Prevalence and Economic Burden of Epilepsy in the Institutionalized Medicare Fee-for-Service Population

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BACKGROUND: Based on data from 2003 to 2007, the prevalence of epilepsy was significantly higher in the institutionalized elderly population than in the noninstitutionalized population, but the recent prevalence and economic impact of epilepsy specifically in the institutionalized Medicare population have not been reported.

OBJECTIVES: To estimate the prevalence and economic burden of epilepsy and inpatient utilization rates among institutionalized Medicare beneficiaries and to provide a 10-year projection of their population size and the associated costs.

METHODS: We performed a cross-sectional analysis of the institutionalized Medicare population with and without epilepsy using Medicare 5% sample claims data from 2013 and 2014. The identification of epilepsy required ≥1 qualifying claims with an epilepsy diagnosis, or ≥2 qualifying claims ≥30 days apart with a diagnosis of convulsion, in 2014. Institutionalized status was identified by having ≥6 consecutive months of nursing facility claims in 2013 or 2014. Inpatient admissions and 30-day readmissions, average allowed costs, and risk-adjusted incremental costs of epilepsy were calculated and compared between the institutionalized population of Medicare beneficiaries with and without epilepsy. The 2015 Medicare 100% and 5% sample data and inputs from other external sources were used to project the 10-year trends in the size and cost of the institutionalized Medicare population with epilepsy.

RESULTS: The prevalence of epilepsy in 2014 was 11.1% in the institutionalized Medicare population. The institutionalized population with epilepsy had significantly higher per-patient per-month (PPPM) costs ($3479 vs $2381, respectively; P < .001), inpatient admissions per 1000 beneficiaries (1105 vs 697, respectively; P < .001), and 30-day readmissions per 1000 beneficiaries (287 vs 145, respectively; P < .001) versus the institutionalized population without epilepsy. The risk-adjusted incremental cost of epilepsy for the institutionalized population was $507.33 PPPM. Based on our model, between 2017 and 2027 an 18% increase in size and a 72% increase in cost are projected for the institutionalized Medicare beneficiaries with epilepsy.

CONCLUSION: The high cost and inpatient resource utilization, as well as the projected growth of the institutionalized Medicare population with epilepsy highlight the need for further investigation of care management opportunities to reduce the cost burden associated with this condition.

KEY WORDS: epilepsy, healthcare utilization, inpatient admissions, institutionalized elderly population, Medicare fee for service

Epilepsy is a debilitating neurologic disease characterized by recurrent seizures that affects approximately 1.2% of the US population, or approximately 3.4 million people. The incidence rates of epilepsy are high in infancy and are even higher in the elderly, exhibiting a U-shaped incidence curve. The incidence of epilepsy rises rapidly for individuals aged ≥60 years with the incidence double that of individuals aged 40 to 59 years. Almost 50% of incident epilepsy in the population aged ≥60 years is caused by cerebrovascular disease, particularly stroke. Other frequently cited causes of epilepsy among the elderly include brain tumors, head trauma, and dementia or Alzheimer’s disease.

Evidence from previous studies suggests that the economic burden of epilepsy among the elderly imposes a large toll on society. The average annual direct cost per elderly patient with epilepsy has been estimated to be...
KEY POINTS

- The prevalence of epilepsy increases with age; the prevalence rate of epilepsy and its economic impact for institutionalized Medicare beneficiaries have not been reported.
- This cross-sectional analysis of the institutionalized Medicare population with and without epilepsy was conducted using Medicare 5% sample claims data from 2013 and 2014.
- The institutionalized Medicare population with epilepsy had higher PPPM costs than the institutionalized population without epilepsy ($3479 vs $2381).
- Institutionalized beneficiaries with epilepsy also had higher rates of inpatient admissions than those without epilepsy and 30-day readmissions.
- The results of this study project an 18% increase in the number of institutionalized Medicare beneficiaries with epilepsy and an associated cost increase of 72% by 2027.
- Understanding the cost burden of epilepsy in the institutionalized Medicare population is vital to healthcare services planning and practice patterns and to ensuring care quality.
- Efficient management of institutionalized Medicare beneficiaries with epilepsy is also needed to manage the economic burden to Medicare.

between $10,612 (2000 $US) and $17,390 (2009 $US), with physician office and ancillary care visits, hospitalizations, and prescriptions as the main cost drivers.

