MONETARY BURDEN OF *TAENIA SOLIUM* CYSTICERCOSIS IN MEXICO

A Dissertation

by

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ABSTRACT

Cysticercosis is a parasitic disease caused by the larva of the cestode *Taenia solium*. The objectives of this study were to estimate 1) the annual cost of neurocysticercoss (NCC) in outpatients and hospitalized patients, 2) the pre-hospitalization, hospitalization, and post-hospitalization costs for hospitalized NCC patients, and 3) the total societal cost of cysticercosis in Mexico. In order to accomplish these objectives, a case series was conducted in two neurology referral hospitals in Mexico City. Information on presenting clinical manifestations, diagnostic tests, hospitalizations, surgical procedures, and other treatments received by NCC patients was collected from medical charts. A questionnaire was used to evaluate productivity losses and out-of-pocket expenses related to NCC. In order to estimate the societal cost of cysticercosis, epidemiologic and economic parameters were obtained from the published literature, government reports, and interviews with ministry of health workers, primary care providers, and secondary care providers.

Interviews were conducted and medical charts reviewed for 224 NCC patients. The annual average per patient direct costs were U.S.$ 503 (95% CI: 414 – 592) and U.S.$ 438 (95% CI: 322 – 571) for outpatients without a history of hospitalization and/or surgery seen at the two referral hospitals. These costs increased to U.S.$ 2,506 (95% CI: 1,797 – 3,215) and U.S.$ 2,170 (95% CI: 1,303 – 3,037) for patients with a history of hospitalization and/or surgery. The medical charts of 108 patients hospitalized for NCC were reviewed to estimate pre-hospitalization, hospitalization, and post-hospitalization costs. The average per-patient pre-hospitalization and hospitalization costs were U.S.$ 257 (95% CI: 185 – 329) and U.S.$ 2,576 (95% CI: 2,244 – 2,908), respectively. Post-hospitalization costs decreased over time, with

estimates for the first five years post-hospitalization of U.S.$ 475 (95% CI: 423 – 527), U.S.$ 228 (95% CI: 167 – 288), U.S.$ 157 (95% CI: 111 – 202), U.S.$ 150 (95% CI: 106 – 204), and U.S.$ 91 (95% CI: 27 – 154), respectively. The total 2012 monetary losses associated with people with NCC-associated epilepsy and NCC-associated severe chronic headaches, in Mexico, along with losses to the agriculture sector, was estimated to be U.S.$ 250,219,772 (95% CR: 145,560,590 - 384,051,262). Cysticercosis continues to create health disparities and significant economic losses in Mexico.

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NOMENCLATURE

CI	Confidence Interval
CR	Credible Region
CSF	Cerebral Spinal Fluid
CT	Computed Tomography
DALYs	Disability Adjusted Life Years
DW	Disability Weight
EITB	Enzyme Linked Immunoelectrotransfer Blot Assay
ELISA	Enzyme Linked Immunosorbent Assay
GBD	Global Burden of Disease
IMSS	Hospital de Especialidades of the Instituto Mexicano del Seguro Social
INNN	Instituto Nacional de Neurologia y Neurocirugia
MRI	Magnetic Resonance Imaging
NCC	Neurocysticercosis
PTO	Person Trade Off
PWE	People with Epilepsy
SF-12 v2	Short Form 12 Version 2
WHO	World Health Organization
YLD	Years of Life Lived with Disability
YLL	Years of Life Lost

TABLE OF CONTENTS

Page

LIST OF FIGURES

LIST OF TABLES

CHAPTER I

INTRODUCTION AND LITERATURE REVIEW*

Taenia solium (*T. solium*) cysticercosis is a cestode zoonosis with public health importance. Pigs are the intermediate hosts and become infected when they ingest *T. solium* eggs that are shed in the feces of infected humans. Ingested larvae hatch in the intestine of the pig, penetrate the intestinal mucosa, reach the blood stream and migrate to tissues, including muscle. Humans are the definitive hosts of *T. solium* and become infected with the intestinal adult tapeworm (taeniasis) by ingesting undercooked pork containing cysticerci. Humans can also become accidental intermediate hosts after ingesting *T. solium* eggs leading to cysticercosis. The condition is predominantly found and considered endemic in Latin American, Asian, and African countries where pigs are raised using traditional methods, meat inspection is insufficient, and sanitation is poor [1-3]. However, it is now increasingly being diagnosed in other regions such as the United States, Western Europe, and Canada due to an increasing flow of immigrants from endemic areas who may have taeniasis or cysticercosis [4-7].

Neurocysticercosis (NCC) occurs when immature *T. solium* larvae migrate to the central nervous system. When NCC manifests, it is often in the form of epilepsy/seizures, hydrocephalus, severe chronic headaches, focal deficits, increased intracranial pressure, dementia, vasculitis, or stroke. Among these clinical manifestations, epilepsy/seizures, headaches, focal deficits and increased intracranial pressure are the most common [8,9]. The social consequences of NCC potentially include stigmatization, incapacitation, and

decreased work productivity [10]. In endemic countries, the stigma associated with epilepsy may have a greater impact on patients' lives than the clinical manifestations of the disease itself [11]. In addition, due to the reduction in quality of life and the psychological effects of the condition, work productivity might be further decreased [9,12,13].

In pigs, infection with the larval stage of the parasite results in the development of cysts in the skeletal muscles and less commonly in the heart, diaphragm, brain, and other organ systems. The presence of these cysts can lead to partial or full condemnation of the carcass and economic losses in areas where meat is inspected [2]. In some areas, pig traders look for the presence of cysts under the tongue before buying pigs, and will offer a lower price for infected animals [2,14]. This parasite can, therefore, reduce the household income of farmers.

There is a need to evaluate the socioeconomic impact, or burden, of this condition on endemic communities. Both non-monetary and monetary methods can be employed [15]. These estimates may then be compared to other locally important health or agricultural conditions to prioritize disease control initiatives. Disease burden estimates can subsequently be used to compare alternative control strategies for cysticercosis, as well as other diseases affecting the population, through cost-utility and cost-benefit analyses. Although NCC is endemic in many areas of the world and is believed to be associated with considerable economic losses, very few studies have been conducted to evaluate the burden of NCC [16-20]. Therefore, more comprehensive studies are needed to estimate the actual burden of NCC in endemic areas in order to allocate resources for health interventions.

I.1 Life cycle

The parasite needs two hosts to complete its life cycle. Humans are the definitive hosts of *T. solium* and pigs are the intermediate hosts. Pigs become infected when they ingest *T. solium* eggs that are shed in the feces of infected humans. Ingested larvae hatch in the pig's intestine, penetrate the intestinal mucosa, reach the blood stream, and migrate to tissues, including muscle [21]. Humans become infected with the adult tapeworm (taeniasis) by ingesting undercooked pork containing *T. solium* cysticerci. Eggs and/or mature proglottids are regularly excreted by human tapeworm carriers. The adult parasite develops proglottids, which mature, become gravid, detach, and migrate to the anus or are passed in the stool. Adult worms can have more than 1,000 proglottids. The eggs contained in the gravid proglottids are released after the proglottids are passed with the feces. A single adult parasite can produce more than 50,000 eggs per proglottid [22]. Humans can also act as accidental intermediate hosts either by ingestion of food contaminated with feces/eggs or by autoinfection. After reaching the small intestine, eggs hatch and the embryos (oncospheres) migrate through the mucosa to enter the circulation, which then carries the larvae to various tissues, including the central nervous system (CNS), eyes, and striated muscle, leading to cysticercosis and/or (NCC [22] (Figure 1).

