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RESEARCH ARTICLE

COMPARATIVE STUDY OF ECONOMIC BARRIER AS INFRINGEMENT OF RIGHT TO HEALTH CARE IN BIPOLAR DISORDER - URBAN RURAL DICHOTOMY

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ABSTRACT

Background: Bipolar disorder despite being episodic illness, due to chronicity imposes a great financial burden of care on service users (patients & caregivers), especially in traditional societies like India where caring for a family member with disability is a norm. Economic burden serves as a barrier in access to health, infringing upon the right to health. Different determinants add to this burden in urban and rural settings, requiring different intervention strategies. There is dearth of health economics data from developing countries. Formal need assessment to influence resource allocation starting from policy level to the affected ones down is needed.

Aims & objectives: (i) To study direct and indirect costs of mental health care in stable patients with bipolar affective disorder and their respective caregivers. (ii) To compare difference in cost of care across urban & rural area setting and its determinants.(iii) Extent of utilization of existing government social welfare measures to reduce economic burden

Methods: Hospital based cross sectional study recruiting fifty stable married homemaker female patients diagnosed bipolar affective disorder (as per ICD 10) in 18-40 years age group with their caregivers following up in OPD for minimum 1 year. Tools used were specific questionnaire designed for the study, Young's mania rating scale (YMRS) and Hamilton Depression Rating Scale (HDRS).

Results: Monthly cost of treatment for bipolar disorder was Rs.2832 for urban residents & Rs.1964 for rural residents. Direct cost of illness was significantly higher for rural residents. Major determinant of direct cost was transportation and out of pocket expenditure for the indirect cost. Government provided measures to reduce economic burden are meager and extent of utilization of existing disability benefits is also very low (<20%) due to poor awareness.

Conclusions: Government initiatives need to focus on increasing awareness regarding available health facilities, strengthen network of district health clinics to reduce money and time spent on travelling especially in rural areas. Since indirect cost of care is significantly high, so, efforts on providing appropriate economic respite care to patients and family caregivers should be considered to reduce 'out of pocket expenditure'.

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INTRODUCTION

Bipolar disorder is a major public health problem due to chronic relapsing nature of disorder causing significant economic burden on service users (patients & caregivers) and society (Judd, 2003). It is characterized by recurrent episodes of mania or hypomania and depression. Patients require acute and maintenance therapy which can be delivered via inpatient and outpatient treatment.

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It has a lifetime prevalence of approximately 0.24% (Perala, 2007). Patients with bipolar disorder often have contact with the social welfare and legal systems. Illness impairs occupational functioning, may lead to premature mortality through suicide (Kleinman *et al*., 2003) and poses a huge caregiver burden. The WHO defines caregiver burden as the "the emotional, physical, financial demands, and responsibilities of an individual's illness placed on the family members, friends or other individuals involved with the individual outside the health care system. Objective burden refers to behavioral phenomenon, e.g., disruption of the caregiver's domestic routine social activities; social isolation;

economic burden. Subjective burden refers to emotional strain on caregivers. (WHO, 2004) Economic burden on the service users clinches upon their access to health services, proving a barrier in health seeking itself (Kukreti, 2016).

To understand economic burden in terms of cost of illness, health economists have divided it into:

Direct cost: It refers to the 'actual money expenditures' on treatment and care e.g. money spent on transportation, medicines and consultation fees.

Indirect cost: It refers to 'losses in productivity'. It includes loss of time and decline in occupational productivity due to illness or caregiving.

Intangible costs: It entails pain suffering and decline in quality of life of patient. Intangible costs are difficult to calculate due to difficulty in quantification and is usually not assessed in most of the studies (Vaughan *et al*., 2002).

