:* All of us are aware that mental health has not received due share in the total health budget. In India, less than 0.9% of the health budget is being spent on the mental health in contrast the developing countries are spending 20-30% of their health budget on mental health. In 1990 United States had spent $1,48,000 million on mental health services.

Barriers in Seeking Treatment

Large number of people suffering from major mental disorders do not seek treatment leading to huge treatment gap. The factors like stigma, discrimination, lack of health insurance, poverty, shortage of mental health facilities, high cost of treatment and location of mental health facilities at long distances are responsible for large treatment gap. Even in the developed countries where there are adequate facilities for the mentally ill persons, large numbers of persons with mental illness are not seeking treatment. The situation in the developing countries, where there is scarcity of mental health services, will be worse.

In a recent survey carried out by the Department of psychiatry, govt. Medical College & Hospital, Sector 32, Chandigarh in a village Kajheri in U.T. Chandigarh, 60% persons suffering from mental disorders are not seeking treatment. The village is just 5 k.m. away from the Govt. Medical College & Hospital, Sector 32, Chandigarh. The situation in the other parts of the country will be worse as the families have to travel long distances to seek treatment. Many parts of the country still do not have sufficient transport facilities and thus bringing the patient to the hospital becomes very difficult. These observations point towards the very grim situation and it demands immediate attention for reaching to the persons who are suffering from major mental disorders.

Many patients suffering from mental illnesses are being taken to faith-healers, who subject these patients to inhumane treatment. Many patients who are suffering from chronic mental illnesses have been isolated and are lodged in religious places including Temples, Dargah and others are being looked after by missionary of charities, where there are no facilities to look after these patients. Many patients with mental illness are in prisons, Juvenile & Delinquent Homes, Nari-Niketan and secluded places looked after by social organizations for charity purposes. These patients are in un-safe hands and are being subjected to isolation and discrimination leading to violation of their basic human rights. The future is bleak for these patients and there is no ray of hope with the current delivery of health care facilities. Erawadi incident of Tamilnadu in which 29 cases of mental illness were burnt alive is still

very fresh in our minds. These persons were chained and thus could not escape.

Burden of Un-treated Mental Disorders

For the purpose of my presentation, I have defined untreated patients as;

(i) Patients of mental disorders who have not received any treatment or have dropped out after initial contact and are not on treatment.

(ii) Patients who are going to faith healers and AYUSH doctors.

(iii) Patients who are seeking treatment from non-psychiatrists.

It has been estimated that half of the cases of mental illness begin by 14 years of age and ¾ develop illness by the age of 24 years. Thus people with mental illness suffer disability when they are in the most productive phase of their life. The impact of mental illness is seen on the person, families, community and the nation. The persons suffering from mental illness face isolation and discrimination and they are not able to participate in work and leisure activities. They also feel guilty as they are not able to contribute to the family and feel themselves as burden on the family. Mental illness also affect school performance and leads to teenage child bearing, early marriage and disruption in the married life. The families of mentally ill also suffer because of the negative effect of stigma and discrimination, disruption in house hold work and restriction of social activities. The adjustment and compromises made by the family members prevent them from achieving their full potential in work, leisure and social relationship. These affects on the families are difficult to be measured but are very important. The community also experiences the impact of mental disorders in terms of cost of providing care, loss of productivity, violence and legal problems associated with medical disorders. The community has to pay for the health care services.

Disability adjusted Life Year (DALY) has been used to quantify the burden of diseases. One DALY can be thought of one lost year of healthy life. In assessing the Global Burden of Disease (GBD), DALY for a disease are sum of the years of life lost due to premature mortility and years lost due to disability. It has been estimated that in 1990, mental and neurological disorders accounted for 10.5% of DALY lost due to all diseases and injuries. In the year 2000, it has gone upto 12.3% and it is likely to reach to 20% by the year 2025.[12]

Economic cost to society can be;

a) Measurable, which includes cost of health and social services, lost employment, decreased productivity, impact on caregivers, crimes, premature mortility.

b) Non-Measurable includes lost opportunities for the persons and the family due to mental illnesses.

