EVALUATING THE HEALTH AND ECONOMIC BURDEN OF NEUROCYSTICERCOSIS USING OREGON'S ALL PAYER ALL CLAIMS DATABASE, 2010-2013

By

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ABSTRACT

Background: Neurocysticercosis, or infection of the brain by larvae of the pig tapeworm, *Taenia solium*, has been reported in the literature with increased frequency during the past 3 decades in the United States. Population-based assessments of NCC are based on hospital discharge data, but do not include the outpatient population of NCC. I provide a population-based perspective of the complete spectrum of care of neurocysticercosis in the insured population of Oregon using the Oregon All Payers All Claims (APAC). I describe the demographic characteristics, frequency of neurocysticercosis-associated diagnoses and procedures, and disease burden of people with neurocysticercosis, and evaluate the APAC database as a source of demographic and financial information about NCC in Oregon.

Methods: A list of unique individuals with at least one paid or capitated neurocysticercosis claim during the study period was generated and all claims for these individuals were extracted from the APAC database. Demographic characteristics, associated diagnoses and procedures and pay information were described in the study population. Truncated negative binomial regression was used to characterize the association between claim counts per quarter and demographic and associated diagnosis variables.

Results: 125 individuals with NCC were identified during the study period with total paid claims of $2,407,532. Over 70% (5887/8224) of their paid and capitated claims did not have an associated neurological diagnosis. A total of 5925 claims, representing 72%

of all paid and capitated neurocysticercosis claims, were made in outpatient settings, while 10% of claims (818) were inpatient, and 337 (<5%) were generated in emergency departments. Half of all individuals with NCC had at least one claim during the study period with a diagnostic code of either mood or anxiety disorder. Univariate analysis of age indicated that among individuals with a neurocysticercosis claim history, for every 10 years of age the estimated mean number of claims per quarter increased by 1% (95% CI: 0-2% increase; p<001). Individuals with a claim history of syncope had 1.8 times as many claims per quarter compared to those without a history of syncope (95% CI: 1.17, 2.67; p=0.01).

Conclusions: Outpatient claims of people with NCC are considerable and the associated diagnoses are different than inpatient claims. Previous studies have underestimated the prevalence of mental illness and headache associated with neurocysticercosis. Greater effort should be made to provide neurocysticercosis education to mental health and primary care providers. The APAC database does not appear to provide reliable demographic or financial information for the assessment of the economic burden of NCC in Oregon.

CHAPTER 1—BACKGROUND ON NEUROCYSTICERCOSIS AND *TAENIA SOLIUM* INFECTION

Introduction

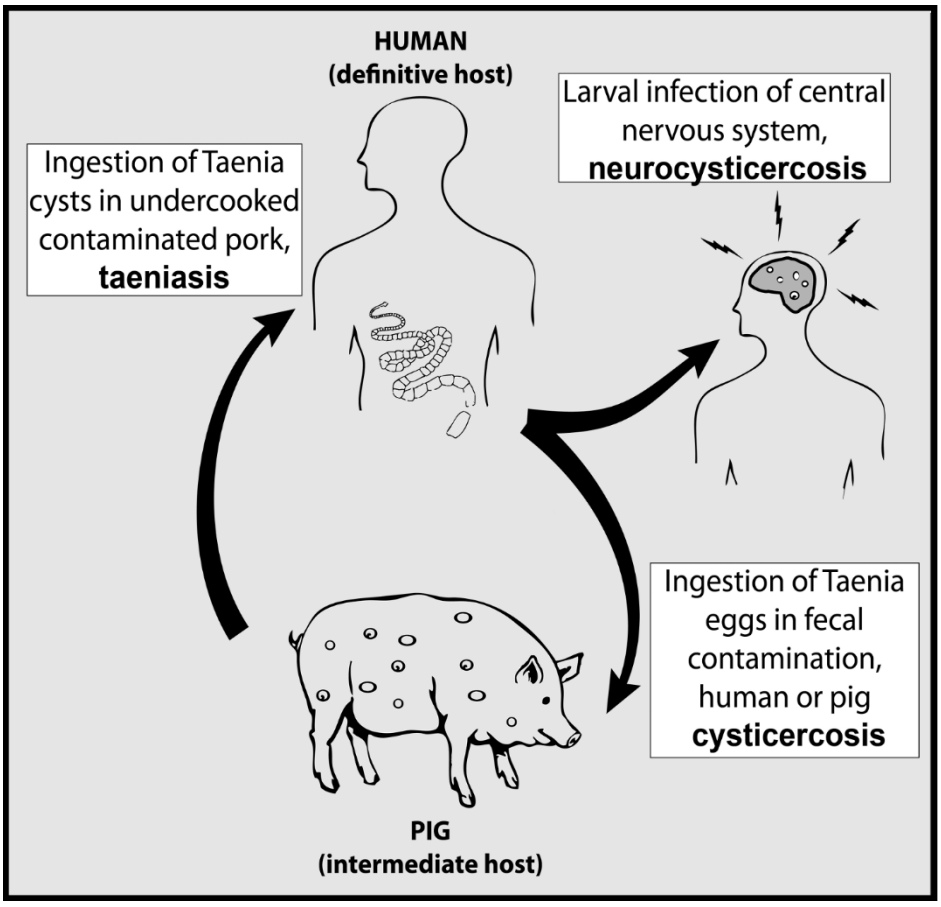
Neurocysticercosis (NCC), or brain infection by the larval form of the pig tapeworm, *Taenia solium*, causes an estimated 30% of all seizure disorders in Latin America, sub-Saharan Africa, and Southeast Asia where sanitation is poor and pigs have access to raw sewage. [1-3] The disease is estimated to affect 50 million people worldwide and is increasingly being identified in migrants and travelers from developing countries. [4-6] NCC is potentially preventable by interrupting the parasite lifecycle or impeding the fecal-oral route of transmission. Although theoretically amenable to control, it is also one of six neglected tropical diseases declared eradicable by the International Task Force for Disease Eradication in 1993. [7,8] NCC remains a neglected disease because of a lack of information about its burden and transmission.

Transmission

Humans are the definitive host of the parasite, harboring the adult intestinal tapeworm (taeniasis), which sheds tapeworm eggs in the host's feces. Pigs consume these eggs when foraging. Once ingested, the eggs develop into infective oncospheres, penetrate the gut wall, and disseminate throughout the body in the bloodstream. They commonly encyst in the larval form in muscle (cysticercosis). The lifecycle completes when people consume raw or undercooked meat infected with larval cysts. The larvae evaginate in the gut, the scolex attaches to the wall of the small intestine, and after 2 to 3 months an adult tapeworm develops capable of producing up to 50,000 eggs per day over a lifespan

lasting several years. [9,10] When humans ingest *T. solium* eggs passed from a person with a tapeworm, cysts can develop, infecting the brain, muscle, or other tissues. Neurocysticercosis occurs when cysts develop in the central nervous system (Figure 1).

Figure 1. Lifecycle of *Taenia solium*, the pork tapeworm



Clinical presentations of disease

The clinical presentation of NCC depends upon number, size, and location of larval cysts, as well as the host immune response. The most common signs among hospitalized patients with NCC include seizure/epilepsy, headache, mental disorders, cognitive

impairment, hydrocephalus, encephalitis/meningitis, stroke, and death.[11, 12] Some individuals with NCC have minimal inflammatory response and little or no symptoms of infection, while others develop obstructive hydrocephalus or cerebral edema requiring surgery or prolonged and expensive care. Parenchymal lesions are considered relatively benign and result most frequently in seizures, although some of these lesions can result in serious cerebral edema. Extraparenchymal forms of NCC are considered more serious causing obstruction of the ventricles, hydrocephalus, and intracranial hypertension. Without intervention, such as ventriculoperitoneal shunting, hydrocephalus can be lethal.

Disease burden in the US and in Oregon

NCC is estimated to affect 50 million people worldwide and is increasingly being identified in migrants and in travelers from developed countries. [4-6] It is also recognized as an important clinical and public health disease in the United States, although limited information about the prevalence and economic burden is available because no national surveillance system exists. Currently, only Arizona, California, New Mexico, Oregon, and Texas require reporting of NCC to state public health agencies, and even in those states, underreporting is a major concern.

In 1989, California was the first state to adopt administrative rules on reporting cysticercosis. In the first year, 112 cases of cysticercosis were recorded, representing a crude annual incidence of 0.02 per 100,000 overall population or 1.5 per 100,000 in Hispanics. [11] However, a 2009 study in California, reported that the number of hospitalized cases exceeded, by a factor of 10, the number reported to the California State

Health Department, illustrating the considerable underreporting of NCC [11,12] In 2002, Oregon adopted mandatory reporting of *T. solium* cases. However underreporting was severe with <10% of known cases reported by clinicians. During the first 5 years of implementation, only 7 NCC cases were reported. [13]

It is clear from population-based studies that NCC has considerable impact, particularly among the US Hispanic population, which maintains elevated risk through ongoing connection to regions where transmission is high. A study using Oregon hospital discharge data from 1995-2000 found an incidence of neurocysticercosis among the Hispanic population in Oregon of 3.1/100,000 (vs. 0.2/100,000 general population), higher than previously reported in Los Angeles County (1.6/100,000 Hispanics) and in Mexico (0.8/100,000). [4,14,15] Of the cases described in this study, 72% were born in Mexico, agriculture or other manual labor was the common job type listed, 40% of patients had no health insurance, and at least 8% of cases appear to have been acquired in the United States.

The most comprehensive epidemiological studies of NCC conducted in the United States have relied on hospital discharge data, limiting the results primarily to the inpatient population. [12,14,17,18] However, the outpatient disease burden of NCC is likely much greater than what is reflected in the hospital case population. In one Oregon study conducted between 2006 – 2009, which used population-based active surveillance, an annual incidence of NCC of 0.5 cases per 100,000 general population was found, with 11 times the incidence among Hispanics. [13] This study documented the highest rate of NCC

within the US, four times the estimates from studies conducted in California during the mid-1980s, and twice the previous estimate for Oregon.[11,14,15] The case-detection methods used included, for the first time, a portion of the outpatient NCC population, which was reflected in the relatively high rate of cysticercosis reported. Even so, the true incidence of NCC was likely underestimated because of incomplete outpatient case capture and the exclusion of suspected cases from incidence calculation. In addition to the lack of available population-based outpatient data, the clinical nature of NCC diagnosis complicates surveillance efforts and contributes to underestimation. No single laboratory test definitely establishes the diagnosis of NCC, and limited provider awareness of the disease results in substantial misdiagnosis.

Until recently no national level assessments of NCC disease burden have been conducted except for a single study describing NCC-associated mortality using the National Vital Statistics System.[16] This study showed 221 cysticercosis deaths in a 13-year period. The first national study to assess the economic burden of NCC used hospitalization discharge data from the Nationwide Inpatient Sample (NIS). A total of 18,584 neurocysticercosis hospitalizations were estimated in the United States for the ten-year period of the study between 2003-2012.[17] The estimated overall mean annual hospitalization rate of 0.65/100,000 population fell between the rates previously observed in California (0.8-1.1 hospitalizations/100,000 population) and Oregon (0.2-0.5 hospitalizations/100,000 population).[11-14] The study verified that NCC disproportionately affects Hispanics, who have a hospitalization rate 35 times that of non-Hispanic whites. The mean charge per hospitalization was nearly $51 thousand, increasing 25% over the study period to almost

$63 thousand in 2012. [17] An earlier study describing the financial burden of NCC in Los Angeles County reported a similar result, with an average NCC hospital charge in 2006 of $56.5 thousand, nearly double the average 2006 hospitalization charge in the United States. [18] A 2009 statewide study of NCC hospitalizations in California found that total charges exceeded $17.1 million annually with an average charge for a NCC hospitalization of $57.8 thousand, substantially higher than the $30.6 thousand average hospitalization charge in the U.S during the same year. [12]

These studies illustrate the considerable economic burden associated with NCC. The complicated nature of acute management results in many hospitalizations involving neurosurgical procedures and intensive care settings. These NCC presentations require intense outpatient follow-up including prolonged regimens of antiparasitic drugs, high-dose corticosteroids, monitoring and repair of ventriculoperitoneal shunts, and treatment of frequent complications from these interventions. [34,35]Prior studies underestimate the true burden of NCC on the healthcare system by failing to capture this outpatient disease burden. Given the chronic nature of NCC, the costs associated with management of the disease may be considerably higher. Specialists manage long-term medical and surgical interventions of these patients in the outpatient setting including many treatment complications, which contribute to poor clinical outcome and to the high cost of management.

