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The Economic Burden of Epilepsy in Bhutan

Leah Wibecan, MPH,^{1,2} Günther Fink, PhD,² Lhab Tshering, BA,³ Verónica Bruno, MD, MPH,² Bryan Patenaude, MA,² Damber K Nirola, MBBS, MPhil,³ Chenchu Dorji, MBBS, MD,³ Ugyen Dema, MBBS, MD,³ Mimi Lhamo Mynak, MD,³ Dilli Ram,³ and Farrah J Mateen, MD, PhD^{1,4}

¹ Harvard Medical School, Boston, MA

² Harvard T.H. Chan School of Public Health, Boston, MA

³ Jigme Dorji Wangchuk National Referral Hospital, Thimphu, Bhutan

⁴ Massachusetts General Hospital, Boston, MA

Corresponding Author:

Leah Wibecan

165 Cambridge St. #627

Boston, MA 02114

Phone: 617-724-8653

lew712@mail.harvard.edu

Abstract

Objective: To assess the economic impact of epilepsy in Bhutan, a lower-middle-income country with a universal health care system, but with limited access to neurological care.

Methods: A cross-sectional survey was conducted of patients with epilepsy at Jigme Dorji Wangchuk National Referral Hospital from January to August, 2016. Data were collected on clinical features, cost of care, impact of epilepsy on school or work, and household economic status of participants and matched comparisons (a sibling or neighbor from a household without epilepsy).

Findings: A total of 172 individuals were included in the study (130 adults and 42 children). One-third of adults and 20 (48%) children had seizures at least once per month. Mean annual direct out-of-pocket costs for epilepsy care was 6,054 BTN (91 USD), of which transportation formed the greatest portion (53%). Direct costs of epilepsy were an average of 3.2% of annual household income. Adults missed 6.8 (SD: 9.0) days of work or school per year on average, and children missed 18.6 (SD: 34.7) days of school. Among adults, 23 (18%) abandoned employment or school because of epilepsy; seven children (18%) stopped school because of epilepsy. Households with a person with epilepsy had lower monthly per-person income (6,434 BTN) than comparison households without epilepsy (8,892 BTN; $p = 0.027$).

Conclusion: In Bhutan, despite universal health care services, households of people with epilepsy face a significant economic burden, which impacts household economic well-being. Indirect costs of epilepsy, including negative effects on school achievement and employment, may disrupt economic potential.

Introduction

While epilepsy is common globally, low- and lower-middle-income countries (LLMICs) bear a disproportionate share of the burden of epilepsy.¹⁻³ With adequate treatment, greater than 70% of people with epilepsy can achieve long-term remission from seizures.⁴ However, access to treatment for epilepsy in LLMICs is generally limited.⁵ Epilepsy – particularly if not effectively treated – places a large physical and emotional burden on patients, and can affect the economic well-being of patients and families, through the cost of medical care and difficulty pursuing income-generating activities. Prior reviews have indicated that the costs of epilepsy may vary with the severity of disease, time since diagnosis, efficacy of antiepileptic drug treatment, and health insurance coverage.^{6,7}

Several recent studies from LLMICs have documented high direct costs of epilepsy, with out-of-pocket costs often accounting for a major proportion of a household's income, as well as high indirect costs, including impacts on school attendance.⁸⁻¹³ However, insufficient data are available on the economic impact of epilepsy in LLMICs or the effect of health system structures on this burden.⁷

In order to assess the economic burden of epilepsy in LLMICs, we developed and implemented a survey for people with epilepsy (PWE) and their families in Bhutan, a lower-middle-income country with a system of universal health care, but with no neurologists or specialized care for epilepsy available in the country. We use the collected survey data to assess the impact of universal health care on costs for PWE, as well as the effect of inadequate access to neurological care.

Methods

Setting

Bhutan, home to approximately 774,800 people, is bordered by India and China and is primarily rural (61% of the population).¹⁴ Bhutan had a gross national income per capita of \$2,370 in 2015.¹⁴ While the total unemployment in Bhutan was low (2.9%) in 2013, youth unemployment was higher (9.6% nationally, and 22.8% in urban areas).¹⁵

The Jigme Dorji Wangchuk National Referral Hospital (JDWNRH), located in the capital city of Thimphu, is the tertiary referral center serving all 20 districts of Bhutan, and is the country's largest hospital, caring for about 13,000 patients per year.¹⁶

Bhutan has a universal health care system that provides medical care, medications, and diagnostic tests free to patients at all hospitals and basic health unit facilities for Bhutanese citizens. The availability of neurological care for epilepsy patients in the country remains extremely limited, with no practicing neurologist and no EEG services available.