So, the facts are that;

i) There is acute shortage of mental health professionals

ii) Shortage of psychiatry beds

iii) Huge treatment gap

iv) Lack of services for social and vocational rehabilitation

v) Inhumane treatment of mentally ill persons

vi) Limited budget for mental health

vii) Misconceptions associated with cause and treatment of mental disorders

viii) Unequal distribution of resources

ix) Stigma and discrimination associated with mental disorders

How do we address the situation which is alarming

The intervention can be at different levels;

i) ***Increasing the manpower:*** The government should increase the number of M.D. psychiatry seats for overcoming the shortage. Efforts can be made to strengthen the infrastructure in the medical college, where there are no facilities for starting post-graduation in Psychiatry. The institutes like PGIMER, AIIMS, SGPGI, JIPMER, IHBAS, NIMHANS etc. can be given permission for larger intake for M.D. Psychiatry as these institutes have adequate training facilities. At the same time, the facilities for the training of Psychiatry Nurse, Psychiatry Social worker and Clinical Psychologists should also be increased as they can share the burden of psychiatrist in the area of psycho-education, social and vocational rehabilitation. They can also be successfully engaged in providing community based care.

ii) ***Increasing the number of beds:*** More number of beds need to be added for the acute and intermediate care of mentally ill persons at District Hospitals. DMHP, which is expanded to 100 districts can be made more effective by adding inpatient services. Such an attempt would improve treatment utilization and will reduce stigma attached to mental disorders.

iii) ***Strengthening of community Based Care:*** Large number of persons suffering from mental illness live in the community and are being looked after by their families. There are hardly any facilities in the community to look after these persons. There is an urgent need to provide day care and Half Way Home facilities in the Community. These facilities will improve social and vocational rehabilitation of mentally ill persons and reduce burden on the caregivers. The Ministry of Social Justice and Empowerment, Govt. of India has decided to provide financial support to NGO for setting up Half Way Home for mentally ill person with residual deficits under Deen Dayal Disabled Rehabilitation Schemes.

iv) ***Capacity building of Caregivers:*** The research has shown that the coping skills of the family members and social support affects the out come of mental illness as well as determines the burden on the caregivers. The caregivers need knowledge and skills to understand the nature of mental illness and the ways to cope with it. It requires close interaction between mental health professionals and the caregivers. The formal courses for the caregivers can be started by some of the institutes as has been done for the mentally challenged persons. The courses can be of 3-6 months duration and caregivers after training can extend services to other families in their neighborhood. It will reduce the burden on the mental health professionals

v) ***Integration with Primary Health Care:*** Though it was one of the objective of our National Mental Health Progamme (NMHP 1982), not much progress has been made. The staff working in primary health care feels already over burdened and is not very keen to accept the responsibility of mental health care. The misconceptions regarding causes and outcome of mental disorders may be discouraging them. The persons suffering from mental illness are perceived as violent, dangerous, unpredictable and resistant to treatment with poor outcome. These misconceptions need to be tackled through mass campaign and documentation of success story of treatment outcome. DMHP services have documented that utilization of mental health services is better if these are provided in the general health care settings close to their homes. Our experience at Raipur Rani by Prof.N.M.Wig and Sakelwara

by NIMHANS team has documented that integration with general health care facilities is feasible. By strengthening the primary health care services at PHC and District level will be more feasible and cost effective than a parallel mental health delivery system. Majority of psychiatric disorders are treated by physicians and only 5% are referred to secondary care.[13] 50% of these patients are perceived suffering from physical disorders wasting money on test and drugs.[14] Thus need of hour is with integration of mental health services, General Health Care. This would require:

- Training of staff for treatment of simple disorders.
- Availability of simple and cheaper drugs "generic name".

vi) ***Posting of other postgraduate in psychiatry***: Non-psychiatrists have unrealistic fear of working with mentally ill patients. Mentally ill patients are perceived dangerous and difficult to handle. They are afraid of entering into a psychiatry ward. Attempts should be made to expose them to mentally ill persons during their training. This can be easily done at the level of institute or at the level of University. The doctors and nursing staff working in emergency settings must be given brief training to handle mentally ill persons.