NCC-associated diagnoses

Several studies report seizure/epilepsy as the most frequent NCC-associated diagnosis among hospitalized patients. [12,17,19,20] In a Houston case series including 112 NCC cases diagnosed between 1985 and 1991, 80% of patients demonstrated seizures and 40% headache at some time throughout their illness. Among 304 NCC cases hospitalized in California in 2009, almost three-quarters demonstrated seizures and one-quarter hydrocephalus, similar to a previous study of NCC patients hospitalized in Los Angeles County (LAC) between 1991-2008, as well as an earlier study of an LAC hospital. [18] In the most recent nationwide study of NCC, epilepsy/convulsions occurred in 57% of hospitalizations, followed by hydrocephalus (17%) and headache (12%). [17]

Although seizure has been reported as the most common NCC-associated diagnosis, only one previous population-based study included outpatient data.[13] However, this study did not assess NCC-associated diagnosis categories. No population-based study has yet to assess the broader spectrum of NCC disease. Existing studies to date only capture the NCC cases that are severe enough to result in hospitalization, leaving uncounted less severe cases and chronic outpatient management of all cases regardless of severity.

Evaluating the entire spectrum of healthcare costs related to NCC

This study evaluates the entire spectrum of healthcare spending for NCC in Oregon using Oregon's All-Payer All-Claims (APAC) data administered by the Oregon Health Authority. In 2009, the Oregon State Legislature passed legislation creating the APAC Data Reporting Program to comprehensively capture medical and pharmacy claims

transactions in Oregon. Data includes claims information from commercial health insurance carriers, licensed third party administrators, pharmacy benefit managers, Medicaid managed care organizations, Medicaid fee-for-service and Medicare parts C and D. This limited-use dataset is accessible for research purposes through application to the Oregon Health Authority.

Thesis objective and aims

The objective of this study was to provide a broader description of the NCC population, including the outpatient disease burden. The new Oregon All-Payers All-Claims database was used to extract demographic and financial data as well as information on co-existing diagnoses and procedures in the insured population with NCC. In addition, the NCC-associated diagnosis groups, mental health disorder and headache, were examined in greater detail to provide information about two common outpatient complaints in individuals with NCC.

Specific aims of this study include:

1. To describe the prevalence, demographic characteristics, frequency of neurocysticercosis-associated diagnoses and procedures, and economic burden of insured individuals with neurocysticercosis;
2. To evaluate whether the APAC database can provide reliable demographic and financial information about NCC in Oregon; and
3. To explore predictors of the number of healthcare claims in people with burden.

CHAPTER 2—METHODS AND RESULTS

METHODS

Study population

The study population included all individuals that, during the course of the study period from 2010 through the second quarter of 2013, had: 1) at least one paid or managed care encounter claim in Oregon's APAC dataset; 2) an International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) code of 123.1 (cysticercosis) in any of the 13 diagnostic fields of the Oregon APAC All-Medical database; and 3) at least one NCC-associated diagnostic, procedure, or CPT code listed in Appendices 2 or 3.

Data Source

The Oregon All-Payers All-Claims (APAC) database is a large-scale database that systematically collects insurance claim information on a quarterly basis from healthcare payers. As of 2014, 16 states have or were in the process of implementing mandatory all-payer claims databases, which require payers to report by state law. [23] In 2009, the Oregon APAC database was established with administrative authority given to the Oregon Health Authority. [24]

APAC captures three categories of data: 1) eligibility files, which provide demographic data such as date of birth, gender, race/ethnicity, and geography and serves to identify claims and providers for data submission; 2) medical and pharmacy claims, which provide payment information, diagnoses, procedures, dispensed pharmaceuticals, length

of stay, Current Procedural Terminology (CPT) and Healthcare Common Procedure Coding System (HCPCS) codes, and HCPCS modifiers; and 3) provider data claims, which include information on provider specialty and place of service. [24-26]

APAC data contain claim information of insured individuals residing in Oregon provided by commercial health insurance carriers and licensed third party administrators with at least 5,000 covered lives, pharmacy benefit managers, Medicaid managed care organizations, Medicaid fee-for-service, Medicare parts C and D, and members enrolled in state-payer insurance plans regardless of residence, including the Public Employees' Benefit Board, Oregon Educators Benefit Board and the Oregon Medical Insurance Pool.[24] Small carriers below the reporting threshold are not currently required to report. In addition, no data are collected on the uninsured, individuals that self-pay, and claims paid by Medicare Fee-For-Service, TRICARE, the Federal Employee Health Benefits program, Indian Health Service, workers compensation, medical liability auto insurance, and stand-alone dental, vision, and prescription plans.

The Oregon Health Authority's APAC program provided a complete dataset for this study, in which all 18 HIPAA identifiers were removed to insure patient confidentiality. Data elements are listed in Appendix 1. The dataset was saved in a password-protected file on an access-restricted folder on the OHSU network.

Coding systems used to identify cases

Diagnostic and procedure codes were based on the International Classification of Diseases, 9th revision, Clinical Modification (ICD-9-CM) diagnostic and procedure codes respectively. The Healthcare Cost and Utilization Project's Clinical Classification Software grouping of ICD-9 codes was used as a guide for compiling a list of diagnostic and procedure codes associated with NCC.[29]

ICD-9 CM procedure codes did not consistently and completely identify NCC associated procedures (e.g. neuroimaging, EEG, CNS surgery, ventriculoperitoneal shunt placement). Therefore, in addition to ICD-9-CM procedure codes, CPT codes were quiered to identify procedures associated with NCC. The CPT code set is a standardized coding system used to provide a consistent method of processing Medicare and other health insurance claims. A CPT code represents a specific medical service or procedure performed. A list of CPT codes for the procedure categories used in this study was compiled by performing a keyword search of procedures using the online search engine Supercoder.com and is available as Appendix 3.[30]

Case definitions

Neurocysticercosis cases were defined as those individuals having at least one paid or managed care encounter claim with an ICD-9-CM code of 123.1 (cysticercosis) and at least one paid or managed care encounter claim with a neurocysticercosis-associated diagnostic, procedure, or CPT code listed in Appendix 2 or Appendix 3 (Figure 2).

The ICD-9-CM code listed in the first diagnostic field is intended to capture the primary reason for the claim. Since there is no specific ICD-9-CM code for neurocysticercosis, coding patterns often vary. For example, a claim for NCC may be coded with a first diagnostic field of 123.1 (cysticercosis) or with an associated neurologic code (such as headache, mental health conditions, seizure/epilepsy, or hydrocephalus) in combination with 123.1 in another diagnostic field.

Figure 2. NCC-associated diagnostic, procedure, and CPT code groupings

Diagnostic code groups

- Meningitis
- Encephalitis
- Epilepsy; convulsions
- Headache
- Cerebrovascular disease
- Hydrocephalus
- Transient cerebral ischemia
- Syncope
- Mental disorders
  - Adjustment disorders
  - Anxiety disorders
  - Attention-deficit, conduct, and disruptive behavior disorders
  - Delirium, dementia, and amnesic and other cognitive disorders
  - Impulse control disorders, NEC
  - Mood disorders
  - Personality disorders
  - Schizophrenia and other psychotic disorders
  - Other mental disorders

Procedure code groups

- Ventriculoperitoneal shunt placement, revision, removal
- CNS surgery: excision, incision
- Electroencephalography (EEG)
- Computerized Axial Tomography (CT)—head, brain, neck
- Magnetic Resonance Imaging (MRI)—head, brain, neck

Methods for case selection

In order to identify individuals with cysticercosis, claims with an ICD-9-CM code of 123.1 in any of the 13 diagnostic fields were extracted from the APAC database during the 14 quarters of the study. This first sweep of the database generated a list of unique individuals with a 123.1 claim. Then all claims for these individuals within the period of the study, past and future relative to their initial 123.1 diagnosis, were extracted from the database. This second sweep of the database provided a compilation of claims in people having at least one cysticercosis claim during the study period. All denied claims were dropped leaving only paid and capitated claims. Claims for individuals without at least one neurocysticercosis-associated diagnostic, procedure, or CPT code listed in Appendix 1 were dropped, leaving a list of people with neurocysticercosis and their accompanied paid and capitated claims. (Figure 3).

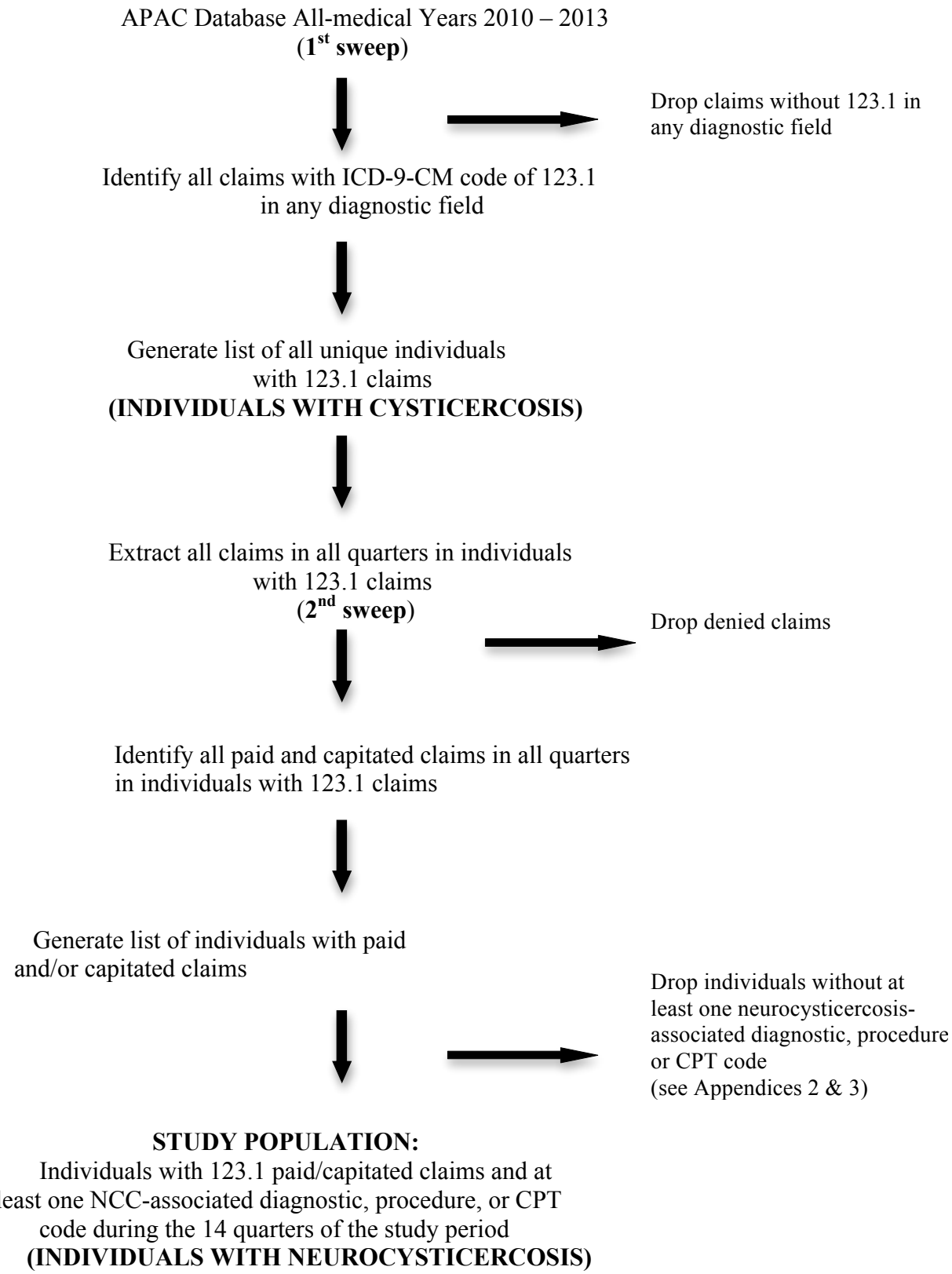
Claims

Claims are comprised of multiple claims lines. Each claim line shares common claim identification number, claim status, and diagnosis and procedure codes, however, separate HCPCS or CPT codes. When the claim is submitted, the insurer uses the HCPCS or CPT code of the claim line to determine charge.