Epilepsy among the elderly residential nursing-home population (ie, the institutionalized population) is more than 7 times more prevalent than in the community-dwelling (ie, “noninstitutionalized”) elderly population. The majority of the institutionalized population is elderly (approximately 85% are aged >65 years), and the total expenditure for the institutionalized elderly in the United States was an estimated $134 billion in 2011, with approximately 28% attributed to Medicare beneficiaries. Of Medicare beneficiaries aged ≥65 years, 2.7% are institutionalized.

Despite the high prevalence of epilepsy among the institutionalized elderly population and the large burden of the institutionalized elderly Medicare population, little is known about the prevalence and cost of epilepsy among the institutionalized Medicare population. Studies on the costs of epilepsy have largely focused on the noninstitutionalized elderly and nonelderly populations that are commercially insured or have Medicaid and Medicare dual coverage and, therefore, are not generalizable to the institutionalized Medicare population.

To date, there are few published reports that project the growing economic burden among patients with epilepsy. The population aged >65 years is projected to increase from 46 million in 2015 to more than 98 million by 2060. Similarly, the total US institutionalized population is also projected to grow; in 2013 approximately 1.4 million individuals were institutionalized in the United States, and that number is estimated to be 2.3 million by 2030. Considering the projected growth in the elderly US population and in the institutionalized population, the population with epilepsy and the institutionalized population with epilepsy will also increase. Understanding the current and future healthcare cost burden of the institutionalized population with epilepsy within the growing elderly population is vital to informing resource and healthcare service planning and practice patterns while ensuring healthcare quality for this population.

The goals of this study were to estimate the prevalence of epilepsy among institutionalized Medicare beneficiaries and compare inpatient utilization rates and the economic burden between institutionalized Medicare beneficiaries with and without epilepsy using data from 2013 and 2014, and to estimate the future prevalence of epilepsy and the associated costs for the institutionalized population.

Methods

We used a cross-sectional design to estimate the current prevalence rates of epilepsy among institutionalized Medicare beneficiaries and to compare the inpatient utilization rates and economic burden between institutionalized Medicare beneficiaries with and without epilepsy. We also sought to develop a projection forecast model using these prevalence, inpatient utilization, and burden estimates of epilepsy to determine the 10-year prevalence and cost trends of epilepsy in the institutionalized Medicare population.

I. Cross-Sectional Analysis

Data source. The data for analysis were from the 2013 and 2014 Medicare Limited Data Set database 5% sample, which contained all Medicare fee-for-service (FFS) Part A and Part B paid claims from a statistically balanced 5% sample of the total Medicare population. In addition to diagnosis codes, procedure codes, site-of-service codes, and diagnosis-related groups (DRGs), these data included dollar amounts paid by Medicare and beneficiary cost-sharing. The data used in this study did not include Part D prescription drug claims.

Study population identification. The data analysis was performed using 2014 as the index year, which was the most recently available data at the time of the anal-
Epilepsy in the Institutionalized Medicare Population

Figure 1  Medicare Population with Epilepsy Sample Selection

Total Medicare 5% sample
2.4 million beneficiaries

Study sample size: 1,435,275 beneficiaries
- ≥1 months of eligibility in 2014 (index year) and 12 months of eligibility in 2013
- Parts A and B eligibility in all eligible months, no HMO enrollment

Noninstitutionalized population: 1,395,453
(97.2% of total Medicare population)

Institutionalized population: 39,822
(2.8% of total Medicare population)

Noninstitutionalized epilepsy population: 33,017
(2.4% prevalence in noninstitutionalized population)

Institutionalized epilepsy population: 4,401
(11.1% prevalence in institutionalized population)

Total epilepsy population: 37,418
(2.6% of total Medicare population)

HMO indicates health maintenance organization.

