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IMHO Keshav Desiraju INDIA MENTAL HEALTH OBSERVATORY

Understanding costs associated with mental health care in India

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Introduction

Health care and treatment comprises a major living expense for most Indians, majority of whom live within meager means. The World Health Organisation (WHO) Health Financing Profile for 2017 shows 68% of total expenditure on health in India was paid out-of-pocket (OOP), a significantly high figure when compared to the world average of 18.2%.[1] OOP expenses in healthcare are the expenses not paid by insurance or obtained through public healthcare and must be paid through an individual's personal cash reserves.

According to a study published in 2018 by the Public Health Foundation of India (PHFI), OOP health expenses drove 55 million Indians into poverty in 2017, a majority of whom, 69% or 38 million, were impoverished by expenditure on medicines alone.[2] The study further found over 80% of Indians incurred OOP payments on health care during 2011-12, an increase from 60% during 1993-1994. Even the Economic Survey of 2021 noted that India has one of the highest levels of OOP expenditures on healthcare, contributing directly to the high incidence of catastrophic expenditures and poverty.[3] The Union health ministry recognizes medicines are the biggest financial burden on Indian households: of more than three lakh crore rupees spent by households on health between 2014-15, around 43% of the total OOP was spent on the purchase of medicines.[4]

The National Health Policy 2017 suggested an increase in public spending from 1% to 3% of GDP, an action that will decrease OOP expenditures from 65% to 30% of overall healthcare spending.[5]

Considering mental health, the National Mental Health Survey (NMHS) 2016 estimated 10.6% of India's population lives with a mental health condition.[6] Mental health conditions place a considerable economic burden on those living with them. The NMHS 2016 found the median OOP expenditure by families on treatment and travel to access care was ₹1,000-1,500 per month. Discussions with survey respondents revealed that expenditure incurred on treatment of mental health conditions often drove families to economic hardship. The survey also found that mental health conditions disproportionately affect households with lower income, less education, and lower employment. Lack of access to quality state services and insurance coverage results in high OOP expenses when treatment is sought, thus worsening the economic strain on the poor and vulnerable.

The Mental Healthcare Act (MHCA), 2017 aims to prioritize inclusion and rehabilitation of mentally ill persons into society and eliminate the stigma attached to mental health conditions. Section 18(1) of the MHCA 2017 mandates that every person has the right to access mental healthcare and treatment from mental health services run or funded by the appropriate Government. Further, sub-section 2 reiterates the right of every person to mental health services at an affordable cost.[7] However, the budget allocated for mental health is 0.05% of the total health care budget, restricting the government's investment in developing public health facilities to provide mental health services. The 75th Round of the National Sample Survey (NSS), a nation-wide survey conducted by the Government of India during 2017-18, found the average cost of hospitalization for psychiatric and neurological ailments was ₹26,843, with an average cost of ₹7,235 for care in public hospitals and ₹41,239 for private hospitals, comparable to costs associated with cardiovascular and musculoskeletal ailments.[8]

To understand the ground realities of spending on mental health care and treatment, we conducted a literature review to determine the OOP expenses incurred by families for treatment of mental health conditions and the resultant economic burden it might create.

Relevant academic research articles were identified using key words of “India”, “cost of care”, “cost of treatment”, “out of pocket expenses”, “mental illness”, “mental disorders” on PubMed and Google Scholar. We found nine studies which discussed the cost of mental health care in India, and we included the following six studies (refer Table 2). Our focus for this brief is on OOP expenses for individuals. Three studies were excluded as they were dated or not relevant. The six studies include Out-patient-Department (OPD) treatment (n=4), In-patient-Department (IPD) treatment (n=1) and one study covers both OPD and IPD patients. The studies are spread across both public as well as private health facilities in different geographies such as rural, semi-urban and urban areas.

The findings from the relevant six studies are summarized below across different cost heads.

The major components of cost of care can be bifurcated into direct costs, the expenditure on treatment of mental health conditions and indirect cost consisting of the monetary value of lost productivity of patients or caregivers, and intangible cost in terms of stress, stigma, etc. borne by those affected. Direct costs are the actual monetary expenditure related to treating an illness or disorder. It includes costs associated with hospitalization, outpatient services, nursing care, drugs, and services of a range of professionals, residential care, day care, domiciliary care and rehabilitation. It also includes provider’s cost which is borne by the hospital for providing medical facilities (not under purview of this brief).