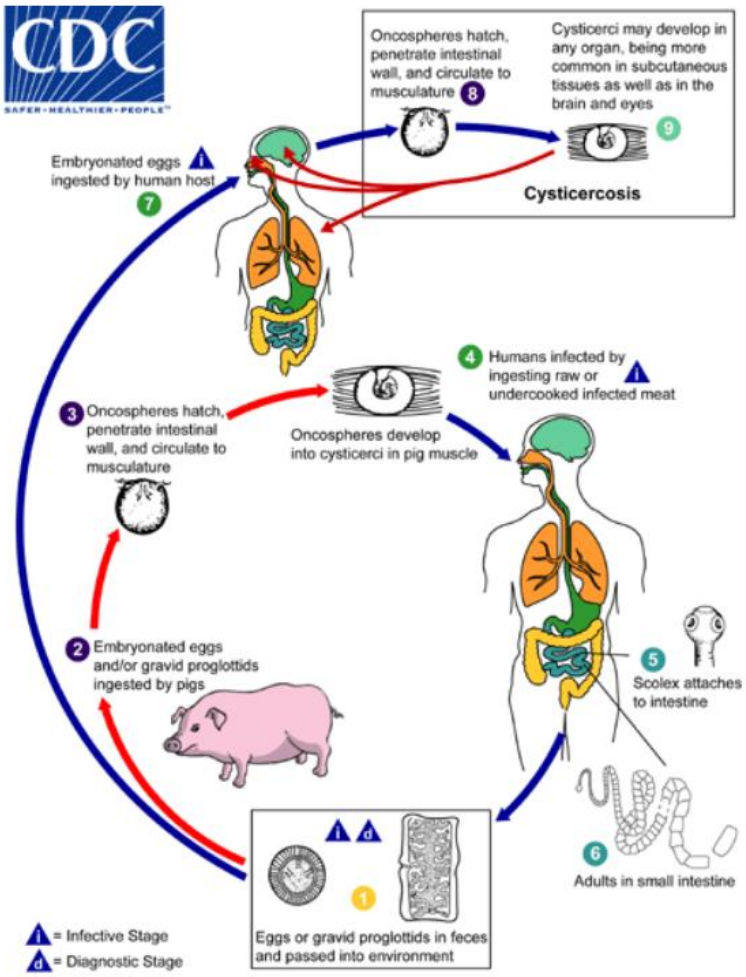

Figure 1: Life cycle of *T. solium* (Adapted from: [22])

I.2 Methods for evaluating the burden of zoonotic infections

Taenia solium cysticercosis results in mortality, morbidity, and economic losses in affected human and animal populations. To evaluate the burden of cysticercosis, the monetary and non-monetary impacts of the disease on human health, agriculture, and society must be considered comprehensively [15]. Measuring the burden of cysticercosis is challenging because it requires various types of data from valid studies conducted in human and pig populations. Because of those challenges, it is recommended to focus the evaluation on a certain period and to

one geographical area where high quality epidemiological and clinical studies have been conducted, preferably in both pigs and humans. The disadvantage of such an approach is that the data cannot be generalized to other areas.

Certain types of epidemiological data are required for the estimation of both the non-monetary and the monetary burden of cysticercosis [15]. In humans, these data include the frequency of disease occurrence, the frequency and duration of each NCC-associated manifestation; NCC-associated mortality; the proportion of patients with NCC who seek care in clinics and hospitals of various levels; the proportion of patients who seek care from traditional healers; and the number (or incidence) of cases of NCC diagnosed after care has been sought. In pigs, the data required include the proportion of pigs that are inspected pre or post-mortem and the proportion of infected pigs diagnosed pre or post-mortem [15]. Such data may be found in the published/unpublished literature and national or regional databases. When some aspects of the data are unavailable, the opinion of local experts may be sought.

In estimating the burden of NCC, there is the additional challenge that the internationally recognized definition of NCC requires the use of diagnostic imaging (computed tomography (CT) scan or magnetic resonance imaging (MRI)) or autopsy [23]. The absence of advanced diagnostic imaging facilities limits the evaluation of the burden of NCC in many areas of the world, and especially in the poorest regions where the disease is likely to be most prevalent. Serological tests are designed to measure the exposure to or current infection with cysticercosis [24], but can show low specificity and sensitivity in the diagnosis of NCC, depending on the number and stages of lesions present in the brain [25]. Therefore, test accuracy needs to be considered when evaluating frequency of infection [26].

I.2.1 Measuring the non-monetary burden of cysticercosis

Specific measures have been designed to estimate the non-monetary burden of human diseases [15,27]. One of the most informative measures of non-monetary burden is “utility”, a health economics concept which measures the preference that people have for certain health status along a continuum [28]. Utility theory arose from Jeremy Bentham's utilitarian philosophy, which was first proposed in 1789. Broadly speaking, utility has always been synonymous with preference, the more preferable an outcome, the greater the outcome’s "utility" [29]. Several Health Adjusted Life Years (HALYs) metrics have been developed as indicators of “utility”. HALYs are summary measures of population health that enable measures of mortality to be combined with measures of disability associated with each sequela (manifestation) of the disease of interest into one metric [28].

There are two types of HALYs that have been commonly used in estimating human burden of disease: Quality Adjusted Life Years (QALYs) and Disability Adjusted Life Years (DALYs). Even though QALYs and DALYs may be used to estimate utility, they were developed to serve different purposes. Where DALYs are meant to be used as an objective, population-based measure, QALYs are meant to be used as a subjective, individual-based measure of utility of health. DALYs are used to compare disease burdens in many different populations on a comparable basis. QALYs are used to assess individual preferences for various outcomes from complex interventions or measure the ability of the subject to perform some task or function. In addition, these measures use opposite scales. The DALY is a negative concept, with one DALY being the equivalent of one year lived completely disabled (analogous to death) whereas the QALY is a positive concept, with one QALY being the equivalent of one year of

healthy life [28]. Therefore, control strategies would aim to minimize DALYs and maximize QALYs.

I.2.1.1 Quality Adjusted Life Years (QALYs)

The ideal way of measuring quality of life is to attribute a utility, or a weighted preference for a certain health status. Utility is not only good for measuring the status of patients who have one clinical manifestation, but also for people suffering from several ailments. In theory, the utility of a health status is best measured with choice-based methods, which include uncertainty, such as the standard gamble method. Other choice-based methods, without uncertainty, include paired person-trade-off and time-trade-off techniques [29]. Utility measures are based on Paretian welfare economics, which requires that each individual be the judge of his or her own welfare. However, in practice, these methods are difficult to implement because different people have different reactions when faced with uncertainty and choices, especially when these are theoretical. For example, in the standard gamble method, the patients are asked to find the probability "*p*" at which they would be unable to choose between remaining in their current state of health or dying immediately with a probability of *p* (and living healthy with a probability of 1-*p*). Given the difficulty in implementing such measures, several groups of researchers have developed multi-attribute classification systems implemented in the form of scale-based questionnaires. Each answer to the scaled questions contributes a certain weight towards calculating utility. The utility weights are determined during studies where both the questionnaire and one of the choice-based methods are used, and then assumed generalizable to other contexts. Multi-attribute questionnaires are more commonly used than choice-based measures in QALYs studies. One advantage of multi-attribute questionnaires is that they may not

only be used to estimate utility, but also to assess the perceptions of patients regarding different aspects of their health (i.e., mental, physical, social functioning).

QALYs combine quantitative estimates of death and frequency and duration of disease with a qualitative assessment of how well (or not) patients can live with the disease. In other words, rather than just counting the number of people with the disease, QALYs try to "adjust" for how well people can live with the disease. Individuals experience different health states, where the health states are weighted according to their utility scores. Utilities are measured on a cardinal scale of 0-1. More preferable states receive more weight. A year of perfect health is worth 1 and a year of less than perfect health is worth less than 1. Death is considered to be equivalent to 0. However, some health states may be considered worse than death and have negative values. Therefore, QALYs are a product of life expectancy and a measure of the quality of remaining life years, with weights placed on time spent in different health states [29].

The multi-attribute measurement scales most commonly used in developing countries, where NCC is endemic, are the Euro-Qol (EQ-5D) and the Short Form-12 (SF-12) [15,30]. These tools provide patient-based determination of quality of life and can be used to compare perceptions of physical, mental, and social health among patients with different diseases (or lack of disease), different stages of the same disease, or before and after treatment of the disease. The latter approach is often used in clinical trials where a drug, while very effective in treating the disease, may be linked to numerous side effects, which could lead to worse quality of life than the disease itself.

Although QALYs are commonly used metrics in health economics, they also present some limitations. For example, adaptation of patients to certain symptoms may mask the impact of chronic disability [31]. In addition, it is difficult to assign a single utility score to those

diseases that cause a variety of clinical manifestations, such as NCC [32]. One important criticism of QALYs (which some view as an advantage), is that QALYs are based on poor measurement techniques. In particular, values are often developed with small, non-representative sample sizes [33]. Measures are subjective and not meant to be generalized to society as a whole. QALYs associated with a disease in one country (or region) could not be used to estimate the burden in another region (or country). For example, having epilepsy in the United States would have very different social and functioning values than in Sub-Saharan Africa. This difficulty in using QALYs for international comparison led a group of researchers to develop a completely different type of metric for measuring burden: the DALY. Lastly, there are several concerns regarding the validity and reliability of measurements focused on the utility value of health status [34]. Since measuring utility values is a challenging process, different QALY methods can produce different results [33]. Also, populations may explain their state of illnesses and wellness differently. For example, physicians might assign different utility values than the general population. This has been shown in a study examining depression where patients assigned a utility value of 0.31 and physician assigned a utility value of 0.42 [35].

