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ORIGINAL ARTICLE

Financial Burden in Families of Children with West Syndrome

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Abstract

Objective To evaluate the illness-related expenditure by families of children with West syndrome (WS) during the first year of illness and to explore the potential determinants of the financial drain.

Methods This cross-sectional study was conducted at a tertiary care hospital between July 2018 and June 2020. Eighty-five children with WS who presented within one year from the onset of epileptic spasms were included. The details of the treatment costs (direct medical and nonmedical) incurred during the first year from the onset of epileptic spasms were noted from a parental interview and case record review. Unit cost was fixed for drugs and specific services. Total cost was estimated by multiplying the unit cost by the number of times a drug or service was availed. The determinants of the financial burden were also explored.

Results The median monthly per-capita income of the enrolled families (n = 85) was INR 3000 (Q1, Q3, 2000, 6000). The median cost of treatment over one year was INR 27035 (Q1, Q3, 17,894, 39,591). Median direct medical and nonmedical expenses amounted to INR 18802 (Q1, Q3, 12,179, 25,580) and INR 6550 (Q1, Q3, 3500, 15,000), respectively. Seven families had catastrophic healthcare expenditure. Parental education and choice of first-line treatment were important determinants driving healthcare expenses. The age at onset of epileptic spasms, etiology, treatment lag, the initial response to treatment, and relapse following initial response did not significantly influence the illness-related expenditure by the families.

Conclusion WS imposes a substantial financial burden on the families and indirectly on the healthcare system.

Keywords Infantile spasms · Financial burden · Cost of illness · India · Children

Introduction

West syndrome (WS) is characterized by clustered epileptic spasms in infancy and hypsarrhythmia on electroencephalogram (EEG) [1]. It is the most common type of infantile-onset developmental and epileptic encephalopathy. A recent study from the United Kingdom suggested that the incidence of WS is 6.7 (95% CI 1.2–5.7)/10,000 live births [2]. It is expected to be higher in developing countries with a higher incidence of perinatally acquired brain injuries, e.g., hypoxic–ischemic and hypoglycemic brain injury [3]. These children often have comorbidities, including developmental delay, locomotor, visual, and hearing impairment necessitating multidisciplinary care for holistic management. The first-line treatment options include adrenocorticotropic hormone (ACTH), oral steroids, and vigabatrin [4]. The short-term management goals are enduring cessation of epileptic spasms and resolution of hypsarrhythmia, which are achieved in nearly one-third of patients after first-line therapy [5]. The long-term neurodevelopmental outcome is often poor and depends on the initial therapeutic response [6]. Unlike the developed countries, the management of WS in India and developing countries has its own intricacies. These include a long treatment lag, preponderance of structural etiology, lack of awareness, and out-of-pocket expenditure for healthcare utilization [5, 7]. Besides, two of the three first-line therapeutic options (ACTH and vigabatrin) are quite expensive, with ACTH often requiring hospitalization for the initiation and monitoring of adverse effects. Vigabatrin is not readily available in India. Considering the comorbidities, cost of drugs, and long-term

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treatment, illness-expenditure might be catastrophic for a low-income family. The financial burden borne by the families having children with WS has not been systematically studied in India.

The financial burden is usually quantified in terms of direct, indirect, and intangible costs due to a specific disease [8]. The direct costs can be classified into medical costs (related to prevention, diagnosis, treatment, and rehabilitation) and non-medical costs (related to travel for hospital visits, food and accommodation, etc.). The indirect costs are estimated in terms of loss of earnings, time, and attributed value of the lost household work. Furthermore, the intangible costs include stress, suffering, or anxiety due to the illness or its treatment [9]. The majority of the studies in adults with epilepsy have focussed primarily on the direct costs because of the inherent difficulty in computing the indirect and intangible costs [8, 9]. WS poses a distinct challenge because of infantile-onset, costly investigations and treatment, and comorbidities management. A lack of universal health insurance in India further contributes to the financial burden handled by the families. Therefore, the present study was performed to evaluate financial spending (direct costs) during the first year of illness in children with WS. Besides, an attempt was made to explore the possible determinants of the financial drain.

