



Impact of insurance status on access to care and out-of-pocket costs for U.S. individuals with epilepsy

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ARTICLE INFO

Article history:

Received 14 May 2011

Revised 12 July 2011

Accepted 15 July 2011

Available online 3 September 2011

Keywords:

Delivery of health care

Health care disparities

Health services accessibility

Medically uninsured

Health care surveys

ABSTRACT

We analyzed data from the 2002–2007 Medical Expenditure Panel Survey (MEPS) to assess whether individuals with epilepsy who are uninsured and those who have Medicaid coverage experience differences in medical resource utilization or out-of-pocket costs compared with those having other types of insurance. With sociodemographic characteristics controlled for, uninsured individuals had significantly fewer outpatient visits, fewer visits with neurologists, and greater antiepileptic drug costs than did those with private insurance. Individuals with Medicaid coverage had similar medical resource utilization rates but lower out-of-pocket costs compared with privately insured individuals. These findings indicate substantial barriers to receipt of appropriate medical care for uninsured individuals with epilepsy, but not for those with Medicaid coverage. Future studies should evaluate whether ongoing changes to the US health care system are able to address the differences in care we found among uninsured individuals with epilepsy and should incorporate measures of disease severity and unmet need.

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1. Introduction

Epilepsy is a chronic neurological condition affecting almost 3 million individuals in the United States. It is estimated that by age 75, three percent of individuals in the United States will have been diagnosed with epilepsy [1,2]. Epilepsy can result in substantial health, quality-of-life, and economic burdens. Begley et al. [3] reported a lifetime per-person cost of epilepsy in 1995 dollars in the United States of more than \$61,000, with a majority attributable to indirect costs. Costs for individuals with refractory epilepsy may be substantially greater [4]. However, a majority of individuals diagnosed with epilepsy can have their seizures eliminated or made rare with appropriate treatment.

Individuals with epilepsy report that access to appropriate medical care services, including health care providers knowledgeable in the management of epilepsy, is crucial for living optimally with epilepsy [5]. Unfortunately, individuals with epilepsy may experience barriers in access to medical care because they are uninsured or underinsured (i.e., covered by health insurance that does not provide all needed services or involves out-of-pocket costs beyond a patient's ability to pay). In the United States, 15.3% of the population were uninsured in 2007 and 13.2% were covered by Medicaid. Among individuals aged

18–64, almost 20% were uninsured [6]. A survey conducted by the Epilepsy Foundation in the 1990s reported that 18% of responding individuals with epilepsy did not have health insurance that covered epilepsy [7]. Of the insured population, 18% were covered by Medicaid. More recently, the 2003 California Health Interview Survey found that 9.8% of individuals with active epilepsy did not have health insurance at the time of the study, and an additional 4.4% had been uninsured at some time in the prior 12 months [8]. In addition, more than half of all surveyed individuals younger than age 65 with active epilepsy reported having Medicaid insurance.

To our knowledge, no recent national information is available on the proportion of individuals with epilepsy who are uninsured or covered by Medicaid programs. However, individuals with epilepsy are more likely to belong to groups that are disproportionately uninsured or underinsured. Individuals with epilepsy have lower household incomes, have fewer years of education, and are less likely to be employed compared with US averages [9]. Among adults with active epilepsy in 19 states, 9.8% were unemployed and 31.3% were unable to work, compared with 5.4 and 4.9%, respectively, of individuals without a history of epilepsy [10]. This suggests that a smaller proportion of individuals with epilepsy receive employer-provided insurance.

There is only limited information on the impact of insurance status and being uninsured on access to care, medical care treatment patterns, and outcomes among individuals with epilepsy. Begley et al. [11] examined rates of medical care resource utilization by insurance status using survey data collected from individuals with epilepsy at

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two treatment sites in Houston and two in New York City. Controlling for clinical characteristics (seizure frequency and other chronic conditions), age, and sex, these researchers found that uninsured individuals were significantly more likely to experience generalist physician visits and emergency department visits than were those with private insurance, but were significantly less likely to have specialist visits. Individuals with Medicaid coverage were also significantly less likely to experience specialist visits. Differences in specialist visits by insurance status remained significant in regression, also controlling for treatment site. A few studies have examined the association between insurance status and receipt of epilepsy surgery, a particularly expensive treatment procedure, finding that adults with temporal lobe epilepsy who had private health insurance were more likely to undergo anterior temporal lobectomy than were those without private insurance [12]. Similarly, children with intractable temporal lobe epilepsy with private insurance were more likely to receive surgical treatment [13].

Literature from other clinical areas suggests that uninsured individuals with epilepsy are likely to experience barriers in access to appropriate medical care. In general, specialist physicians are less likely to see uninsured patients and those covered by Medicaid, and these patients experience longer delays to be seen even when they are offered appointments [14,15]. Among individuals with another neurological condition, multiple sclerosis (MS), those who are uninsured are less likely to receive care from a neurologist [16] and less likely to receive disease-modifying drugs [17]. Approximately one-third of patients with MS in a Medicaid-managed care plan reported never having seen an MS specialist; a similar proportion was not receiving immunomodulatory therapy [18].