I.2.1.2 Disability Adjusted Life Years (DALYs)

DALYs were first constructed for the Global Burden of Disease (GBD) Study in 1990 in order to provide a comparable measure of output for interventions, program and sector evaluations, and planning [36]. The GBD Study was conducted to evaluate the non-monetary burden of a variety of infectious and non-infectious conditions, as well as risk factors, on pre-defined regions of the world. The latest comprehensive assessment of the burden of diseases was for the year 2016 [37]. The DALY is a summary measure of population health that assesses the

disability and early mortality associated with the condition of interest. DALYs measure the gap in years between age at death and standard life expectancy and combines it with time lived in states other than excellent health (disabled). They are obtained by summing years of life lost (YLL) from premature death and healthy years lost due to disability (YLD). The formulas used for the calculation of YLL and YLD are described below:

YLL = N * L…….Eq. 1

where N = number of deaths per age-sex group, L = remaining life expectancy at age of death

YLD = I * DW * D…….Eq. 2

where I = age and sex specific estimates of incidence, DW = disability weight, D = average duration of disability.

The GBD Study 2010 and subsequent versions (GBD 2013, 2015 and 2016) based the YLD calculation on prevalence rather than incidence [37-39]:

YLD = P * DW.....Eq. 3

where P = number of prevalent cases, DW= disability weight.

The incidence-based YLD approach has many disadvantages [40]. If only incidence is considered, the measure will not reflect the current prevalent burden of disabling sequelae for a condition for which incidence has been substantially reduced [39]. In addition, the incidence-based YLD calculation requires estimates of both incidence and average duration of disease

sequelae, whereas for many health conditions such as NCC, primarily prevalence data are collected. Using an incidence-based approach, all YLDs for a condition are assigned to the age-groups at which the condition is first diagnosed, whereas the policy-maker is often more interested in the ages at which loss of health is experienced [39]. Finally, incorporation of comorbidity is more straightforward in a prevalence approach than an incidence approach [40]. In the prevalence approach, all conditions present at a point in time are measured or estimated to adjust for comorbidity, whereas in the incidence approach, each age-sex-geography-time group is modeled from the incidence of all conditions and their associated excess mortalities. This task is information intensive and computationally challenging.[39]

Disability weights represent the magnitude of health loss associated with the outcome. Disability is placed on a uni-dimensional scale between 0 (perfect health) and 1 (death). In theory, utility is equal to 1-disability weight. Disability weights of clinical manifestations (referred to as indicator states) were determined for the original GBD Study by the person trade-off (PTO) method [41]. The PTO method is a way of estimating social preferences for different health states by asking experts or a specific group of individuals how many people affected by the health state of interest they would be willing to trade for extending the lives of 100 healthy people.

The GBD 2010 Study undertook a comprehensive re-estimation of disability weights through surveying respondents in two ways: household surveys (face-to-face interviews in Bangladesh, Indonesia, Peru, Tanzania; telephone interviews in USA) and an open-access web-based survey (included respondents from most countries of the world) [42]. Data were collected from 13,902 household surveys and 16,328 web-based surveys. The GBD 2010 Study estimated disability weights for 220 health states using a method involving discrete choice comparisons of

"health" for pairs of health states described using lay descriptions consisting of a brief summary of the health state of an average or modal case in 30 words or less [42].

The GBD 2013 Study evaluated data from new web-based surveys of participants aged 18–65 years, completed in four European countries (Hungary, Italy, the Netherlands, and Sweden), combined with data previously collected in the GBD 2010 disability weights measurement study [43]. Similar to the GBD 2010 Study, the GBD 2013 study also used paired comparison questions for which respondents considered two hypothetical individuals with different health states and specified which person they deemed healthier. The GBD 2015 and 2016 calculated DALYs using the 2013 disability weights [37,44]. Changes implemented since the GBD 2013 include incorporation of sources of new mortality and morbidity data, important model improvement for certain diseases such as HIV, malaria, tuberculosis, injuries, diabetes and cancers, and disaggregation of specific causes into subgroupings to provide additional detail.

The original GBD Study calculations considered two additional parameters: 1) discounting future time and 2) age weighting [36]. Discounting future time is a common concept in economic and social policy. In burden of disease estimations, a discount rate is applied so that future healthy life has less value than the net value of life today [41]. In the context of DALYs, a disability occurring today is worth more than the same disability occurring in the future. The subject of discounting is complex and several papers have been published in favor and against its use in the context of DALYs and health outcomes [41,45-47]. By including age weighting, the original GBD Study incorporated social preferences for the value of life lived during adulthood over life lived during childhood or later years. However, subsequent GBD studies did not include age weighting in the DALYs calculations. Therefore, the influence of age weighting was eliminated [39].

The original GBD Study had several limitations [45,47-50]. For example, the study calculated the years of life lost due to premature mortality by comparing study population life spans to the average life expectancies (life expectancy of 82.5 years at birth for women and a life expectancy of 80.0 years at birth for men) of the population of Japan. Therefore, DALYs understated the burden of disease of females relative to males since the standard expectation of life at birth in Japan is very similar in men and women [45]. The DALY also does not take into consideration cultural or socioeconomic differences in populations so that it underestimates the disease burden in developing countries [48]. In addition, the discounting and age weighting used in the original GBD Study have been widely criticized [45,47].

The GBD 2010 Study and onwards addressed some of these limitations by developing new disability weights, removing influence of age weighting and discounting, and using more appropriate life tables. Although DALYs are commonly used to measure the burden of zoonotic diseases, they are not capable of capturing the burden of disease associated with animal infections. However, even with these shortcomings, the DALY is a useful metric to measure and compare the disease burdens.

I.2.2 Measuring monetary burden

Estimates of the monetary burden of zoonotic diseases that impact both human and livestock health should include assessment of both human health costs and animal health costs. The overall estimated cost can be calculated using the following equation:

$$\sum_{s=1}^{S}\sum_{a=1}^{A}\left[N_{a,s}\beta_{a,s}\left(\sum_{x=1}^{X}\pi_{x,a,s}C_{x,a,s}\right)\right] \quad \text{.....Eq. 4 [51]}$$

This equation corresponds to the additive societal costs for all affected species (S) across all age groups (A). For the age-species-specific population of size ($N_{a,s}$), with the age-species-specific annual incidence ($ß_{a,s}$), there is an age-species proportion ($\pi_{x,a,s,}$) of infected individuals with symptoms X. The treatment and consequences of each of these symptoms have a monetary burden of $C_{x,a,s}$. Ideally, the whole spectrum of symptoms and losses in humans and animals is included in the estimate [51].

I.2.2.1 Human health costs

Human health costs are classified into direct and indirect costs [15,29,52]. Direct costs are costs associated with the diagnosis and treatment of patients whereas indirect costs are costs associated with loss of working days due to illness. Commonly used diagnostic tests for NCC incorporated into direct cost estimates include diagnostic imaging, sero-immunological and blood tests, and tests on cerebral spinal fluid (CSF). Diagnostic costs, for a neurological condition such as NCC, can be high since CT scans and MRI confirmatory tests are not readily available in developing countries and, if available, are often distantly located and expensive [53]. Cost of treatment typically includes the cost of medicines, medical consultations, surgical charges, and hospital charges. In contrast to direct costs, indirect costs include costs of working days lost due to clinical manifestations or visits to hospitals, losses in productivity, buying over-the-counter drugs to relieve symptoms, costs of traditional treatment, cost of transportation to and from medical treatment, and family member costs during their roles as caregivers [15].

Human health costs can also be divided into 1) hospital costs, 2) community care costs, 3) patient and family costs, and 4) costs related to other sectors [29]. Hospital costs include diagnostic testing, hospitalization, and outpatient visits. Community care costs include general

practitioner visits, nurse visits, and ambulance use. Patient and family costs include patients' and relatives' time lost while seeking and receiving care and out-of-pocket expenses for over the counter medicines. Costs related to other sectors include social worker and home help visits [29].