Claim status is classified as either a denied or paid claim, or a managed care encounter.

- Denied claims were those rejected by the insurer. Because denied claims that are re-submitted by the healthcare provider receive different identification numbers and are considered new claims, they were not included in claim counts or other data analysis in this study in order to avoid duplicate claims.

Figure 3. Algorithm for selecting study population.



- Paid claims were those for which the provider received reimbursement, either from the insurer and/or the patient. All paid claims were included in count analysis and claim payment assessment.

- Managed care encounters (capitated claims) were claims associated with providers enrolled in managed care plans that receive a capitated, per-member-per-month payment. Managed care encounters are recorded to allow the Medicaid agency to track the services received by members enrolled in managed care. The insurer is not responsible for processing a claim or paying the provider for the rendered service. Managed care encounter data typically come from billed claims that providers submit to managed care plans for reimbursement of services [27]. Since payment information associated with managed care encounter claims does not truly reflect the amount paid to the provider, in this study capitated claims were excluded from claim payment assessment. However, for the purposes of analyzing other claim information such as claim counts, capitated claims were included.

Claim payments

Claims payments are represented in US dollars ($USD), adjusted for inflation by using the Consumer Price Index and setting the base year to 2010. Payments are calculated by totaling the sum of insurer and total patient pay amounts of each claim line for each claim. Total patient pay amount includes patient co-payments, co-insurances, and deductibles.

Statistical Methods

Analysis was performed using the statistical software STATA 13.1 (StataCorp, College Station, Texas). Summary statistics of neurocysticercosis cases and claims were provided including frequency and costs of healthcare related to NCC in Oregon, total number of unique individuals with paid NCC claims tabulated by age and gender, associated diagnostic and procedure categories, healthcare settings, claim payers and types, and total claims payments by type for these individuals. The one-year prevalence of neurocysticercosis was calculated as the number of neurocysticercosis cases identified during the 3.5-year study period divided by 3.5 (numerator), over the insured population of Oregon as estimated in 2010 by the United States Census Bureau (denominator).

Patient characteristics, which might be associated with frequent healthcare utilization, were examined in regression analyses. Since each patient has at least 1 claim, zero-truncated negative binomial regression was used to test the association between claim count per quarter and the age, sex and claims history of individuals with neurocysticercosis. Neurocysticercosis-associated diagnostic categories of interest included mental health disorder, obstructive hydrocephalus, headache, epilepsy/seizure, stroke, syncope, and meningitis/encephalitis. In addition, another variable, "reclassified seizure" was generated, which combined seizure and syncope claims. Because there is no biological plausibility of an association between syncope and NCC, except the unusual phenomenon of intraventricular NCC leading to episodic obstructive hydrocephalus, a

relationship between seizure and syncope was explored with the assumption that most cases of syncope are misclassified seizures.

Each variable was analyzed individually using univariate analysis. Those variables that were significant ($p \leq 0.20$) were included in a multivariable model. Non-significant variables ($p \geq 0.05$) were excluded from the final model. Akaike's information criterion (AIC) and Bayesian information criterion (BIC) were used to compare models.

Human Subjects Protections

The study protocol was reviewed and approved by the OHSU IRB and the Information Privacy and Security Office of the Oregon Health Authority. Because NCC is an uncommon disease and data were considered potentially identifiable despite removal of all 18 HIPAA identifiers, standard institutional practices were followed as described in the OHSU Information Security and Research Data Resource Guide (http://ozone.ohsu.edu/cc/sec/isg/res_sec.pdf) to maintain the confidentiality and security of data collected in this study. Specifically, electronic data were stored in a password-protected file on an access-restricted folder on the OHSU network. Only those investigators and research staff specifically identified in the APAC data use agreement had access to this electronic folder. The dataset was not shared with other investigators or groups.

RESULTS

There were 137 individuals with a total of 488 healthcare claims, which included an ICD9-CM code of 123.1 in the APAC database for the 14 quarters of this study (Figure 1). Of these individuals, 133 had paid and capitated claims, and 125 had at least one claim with a neurologic code listed in Appendix 1, meeting the case definition of neurocysticercosis. Total healthcare claims for these 125 individuals was 8224.

Demographic characteristics

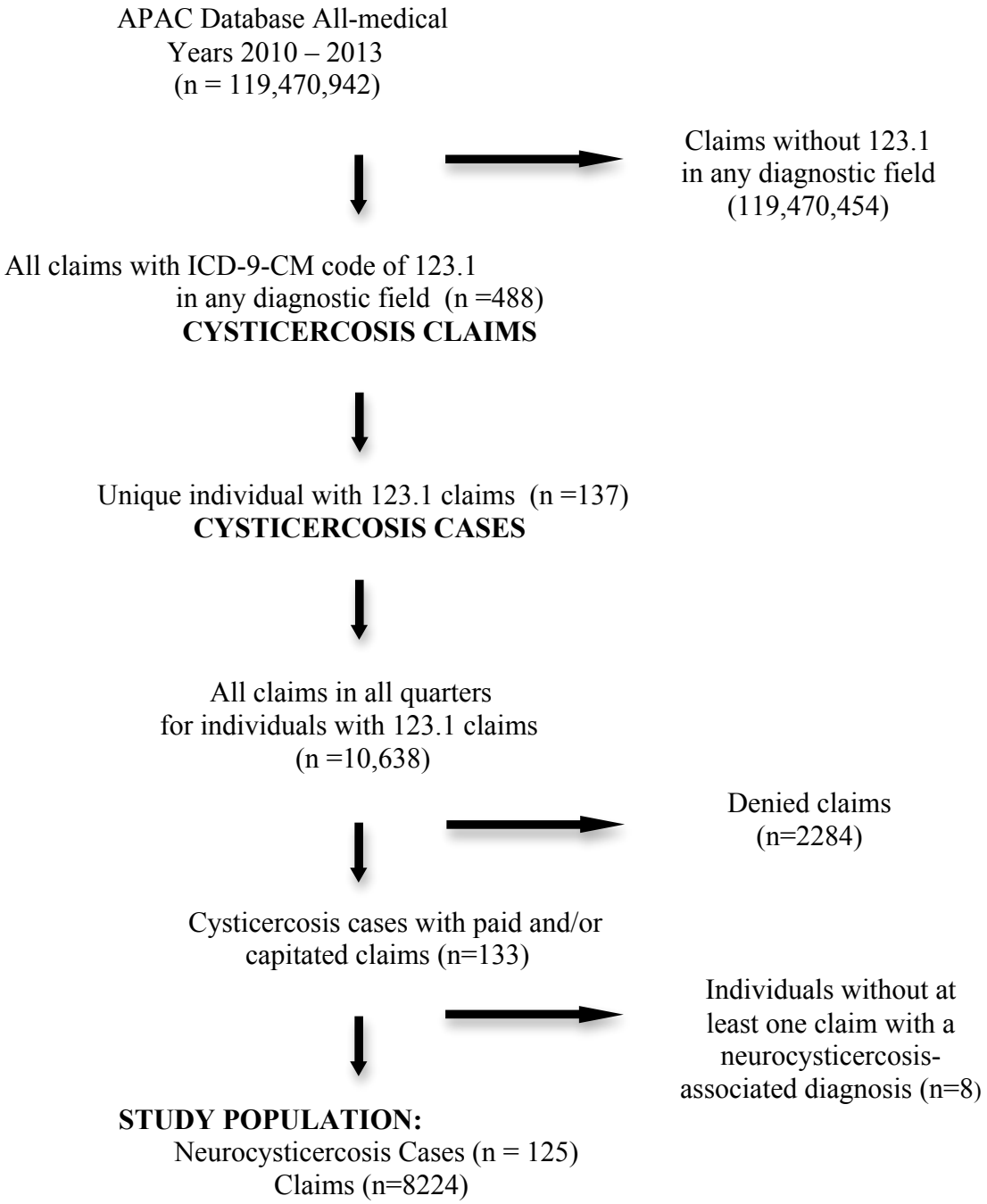
Demographic characteristics for the 125 people with neurocysticercosis are presented in Table 1. The age range of individuals with neurocysticercosis was between 3 and 84 years with a mean age of 48.6 yrs. (sd=16.1 yrs.). Approximately half of these (67/125, 54%) were between the ages of 20 and 44 (Table 1). Only 7% were under 20 years of age, and 10% older than 64 years of age. The majority (69/125; 55%) of individuals were female. Over half the study population was coded with unknown value for race and ethnicity. Hence, demographic results pertaining to these variables were not reported.

Claims

Over 80% of claims occurred in individuals 20-64 years of age. There were more claims per case in older as compared to younger individuals. Individuals 65 years of age and older had twice as many claims per case compared to those 20 – 44 years of age, and nearly four times as many claims per case compared to those less than 20-years of age. The total number of claims in females with a claim history of neurocysticercosis was disproportionately higher than in males, representing nearly two thirds of the total paid

and capitated claims (Table 2). However, sex and number of claims was not found to be significantly associated (p=0.36).

Figure 4. Flow chart for selection of study population



Associated diagnoses and procedures

Over 70% (5887/8224) of paid and capitated claims in people with NCC did not have an associated neurological diagnostic or procedural code. Of the neurocysticercosis claims with neurological diagnoses, mental health disorders and headache comprised the most commonly associated diagnostic categories, each occurring in approximately half of the total number of cases (Table 3). There were over 700 mental health claims, comprising 8.6% of the total paid and capitated claims in neurocysticercosis cases. Over 6% of claims were headache. Epilepsy was diagnosed in almost one-third of all cases and resulted in over 5% of the total number of claims. Stroke was coded in almost 14% of individuals. Neuroimaging was performed in over half of individuals diagnosed with neurocysticercosis, although it resulted in only 5% of total paid and capitated claims. Almost 45% (54/125) of cases received MRI, and over 35% (46/125) were imaged using CT.

Payments

Total paid claims of $2,407,532 were generated during the study period for individuals with neurocysticercosis (Table 2). 85% of payments occurred in individuals between the ages of 20 and 64 years. Claim payments per case were over 33% higher in individuals 45-years of age and older as compared to those 20 – 44 years of age and almost five times as high when compared to young individuals less than 20 years of age.