ysis. Regardless of age, eligible Medicare beneficiaries for this analysis met the following criteria: having 12 months of Parts A and B coverage in 2013 (ie, the baseline year); at least 1 month of coverage in 2014 with Parts A and B eligibility; and no health maintenance organization enrollment in any of the months of eligibility. Using the Medicare eligibility file, each beneficiary’s Medicare eligibility status was identified as either disabled, end-stage renal disease, aged dual-eligible (ie, receiving Medicare and Medicaid), or aged non–dual-eligible. From the sample of all these beneficiaries, the institutionalized beneficiaries were identified by the presence of ≥6 consecutive months of nursing facility or professional claims with a place of service of nursing facility. The eligibility file that accompanies the Medicare 5% sample data did not provide an indicator for institutional status. The requirement of ≥6 consecutive months of nursing-facility place of service claims was used as a proxy for institutional status.

Among the institutionalized Medicare 5% sample population, the identification of epilepsy required ≥1 qualifying claims with an International Classification of Diseases, Ninth Edition (ICD-9) diagnosis of epilepsy (ICD-9 codes 345.00-345.51, 345.70-345.91) in any position, or ≥2 qualifying claims at least 30 days apart with a diagnosis of convulsion (ICD-9 codes 780.33 or 780.39) in any position of the claim, during calendar year 2014 (ie, the index year). The qualifying claims included facility and professional claims that represented in-person encounters with a medical professional. All other institutionalized Medicare beneficiaries were designated as the population without epilepsy. (A matched population methodology was not used, because this study was designed to be a descriptive analysis of the cost and utilization of institutionalized Medicare beneficiaries with and without epilepsy.)

Study Measures
The prevalence of epilepsy during calendar year 2014 was identified in the total Medicare and institutionalized populations, and the 2 groups were compared. Patient demographics (including age, sex, and Medicare eligibility status), annual all-cause mortality rate, and prevalence of epilepsy-associated conditions were summarized and compared for the Medicare institutionalized populations with and without epilepsy using claims from 2014.

The Centers for Medicare & Medicaid Services (CMS) hierarchical condition categories (CMS-HCC)
Table Characteristics of the Institutionalized Medicare Study Population

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Institutionalized population with epilepsy (N = 4401)</th>
<th>Institutionalized population without epilepsy (N = 35,421)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average age, yrs</td>
<td>70</td>
<td>81</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Female, %</td>
<td>53.5</td>
<td>70.0</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Average CMS-HCC score</td>
<td>2.83</td>
<td>2.27</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Annual all-cause mortality rate, %</td>
<td>14.3</td>
<td>20.3</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Eligibility status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aged dual-eligibility, %</td>
<td>43.4</td>
<td>49.7</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Aged non-dual-eligibility, %</td>
<td>21.5</td>
<td>40.3</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Disabled, %</td>
<td>32.4</td>
<td>8.1</td>
<td></td>
</tr>
<tr>
<td>End-stage renal disease, %</td>
<td>2.7</td>
<td>1.9</td>
<td>.001</td>
</tr>
<tr>
<td>Selected comorbidities</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Schizophrenia, bipolar disorder, or major depressive disorder, %</td>
<td>34.9</td>
<td>24.6</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Cognitive impairment, %</td>
<td>65.6</td>
<td>72.2</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Hyponatremia, %</td>
<td>18.7</td>
<td>13.7</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Parkinson’s disease, %</td>
<td>9.0</td>
<td>9.0</td>
<td>.871</td>
</tr>
<tr>
<td>Cerebrovascular disease, %</td>
<td>50.9</td>
<td>34.7</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Having &gt;1 annual convulsion claim, %</td>
<td>68.6</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

CMS-HCC indicates Centers for Medicare & Medicaid Services hierarchical condition categories.  
Source: Milliman analysis of 2013-2014 Medicare 5% sample.

risk scores were calculated using the 2013 baseline-year data that project the costs from 2014 based on each beneficiary’s demographics, Medicare eligibility status, and comorbidities. CMS uses the CMS-HCC scores to adjust the Medicare Advantage premium rates to account for differences in the risk profile of each Medicare Advantage member and the expected differences in costs.