I.2.2.2 Animal health costs

Costs associated with animal disease can also be divided into direct and indirect costs [52]. Direct costs can result from the condemnation of all or part of an infected carcass. For example, the partial or full condemnation of a pig carcass with a heavy cysticercosis infection. The value of live animals can also be reduced [15]. Indirect costs are costs related to other disease-related production losses [52].

I.2.3 Decision tree analysis

Decision trees are helpful in organizing the information gathered on the distribution of manifestations and treatment-seeking pattern in the study population. They can also be used to incorporate the probability of receiving different types of diagnoses and treatments [54]. The tree usually starts with a "trunk" which is the population of interest. From this trunk, a probability (chance node) corresponding to the frequency of the disease (in the case of NCC, this can be epilepsy) is used to create the first two "branches" of the tree: the presence or absence of the disease in the study population. Additional branches are added each time a new probability is added. Each probability (node) may lead to more than two branches. The end of each branch corresponds to the patient's probability of following a certain treatment/diagnosis path, including the path of not seeking any medical care. The probability of each branch of a path can be multiplied by the costs corresponding to the options in that branch. As an example, the use of

decision tree analysis to estimate the non-monetary burden of NCC in urban Mexico is shown in Figure 2. In this example, for the branch of people with epilepsy who have NCC and seek medical attention, we would multiply 0.69% by 25% by 13% to obtain the frequency of having NCC and being treated (0.0224%, as shown in Figure 2) [55-58]. Such trees can be developed for very complex treatment paths and for the impact of animal disease.

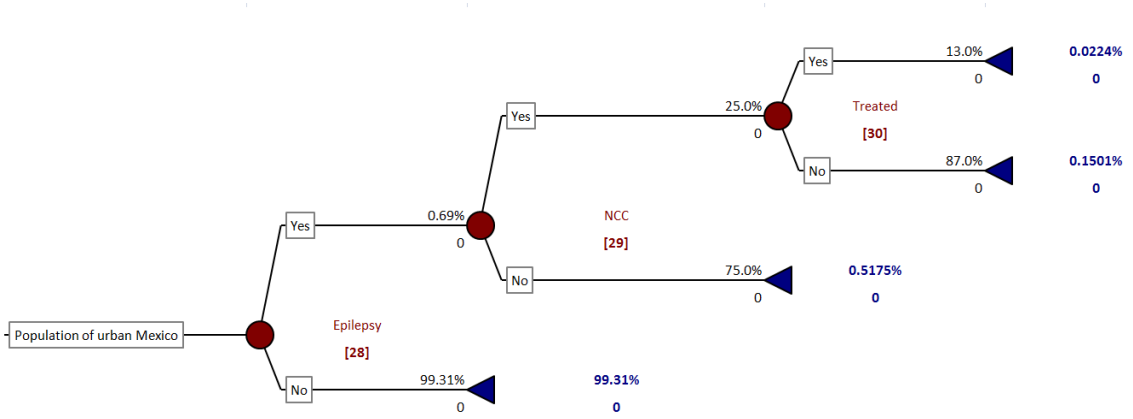

Figure 2: Decision tree analysis for estimating the non-monetary burden of NCC in Mexico. Circle is a chance node and triangle is an end node [23].

In some cases, the sum of all probabilities from one node may be more than one. This is common when we look at diagnosis or treatments of patients, where patients may receive different tests or drugs [58]. Figure 3 shows a decision tree where the sum of the probabilities from one node was more than one.

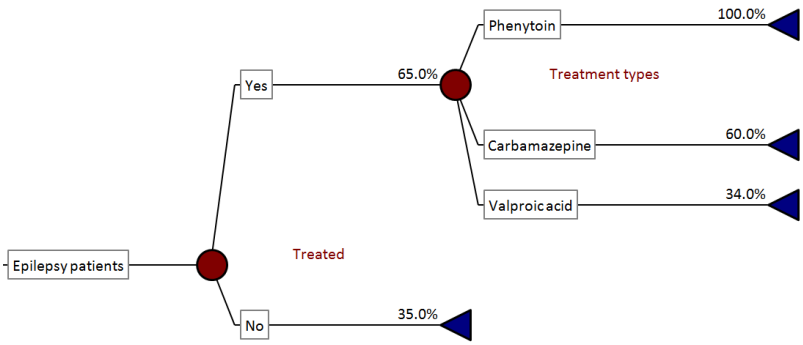

Figure 3: Decision tree analysis for estimating the monetary burden of NCC patients receiving antiepileptic treatment

I.2.4 Uncertainty and sensitivity analysis

Common sources of epidemiological and economic data used in the assessment of disease burden include government and agency reports and values reported in the scientific literature [15]. Values for neglected zoonotic diseases, such as *T. solium* cysticercosis, are often underreported or else the method of collection might be biased. In short, exact estimates of these parameters are difficult to identify. Therefore, in order to account for uncertainties or to minimize collection bias, the distribution of these parameters should be selected carefully. Therefore, instead of using an exact value for each probability and cost, a distribution of values is used to reflect uncertainty [58]. Monte Carlo or Latin Hypercube sampling methods are often applied to incorporate the various distributions into the final estimate, which will itself be a distribution reflecting the uncertainty of all included parameters [58].

Uniform distributions can be applied to parameters for which we have very limited knowledge and state that the shape of the uncertainty is flat [16,58]. The sampling method would start by sampling one value (for example, 1%) from this distribution, and then save the estimate of the cost of NCC using this value. Next, another value would be sampled from the distribution resulting in another estimated cost, which will also be saved. This process is usually repeated up

to 10,000 times until a distribution of the overall costs is obtained. The Latin Hypercube and Monte Carlo methods are efficient tools allowing sampling of several uncertain parameters iteratively [59].

The sampling method described above will generate a database of 10,000 observations each associated with different values for the uncertain parameters. We can then employ linear regression using the estimated costs as the outcome and all of the uncertain parameters as "independent" variables to assess which uncertain parameters have the largest impacts on the estimated costs. The uncertain parameters with the largest impacts should be those that need to be better studied in the future because they have a strong influence on how much a disease costs a society.

I.3 The non-monetary and monetary burden of cysticercosis

I.3.1 Non-monetary burden

The GBD Studies 2010, 2013, 2015 and 2016 as well as the World Health Organization (WHO) (2010) have published non-monetary estimates for cysticercosis [37-39,44,60]. In addition, five independent studies have estimated the non-monetary burden of cysticercossi in Cameroon, Mexico, Tanzania, India and Nepal [17,18,20,58,61]. Table 1 compares *T. solium* cysticercosis disease burden estimates from the GBD 2010, 2013 and 2016 with individual investigator estimates.

The goal of the 2010 WHO study was to provide estimates of the global burden of foodborne diseases according to age, sex, and region for a defined list of infectious and non-infectious causes. This study only published data at a regional level. Therefore, it has been excluded from table 1 [60]. The WHO study utilized the number of prevalent cases of epilepsy

used in the GBD 2010 Study to estimate the number of prevalent cases of epilepsy-associated NCC. Population at risk was estimated by taking into consideration religion, sanitation and pig population.

According to a recent meta-analysis, approximately 29.0% (95% UI 22.9%– 35.5%) of people with epilepsy in populations living in *T. solium*-endemic areas have brain lesions due to NCC [56]. Therefore, twenty-nine percent of the burden of epilepsy from the GBD 2010 Study was applied to the population at risk to estimate the burden of epilepsy attributable to NCC [39]. The GBD 2010 Study has not published their modeling methodology for estimating the burden of cyscticercosis and, therefore, it remains unclear how they obtained their estimates. The GBD 2013 Study used the proportion of epilepsy patients with NCC based on studies in endemic areas and applied this proportion to prevalent epilepsy cases [38], whereas the GBD 2015 and 2016 studies used similar methodologies to the WHO study [37,44].

The estimated numbers of DALYs lost based on independent studies were higher than those from the GBD studies. Differences in methodology as well as model inputs likely contributed to estimate disparities. While the GBD studies calculated prevalence-based DALYs, the independent studies calculated incidence-based DALYs. Other methodological differences include how populations were stratified. For example, the Mexico and India studies stratified by urban/rural areas, age groups, and gender whereas the other studies did not use such stratifications [20,58]. All studies, excluding the Mexico study, based its cysticercosis estimates solely on epilepsy cases whereas, the 2012 Mexico study evaluated both epilepsy and severe chronic headaches cases [58]. In addition, three percent discounting and non-uniform age-weighting were applied in the Mexico and Cameroon studies. Therefore, the number of DALYs lost would be even higher if the discounting and age-weighting effect were removed.