Economic studies have found the burden of bipolar disorder to be extremely high. Estimates of total costs of affective disorders in the US range around $US30.4-43.7 billion (1990 values). In the prevalence-based cost-of-illness study on bipolar disorder, total annual costs were estimated at $US 45.2 billion (1991 values) (Kleinman *et al*., 2003). In the UK, in 1998, the annual burden of bipolar disorder was estimated at $3 billion. (7) The annual economic burden of bipolar disorder in Australia (2004) was between AUD$3.97 billion (US$3.61 billion) to AUD$4.95 billion (US$4.50 billion) (Fisher *et al*., 2007). 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 more affected by having a family member with bipolar disorder, but actual epidemiological data is not available. Developing countries like India, besides many heterogeneities also has urban rural divide, where illness trends, health beliefs, level of awareness, access to health care resources, burden, care giving appraisal and cultural acceptance of modes of treatment are different for both the groups (Jiloha *et al*., 2016). Studies comparing emotional and social burden across urban rural settings are many but only one study by Zhai *et al*. in 2013 explored economic burden of all mental illnesses, reporting direct and total economic burden to be higher for urban caregivers than rural in schizophrenia. (Zhai, 2013). No such studies in regard of bipolar disorder are available. Current study aimed at calculating monthly cost of providing care in stable patients of bipolar disorder in a public psychiatry hospital where medicines and consultation is provided free of cost. Also to simultaneously analyze government provided existing measures to address this burden and their service utilization.

MATERIALS AND METHODS

It was a cross sectional hospital based study conducted in outpatient department of a government run neuropsychiatry centre, catering to clients from Delhi NCR and adjoining states. Married women having children in the age group of 18 to 40 years diagnosed with bipolar disorder as per ICD 10 DCR (11) criteria and/or caregivers ready to give informed consent coming on follow up for a minimum of 1 year were included. Married housewives having children were selected to ensure a homogenous group for calculating indirect cost of care giving. Patients suffering from any other independent or co morbid psychiatric disorder or physical disability were excluded to remove confounding factors adding to the cost of illness. Patients and caregiver were divided into two equal groups of 25 each of patients coming from urban areas of Delhi / NCR and patients coming from rural area outside it. This division was done to ensure a fair estimation of direct cost (including cost of transport) and indirect cost (including time in transportation) in both groups, which will be different in Delhi and outside Delhi rural group. Following purposive sampling, patients and caregivers following up on a particular unit of OPD fulfilling the selection criteria were recruited after taking informed consent on alternative OPD days in every successive week e.g. Monday in 1st week, Wednesday in 2nd week, Friday in 3rd week and so on, to remove bias arising due to a particular group of patients following up on a weekday. The Hamilton Rating Scale for Depression (HRSD) (17 item) scale to rate the severity of depression (Hamilton, 1981) and Young's Mania Rating Scale (YMRS) was used to rate severity of mania (Young *et al*., 1978) were used. Descriptive statistics was used to summarize the data with use of mean or median with standard deviation as required. The chi-square test and Fisher Exact test was used to compare categorical variables between the groups. The *p* values were corrected for multiple testing using procedure of Bonferroni-Holm, a corrected *p* value of < 0.05 was considered statistically significant. Approval was obtained from institutional ethical clearance committee. The confidentiality nature of any information in the study was assured by data collectors. People unaware of their rights and state disability welfare measures were sent to psychiatry social worker for appropriate psychoeducation.

RESULTS

Socio-demographic profile and illness variables: Most patients were young adults, living with family and had spouse as a caregiver. Urban residents mostly were engaged in private job and had nuclear family, whereas rural residents were mostly engaged in agriculture related work and had joint family. Details of sociodemographic data are given in Table 1. Mean age of onset of illness was 20 years and duration of illness on average was 2.9 years. Majority patients interviewed were in complete remission (76% to 84%). In both the groups, 1 caregiver was accompanying the patient and patients were following up nearly once in a month. Median hospitalization rate in last year was 2.5. Details of illness variable are given in Table 2.

Cost of illness: Total monthly cost of illness for urban and rural residents was found to be Rs.2832 and Rs. 1964 respectively.

Direct cost (Table 3, 4): Direct cost constituted 41.9% and 78% of total cost in urban and rural residents respectively. In rural area patients, maximum expense was on transport (39% of the direct cost) followed by money spent on faith healing (13.8% of the direct cost). Delhi residing urban patients had maximum expense on faith healing (26% of direct cost) followed by money spent on travelling (21% of direct cost).