vii) ***Strengthening of UG Training:*** We have been talking about it at all the forum and may be we will achieve it some day.

viii) ***Open Communication among professionals and caregivers:*** Most of the mental health professional avoids telling the diagnosis to the families and it is not mentioned on the patient OPD records. If we tell the caregivers that the person is suffering from schizophrenia, it will give reassurance to the family that it is an illness which needs treatment. Open discussion about the mental disorders will reduce stigma associated with these disorders.

ix) ***Creating awareness about guardianship, disability benefits and laws for protecting human rights of mentally ill persons:*** Biggest worry for the families is that who will take care of their wards after their death. Where do they abandon their young daughters and sons so that they are saved from the clutches of exploitation? Even if one has adequate financial resources, there are hardly any facilities where a person with chronic mental illness can live with dignity and respect.

Under Mental Health Act 1987, there is provision of appointment of guardianship for the person, property or both for a mentally ill person who is unable to take care of himself/herself and need assistance in day to day life. But the procedure is very lengthy and cumbersome and only very few apply for guardianship. There is an urgent need to simplify the procedure as has been done in mental retardation under National Trust Act 1999.

Under Section 23(1) Mental Health Act 1987, the SHO in his jurisdiction is responsible for the care and protection of human rights of mentally person. But such provisions are neither known to SHO nor to the Society. All of us see mentally ill persons wandering on roads in a dishelved condition. It has become a routine and it no longer evokes any concern. In Chandigarh, with the help of Chandigarh police and social welfare department, we have brought many such persons into the treatment though our "Aasha Helpline" and "Crisis Intervention Team". These persons have been either restored to their families or have been rehabilitated through NGOs.

Mental illness has been included in the list of disabilities under PWD Act 1995 and persons

with mental illness with more than 40% disability are entitled to certain benefits by the state and central Government. These includes railway concession upto 75%, disability pension, income tax rebate upto 75,000, reservation in allotment of plots and houses, loan facility on low interest etc. According to the notification by Government of India a permanent disability certificate can be issued to a mentally ill peson who has more than 40% disability on IDEAS irrespective of the diagnosis. But obtaining a disability certificate is very difficult.

x) Preventive Strategies: There is evidence for the effectiveness of primary prevention strategies especially for mental retardation, epilepsy, vascular dementia and alcohol and drug abuse. There are kits available for neonatal screening for congenital hypothyroidism, phenylketonuria, congenital adrenal hyperplasia, G6PD deficiency and galactosemia. The procedure is very simple. A drop of blood is collected on a filter paper after 72 hours of birth. Filter paper is dried and sent to the genetic lab for screening. There are also kits (marketed by Perkin Elmer) for mass screening of mothers during pregnancy to detect Down's syndrome and other genetic disorder. Department of Psychiatry, GMCH-32, Chandigarh has such facilities.

Let me summarize the facts and figures;

	Resources	Expected
1)	4000 psychiatrist 0.4/1,00,000	i.e.10,000 psychiatrists

No of psychiatrist per year 130

No. of year required to meet the demand: $\frac{6000}{130}$ = 46 years

2) Beds:

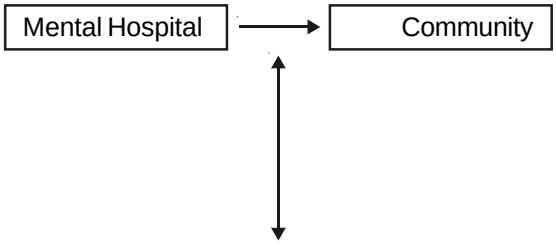
2.5 beds per 1 lac = 25,000 10 beds / lac = 1,00,000

Maintenance cost of additional beds = 1000x30x12x75,000=2700 crore/years + cost of infrastructure at a territory hospital

However adding additional beds at District Hospital is cheaper.

What alternatives do we have?

Paradiagm shift



Obstacles

i) Absence of community services
ii) Lack of political will
iii) Stigmatization
iv) High transition cost
v) Lack of cooperation between different department etc. health, Housing, Education, employment, criminal, justice, social welfare and women's affair.

Most crucial is to designate a nodal ministry for comprehensive services for the mentally ill.

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