Epilepsy is a common neurologic disorder in the United States, with an estimated prevalence of 3.4 million cases, and approximately 150,000 new cases of epilepsy are diagnosed annually.\textsuperscript{1,2} Epilepsy is characterized by recurring seizures that involve either a part of the body (ie, partial-onset seizure) or the whole body (ie, generalized seizure).\textsuperscript{3} Partial-onset seizures are the most common type of seizures in patients with epilepsy.\textsuperscript{1} Episodic seizures of partial-onset seizures may be accompanied by other symptoms, including loss of consciousness or other cognitive dysfunction, such as mental slowness, attention deficit, speech problems, memory difficulties, and hallucinations. In addition to the significant impact on patients, the unpredictability of seizures often also affects family members or caregivers. Caregiver burden in relation to patient treatment may help to guide treatment choices for patients. Quantitative evidence about the relationship between workplace absences, costs, and treatment burden among caregivers of patients with partial-onset seizures is lacking.

**BACKGROUND:** Partial-onset seizures are the most common type of seizures in patients with epilepsy. In addition to the significant impact on patients, the unpredictability of seizures often also affects family members or caregivers. Caregiver burden in relation to patient treatment may help to guide treatment choices for patients. Quantitative evidence about the relationship between workplace absences, costs, and treatment burden among caregivers of patients with partial-onset seizures is lacking.

**OBJECTIVE:** To compare direct and indirect healthcare costs and absences among employed caregivers of patients with partial-onset seizures who are receiving monotherapy or adjunctive therapy with antiepileptic drugs (AEDs).

**METHODS:** This retrospective study analyzed data of employed caregiver spouses of patients with partial-onset seizures and paired them with the patients into 2 groups based on the patient’s therapy: the monotherapy cohort or the adjunctive therapy cohort (ie, >90 days of concomitant use of ≥2 AEDs). Patients and caregivers had to have ≥12 months of continuous data after the index date. Separate 2-part regression models were used to compare direct medical and prescription costs; indirect costs (ie, sick leave, short-term and long-term disability, and workers’ compensation); and differences in work absences for caregivers.

**RESULTS:** The baseline caregivers’ characteristics were similar in the monotherapy cohort (N = 238) and the adjunctive therapy cohort (N = 129). Caregivers’ total direct costs were $4231 in the monotherapy cohort and $7217 in the adjunctive therapy cohort. The caregivers of patients in the monotherapy cohort were less likely to use inpatient hospital services than caregivers of patients in the adjunctive therapy cohort (1.3% vs 9.9%, respectively; \( P = .0016 \)). The caregivers’ total indirect costs were $912 and $1192 in the monotherapy and adjunctive therapy cohorts, respectively. Sick days were significantly lower in the monotherapy cohort (2.4 days vs 4.4 days annually; \( P < .0001 \)), with an associated cost difference of $541.

**CONCLUSION:** Caregivers of patients with partial-onset seizures in the adjunctive therapy cohort had significantly greater medical and sick day costs than caregivers in the monotherapy cohort. These findings suggest that higher treatment burden among patients with epilepsy is associated with greater direct and indirect healthcare costs for their caregivers.

**KEY WORDS:** absenteeism, adjunctive therapy, antiepileptic drugs, caregiver burden, caregivers, direct healthcare cost, epilepsy, indirect healthcare cost, monotherapy, partial-onset seizures, treatment decision-making
nations. Patients with epilepsy face high rates of comorbidities, including cardiovascular, respiratory, and metabolic disorders, as well as an increased risk for early mortality. Patients with this disease are also known to suffer from social stigma that results in lower self-esteem, reduced social support, discrimination, and unemployment, which often contributes to psychiatric issues that reduce quality of life and may pose a greater burden than the seizures themselves. 

Although epilepsy has a profound adverse impact on patients’ lives, the unpredictability of seizures also often affects the family members or caregivers of patients with epilepsy in various ways. First, the variability of seizure control among patients may have an impact on the caregiver’s feelings of anxiety about the patient. Caregivers may also have responsibilities regarding the patient in providing medication reminders, monitoring treatment adherence, and offering general and emotional support that can often vary by the type (ie, partial or generalized) and severity of seizures. In addition, families of patients with epilepsy have reported dissatisfaction with restricted lives and with increased levels of anxiety and depression. Furthermore, caregivers may bear a financial burden either directly through financial assistance to the patient or housing for the patient, or indirectly because of their own work-related absences or reduced productivity as a result of caregiving responsibilities.