Mental health disorder ranked highest in total claim payments of all neurocysticercosis-associated diagnostic categories, resulting in paid claims exceeding $279,000 during the study period. Epilepsy resulted in claim payments totaling almost $270,000 and headache over $168,000. Although CNS surgery was only performed in 4% of all neurocysticercosis cases and comprised just 0.1% of total paid and capitated claims, payments per paid claim were substantially higher than with any other procedure and over 67% higher than that of shunt placement/revision/removal. Obstructive hydrocephalus represented the diagnostic category with the highest total payment per case, exceeding $13,600. Individuals with cerebral edema had paid claim payments of over $9600 each.

Cerebral edema represented the diagnosis category with the highest payment on a per claim basis, exceeding $6000 or over twice that of obstructive hydrocephalus. Ventriculoperitoneal shunt was the procedure category with the highest total payment on a per case basis with payments exceeding $26,000. CNS surgery exceeded $24,000 per case.

Healthcare utilization (crude associations)

The count of healthcare claims per individual was analyzed as a means of estimating healthcare utilization and disease burden (Table 4). Univariate analysis of sex and age indicated that among individuals with a neurocysticercosis claim history, for every 10 years of age the estimated mean number of claims per quarter increased by 15% (95% CI:

7-25% increase; $p<0.01$). No significant association was noted between sex and mean number of claims per quarter ($p=0.36$).

Analysis of diagnostic categories indicated that the mean number of claims per quarter was 45% lower for individuals with a claim history of hydrocephalus compared to those without a history of hydrocephalus, although the significance was marginal. (95% CI: 0-70% lower; $p=0.05$). However, there was a significant association between a claim history of syncope and claim count per quarter. Individuals with a claim history of syncope had 1.8 (95% CI: 1.17, 2.67; $p=0.01$) times as many claims per quarter compared to those without a history of syncope. However, no overt biological association between neurocysticercosis and syncope has been described unless unwitnessed seizures are misdiagnosed or miscoded as syncopal events. To explore this, a regression model was analyzed in which syncope and seizure were combined into a single variable named "reclassified seizure".

Analysis of the new reclassified seizure variable demonstrated that history of a reclassified seizure claim and the number of claims per quarter was associated with marginal significance ($p = 0.06$). Multivariable analysis was then performed to explore the joint association between reclassified seizure, other neurocysticercosis-associated diagnoses, sex, and the number of claims per quarter. The final model described the following relationships:

- Among individuals of similar reclassified seizure and headache claim history, for every 10 years of age there was an estimated 1.2 times as many claims per quarter (95% CI: 1.09 to 1.26 as many; $p<0.001$).
- Among individuals of similar age and headache exposure, those with a reclassified seizure history had 1.4 times as many claims per quarter (95% CI: 1.12 to 1.85 as many; $p=0.004$) as individuals with no history of seizure.
- Among individuals of similar age and reclassified seizure history, the mean number of claims per quarter was 27.2% higher for those with headache compared to individuals without headache (95% CI: 0.2% higher up to 61.4% higher; $p=0.05$).
- After accounting for age and claim history of reclassified seizure, claim histories of headache, hydrocephalus, stroke, mental disorders, and meningitis/encephalitis were found not to be significantly associated with the mean number of claims per quarter, X^2 (5df) = 5.46, $p=0.36$.

Payer type and source

Payment type was available for all neurocysticercosis claims (N=8224). Private insurance carriers, which include Medicare Advantage and other commercial payers, were the primary payers of paid neurocysticercosis claims accounting for over half the payments provided (Table 5.). Federally-funded pay sources (Medicare parts A and B and Medicaid) provided payment for almost 40% of claims, while self-funded third-party administrators and other government agencies were the source of payment for the remaining claims.

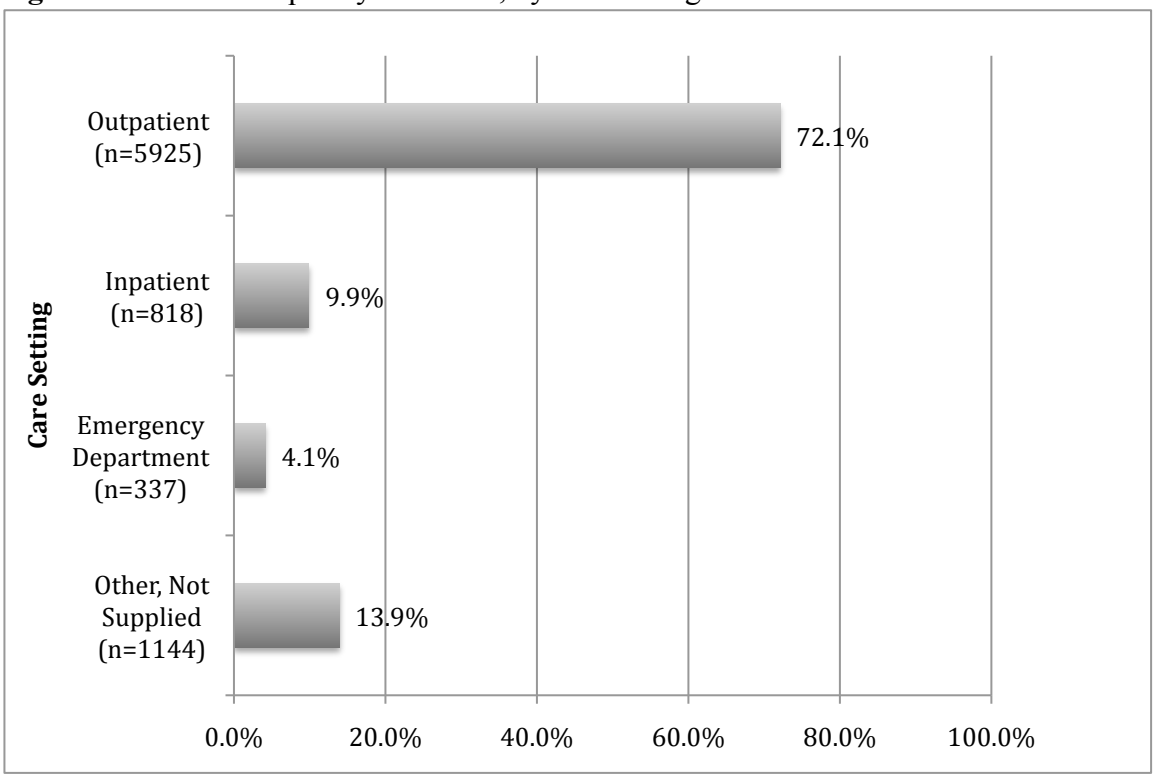
Commercial payers represented the pay source for the highest number of claims and the greatest total payments (Table 6). Private carriers represented the majority payer type of outpatient claims, while Medicaid provided payment for almost three-quarters of inpatient claims (Table 7).

Distribution of diagnostic and procedure categories by care setting

A total of 5925 claims, representing 72% of all paid and capitated neurocysticercosis claims, were made in outpatient settings, while 10% of claims (818) were inpatient, and 337 (<5%) were generated in emergency departments (Figure 2). Over one-third (47/125) of individuals with NCC had a claim history which included both outpatient and inpatient claims during the study period.

Figure 6 illustrates the frequency of claims of each of the associated diagnosis categories made in each health care setting. Paid and capitated claims associated with mental health disorders, headache, seizure/epilepsy, and syncope were primarily made in outpatient settings, while claims associated with hydrocephalus, cerebral edema, and cerebrovascular disease were made in inpatient settings. Claims associated with encephalitis/meningitis were almost equally generated in both outpatient and inpatient settings. Almost 10% of syncope claims, 8.5% of cerebrovascular disease claims, and over 7% of headache claims were made in the emergency department.

Figure 5. Relative frequency of claims, by care setting



Half (114/228) of all neuroimaging claims were generated in an outpatient setting (Figure 7) including 70% of all MRIs. However, over 40% of all CT claims occurred in the emergency department. During the study period, 4 of the 6 CNS surgery claims were made in inpatient settings with the place of service of the remaining 2 claims not supplied.

Figure 6. Frequency of neurocysticercosis claims by associated diagnosis and health care setting