These independent studies have some limitations. Incidence was obtained by dividing the prevalence by the duration of symptoms. In addition, the duration of epilepsy and severe chronic headaches was assumed the same among treated and untreated cases, which is unlikely to be true. Due to limited published peer-reviewed data, several input parameters for estimating DALYs were based on systematic reviews of the literature, dissertations and data from other countries, indicating the need for additional studies.

Table 1: Comparison of the non-monetary burden of cysticercosis estimated by the GBD studies [37-39,44], and independent studies conducted in Mexico, Cameroon, Tanzania, India and Nepal [17,18,20,58,61]

Country	**DALYs attributed to cysticercosis by the GBD Study 2010**	**DALYs attributed to cysticercosis by the GBD Study 2013**	**DALYs attributed to cysticercosis by the GBD Study 2016**	**DALYs attributed to cysticercosis by independent studies (Year of the study)**
Mexico	7,649; 95% CR:2,629 – 20,559	28,299; 95% CR:19,412 – 39,365	13,897; 95% CR: 9,256 - 19,921	25,341; 95% CR: 12,569–46,640 (2012)*
Nepal	4,220; 95% CR:2,785 – 6,022	1,453; 95% CR: 600 – 2,670	2,656; 95% CR: 1,537 - 4,444	14,268; 95% CR: 5,450–27,694 10,924; 95% CR:4,270 – 21,301* (2014)
Cameroon	9,025; 95% CR: 6,238 – 12,519	6,025; 95% CR: 2,613 - 13,046	9,135; 95% CR: 4,823 - 15,026	45,838; 95% CR: 14,108 – 103,469 (2009)*
Tanzania	14,230 95% CR: 9637–20,047	3,900; 95% CR: 1,800 - 6,400	5,018; 95% CR: 3,284 - 7,202	27,225; 95% CR: 8129–58,921 (2012)*
India	Not available	68,700; 95% CR: 34,900 - 124,300	127,744 95% CR: 81,039 - 180,589	1,279,490 95% CR: 697,795–2,271,556 (2011)*

* based on three percent discounting and non-uniform age-weighting

I.3.2 Monetary burden

Very few studies have been conducted to evaluate the economic burden of cysticercosis. Table 2 compares monetary burden estimates for *T. solium* cysticercosis, in U.S. dollars, from three studies which estimated the country-level cost of cysticercosis, including both human and agricultural losses [16-18]. A study conducted in India was not included in this comparison due to methodology differences, including using annual incident cases as compared to prevalent cases to calculate the monetary burden and excluding pig losses [20]. A study conducted in Lao PDR was also not included in the comparison due to unclear methodology [19]. For example, in the Lao PDR study, it was not clearly mentioned how the authors estimated the number of NCC-associated epilepsy cases [19].

Table 2: Comparison of the monetary burden due to *T. solium* cysticercosis in Eastern Cape Province, South Africa, West Cameroon and Tanzania (in U.S. $)

Estimate	Eastern Cape Province, South Africa [16]	West Cameroon [17]	Tanzania [18]
Study year	2004	2009	2012
Country population	7,088,000	5,065,382	44,928,923
Estimated number of NCC-associated epilepsy cases	34,662	50,326#	47,804
Overall monetary burden, including NCC-associated epilepsy losses and pig losses	18.6 - 34.2 million**	14.9 million*	7.9 million
% due to porcine cysticercosis	14.6 - 26.9%	4.7%	35.4%
Average cost per NCC-associated epilepsy patient	632 - 844	240	106
Average cost per capita	2.6 - 4.2	2.9	0.176

* based on a 2009 exchange rate of 1 U.S.$ = 0.69 Euro

** The range is due to the application of different calculation methods for wage and productivity losses (mean wage approach, generalist replacement costs, and opportunity costs).

In the Eastern Cape Province (ECP) of South Africa, the average cost per NCC-associated epilepsy case per year was U.S.$ 632-844 while in Cameroon and Tanzania, the average cost was estimated to be much lower at U.S.$ 240 and U.S.$ 106, respectively [16-18]. The large difference in cost per NCC-associated epilepsy case may be due to lower salaries and treatment costs in Cameroon and Tanzania compared to the ECP. In all three studies, a large proportion of the total costs were related to indirect costs. In the ECP and Cameroon, agricultural losses contributed less to the total costs than in Tanzania. Compared to Tanzania, the pig population was also about four to five times lower in the ECP and Cameroon. In addition, the proportion of infected pigs as well as reduction in the price of infected pigs were lower in the ECP and Cameroon compared to Tanzania. All three studies only evaluated NCC cases presenting with epilepsy. Therefore, the total estimated costs were likely underestimated.

Few studies have been performed to evaluate the economic burden for patients with NCC. A study conducted in India, in 1997, estimated the cost of treating seizure disorders associated with solitary cysticercus lesions at U.S.$ 174.66 per patient [62]. Indian patients, in this study, were spending a considerable proportion (50.9%) of their per capita gross national product on treatment-related expenses. This study was conducted in a reference center and only represented a fraction of the total regional population with NCC, with an over-representation of more severe cases. Therefore, the overall cost per NCC case was not generalizable to all NCC cases. In addition, this study only estimated the cost of epilepsy due to a solitary cysticercus granuloma. These granulomas not only cause seizures, but also cause other clinical manifestations including severe chronic headaches, hydrocephalus, stroke, and dementia. The cost of treating these other clinical manifestations would increase the reported estimates. NCC is

also not only caused by solitary cysticercus granulomas and this study did not include clinical manifestations associate with multiple cystiscercus lesions and calcified cysts.

Another study conducted in a reference center for neurological disorders in Peru from 1999 - 2002 estimated a mean cost of U.S.$ 966 per NCC patient, including treatment costs and wage/productivity losses due to NCC over a two-year treatment period [63]. Patients enrolled in the study reported seizures (21%), headaches (55%), unusual behavior changes (51%) and memory loss (57%). Treatment costs and wage/productivity losses were equivalent to 54% of an annual minimum wage salary during the first year of treatment and 16% of an annual minimum wage salary during the second year of treatment [63]. Similar to the Indian study, this study was also conducted in a reference center and only represented a fraction of the total regional population with NCC, with an over-representation of more severe cases. Therefore, the overall cost per NCC case was not generalizable to all NCC cases in Peru.

A study conducted in a referral hospital in Santiago, Chile from 2006 – 2010 reported that the median cost of treating NCC was U.S.$ 1293. However, the number of patients was very small (six) and of the clinical manifestations presented by patients were not mentioned [64]. Two studies have been carried out in the U.S. The first study estimated an average hospitalization charge per NCC patient over the duration of treatment of U.S.$ 37,600 based on 1991-2008 California hospital discharge data [65]. The second study estimated that there were 28,565 cysticercosis-related hospitalizations during 1998 – 2009 based on a nationwide inpatient sample of annual hospital discharge records, representing a hospitalization rate of 8.16 persons per million population [66]. There were an estimated 364 NCC-associated deaths in the U.S. during 1998 - 2009, representing an overall case-fatality rate of 1.28% and a nationwide in-hospital mortality rate of 0.1 deaths per million population. National estimates of charges for

cysticercosis-related hospitalizations amounted to approximately U.S.$ 996 million for the twelve-year study period. The average annual charge per hospitalization discharge record was estimated at U.S.$ 37,140 [66]. Costs associated with healthcare provider visits and certain diagnostic techniques used before and after hospitalization were not included in either U.S.-based estimate, likely resulting in an underestimate of actual treatment costs.

The findings from above studies suggest that *T. solium* can result in considerable monetary losses. These results can be used to show the importance of introducing control efforts to reduce or eliminate this disease in endemic areas. Since this infection is preventable, these results can be used to assist stakeholders in allocating scarce health and agricultural resources in endemic countries.

I.4 Cysticercosis in Mexico

Mexico is the third largest country in Latin America, with a 2017 population of almost 124 million and an annual population growth rate of 1.2%. Seventy-eight percent of the population lives in urban areas. The official literacy rate is 93.5% [67]. Traditional pig rearing practices (free roaming) in *T. solium* endemic areas allow pigs to have access to human feces in open fields, facilitating the completion of the parasite's life cycle [68,69]. Confined pigs in yards next to dwellings may also have direct access to poorly maintained and sealed outdoor latrines [70].