Material and Methods

This cross-sectional, descriptive, observational study was conducted between July 2018 and June 2020 in the Department of Pediatrics, Postgraduate Institute of Medical Education and Research, Chandigarh, a tertiary-care government children hospital in North India. The study was approved by the Institute Ethics Committee. Children with WS (epileptic spasms and hypsarrhythmia in EEG) attending outdoor clinics of the Pediatric Neurology unit were screened. All consecutive children who presented within one year from the onset of epileptic spasms were considered eligible for inclusion. Detailed informed consent was obtained from the parents at the time of enrollment. Those who declined consent were excluded from the study.

The parents/guardians of the enrolled children were interviewed for the sociodemographic aspects and details of the treatment costs incurred. The clinical and investigational details were retrieved from the medical records. The data on demographic characteristics, age at onset of epileptic spasms, presence of any specific perinatal insult, parental educational status, monthly family income, delay in seeking treatment, diagnosis, and the start of appropriate first-line treatment were collected. It was noted whether the children were beneficiaries under the poor free scheme for below poverty line (BPL) families. The criterion for inclusion in the BPL facility was a provision of yellow ration cards to the families by the Government of India. It was also noted whether infants were benefitted from Janani Shishu Suraksha Karyakram (JSSK).

The costs incurred in a year were determined by interviewing the caregivers. The bottom-up approach of cost analysis was used wherein, every single area of expenditure was calculated. Costs were categorized as: a) direct medical costs including the cost of outpatient consultation, hospital admission, drugs, investigations, and ancillary services; b) direct nonmedical costs involving an expenditure of travel to and from the health setup, the cost of food, and accommodation while being stationed at the hospital with the child (two caregivers per patient).

Unit cost (under the direct medical costs) was fixed for each commodity based on the price at the index institute (Supplementary Table 1). Total cost was calculated by multiplying the unit cost by the number of times a service or product was availed. Direct nonmedical costs were noted at first admission (or at first contact for those who were never admitted) at the index institute, and it was assumed that the pattern of expenditure on these components remained the same throughout the year. Parents were interviewed at the first visit and asked to keep records of the purchases being made for drugs and investigations. They were followed-up 3-monthly to gather data of expenditure made in the past 3 mo. The expenses made on drugs and investigations were cross-checked from the medical records. Children belonging to BPL families and under the JSSK scheme were exempted from expenses made on investigations and hospital admission charges. The expenditure was calculated in Indian rupee (INR) and the United States dollar (USD) as on August 8, 2020. Figure 1 shows an outline of potential cost-driving factors considered during the collection of data. Annual direct medical and nonmedical costs were calculated, and their relationship with sociodemographic and disease-specific variables was analyzed.

Statistical Analysis Descriptive statistics like mean, median, interquartile range (IQR), and 95% confidence interval were used for various heads of total expenses and their determinants. The sign test was employed to study the significance of the median value of total cost among its determinants. All calculations were done with p value level of ≤ 0.05 as statistically significance. The analysis was done by the Statistical Package for the Social Sciences (SPSS) 22·0 version (IBM Corporation, USA).

Results

A total of 138 children were initially enrolled. However, there was significant attrition of 53 children (38%) due to follow-up difficulties and inability to provide accurate details on financial expenditure incurred over one year. Hence, 85 children