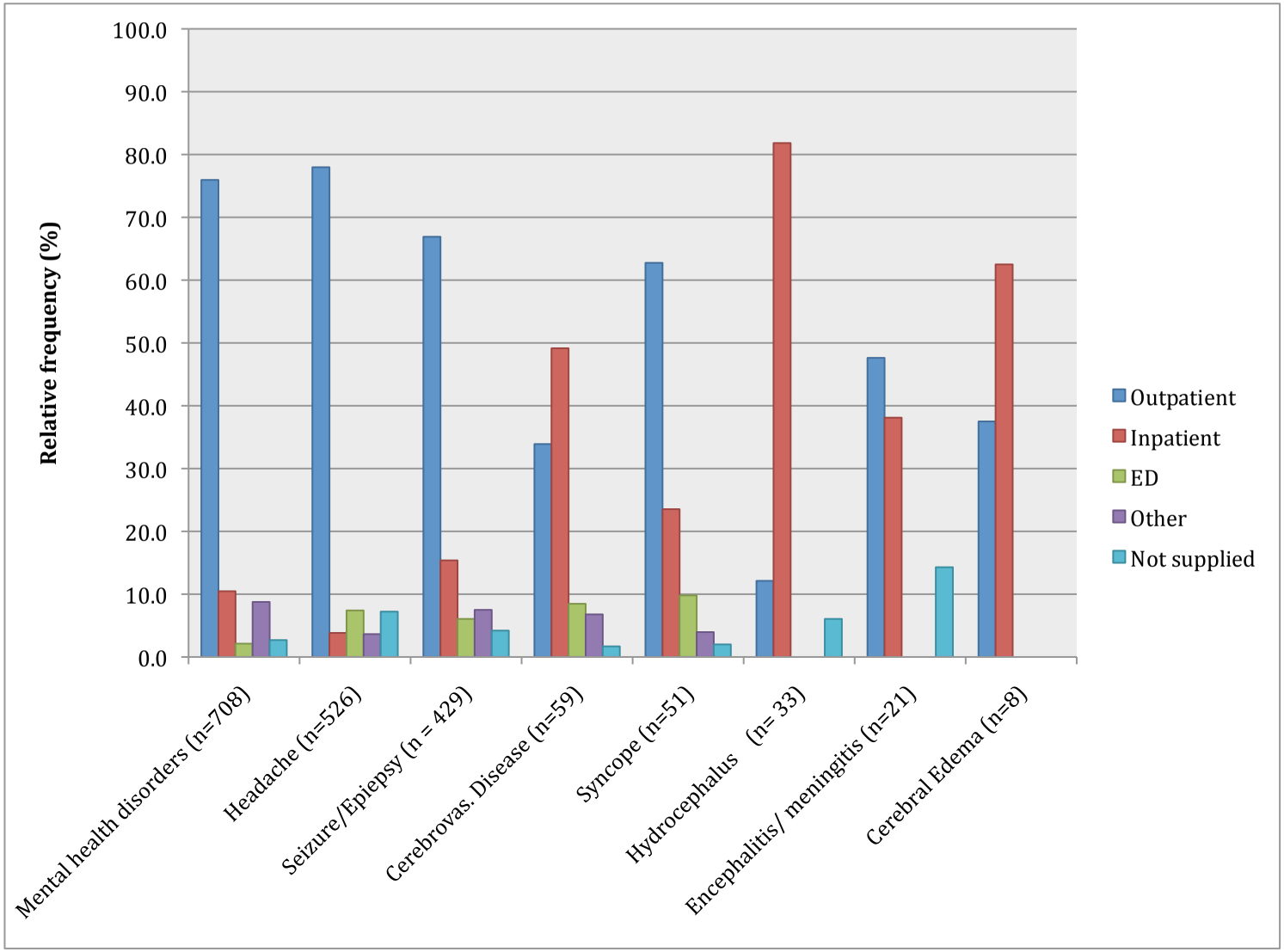
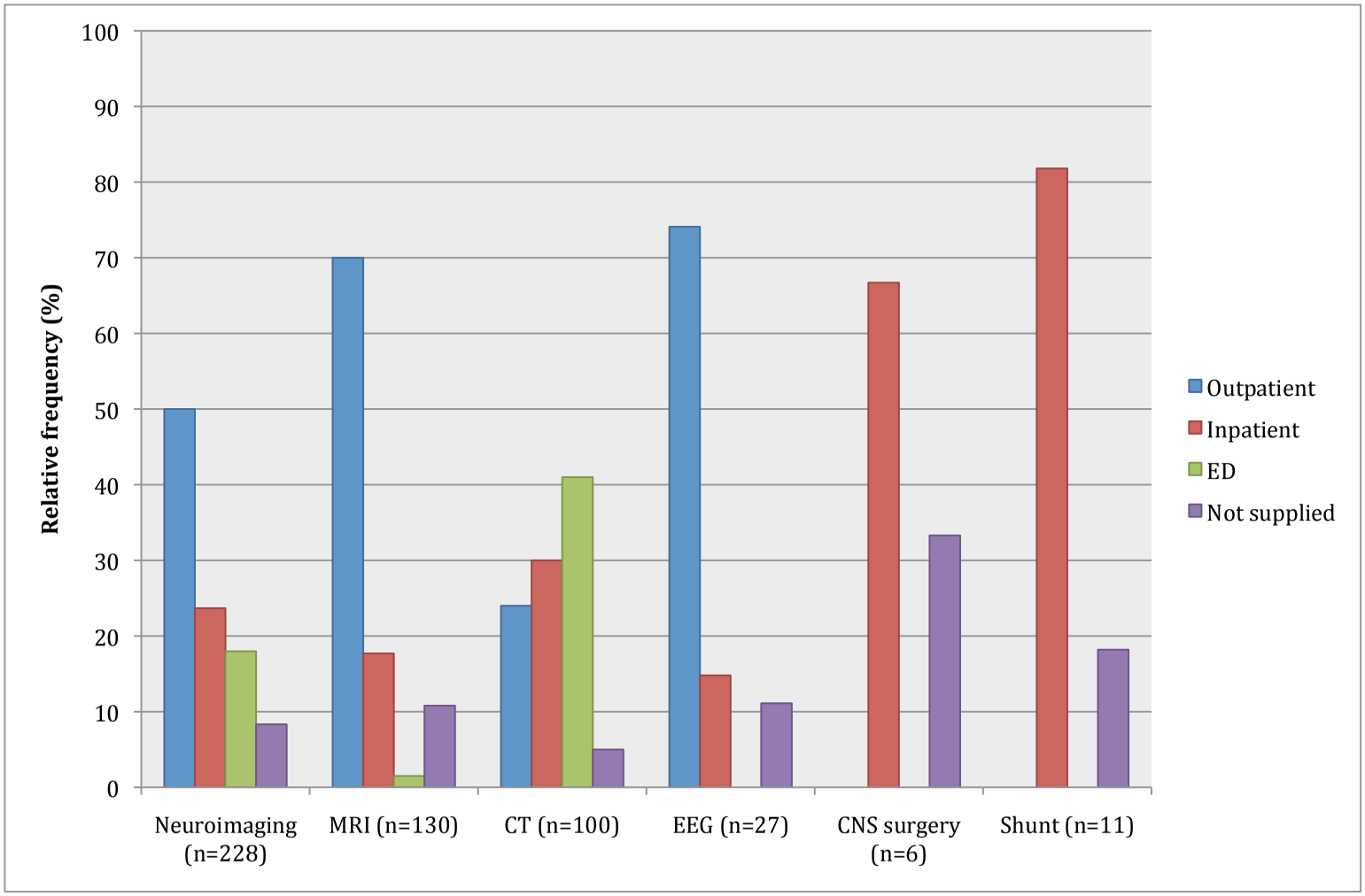


Figure 7. Frequency of neurocysticercosis claims by procedure and health care setting.


100
90
80
70
60
50
40
30
20
10
0
Relative frequency (%)
Neuroimaging (n=228)
MRI (n=130)
CT (n=100)
EEG (n=27)
CNS surgery (n=6)
Shunt (n=11)
Outpatient
Inpatient
ED
Not supplied

Length of Stay

One third (42/125) of all individuals with NCC had at least one claim with a hospitalization length of stay of at least 1 day. Length of stay ranged from 1 day to a maximum of 70 days. However, several claims can potentially represent a single hospitalization. Because it is not possible to differentiate hospitalization episodes and each claim of a hospitalization episode is coded with the same length of stay (resulting in duplication of length of stay values and positively biasing the mean), mean length of stay could not be determined and is therefore not presented in the results.

Distribution of major categories of mental health disorder associated with neurocysticercosis

Half of all individuals with NCC had at least one claim during the study period with a diagnostic code of either mood or anxiety disorder. Paid claims with diagnostic codes of mood disorders had substantially greater claim payments, representing over three times that of anxiety claims. Although only 8 individuals (~6% of all individuals with NCC) had claims with diagnostic codes of schizophrenia and other psychotic disorders, the number of paid and capitated claims approached 200 and claim payments approached $100,000.

Table 1: Demographic characteristics of 125 paid and capitated NCC cases and their claims in Oregon by demographic group, 14 quarters 2010-2013.

Characteristic	Cases (#)	%	Claims (#)	%	Mean claims per case
Age, y					
< 20	9	7.2	249	3.0	27.7
20 - 44	67	53.6	3413	41.5	50.9
45 - 64	36	28.8	3213	39.1	89.3
≥ 65	13	10.4	1349	16.4	103.8
Sex					
Male	56	44.8	2933	35.7	52.4
Female	69	55.2	5291	64.3	76.7
Total	125		8224		65.8

Table 2: Payments of 116 paid NCC cases and their claims in Oregon by demographic group, 14 quarters 2010-2013.

Characteristic	Cases (#)	Claims (#)	Total payment ($)	Mean payments per case ($)
Age, y				
< 20	9	242	42,961	4,773
20 - 44	59	2928	1,204,054	17,971
45 - 64	36	3104	861,922	23,942
≥ 65	12	1349	298,593	22,969
Sex				
Male	53	2732	1,066,733	19,049
Female	63	4891	1,340,798	19,432
Total	116	7623	2,407,532	19,260

Table 3. Associated diagnostic and procedure categories and payments NCC cases and claims, Oregon 14 quarters 2010 – 2013.

	Paid and capitated cases (n=125) and claims (n=8224)					Paid only cases (n=120) and claims (n=7691)				
Diagnostic Categories	**Cases (#)**	**%**	**Claims (#)**	**%**	**Mean claims per case (#)**	**Cases (#)**	**Claims (#)**	**Total Payments ($)**	**Payment per claim ($)**	**Mean payment per case ($)**
Mental health disorder	64	51.2	708	8.6	11.1	56	598	279,088	467	4,984
Obstructive hydrocephalus	7	5.6	33	0.4	4.7	7	33	95,774	2,902	13,682
Headache; including migraine	63	50.4	526	6.4	8.3	56	491	168,384	343	3,007
Epilepsy; convulsions	41	32.8	429	5.2	10.5	37	364	269,138	739	7,274
Cerebrovascular disease	17	13.6	59	0.7	3.5	17	59	40,403	685	2,377
Syncope	12	9.6	51	0.6	4.3	12	51	18,979	372	1,582
Cerebral edema	5	4.0	8	0.1	1.6	5	8	48,239	6,030	9,648
Encephalitis / meningitis	5	4.0	21	0.3	4.2	5	21	34,941	1,664	6,988
Procedure Categories										
Shunt	5	4.0	11	0.1	2.2	5	11	132,185	12,017	26,437
CNS Excision/Incision	5	4.0	6	0.1	1.2	5	6	121,344	20,224	24,269
EEG	18	14.4	27	0.3	1.5	16	23	7,080	308	433
Neuroimaging	69	55.2	228	2.8	3.3	66	197	125,897	639	1,908
CT	46	36.8	100	1.2	2.2	45	97	35,319	364	785
MRI	54	43.2	130	1.6	2.4	48	102	95,147	933	1,982

Table 4. Crude and adjusted zero-truncated negative binomial regression results relating number of claims (response characteristic) to selected explanatory variables.

	Unadjusted			Adjusted		
Variable value	Estimate	(95% CI)	p-value	Estimate	(95% CI)	p-value
Age (per 10 yrs)	1.15	(1.07, 1.25)	<0.01	1.18	(1.10, 1.26)	<0.001
Sex						
Female (n=69)	--(ref)--					
Male (n= 56)	0.88	(0.68, 1.14)	0.36			
Mental Disorder						
No (n=61)		--(ref)—				
Yes (n=64)	1.09	(0.84, 1.41)	0.48			
Headache						
No (n=62)		--(ref)—			--(ref)--	
Yes (n=63)	1.14	(0.88, 1.47)	0.31	1.27	(1.00, 1.61)	0.048
Reclassified Seizure (seizure + syncope)						
No (n=80)		--(ref)—			--(ref)--	
Yes (n=45)	1.27	(0.98 1.65)	0.06	1.44	(1.12, 1.86)	0.004
Seizure						
No (n=84)		--(ref)—				
Yes (n=41)	1.02	(0.78, 1.34)	0.86			
Stroke						
No (n=108)		--(ref)—				
Yes (n=17)	1.31	(0.91, 1.89)	0.13			
Syncope						
No (n=113)		--(ref)—				
Yes (n= 12)	1.77	(1.17, 2.67)	0.01			
Hydrocephalus						
No (n=118)		--(ref)—				
Yes (n= 7)	0.55	(0.30, 1.00)	0.05			
Meningitis/Encephalitis						
No (n=120)		--(ref)—				
Yes (n= 5)	1.12	(0.59, 2.13)	0.72			

Table 5. Oregon APAC payer type, 14 quarters 2010-2013.

APAC Payer Type	Paid and capitated claims (#)	%	Total payments, paid claims ($)
Carrier (commercial payers)	4504	54.8	1,412,822
Medicaid	3152	38.3	859,310
Other government agency	42	0.5	8,457
Third-party administrator (self-funded)	526	6.4	126,942

Table 6. Oregon APAC payer source, 14 quarters 2010-2013.

APAC Payer Source	Paid and capitated claims (#)	%	Total payments, paid claims ($)
Medicare Advantage	1178	14.3	239,657
Dual eligible (Medicare and Medicaid)	931	11.3	60,301
Medicaid fee for service	510	6.2	357,630
Medicaid managed care	1731	21.1	445,989
Public Employees Benefits Board	599	7.3	162,712
Oregon Educators Benefits Board	222	2.7	80,369
Other commercial payer	3045	37.0	1,058,303
Unknown	8	0.1	2,567

Table 7. Place of Service and Payer Type, 14 quarters 2010-2013.