There is currently a debate regarding the epidemiological status of cysticercosis in Mexico [71,72] and hence, it is important to find out to what extent it is still a significant burden to the society. According to Fleury et al., 2010, NCC is still a public health problem in Mexico. This article showed that NCC frequency had not significantly changed between 1994 and 2009

among patients attending a tertiary care hospital in Mexico City [71]. However, the study was conducted in a single reference hospital and the results might not be applicable to the entire country. On the other hand, according to Flisser and Correa 2010, improving socioeconomic conditions have resulted in a decrease in the number of cysticercosis cases in Mexico from 1995 (reported cases: 1,608) to 2009 (reported cases: 231) [72].

Studies are needed to estimate the current burden of cysticercosis in endemic countries, such as Mexico, to facilitate international comparison of disease burdens and identify priorities for control. To assess the current socioeconomic impact of cysticercosis in Mexico, it is important to estimate the costs incurred by NCC patients and society as a whole. The objectives of the research presented here are:

I. To estimate the direct and indirect per-patient annual costs associated with the treatment of NCC outpatients receiving care between July 2007 and August 2008 in two tertiary care hospitals in Mexico City, Mexico

II. To estimate the direct costs associated with pre-hospitalization, hospitalization, and post-hospitalization for NCC patients seeking care at a referral hospital in Mexico City, Mexico

III. To estimate the monetary burden of cysticercosis in Mexico, incorporating two common clinical manifestations of patients with NCC, epilepsy and severe chronic headaches, as well as pig infection-associated losses.

CHAPTER II

COST OF NEUROCYSTICERCOSIS PATIENTS TREATED IN TWO REFERRAL HOSPITALS IN MEXICO CITY, MEXICO**

II.1 Introduction

Neurocysticercosis (NCC) is a parasitic disease, which most often manifests as epilepsy, hydrocephalus, severe chronic headaches, increased intracranial pressure, dementia, vasculitis, or stroke [8]. NCC occurs when a human ingests parasite eggs shed in the feces of a person infected with the intestinal form of *Taenia solium,* with the eggs developing into larvae in the central nervous system. The epidemiological status of NCC in Mexico is being debated [71,72]; hence, it is important to determine to what extent this disease is still a burden to society. The burden of a disease can be assessed qualitatively through the description of how it affects patients' quality of life or quantitatively through the estimation of its morbidity, mortality or costs to the patients and the society where they live [15].

In Mexico, NCC-associated severe chronic headaches and epilepsy were recently reported to reduce the quality of life of NCC patients under care [9] and incur a life of NCC patients has also been reported in Brazil and Peru [13,73] and substantial numbers of NCC-associated DALYS have been reported from Nepal and Cameroon [17,61].The monetary impact of NCC has been reported as the average treatment cost per patient under care for patients in

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considerable number of disability adjuste life years (DALYs) [58]. Reduction in the quality of India and Peru [62,63]. Direct costs associated with treatment of NCC have also been assessed in California, U.S.A. [65]. In addition to focusing on NCC in humans, three studies have evaluated NCC-associated monetary losses to both the human health and agricultural sectors in South Africa, Lao PDR and Cameroon [16,17,19]. The objective of this study was to estimate the direct and indirect per-patient annual costs associated with the treatment of 224 NCC patients receiving care between July 2007 and August 2008 in two tertiary care hospitals in Mexico City, Mexico.

II.2 Materials and methods

II.2.1 Study location

This study was conducted in the two main referral hospitals for adult neurological cases in Mexico City, Mexico: the Instituto Nacional de Neurologia y Neurocirugia (INNN) and the Hospital de Especialidades of the Instituto Mexicano del Seguro Social (HE-IMSS). The INNN is a referral institution that accepts patients who do not have medical coverage through their employment. The HE-IMSS is a referral institution that provides medical services to patients with social security coverage.

II.2.2 Definition and study populations

NCC was defined based on the presence of compatible cerebral lesions on a computed tomography (CT) scan, by magnetic resonance imaging (MRI), or both [23]. Outpatients diagnosed with NCC and with a clinical appointment between July 17 and December 7, 2007 at the INNN and between June 2 and August 12, 2008 at the HE-IMSS were eligible to participate

in the study. Eligible patients were identified using outpatient appointment books, which allowed the research assistant to explain the study and ask for patient consent at the time of the appointment. At least 100 NCC outpatients were enrolled from each participating hospital. For data analysis purposes, the study population was broken down into those patients that had been previously hospitalized and/or undergone a surgical procedure for the diagnosis or treatment of NCC (referred to as patients with a history of hospitalization) and those patients without a history of hospitalization or surgery (referred to as patients without a history of hospitalization). The study population was further stratified based on presenting clinical manifestations.

II.2.3 Data collection

After obtaining informed consent, patients were interviewed by a trained member of the research team (e.g., a Mexican medical student, intern, or resident) at the time of their appointment. Questions focused on socio-demographic factors, knowledge of *T. solium* transmission, and time and monetary losses due to the inability to work or conduct their usual activities due to NCC. The questionnaire was originally written in English, translated into Spanish, back-translated into English by two independent persons, and pilot tested locally prior to use (Appendix A and B).

The medical charts of all participating NCC patients were reviewed between July 17 and December 7, 2007 at the INNN and between June 2 and August 12, 2008 at the HE-IMSS. Intake forms were used to record information on the clinical manifestation(s) of NCC that caused the patient to be referred to the hospital. Diagnostic and treatment forms were used to record information on techniques used for the confirmation of NCC and the drugs and procedures used for its treatment. Inpatient and outpatient forms were used to record information on the number

of times patients were hospitalized or had an outpatient appointment for the treatment and management of NCC (Appendix C, D, E and F).

II.2.4 Frequency of use of healthcare resources

The frequency of appointments with various healthcare providers (neurologists, neurosurgeons, psychiatrists, neurotologists and general practitioners), prescription medication use, hospitalizations, surgical interventions, and diagnostic testing (computed tomography (CT) scans, magnetic resonance imaging (MRI), cerebral spinal fluid (CSF) testing, enzyme-linked immunosorbent assays (ELISA), electroencephalograms (EEG), enzyme-linked immunoelectrotransfer blot **(**EITB), biopsies and neurological examinations) was estimated using the forms described above. The average number of times per year that study participants consulted with a healthcare provider or utilized a service was calculated by taking the total number of times each patient consulted each service and dividing this value by the number of years of follow-up.

II.2.5 Estimation of direct costs

Patients seen at the INNN pay medical fees according to their household income. There are seven levels of payment. Patients with a very low household income (level 0) do not pay anything out of pocket and all costs associated with treatment are paid for by the government (from here on referred to as health care provider (HCP) costs). Levels 1-6 pay increasingly more for services. When information on the payment level was not available, the median level of other patients was used (level 2). Patients treated at the HE-IMSS do not pay anything out-of-pocket and all medical costs, including prescription medication costs, are charged to the social security

administration at level 6 prices. Since it is believed that level 5 costs best represent the actual costs of products and services, this level was used as the base HCP costs (Flisser, personal communication, 2014).

Direct costs associated with hospitalization, diagnostic testing, surgery, and doctor visits were based on the year 2006 tariffs for healthcare services at the INNN, which were presumed to be the same as the tariffs for the HE-IMSS [74]. Table 3 contains the costs for NCC-related services and procedures, by level, in 2006 U.S. dollars. Direct costs associated with prescribed medications were based on actual prices obtained from several pharmacies in Mexico City, Mexico. All patients seen at the INNN pay for prescription medications out-of-pocket. A 2006 exchange rate of 10.80 Mexican pesos for 1 U.S. dollar was used [75].

Table 3: Level 0-6 patient cost per service/procedure (in U.S. dollars)

Parameter	Level 0	Level 1	Level 2	Level 3	Level 4	Level 5*	Level 6
Cost for a visit to a neurologist	0	0.55	1.47	4.32	11.04	19.78	29.07
Cost for a visit to a neurosurgeon	0	0.55	1.47	4.32	11.04	19.78	29.07
Cost for a visit to a general practitioner	0	0.55	1.47	4.32	11.04	19.78	29.07
Cost for a visit to a psychiatry	0	0.55	1.47	4.32	11.04	19.78	29.07
Cost for a visit to a neurotologist	0	0.55	1.47	4.32	11.04	19.78	29.07
Cost of a CT scan	0	5.98	15.08	45.17	114.35	204.60	300.93
Cost of an MRI	0	6.16	15.36	46.18	117.02	209.48	308.02
Cost of an ELISA	0	0.92	2.30	6.90	17.48	31.19	45.91
Cost of an EEG	0	3.04	7.54	22.54	57.13	102.30	150.42
Cost of an EITB	0	3.04	7.63	22.91	58.05	103.77	152.63
Cost of CSF examination	0	0.55	1.49	4.26	10.30	18.40	27.14
Cost of a biopsy	0	15.55	38.27	114.72	290.35	519.06	763.32
Cost of a neurological exam	0	0.55	1.47	4.32	11.04	19.78	29.07
Cost of a one day stay in a hospital's general ward	0	2.02	4.97	14.99	37.99	68.08	100.01
Cost of a one day stay in a hospital's private ward	0	2.39	5.98	17.94	45.54	81.42	119.78

*Actual unit cost

Note: CT = Computed Tomography, MRI = Magnetic Resonance Imaging, ELISA = Enzyme-linked immunosorbent assay, EEG = Electroencephalography, EITB = Enzyme-linked immunoelectro transfer blot test, CSF = Cerebrospinal Fluid.