Epilepsy-associated conditions were identified based on ≥1 qualifying claims with any of the following ICD-9 diagnosis codes in any position of the claim, or an inpatient claim with any of the following DRGs: schizophrenia (ICD-9 codes 295.00-295.95), bipolar disorder (ICD-9 codes 296.00-296.16, 296.40-296.89), major depressive disorder (ICD-9 codes 296.20-296.36), cognitive impairment (ICD-9 codes 290.0-290.9, 291.1, 291.2, 292.82, 294.10-294.21, 310.89, 331.0, 331.11-331.19, 331.2, 331.5, 331.6, 331.82, 331.83, 438.0), hyponatremia (ICD-9 code 276.1), Parkinson’s disease (ICD-9 code 332.0), or cerebrovascular disease (DRG codes 061-069; ICD-9 codes 430, 431, 432.0-435.9, 436, 437.0-438.9).

The utilization of inpatient care was measured as annual inpatient admissions per 1000 beneficiaries and the all-cause 30-day readmissions per 1000 beneficiaries. The costs reflected the allowed amounts paid to providers and included Medicare payments and patient cost-sharing. The claims were grouped into major health service categories using the Milliman Health Cost Guidelines group, which is a proprietary coding algorithm that includes Current Procedural Terminology codes, ICD-9-Clinical Modifications diagnosis and procedure codes, revenue codes, site of service codes, and DRG codes. These categories reflect the major cost drivers and include inpatient facility, skilled-nursing facility, outpatient facility, professional (ie, provider) fees, and other costs (ie, costs for home health or hospice, durable medical equipment, ambulance, and prosthetics). Overall, these costs were reported as per-patient per-month (PPPM) amounts, which represented costs for the respective samples, divided by their total number of eligible member months.

Data Analysis

We performed descriptive analyses for the patient demographic characteristics, annual admission and readmission rates, and the costs for the institutionalized beneficiaries with and without epilepsy. The demographics, costs, and healthcare resource utilization measures were tabulated as means and percentages. t-tests were used to measure the statistical significance of differences between the institutionalized populations with and without epilepsy. The incremental cost of epilepsy was calculated using CMS-HCC risk scoring to compare the average beneficiary costs on a risk-adjusted basis at the population level between institutionalized groups with and without epilepsy. This analysis used SAS version 9.3 (SAS Institute, Inc; Cary, NC) and Microsoft Excel.

II. Projection Model

Data sources. Inputs for the projection model were based on Medicare claims data and outcomes from the cross-sectional analysis described above. Membership inputs, including institutionalization and epilepsy prevalence, were identified in the 2015 Medicare 5% sample. Part A and B costs were identified in the 2014 Medicare 5% sample and were extrapolated to match the 2015 total Medicare costs reported in the 2016 Annual Report of the Boards of Trustees of the Federal Hospital Insurance and Federal Supplementary Medical Insurance Trust Funds.

To establish the total Medicare FFS starting population by age and sex, we used the 2015 Medicare 100% sample, which includes all Medicare FFS Parts A and B paid claims (excluding professional claims) from the total Medicare population. The population size projections were based on inputs from the US Census National Population Projections and the US Social Security Life Tables, which include mortality rates by demographics. The 2016 Annual Report of the Boards of Trustees was used to source the short-term and long-term projections of Medicare enrollment and the cost trend factors.

Study measures. The primary study measures for this
analysis were the projected size and cost from 2017 to 2027 of the institutionalized population with epilepsy.

Forecast model analysis. Using the demographic, prevalence, cost, and mortality information from the cross-sectional Medicare claims analysis, the size and total Medicare spending of the population with epilepsy were extrapolated to the total Medicare population reported in the 2016 Annual Report of the Boards of Trustees. We applied a deterministic modeling approach, age- and sex-specific population trends from the Census Bureau’s national population projections, and annual cost trends from the 2016 report to estimate the size and cost from 2017 to 2027 of the institutionalized population with epilepsy.