Place of Service	Payer Type		
	Carrier	Medicaid	Other
Outpatient (n=5929)	56.8%	36.8%	6.4%
Inpatient (n=819)	22.6%	71.9%	5.5%
Emergency Department (n=343)	49.9%	47.8%	2.3%

Table 8. Distribution of major categories of mental disorder associated with neurocysticercosis

	PAID and CAPITATED claims		PAID claims only
Mental Disorder	**No. of individuals**	**No. of claims**	**Claim Payments ($)**
Mood disorders	32	209	106,680
Anxiety disorders	31	150	33,087
Delirium / dementia/ cognitive disorders	11	49	18,363
Schizophrenia and other psychotic disorders	8	194	98,940
Other mental disorders	28	106	14,051

CHAPTER 3—DISCUSSION, CONCLUSION, RECOMMENDATIONS

Prevalence and Demographics

The one-year prevalence of neurocysticercosis in the general population was 0.93 cases per 100,000 individuals. The APAC database did not supply reliable race and ethnicity information so race composition from previous studies, which indicate that Hispanics comprise between 74% and 91% of total neurocysticercosis cases (HCUP, Crocker, 2010; US Census), was used to approximate the prevalence of neurocysticercosis in the Hispanic population, which was estimated at 5.87– 7.22 per 100,000 individuals.

All-Payers data has the advantage as compared to hospital-based databases of capturing a broader spectrum of disease, including outpatient and emergency department claims. The ability to capture these additional cases most likely contributed to the disease prevalence

noted as well as the unique composition of the study population addressed later in this discussion. However, even with the inclusion of outpatient and emergency department claims, several factors probably contributed to an underestimate of claim counts and cases.

First, denied claims were excluded from counts. It is unclear whether denied claims represent claims with errors or omissions in diagnosis and procedure coding, incomplete or inaccurate insurance information, non-capture of tests or procedures, or lack of pre-certification or prior authorization. However, at least a portion of denied claims are valid, which for various reasons do not receive insurance reimbursement and hence are not included in the claims count. Of the original 137 individuals with a claim including a 123.1 diagnosis code (including paid, capitated and declined claims), 131 had at least one neurocysticercosis associated diagnosis. Including these 6 potential cases increases the mean one-year prevalence of neurocysticercosis in the general population to 1.0 cases/100,000 and in the Hispanic population to 6.15-7.57 cases/100,000.

Second, the APAC database excludes the uninsured population estimated to comprise 40% of total neurocysticercosis cases.[14] It also fails to capture individuals who self-paid and those who do not or cannot seek healthcare services. Neurocysticercosis is prevalent in the United States primarily in immigrants from rural regions of Latin America. Many of these individuals do not have legal immigration status and lack health insurance. If they seek healthcare, it is provided by indigent medical services or emergency

departments, which often absorb the cost of care. These cases are not captured in the APAC database.

Third, the definition of neurocysticercosis used in this study required a cysticercosis claim (ICD-9-CM diagnostic code of 123.1) with an additional supportive diagnostic, procedural, or CPT code. The purpose of this requirement was to reduce the likelihood of capturing claims unrelated to neurocysticercosis. However, some claims associated with neurocysticercosis sequellae or co-morbidities may not have included a cysticercosis ICD-9 code. For instance, a neurocysticercosis-associated claim filed prior to neurocysticercosis diagnosis would not be captured in this study if diagnosis was made after the study period even though neurocysticercosis provided the underlying etiology of the claim.

Fourth, misdiagnosis probably results in underestimates. Since neuroimaging is necessary for diagnosis, and clinical signs can be variable and vague, a medical provider unaware of the disease and who is not diagnostically aggressive could fail to make a correct diagnosis of NCC.

Age

The median age of individuals with neurocysticercosis in this study was 42.6 years, similar to that reported in California in 2008-2009, but substantially higher than that found in the 2004 Oregon study (24 yrs.), and in the 2011 Houston study (28.6 yrs.).[12,14,20] Several investigators hypothesize that the higher median age noted in later studies

indicates a greater frequency of individuals with chronic disease or may be associated with declining incidence of neurocysticercosis in endemic regions. However, no robust studies have been conducted to support either of these suppositions. [12, 28]

Gender

Unlike previous studies, which describe a higher prevalence of neurocysticercosis in males this study found the majority (55%) of neurocysticercosis cases in females and more neurocysticercosis claims in females than in males (64.3% vs. 35.7). [12-14,17,20] Although the association of claim counts per quarter and gender was not found to be statistically significant, the higher representation of claims in women in this study may be associated with gender differences in the utilization of health care services. Several previous studies have shown that women use more healthcare services than men even after controlling for health status, sociodemographics, and clinic assignment. [31]

Claim payments

The APAC database was developed for the purpose of measuring the quality, quantity, and value of health care in Oregon. [24] However, the data provided by APAC proved disappointing when assessing the financial burden of neurocysticercosis. Procedure categories with expected high claim payments or high per case payments, such as CNS surgery or ventriculoperitoneal shunt placement/removal, seemed unusually low. Mean payment of CNS surgery claims was only $24,000, a fraction of the expected claim payment for an intensive procedure. As a means of comparison, the mean cost of 2012

hospitalizations with 123.1 as the principal diagnosis in the Western Region was $20,393.[17]

There is no clear explanation of why the APAC database provided such low financial estimates. Possible factors include:

1. Exclusion of capitated claims from claim payments.

   Capitation is a payment arrangement in which healthcare providers are paid a set amount for each enrolled person assigned to them per period of time. Claim information for individuals with capitation policies does not reflect actual costs or charges. This study excluded capitated claims during the assessment of financial information, which resulted in lower total claim payments. The population of individuals with capitation policies was not extensively evaluated. It is possible that they represent a sub-population of neurocysticercosis cases with higher medical care costs, however individual case review would be necessary to determine if this is evident.

2. Exclusion of denied claims from claim payments.

   Some denied claims are valid with real costs. However, if they are not resubmitted for payment, the costs of these uncontested denied claims are either borne by the insured or the provider and are not represented in the APAC database.

3. All-payers data does not capture healthcare services of the uninsured or the self-pay.

   Exclusion of the uninsured population may negatively bias financial results. In addition, it is possible the uninsured represent the most severely affected individuals with the highest potential healthcare costs.

4. Error in APAC

Errors in data reporting and assimilation could contribute to inaccuracies associated with APAC data, potentially biasing analyses. This is a new data reporting system and has not yet been rigorously analyzed.

Healthcare utilization and disease burden

Although, for the purpose of this study, claim numbers were used to describe disease prevalence, claim numbers may not be a reliable proxy for healthcare utilization. There is no consistent formula for claim submittal, and claim number may not necessarily correlate with the number of visits, case complexity, or claim payments, all of which help describe disease burden. Claims are entered by a variety of coders in numerous ways and are dependent upon the providers associated with the claim. The inconsistency of claim coding patterns may have contributed to the lack of significant results (non-differential misclassification) when assessing associations between the demographic variables, diagnosis variables and claim numbers noted in this study.

Payer type and payment source

Publically funded insurance was the primary payer of inpatient claims while private carriers represented the majority payer type of outpatient claims. These results are similar to those found in two previous hospital-based studies, which reported that publically funded insurance (Medicaid or Medicare) was the primary payer for neurocysticercosis hospitalizations. [12,17]

Place of Service / Health Care Settings

Prior studies do not include outpatient data so are negatively biased. This study provides a more complete picture of the spectrum of healthcare utilized by NCC cases and illustrates the substantial contribution of outpatient claims to the overall burden of neurocysticercosis. Furthermore, it highlights the different characteristics of inpatient and outpatient claims. Three-quarters of all claims in this study were from outpatient settings, which may explain the greater distribution of mental health and headache claims as compared to previous hospital-based studies, which report a greater distribution of seizure. Previous population-based studies do not include the outpatient population and primarily report presentations of greater clinical severity requiring inpatient admission.

Mental health disorders and headache associated with neurocysticercosis

Mental health disorders and headache occurred in approximately half of the total number of neurocysticercosis cases in the study, while seizure/epilepsy was diagnosed in less than one third of all individuals with neurocysticercosis and resulted in only 5% of the total number of claims in people with neurocysticercosis. This is in contrast to previous studies, which describe seizure/epilepsy as the most frequent NCC-associated diagnosis, and headache represented substantially less. [12,13,17,33]

There were over 700 mental health claims, comprising 8.6% of total paid neurologic claims in people with neurocysticercosis, while just over 6% of claims in people with neurocysticercosis were headache. The disease burden associated with mental health and headache claims has not been captured in other studies which rely on hospitalization data

only. This study captured the chronic presentations and manifestations of NCC, in addition to the acute health crises. It is apparent that healthcare providers who are unaware that mental health disorders and headache are common neurocysticercosis clinical presentations may overlook the diagnosis of neurocysticercosis if not aggressively searching for underlying etiologies.

The prevalence of mood and anxiety disorder claims suggests a common manifestation of disease in people with neurocysticercosis. Because symptom onset can often predate clinical diagnosis, education of health care providers, especially those involved in mental health and primary care, and particularly those who care for Hispanic immigrant populations, may aid in early identification and referral preventing serious complications.

Study Strengths and Weaknesses

All epidemiologic studies reliant upon administrative data have inherent limitations. The Oregon APAC database obtains information from insurance claims, which excludes a large and important uninsured population. As previously discussed, this results in substantial underestimation of claims and cases. It also presents a potentially biased view if uninsured cases differ in any way from insured cases. Frequency of outpatient visits or healthcare utilization is an obvious expected difference since the uninsured likely access healthcare less.

Furthermore, APAC data is entered by insurance claims coders who are not necessarily trained in scientific data entry. Coders may be biased and pressured to maximize claim

charges, which don't necessarily reflect the medical accuracy of the case. Non-essential insurance claim information may be omitted which results in data gaps. In addition, multiple coders may code a single case. Separation of coding by department and provider further compounds data entry. All of these issues potentially bias data, reduce the accuracy of the results, and make interpretation difficult. Lastly, there is no simple mechanism other than individual chart review, which is not possible given privacy requirements of the APAC program, to verify the medical accuracy of claims data.

However, this study was able to capture a broader spectrum of the population than previous studies and describes both inpatient and outpatient neurocysticercosis claims. In addition, APAC data allows for longitudinal tracking of claims, which provided chronological ordering of diagnoses and procedures. In this study, the date variable was not available to provide more accurate chronological tracking, although information representing the quarter in which the claim was made was provided. In future studies using APAC data, the date variable should be included to better describe longitudinal relationships.

Future Studies

A descriptive analysis of NCC-associated diagnoses, such as mental illness, headache, and seizure in the general population could be used to contrast the findings from this study and help determine the relative risk of outcomes associated with NCC. In addition, studies assessing claims prior to NCC diagnosis would improve understanding of early presentations of the disease. Further investigation of neurocysticercosis sequallae

associated with treatment, such as diabetes and other medication side effects, would provide more robust assessment of disease burden. A comparative analysis of medical providers and claim coders could help improve the accuracy of NCC claim coding, and identify coding bias.

Conclusion

Neurocysticercosis is prevalent in Oregon and is likely underestimated because cases are severely underreported and since there is no one database that captures the entire spectrum of disease. Because the onset of clinical signs often predates diagnosis, it may take considerable time and several episodes of care before a healthcare claim reflects the underlying etiology. Although not shown in this study, neurocysticercosis has a substantial effect on the immigrant Hispanic population as a result of healthcare burden. In addition, Hispanics are among the fastest growing US population groups and play a vital role in providing entry-level workers in the construction, agriculture, and the leisure and hospitality workforce. The reduction in worker productivity should be considered in the analysis of economic burden of the disease.

Outpatient claims are considerable and the associated diagnoses are different than inpatient claims. Previous studies have underestimated the prevalence of mental illness and headache associated with neurocysticercosis. Subsequently, greater effort should be made to provide neurocysticercosis education to mental health and primary care providers. In addition, more aggressive diagnostic workups should be considered for cases involving mental health illness and headache in Hispanic patients.

The APAC database does not appear to provide reliable demographic or financial information. Although this was a disappointing finding, it is possible that in the future, as the database is utilized with greater frequency, improvement of coding and reporting procedures may help improve the accuracy and completeness of information, which will allow greater utilization of the data by public health investigators and policy makers.

