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RESEARCH ARTICLE

ECONOMIC BURDEN OF HEALTH CARE IN SEVERE MENTAL ILLNESSES: INDIAN PERSPECTIVE

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ABSTRACT

Mental health problems impose sizeable public health burden across the world and contribute to the huge economic burden at the Individual, community and national level. Serious mental illnesses like schizophrenia and bipolar disorder are disabling conditions, which have their onset in early adulthood leads to sub-optimal productivity. Also unlike other medical illnesses, severe and protracted mental illnesses pose more indirect burden that is way beyond the scope of existing government provided free health services. But still in developing countries like India, budget for the mental disorders gets thwarted underneath the huge burden of communicable diseases which appear of paramount importance in mortality census. There is need of nationwide burden assessment studies and effective health policy planning to be tuned in accordance with the available evidence of huge economic burden of mental disorders.

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INTRODUCTION

Mental disorders pose a huge burden at individual and community level. Yet they are given very low priority by the government, when it comes to resource allocation. This may be largely due to higher priority given to communicable diseases and nutritional problems. Also, differential resource allocation is partly attributed to the way of thinking in disease burden measurement, where morbidity and mortality from communicable and nutritional diseases dominate over morbidity and disability of mental disorders. The economic burden of severe mental disorders is still an untapped area of research in India and other developing countries. While there is abundant research on the economic burden of mental disorders in high-income countries (1, 2), information on the economic consequences of poor mental health in low-and middle-income countries is limited (3, 4). Research data do exist from few isolated pockets of our country (5, 6, 7, 8), but "these estimates are likely to be conservative; few take account of the ways in which families mobilise and redirect resources that adversely affect them, worsening and perpetuating socio-economic inequalities. When aggregated across an economy, these household costs have an important impact on the size and productivity of the labour force and on national income'' (9).

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Economic burden of severe mental illnesses not only affects individual, but the family as a whole. They have a huge 'rippling effect' on the family and caregivers to which most of the main health policies has attitudinal neglect. Government policies are yet more focused on providing free hospital based acute care than community based services and rehabilitation. The latter two are still far more neglected areas. Practically, no measures exist to address caregiver burden or respite care. The increased burden becomes a significant barrier to the basic human 'right of access to health' (10). It raises a thought that indirect burden posed by severe mental illnesses is probably beyond the scope of government provided free health services (11)

Economic burden of mental and behavioural disorders

Huge public health burden of mental illnesses is reflected in the global burden of disease studies 2010 (12). The burden, however, is not just on the individuals with the disorders but also on households, communities, employers, healthcare systems and government budgets. The inextricable relationship between mental health and poverty is a vicious cycle (13). Mental disorders perpetuate the cycle of poverty by interfering with the individual's capacity to function, leading to decreased productivity. The overall economic burden of mental disorders on sufferers, family, employers and society is wide ranging (14). On sufferers, it has the cost of health care and treatment, reduced productivity as a result of work disability and lost

earnings and other costs of anguish, treatment side-effects and at times suicide. On family, it has the cost of informal care giving, less productivity due to time off work and other costs of anguish, isolation and stigma. On employers, it has the cost of contributions to treatment and care and diminished productivity of a worker due to mental disorder. On society, it has cost of provision of mental health and general medical care, reduced productivity, and other costs due to loss of lives, untreated illnesses with unmet needs and social exclusion. In many low- and middle-income countries, where universal access to health care and financial and social protection systems are often lacking, caregivers with mental illness may spend much of their savings or borrow money to buy conventional and/or traditional medicines and may have transportation difficulties in accessing these services.