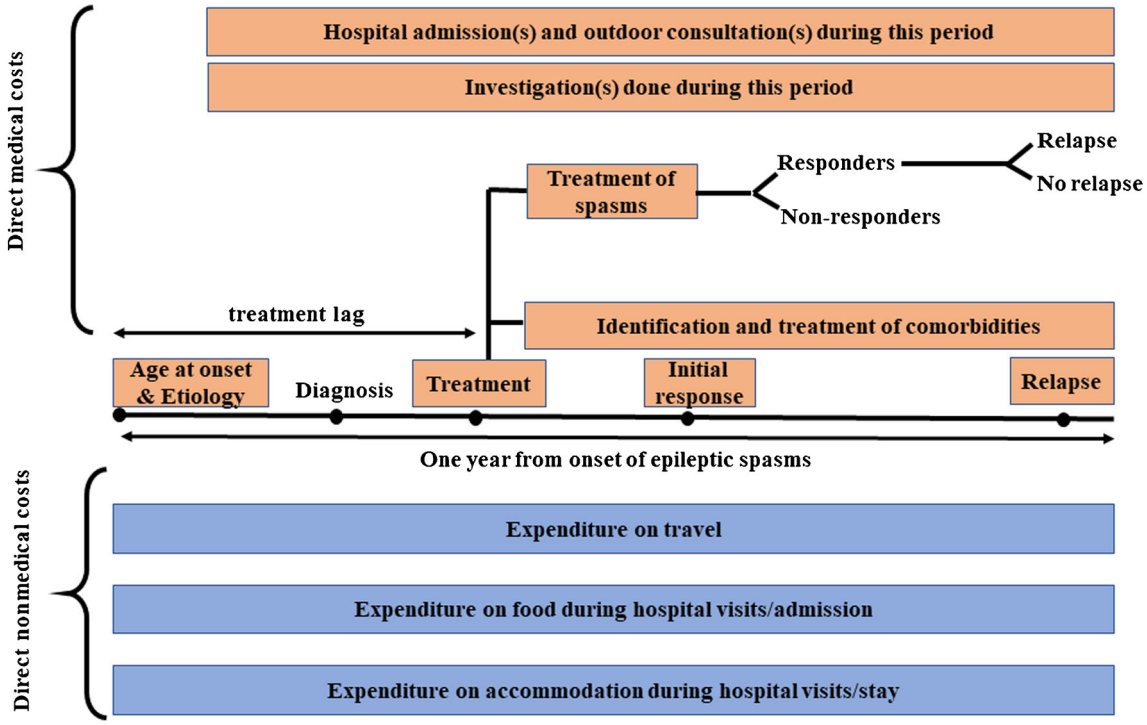

Fig. 1 Potential factors contributing to the financial burden on families of children with West syndrome

(67 boys) completed the one-year follow-up and formed the study population. The majority of the children were from North India. Statewise distribution was as follows: Haryana (n = 30, 35.3%), Punjab (n = 22, 25.9%), Himachal Pradesh (n = 15, 17.6%), Chandigarh (n = 8, 9.4%), Jammu and Kashmir (n = 3, 3.5%), Uttarakhand (n = 2, 2.3%) and Uttar

Table 1 Demographics of the study population

Characteristics	Total (n = 85)
No. of boys	67
No. of girls	18
No. of children from urban area	41
No. of children from rural area	44
No. of children requiring hospital admission	54
No. of children requiring hospital admission twice	9
No. of children requiring hospital admission more than two times	1
Rehabilitative services availed by	85
No. of families that spent money on accommodation	12
No. of families that spent money on food	45
No. of children with complete response to primary treatment	34
No. of children with relapse following complete response to primary treatment	7
Age at onset of spasms; median (IQR)	7.5 (5–10)
Age at enrolment; median (IQR)	9.5 (7–13)
No. of days of IPD admission; median (IQR)	4 (5.3)
OPD charges; median (IQR)	30 (30) [0.4 USD]
IPD charges; median (IQR)	460 (615) [6.1 USD]
Drugs charges; median (IQR)	15,286 (11205) [203.7 USD]
Travel charges; median (IQR)	5000 (11580) [66.6 USD]
Food charges; median (IQR)	360 (1225) [4.8 USD]

Costs described in Indian rupee (INR); values in square brackets have cost in US dollar (conversion as of August 8, 2020, $1 = 75.04)

IPD Inpatient department, *IQR* Interquartile range, *OPD* Outpatient department rupees, *USD* US dollar

Pradesh (n = 2, 2.3%). Three (3.5%) children were from distant states: Bihar (n = 2) and Madhya Pradesh (n = 1). Among the study cohort, 44 children belonged to rural areas, while 41 were from urban areas. The median monthly per capita income of families enrolled was INR 3000 (USD 40), IQR: (2000, 6000; USD 26.6, USD 79.9). The demographics of the study population have been detailed in Table 1.