The cost heads (refer Table 1) include cost of medicines, investigations or tests, food & travel and loss of wages to the patient as well as the caregivers (Not all costs are available for all studies):

Table 1: Direct and Indirect Costs related to Mental health conditions

Direct Costs	Cost of Consultation	Costs incurred to meet with a psychiatrist or other mental health professional. Consultations are free or available at minimal fee in government settings but chargeable in private settings.
	Cost of Medicines	Costs incurred to purchase psychotropic medications. Psychotropic medicines are meant to be available free of cost or at a subsidised rate through government facilities. However, they are chargeable in private facilities.
	Cost of Investigations	Costs incurred for investigative laboratory tests such as blood tests and scans.
	Cost of travel	Costs incurred for travel from place of residence/work to place of public or private health facility. This can refer to either public or private transport. The cost also includes transport costs for accompanying caregivers.
	Cost of Food	Costs incurred for food for patient and accompanying caregivers during length of travel and hospital stay.
Indirect costs	Loss of Wages to Patient	Costs incurred when patients take time off from work for consultations/ follow up and face subsequent loss of wages.
	Loss of Wages to Caregiver	Costs incurred when caregivers take time off from work for consultations/follow up and face subsequent loss of wages.

Table 2. Details on the studies included in this review

#	Name of Study	Author(s)	Type of condition	Setting	Year	Location
1.	Impact of community-based rehabilitation for mental illness on 'out of pocket' expenditure in rural South India	Sivakumar et al.	Psychosis, Bi-polar Disorder	OPD	2019	Jaglaru, rural Karnataka
2.	A Prospective Study To Assess The Out-of-Pocket Expenditure Among Psychiatric Patients Attending Tertiary Care Service by	Mandal et al.	N/A	OPD and IPD	2018	Tertiary unit hospital, North India
3.	Cost-of-treatment of Clinically Stable Severe Mental illnesses in India and comparison with per Capita income	Sarkar et al.	Schizophrenia, Psychosis, Bipolar Affective Disorder, Recurrent Depressive Disorder	OPD	2017	Multi-speciality hospital, South India
4.	Cost of Care: A study of patients hospitalized for psychotic illness	Rejani et al	Bipolar Disorder, Schizophrenia, Psychotic Disorder	IPD	2015	Medical College Hospital, Thrissur, Kerala
5.	Comparative study of cost of care of outpatients with bipolar disorder and schizophrenia	Somaiya et al.	Bipolar Disorder, Schizophrenia	OPD	2014	Post Graduate Institute of Medical Education and Research, Chandigarh
6.	An estimate of the monthly cost of two major mental disorders in an Indian metropolis	Sharma et al.	Schizophrenia, Bipolar Disorder	OPD	2006	Ram Manohar Lohia Hospital, New Delhi

1. Impact of community-based rehabilitation for mental illness on 'out-of-pocket' expenditure in rural South India (2019) Sivakumar et al.[9]

This study examined the impact of a community-based rehabilitation (CBR) program, a private-public partnership of National Institute of Mental health and Neurosciences (NIMHANS) with the state government which began in 2015 in Jagaluru taluk, an administrative block in rural Karnataka on OOP expenditure for persons with severe mental health conditions.

The CBR programme consisted of mental health camps organized twice a month at the ten PHCs in the taluk as well as the taluk hospital, visits by consultant psychiatrists, psychotropic medicines provided free of costs, detailed follow-up, family psycho-education, home visits by social workers and presence of a large team of supporting health activists and nurses.

In this study, 95 out 275 persons with psychosis or bipolar disorder who had availed of the services of the CBR program for over a year and their families were interviewed on details of their mental health conditions, treatment frequency and costs. The sociodemographic details of the sample showed an equal split between men and women, with an average age of 40 years old and an average length of illness of 11 years. The 95 individuals had previously visited government or private facilities regularly for treatment of their mental health conditions. Where possible, the figures obtained through interviews were cross-referenced with receipts of any expenses.