Table 1. Comparison of socio demographic data

Variables	Urban Resident N=25	Rural Resident N=25	*p* value
Age in years (mean ± SD)	29.92 ±5.69	28.64 ± 4.71	0.59
Years of education (mean ± SD)	8.04 ± 4.12	5.92 ± 3.37	0.006
Parent	2(8%)	4(16%)	0.48
Spouse	18(72%)	17(68%)	
Siblings	2(8%)	3(12%)	
Children	3(12%)	1(4%)	
Unemployed	0	0	0.006
Agriculture	0	17 (68%)	
Student	0	0	
Businessman	3(12%)	2(8%)	
Government job	6(24%)	0	
Private job	15(60%)	6(24%)	
Retired	1(4%)	0	
Others	0	0	
Nuclear	16 (64%)	10(40%)	0.05
Joint	9(36%)	15(60%)	
Salary/ Wages	24(96%)	25(100%)	
Pension	1(4%)	0	
<5000	2	10	
5000-10000	8	11	
10000-15000	11	4	
>15000	4	0	
No. of DEPENDANT FAMILY MEMBERS (mean)	2.5	5	

Table 2. Illness Variables

Variables	Urban Resident N=25	Rural Resident N=25	*p* value
AGE OF ONSET of illness (mean in years)	20.80 ± 4.04	19.32 ± 3.59	0.12
DURATION of illness (mean in years)	3.12 ±0.92	2.81 ±0.87	0.736
NUMBER OF HOSPITALISATIONS in past 1 year (median)	1	2	
COURSE OF ILLNESS			
Course Specifiers for BPAD as per ICD 10			
Mania	0	0	
Depression	6(24%)	4(16%)	0.87
Mixed	0	0	
Remission	19(76%)	21(84%)	

Table 3. Transportation and visits to hospital

Variables	Urban Resident N=25	Rural Resident N=25
Distance from hospital		
<10 Km	17(68%)	0
10-20 Km	6(24%)	0
21-50 Km	2(8%)	0
> 50 Km	0	25(100%)
No. of persons accompanying median)	1	1
Number of follow up visits (median)		
in past 1 month	2	1
in past 3 months	2	1

Table 4. Direct Cost

Variables	Urban Resident N=25	Rural Resident N=25	p value
Money spent on medicines per month (in Rs.)	224 ± 277.31	196 ± 303.42	0.98
Money spent on investigations in last month (mean in Rupees)	236 ± 386.90	290 ± 415.33	0.63
Money spent on treatment Seeking in last month (mean in Rupees)			
Private psychiatrists consultation	300 ±256.45	124 ±235.46	0.90
Faith Healer	312 ±795.99	200 ±515.59	0.83
Cost of transport to and fro per visit (in Rupees)	246.80 ± 190.59	572.40 ± 316.34	C&D p=0.0001
Money spent on meals per visit (mean in Rupees)	62.40±76.23	150 ± 108.97	C&D p=0.002

Interestingly, across both the groups, average money spent on fees of a faith healer per visit ranges from Rs. 200 to Rs. 1000 which was more than the average money spent on fees of a private psychiatrist's single visit, which was in range of Rs. 124 to Rs. 500.

On average, rural patients were spending significantly (p=0.000) more money on meals (Rs. 150) in a single visit than their urban counterparts (Rs. 62). Detail of direct cost incurred by caregivers is described in Table 4.

Indirect cost (Table 5): Indirect cost constituted 58% and 22% of total cost in urban and rural residents respectively. Maximum share of indirect cost was on the extra expenditure done on care giving by the family members and it was significantly (p=0.000) higher for urban patients from. For urban versus rural residents, it was 29.8% & 8.5% of total cost in bipolar respectively. On average, monthly estimated income loss was significantly higher for rural group (p=0.004) than urban resident group. Average monthly income loss was Rs. 804 & Rs. 272 respectively for urban and rural residents. Time spent for each OPD consultation was average 4.5 hours for urban patients and 7.5 to 8.5 hours for rural patients. None of the caregivers interviewed reported to have lost job due to care giving.