Economic burden of schizophrenia

Schizophrenia is a disorder affecting thought, affect, perception and cognition. It usually has a chronic course and causes a high degree of disability in self care, occupational performance, functioning in relation to family and social stigma (15). Limited help seeking, rejection of treatment, homelessness, suicide and co-morbidity with depression, cardiovascular diseases, increased cigarette smoking, recreational use of alcohol and psychoactive drugs common in schizophrenia increases the cost of illness further (15, 16). Its burden represents 0.3 to 3 percent of annual healthcare budget in developed countries (16). In USA, Wu *et al* in 2005 estimated the overall cost of schizophrenia to be US$62.7 billion, with US$32.4 billion being the indirect cost (17). Phanthunane *et al* in 2008, in Thailand, estimated the annual overall cost of schizophrenia to be US$ 2600 per person or 925 million for the entire population with schizophrenia and indirect costs accounted for 61% of the total economic burden of schizophrenia (18).

Economic burden of bipolar disorder

Bipolar disorder is a chronic affective disorder characterised by recurrent episodes of mania or hypomania and depression that causes impairment in functioning and health-related quality of life. It is a major public health problem due to its chronic and recurrent nature (19). Economic studies have found the burden of bipolar disorder to be extremely high. Estimates of total costs of affective disorders in the US range from $US30.4-43.7 billion (1990 values) (20). In the UK, in 1998, the annual burden of bipolar disorder was estimated at $3 billion (21). However, little is known about how the economic and family caregiver burden in families with bipolar disorder patients changes over time. Furthermore, almost all studies of the economic and caregiver burden of bipolar disorder have been conducted in high-income countries. In low-income countries, families already living in poverty may be disproportionately affected by having a family member with bipolar disorder

Mental Health Care in India

Background of burden of mental health in India

In terms of numbers, people in Africa and India make up one third of the world's population. They together contributed to about half of the total global burden of disease in 2002 (22). The prevalence of major mental and behavioural disorders at any given point of time in Indian adults was estimated at 65/1000 population in all ages and both sexes based on the average value of two pooled studies (23, 24) and for the year 2001, total number of persons affected with major mental disorders was estimated to be 67million (25). In 2008, a joint publication by India's National Human Rights Commission and the National Institute of Mental Health and Neurosciences reported that "Morbidity on account of mental illness is set to overtake cardiovascular diseases as the single largest health risk in India by 2010." The preliminary findings of a WHO-supported multicentre study on mental health in India also indicated that about 10% of the population in India will develop mental health problems, according to a recent report by The Lancet (26).

Treatment gap in mental health care in India

With the surmounting burden of mental illness, India just spends 0.83% of its total health budget on mental health (27, 28). WHO's Mental Health Atlas 2005 says that as far as community care for mental health is concerned, South East Asia including India lag behind the rest of the world (29). Also India has very limited numbers of mental health facilities and professionals. The few steps taken for mental health promotion like the launching of the National Mental Health Programme-NMHP (1982), adoption of Mental Health Act (1987), persons with disability Act (1995), and integration of the mental health with primary health care at district level have not served the purpose of reaching out to the huge number of people in need (30).

Types of health care cost: conceptual issues and estimation

The health economists for simplifying operational research criteria have divided cost of illness into the following types (31):

1. **"Direct costs** are 'actual money expenditures' and in kind contributions incurred by patients, their families, and third parties to purchase medical goods and services. Costs of non-medical goods and services ordinarily incurred to obtain medical services such as transportation to medical facilities are additional direct costs. In-kind contributions are donations of goods or services that would otherwise have to be purchased through actual cash outlays (31)''.
2. **"Indirect costs** are derived from 'human capital approach' to valuing life. It includes 'losses in productivity' associated with symptoms, treatment, disability and premature death. Indirect costs include the value of lost opportunities to work in the general economy because of sick leave, disability leave and unemployment associated with illness or in the household. Relatives who divert time from work to provide care or assistance with household work also incur opportunity costs (31)''.
3. **"Intangible costs** entail pain and suffering as well as changes in quality of life. They include effects on the patient (e.g., despair and the side effects associated with medication) and on the carer (e.g., isolation, uncertainty, stress). Intangible costs are not ordinarily calculated

because they have not been successfully quantified in a monetary sense (31).''