The median age at onset of epileptic spasms was 7.5 (IQR 5–11) mo. A structural etiology was observed in 71 (83.5%) children, whilst 14 (16.5%) had presumed genetic etiology. Structural causes were as follows: hypoxic–ischemic brain injury (n = 34, 48%), neonatal hypoglycemic brain injury (n = 18, 25%), postmeningitic hydrocephalus (n = 5, 7%), intracranial hemorrhage sequelae (n = 4, 6%) and others (n = 10, 14.0%). Of 14 children with presumed genetic etiology, two were tested with clinical exome sequencing. Constipation (n = 18, 21.1%), visual impairment (n = 13, 15.2%), gastroesophageal reflux (n = 6, 7.0%), hearing impairment (n = 5, 5.8%), hemiparesis (n = 3, 3.5%), infantile tremor syndrome (n = 2, 2.3%), congenital heart disease (CHD; n = 2, 2.3%) and hypothyroidism (n = 1, 1.2%) were notable comorbidities apart from global developmental delay. Three children had Down syndrome (one had comorbid CHD and hypothyroidism, and one had CHD alone). The median diagnostic lag was 7 wk (Q1, Q3, 3, 16 wk), and the median treatment lag was 10 wk (Q1, Q3, 4.7, 18.2 wk). Initial therapeutic choices were ACTH (n = 58, 68.2%), prednisolone (n = 20, 23.5%), and vigabatrin (n = 7, 8.2%). Of 85 children, 49 received only one of the first-line drugs. Crossover of first-line drugs was seen in 36 (42.3%) children. Of 58 children with initial ACTH therapy, 4 subsequently received high-dose prednisolone, 11 vigabatrin, and 6 a combination of prednisolone and vigabatrin. Of 20 children with initial high-dose oral prednisolone therapy, 3 were subsequently received ACTH, 6 vigabatrin, and 1 a combination of ACTH and vigabatrin. Of seven with initial vigabatrin therapy, 3 subsequently received ACTH, and 2 oral prednisolone. Complete response, as defined by enduring cessation of epileptic spasms for 4 wk, to any of the first-line therapies was seen in 40% of children (n = 34). Of those with complete response, 20.5% (n = 7) had a relapse requiring additional antiseizure medications. Relapse was defined by a recurrence of epileptic spasms after achieving a complete initial response.

The median cost of treatment was INR 27035 (Q1, Q3, 17,894, 39,591; USD 238.4, USD 527.5). Median direct medical expenses amounted to INR 18802 (USD 250.6) (Q1, Q3, 12,179, 25,580; USD 162.3, USD 340.8), and nonmedical expenses amounted to INR 6550 (USD 87.3) (Q1, Q3, 3500, 15,000; USD 46.6, USD 199.8). Eight patients in the present study received government assistance under the BPL scheme. Seven patients in the study had catastrophic healthcare expenditure (CHE), i.e., healthcare expenditure was more than 30% of total family income during the study period. depict the distribution of expenditure made over 1 y from the onset of epileptic spasms Fig. 2.

The families coming from nearby states of Punjab, Haryana, and Chandigarh spent significantly less than those coming from far-off states (Table 2). There was no significant difference in the median expenditure based on the gender of the child, locality of residence (rural versus urban), and occupation of parents. However, the cost borne by parents with higher educational status was significantly more.

