Household Characteristics, Cost of Illness and Coping Mechanism of Families of Hospitalized Acute Encephalitis Syndrome Children: A Mix Method Study

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A B S T R A C T

Background: AES is responsible for causing high social and economic burden to the affected families. The study was conducted to know the household characteristics, cost of illness and coping strategy adopted by the family members of AES children admitted to a tertiary care facility in Assam, India.

Methods: It was a sequential exploratory mixed method study, with a cross-sectional survey among AES children and their guardians, followed by In Depth interview.

Results: Out of 51 cases 55% were male. The median age was 11 years. 53% of the families belonged to lower socioeconomic class. 96% of families reported to reside in rural areas. Commonly reported household assets were mobile phone 94%, bicycle 86%, television 31% and motorcycle 29%. Three major themes were emerged to contribute towards economic burden. The first major theme is "Direct cost" due to patient transportation cost (mean Rs 1161.00) and hospital costs: mostly due to medicinal cost (mean Rs1955.00), investigational cost (mean Rs 2920.00) and food cost (mean Rs 8375.00). The second theme "Indirect cost" is due to work days loss: 100% care providers had missed work days during hospital stay of their children and 84% had missed work days during post hospital care. The third theme is "Inherent cost spotted through coping mechanisms" which mostly 94% included borrowing money from the market and 31.4% selling household assets.

Conclusion: Cost of illness is a huge burden to the AES afflicted families which demands reforms in health care financing and reimbursement in current context.

Key words: AES, Cost of illness, Family, Mixed method approach, Household characteristics

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INTRODUCTION

Asian countries are known to be endemic for Acute Encephalitis Syndrome (AES) since long. Every year around 133,000 pediatric cases are reported to hospital with AES.¹ Assam is one of the worst affected states in India after UP and before Bihar reporting very large numbers of AES cases.²

Social and economic burden due to AES to the afflicted families is significantly high in endemic region. In recent years studies on cost-of-illness (COI) are receiving much more attention. Effects of economic hardship on families of AES children presented to tertiary care settings have never been explored in recent past. Very little is known on the household COI, their coping mechanism and implication of their housing environment on AES tormented families.

The present study was conducted to know the household's characteristics, cost of illness and coping strategy adopted by the family of Acute Encephalitis Syndrome Children admitted to tertiary care facility in Assam, India.

MATERIALS AND METHODS

Study setting and design: This is a descriptive cross-sectional study and data were collected by mixed method approach. The study was conducted between May, 2019 to May, 2021 at Jorhat Medical College and Hospital (JMCH), Jorhat, Assam. It is a tertiary care teaching hospital catering to nearby districts namely Jorhat, Sivasagar, Majuli, Lakhimpur, Golaghat and Karbi Anglong and bordering districts of state Nagaland. Mostly referred patients from catering areas are being treated in this teaching hospital. A total of 206 AES children below 15 years of age were admitted in children ward during the study period.

Out of the total admitted AES children, family of 51 AES were explored in this study which were found to be suitable for follow through according to inclusion criteria (Figure 1).

Inclusion criteria: All probable AES cases in the age group of 1-15 years as per WHO AES case definition, ³hospitalized in pediatric ward of JMCH and able to obtain written informed consent from Legally Acceptable Representative (LAR) at discharge and at follow up visit. We did not include Discharged Against Medical Advice (DAMA), Leaving Against Medical Advice (LAMA), cases referred to specialized center and those who could not be located during post discharge follow up due to the administrative and geopolitical reason.

Data collection: A mixed method approach was executed for data collection. We conducted a cross sectional household survey among the families of AES children who fulfilled the inclusion criteria and interviewed their guardians about household characteristics, COI and impact on the affected family due to illness. An economic questionnaire (EQ) was used for cost of illness data at hospital discharge after obtaining written informed consent from LAR. Later, one follow-up visit was given for each enrolled child within 6 to 12 months after hospital discharge to visually verify household characteristics. An In-Depth Interview was executed with the guardians of the admitted AES children to collect information on post hospital carer characteristics and coping mechanism to cost of illness. Families who could not be visited during Corona pandemic were interviewed over phone or patient's custodians were called to health facility with mutually convenient time.

Economic Questionnaire (EQ): To assess the household characteristics, COI and its impact on the affected family due to illness of JE/AES an EQ was structured and validated it among the JE/AES cases both in hospital and community. The EQ comprises of three sections. The first section was a short household survey which gave baseline information in regard to parent's level of education, occupations, household income and household characteristics. The second section of the EO had questions about out-of-pocket expenditures, cost to the family secondary to child illness. The third section was related to additional cost after discharge from the hospital such as medication, transport, Child equipment and credit treatment if any. In this section we also included time loss in days of the care provider to take care of the ill child after discharge as well as coping up mechanism to the catastrophic cost.

