

THE CAREGIVER'S DIRECT MEDICAL COSTS IN EPILEPSY

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RATIONALE

- There are approximately 2.9 million children and adults in the US with diagnosed active epilepsy.¹
- While some persons with epilepsy (PWE) receive assistance from hired professionals (e.g., home nursing staff), care is often provided informally by a family member.
- For caregivers, such responsibilities have been shown to increase stress, anxiety, and depression.²
- Direct costs of healthcare utilization has been examined for PWE, however the economic impact of increased utilization among caregivers is not typically studied.
- Using results from a caregiver survey, we estimated healthcare utilization and direct medical 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:
 - Primary care doctor visits
 - Psychiatrist visits
 - Emergency room (ER) visits
 - Inpatient hospitalizations
- IRB approval was obtained through the Sterling Institutional Review, Atlanta, GA.

ANALYSIS COMPARATORS

- Direct medical costs were estimated for the following populations:
 - All caregivers of PWE
 - Four subgroups of caregivers, partitioned by:
 - PWE age (adult/child)
 - Disease severity (low vs. high seizure frequency epilepsy, defined as 0 vs. 1+ seizure in prior month)
 - The comparator group was defined as the general population of adults in the US
- Total caregiver burden was defined as the difference between the caregiver group and the general population.

CALCULATION OF DIRECT COSTS

- Caregiver-reported six-month utilization rates were multiplied by two to calculate annual medical encounters.
- Primary care doctor and psychiatrist visits were combined into a category called physician visits.
- Resource utilization for the general population of adults in the US was based on data from the 2013 Medical Expenditures Panel Survey (MEPS).
- Cost per encounter was based on the 2013 MEPS responses (Table 1).³