The researchers found prior to joining the programme, around 84% of the patients had sought private treatment despite public services being available. The authors cite a range of factors for this, including a lack of awareness of services available in public sector and a general mistrust of the government health facilities. The average total annual expenditure per patient among the 95 participants who availed government or private services was ₹15,074, which reduced to ₹492 when they switched to the CBR programme. This resulted in savings of Rs 13,59,780 per annum to 95 families of patients who had switched to the CBR services.

Thus, the researchers found the CBR programme reduced expenses and cost burden on the families significantly. The highest expenditure category prior to joining the programme were 'medicine costs' (₹9,911), which, along with 'Psychiatrist fee' (₹619), reduced to zero when free services and medicine were availed through the CBR programme. As the CBR programme provided services at PHCs and offered home-based treatments, indirect costs such as travel costs (₹2,789) and loss of wage (₹1,469) reduced significantly as well to ₹53 and ₹413 respectively. Based on their findings, the authors recommend a community-based model of care.

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Table 3. Average monthly Out of pocket expenditure per person with mental health conditions disaggregated by type of services availed (₹) (Sivakumar, 2019) (*annual expenses in actual studies pro-rated to monthly **)**

Type of Service Availed	Counsutlation	Medicines	Travel	Investigation	Food	Loss of Wages	Total
Government or private services (for the year before CBR)	52	826	232	NA	NA	122	1,256
Community Based Rehabilitation	0	0	4	NA	NA	34	41

2. A Prospective Study To Assess The Out-of-Pocket Expenditure Among Psychiatric Patients Attending Tertiary Care Service (2018) Mandal et al.[10]

This paper assessed OOP expenditure among psychiatric patients attending a public tertiary level urban hospital in North India – PGIMER (Post Graduate Institute of Medical Education and Research, Chandigarh). The study was conducted in July-August 2016 and 200 patients seeking inpatient as well as outpatient services were interviewed, most of them outpatients.

10% of patients were randomly selected for interviews from a single day's OPD attendance. All the inpatients during this period were included in the study. Semi-structured interviews were conducted for measuring OOP. For OPD patients, a single interview was conducted and for IPD patients, alternative day interviews were held for the duration of stay. Interviews were conducted for patients as well as their caregivers.

Among the OPD patients, 37.5% belonged to age group of 31-45 years, 52.5% were females and, 65% were married. 51.5% of the patients were from rural areas and 41% of the people were unskilled workers. Per capita income per month of 42% of patients was up to ₹3,000. The mean per capita income was around ₹6,500 per month.

Among 20 admitted patients, 65% of the inpatients incurred up to ₹25,000 as expenditure for hospitalization, 25% inpatients incurred expenditure in between ₹25,001-50,000 and only 10% patients had more than ₹50,000 total OOP expenditure during their present hospitalization. The duration of stay in hospital was approximately 2 months. The costs for medicines and investigations were high and contributed to the overall costs. Whereas, among outpatient expenses, medicines were a major direct expense and travel & food were major indirect expenses according to the study.

Further, prevalence of catastrophic health expenditure among outpatients was 18.9% and among inpatients it was 25%. Catastrophic health expenditure was defined as expenditure that exceeded 25% of family income. At catastrophic level of expenditure, the health expenditure eats into family's income and affects food patterns and daily basic needs of patients and family members. This leads to further impoverishment, setting up a vicious cycle of poverty and ill health fueling each other.

The loss of wages was not available for this study.

Table 4. Average monthly cost per patient with mental health conditions disaggregated by type of services availed (in ₹) (Mandal et al, 2018)

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Type of Service Availed	Consultation	Medicines	Travel	Investigation	Food	Indirect Expenses	Total
OPD	12	731	243	828	692	NA	57
IPD	6,988	1,273	1,361 +266 (ECT)	2,622	5,541	Indirect expense (not specified) 3,590	266

3.Cost-of-treatment of Clinically Stable Severe Mental illnesses in India and comparison with per Capita income (2017) Sarkar et al.[11]

Sarkar et al. in 2017 published a study to assess the direct and indirect costs of treatment for four types of severe mental health conditions. The study is uniquely positioned as it examines the treatment costs against the per-capita income of the patient to provide insight into the financial burden of such expenditures.