Results

Cross-Sectional Analysis

Of the 2.4 million Medicare beneficiaries in the 2014 Medicare 5% sample, 1,435,275 beneficiaries met the study inclusion criteria; of these beneficiaries, 37,418 were identified as having epilepsy, yielding a prevalence of 2.6% (Figure 1). This population comprises all Medicare eligibility categories, including the disabled population aged <65 years. For the Medicare population aged ≥65 years, 1,190,331 beneficiaries met the study inclusion criteria, and 19,705 of them were identified as having epilepsy. This yields an epilepsy prevalence rate of 1.66% only for the Medicare beneficiary population aged >65 years.

Of all the Medicare beneficiaries who met the study inclusion criteria, 39,822 (2.8%) members were institutionalized. The prevalence of epilepsy was higher in the institutionalized population than in the noninstitutionalized population (11.1% vs 2.4%, respectively; \( P < .001 \)). Among the institutionalized population aged ≥65 years, the prevalence of epilepsy was 8.15%.

The patients’ demographic and comorbidity characteristics varied significantly between the institutionalized populations with and without epilepsy (Table). The mean age of the institutionalized population with epilepsy was 70 years and the mortality rate was 14.3% versus a mean age of 81 years and a mortality rate of 20.3% in the institutionalized population without epilepsy (\( P < .001 \) for both). Of the institutionalized population, 32.4% of those with epilepsy had disabled status versus 8.1% of those without epilepsy (\( P < .001 \)). Furthermore, the institutionalized population with epilepsy had an average CMS-HCC risk score of 2.83 versus 2.27 in the institutionalized population without epilepsy (\( P < .001 \)). A higher proportion of the institutionalized population with epilepsy had mental disorders, hypotension, and cerebrovascular disease than the institutionalized population without epilepsy (\( P < .001 \) for all).

The total inpatient admission rates were significantly higher in the institutionalized population with epilepsy than in the institutionalized population without epilepsy (1105 per 1000 beneficiaries vs 697 per 1000 beneficia-
Epilepsy is a prevalent condition in the elderly population, particularly among patients who are institutionalized. The present analysis used the 2014 Medicare 5% sample to determine a 2.6% prevalence rate of epilepsy in the Medicare FFS population across all Medicare eligibility categories, including the disabled population aged <65 years. The epilepsy prevalence rate for beneficiaries aged ≥65 years was 1.66%, which was higher than the rates of 1.08% to 1.5% that were reported in a previous study based on Medicare 5% sample claims data between 2001 and 2005.

The current analysis further identified an 11.1% prevalence rate for epilepsy in the institutionalized Medicare population across all Medicare eligibility categories, including the disabled population aged <65 years. The epilepsy prevalence rate for the institutionalized population aged ≥65 years was 8.15%. This compares closely with the 7.7% epilepsy prevalence rate reported in the study by Birnbaum and colleagues that was based on data from 2003 to 2007.

The projected 10-year growth in the institutionalized Medicare population with epilepsy is presented in Figure 4. Between 2017 and 2027, the number of institutionalized beneficiaries with epilepsy is projected to grow by 18% from approximately 168,500 beneficiaries in 2017 to 198,500 beneficiaries in 2027. Furthermore, the total annual cost of the institutionalized population with epilepsy is projected to increase from an estimated $6.82 billion in 2017 to $11.75 billion in 2027, for a 72% increase in the total costs (data not shown in Figure 4).

### Discussion

Epilepsy was risk adjusted to match that of the institutionalized population with epilepsy, which yielded a risk-adjusted PPPM of $2972 for the institutionalized population without epilepsy.

### Projection model

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the institutionalized population with epilepsy, Medicare healthcare costs are substantially higher than for the institutionalized population without epilepsy—$41,749 versus $28,569 average annual allowed costs per beneficiary. This is partly driven by the higher hospital admission rates and 30-day readmission rates among the institutionalized population with epilepsy compared with the institutionalized population without epilepsy.

This analysis also identified a higher prevalence of mental illness in the institutionalized population with epilepsy than in the institutionalized population without epilepsy (34.9% vs 24.6%, respectively). The treatment for mental illness typically requires more care resources in the institutional setting, which may contribute to the total cost burden of the institutionalized population with epilepsy.