Recommendations

1. NCC should be included in the differential diagnoses list for cases involving mental heath illness and headache in Hispanic patients.
2. Greater effort should be made to provide neurocysticercosis education to mental health and primary care providers.
3. APAC in its current form should not be used for economic or demographic analysis of NCC.

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Appendix 1. Requested data elements

ALL MEDICAL CLAIMS

Data Elements

Name	Long Name	Requested?	Justification
year	Calendar year	YES	Always provided; no justification necessary
clmid	Claim ID	YES	To control for duplicate claims
line	Claim line	NO	
clmstatus	Claim status	YES	To categorize payer burden
cob	COB status	NO	
paytype	Payer type	YES	To categorize payer burden
prod	Product code	NO	
payer	APAC Payer	YES	To categorize payer burden
medflag	Medical coverage flag	NO	
rxflag	Pharmacy coverage flag	NO	
ohvmhflag	High value medical home flag	NO	
pebb	PEBB flag	NO	
oebb	OEBB flag	NO	
patid	Encrypted patient ID	YES	To group all claims by individual
personkey	Unique person identifier	YES	To group all claims by individual
gender	Gender	YES	For demographic analysis of cases
yob	Birth year	YES	For demographic analysis of cases
race	Race	YES	For demographic analysis of cases
ethn	Ethnicity	YES	For demographic analysis of cases
lang	Primary spoken language	YES	For demographic analysis of cases
msa	MSA	YES	For demographic analysis of cases
state	State	YES	To verify Oregon resident status
zip	ZIP code	NO	
prisk	ERG prospective risk	YES	To evaluate further potential disease burden
rrisk	ERG retrospective risk	YES	To evaluate further potential disease burden
pcat	ERG prospective risk category	YES	To evaluate further potential disease burden
rcat	ERG retrospective risk category	YES	To evaluate further potential disease burden
fromdate	From date	NO	
todate	To date	NO	
paydate	Payment date	NO	
paid	Total payment	YES	To evaluate economic burden of disease
copay	Co-payment	YES	To evaluate economic burden of disease
coins	Co-insurance	YES	To evaluate economic burden of disease
deduct	Deductible	YES	To evaluate economic burden of disease
oop	Patient pay amount	YES	To evaluate economic burden of disease
tob	Type of bill	NO	
pos	Place of service code	YES	To evaluate place of care
revcode	Revenue code	NO	
qty	Quantity	NO	
dx1	Principal diagnosis	YES	To define cases
dx2	Diagnosis 2	YES	To define cases
dx3	Diagnosis 3	YES	To define cases
dx4	Diagnosis 4	YES	To define cases
dx5	Diagnosis 5	YES	To define cases
dx6	Diagnosis 6	YES	To define cases
dx7	Diagnosis 7	YES	To define cases
dx8	Diagnosis 8	YES	To define cases
dx9	Diagnosis 9	YES	To define cases
dx10	Diagnosis 10	YES	To define cases
dx11	Diagnosis 11	YES	To define cases
dx12	Diagnosis 12	YES	To define cases
dx13	Diagnosis 13	YES	To define cases
poa1	POA code 1	YES	To evaluate time of diagnosis
poa2	POA code 2	YES	To evaluate time of diagnosis
poa3	POA code 3	YES	To evaluate time of diagnosis
poa4	POA code 4	YES	To evaluate time of diagnosis
poa5	POA code 5	YES	To evaluate time of diagnosis
poa6	POA code 6	YES	To evaluate time of diagnosis
poa7	POA code 7	YES	To evaluate time of diagnosis
poa8	POA code 8	YES	To evaluate time of diagnosis
poa9	POA code 9	YES	To evaluate time of diagnosis
poa10	POA code 10	YES	To evaluate time of diagnosis

poa11	POA code 11	YES	To evaluate time of diagnosis
poa12	POA code 12	YES	To evaluate time of diagnosis
poa13	POA code 13	YES	To evaluate time of diagnosis
px1	Principal inpt procedure	YES	To evaluate frequency of related clinical procedures
px2	Procedure 2	YES	To evaluate frequency of related clinical procedures
px3	Procedure 3	YES	To evaluate frequency of related clinical procedures
px4	Procedure 4	YES	To evaluate frequency of related clinical procedures
px5	Procedure 5	YES	To evaluate frequency of related clinical procedures
px6	Procedure 6	YES	To evaluate frequency of related clinical procedures
px7	Procedure 7	YES	To evaluate frequency of related clinical procedures
px8	Procedure 8	YES	To evaluate frequency of related clinical procedures
px9	Procedure 9	YES	To evaluate frequency of related clinical procedures
px10	Procedure 10	YES	To evaluate frequency of related clinical procedures
px11	Procedure 11	YES	To evaluate frequency of related clinical procedures
px12	Procedure 12	YES	To evaluate frequency of related clinical procedures
px13	Procedure 13	YES	To evaluate frequency of related clinical procedures
proccode	CPT or HCPCS procedure code	YES	To evaluate frequency of related clinical procedures
mod1	Prodcure code modifier 1	YES	To evaluate frequency of related clinical procedures
mod2	Prodcure code modifier 2	YES	To evaluate frequency of related clinical procedures
mod3	Prodcure code modifier 3	YES	To evaluate frequency of related clinical procedures
mod4	Prodcure code modifier 4	YES	To evaluate frequency of related clinical procedures
ptstatus	Discharge status	YES	To assess outcome of disease
los	Length of stay	YES	To assess burden of disease
msdrg	MS-DRG	YES	To evalaute alternative case definitions
attid	Attending provider ID	NO	
spec	Attending provider specialty	YES	To evaluate burden of care
billid	Billing provider ID	NO	
entity	Billing provider entity name	NO	

Appendix 2. List of NCC associated ICD-9-CM diagnosis and procedure codes

Technical Appendix. The study case definition required an ICD-9-CM diagnostic code for cysticercosis (1231) *and* at least one other ICD-9-CM diagnostic or procedural code for a neurologic manifestation associated with neurocysticercosis.

ICD-9-CM Diagnostic codes

Meningitis (except that caused by tuberculosis or sexually transmitted disease)
00321 0360 0470 0471 0478 0479 0490 0491 0530 05472 0721 10081 11283 1142 11501 11511 11591 3200 3201 3202 3203 3207 3208 32081 32082 32089 3209 3210 3211 3212 3213 3214 3218 3220 3221 3222 3229

Encephalitis (except that caused by tuberculosis or sexually transmitted disease)
0361 0462 0498 0499 0520 0543 0550 05601 05821 05829 0620 0621 0622 0623 0624 0625 0628 0629 0630 0631 0632 0638 0639 064 0662 0722 1300 1390 3230 32301 32302 3231 3232 3234 32341 32342 3235 32351 32352 3236 32361 32362 32363 3237 32371 32372 3238 32381 32382 3239 34120 34121 34122

Other CNS infection and poliomyelitis
04500 04501 04502 04503 04510 04511 04512 04513 04520 04521 04522 04523 04590 04591 04592 04593 0460 0461 04611 04619 0463 04671 04672 04679 0468 0469 048 138 3240 3241 3249 326 V1202

Epilepsy; convulsions
3450 34500 34501 3451 34510 34511 3452 3453 3454 34540 34541 3455 34550 34551 3456 34560 34561 3457 34570 34571 3458 34580 34581 3459 34590 34591 7803 78031 78032 78033 78039

Headache; including migraine
33900 33901 33902 33903 33904 33905 33909 33910 33911 33912 33920 33921 33922 3393 33941 33942 33943 33944 33981 33982 33983 33984 33985 33989 3460 34600 34601 34602 34603 3461 34610 34611 34612 34613 3462 34620 34621 34622 34623 34630 34631 34632 34633 34640 34641 34642 34643 34650 34651 34652 34653 34670 34671 34672 34673 3468 34680 34681 34682 34683 3469 34690 34691 34692 34693 7840

Coma; stupor; and brain damage
3481 7800 78001 78003 78009

Inflammation; infection of eye (except that caused by tuberculosis or sexually transmitted disease)
0213 03281 05320 05321 05322 05329 05440 05441 05442 05443 05444 05449 05571 0760 0761 0769 0770 0771 0772 0773 0774 0778 0779 07798 07799 11502 11512 11592 1301 1302 1391 36000 36001 36002 36003 36004 36011 36012 36013 36014 36019 36300 36301 36303 36304 36305 36306 36307 36308 36310 36311 36312 36313 36314 36315 36320 36321 36322 36400 36401 36402 36403 36404 36405 36410 36411 36421 36422 36423 36424 3643 37020 37021 37022 37023 37024 37031 37032 37033 37034 37035 37040 37044 37049 37050 37052 37054 37055 37059 3708 3709 37200 37201 37202 37203 37204 37205 37206 37210 37211 37212 37213 37214 37215 37220 37221 37222 37230 37231 37233 37239 37300 37301 37302 37311 37312 37313 37331 37332 37333 37334 3734 3735 3736 3738 3739 37500 37501 37502 37503 37530 37531 37532 37533 37541 37542 37543 37600 37601 37602 37603 37604 37610 37611 37612 37613 37730 37731 37732 37733 37734 37739 37900 37901 37902 37903 37904 37905 37906 37907 37909 37960 37961 37962 37963

Other nervous system disorders
325 32702 32715 32730 32731 32732 32733 32734 32735 32736 32737 32739 32753 33183 3321 33720 33721 33722 33729 3380 33811 33812 33818 33819 33821 33822 33828 33829 3383 3384 3410 3411 3418 3419 34461 347 34700 34701 34710 34711 3480 3482 3483 34830 34831 34839 3484 3485 3488 34881 34882 34889 3489 3492 34981 34982 34989 3499 3501 3502 3508 3509 3510 3511 3518 3519 3520 3521 3522 3523 3524 3525 3526 3529 3530 3531 3532 3533 3534 3535 3536 3538 3539 3540 3541 3542 3543 3544 3545 3548 3549 3550 3551 3552 3553 3554 3555 3556 3557 35571 35579 3558 3559 3560 3561 3562 3563 3564 3568 3569 3570 3571 3572 3573 3574 3576 3577 3578 35781 35782 35789 3579 3580 35800 35801 3581 3582 35830 35831 35839 3588 3589 3590 3591 3592 35921 35922 35923 35924 35929 3593 3594 3595 3596 35971 35979 3598 35981 35989 3599 7810 7811 7812 7813 7817 7818 7820 7843 7845 78451 78452 78459 78460 78461 78469 7920 7930 79400 79401 79402 79409 79410 79411 79412 79413 79414 79415 79416 79417 79419 7961 79951 79952 79953 79954 79955 79959 V124 V1240 V1241 V1242 V1249 V415 V452 V484 V485 V493 V530 V5301 V5302 V5309

Acute cerebrovascular disease
34660 34661 34662 34663 430 431 4320 4321 4329 43301 43311 43321 43331 43381 43391 4340 43400 43401 4341 43410 43411 4349 43490 43491 436

Other and ill-defined cerebrovascular disease
4370 4371 4373 4374 4375 4376 4377 4378 4379

Transient cerebral ischemia
4350 4351 4352 4353 4358 4359

Syncope
7802

Adjustment disorders
3090 3091 30922 30923 30924 30928 30929 3093 3094 30982 30983 30989 3099

Anxiety disorders
29384 30000 30001 30002 30009 30010 30020 30021 30022 30023 30029 3003 3005 30089 3009 3080 3081 3082 3083 3084 3089 30981 3130 3131 31321 31322 3133 31382 31383

Attention-deficit, conduct, and disruptive behavior disorders
31200 31201 31202 31203 31210 31211 31212 31213 31220 31221 31222 31223 3124 3128 31281 31282 31289 3129 31381 31400 31401 3141 3142 3148 3149