The study was conducted in a multispecialty hospital in South India. The patients selected for the study were mostly from households with an average monthly per-capita income of ₹1,680 and were given an ICD-10 diagnosis of schizophrenia, unspecified nonorganic psychosis, bipolar affective disorder, and recurrent depressive disorder. All patients who were a part of the study were receiving outpatient care for over a year.

Information was collected from patients and caregiver records as well through surveys. The direct expense heads included cost of psychotropic medication, hospital consultation fees and travel. In this setting, the main cost to the patient were for travel and medication purchased outside the hospital premises.

The study does not present any indirect costs such as loss in income to patients and/ or caregivers. The study estimated the average monthly cost of psychiatric treatments at ₹770 for each patient. The largest expense was towards medication at ₹390 each month per patient however 88% of the cost was borne by the hospital pharmacy. The average consultation cost was ₹260 per patient per month. Across all mental health conditions, the major costs were borne by the hospital.

The highest average monthly expenditure was among patients living with bipolar disorder at ₹830 per patients and the lowest as calculated by the researchers was for patients living with schizophrenia at ₹720.

12% per-capita of patients' income were spent on mental healthcare. Among those patients surveyed, 4% spent more than 100% of their income on their treatment an indication of the heavy and unsustainable burden that treatment costs levy on an individual.

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Table 5. Average monthly expenditure per person with mental health condition disaggregated by type of mental health condition (in ₹) (Sarkar et al. 2017)

Condition	Medication expenses borne by patient	Consultation	Travel	Total Cost to patient
Schizophrenia	20	Borne by hospital	160	180
Psychosis NOS	90		120	210
Bipolar Affective Disorder	40		130	170
Recurrent Depressive Disorder	20		70	90

4. Cost of Care: A study of patients hospitalized for psychotic illness (2015) Rejani et al.[12]

The study by Rejani et al, the only other study from our review that assessed IPD services, was conducted in 2015 at the Medical College Hospital, Thrissur, Kerala, a public hospital in a semi-urban facility. The study included 100 patients hospitalized with schizophrenia, bipolar disorder and psychotic disorder during a period of 6 months. The study included 54 males and 46 females. The mean age was 35.6 years (range 17-70 years). Most of the patients (67%) were from households classified as below the poverty line. The average daily and monthly family income was ₹300 and ₹8,000 respectively. 49% of the patients were engaged in semi-skilled or unskilled work before hospitalization.

The data was collected through direct personal interviews using specially designed proforma. The average direct expenses incurred during hospitalization amounted to ₹2,421.

The average total expenses, including indirect expenses was ₹3,975, increased with the duration of hospital stay. Average duration of hospital stay was 13 days.

These services are typically accessed by patients living below the poverty line. Almost 45% of the families had availed loans for different purposes and 22% had availed loans for meeting hospitalization expenses related to psychosis, while around one-fifth borrowed money to meet expenses. Travel and investigation charges had the largest strain on financial expenses. This study noted financial burden on families across different economic strata not only due to hospitalization but also due to expenses on continued treatment and recommended financial support from the government for treatment of psychotic illness.

Table 6. Average cost per hospitalization per person with mental health conditions (in ₹) (Rejani et al, 2015).

Condition	Consultation	Medicines	Investigation	Travel	Food	Loss of wages	Misc.
Bi-polar/ Schizophrenia/ Psychotic disorder	0	198	300	396	1,200	Patient: 2,000 Caregiver: 1,500	100

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5. Comparative study of cost of care of outpatients with bipolar disorder and schizophrenia (2014) Somaiya et al. [13]

This study by Somaiya et al. was conducted in 2014 at the Post Graduate Institute of Medical Education and Research (PGIMER), Chandigarh, in an urban setting. The purpose was to compare the cost of care of OPD patients with bipolar disorder and schizophrenia. It covered 75 patients with bipolar disorder and 53 patients with schizophrenia. The group of patients diagnosed with bipolar disorder were 69% male and those with schizophrenia were 51% male. 95% from the bipolar disorder group and 74% of patients with schizophrenia were married. 61% of patients with bipolar disorder and 76% of patients with schizophrenia were from rural area. 55% of patients with bipolar disorder and 66% of patients with schizophrenia were from upper/upper-middle class socio-economic strata

Data was collected from July 2010 to June 2011 through semi-structured interviews with patients. As per this study, the OPD cost of treatment for the patient of bipolar disorder was ₹17,232 and for schizophrenia was ₹32,511.