PWE presenting to JDWNRH for epilepsy care are cared for by psychiatrists and psychiatry assistants (for adults) and general pediatricians. Some patients may also receive epilepsy care from army hospital facilities, general practitioners, local health centers, and traditional healers. Computed tomography (CT) scan, magnetic resonance imaging (MRI), and standard laboratory

services (but not tests for antiepileptic drug levels) were available at the JDWNRH. According to the Ministry of Health, there were 1559 cases of epilepsy in Bhutan in 2015.¹⁶

Ethics

This study received approval from the Partners Healthcare Institutional Review Board as well as the Research Ethics Board convened by the Bhutanese Ministry of Health. For PWE under 18 years old, the parent or guardian provided written consent and answered the survey questions about the child participant.

Study Participants, Recruitment, and Enrollment

Participants were PWE of any age who presented to the JDWNRH Department of Psychiatry's outpatient clinic for epilepsy care between January and August 2016. Recruitment occurred via two methods: (1) PWE presenting for their regularly scheduled epilepsy appointments, and (2) PWE were selected from the registry and contacted to participate in a separate study through the Bhutan Epilepsy Project on the diagnostic utility of routine EEG in a low-resource setting; these participants were asked to participate in the economic impact survey on the day of their EEG study.

Epilepsy was defined as having two or more unprovoked seizures greater than 24 hours apart,¹⁷ with the diagnosis confirmed by a psychiatrist in Bhutan as well as a US-based neurologist. All patients with a history of only one seizure, seizure only in the presence of fever, or who were determined through clinical assessment by a research team neurologist to have psychogenic non-epileptic events, syncope, or other non-epileptic events were excluded.

Comparison households

Each participant was asked to identify a sibling or friend living in the same town or city as the participant, but in a separate household (without epilepsy). This individual was used as a matched comparison, matched for geographic region, urban versus rural setting, and additional cultural factors that may influence socioeconomic status. Participants were asked questions about the demographic information and household economic status (including household assets, income, and expenses) of the comparison household they selected.

Data Collection and Analysis

Survey questions are available in Appendix 1. Data were collected by research staff from the Bhutan Epilepsy Project, who were unaffiliated with JDWNRH. Data were entered into a RedCap database¹⁸ using tablets. All analyses were conducted using Stata version 14 (College Park, TX). For currency conversion, the rate of 1 USD = 66.4 Bhutanese Ngultrum on May 1, 2016 (approximately the study midpoint) was used (www.exchangerates.co.uk).

Epilepsy Assessment

To assess disease severity, participants provided detailed accounts of their symptoms and events, including seizure frequency over the prior month and year. Epilepsy duration was counted from the time of first seizure onset until the interview date, excluding childhood febrile seizures.

Economics Evaluation

To assess out-of-pocket direct costs of epilepsy, participants (or parents/guardians in the case of child participants) provided self-reports of number of visits to and payments for outpatient clinics (both to local health centers and the epilepsy clinic at the main hospital), number of days and daily cost of inpatient hospitalizations, cost of medications, diagnostic tests performed and payments for these tests, and round-trip transportation to clinics. Costs of traditional medicine or other alternative therapies were not included in this study. Participants were asked to recall these health expenditures over the prior year; all reported payments were out-of-pocket costs only.

Indirect costs included days of work or school missed by the PWE per year due to epilepsy, as well as days of work missed by others in the family because of caring for the individual with epilepsy. School-age was defined as age 6 through 17 years, in line with the standard age of school entry and secondary school graduation for children in Bhutan. Employment status was assessed; for this purpose, individuals who served as monks or nuns were considered to be employed.

Participants reported monthly household income and total expenses for all members in the household. For household socioeconomic status, information on a list of household characteristics was collected, and converted into a single score using principal component analysis.¹⁹ Households were then classified into five wealth quintiles based on the first principal component score. Differences in socioeconomic outcomes between participants and comparisons were assessed using paired t-test.

Multivariable linear regression analysis was conducted to assess the relationship between potential explanatory variables and economic outcomes such as household income and school attainment among both participant and comparison households. A backwards, stepwise approach was used to select covariates with a threshold of $p < 0.05$.

Results

Participant characteristics

Participants included 130 adults, (46% male), and 42 children, (57% male; Table 1). The average duration of epilepsy since symptom onset among adult participants was 8.0 years (SD: 7.1 years), while child participants had an average epilepsy duration of 5.9 years (SD: 5.3 years). Participants had an average delay of 1.8 years (adult) or 1.5 years (child) between seizure onset and epilepsy diagnosis.

