

# ESTIMATING THE ECONOMIC BURDEN OF CAREGIVING IN EPILEPSY

Shaun A. Hussain, MD, MS<sup>1</sup>, Jesse D. Ortendahl, MS<sup>2</sup>, Tanya G.K. Bentley, PhD<sup>2</sup>, Amanda L. Harmon, MPH<sup>2</sup>, Shaloo Gupta, MS<sup>3</sup>, Charles E. Begley, PhD<sup>4</sup>, Russell L. Knoch, PhD<sup>5</sup>

<sup>1</sup>Division of Pediatric Neurology, Mattel Children's Hospital, David Geffen School of Medicine, UCLA; <sup>2</sup>Partnership for Health Analytic Research, LLC; <sup>3</sup>Kantar Health; <sup>4</sup>University of Texas, School of Public Health; <sup>5</sup>Eisai Inc.

## RATIONALE

- There are approximately 2.9 million children and adults in the US with a diagnosis of active epilepsy.<sup>1</sup>
- Care for persons with epilepsy (PWE) is often provided by an informal caregiver, such as a family member. Caregivers are needed to perform the following types of tasks:<sup>2,3</sup>
  - Keeping PWE safe during a seizure
  - Providing first aid for seizures or calling for medical help
  - Seizure recall and prevention
  - Medication administration and adherence
  - Transportation
  - Accompanying PWE to medical appointments
  - Assisting PWE navigate the healthcare system
- While the direct and indirect economic burden of epilepsy has been examined for PWE, the impact on caregivers has been of less interest.
- We conducted a survey to estimate the direct and indirect costs associated with caregiving for PWE.

## SURVEY

- Eligible survey participants were:
  - ≥18 years old
  - Living in the US
  - Able to read and write in English
  - Provided informed consent
  - Self-identified as caregivers of PWE
- 500 caregivers of PWE were recruited through the Epilepsy Foundation and Lightspeed Research panels and surveyed.
- Survey questions included:
  - Demographic information
  - Healthcare utilization
  - Work productivity and impairment via the Work Productivity and Activity Impairment (WPAI) survey<sup>4</sup>
- IRB approval was obtained through the Sterling Institutional Review, Atlanta, GA.

## DATA

- Direct medical costs:
  - Defined as physician outpatient visits, emergency room (ER) visits, hospitalizations
  - Utilization estimated from the survey, and per-visit costs from the Medical Expenditure Panel Survey (MEPS)<sup>5</sup>
- Indirect costs:
  - Defined as productivity losses
  - Estimated from the WPAI-reported rates of absenteeism and presenteeism, and multiplied by hourly wages from survey respondents
- Comparator group:
  - Defined as general population
  - Estimated using publically available data and published literature<sup>5,6</sup>