With the help of In Depth Interview (IDI) of the guardians and family members of the patients we tried to cross validate the data obtained from cross sectional survey regarding hospital and post hospital expenditure and means opted by the families to meet the cost of ailment.

Cost Assessed: Direct cost: Direct patient costs included all out-of-pocket expenditures of patients that were attributed to their illness. ⁴ Direct cost included acute medical and non-medical cost. Acute medical cost refers to the hospital bills related to child hospital admission such as hospital bed, medication and investigations. Acute non-medical cost included transport to hospital, accommodation and food for the family members taking care of the patient during acute admission and extra miscellaneous expenditures related to hospitalization.

Indirect Cost: Cost referred to the loss of workdays by the care givers due to illness of the child.

Intangible Cost: Cost referred to patient's/parent's psychological pain and discomfort but have never quantified in monetary terms were appraised during qualitative in-depth interview. ⁵

Post discharge Cost: Cost referred in respect of purchase of medications and medical aids, transport cost to get the medication or attending the doctors/faith healers.

Analysis Plan: Quantitative data collected were entered into Microsoft Excel for descriptive analysis and presented in the form of tables and diagrams. Percentage, proportion, mean and range were calculated in Microsoft excel. Qualitative data were analyzed by doing thematic analysis. The data were turned into categories with the help of descriptive codes. These categories were clubbed into themes. Later these themes (data on cost and time loss due to taking care of the AES children by care givers) were quantified and mean and range value were calculated for the COI and time loss for easy comparisons with other published cost estimates. ^{6,7}

Ethical Clearance: Voluntary written informed consent was obtained from the LAR of each study participants. We could not obtain any assent (oral 7 to 12 years and written 12 to 15 years) as the study participant.

ipants were not in a position to give assent due to altered sensorium following CNS involvement. Ethical approval to conduct the study was obtained from IEC (H) of Jorhat Medical College and Hospital, Jorhat, Assam. India

RESULTS

Patient characteristics: During the study period 206 AES cases were hospitalized in pediatric ward of JMCH. Patient who died in hospital or at home before follow up and those who could not be traced in person or over phone during COVID-19 pandemic were excluded from the present analysis (Figure 1). We could enrol 51 AES patients in this study who were found suitable as per inclusion criteria and could obtain the informed consent from the LAR of the same. Out of 51 cases 55% were male and majority 69.4% of the participants were 5 to 15 years old. The median age of the eligible 51 AES children was 11 years.

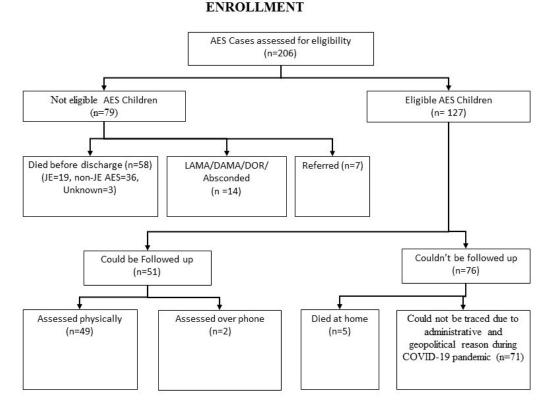


Figure 1: Flow chart showing of study participants.

Paternal education level of all the families interviewed for cost analysis reported some level of school education other than 7 mothers who did not receive any formal education. The most common occupation reported was labouring 24 (47%) followed by farming 12 (23.5%). Most of the families belonged to lower socioeconomic class 27(53%). In general, our study participants included more nuclear families 36 (70.6%) than joint families 15 (29.4%) (Table 1). **Household characteristics:** In our study almost all the families 49 (96%) were reported residing in rural areas. We observed that all the houses had corrugated roofing materials. Type of walls were mainly mud plastered 29 (57%) followed by burned brick 12 (23.5%). Around 34 (67%) of household had a flush toilet connected to a septic tank. Access to clean water was available to all the household (100%). Among them majority 48(94%) reported tube well as the source of water while only 3(6%) households

Table 1: Sociodemographi	c profile	of participants
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Table 2: Household characteristics (n= 51)