Twenty-three (18%) adults and two (5%) children had well-controlled epilepsy with no seizures in the prior one year (Table 1). About one-third of adults and almost half of children had seizures at least once per month, of whom 28 (22%) adults and 15 (36%) children had at least weekly seizures.

Direct costs of epilepsy

On average, participants visited their local health center for epilepsy 6.1 (SD: 4.8) times during the year, and visited the epilepsy clinic at the main referral hospital 5.7 (SD: 4.7) times per year. Out-of-pocket costs for these outpatient visits (excluding transportation) averaged 1,572 BTN per year (24 USD; range 0 to 72,000 BTN). Twenty-three (13%) participants were hospitalized in the prior year, however only one participant reported having to pay out-of-pocket costs for the hospitalization (98,000 BTN, 1475 USD). While 155 (90%) participants did not pay any out-of-pocket costs for medications, among participants who did pay for medications, cost of medications for one year averaged 5,265 BTN (79 USD; range 120 to 20,000 BTN). For epilepsy-related diagnostic testing, 44 (26%) participants had an MRI in the past year, 6 (3%) had a CT scan, nine (5%) had an EEG, and 18 (10%) underwent blood tests. Just seven (4%) participants reported out-of-pocket costs for diagnostic testing in the prior year, which averaged 3957 BTN (60 USD; range 700 to 11,000 BTN). Although health services in Bhutan are normally provided free of charge to the patient through the public system, some individuals reported receiving care from private providers or traveled outside of the country for care.

Among participants who visited a local health center for epilepsy, almost half lived less than 30 minutes from the center. For transportation to the epilepsy clinic at the main hospital, 67 (40%) participants traveled less than 30 minutes to the hospital, while 36 (22%) participants traveled at least five hours (up to two to three days) each direction. Out-of-pocket costs for transportation for clinic or hospital visits for epilepsy care averaged 3,231 BTN (49 USD) per year.

The mean total direct out-of-pocket cost for epilepsy per year (Table 2), including outpatient visits, hospitalizations, medications, diagnostic tests, and transportation, was 6,054 BTN (91 USD; range 0 to 127,000 BTN). Of this average total cost, transportation costs accounted for the largest component (53%). On average, direct out-of-pocket costs of epilepsy accounted for 3.2% of yearly household income. Transportation costs alone accounted for an average of 1.7% of yearly household income. Several households were outliers, suffering a particularly high cost of medical care (Figure 1). Twenty-two households spent 5% or greater of household income on direct costs of epilepsy (Figure 2); of these households, transportation accounted for an average of 56% of their direct costs.

Indirect costs of epilepsy

Days of work missed by adults and children with epilepsy and the adult family members caring for them are illustrated in Table 3. Among adult participants, 23 (18%) stopped work or school entirely because of their seizures. Of the 38 children 6 years of age or older, seven (18%) had withdrawn from school because of seizures.

In a multivariate linear regression model, we identified older age (Coef: -0.026; $p < 0.001$) and higher frequency of seizures in the past month (Coef: -0.227; $p = 0.011$) as statistically significant predictors of lower levels of school attainment (Appendix 2).

Socioeconomic status in households with versus without PWE

Median monthly household income (total combined income of all household members) was 25,000 BTN (377 USD), IQR 25,000 BTN (377 USD). The median monthly income per person in the household was 5,000 BTN (75 USD), IQR 4,500 BTN (68 USD). Compared to households of matched siblings or friends without epilepsy (Table 4), households of participants with epilepsy had lower per-person monthly household income (6,434 BTN [97 USD] vs. 8,892 [134 USD], $p = 0.027$). There was no significant difference in wealth quintile (3.02 in households with epilepsy vs. 3.01 in households without epilepsy, $p = 0.871$).

On multivariate linear regression, there was a significant association between having a PWE in the household and a lower per-person household income (Coef: -2,607; $p = 0.027$), when controlling for town size.

Discussion

Our major findings are threefold. First, most people with epilepsy in Bhutan receive health services at low to no out-of-pocket cost, reflecting the country's policy of universal health care. Second, despite this, many families still spent a notable proportion of household income on care for the person with epilepsy, with transportation costs alone accounting for an average of 1.7% of annual household income. Third, in this environment where control of epilepsy was often poor, participants reported high indirect costs of epilepsy, including major negative impacts on school attendance and employment.