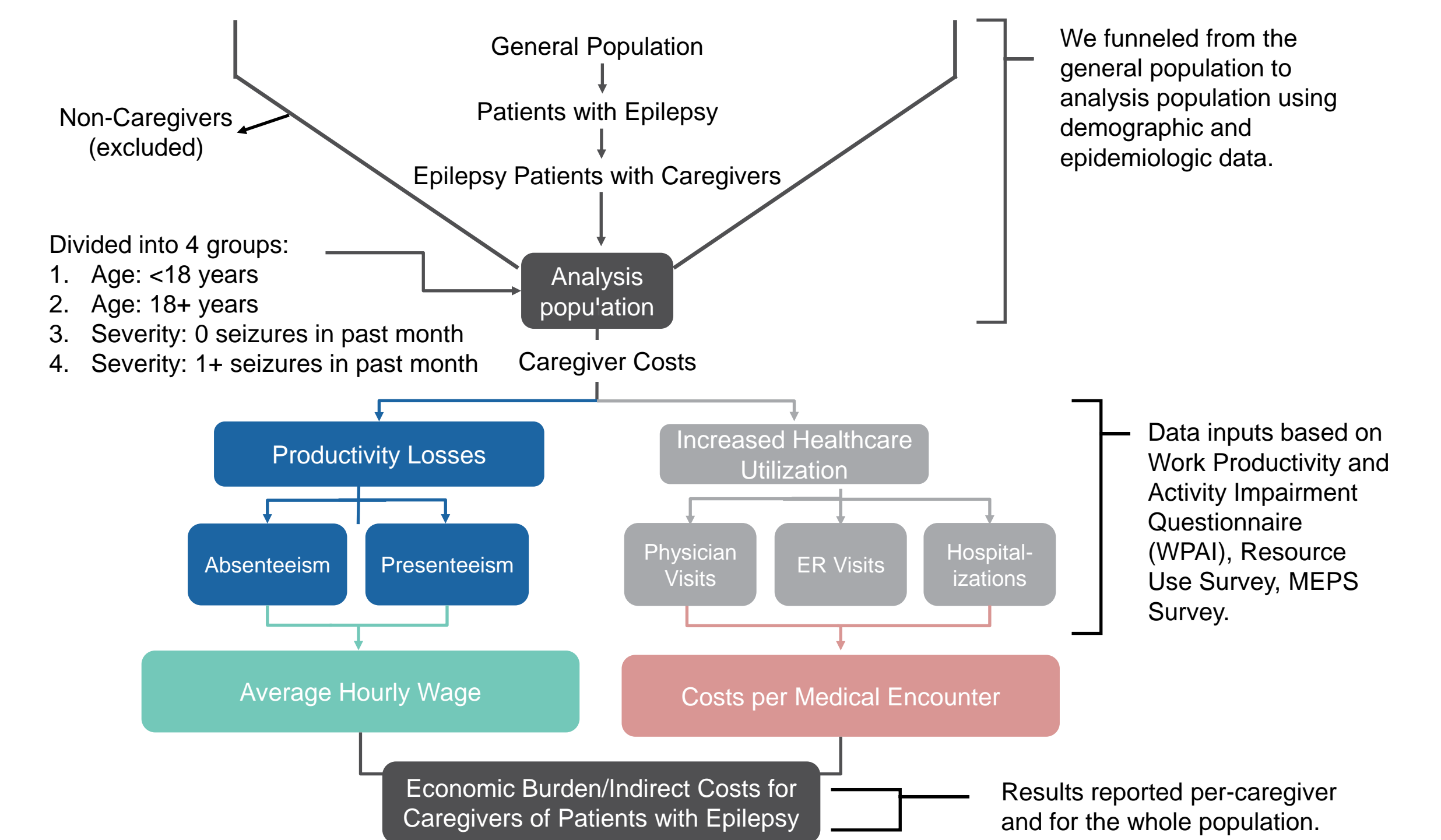
## ANALYSES

- Direct and indirect costs were estimated for the general population, all caregivers, and for four subgroups of caregivers, stratified by:
  - PWE age (adult vs. child)
  - Disease severity (low vs. high seizure frequency epilepsy, defined as 0 vs. 1+ seizure in prior month)
- The caregiving burden was defined as the incremental costs for caregivers compared to the general population.
- Costs were estimated per person and for the US population of caregivers of PWE.
- Because of data limitations, the estimate of total US caregivers relied on a simplifying assumptions, expert opinion, and an article with a limited sample size.<sup>7</sup>

## STATISTICAL METHODS

- Statistical calculations were carried out using SAS software 9.3 (SAS Institute, Cary, NC).
- Continuous summary data were presented as means with standard deviations and medians.
- Due to the non-normal distributions of the measures, comparisons were made within each age group, assessing differences between severity using the Wilcoxon rank-sum test.
- Comparisons of all caregiver subgroups simultaneously were conducted using ANOVA F-tests.

Figure 1. Analysis Population, Costs, and Outcomes



## RESULTS

- Comparing our survey population and the MEPS respondents, survey respondents were older, more likely to be female, and more likely to be employed (Table 1).

Table 1. Survey Respondents and MEPS Population: Demographics

	All Caregivers of Persons with Epilepsy (N=488)	MEPS Survey Respondents
Age (years), mean ± SD	44.5 ± 12.9	38.9
Sex, n (%)		
Male	97 (19.9%)	48.8%
Female	391 (80.1%)	51.2%
Employment Status, n (%)		
Currently employed	276 (56.6%)	47.6%
Not currently employed	212 (43.4%)	52.4%
Annual household income, n (%)		
< \$50,000	240 (49.2%)	-
> \$50,000	248 (50.8%)	-