Finally, a patient’s antiepileptic drug (AED) regimen (ie, adjunctive or monotherapy AED regimen and varying treatment-related burden) may impose a compounding effect on the magnitude of overall caregiver burden. Little objective research has examined the different burdens on caregivers of patients who are receiving various AED treatment regimens. Evidence that expands the understanding of differences in caregiver burden between caregivers of patients who receive AED monotherapy or AED adjunctive therapy is needed, because this may play an underrecognized role in treatment choice and decision-making.

The objective of this study was to examine the potential differences in the annual direct healthcare costs, indirect costs (ie, payments made for absences resulting from sick leave, short- or long-term disability, and workers’ compensation), and lost time because of absences among employed caregivers of dependent spouses with partial-onset seizures who received monotherapy or adjunctive AEDs.

Methods

This retrospective cohort study was based on administrative claims from an integrated employer database.
Table 1 Baseline Cohort Demographics

<table>
<thead>
<tr>
<th>Variable</th>
<th>Monotherapy cohort</th>
<th>Adjunctive AED therapy cohort</th>
<th>Difference between cohorts</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>AED cohort with annual salary (N = 238)</td>
<td>AED therapy cohort with annual salary (N = 129)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age at index date, yrs, mean (SE)</td>
<td>45.15 (0.67)</td>
<td>44.14 (0.87)</td>
<td>−1.01</td>
<td>.3687</td>
</tr>
<tr>
<td>Duration of employment, yrs, mean (SE)</td>
<td>9.86 (0.59)</td>
<td>10.24 (0.80)</td>
<td>0.38</td>
<td>.7062</td>
</tr>
<tr>
<td>Female, %</td>
<td>31.5</td>
<td>27.9</td>
<td>−3.6</td>
<td>.7693</td>
</tr>
<tr>
<td>White, %</td>
<td>38.2</td>
<td>37.2</td>
<td>−1.0</td>
<td>.9815</td>
</tr>
<tr>
<td>Hispanic, %</td>
<td>5.5</td>
<td>7.8</td>
<td>2.3</td>
<td>.7132</td>
</tr>
<tr>
<td>Black, %</td>
<td>5.5</td>
<td>5.4</td>
<td>0.0</td>
<td>.9699</td>
</tr>
<tr>
<td>Other race, %</td>
<td>2.1</td>
<td>2.3</td>
<td>0.2</td>
<td>.9905</td>
</tr>
<tr>
<td>Race missing, %</td>
<td>48.7</td>
<td>47.3</td>
<td>−1.5</td>
<td>.9654</td>
</tr>
<tr>
<td>Exempt from certain time-tracking requirements (salaried), %</td>
<td>47.9</td>
<td>37.2</td>
<td>−10.7</td>
<td>.1369</td>
</tr>
<tr>
<td>Annual salary (Dec 2017 dollars), $, mean (SE)</td>
<td>76,062 (2969) 18</td>
<td>65,938 (3395) 18</td>
<td>−10,125</td>
<td>.0341</td>
</tr>
<tr>
<td>Full-time employment, %</td>
<td>98.7</td>
<td>98.4</td>
<td>−0.3</td>
<td>.9758</td>
</tr>
<tr>
<td>CCI score, mean (SE)</td>
<td>0.37 (0.07)</td>
<td>0.31 (0.08)</td>
<td>−0.06</td>
<td>.6361</td>
</tr>
<tr>
<td>Age at index date, yrs, mean (SE)</td>
<td>44.65 (0.68)</td>
<td>43.38 (0.90)</td>
<td>−1.27</td>
<td>.2657</td>
</tr>
<tr>
<td>Female, %</td>
<td>68.1</td>
<td>72.1</td>
<td>4.0</td>
<td>.7217</td>
</tr>
<tr>
<td>CCI score, mean (SE)</td>
<td>0.96 (0.11)</td>
<td>1.05 (0.17)</td>
<td>0.09</td>
<td>.8408</td>
</tr>
<tr>
<td>Time from first partial-onset seizure diagnosis to initiation of therapy, mean, days</td>
<td>17.8</td>
<td>56.6</td>
<td>—</td>
<td>—</td>
</tr>
</tbody>
</table>

**Note:** Some discrepancies may occur when adding up numbers because of rounding. AED indicates antiepileptic drug; CCI, Charlson Comorbidity Index; SE, standard error.