Compared to estimates of annual direct out-of-pocket costs in other LLMICs, including in India in 1998 (93 USD per patient),⁹ and in the past decade in China (372 USD per patient)⁸ and Nigeria (163 USD per patient in one study,¹² 288 USD per patient for medications alone in another¹¹), the average out-of-pocket direct costs of epilepsy in Bhutan of 91 USD per patient per year was lower. Adjusting for purchasing power parity, these differences become smaller, with an estimated direct cost of 297 international dollars (I\$) yearly per patient in Bhutan compared to I\$ 371 in India, I\$ 801 in China and I\$ 321 in the first study in Nigeria. However, out-of-pocket costs for PWE in Bhutan accounted for an average of 3.2% of annual household income; as a comparison, a study in Nigeria, where very few patients had any form of insurance, found that more than half of families spent at least 20% of their household income on epilepsy care yearly.¹¹ Universal health care in Bhutan may reduce the direct economic burden of epilepsy on families compared to other locations.

However, many participants faced substantial out-of-pocket costs for transportation to and from frequent outpatient clinic visits for medication refills or follow-up visits, which account for a majority of the overall out-of-pocket epilepsy-related expenditures. This result parallels studies in India⁹ and the Netherlands²⁰ that identified transportation as one of the largest contributors to out-of-pocket costs of epilepsy to patients.

With no neurologist in the country, PWE in Bhutan rely on general practitioners, pediatricians, or psychiatrists for medical care for this condition. Generally, participants in this study had poor seizure control, with less than one quarter of adults and just 5% of children in remission from seizures for at least one year, a finding consistent with prior evidence of suboptimal medical

management of seizures in Bhutan.²¹ Many individuals with epilepsy were experiencing seizures on a weekly or daily basis, with significant potential to disrupt their daily activities and productivity. In fact, on multivariate linear regression, higher frequency of seizures was a significant predictor of lower levels of school completion.

In this setting, people with epilepsy in Bhutan face substantial indirect economic costs. Children attending school missed nearly four weeks of school per year on average, while many other children (18%) had dropped out of school entirely because of their epilepsy. Among adults with epilepsy, 28% were out of work or school, a number that compares poorly to the country's overall unemployment rate of 3%, or youth unemployment rate of 10%.¹⁵ Nearly one in five adults had stopped working or attending school because of their epilepsy – citing reasons ranging from inability to function effectively due to frequent seizures to feelings of shame or embarrassment.

Family members of those with epilepsy are also affected, with other adults in the family missing an average of seven days of work each year to provide care if the PWE is an adult, and nearly 17 days if the PWE is a child. Overall, our findings indicate that, even in a setting where direct medical costs are low, indirect costs of epilepsy from lost productivity can place a major economic burden on families, particularly when control of seizures is poor and perceived stigma towards those with epilepsy is high.²²

Finally, we compared the economic status of participants with epilepsy and matched comparisons, and found a significant difference in per-person monthly household income between households with and without an individual with epilepsy. This suggests that the direct and indirect costs of epilepsy may negatively affect a household's overall economic well-being in Bhutan. However, we did not find any difference in wealth quintile between households with and without epilepsy, indicating that these differences in incomes may not necessarily translate into differences in household assets.

Several limitations of this study must be acknowledged. First, our study relied on participant self-report of costs, as well as of comparison households' information. Without comprehensive financial records available, this was the most feasible means of obtaining cost information, as is the case in many LLMICs. We mitigated this limitation by having participants provide information about costs they were likely familiar with, such as transportation from home to a health center, that occurred within the prior year only, as well as comparison household information about people they knew well (siblings and friends).

Referrals to the epilepsy clinic may have been biased towards individuals with epilepsy that was more difficult to control. Individuals living in Thimphu, the capital city, were also likely overrepresented in our sample; more than one-third of our participants yielded from Thimphu, while the population of Thimphu represents just 16% of the population of Bhutan.²³ Finally, we were unable to assess the population of PWE who have not received care at the main hospital; these individuals may have greater difficulty accessing medical care for epilepsy.

Conclusion

Universal health care may protect families in Bhutan from some of the direct cost burden of caring for a person with epilepsy. As transportation constituted the greatest component of out-of-pocket costs for payments, reducing the frequency of in-person visits for medication refills, or providing travel reimbursement, could further reduce the cost of epilepsy to families. However, we also identify large indirect costs of epilepsy to families, affecting education and employment, with the potential to heavily impact economic prospects. At a societal level, partnering with school teachers and employers to promote safe and welcoming school and work environments may support the progress of individuals with epilepsy. This study emphasizes the urgent importance of ensuring that individuals with epilepsy in LLMICs have access to high-quality care. Promoting the capacity of health providers to care for patients with epilepsy, both by providing specialized neurological care as well as by training local health providers in epilepsy diagnosis and treatment, could improve seizure management, which may help to reduce the economic burden of this condition.