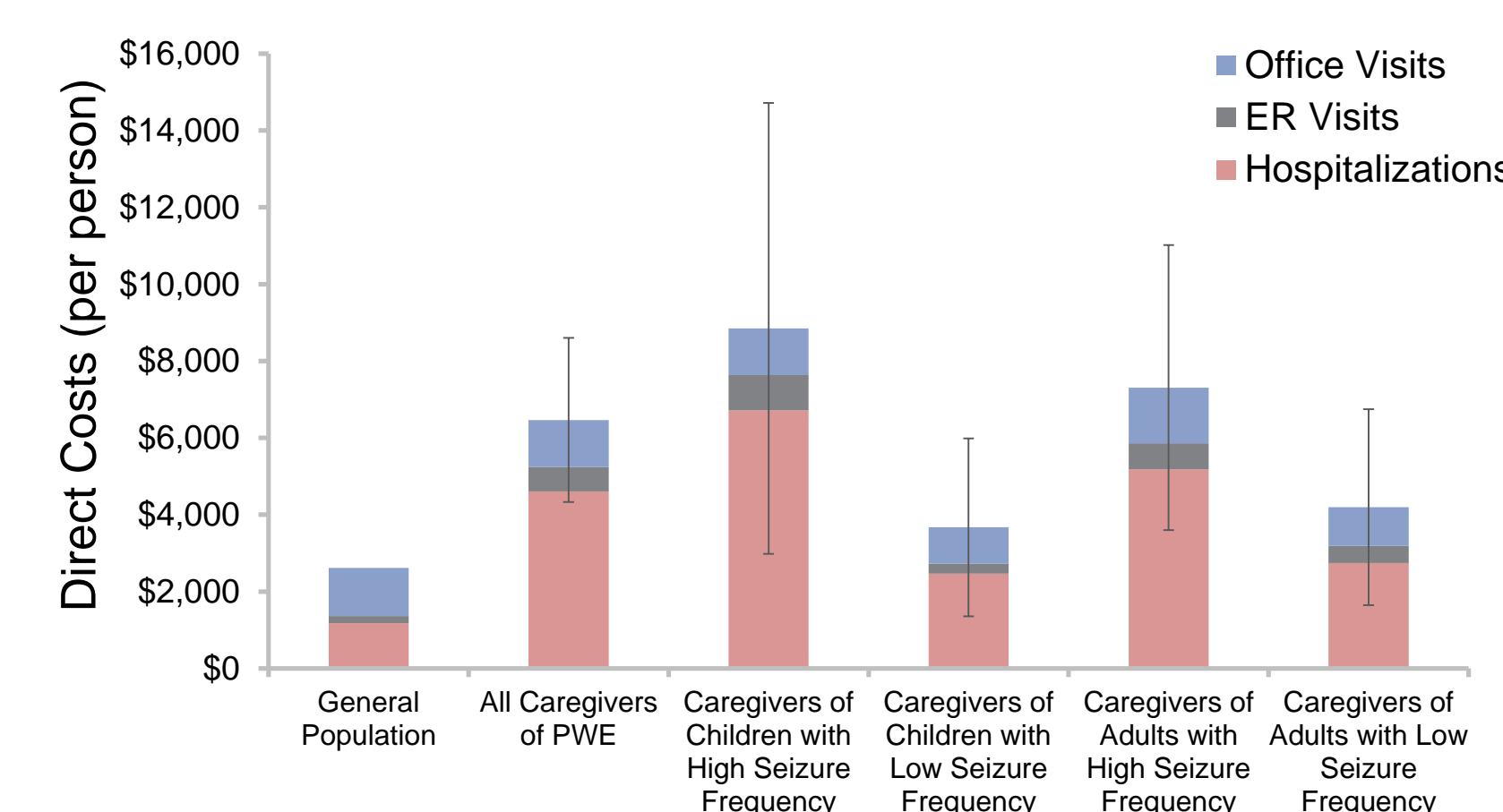
- Total and component per-person mean and median costs for caregivers, and per-person mean costs for the general population, are shown in Table 2.
- For both groups, productivity losses, and more specifically costs due to presenteeism, far exceeded expenditures due to resource utilization.
- Incremental indirect costs, indicating the burden on caregivers, exceeded \$21,000.