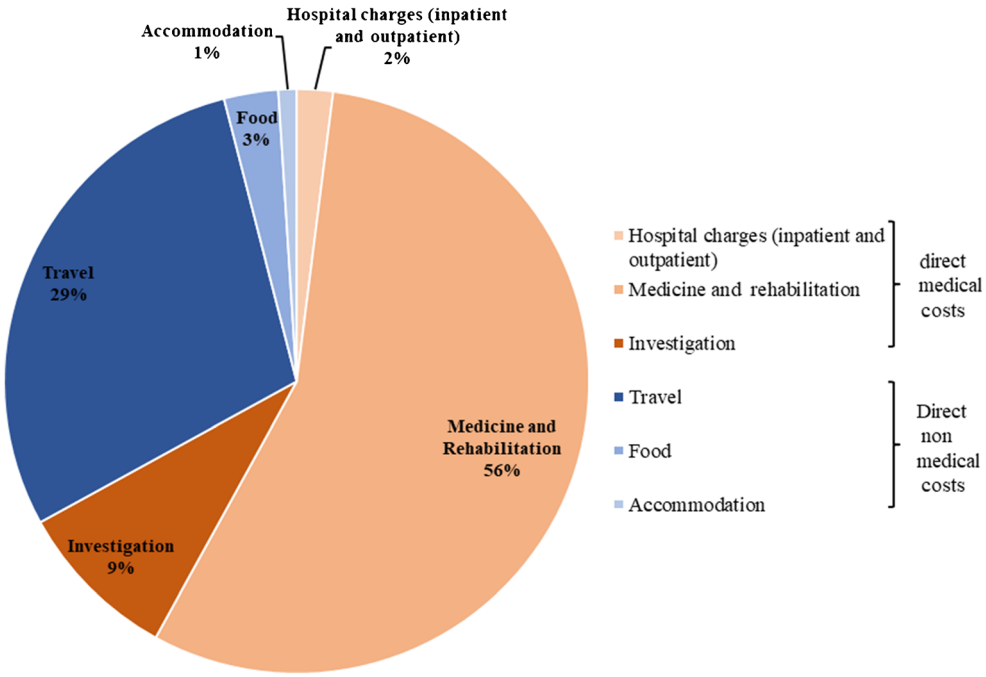

Fig. 2 Utilitywise distribution of annual expense incurred by families of children with West syndrome

Table 2 Sociodemographic determinants of the total cost incurred by families of children with West syndrome

Factors	Variables	N	Median total cost in INR	IQR		95% CI		*p* value
				Q1	Q3	Lower limit	Upper limit	
Gender	Male	67	26,815	17,894	37,763	25,252	34,626	0.75
	Female	18	29,812	16,859	42,923	22,625	36,790	
Locality	Urban	41	27,035	13,410	39,890	23,036	37,363	0.92
	Rural	44	27,076	20,938	39,278	25,734	33,470	
State of residence	Chandigarh, Punjab, or Haryana	60	23,452	16,423	35,163	22,300	28,961	< 0.01*
	Other states**	25	37,763	26,027	46,276	30,197	50,031	
Education of father	Illiterate	5	18,389	7875	30,244	7067	30,784	< 0.01*
	Up to class 12	50	22,379	15,098	30,026	20,484	27,978	
	College graduate and above	30	38,396	30,541	45,215	33,402	48,897	
Education of mother	Illiterate	7	13,519	7265	19,808	8148	22,439	< 0.01*
	Up to class 12	45	23,834	16,809	31,899	21,581	32,894	
	College graduate and above	33	36,545	26,008	44,739	30,900	42,306	
Occupation of father	Unemployed	1	–	–	–	40,680	40,680	–
	Employed	84	26,815	17,470	39,278	25,753	33,771	
Occupation of mother	Unemployed	73	26,539	17,208	37,426	24,885	33,608	0.33
	Employed	12	34,675	37,426	44,521	24,397	43,216	
Financial assistance	BPL government assistance	8	16,460	6042	20,605	9098	22,534	0.03*
	Self-financed	77	28,143	19,160	40,379	27,152	35,553	

*p value <0.05 was considered as statistically significant; **Other states include Jammu & Kashmir, Himachal Pradesh, Uttar Pradesh, Uttarakhand, Bihar, and Madhya Pradesh

CI Confidence interval, *INR* Indian rupee, *IQR* Interquartile range, *Q1* First quartile, *Q3* Third quartile, *USD* US dollar

Expenditure on the illness was considerably less in families receiving government assistance under the BPL scheme.