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Disclosure of Conflicts of Interest

None of the authors has any conflict of interest to disclose.

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Table 1: Demographic and clinical characteristics

		Adults (n = 130)		Children (< 18) (n = 42)	
		n	%	n	%
Sex	Female	70	54	24	57
	Male	60	46	18	43
Age (years)	≤ 12	--	--	17	40
	13-17	--	--	25	60
	18-30	95	73	--	--
	31-60	29	22	--	--
	> 60	6	5	--	--
Community size (number of people)	< 1,000	32	25	8	19
	1,000 to < 10,000	30	24	16	38
	10,000 to < 100,000	13	10	3	7
	≥ 100,000	52	41	15	36
Employment	Student	30	23	29	69
	Employed	56	43	1	2
	Household work	7	5	--	--
	Unemployed or out of school	37	28	12	29
Duration of epilepsy at time of enrollment (years)	< 1	8	6	8	19
	1-5	48	37	17	40
	6-10	37	28	6	14
	> 10	37	28	11	26
Time from symptom onset to diagnosis (years)	< 1	64	52	25	64
	1-2	33	27	7	18
	3-5	17	14	2	5
	> 5	10	8	5	13
Seizure frequency	Remission (no seizures in ≥ 1 year)	23	18	2	5
	< 1 seizure per month	66	51	20	48
	1-3 seizures per month	13	10	5	12
	1-6 seizures per week	22	17	8	19
	Daily seizures, mean	6	5	7	17
Number of anti-seizure medications presently used	None	6	5	5	12
	1	96	74	31	74
	2	24	18	5	12
	≥ 3	4	3	1	2
Travel time to local health center	< 30 minutes	17	43	7	54
	30 minutes to 1 hour	16	40	1	8
	> 1 to 4 hours	5	13	4	31
	5 hours to 1 day	2	5	--	--
	2 to 3 days	--	--	1	8
Travel time to main hospital/epilepsy clinic (JDWNRH)	< 30 minutes	53	42	14	35
	30 minutes to 1 hour	22	17	6	15
	> 1 to 4 hours	27	21	9	23
	5 hours to 1 day	21	17	8	20
	2 to 3 days	4	3	3	8

Table 2: Direct costs of epilepsy –annual out-of-pocket epilepsy-related costs per patient in BTN (1 USD = 66.4 BTN as of May 1, 2016)

	Median	IQR	Mean	Range
Outpatient visits	0	0	1,572	[0 – 98,000]
Hospitalization	0	0	570	[0 – 72,000]
Medications	0	0	520	[0 – 20,000]
Diagnostic tests (MRI, CT, EEG, blood tests)	0	0	161	[0 – 11,000]
Transportation	1,220	3,520	3,231	[0 – 48,000]
Total	1,960	5,180	6,054	[0 – 127,800]

Table 3: Indirect costs of epilepsy – work or school missed by patient or adult family members because of epilepsy

	Adults	Children (< 18)
Days of work/school missed per year (mean ± SD)	6.8 (± 9.0)	18.6 (± 34.7)
Days of work missed by other family members per year (mean ± SD)	7.1 (± 34.0)	16.5 (± 33.1)
Person with epilepsy stopped work/school because of seizures (number, % of total)	23 (18%)	7 (17%)

Table 4: Household wealth comparison – households of individuals with epilepsy vs. comparison households (1 USD = 66.4 BTN as of May 1, 2016)

	Affected household mean (BTN)	Comparison household mean (BTN)	P-value
Total combined monthly household income of all members	29,185	37,192	0.099
Per-person monthly household income	6,434	8,892	0.027
Wealth Quintile (mean)	3.02	3.01	0.871