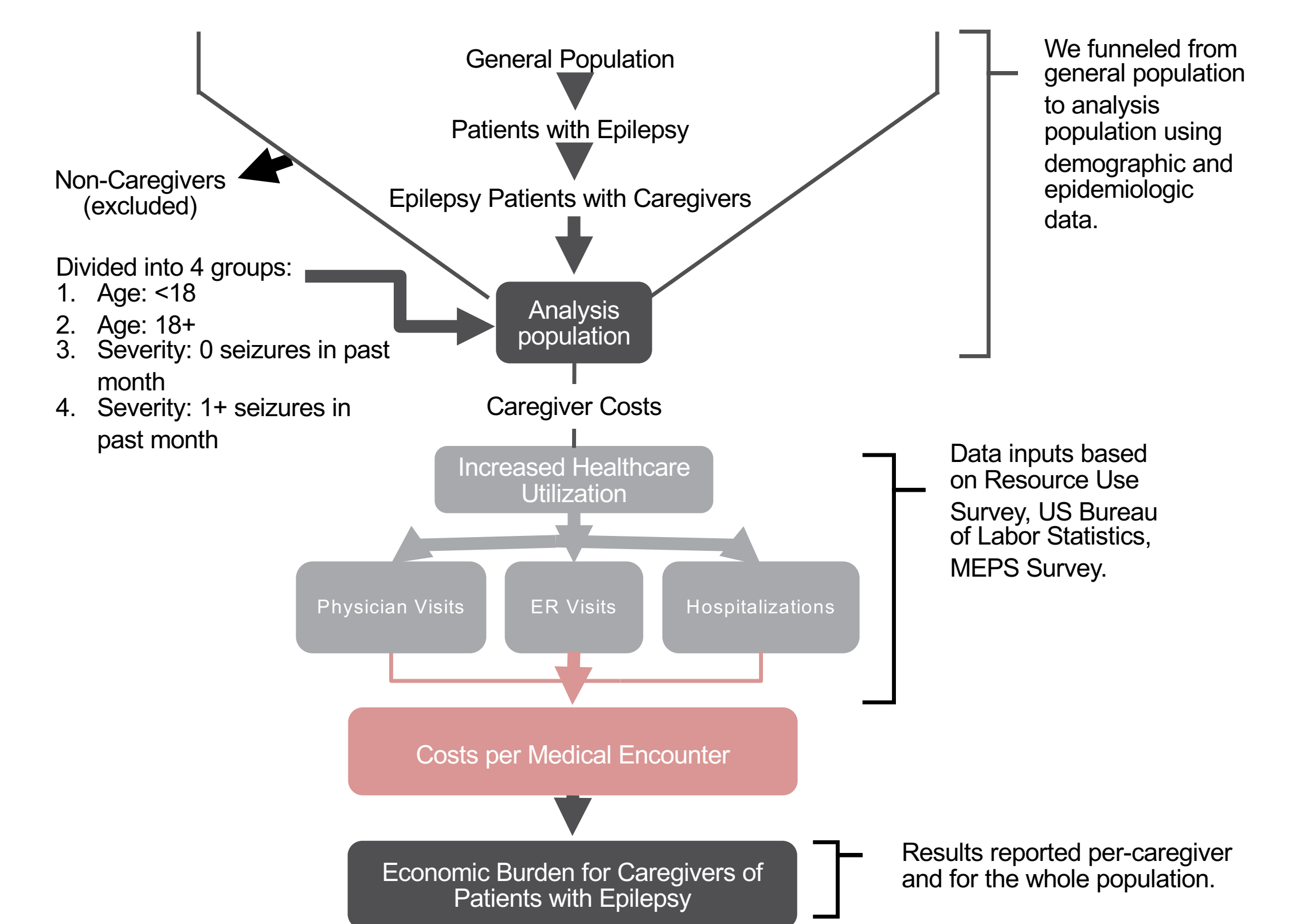
Table 1. Direct Cost Inputs

| | Office Visit | ER Visit | Hospitalization |
|----------------------------|--------------|----------|-----------------|
| Cost per Medical Encounter | \$227 | \$999 | \$13,079 |

ANALYSES AND STATISTICAL METHODS

- Statistical calculations were carried out using Statistical Analysis System software 9.3 (SAS Institute, Cary, NC).
- Continuous summary data were presented both 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