Table 2. Direct and Indirect Costs for the General Population and Caregivers of Persons with Epilepsy

	Direct Costs			Indirect Costs			
	Office Visits	ER Visits	Hospitalizations	Total Direct Costs	Presenteeism	Absenteeism	Total Indirect Costs
General Population-Mean	\$1,258	\$190	\$1,177	\$2,620	\$3,907	\$1,152	\$5,015
Caregivers of PWE-Mean	\$1,228	\$631	\$4,610	\$6,468	\$19,689	\$6,821	\$26,188
Caregivers of PWE-Median	\$908	\$0	\$0	\$908	\$12,019	\$0	\$17,788
Incremental Mean Caregiver Costs	-\$30	\$441	\$3,433	\$3,848	\$15,782	\$5,669	\$21,173

ER, emergency room; PWE, persons with epilepsy.

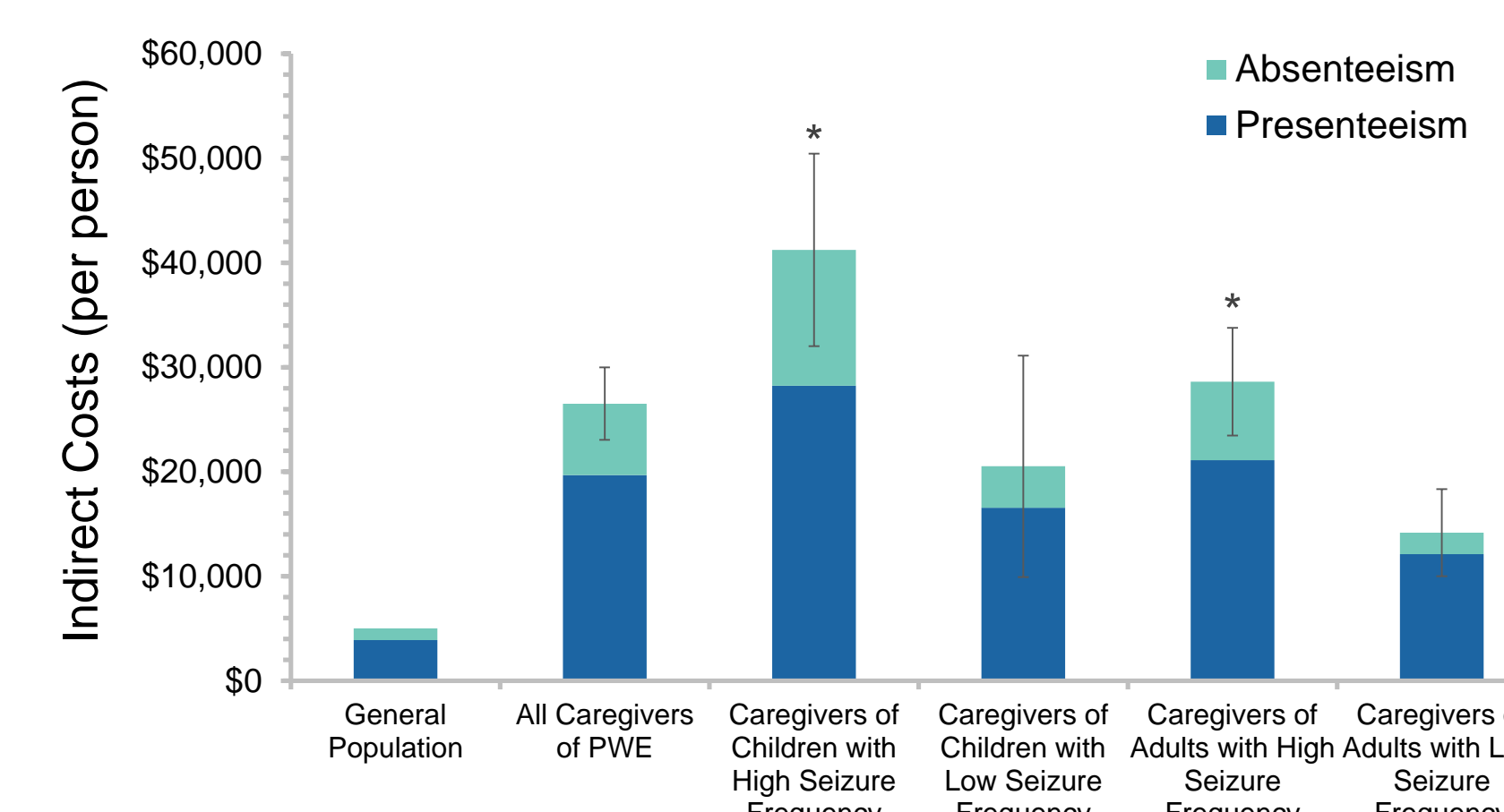
Figure 2. Mean Healthcare Utilization Costs for the General Population and Caregivers of Persons with Epilepsy



ER, emergency room; PWE, persons with epilepsy. Error bars represent 95% confidence interval around total direct medical costs. Findings were not significantly significant at p=0.05 when comparing between median costs within subgroups of caregivers of like-aged PWE.