Healthcare claims, inpatient utilization, pharmaceutical expenditure data, time lost from work absences, and payments made to employees were obtained from the Human Capital Management Services (HCMS) integrated employer database between January 1, 2001, and June 30, 2014. At the time of this study, the HCMS database represented multiple employers in retail, service, manufacturing, and financial industries across the United States, and included information on 2 million employees plus their spouses and eligible dependents.

Data were deidentified to comply with the Health Insurance Portability and Accountability Act and the contractual obligations between HCMS and their employer-contributors. As a retrospective study using deidentified patient-level data that did not affect patient care, Institutional Review Board approval was not required.

The caregivers were identified as employed spouses of patients with partial-onset seizures, which was defined by any primary, secondary, or tertiary claims containing *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM) codes for localization-related epilepsy and epileptic syndromes with complex partial seizures (ICD-9-CM code 345.4x) or with simple partial seizures (ICD-9-CM code 345.5x). Caregivers with epilepsy were excluded from the cohorts.

The 2 cohorts consisted of caregiver-patient pairs with information in the HCMS database. The caregiver-patient pairs were allocated into the monotherapy or adjunctive therapy cohorts based on the patient’s mode of therapy (Figure 1).

Adjunctive therapy was defined as more than 90 days of concomitant use of ≥2 AEDs. The index dates in the monotherapy cohort were the date of the first AED prescription for each caregiver-patient pair. The index dates for the adjunctive therapy cohort were the date of the first additional therapy for each caregiver-patient pair. Each pair was required to have 1 or more years of continuous data in the database after their index date.

**Study Measures**

The annual caregiver healthcare utilization and costs were calculated for the direct health benefit costs, including the medical and prescription costs for the caregiver, as well as for the indirect costs that result from the caregiver’s workplace absences over a 12-month follow-up period. The indirect costs that resulted from absences were calculated from payments for sick leave, short-term disability, long-term disability, and workers’ compensation. The workers’ compensation costs also included medical claims paid under the workers’ compensation benefit.

The likelihood of point-of-service use, the per-person direct medical costs, and the number of visits for each service among caregivers were assessed based on the available point-of-service (ie, doctor’s office, inpatient hospital, outpatient hospital or clinic, emergency department, laboratory, and other) data. Logistic regression that controlled for age, tenure, marital status, caregiver race, work-related components (ie, exempt status, full- and part-time status, and salary), location, and Charlson Comorbidity Index (CCI) score was used to model the likelihood of using each point of service. The per-person medical costs, absence payments, and absence time were modeled using sequential 2-part regression analysis that controlled for age, tenure, marital status, caregiver race, exempt status, full- and part-time status, salary, location, and CCI score.

All costs were inflation-adjusted to December 2017 US dollars; the medical costs used the medical cost component of the Consumer Price Index, the prescription costs used the prescription component, and all the other costs used the overall component of the Consumer Price Index.18

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398 | American Health & Drug Benefits | www.AHDBonline.com | November 2018 | Vol 11, No 8
Statistical Analysis

The baseline demographic and job-related variables were compared between the cohorts using t-tests for continuous variables and chi-square tests for binary variables. Separate 2-part regression models were developed to assess the differences in cost and absence time between the caregiver cohorts of patients with partial-onset seizures who were receiving monotherapy or adjunctive therapy. In the first part of the model, logistic regression was used to predict the likelihood of caregivers having any costs or absence time. In the second part of the model, generalized linear models with a gamma distribution and a log-link function calculated the costs or absence time for caregivers with more than zero costs or absences.

All models controlled for differences in age, tenure (years with current employer), sex, marital status, race, exempt and nonexempt status (exempt employees were not paid on an hourly basis or for overtime work), full- and part-time status, salary, caregiver’s CCI score, and geography. The indirect costs were summed over all the absence claims during the 12-month postindex period. The differences were considered significant if $P < .05$.

Results

Approximately 65% of the 367 caregiver-patient pairs were in the monotherapy cohort and 35% were in the adjunctive therapy cohort. Caregivers in both cohorts had similar age, duration of employment, sex, race, and mean CCI score; however, caregivers in the monotherapy cohort had significantly higher annual salaries than those in the adjunctive therapy cohort. The patients’ age and sex were similar between the 2 cohorts (Table 1).

The medical treatment costs were significantly lower for caregivers in the monotherapy cohort than in the adjunctive therapy cohort ($2751 vs $5269; P = .0002$), but the caregiver’s prescription drug costs were similar in the 2 cohorts (Table 2).

Caregivers in the monotherapy cohort were absent from work for a total of 2.7 days annually compared with 5.1 days annually for caregivers in the adjunctive cohort, who had significantly more absences as a result of sick leave (Figure 2).