Delirium, dementia, and amnestic and other cognitive disorders
2900 29010 29011 29012 29013 29020 29021 2903 29040 29041 29042 29043 2908 2909 2930 2931 2940 2941 29410 29411 29420 29421 2948 2949 3100 3102 3108 31081 31089 3109 3310 3311 33111 33119 3312 33182 797

Impulse control disorders, NEC
31230 31231 31232 31233 31234 31235 31239

Mood disorders
29383 29600 29601 29602 29603 29604 29605 29606 29610 29611 29612 29613 29614 29615 29616 29620 29621 29622 29623 29624 29625 29626 29630 29631 29632 29633 29634 29635 29636 29640 29641 29642 29643 29644 29645 29646 29650 29651 29652 29653 29654 29655 29656 29660 29661 29662 29663 29664 29665 29666 2967 29680 29681 29682 29689 29690 29699 3004 311

Personality disorders
3010 30110 30111 30112 30113 30120 30121 30122 3013 3014 30150 30151 30159 3016 3017 30181 30182 30183 30184 30189 3019

Schizophrenia and other psychotic disorders
29381 29382 29500 29501 29502 29503 29504 29505 29510 29511 29512 29513 29514 29515 29520 29521 29522 29523 29524 29525 29530 29531 29532 29533 29534 29535 29540 29541 29542 29543 29544 29545 29550 29551 29552 29553 29554 29555 29560 29561 29562 29563 29564 29565 29570 29571 29572 29573 29574 29575 29580 29581 29582 29583 29584 29585 29590 29591 29592 29593 29594 29595 2970 2971 2972 2973 2978 2979 2980 2981 2982 2983 2984 2988 2989

Suicide and intentional self-inflicted injury
E9500 E9501 E9502 E9503 E9504 E9505 E9506 E9507 E9508 E9509 E9510 E9511 E9518 E9520 E9521 E9528 E9529 E9530 E9531 E9538 E9539 E954 E9550 E9551 E9552 E9553 E9554 E9555 E9556 E9557 E9559 E956 E9570 E9571 E9572 E9579 E9580 E9581 E9582 E9583 E9584 E9585 E9586 E9587 E9588 E9589 E959 V6284

Miscellaneous mental disorders
29389 2939 30011 30012 30013 30014 30015 30016 30019 3006 3007 30081 30082 3021 3022 3023 3024 30250 30251 30252 30253 3026 30270 30271 30272 30273 30274 30275 30276 30279 30281 30282 30283 30284 30285 30289 3029 3060 3061 3062 3063 3064 30650 30651 30652 30653 30659 3066 3067 3068 3069 3071 30740 30741 30742 30743 30744 30745 30746 30747 30748 30749 30750 30751 30752 30753 30754 30759 30780 30781 30789 3101 316 64840 64841 64842 64843 64844 V402 V403 V4031 V4039 V409 V673

ICD-9-CM Procedural codes

Incision and excision of CNS
0101 0109 0121 0122 0123 0124 0125 0126 0127 0128 0131 0132 0139 0141 0142 0151 0152 0153 0159

Insertion; replacement; or removal of extracranial ventricular shunt
0231 0232 0233 0234 0235 0239 0242 0243

Computerized axial tomography (CT) scan head
8703

Magnetic resonance imaging
0032 8891 8892 8893 8894 8895 8896 8897 8899

Electroencephalogram (EEG)
8914

Appendix 3. List of NCC-associated CPT procedure codes

EEG	
95827	Electroencephalogram (EEG); all night recording
95812	Electroencephalogram (EEG) extended monitoring; 41-60 minutes
95824	Electroencephalogram (EEG); cerebral death evaluation only
95822	Electroencephalogram (EEG); recording in coma or sleep only; 20-40 minutes
95813	Electroencephalogram (EEG) extended monitoring; greater than 1 hour
95816	Electroencephalogram (EEG); including recording awake and drowsy; 20-40 minutes
95819	Electroencephalogram (EEG); including recording awake and asleep; 20-40 minutes
95830	Insertion by physician or other qualified health care professional of sphenoidal electrodes for electroencephalographic (EEG) recording
95955	Electroencephalogram (EEG) during nonintracranial surgery (eg, carotid surgery)
95957	Digital analysis of electroencephalogram (EEG) (eg, for epileptic spike analysis) When extra time is needed by the technician to process the data or physician to analyze the data (eg, dipole analysis).
95958	Wada activation test for hemispheric function, including electroencephalographic (EEG) monitoring

95950	Monitoring for identification and lateralization of cerebral seizure focus, electroencephalographic (eg, 8 channel EEG) recording and interpretation, each 24 hours
95951	Monitoring for localization of cerebral seizure focus by cable or radio, 16 or more channel telemetry, combined electroencephalographic (EEG) and video recording and interpretation (eg, for presurgical localization), each 24 hours
95953	Monitoring for localization of cerebral seizure focus by computerized portable 16 or more channel EEG, electroencephalographic (EEG) recording and interpretation, each 24 hours, unattended
95956	Monitoring for localization of cerebral seizure focus by cable or radio, 16 or more channel telemetry, electroencephalographic (EEG) recording and interpretation, each 24 hours, attended by a technologist or nurse
95954	Pharmacological or physical activation requiring physician or other qualified health care professional attendance during EEG recording of activation phase (eg, thiopental activation test)

CT

70450	Computed tomography, head or brain without contrast material
70460	Computed tomography, soft tissue neck without contrast material
70490	Computed tomography, soft tissue neck without contrast material
70491	Computed tomography, soft tissue neck with contrast material(s)
70486	Computed tomography, maxillofacial area without contrast material
70487	Computed tomography, maxillofacial area with contrast material(s)
70470	Computed tomography, head or brain without contrast material, followed by contrast material(s) and further sections
70480	Computed tomography, orbit, sella, or posterior fossa or outer, middle, or inner ear without contrast material
70481	Computed tomography, orbit, sella, or posterior fossa or outer, middle, or inner ear with contrast material(s)
70498	Computed tomographic angiography, neck, with contrast material(s), including noncontrast images, if performed, and image...
70482	Computed tomography, orbit, sella, or posterior fossa or outer, middle, or inner ear without contrast material, followe...
70496	Computed tomographic angiography, head, with contrast material(s), including noncontrast images, if performed, and image...

MRI

70551	Magnetic resonance (eg, proton) imaging, brain (including brain stem) without contrast material
70552	Magnetic resonance (eg, proton) imaging, brain (including brain stem) with contrast material(s)
70554	Magnetic resonance imaging, brain, functional MRI including test selection and administration of repetitive body part m...
70555	Magnetic resonance imaging, brain, functional MRI requiring physician or psychologist administration of entire neurofun...
70543	Magnetic resonance (eg, proton) imaging, orbit, face, and/or neck without contrast material(s), followed by contrast ma...
70557	Magnetic resonance (eg, proton) imaging, brain (including brain stem and skull base), during open intracranial procedure...
70558	Magnetic resonance (eg, proton) imaging, brain (including brain stem and skull base), during open intracranial procedure...
70559	Magnetic resonance (eg, proton) imaging, brain (including brain stem and skull base), during open intracranial procedure...

Shunt

62160	Neuroendoscopy Procedures on the Skull, Meninges, and Brain
62161	Neuroendoscopy Procedures on the Skull, Meninges, and Brain
62256	Removal of complete cerebrospinal fluid shunt system without replacement
62252	Reprogramming of programmable cerebrospinal shunt
62225	Replacement or irrigation, ventricular catheter
62258	Removal of complete cerebrospinal fluid shunt system with replacement by similar or other shunt at same operation
62194	Replacement or irrigation, subarachnoid/subdural catheter
61070	Injection, Drainage, or Aspiration Procedures on the Skull, Meninges, and Brain
62201	Ventriculocisternostomy, third ventricle stereotactic, neuroendoscopic method
62200	Ventriculocisternostomy, third ventricle
62220	Creation of shunt ventriculo-atrial, -jugular, -auricular
62223	Creation of shunt ventriculo-peritoneal, -pleural, other terminus
62190	Creation of shunt subarachnoid/subdural-atrial, -jugular, -auricular
62192	Creation of shunt subarachnoid/subdural-peritoneal, -pleural, other terminus
62180	Ventriculocisternostomy (Torkildsen type operation)
61107	Twist drill hole(s) for subdural, intracerebral, or ventricular puncture for implanting ventricular catheter, pressure ...
61210	Burr hole(s) for implanting ventricular catheter, reservoir, EEG electrode(s), pressure recording device, or other cere...
61026	Ventricular puncture through previous burr hole, fontanelle, suture, or implanted ventricular catheter/reservoir with i...
62230	Replacement or revision of cerebrospinal fluid shunt, obstructed valve, or distal catheter in shunt system

Surgery: Central Nervous System

61320	Craniectomy or craniotomy, drainage of intracranial abscess supratentorial
61321	Craniectomy or craniotomy, drainage of intracranial abscess infratentorial
61521	Craniectomy for excision of brain tumor, infratentorial or posterior fossa midline tumor at base of skull
61522	Craniectomy, infratentorial or posterior fossa for excision of brain abscess
61218	Craniectomy for excision of brain tumor, infratentorial or posterior fossa except meningioma, cerebellopontine angle tu...
61514	Craniectomy, trephination, bone flap craniotomy for excision of brain abscess, supratentorial
61570	Craniectomy or craniotomy with excision of foreign body from brain
61524	Craniectomy, infratentorial or posterior fossa for excision or fenestration of cyst
61510	Craniectomy, trephination, bone flap craniotomy for excision of brain tumor, supratentorial, except meningioma
61516	Craniectomy, trephination, bone flap craniotomy for excision or fenestration of cyst, supratentorial
61534	Craniotomy with elevation of bone flap for excision of epileptogenic focus without electrocorticography during surgery
61536	Craniotomy with elevation of bone flap for excision of cerebral epileptogenic focus, with electrocorticography during s...
61537	Craniotomy with elevation of bone flap for lobectomy, temporal lobe, without electrocorticography during surgery
61575	Transoral approach to skull base, brain stem or upper spinal cord for biopsy, decompression or excision of lesion
61323	Craniectomy or craniotomy, decompressive, with or without duraplasty, for treatment of intracranial hypertension, withou...

61576	Transoral approach to skull base, brain stem or upper spinal cord for biopsy, decompression or excision of lesion requi...
62164	Neuroendoscopy, intracranial with excision of brain tumor, including placement of external ventricular catheter for dra...
61600	Resection or excision of neoplastic, vascular or infectious lesion of base of anterior cranial fossa extradural
61601	Resection or excision of neoplastic, vascular or infectious lesion of base of anterior cranial fossa intradural, includ...
61750	Stereotactic biopsy, aspiration, or excision, including burr hole(s), for intracranial lesion
61605	Resection or excision of neoplastic, vascular or infectious lesion of infratemporal fossa, parapharyngeal space, petrous...
61606	Resection or excision of neoplastic, vascular or infectious lesion of infratemporal fossa, parapharyngeal space, petrous...
61607	Resection or excision of neoplastic, vascular or infectious lesion of parasellar area, cavernous sinus, clivus or midlin...
61608	Resection or excision of neoplastic, vascular or infectious lesion of parasellar area, cavernous sinus, clivus or midlin...
61615	Resection or excision of neoplastic, vascular or infectious lesion of base of posterior cranial fossa, jugular foramen, ...
61616	Resection or excision of neoplastic, vascular or infectious lesion of base of posterior cranial fossa, jugular foramen, ...
61781	Stereotaxis Procedure on the Skull, Meninges, and Brain