Table 5. Indirect Cost

Variables	Urban Resident N=25	**Rural Resident N=25**	p value
Estimated income loss per month (in Rupees)	804±706.86	**272±391.07**	0.002
Extra caregiver expenditure incurred per month (in Rupees)	840 ± 270	**160 ±264.58**	0.0001
Total time spent per consultation (mean in hours)	4.5±1	**7.5±2.6**	0.0001
Time spent in travelling to and fro	1.5±0.5	**3.5±2.1**	
Time spent in hospital opd	3.5±0.5	**4.5±0.5**	
Job lost due to caregiving	-	-	

Table 6. Government Provided facilities to Address physical barrier

Variables	Urban Resident N=25	Rural Resident N=25
Presence of psychiatric facility within 10 km of residence other than this tertairy care centre		
Residing within 5 KM of index hospital	12(48%)	-
DMHP (district mental health program) clinics	10(40%)	-
Other GHPUs	7(28%)	-
Other Mental Hospitals	-	6(24%)
Private psychiatry clinics	12(48%)	7(28%)

Table 7. Trends of utilisation of government provided facilities to address economic barriers

Variables	Urban Resident N=25	Rural Resident N=25
Disability Benefits		
Disability certificate issued	6(24%)	5(20%)
Disability pension/unemployment pension	6(24%)	5(20%)
Concessional bus passes	3(12%)	4(16%)
Railway concession	5(20%)	5(20%)
Disabled person's scholarship	-	-
Adhar scheme helping to set up small shops	-	-
Financial aid to set up Telephone booth	-	-
Free education up to 18 years	-	-
Free legal aid	-	-
3% Job reservation	-	-

Assessment of existing government facilities to address the cost of illness

Measures to address physical barrier for access to health & its utilization: It was found in the study that of all the patients interviewed majority had a psychiatric facility (government or private) situated within 10 km of their residence, 12% urban residents and 48% rural residents reported having no mental health facility within 10km of their residence. 48% of urban residents were staying within 5km of index hospital area, 40% reported having a district mental hospital clinic near their home and 28% reported having general hospital psychiatry near their home and 48% had access to nearby private psychiatrists. Of all the reasons, most commonly cited for not visiting nearby mental health facilities and travelling so far were belief like index hospital being the largest psychiatric facility in city, current hospital providing free medications and providing medications for a month as compared to other government hospitals providing 15days medicine per visit. Twenty four percent of rural residents reported having a mental hospital and 28% having a private psychiatric facility situated within 10km of their residence. When asked for the reasons of travelling so far, the most commonly cited reasons were being free medicines for a month and belief of having shown in a big hospital of national capital, which as per them must be better than their area mental health facility. Nearly 35% reported being not aware of any nearby psychiatry facility.

Measures to address economic barrier for access to health & its utilization: Government has in place disability benefits being provided after a disability certification done from concerned mental hospital of the state. These disability benefits are in form of disability pension, scholarships, financial aid to set up telephone booth/small shops, free education, free legal aid, concession in travel (in bus/railway), income tax rebate and reservation in job. (14,15) Government also has in place. To address the direct economic assistance, certain schemes of 'health insurance cover', particularly to the economic weaker section category are available e.g. *Rashtriya Swasthya Bima Yojna* and *Aapka Swasthya Bima Yojna.* (16) Twenty four percent of urban patients & 20% of rural residents had disability certificate. All the patients having issued certificate were availing certificate for disability pension. Rest all existing

disability benefits were hardly being utilized due to poor awareness. Only 12% to 20% were using it for bus/railway concession passes and none were availing any other existing facility.

DISCUSSION

In this study, we described the direct and indirect cost during stable phase of one of the severe mental illnesses, bipolar disorder, incurred by patients and their family in a public funded psychiatric facility located in urban area. It was a cross sectional study based on prevalence mode and it employed human capital base approach & bottom up technology (Hodgson and Sarma, 2000). We found that the indirect cost of care was higher for rural area patients due to more money spent on travel. Whereas for urban area patients, cost of direct care was higher. In other studies too, direct cost has been ranging from 13% to 53% of the total cost and indirect cost from 47% to 87 %. (Sarma, 2000; Patel, 2003; Sarma, 2006 and Ababi Zergaw *et al*., 2008), Of the direct cost, we found maximum money was spent on travel constituting 21% to 45% of total direct cost followed by faith healing. Other studies from country have shown most share of direct cost being money spent on travel and drugs, (Sarma, 2000; Patel, 2003; Sarma, 2006 and Ababi Zergaw *et al*., 2008). However, in current study, medications accounted for nearly 7.2% to 10% of the total cost, may be due to free medications being provided from the hospital to all. Patients and caregivers were spending much more time in reaching till the consultant psychiatrist than actually meeting the psychiatrist in the hospital. Travelling to hospital so far off and waiting in queues to reach till the doctor and then standing in free medicine dispensing queue was further more time consuming. This emphasizes the need to have more community mental health centers. Consultation fees hardly accounted for 3.8% to 6.6%, in view of the fact that consultation at index hospital was free of cost; it was due to only occasional visit to a private psychiatrist by few. Interestingly, more money was being spent on faith healers as compared to fees of even a private psychiatrist. Similar results were reported by De silva *et al*. in a subset of schizophrenia patients, but no such studies have been done for bipolar disorder patients. (De Silva, 2012). In current circumstances, informal treatment from traditional healers results in significant financial loss to the family. Patients on interview reported, geographical inaccessibility of mental health services, lack of awareness of mental health services, lack of awareness about effectiveness of medical treatment for mental illnesses, fear of being stigmatized by visiting a psychiatrist and cultural acceptability of traditional faith healing methods as the main reasons of visiting faith healers.