Looking at the disease-specific parameters, age at onset, etiology, the initial response to treatment, and relapse following initial response did not significantly influence the costs borne by the families (Table 3). The cost of treatment was slightly lower in those with a longer treatment lag. Children initiated on expensive drugs like ACTH and vigabatrin had higher medical costs as compared with those who started on prednisolone. It was seen that choice of primary therapy (ACTH vs. steroids) was driven by the affordability of the families.

Discussion

With India's public health expenditure being less than 2% of GDP [10], it is important to evaluate the out-of-pocket expenditure and understand the distribution of costs for healthcare utilization for different chronic disorders. WS, often associated with multiple comorbidities, merits attention in this regard. This will not only assist in the identification of cost-effective management strategies but also guide administrative authorities in reducing the burden on families by recognizing important issues related to licensing and availability of drugs, and increasing government aid and expenditure on healthcare infrastructure.

The current study evaluated the expenditure on children with WS from diverse economic backgrounds and different states. The median age at onset of epileptic spasms in the present study population and a preponderance of the male gender was in agreement with the reported literature from India [6]. The most common etiology was structural, with adverse perinatal insults such as hypoxic–ischemic encephalopathy, neonatal hypoglycemia, and neonatal meningitis being the predominant causes. This was concordant with previously published literature [5, 6, 11–13]. The median diagnostic and treatment lag were significant and were comparable to that reported in different Indian studies [5, 6, 11–13].

The median direct medical cost in the first year of illness exceeded the direct nonmedical costs. Like other studies evaluating the costs involved in the management of epilepsy and refractory epilepsy syndromes, the cost of medications formed the major bulk of direct medical as well as total costs [14, 15]. Hence, the choice of first-line therapy significantly affected the expenses borne by the family. The choice of first-line therapy, in turn, is affected by several factors such as affordability, the feasibility of daily injections, and monitoring, parental understanding and beliefs. Expensive first-line therapy (ACTH) had been used mostly by families with higher income. Despite receiving the cheapest first-line option, families

Table 3 Disease-specific determinants of the total cost incurred by families of children with West syndrome

Factors	Variables	N	Median total cost in INR	IQR		95% CI		*p* value
				Q1	Q3	Lower limit	Upper limit	
Etiology	Structural	71	17,546	11,527	22,070	15,450	21,418	0.13
	Nonstructural	14	28,223	15,004	37,010	20,714	33,212	
Age at onset of epileptic spasms	≤ 5 mo	24	12,886	6025	20,915	11,077	19,977	0.14
	> 5 mo	61	19,155	14,431	26,572	18,298	25,039	
Treatment lag	≤ 4 wk	21	25,580	14,745	35,849	19,598	35,415	0.13
	> 4 wk	64	17,258	10,665	22,093	15,125	19,836	
Primary treatment	ACTH	58	19,625	15,085	27,343	19,141	25,545	< 0.01*
	Oral steroids	20	6539	4105	12,918	6230	16,164	
	Vigabatrin	7	19,557	14,459	34,368	14,277	33,282	
Response to primary treatment	Lack of complete response	51	18,749	11,527	27,303	16,797	24,844	0.89
	Complete response	34	18,265	12,141	22,186	14,981	21,753	
Relapse[a]	No	27	18,695	12,450	22,070	14,957	21,476	0.67
	Yes	7	12,170	7547	30,769	7613	30,281	
Comorbidities[b]	Absent	46	18,965	12,382	28,861	17,315	23,872	0.58
	Present	39	17,546	9935	23,020	14,291	23,606	