According to this study, the cost of medicines was the highest cost among the direct costs at ₹3,993 per annum for bipolar disorder and ₹3,027 per annum for schizophrenia. This was despite medicines being available at the hospital at subsidized rates. Travel formed a large proportion of the cost of care. The biggest concern was the loss of wages borne by patients as well as the caregiver due to health issues as well as time needed for seeking treatment. The patient and their families bore the large part of financial burden approximately 96% of the total cost.

Table 7. Average annual Out of pocket expenditure per person with mental health conditions (₹) (Somaiya, 2014) (Converted to monthly on pro-rata basis)

Condition	Paperwork, Sundry & Misc.	Medicines	Investigation	Travel	Food	Loss of wages
Bipolar disorder	9	333	79	191	31	Patient: 547 Caregiver: 248
Schizophrenia	9	252	55	119	45	Patient: 1,311 Caregiver: 910

6. An estimate of the monthly cost of two major mental disorders in an Indian metropolis (2006) P. Sharma et al. [14]

This study estimated the cost of major chronic mental health conditions to families and patients visiting Dr. Ram Manohar Lohia Hospital (RMHL), New Delhi, a tertiary care general hospital which provides free consultation costs for both inpatient and outpatient care.

117 people between the ages of 18-60 living with schizophrenia (n=95 or 81%) or bipolar disorder (n=22 or 19%) using services of RMHL were interviewed, to estimate costs incurred over 3 months prior to the interview. The patients were a mix of both genders, a majority were under the age of 45 and predominantly belonged to lower middle-income groups living in urban localities. None of the patients lived alone, with 89% living with their spouse, children or parents and 11% lived with other relatives. The researchers used tools such as the '*Economic Burden Questionnaire*' to gather information. The researchers defined direct treatment cost as consultation and medication and defined indirect costs as time spent by caregiver for consultation, time spent caring for the patient, wage loss due to caregiving and job loss due to caregiving among others.

The researchers found the cost of informal caregiving further increased the cost of mental health conditions. Comparing between the type of services availed, costs were found to be significantly lower in both persons with schizophrenia and bipolar disorder who availed services at RMLH, and costs higher for those who visited primary health care facility and traditional healers. When comparing time spent in care for persons between the two conditions, time spent for persons with bipolar disorder was lower compared to that for schizophrenia. The average time spent per month was 4 hours in consultation, and between 33 to 124 hours in caregiving for patients with schizophrenia; whereas it was 16 hours in consultation and between 50-153 hours in caregiving for patients with bipolar disorder per month.

Table 8. Average monthly expenditure per person with mental health conditions (in ₹) (Sharma, 2006)

Condition	Consultation fee*	Medicines	Travel*	Investigation	Food	Loss of income	Misc. (caregiving hours per month)
Schizophrenia	0 – 468	288	66 – 482	NA	NA	567-2,000	33-124 hours
Bipolar disorder	0 – 2833	364	97 – 1,676	NA	NA	600-2,750.	50-153 hours

**Depending on RMLH, PHC, or traditional healer*

Table 9. Average monthly expenditure per person with mental health conditions for studies (in ₹) (1/2)

Studies	Type of service availed	Condition	Consul-tation fee	Medicines	Travel	Invest-igation	Food	Loss of wage	Total
Impact of community-based rehabilitation for mental illness on 'out of pocket' expenditure in rural South India (2019) OOP*	Government or private services (for the year before CBR)	Psychosis or bipolar disorder	52	826	232	NA	NA	122	**1,256**
	Community Based Rehabilitation		0	0	4	NA	NA	34	**41**
A Prospective Study To Assess The Out-of-Pocket Expenditure Among Psychiatric Patients Attending Tertiary care Service	OPD	NA	12	731	828	243 ECT: 57	892	NA	**2,763**
	IPD		Bed charge: 6,988	1,273	2,622	1,361 ECT: 266	5,541	NA	**11,063**
Cost-of-treatment of Clinically Stable Severe Mental illnesses in India and comparison with per Capita income	OPD	Schizophrenia	NA	20	160	NA	NA	NA	**180**
		Psychosis	NA	90	120	NA	NA	NA	**210**
		Bipolar disorder	NA	40	130	NA	NA	NA	**170**
		Recurrent depressive disorder	NA	20	70	NA	NA	NA	**90**