The number of days lost as a result of short-term disability was 0.3 days in the monotherapy cohort and 0.7 days in the adjunctive therapy cohort, although this difference was not statistically significant. The caregivers in the monotherapy and adjunctive therapy cohorts incurred $912 and $1192, respectively, of total indirect costs (Table 2). Workers’ compensation cost was significantly higher in the monotherapy cohort, whereas the sick leave cost was significantly higher in the adjunctive therapy cohort. The difference in short-term disability costs was not significant between the 2 groups.

The rate of inpatient hospital services among caregivers was 1.3% in the monotherapy cohort and 9.9% in the adjunctive therapy cohort ($P = .0016$; Table 3). No significant difference was observed between the cohorts in the likelihood of using other services.

Significant differences in direct healthcare costs were observed among caregivers for doctor’s office ($1062 with monotherapy vs $1420 with adjunctive therapy), inpatient hospital ($46 vs $1696, respectively), and “other”

---

### Table 2

<table>
<thead>
<tr>
<th>Caregiver cost category</th>
<th>Monotherapy, $ (N = 238)</th>
<th>Adjunctive therapy, $ (N = 129)</th>
<th>Cost difference, mean, $</th>
<th>( P ) value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct costs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical</td>
<td>2751 (239)</td>
<td>5269 (637)</td>
<td>2517</td>
<td>.0002</td>
</tr>
<tr>
<td>Prescription drug</td>
<td>1480 (135)</td>
<td>1940 (242)</td>
<td>460</td>
<td>.0907</td>
</tr>
<tr>
<td>Total caregiver direct cost</td>
<td>4231</td>
<td>7217</td>
<td>2986</td>
<td></td>
</tr>
<tr>
<td>Indirect costs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sick leave</td>
<td>582 (38)</td>
<td>1123 (90)</td>
<td>541</td>
<td>.0001</td>
</tr>
<tr>
<td>Long-term disability</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total indirect cost</td>
<td>18 (16)</td>
<td>62 (32)</td>
<td>44</td>
<td>.2200</td>
</tr>
<tr>
<td>Total cost (direct + indirect)</td>
<td>5144</td>
<td>8410</td>
<td>3266</td>
<td></td>
</tr>
</tbody>
</table>

NOTE: Some discrepancies may occur when adding up numbers because of rounding. SE indicates standard error.

### Figure 2: Annual Absence Days* per Caregiver

<table>
<thead>
<tr>
<th>Absence type</th>
<th>Annual days lost as a result of absence (per employee), N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sick leave</td>
<td>2.4</td>
</tr>
<tr>
<td>Short-term disability</td>
<td>0.3</td>
</tr>
<tr>
<td>Total absence days</td>
<td>2.7</td>
</tr>
</tbody>
</table>

*Absence days were calculated using 2-part (logistic-generalized linear model) regression modeling. $P < .0001$. $P < .05$.  

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services ($25 vs $71, respectively). There were significant differences associated with the caregivers in the monotherapy and adjunctive therapy cohorts in the number of doctor’s office visits (5.68 vs 7.23, respectively) and inpatient hospital visits (0.04 vs 0.29, respectively).

**Discussion**

To our knowledge, this is the first attempt to analyze and quantify the impact of patients’ differing AED therapy regimens for partial-onset seizures and their associated burden on caregivers’ direct and indirect healthcare costs and absenteeism. Although the study does not establish causation, it demonstrates a strong association between patients’ AED treatment burden and caregivers’ direct and indirect costs.

In this study, caregivers of patients who were receiving adjunctive therapy incurred 1.7 times greater direct costs and 2.2 times higher indirect costs than caregivers of patients receiving monotherapy. Of the total direct costs incurred by caregivers, the direct medical care costs accounted for more than 65% of the direct costs for caregivers in both cohorts.

When analyzed by point of service, caregivers in the adjunctive therapy cohort had a greater likelihood of receiving inpatient hospital care than those in the monotherapy cohort. This was further illustrated by the significantly higher cost and the number of hospital care services received by caregivers of patients in the adjunctive therapy cohort. Similarly, the indirect costs related to absences were higher among caregivers of patients in the adjunctive therapy cohort.

Although the burden among caregivers of patients with partial-onset seizures has been hypothesized to be significant, little is known about the potential healthcare resource utilization and costs among such caregivers. The database used in this study represented employers from various industries. Although the direct and indirect healthcare costs have increased in both study cohorts, it is plausible that factors such as industry sector, job level, and employer benefit coverage may influence caregiver healthcare utilization to varying degrees, which warrants examination in future studies.