To assess whether individuals with epilepsy who are uninsured and those who have Medicaid coverage are less likely to see neurologists, be prescribed newer antiepileptic drugs (AEDs), experience other differences in medical care resource utilization, or have greater out-of-pocket costs, we analyzed data from the Medical Expenditure Panel Survey (MEPS). This national survey collects detailed information on sociodemographic characteristics, insurance status, receipt of medical care, and out-of-pocket expenses for a representative sample of US residents. The MEPS has been used in a broad range of studies assessing treatment patterns and costs, including a recent evaluation of excess medical expenditures among individuals with epilepsy [19].

2. Methods

2.1. Data source

Data for this study were obtained from the household component of the 2002–2007 MEPS. The MEPS uses the National Health Interview Survey (NHIS) conducted by the National Center for Health Statistics as its sampling frame, which provides a nationally representative sample of the US civilian non-institutionalized population and reflects an oversampling of blacks and Hispanics. Data are collected at person and household levels in a series of five in-person interviews over the course of a 2.5-year period. All data for a household are reported by a single household respondent [20]. Respondent sociodemographic information is collected in the MEPS using the same approach as employed in the NHIS.

The 2002–2007 Medical Expenditure Panel Survey contains detailed information on demographics, expenditures, health status, and medical care utilization. Files used in this analysis were the hospital stay, medical provider visit, outpatient department, emergency room, and prescribed medicines files of the household component event files. The full-year-data consolidated file was also used for each study year to link each individual's sociodemographic characteristics and insurance with the medical care utilization data. A validation study comparing MEPS estimates of separately billed

doctor expenses for Medicare enrollees with corresponding costs from Centers for Medicare & Medicaid Services (CMS) claims data found that MEPS estimates were similar to those from CMS claims (MEPS estimates were 2–5% lower), and concluded that the MEPS provides accurate information for these expenses [21].

2.2. Study population

In the MEPS, individuals with epilepsy were self-identified in household interviews. During the interviews, a medical condition roster is created for each member of the household based on responses to questions about health problems, conditions associated with medical events or prescribed medicines, and reasons for bed, disability, and work loss days. Interviewers prompted respondents to provide information on conditions rather than symptoms [22]. Responses were recorded verbatim and then coded by professional coders to fully specified ICD-9-CM codes; error rates did not exceed 2.5% for any coder [23].

With telephone interviews with a subset of the hospitals and physician offices specified as sites of care by MEPS respondents as a “gold standard,” approximately 79% of individuals accurately identified themselves as having epilepsy [22]. For this study, individuals with epilepsy were identified (based on self-reports of this condition) using the ICD-9 diagnosis code 345; fourth and fifth digits of ICD-9 diagnosis codes are not included in the MEPS, so we were unable to classify individuals on the basis of whether or not their epilepsy is categorized as intractable. Further, the MEPS did not include any variables that directly corresponded to severity of epilepsy (e.g., seizure type/frequency or lack of seizure control). Respondents who reported experiencing seizures or convulsions (ICD-9 diagnosis code 780.03), but not epilepsy, were coded separately in the MEPS and are not included in this study. To help validate the self-reported diagnosis of epilepsy, we determine the proportion of individuals in the study population who had at least one prescription for an AED; this ranged from 87.5% for uninsured individuals to 98.8% for those covered by Medicare (data not shown).

Individuals with epilepsy were classified into one of five mutually exclusive insurance status categories: private insurance; Medicare among individuals younger than age 65; Medicare among those 65 or older; Medicaid/other public insurance; or uninsured. As Medicare patients younger than age 65 are covered by this insurance program generally because of permanent disability and may be significantly different from those Medicare patients aged 65 or older, separate categories were created for these two groups. Individuals were classified based on the type of insurance they had for at least 8 months in a calendar year; those with a single type of insurance for less than 8 months in a year were excluded from the study.

The initial study population consisted of 574 persons over the 6 years of data (i.e., 574 person-years). Forty-eight of these individuals (8.4%) were excluded for not having one type of insurance for 8 months of a year, resulting in a sample population of 526 person-years. Using the national weights provided by the Agency for Healthcare Research and Quality (AHRQ) for analysis of multiple years of MEPS data, this corresponded to 4,157,950 person-years: 2,233,031 with private insurance; 445,316 with Medicare aged younger than 65; 330,141 with Medicare aged 65 or older; 736,597 with Medicaid; and 412,689 uninsured.

2.3. Analysis

National estimates of medical resource utilization and patient costs for individuals with epilepsy were determined using the final patient weights provided with the MEPS household component files. To provide more stable estimates from the small number of individuals with epilepsy included in the survey each year, data were combined for the most recent 6 years of available data at the

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