Cost of illness studies in India

As far as health economics is concerned, very few Indian studies have attempted to evaluate the cost of mental illness. Girish *et al* (32) found that antipsychotic drugs are affordable and are comparable to drug treatment costs of other chronic physical illnesses. They concluded that although antipsychotic drugs are affordable, the other costs associated with treatment make them more expensive; these could be cost of co-prescribed drugs like antiparkinsonian agents, antidepressants, anxiolytics, etc. Sarma showed that cost of one psychiatry consultation visit on outpatient basis was Rs 201 (US$2.97) in which the contribution of the health provider was 68% and the patient's contribution was 32%. It was found that of the total cost, 48% was the out of pocket expenditure by the family and cost of drugs only accounted for 17% of the total cost. (5). Grover *et al* conducted a cost of illness study in 50 out-patients with schizophrenia assessed over a 6-month period and compared with 50 out-patients with diabetes mellitus. Results showed that the total annual costs of care of schizophrenia were US$274; these were not significantly different from diabetes mellitus. The main brunt of financial burden was borne by the family. Total treatment costs in schizophrenia were significantly higher in those who were unemployed, those who visited the hospital more often, and were more severely ill and disabled (8).Thus, government measures of providing free consultation and drugs in public sector hospital as respite are only taking care of small component of direct cost of care, leaving still a huge chunk on care givers.

Mental health services in India and the financing

In developed countries, most common method of financing mental health care is tax-based (60.2%) or social insurance (18.7%). However,in the 30% of the South-East Asia region countries,'out-of-pocket payment is the primary method of financing health care (29). The National Commission on Macroeconomics and Health, using new methodologies, estimated in 2005 that households in India used their own resources for 68.8 % of the aggregate national spending on health, while the share of the central and state governments together was only 21.6% (the rest was accounted for by public sector, private, and charitable sources) (33, 34).

Government initiatives for addressing economic burden of mental illness

Existing laws

- Mental Health Act 1987: It lays down laws in regard to admission and discharge procedures and licensing of mental health facilities. It has no provision to address economic burden on service users directly.
- People with Disability Act, 1995: It includes all the relevant disability benefits. It has provision of providing social welfare and economic benefits to the persons with mental illness in form of state provided disability pension, provision of concession in travel, income tax rebates for the caregivers, 3% reservation in job for persons with disability. But, this 3% subsumes all disabilities physical as well as mental, leaving very less judicious allocation.

United Nations Convention on Rights of Persons with Disability (UNCRPD)

India signed UNCRPD on 30th March, 2007, was ratified and came into force on 3May 2008. It's article 25 is "right to Health'', which states:

- **States Parties recognize the right to the 'highest attainable standard' of health without discrimination:**

- Same range, quality and standard of free or affordable health care
- Provide disability-specific services such as early intervention
- Provide services as close as possible to peoples' communities
- Requirement on health professionals to provide same quality of care to persons with disabilities as they provide to others
- Prohibit discrimination in health insurance
- Prevent discriminatory denial of health care or health services on the basis of disability

Four Essential Elements of the 'Right to Health' described in it are:

- Availability
- **Accessibility** (non-discrimination, physical accessibility, **economic accessibility**, information accessibility)
- Acceptability
- Quality

Thus, two important obligations that arise for the government following ratification of UNCRPD are:

(a) Implementation of provisions of the UNCRPD
(b) Harmonization of Indian Laws with the UNCRPD

Government is still in process of coming up with new and better laws as compared to the previous two mentioned:

- Mental Health Care Bill 2014: It will replace existing Mental Health Act 1987. It is in legislative assembly currently for final approval. It has a chapter on 'right to access mental health care'. It ensures that a range of affordable, acceptable, good quality, sufficient quantity services to be provided without discrimination on the basis of gender, sex, sexual orientation, religion, culture, caste, social or political beliefs, class, disability or any other basis. It has a provision that if minimum mental health services are not available in the district where a person with mental illness resides, then the person with mental illness is entitled to access any other mental health service in any other district and the costs of treatment at such establishments in that district will be borne by the Government. Persons with mental illness living below the poverty line whether or not in possession of a below

poverty line card, or who are destitute or homeless shall be entitled to mental health treatment and services free of any charge and at no financial cost at all mental health establishments run or funded by the appropriate Government

- People with disability bill 2012: This bill is currently is undergoing revision and is in its drafting stage. It has expanded provisions of social security, health, rehabilitation & recreation existing in the previous act.