They also reported, faith healers spend more time with patient and family than psychiatrists. Similar reasons were cited in a study conducted by Lahariya *et al* to study pathways of care. (Lahariya, 2010). In Indirect cost, major share was formed by out of pocket expenditure by the family which came out to be average 14% to 28% of total cost. Urban residents had significantly more income loss and more out of pocket expenditure being incurred by caregivers as compared to rural area patients. The answer to this difference lies in the group s socio demographic data, the people coming from outside Delhi had more of agriculture as predominant profession, causing lesser number of income loss as compared to private job of caregiver residing in urban area. Moreover, rural area residents had more of joint families providing strong social support system for patient care as compared to nuclear families of urban area, where cost of arranging a maid for care of patient and other household support increases expenditure. For care giving, extra money is being spent on loans taken, appointing nurse/ servant, sending children to boarding, making extra phone calls, loans taken, savings spent, patients implicated in accident/crime/legal problem/property damage.

This Out of pocket expenditure for illness is known to precipitate and worsen poverty in the vulnerable. For low income families, spending 10% of household income on illness can be potentially catastrophic (Kawabata *et al*., 2002 and Ranson *et al*., 2002). This could force households to cut their spending on essentials such as food, clothing and education and trigger off sales of productive assets or resort to high cost borrowing from money lenders. This phenomenon is described as the 'medical poverty trap' (Russell, 2005). Though free health services protect against high out of pocket expenditure. But there should be provision for insurance service schemes for mental illness. India has ratified United Nations Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities in 2007, which empowers persons with disability with the right to access as per article 9 and right to the enjoyment of highest attainable standards of health as per article 25. (Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, 2006). For its implementation, it mandates as per article 2, general obligation for the state to provide a range of affordable health care to people with disability without discrimination (Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, 2006). Government though claims to have put efforts in place by removing physical barriers to health by district mental health programme (DMHP), which is currently operational in 120 districts (DMHP, 2016). But still the service utilization rates are low. Despite many of the services being available, due to lack of awareness, they are not being utilized. As in current study, as many as 20% have more than 1 mental health facility near their home, but still were travelling far across. Also, in our study, disability benefits were highly underutilized, due to poor awareness and lack of education. Kashyap *et al* in 285 patient's retrospective study too found under utilization of available welfare measures by persons with mental disability (Kashyap, 2012). Limitations of the study were, it involved only married women with children limiting its generalizability. Patients recruited were in stable phase, findings were based on recall and done in a government hospital where medicines and consultation are free; so, there is possibility of indirect cost having been minimized. It just reflects a cross sectional assessment, a longitudinal analysis could have shown better results of changing costs across various phase of illnesses.

Conclusion and future implications

Government initiatives need to focus on increasing awareness regarding available health facilities, strengthen network of district health clinics to reduce money and time spent on travelling especially in rural areas. Since indirect cost of care is significantly high, so, efforts on providing appropriate

economic respite care to patients and family caregivers should be considered to reduce 'out of pocket expenditure' and insurance mechanisms to be made in place for mental illnesses too. Future studies need to focus more on how to devise feasible intervention strategies to lessen economic and family burden due to severe mental illnesses and also need to define cultural norm of care giving in the rural and urban community. In addition, it would be better to conduct longitudinal nationwide more representative economic burden study for mental illnesses along with epidemiological surveys.

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