Variables	Participants (n=51)(%)	Household Characteristics	Participants (%)
Sex Distribution		Main Roofing material of the house	
Male	29 (56.9)	Thatched	0 (0)
Female	22 (43.1)	Corrugated	51 (100)
Age Group		Tiles	0 (0)
< 1 year	7 (13.7)	Other (Specify)	0 (0)
1-5 years	11 (21.6)	Type of wall of the house	
5 to 15 years	33 (64.7)	Burned brick	12 (23.5)
Father's Education	Father (%)	Unburned brick	1 (2)
None	0	Mud	29 (56.9)
Primary Complete	9 (17.6)	Bamboo	7 (13.7)
Primary incomplete	16 (31.4)	Other (specify)	2 (3.9)
Secondary Complete	6 (11.8)	Toilet flush to specific tank	
Secondary incomplete	19 (37.3)	Yes	34 (66.7)
Technical, Skilled job training	1(2)	No	17 (33.3)
Bachelor degree	0	Source of clean water	
PG degree	0	Tube well	48 (94.1)
Mother's Education		Community Supply Water	3 (5.9)
None	7(13.7)	Type of livestock (multiple response	
Primary Complete	2(3.9)	Cattle	24 (47.1)
Primary incomplete	19(37.3)	Chicken	40 (78.4)
Secondary Complete	1 (2)	Pigs	8 (15.7)
Secondary incomplete Technical, Skilled job training	22 (43.1) 0	Goats	22 (43.1)
Bachelor's degree	0	Duck	23 (45.1)
PG degree	0	None	8 (15.7)
Occupation of Father	0	Own land for cultivation	
Farming-home Garden	12 (23.5)	Yes	23 (45.1)
Fishing	0 (0)	No	28 (54.9)
Labouring	24 (47.1)	Household assets (multiple responses)	
Office Job	6 (11.1)		-
Business	9 (17.6)	Electricity Radio	49 (96.1)
Socio Economic Status	<i>y</i> (11.0)	Television	2 (3.9)
Upper Lower class	27 (52.9)		16 (31.4)
Lower Middle class		Refrigerator	3 (5.9)
	22 (43.1)	Bicycle	44 (86.3)
Upper Middle Class	2 (3.9)	Motorcycle	15 (29.4)
Type of Family		Mobile hand set	48 (94.1)
Nuclear	36 (70.6)	Car	0 (0)
Joint	15 (29.4)		

reported community supply water as the source. Survey on availability of domestic livestock showed that other than 8 families all the household had practice of rearing different livestock. Most common livestock were namely Chicken (78.4%), Cattle (47.1%), Duck (45.1%), Goats (43.1%) and Pigs (15.7%). It was reported that majority of the household 28(55%) did not have their own farming land for cultivation. Among the household's commonly reported assets were mobile phone 48 (94%), Bicycle 44 (86%), Television 16 (31%), Motorcycle 15 (29%), Refrigerator 3 (6%), and Radio 2(4%). We recorded electrification in 49 (96%) household (Table 2).

Themes related to Economic Effects:

The major themes with categories that emerged as contributing factors to the severe economic effects on the families were 1) Direct cost – a. Transportation cost, and b. Hospital cost, 2) Indirect cost - Work Day lost, and 3) Cost deciphered through coping mechanism

Direct Cost:

Transportation Cost: In the present study we looked for mode of transport used to transfer the AES children from household to hospital. The most commonly availed mode was 108 Mrityunjoy Ambulance 21(41%) under emergency response services of state government and private transport 30 (59%). While exploring the travel time required to reach hospital, it was ranged from minimum 30 minutes to maximum 4 hours. Affected family had to bear a mean transportation cost of Rs 1161.00 (range 0 to 3500.00) for taking their AES children from household to tertiary care hospital. This cost is mostly for hiring private vehicles as the free Government provision for transporting AES children is difficult to access at the time of crisis.

Respondents informed "We could not wait hours together for availing free transport services. Service provider was busy in transporting another patient. Our child was seriously ill and we had to rush to hospital which is far away from our home. Therefore, we availed private transport and borrowed money from mortgagee."

Hospital Cost: Hospital expenditures of patients were varied widely based on duration of hospital stay and complications developed due to AES. The total hospital cost of illness (direct cost) ranged from Rs 6090.00 to Rs 110000.00. The hospital costs we explored mostly on medicinal cost (mean Rs1955.00 range Rs 900.00-Rs 6000.00), Investigational cost (mean Rs 2920.00, range Rs 1750.00-Rs 15000.00) and meal or food cost (mean Rs 8375.00, range Rs 800.00-Rs 31900.00) (Table 3).