Table 9. Average monthly expenditure per person with mental health conditions for studies (in ₹) (2/2)

Studies	Type of service availed	Condition	Consultation fee	Medicines	Travel	Investigation	Food	Loss of wage	Total
Comparative study of cost of care of outpatients with bipolar disorder and schizophrenia OOP*	OPD	Bipolar disorder	0	333	191	79	31	Patient: 547 Caregiver: 248	**1,430**
		Schizophrenia	0	252	119	55	45	Patient: 1,311 Caregiver: 910	**2,693**
An estimate of the monthly cost of two major mental disorders in an Indian metropolis	OPD	Schizophrenia	0 – 468*	288	66-482*	NA	NA	567-2,000	**3,238**
		Bipolar disorder	0 – 2,833*	364	97-1,676*	NA	NA	600-2,750.	**7,623**
Cost of Care: A study of patients hospitalized for psychotic illness	IPD	NA	NA	198	396	1200	300	Patient 2,000 Caregiver 1,500 Misc 100	**5,694**

Lack of reliable and comprehensive data on this subject has led to fewer policy interventions on the important issue of affordability of treatment of mental health conditions. The studies reviewed have certain limitations. Arriving on estimates for the cost of care for mental health conditions is a challenge, given the varied contexts involved, including the nature of mental health condition, type of treatments and services availed, population groups and geographic location. The scope of this review and analysis was restricted by the limited number and varied nature of the studies covering cost of mental health in India as well as how researchers define and measure time and costs. Most of the studies concentrated on severe mental disorders such as bipolar disorder, schizophrenia and psychosis. We could not find data around common mental disorders such as depression, anxiety and addiction. The sample size within the studies analysed was limited to 100-200 patients each and the findings may not be representative of the larger population. Other than a brief mention in the NMHS 2016 and NSS 2017-18, (which only provides aggregated data on psychiatric and neurological conditions together), we could not find any comprehensive large-scale government data sets detailing the OOP expenditure on mental health conditions. Thus, to develop a more representative and comprehensive understanding of OOP for mental health across the country, we require more dedicated studies or surveys with a larger sample size that examine a range of mental health conditions.

Despite the limited number of studies, few points are clear:

1. There is significant loss of income to the patient and caregiver when seeking mental health care. This in turn, may impact care seeking behavior and location or quality of service sought.
2. The vicious circle of poverty impacts those with mental health conditions. Loss of income as a result of time spent seeking treatment translates into not having enough money to spend on mental health care, thus exacerbating the situation by limiting access to adequate work opportunities. People with low income are financially stretched due to the direct and indirect expenditure incurred. which leads to other problems such a poverty, loss of income and avoiding health care highlighted by studies.
3. Cost of medicines and travel are two large direct costs across studies in seeking treatment. This issue can be addressed by making medicines available free of cost for a longer period or at more locations closer to patients' residence so that frequent need for re-fills are prevented. More studies can be conducted to decide what kind of transportation allowance can be given to people to soften the blow of transportation expenses.
4. Across studies, indirect costs are significant and a burdensome component of total cost. More studies will enable us to understand the ground reality and help the government form evidence-based policies in disbursement of disability allowance to cover for such loss of income

Data and research in the field of cost of mental healthcare is critical for informed policy decisions and system-level changes so that services are more affordable and people with mental health conditions can lead fruitful lives. In addition to more empirical studies, the research should also focus on i) narrative experiences of how living with mental health issues and seeking mental healthcare qualitatively affects one's life and their families from financially including the trade-offs that people make for their treatment and other expenses; and ii) the economic implications on those in informal daily wage work where catastrophic health expenses may lead to unemployment because of the unpredictability and volatile nature of such work.

This means people rely heavily on private facilities and have to spend a high recurring OOP expense if at all they decide to seek treatment. For the poor, who seek treatment at public facilities, loss of wages to self and caregiver are substantial. We hope that evidence-based policies around the affordability of mental healthcare and treatment is prioritized by the government in the future in line with the implementation of MHCA, 2017.

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