Previous studies have focused on the relationship between caregiving and emotional health and quality of life; however, the impact of caregiving on physical health has been less clear. The findings from this study show that caregivers of patients with epilepsy who are receiving adjunctive therapy have a greater likelihood of receiving hospital care, which results in increased healthcare resource utilization and costs. Research on caregivers and patients with other chronic illnesses suggests that health problems associated with caregiving are related to the degree of patient dependence.

In epilepsy, the burden on a caregiver’s general health may also be related to the patient’s seizure type and severity. The greater medical costs observed with patients receiving adjunctive therapy in this study (data reported elsewhere) may reflect greater patient dependency on their caregivers, which adversely affects the health of the caregivers. The study, however, had surprisingly similar prescription costs among caregivers of patients receiving adjunctive therapy with AEDs and caregivers of patients who received monotherapy. Although the reasons for the similarities in prescription drug costs among the caregivers in both groups are unclear, similar baseline CCI scores suggest that caregivers...
may have comparable comorbid and disease characteristics, which can potentially lead to parallel pharmacy utilization needs and patterns.

This study assessed payroll, disability claims, and workers’ compensation claims data to objectively measure indirect costs and absence days, rather than inferring this information from medical claims data or surveys. Furthermore, work absence data were based on filed claims and were not subject to recall bias. This research included the 2-part regression methodology that has been shown previously to effectively account for nonnormal distributions of outcome variables.21,22

**Limitations**

As with all research, this analysis is limited mainly by the retrospective claims data design. The coding for epilepsy or partial-onset seizures was not verifiable, given the absence of clinical diagnostic variables in claims. Furthermore, patients with seizure activity that was coded other than with ICD-9 codes 345.4x or 345.5x or those who did not seek medical care were excluded. Given the absence of disease severity, level of seizure control, and other relevant clinical diagnostic information within administrative claims, it is possible that these variables play a role in caregiver burden.

In addition, the identification of caregiver-patient pairs depended on marital status identifiers. Cohabitation of the pairs could not be confirmed, and the patients might have received care from persons other than their spouse. Therefore, the impact on the caregiver might have been underestimated. Nevertheless, the cost differences between the cohorts were high after adjusting for potential confounders, which indicates a potentially strong association between patients’ disease severity and caregivers’ costs and burden.

Furthermore, patients in the adjunctive therapy group might have had additional AEDs added to their regimen during the 12-month follow-up period. Neither the number of drugs nor the addition of drugs to patients in the adjunctive therapy cohort was evaluated in the analysis; both situations would potentially imply an increased need for care and time, which can impose a greater burden on their caregivers.

Finally, the study population may not be representative of the real-world experience of caregivers of patients with partial-onset seizures across the entire socioeconomic spectrum, because caregivers in this study received health benefits and have compensation levels that are associated with moderate or higher socioeconomic status groups, whereas epilepsy is more prevalent among lower socioeconomic status groups.23,24 Future research should evaluate epilepsy patient caregiver burden in a wider range of socioeconomic statuses.

**Conclusion**

The present analysis found that caregivers of patients with partial-onset seizures who received adjunctive therapy had approximately twice the direct healthcare costs of, and used more sick days than, caregivers of patients who received monotherapy. Although the prevalence of partial-onset seizures is low, research with representatively large cohorts would be important to understand the relationship among the specific attributes of AED treatment burden that adversely affect caregiver burden. In addition, individual employer plans vary widely in benefit design and as such, there may be differences based on employer plans, as well as between industry sectors, that may have an additive impact on the magnitude of caregiver burden. Therefore, the caregiver burden in different employer sectors and among the unemployed data in a real-world setting should be studied further.

Adding concerns about the health of the caregiver to the existing family burden may have a further impact on the caregiver and the family. Understanding the types of preventive services that could lead to proactive care for the caregiver may improve preventive services and caregiver outcomes and reduce the overall healthcare costs.

Future studies should include an evaluation of the impact of programs such as counseling, diet, and exercise, on the healthcare needs of the caregiver. Such evidence may guide the development of potential self-management strategies for patients that would mitigate the overall burden on caregivers of patients with partial-onset seizures.

**Acknowledgments**

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**Author Disclosure Statement**

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**References**

The Importance of Clinical and Economic Support Systems for Caregivers

By Michael Kleinrock
Research Director, IQVIA Institute for Human Data Science
Plymouth Meeting, PA

The economic and social impacts of any disease are an important consideration to payers, providers, patients, employers, and researchers. These impacts are very difficult to measure empirically, especially to gain consensus on the appropriate measurement of the economic effects of a disease on a population. Even more obscure are the issues regarding building consensus on the secondary effects of a disease on the family or the caregivers of a patient.