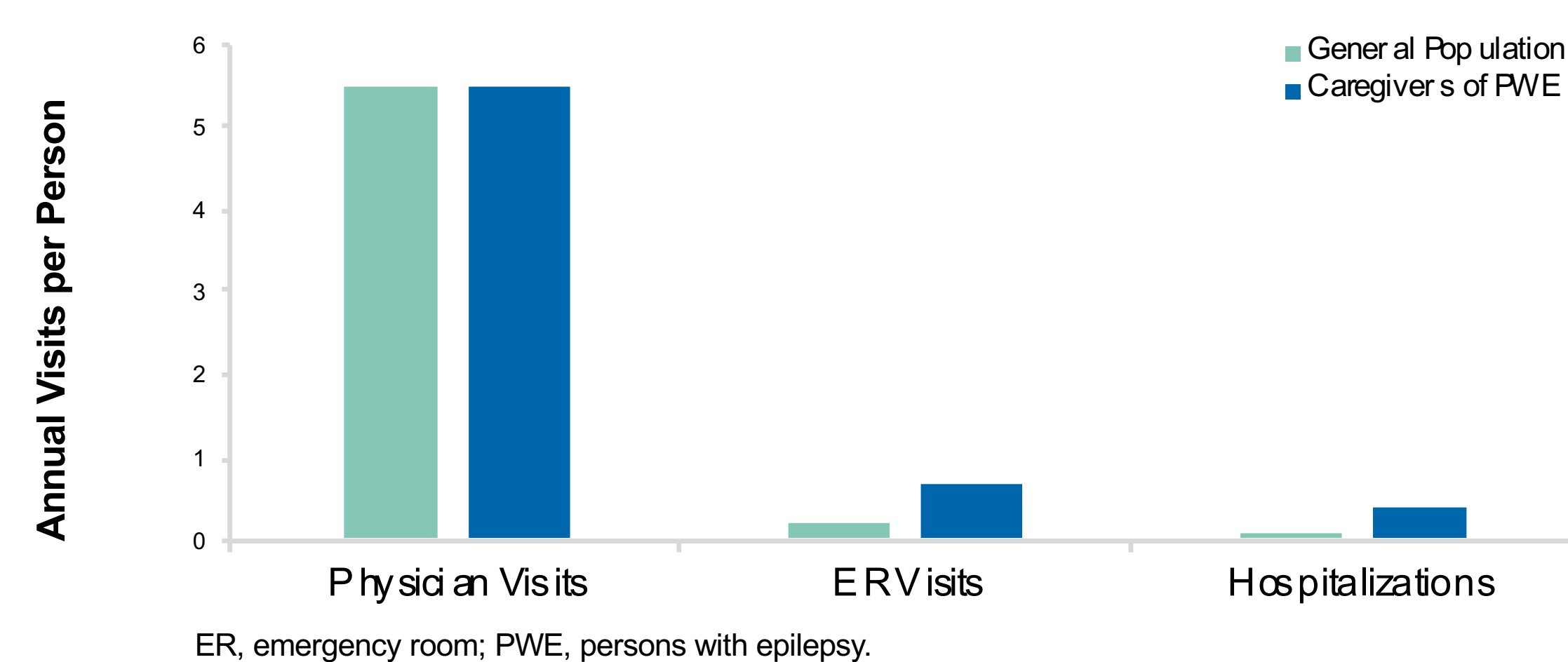
RESULTS

- Annual rates of hospitalizations and ER visits were higher in caregivers of PWE than the general population of US adults, and highest among those caring for children with high seizure frequency epilepsy (Table 2, Figure 2).

Table 2. Healthcare Utilization Rates

| | CAREGIVER OF ADULT WITH EPILEPSY | | CAREGIVER OF CHILD WITH EPILEPSY | | GENERAL POPULATION OF US ADULTS |
|-----------------------|----------------------------------|------------------------|----------------------------------|------------------------|---------------------------------|
| | Low Seizure Frequency | High Seizure Frequency | Low Seizure Frequency | High Seizure Frequency | |
| Physician Visits | 4.44 | 6.38 | 4.16 | 5.34 | 5.52 |
| Emergency Room Visits | 0.46 | 0.68 | 0.26 | 0.92 | 0.19 |
| Hospitalizations | 0.20 | 0.40 | 0.18 | 0.52 | 0.09 |

Figure 2. Healthcare Utilization For Caregivers of PWE and the General Population



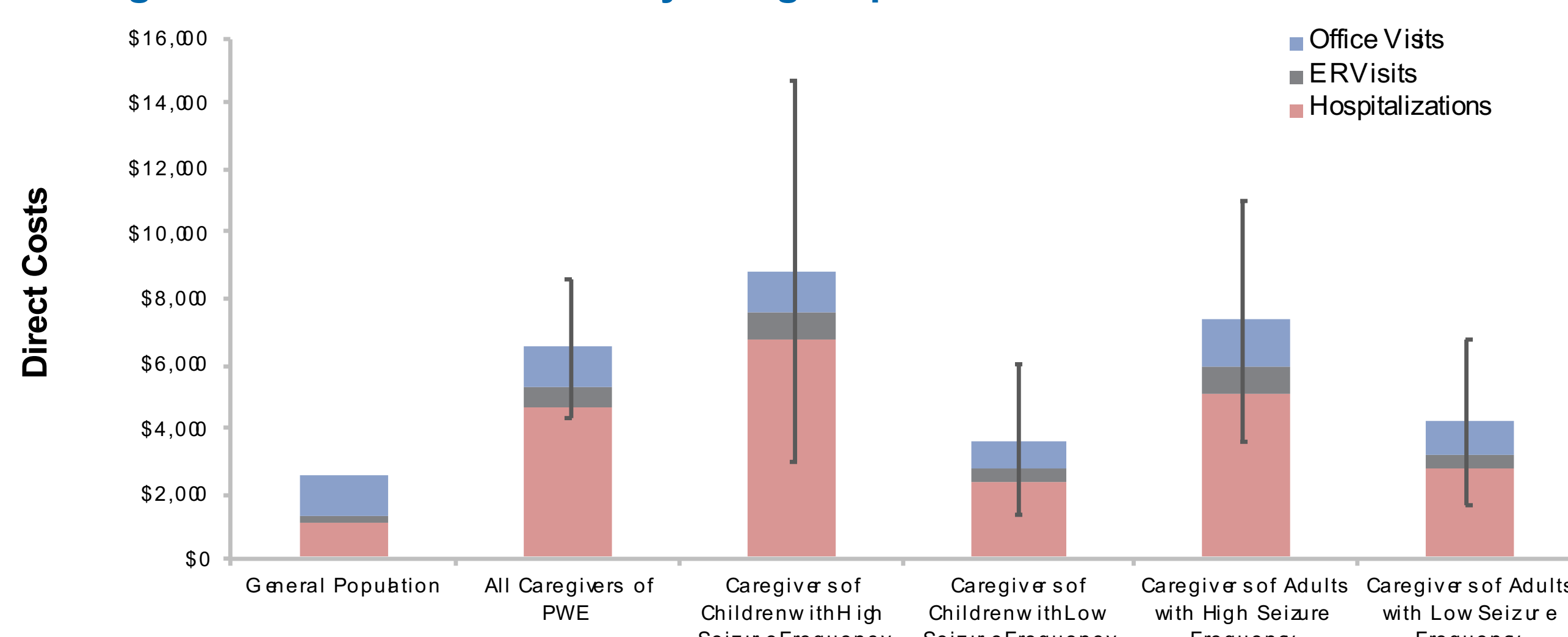
- Direct medical costs for all subgroups of caregivers of PWE exceeded those from the general population of US adults. (Table 3, Figure 3)