II.2.6 Estimation of indirect costs

Indirect costs included the loss of working days due to treatment seeking behavior and symptoms in addition to transportation costs to and from the hospital and doctor visits. Due to lack of available data, losses due to the purchase of over-the-counter medications, use of traditional healers, and time lost by the patients' families were not included in indirect cost estimates. Patient information on occupation, monthly salary, numbers of sick days not involving a hospital or clinic visit, and means of transportation to and from treatment were collected from the questionnaire.

Although 99% of the patients reported their occupation, 50% did not report their monthly salary. For missing data on monthly salary, the median salary provided by other patients, with the same occupation, was used when there were at least three other patients with available salary information. Missing wages for less common (<3 patients) occupations were based on the lowest estimated salaries provided by three sources: the international average salary income database, Mexico's Department of Labor and the reported salaries of IMSS employees, for the year 2006 [76-78].

With the exception of retirees, unemployed citizens in Mexico do not receive government benefits. Retirees did not report their monthly salary or previous occupation. Therefore, it was assumed that retirees received 80% of the minimum wage as their pension [79]. Three approaches were used to capture productivity losses for housewives and the non-retired unemployed. The first method used traditional "opportunity costs" where work time was only lost for those who are currently employed outside of the home. The second method used the minimum wage approach where time lost was estimated at an 8-hour work day paid at Mexico's 2006 minimum wage of U.S.$ 4.34 per day [80]. For the third method, time lost was estimated at

an 8-hour work day paid at the 2006 mean salary estimate of U.S.$ 5.48 per day for a house cleaner in Mexico [80].

Treatment-related productivity losses were measured in units of time and monetized for wage earners by occupation. These productivity losses were based on the number of hours NCC patients lost due to hospitalization and treatment seeking behavior. It was assumed that patients who had to travel more than 2 hours for treatment lost an entire day of work whereas patients that traveled less than 2 hours for treatment lost half a day of work.

Symptom-related productivity losses were those losses which occurred due to the inability to work due to illness, but did not involve a visit to the hospital or other healthcare provider. The questionnaire included a question on the number of working days lost due to illness in the past year and the past month. When available, lost working days over the past year were included in indirect cost estimates. When only lost working days in the past month were provided, this number was multiplied by the ratio of lost working days in the past year to lost working days in the past month obtained from patients reporting both values and then multiplied by 12.

Transportation costs were estimated based on the mode of transportation and the distance travelled. Cost of transportation was estimated using the year 2014 cost of U.S.$ 9.60 per 10 km for transportation by taxi, U.S.$ 1.00 per liter of gasoline for transportation by personal vehicle, and U.S.$ 4.50 per hour for transportation by bus [81]. Cost of transportation, for those patients who travelled less than 1 hour by bus, was estimated using a fixed rate (U.S.$ 0.92) for local bus service in Mexico City in 2014 [81]. These 2014 values were converted to their 2006 values according to the Consumer Price Index for Mexico [82].

II.2.7 Statistical analysis

The average annual actual direct cost per NCC patient was calculated by adding the level 5 costs per patient and dividing this total cost by the number of years of follow-up. The average annual indirect cost per NCC patient was estimated by adding the productivity losses and transportation costs per patient and dividing this total cost by the number of years of follow up. The average annual per patient out-of-pocket expense for INNN patients and the average annual per patient cost charged to the social security administration for IMSS patients were also calculated using this method. The average annual actual cost per NCC patient was calculated for all study patients and then stratified by hospitalization history and presenting clinical manifestation(s). Since the number of observations was small after stratifying the patients based on clinical manifestations, the variance of the cost estimates was calculated using bootstrap techniques. The average annual costs along with their 95% confidence intervals (CIs) were estimated using Stata® (StataCorp. 2011. Stata® Statistical Software: Release 11.2. College Station, TX: StataCorp LP).

II.2.8 Ethical approval

This study received IRB approval from Texas A&M University (2006-0606 and 2014-0702), the INNN, and the HE-IMSS.

II.3 Results

II.3.1 Patient demographics

Chart reviews were conducted for 123 patients from the INNN and 101 patients from the HE-IMSS. The majority of the patients (82%) interviewed at the HE-IMSS were from Mexico

City. Patients interviewed at the INNN were primarily from the State of Mexico (41%) and Mexico City (25%). Among the 224 outpatients, 65% had a history of hospitalization. Table 4 shows the patient demographics.

Table 4: Demographics of patients seeking treatment at the INNN and HE-IMSS

Category	**Number of patients**				
	HE-IMSS		**INNN**		**Total**
	Number	**Proportion**	**Number**	**Proportion**	
Total number of patients	101	0.45	123	0.55	224
Sex					
Male	50	0.22	55	0.25	105
Female	51	0.23	68	0.30	119
Age					
$\leq$ 45 years	35	0.16	66	0.29	101
$\geq$46 years	66	0.29	57	0.26	123
Number of patients who were hospitalized	54	0.24	68	0.30	122

II.3.2 Clinical manifestations

The most common presenting symptoms of participating NCC patients were hydrocephalus (48%), severe chronic headaches (47%), and epilepsy (31%) (Table 5).

Table 5: NCC-related clinical manifestations of patients seeking treatment at the INNN and HE-IMSS

Symptoms	Number of patients			Percentage	Final analysis group
	HE-IMSS	INNN	Total		
Epilepsy and seizures	22	42	64	28.57	
Hydrocephalus	26	15	41	18.30	
Severe chronic headaches and hydrocephalus	16	21	37	16.52	
Severe chronic headaches	17	12	29	12.95	
Seizures/ epilepsy and severe chronic headaches	7	7	14	6.25	
Severe chronic headaches, increased intracranial pressure, and hydrocephalus	0	9	9	4.02	Included in the severe chronic headaches and hydrocephalus group
Severe chronic headaches and increased intracranial pressure	1	4	5	2.23	Included in the severe chronic headaches group
Seizures/epilepsy, severe chronic headaches, and hydrocephalus	6	1	7	3.13	
Seizures/epilepsy and hydrocephalus	5	3	8	3.57	
Stroke	0	2	2	0.89	
Dementia	0	1	1	0.45	
Seizures/epilepsy, increased intracranial pressure, and severe chronic headaches	0	1	1	0.45	Included in the seizures/ epilepsy and severe chronic headaches group
Increased intracranial pressure and seizures/epilepsy	0	1	1	0.45	Included in the seizures/epilepsy group
Increased intracranial pressure and vasculitis	0	1	1	0.45	Included in the hydrocephalus only group
Hydrocephalus, vasculitis, and severe chronic headaches	0	1	1	0.45	Included in the hydrocephalus and severe chronic headaches group
Seizures/epilepsy, hydrocephalus, vasculitis, and severe chronic headaches	0	1	1	0.45	Included in the seizures/epilepsy, hydrocephalus, and severe chronic headaches group
Seizures/epilepsy, hydrocephalus, and increased intracranial pressure	1	0	1	0.45	Included in the seizures/epilepsy and hydrocephalus group

Table 5: Continued

Symptoms	Number of patients			Percentage	Final analysis group
	HE-IMSS	INNN	Total		
Seizures/epilepsy, severe chronic headaches, hydrocephalus, and increased intracranial pressure	0	1	1	0.45	Included in the seizures/ epilepsy, severe chronic headaches, and hydrocephalus group
Total	101	123	224	100.00	

II.3.3 Frequency of use of healthcare resources

Tables 6 and 7 show the average number of times per year that patients without a history of hospitalization (Table 6) and with a history of hospitalization (Table 7) consulted with each type of healthcare provider and had each type of diagnostic tests performed stratified by the presenting symptom.