We found that every admitted patient had to bear per day hospital accommodation cost at a fixed rate of Rs 20.00 if the patient age is more than 1 year. The total hospital accommodation mean expenditure was Rs 300.00 and ranged between Rs 100.00 to Rs 1160.00. Although in general, there was a provision for reimbursement of the said expenditure under social security for the BPL card holders, some parents reported that they had to bear hospital accommodation cost namely for bed charges, ICU charges with or without ventilators etc.

Variables	Participants (%)	
Pre-hospital		
Mode of transport used for going to hospital		
Public108/108+Others	21 (41)	
Private car/others	30 (59)	
How long was the journey (in hours) n=41		
<1hr	2 (4)	
1 hr to 3 hr	23 (65)	
3 to 4 hr	16 (31)	
Cost of Illness		
Direct costs (Rs)	Mean (Range)	
Cost on transport to going hospital	1161 (0-3500)	
Duration of hospital stay (in days)	15 days (4-58 days)	
Medication cost	1955 (900-6000)	
Investigation cost	2920 (1750-15000)	
Meal cost	8375 (800-31,900)	
Total cost of hospitalization (Rs)	28257 (6090-110000)	

Table 3: Direct Cost of illness for the AES patients (n=51)

Variables	During Hospitalization (%)	After Hospitalization (%)	
Carer of the child	Study participants (%)	Study participants (%)	
Father	1(1.9)	0(0)	
Mother	17(33)	47(92)	
Sibling	0	1(1.9)	
Parents	33(65)	2(4)	
Others	0(0)	1(1.9)	
Study/Workdays Missed	51(100)	43(84)	

Indirect Cost:

Carer characteristics: It was noted while interviewing the respondents that in majority 33 of 51(65%)AES cases parents were the prime care provider during hospitalization period of their children and in some cases, 17/51(33.3%) mothers alone took the responsibility of taking care of her child. However, in case of only one child father had to take care of the diseased child and cited that mother could not come to hospital as she had to be at home for providing care of her small baby. It was quite common to note that all the care providers (100%) had missed work days at the time of hospitalization of their children. Similarly, 43 of 51 (84%) AES affected families informed that they had missed work days during post hospitalization period too for taking care of their sick children as many of the AES children developed complications with neuropsychiatric sequelae. During this period carer was primarily mother 47/51(92%) (Table 4). On an average work day lost was 15 days (range 4-58 days) plus widely varied post hospital recovery period ranging from few weeks to year. In in-depth interviews with the family heads of AES children revealed that indirect cost of illness was much more expensive to cope up. The amount of psychological pain and discomfort felt by patients/parents in terms of intangible cost could not be quantified.

One of prime care givers described "We lost our job following hospitalization of our ill child. We are contractual wage earners, no work no money is the policy here. No one would understand our pain and mental sufferings. It is not easy to support a sick child without financial support for a family like us. Government supports are beyond our reach, no one listen to us." **Coping Mechanism:** Analysis of Key Informant Interviews (KII)at household level revealed that majority of the AES afflicted families had to borrow money (94%) from the market at higher interest rate or sell their household resources (31.4%). (Figure-2) Another most Common coping up mechanism adopted for the unforeseen cost of ailment was taking gift or donation from the relatives or well-wishers. Few of the families informed that they had to mortgage their

harvested saplings or farming land or even jewellery items for arranging costs. There was provision for waiving off hospital/investigational charges in the study center for the below poverty line families and subsidized rate for above poverty line families. However, affected family informant revealed that it was not easy to avail those opportunities at the time of crisis as it demands many official formalities (Figure 2).

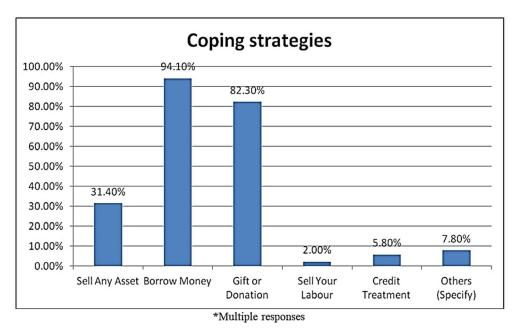


Figure 2: Means opted by the families to meet the cost of ailment.

DISCUSSION

To our knowledge, the present study on household characteristics, cost of illness and coping mechanism by family of AES children is a novel study in NE region. We attempted to comprehend the characteristics of the household from where the AES children were prevailed, what was the burden of catastrophic cost due to illness and how the family had to cope up with unforeseen out of pocket expenditures.