Figure 1: Box plot of total yearly direct out-of-pocket costs for epilepsy

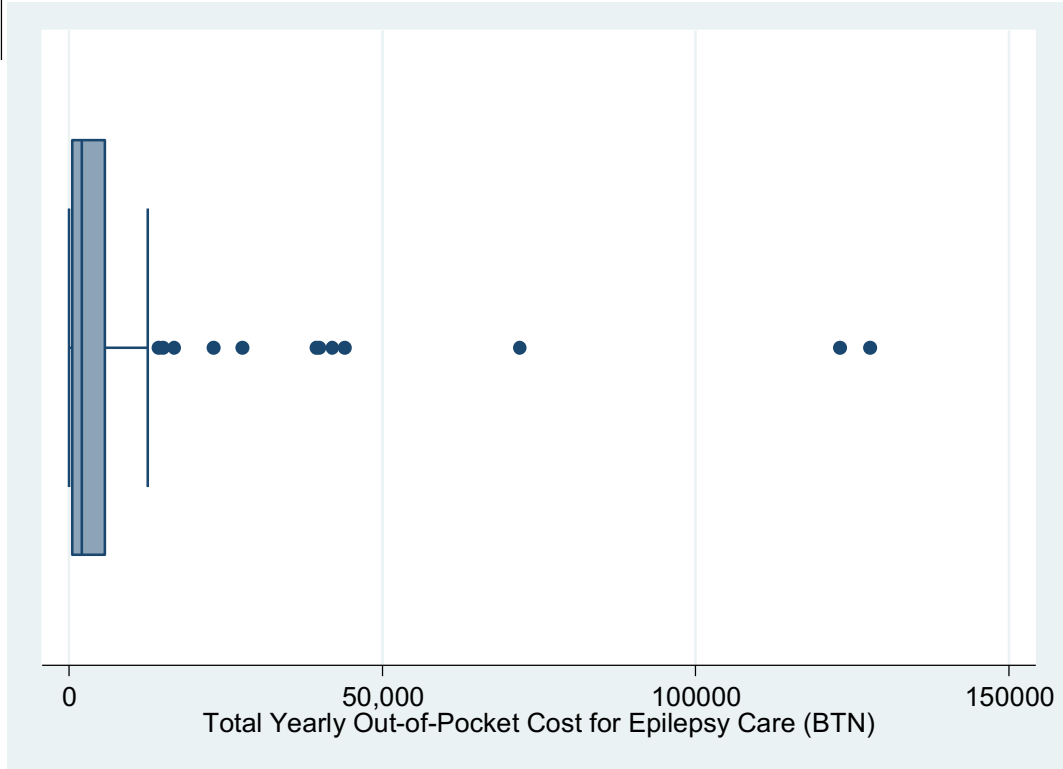
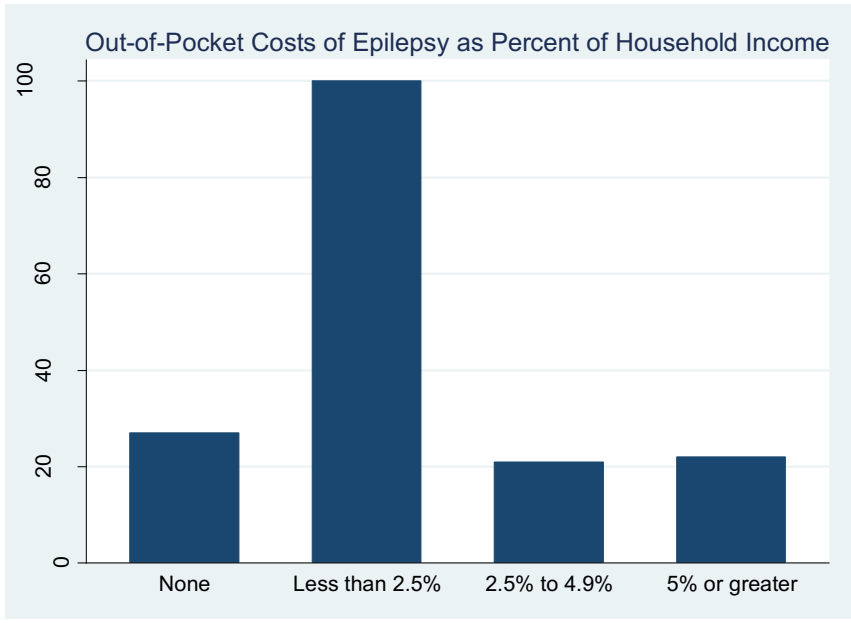


Figure 2: Out-of-Pocket Costs of Epilepsy as Percent of Household Income



Appendix 1: Survey questions

International Economic Impact of Epilepsy Survey

Principal Investigator: Dr. Farrah Mateen

Adult Survey

Participant Information

Participant code: _____

Interviewer(s): _____

Name: _____

Languages: _____

Village: _____

Gewog: _____

District: _____

Phone number: _____

Email: _____

International Economic Impact of Epilepsy Survey

Background and Demographic Information

Participant code: _____

Age: _____

Sex: Male Female

Marital status: Single Married Divorced Widowed Other: _____

How many people live in the town that you currently live in: _____

Who is answering the survey questions? Participant Parent Sibling Aunt/Uncle

Other: _____

If the participant is not the one answering, what is the reason? _____

International Economic Impact of Epilepsy Survey

Clinical Questionnaire

For patients diagnosed with epilepsy only. Record all costs in BTN.