- Caregivers of children with high seizure frequency had the highest costs related to hospitalization and ER visits (Figure 2).
- When comparing all subgroups simultaneously, the direct cost differences were not statistically significant (hospitalization, p=0.47; ER visits, p=0.12).

Figure 3. Mean Indirect Costs of Presenteeism and Absenteeism for the General Population and Caregivers of Persons with Epilepsy



PWE, persons with epilepsy. Error bars represent 95% confidence interval around total mean indirect medical costs. \*Asterisks denote subgroups in which median costs are statistically significant (p<0.001) compared to caregivers of persons with low seizure frequency in the same age group.

- Productivity losses were higher in caregivers of children with epilepsy than caregivers of adults with epilepsy, and for caregivers of those with high seizure frequency (Figure 3).
- Median costs were significantly higher for caregivers of PWE with high seizure frequency in both children and adults (p<0.001).
- Our estimates indicate there are ~1.9 million caregivers of PWE in the US and 25% are caregivers of children with epilepsy.
- Among the US population of PWE caregivers:
  - Annual direct caregivers costs: \$11.9 billion
  - Annual indirect caregiver costs: \$48.3 billion
- For comparison, the costs for the same number of people from the general population:
  - Annual direct costs: \$4.9 billion
  - Annual indirect costs: \$9.3 billion
- The burden on caregivers was:
  - Incremental direct costs: \$7 billion
  - Annual indirect costs: \$39 billion

## CONCLUSIONS

- Both direct and indirect costs for caregivers of PWE exceeded those for the general population.
- Costs were greater for caregivers of children than caregivers of adults, and for caring for patients with higher seizure frequency.
- Incremental costs of \$46 billion are far beyond a widely cited estimate of annual PWE direct and indirect costs of \$12.5 billion in 1995 dollars, (\$19.4 billion in 2015 dollars).<sup>8</sup>
- Results should be considered in light of limitations, including demographic differences between the general population and survey respondents, and uncertainty in the number of caregivers.
- While further research should be conducted to support this analysis, preliminary results suggest caregiver costs should be considered when estimating the value of interventions that prevent or reduce epilepsy symptoms.

## REFERENCES

- Centers for Disease Control and Prevention. Epilepsy Fast Facts. 2016. <http://www.cdc.gov/epilepsy/basics/fast-facts.htm>. Accessed April 21, 2016.
- The National Society for Epilepsy. Caring for someone with epilepsy. *Epilepsy Society*. <https://www.epilepsysociety.org.uk/caring-someone-epilepsy>. Published March 2016. Accessed October 14, 2016.
- Institute of Medicine (U.S.), England MJ, eds. *Epilepsy across the Spectrum: Promoting Health and Understanding*. Washington, D.C: National Academies Press; 2012.
- Reilly MC, Zbrozek AS, Dukes EM. The validity and reproducibility of a work productivity and activity impairment instrument. *Pharmacoeconomics*. 1993;4(5):353-365.
- Medical Expenditure Panel Survey Home. <https://meps.ahrq.gov/mepsweb/>. Accessed Oct 14, 2016.
- Csotho C, Witt EA, Villa KF, et al. The humanistic and economic burden of providing care for a patient with schizophrenia. *Int J Soc Psychiatry*. 2015;61(8):754-61.
- Karakis I, Cole AJ, Montouris GD, San Luciano M, Meador KJ, Piperidou C. Caregiver Burden in Epilepsy: Determinants and Impact. *Epilepsy Research and Treatment*. 2014;2014:e808421. doi:10.1155/2014/808421.
- Begley CE, Famulari M, Annegers JF, et al. The cost of epilepsy in the United States: an estimate from population-based clinical and survey data. *Epilepsia*. 2000 Mar;41(3):342-51.