Table 3. Per-person Direct Costs for Caregivers and the General Population

| | Office Visits | ER Visits | Hospitalizations | Total Direct Costs |
|---------------------------|---------------|-----------|------------------|--------------------|
| General Population- Mean | \$1,258 | \$190 | \$1,177 | \$2,620 |
| Caregivers of PWE- Mean | \$1,228 | \$631 | \$4,610 | \$6,468 |
| Caregivers of PWE- Median | \$908 | \$0 | \$0 | \$908 |

ER, emergency room; PWE, persons with epilepsy.

Figure 3. Mean Healthcare Utilization Costs for the General Population and Caregivers of PWE: Total and by Subgroup



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.

- Mean direct costs by caregiver subgroup are found in Table 4. Cost differences were not statistically significant when making pairwise comparisons based on severity, or when comparing all subgroups simultaneously (hospitalization, p=0.47; ER visits, p=0.12).

Table 4. Annual Direct Costs by Caregiver Subgroup

| | CAREGIVER OF ADULT WITH EPILEPSY | | CAREGIVER OF CHILD WITH EPILEPSY | |
|-----------------------------|----------------------------------|------------------------|----------------------------------|------------------------|
| | Low Seizure Frequency | High Seizure Frequency | Low Seizure Frequency | High Seizure Frequency |
| Annual Direct Medical Costs | \$4,200 (± \$14,493) | \$7,310 (± \$26,891) | \$3,674 (± \$8,611) | \$8,848 (± \$31,261) |

- In the US, we estimated there would be ~1.9 million caregivers of PWE, distributed as caregivers of:
 - Children with low seizure frequency epilepsy: 7%
 - Children with high seizure frequency epilepsy: 17%
 - Adults with low seizure frequency epilepsy: 29%
 - Adults with high seizure frequency epilepsy: 47%
- Annual direct medical costs for all US caregivers of PWE were \$12 billion.
- Direct medical costs for the same number of people from the general population of US adults was \$11.9 billion, resulting in an incremental cost for caregiving of >\$7 billion.

CONCLUSIONS

- Healthcare utilization among caregivers of PWE was typically greater than that of the general population and increased with disease severity.
- Direct medical costs increased for caregivers of children vs. adults and with epilepsy severity. Differences were not statistically significant, in part due to the sample sizes obtained when partitioning the surveyed population.
- The total costs for caregivers of \$11.9 billion far exceed the calculated costs for the general population (\$4.9 billion) and an estimate of costs to the patients themselves (\$1.7 billion in 1995 US Dollars).⁴
- Results should be considered in light of limitations, including demographic differences between sources for caregivers and the general population, and assumptions required to estimate the total US caregiver population.
- These preliminary results should be considered when evaluating the economic impact of epilepsy treatments, especially from the prospective of insurers covering entire families.

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