We found that most of the AES children were between 5 to 15 years old and mostly from nuclear families. Education is a key determinant of the lifestyle and status an individual enjoys in a society. It affects many aspects of life, including demographic and health behaviour.8(pp-13) In our study majority of the parents had some level of school education. Occupation was mainly labouring and farming. The affected families were mostly from rural areas, corrugated roofing materials and mud plastered walls were seen in the dwelling units. The type of material used for flooring and walls is an indicator of the economic standing of the household.8(pp-23) Source of drinking water for larger proportion of the dwellings were tube well. We observed that most of the household had the practice of keeping income generating domestic animals and poultries. Contrary to this, it was quite common to see that the affected household did not have their own land for farming. Therefore, cultivating families had to hire farming land on fifty percent benefit sharing basis. Though most of the families were belong to lower socioeconomic class we found that almost all the family had a mobile phone and next common household asset was bicycle. Other least common available assets were radio, television, refrigerator etc. Ownership of these assets provides us an indication of economic status of the family as well as other information about the life style of the residents. Ownership of a bicycle, motorcycle, or car reflects means of transport, which can be important for seeking emergency medical care.^{8(pp-23)} Having a cell phone at household level gives opportunity for communication with other users and availing services from health care service providers in need. Ownership of a refrigerator gives information on hygienic food storage at household level as a preventive measure of food borne diseases.8(pp-23) Our findings highlight substantial socioeconomic burden to the affected family following AES due to poor household features.

We assessed economic burden to the families following AES illness of their children aiming to measure the direct and indirect cost related to AES. One of the predominant out-of-pocket costs was transportation cost. It is a common direct cost faced by the affected families. Greater proportion of the family had to hire private vehicle to transport their AES children to health care facility. While enquiring to the family respondents it was informed that during emergency it is difficult to get government sponsored free emergency transport services. Many a time Emergency Response Centre (ERC) does not pick up their phone, service providers cannot come to household location due to poor road condition etc. Few families informed that govt service providers were busy at the need of the hours. At times it is problematic to reach the hospital on time. Multiple studies across different states in India that have evaluated various aspects of the functionality of ambulance services have highlighted similar gaps in functionality and access emergency ambulance services.9

Other most striking findings of the study were substantial out-of-pocket costs of AES illness to families. It was seen that total out-of-pocket cost due to illness was three times more than the considered families mean monthly income during the illness months. Expenditures were mainly on medication, investigation and cost incurred on food or meal for the care takers of the ill child during the hospital stay. Similar study conducted earlier in Nepal on AES presented even five times higher expenditure than their estimated monthly family income.¹ Another major component of COI in our study was indirect cost (time loss of care takers, relatives, school days loss etc.) which was substantially high but difficult to capture through the questionnaire.¹⁰ Loss of income because of a reduction or termination of parental employment is so shattering that at time most of the affected families can have long term effects on the financial security, quality of life and future wellbeing of the whole family as well as siblings of the affected child.11

Our study revealed that AES illness pushed many of the affected families from non-poor to poor, poor to marginal poor.

We questioned about the coping mechanism for the financial adversity confronted by the families due to catastrophic illness. The emerging theory from the KII is that none of the public or private social support system is effective to support the families who care for children with AES illness. Noteworthy to mention that parents struggled with financial hardship and as a coping mechanism almost all the families had to mortgage or sell their household possessions which pushed them to impoverishment.¹² One of the family revealed that how challenging it was for them to recover from financial stresses and were still paying off debts months after hospital discharge for the betel nut trees they mortgaged at the time of hospitalization of their child. Similar findings of long-term effect on the financial stability were also observed in earlier studies on economic impact on families when a child was diagnosed with catastrophic illness.¹³ Conversely, we found that domestic poultry, household weaving, financial gift or donation from relatives or well-wishers etc. is commonly practiced in rural areas, has a sort of cushioning effect to the catastrophic cost of illness.

LIMITATION

This study has some limitations that need to be acknowledged. The validation of indirect costs in terms of money, including coping and intangible cost incurred due to illness, was not possible due to the non-uniform availability of these documents among participants and difficulty to express intangible cost in monetary terms. Therefore, the authors refrained from using the same to avoid any bias of differential cost calculation among subsets of the study population. However, in this study, we have attempted to express the indirect cost in terms of work days loss, the importance of which is also undeniable.

CONCLUSION

The economic impact of AES illness in affected family is significantly disastrous to cope up. Most of the family became bankrupted following the acute episodes of illness. The poor environmental conditions, lack of optimum household assets, high out of pocket expenditures, productivity losses and poor knowledge on insurances financing health worsened the economic health of the family resulting impoverishment. Reforms in health care financing and reimbursement in AES affected settings need to be considered for these poor parents who care for children with catastrophic illnesses so that parents do not have to struggle financially in a welfare country like India.

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