Remedial actions taken by Government of India after ratification of UNCRPD

Following steps have been taken by government in past 5 years for addressing economic burden of persons with disability (35-38):

- **National Policy for Persons with Disabilities, 2006:** It recognises persons with disabilities as valuable human resources and seeks to create an environment that provides them with equal opportunities, protection of their rights & full participation in society. One of its main components is also economic rehabilitation, for a dignified life in society.
- **Nodal Ministry**: The Ministry of Social Justice & Empowerment is the nodal ministry for coordination for ensuring welfare measures.
- **National institute working in the field of mental disability:** National Institute for the Mentally Handicapped (NIMH), Secunderabadis working in the field of rehabilitation.
- **Disability Certificates:** Following PWD 2009 amendment, certification procedure for providing welfare benefits was simplified so that people can easily procure government provided welfare measures.
- **Components of Rehabilitation for Persons with Disabilities**

Some of the main components of rehabilitation of persons with disabilities are:

(i) Provision of assistive aids and appliances
(ii) Education
(iii) Vocational training
(iv)Assistance for employment
(v) Training in or assistance for independent living

- **Schemes of the Ministry of Social Justice and Empowerment (MSJE)** incorporates the following social & welfare benefits:

1. Disability pension/unemployment pension
2. Disabled person's scholarship
3. Insurance scheme for the mentally challenged
4. Adhaar scheme (financial help) helping to set up small shops/ Telephone booth
5. Free education up to 18 years
6. Free legal aid
7. Aids and appliances (for multiple disabilities)
8. Three percent of Job reservation (only cerebral palsy included)
9. Concessional bus passes
10. Railway concession
11. Income tax rebate for the caregiver

Economic Empowerment

A. National Handicapped Finance & Development Corporation is an apex institution for channelizing the funds to persons with disabilities through the State Agencies under Micro Credit Scheme with the following purposes:

a) To promote self-employment ventures for the benefit of persons with disability.
b) To extend loan to the persons with disability for up gradation of their entrepreneurial skill
c) To extend loans to persons with disability for pursuing professional/technical education
d) To assist self-employed persons with disability in marketing their produce

B. Trust Fund for Empowerment of Persons with Disabilities: In pursuance of the directions of the Supreme Court ruling dated 16.04.2004, a Trust Fund for Empowerment of Persons with Disabilities (chaired by Comptroller & Auditor General of India) was registered on 21.11.2006.

C. Health Insurance provisions being suggested: Till now, no existing health insurance provisions are there for mental illness. Now government is trying to come with 'Rashtriya Arogya Nidhi' a new insurance venture.

Policies on Paper and Ground Realities

It has been seen that most of these benefits are utilised by persons with physical disability. Persons with mental illness are still neglected. Chaudhary and Deka (39) found that only 6% of the guardians of mentally retarded were aware of the persons with disabilities (PWD) Act. Singh and Nizamie (40) reported poor awareness and underutilization of disability benefits in persons with mental illness. Kashyap *et al* (41) reported underutilisation of disability benefits due to poor awareness. Hence, in practice, disability benefits are still elusive for persons with mental disorders.

Conclusion

Most of the studies quantifying economic burden of severe mental disorder originate from developed countries where the level of health care provision is quite different. In traditional societies like India, where caring for a family member with mental illness is a norm, individual patients and families are bearing the brunt of economic burden. Economic burden imposed on them is sheer violation of their right to health; as it serves as a barrier in access to health. The family burden on the needs to be unveiled in order to influence resource allocation staring from policy level down to the affected ones. Health policy planning and prioritisation needs to be tuned in accordance with the available evidence of huge economic of mental disorders.

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