A Medicare report to Congress estimated that approximately 20% of the US population, or 67 million individuals, will be aged ≥65 years by 2030. With this increase in the elderly population, the number of elderly individuals who have epilepsy will also increase, and an increase in the number of elderly patients in an institutional setting is expected as well. Our study projected the size of the institutionalized Medicare population with epilepsy to grow by 18% from 2017 to 2027 and the cost of the institutionalized Medicare population with epilepsy to increase from an estimated $6.82 billion in 2017 to $11.75 billion in 2027, for a 72% increase in total costs.

With a growing focus on the institutionalized population as a significant cost driver for Medicare and state Medicaid budgets, understanding the growth trends in the prevalence rates of high-cost subpopulations with chronic conditions, such as epilepsy, among the institutionalized population may be of interest to CMS to plan for effective treatments and the management of resources.

Limitations

Our analysis has several limitations. This is a descriptive analysis comparing annual healthcare resource utilization and costs of institutionalized beneficiaries with and without epilepsy. Thus, the study results may be subject to confounding effects that are not accounted for in this comparison. We chose not to create a matched cohort of controls without epilepsy to provide the results among the population without epilepsy that were representative of the actual Medicare population. To calculate the incremental cost associated with epilepsy in the institutionalized population, this analysis used CMS-HCC risk adjustment to adjust for differences in demographics and other comorbidities that might explain the variation in cost. It is plausible that other factors that are not accounted for with this risk adjuster may influence an individual’s healthcare costs and utilization, such as differences in regional practice patterns, the severity level of comorbidities that are not specified by ICD-9 codes, and socioeconomic factors.

Claims coding is subject to bias and inconsistencies that may not reflect the actual medical experience of the beneficiaries included in this analysis. This is related to possible variation in the comprehensiveness of providers’ coding on insurance claims, which may underreport the existence of some conditions. It is also possible that patients with epilepsy might not have had significant interaction with the healthcare system during the year, in which case these patients would not be identified as having epilepsy in this analysis, resulting in underestimation of the prevalence rates. In addition, the identification of beneficiaries who are considered institutionalized is based on a proprietary claims-based algorithm that has not been validated by an external source and could result in the over- or underidentification of institutionalized Medicare beneficiaries.

The anticipated growth trends in the prevalence and costs of the institutionalized population with epilepsy are estimated based on sourced assumptions, and it is
plausible that actual future experience may differ from these estimates.

Because the Medicare 5% sample data do not include Part D costs, the analysis did not include the costs of prescription drugs that were incurred by the institutionalized population with epilepsy versus the institutionalized population without epilepsy. The difference in prescription drug costs between these 2 populations could increase or decrease the difference in the total cost of care when comparing these populations.

Notwithstanding the limitations described above, this analysis is the first of its kind to estimate the prevalence, inpatient use of healthcare resources, and economic cost of epilepsy specifically in institutionalized patients with Medicare coverage. Because the population of institutionalized patients with epilepsy is expected to grow rapidly, the 10-year projection is especially important for understanding the economic burden of these changes.

**Conclusion**

Epilepsy drives healthcare resource utilization and cost specifically among Medicare beneficiaries. This analysis demonstrates that for the institutionalized population with Medicare, the prevalence of epilepsy is higher than previously reported, and the cost of healthcare is significantly higher among the institutionalized population with epilepsy compared with the institutionalized population without epilepsy.

The growing elderly population that is entering Medicare eligibility in the coming years will increase the institutionalized population with epilepsy. The higher costs and inpatient resource utilization of institutionalized Medicare beneficiaries with epilepsy relative to the institutionalized beneficiaries without epilepsy, coupled with the projected increase in the size and cost of this population in the coming decade, highlight the need for closer examination of opportunities for the efficient management of this population to control the cost burden to Medicare.

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**Author Disclosure Statement**

Ms Fitch, Ms Lau, and Mr Engel are consultants to Sunovion; Dr Pan was an employee of Sunovion during the study; and Dr Rajagopalan is an employee of Sunovion.

**References**