CI Confidence interval, *INR* Indian rupee, *IQR* Interquartile range, *Q1* First quartile, *Q3* Third quartile, *USD* US dollar

*p value < 0.05 was considered statistically significant

[a] relapse was described only for those who initially showed complete response to primary therapy

[b] Constipation, vision impairment, gastroesophageal reflux, hearing impairment, hemiparesis, infantile tremor syndrome, congenital heart disease, and hypothyroidism were considered

of children who received oral steroids went on to spend over 10% of their income. The Child Neurology Society and the South Asian West syndrome research group have suggested high-dose prednisolone as the preferred first-line therapy for WS during the coronavirus disease 2019 (COVID-19) pandemic to minimize healthcare visits [16, 17]. This strategy can also prove beneficial from an economic point of view, especially for developing countries, including India. With the marked contraction of the Indian economy due to the pandemic containment measures, using oral steroids as the preferred first-line option may reduce the initial financial burden on families of affected children during this crisis. Regardless of the implementation of JSSK since 2014, many families in this study did not access free transport to public health institutions. Hence, there is a need to facilitate patient transport services under JSSK once the halted transport services commence.

Although the number of girls in this cohort was less, the fact that parents of girl-child spent equally on treatment as parents of boys was reassuring. The expenses borne by families were associated with parental education. This might be due to the relatively higher income of these families and due importance of health for educated parents. However, the expenses were not affected by the occupation, which is also an important determinant of income. Government assistance under the BPL scheme protected poor families from CHE and further impoverishment. It was interesting to note that none of the disease-related factors, except the choice of first-line therapy, significantly affected the total costs incurred.

Like the present study, the studies on cost-of-illness evaluation in various chronic childhood disorders like epilepsies, leukemia, and thalassemia have also concluded that the direct medical costs exceed the nonmedical costs [14, 15, 18–20]. Cost of drugs has been reported as the predominant part of the direct medical cost, which is again in concordance with previous studies [14, 15, 18–20].

The present study assessing the financial spending on WS treatment is the first of its kind from the Indian subcontinent. Besides the epilepsy syndrome, the expenditure made on the treatment of comorbidities including cerebral palsy, constipation, visits made to ophthalmology and otorhinolaryngology specialists for assessment, and follow-up of disabilities was also taken into account because these comorbidities are an indispensable part of the care of such children. Unit cost was fixed for drugs and most services, thereby reducing the recall bias.

However, the present study is a single-center study. The subsidized rates from a public setup hospital may not apply to the hospitals in the private sector, which cater to India's significant healthcare needs [21]. The sample size was limited because of which, many potential factors affecting financial burden could not be assessed. The treatment expenditure was relatively lower in those with a long treatment lag, as expenditure assessment was performed until 1 y from the onset of

epileptic spasms. Besides, cost-effectiveness analysis and indirect costs estimation were not performed.

Conclusion

The present study provides a realistic magnitude of financial burden due to WS in the first year of illness. WS imposes substantial financial burden on the families and indirectly on the health system. The selection of ACTH therapy requiring initial inpatient care was a significant cost determinant. Further studies are warranted to quantify the indirect costs arising from the parents' loss of workdays, government expenditure, etc. Furthermore, cost-effectiveness analysis for different therapies, especially ACTH and oral steroids, may further help in identifying cost-effective strategies.

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Authors' Contribution DR: Study design, data acquisition, data interpretation, data analysis, prepared the initial draft of the manuscript and subsequent revision. SB, PM, SKR and SN: Data interpretation, data analysis, manuscript writing and final approval of the manuscript. LS, BB, and SP: Study design, interpretation of the data, data analysis and final approval of the manuscript. JKS: Concept, design, interpretation of the data, critical revision for intellectual content, and final approval of the manuscript. All authors approved the final version of the manuscript.

Declarations

Conflict of Interest None

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