RESEARCHERS: The article by Brook and colleagues uses a relatively rare kind of anonymous patient data that allow the linking of caregivers to the target patient and then to track the disease impacts and costs for both.1

As a healthcare researcher, I routinely find myself avoiding this kind of analysis, because it is qualitative rather than quantitative, and I have seen the reticence other stakeholders have in absorbing these types of findings. This reflects a general perception that the modeling of costs and benefits in that manner lacks the rigor of using a “real” database, and that would generally be true of most societal impact modeling.

In this article, however, the researchers have been able to bring forward database rigor as a result of the unique features of the source database, which is impressive and important. As the authors note, “This study assessed payroll, disability claims, and worker’s compensation claims data to objectively measure indirect costs and absence days, rather than inferring this information from medical claims data or surveys.”1

This kind of study is a helpful reminder of the limits of anonymous patient-level data, and of the value of...
what I'll call “anonymous family-level data.” The obvious privacy and data security concerns of linking patients to such data remain with any analysis. The potential for reidentification of anonymous patients could be elevated, but it is mitigated by how rare this type of data is. Overall, the study findings are helpful to understanding the challenges of being a caregiver, and the study is helpful as an analogue for other patient–caregiver situations.

The worries that some beneficiaries may have about being blocked from coverage as a result of preexisting conditions of a family member are moot, at least as long as the current US healthcare law (ie, the Affordable Care Act) remains in effect. Even with all these concerns in mind, healthcare data are still incredibly powerful as a tool to consider the broader impact of disease on a family unit, which is arguably how the effect of a loved one’s disease on caregiver burden develops and spreads, as suggested in this current article.

Payers/Providers: Payers and providers should read these findings with significant interest and should further adjust their practices to identify and mitigate the risks, such as healthcare cost and workplace absences, related to the caregivers themselves. One analogy for this is when on an airplane, one is asked to “affix your own mask before helping others.” Similarly, the caregivers in this study are likely distressed by the circumstances affecting their family member and, therefore, may not be taking care of themselves.

Whether this lack of self-care is an issue of prioritization, focus, or of a purely financial nature, the resultant worse outcomes that these caregivers have are costly and avoidable enough to be a focal area of interest for stakeholders. For healthcare providers and payers, understanding the kinds of preventive services, such as counseling or diet and exercise advice, which caregivers would benefit from could lead to proactive care programs for the caregiver that could improve healthcare outcomes and potentially reduce costs.

Patients/Caregivers: Overall, this study is a reminder that disease is behaviorally linked for the majority of our outcomes—having a family member undergoing trauma of any kind, including chronic disease, is in itself traumatic. One could imagine this type of study being applied to patients with cancer, particularly childhood cancer, or to diseases of the elderly, such as Alzheimer disease.

Caregivers for patients with the very serious condition of epilepsy discussed in this article, have poor health prognoses themselves. As this study suggests, the caregivers of patients with partial-onset seizures who are receiving adjunctive therapy (which by inference are those with the more severe kinds of seizures requiring the addition of another drug to their regimen) have worse health outcomes, and use more healthcare services too. It’s very difficult to get at the connection between a patient’s health status and their family’s health status, but the authors used an approach that can effectively achieve this.

The greater understanding of the environment around a patient with a difficult-to-manage disease, such as partial-onset seizures, as well as the prevention of adding the caregiver’s heart condition or other health issues to the existing family burden, are critical to improving the patient’s health status, as well as that of the caregiver. Exactly how caregivers can achieve better cardiovascular health is not an intractable issue. There are clear paths to achieving better health outcomes as suggested in the article, but these paths overall lack focus or funding in the current healthcare system.

If there is a lack of an appropriately trained home care nurse, and external caregiver costs would erode the economic health of the family, that could “trap” a caregiver in the home. It may be difficult for that caregiver to prioritize a visit to the gym or some other form of exercise when a family member’s life is in danger.

Ultimately, this study points to the need to find clinical and economic support systems for families that are in the greatest need, not simply for patients, but also for the caregivers who are burdened while helping their family member. One could imagine using the lessons from this study for the parents (as caregivers) of children with muscular dystrophy, cystic fibrosis, or other such rare diseases, which would likely involve similar issues and costs related to the health of the caregiver.