Participant code: _____

Clinical History

Do you have a parent, sibling, or child with epilepsy? None Parent Sibling Child

Do you drive a motor vehicle? Yes No

Have you ever had a head injury in which you lost consciousness?

Yes No Unknown *If yes, describe:*

Have you ever had any injuries related to having a seizure? Yes No

If yes, select all that apply: Burns Breaking bones or dislocations Head injury

Car accidents Other: _____

Do you have cognitive or motor development delay? Yes No Unsure

Other medical conditions:

How old were you when you had your first seizure? _____

Have you ever been diagnosed with epilepsy? Yes No

If yes, who diagnosed you: _____

If yes, when were you diagnosed: _____

How many seizures have you had total in your life (provide as much information as possible)?

How many seizures have you had in the past month (provide as much information as possible)?

How many seizures have you had in the past year (provide as much information as possible)?

How long ago was your last seizure?

- 0-7 days 1-4 weeks 1-3 months
 3-6 months 6-12 months >12 months

Do you have more than one type of seizure? Yes No

Description of seizures:

Does anything trigger your seizures?

- Illness Lack of sleep Lights Stress
 Forgetting to take medication Other: _____

What medication(s) are you currently taking?

- carbamazepine *daily dose:* _____ *mg* phenobarbital *daily dose:* _____ *mg*
 phenytoin *daily dose:* _____ *mg* lamotrigine *daily dose:* _____ *mg*
 levetiracetam *daily dose:* _____ *mg* sodium valproate *daily dose:* _____ *mg*
 benzodiazepines *daily dose:* _____ *mg*
 other: _____ *daily dose:* _____ *units:* _____

Do you take your seizure medication(s) daily? Yes No N/A

Describe any side effects related to your medications:

Healthcare Costs

Where do you receive your medical care for epilepsy (select all that apply)?

- None
 Main hospital
 Local hospital
 Health post
 Community health center
 Military hospital
 Traditional healer
 Other: _____

How many times in the past year have you sought medical care for epilepsy at a local health center? ___

On average, how much money did you spend at each medical visit at a local health center? _____

How much does it cost to travel from your home to the local health center that you visit most often (round trip)? _____

How far from your home is the local health center that you visit most often? _____

How do you travel from your home to the local health center that you visit most often?

- Walk
 Bus
 Car
 Taxi
 Other: _____

How many times in the past year have you sought medical care for epilepsy at the main hospital (epilepsy clinic)? _____

On average, how much money did you spend at each medical visit at the main hospital (epilepsy clinic)? _____

How much does it cost to travel from your home to the main hospital (round trip)? _____

How far from your home is the main hospital? _____

How do you travel from your home to the main hospital?

- Walk
 Bus
 Car
 Taxi
 Other: _____

How many times in the past year have you been hospitalized for epilepsy? _____

How many days, in total, did you spend in the hospital in the past year for epilepsy? _____

On average, how much did you spend per day for the hospitalization, including drugs, tests, and all other costs? _____

How much do you estimate that you have spent, in total, over the past year for the following (for epilepsy only):

Health care	Amount spent:
Medications	
Transportation to health center	

How many times have you had the following tests for epilepsy:

Test	In the past year:	Total until now:	How much did you spend on each test?
EEG			
MRI			
CT			
Antiepileptic drug levels			
Other blood test			

Work and School

Are you currently working: Yes No

If yes, what type of work:

Are you currently in school: Yes No

If you are not currently working or in school, what is the reason?

If you are not currently working or in school, when is the last time you were working or in school?

How many days of work/school have you missed because of epilepsy:

In the past month? _____ In the past year? _____

If you missed work/school during the past year because of epilepsy, what was the primary reason?

How many days of work did other adults in your family lose because of having to take care of your epilepsy (including accompanying you to healthcare visits):

In the past month? _____ In the past year? _____

Economics: Participant

How many people live in your house? Total: _____

Under 18: _____ Age 18 – 64: _____ Age 65 or older: _____

Select the type of energy or fuel mainly used for cooking:

- Electricity Liquefied Petroleum Gas (LPG) Kerosene Wood
- No food cooked in house Other (*examples: natural gas, biogas, coal, charcoal*) _____

Select where the cooking is usually done:

- In your house in a separate room used as kitchen Elsewhere in the house
- In a separate building Outdoors Other (*specify*) _____

Select the things owned by your household:

- Electricity Radio Television Refrigerator Mobile telephone
- Bicycle Motorcycle/Scooter Animal-drawn cart
- Car/Truck Running water Toilet Latrine

Does anyone in your household own your home? Yes No

How many acres of land does your household own for gardening or farming? _____

How many of the following animals does your household have?

Cattle, cows, bulls, or oxen: _____ Horses, donkeys, or mules: _____ Goats: _____ Chickens: _____

Does any member of your household have a bank account? Yes No Unsure

Over the past seven days, how much did your household spend on food? _____

Over the past seven days, how much did your household spend on health-related costs? _____

In a typical month, how much money does your household usually need to cover all expenses, including rent, food, schooling, household goods? _____

In a typical month, how much income do you have available in your household, including from work, selling items, or remittances? _____

Economics: Comparison Household

Do you have a sibling who lives in the same town as you, who does NOT have seizures, and does NOT live with you?

- Yes *If yes, please complete the questions below the line about this sibling*
No *If no, continue to next question about best friend*

Do you have a best friend, who lives in the same town as you, who does NOT have seizures, and does NOT live with you?

- Yes *If yes, please complete the questions below the line about this best friend*
No *If no, skip this section*
-

Sibling/best friend's age: _____ **Sibling/best friend's sex:** Male Female

Sibling/best friend's marital status: Single Married Divorced Widowed

Other: _____

Sibling/best friend's number of years of school completed:

No school 1 2 3 4 5 6 7 8 9 10 11 12 13+

Unknown Other: _____

How many people live in your sibling/best friend's house? Total: _____

Under 18: _____ Age 18 – 64: _____ Age 65 or older: _____

Select the type of energy or fuel mainly used for cooking at your sibling/best friend's house:

- Electricity Liquefied Petroleum Gas (LPG) Kerosene Wood
 No food cooked in house Other (*examples: natural gas, biogas, coal, charcoal*) _____

Select where the cooking is usually done at your sibling/best friend's house:

- In your house in a separate room used as kitchen Elsewhere in the house
 In a separate building Outdoors Other (*specify*) _____

Select the things owned by your sibling/best friend's household:

- Electricity Radio Television Refrigerator Mobile telephone
- Bicycle Motorcycle/Scooter Animal-drawn cart
- Car/Truck Running water Toilet Latrine

Does your sibling/best friend (or someone living in their household) own their home?

- Yes No Unsure

How many acres of land does your sibling/friend's household own for gardening or farming? (if none, write 0) _____

How many of the following animals does your sibling/best friend's household have?

Cattle, cows, bulls, or oxen: _____ Horses, donkeys, or mules: _____ Goats: _____ Chickens: _____

Does any member of your sibling/best friend's household have a bank account?

- Yes No Unsure

Over the past seven days, how much do you estimate your sibling/best friend's household spent on food? _____

Over the past seven days, how much do you estimate your sibling/best friend's household spent on health-related costs? (if none, write 0) _____

In a typical month, how much money does your sibling/best friend's household usually need to cover all expenses, including rent, food, schooling, household goods? _____

In a typical month, how much income does your sibling/best friend have available in their household, including from work, selling items, or remittances? _____

Appendix 2: Multivariate regression models

Multivariate linear regression model¹ among patients and comparisons with predictors of per-person household income

Per-person household income	Coefficient	95% Conf. Interval	P> z
Larger town size category	1,477	528 to 2,426	0.002
Presence of epilepsy in household	-2,607	-4,914 to -299	0.027
Constant	6,484	4,149 to 8,819	< 0.001

¹Adjusted R-squared = 0.0383

Multivariate linear regression model¹ (among patients only) with predictors of total direct costs of epilepsy

Total yearly direct medical costs	Coefficient	95% Conf. Interval	P> z
Number of medications	6,917	3,226 to 10,608	< 0.001
High vs. low distance to hospital	5,268	1,036 to 9,500	0.015
Age (years)	261	87 to 434	0.003
Constant	-11,316	-17,584 to -5,048	< 0.001

¹Adjusted R-squared = 0.1485

Multivariate linear regression model¹ among patients and comparisons with predictors of school attainment

Schooling completed	Coefficient	95% Conf. Interval	P> z
Age	-0.026	-0.038 to -0.014	< 0.001
Higher seizure frequency	-0.227	-0.402 to -0.053	0.011
Epilepsy vs. comparison	0.069	-0.329 to 0.467	0.734
Constant	2.828	2.422 to 3.233	< 0.001

¹Adjusted R-squared = 0.0619