Table 6: Average number of times patients at the INNN and HE-IMSS without a history of hospitalization for NCC used healthcare resources per year

	Hydrocephalus only		**Severe chronic headaches only**		**Epilepsy/seizures only**		**Stroke**		**Dementia**		**Epilepsy/seizures and hydrocephalus**		**Severe chronic headaches and hydrocephalus**		**Epilepsy/seizures, severe chronic headaches, and hydrocephalus**		**Epilepsy/seizure and severe chronic headaches**	
	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN
Number of patients	5	7	14	3	16	34	0	1	0	1	0	0	2	7	2	0	6	5
Consultation with specialist																		
Neurologist	2.50	2.30	1.96	1.17	3.41	2.10	-	1	-	2	-	-	1.30	2.12	1.55	-	2.46	2.15
Neurosurgeon	0	0.04	0.05	0	0.05	0.02	-	0	-	0	-	-	0	0.17	0	-	0.03	0
General practitioner	0	0	0	0	0	0.04	-	0	-	0	-	-	0	0.06	0	-	0	0.07
Psychiatrist	0	0	0	0	0.02	0.09	-	0	-	0	-	-	0	0	0	-	0.13	0
Neurotologist	0	0	0	0	0	0.02		0		0	-	-	0	0	0	-	0	0
Diagnostic tests																		
CT scan	0.70	0.30	0.30	0.10	0.70	0.93	-	1	-	0.36	-	-	0.16	0.36	0.31	-	0.67	0.12
MRI	0.30	0.80	0.20	0.10	0.50	0.60	-	0	-	0	-	-	0	0	0.07	-	0.43	0.45
EEG	0	0	0.10	0	0.40	0.20	-	0	-	0	-	-	0	0.14	0.08	-	0	0.42
CSF	0	0.45	0.03	0.32	0.05	0.31	-	0	-	0.2	-	-	0	0.69	0	-	0.27	0.04
ELISA	0	0.30	0	0.31	0.01	0.33	-	0	-	0.2	-	-	0.08	0.65	0	-	0	0
EITB	0	0	0.01	0	0.23	0	-	0	-	0	-	-	0	0	0	-	0.06	0
Biopsy	0	0	0	0	0	0	-	0	-	0	-	-	0	0	0	-	0	0
Neurological exam	1.91	0.32	1.30	0.31	1.94	0.61	-	1	-	0	-	-	1.30	0.45	0.92	-	1.25	0.28

Note: CT = Computed Tomography, MRI = Magnetic Imaging Resonance, EEG = Electroencephalography, ELISA = Enzyme-linked immunosorbent assay, EITB = Enzyme-linked immunoelectro transfer blot test, CSF = Cerebrospinal Fluid

Table 7: Average number of times patients at the INNN and HE-IMSS with a history of hospitalization for NCC used healthcare resources per year

	Hydrocephalus only		**Severe chronic headaches only**		**Epilepsy/seizures only**		**Stroke**		**Dementia**		**Epilepsy/seizures and hydrocephalus**		**Severe chronic headaches and hydrocephalus**		**Epilepsy/seizures, severe chronic headaches, and hydrocephalus**		**Epilepsy/seizures and severe chronic headaches**	
	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN
Number of patients	19	11	4	13	6	9	0	1	0	0	6	3	14	24	4	3	1	4
Consultation with specialist																		
Neurologist	2.29	1.58	2.31	1.90	2.02	1.84	-	2.48	-	-	2.11	1.61	1.91	2.75	2.38	1.01	2.68	3.03
Neurosurgeon	0.36	0.81	0.55	0.23	0.14	0.13	-	0	-	-	0	0	0.34	0.18	0.06	0	0	0.07
General practitioner	0	0.25	0	0.28	0	0	-	0	-	-	0	0	0	0.05	0	0	0	0
Psychiatrist	0.03	0	0	0.31	0	0.1	-	0	-	-	0	0	0	0.08	0	0	0	0
Neurotologist	0	0	0	0	0	0	-	0	-	-	0	0	0	0.27	0	0	0	0.37
Diagnostic tests																		
CT scan	0.32	0.44	1.11	0.37	0.37	0.50	-	0.74	-	-	0.58	1.65	0.91	0.67	0.21	0.92	0.67	1.12
MRI	0.57	0.85	1.16	1.05	0.2	1	-	1.24	-	-	0.55	0.81	0.35	1.00	0.35	0.53	0.17	0.42
EEG	0.01	0.17	0.35	0.27	0.07	0.20	-	0.24	-	-	0.03	0.39	0.01	0.05	0.12	0.41	0.16	0.17
CSF	0.18	0.62	0.13	0.57	0.06	0.50	-	2.47	-	-	0.07	1.08	0.13	1.06	0	0.85	0	1.16
ELISA	0	0.59	0	0.69	0	0.60	-	0	-	-	0	0.62	0	0.78	0	0.41	0	1.31
EITB	0.04	0	0	0	0.03	0	-	0	-	-	0	0	0	0	0.06	0	0	0
Biopsy	0	0	0	0.21	0	0	-	0	-	-	0	0.09	0	0.01	0	0	0	0.07
Neurological exam	1.40	0.74	3.06	0.72	1.5	1.04	-	0.24	-	-	1.32	1.71	1.64	1.15	1.69	1.75	1.85	0.76
Number of surgeries	0.51	0.66	0.45	0.14	0.24	0.35	-	2.00	-	-	0.46	1.11	0.74	0.63	0.21	0.58	0	0.44
Number of days hospitalized	5.44	10.87	5.97	5.84	2.24	7.25	-	13.86	-	-	2.22	12.03	5.58	5.24	2.57	9.19	1.67	11.32

Note: CT = Computed Tomography, MRI = Magnetic Imaging Resonance, EEG = Electroencephalography, ELISA = Enzyme-linked immunosorbent assay, EITB = Enzyme-linked immunoelectro transfer blot test, CSF = Cerebrospinal Fluid

II.3.4 Direct costs

The majority of outpatients treated at the INNN paid for their treatment. However, out-of-pocket expenses were usually less than the actual cost, with 0.6 % paying nothing (level 0), 30.5% paying at level 1, 49.1% paying at level 2, 10.2% paying at level 3, 1.1% paying at level 4, 3.4% paying at level 5, and 2.8% paying at level 6. The payment levels of four INNN outpatients were missing and imputed as being level 2.

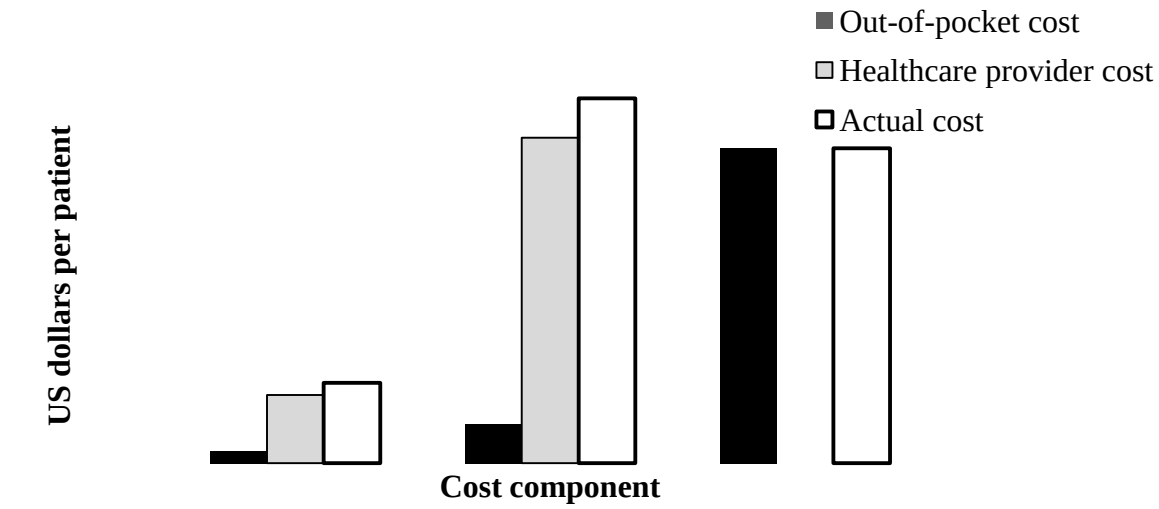
The annual average actual (level 5) direct costs were U.S.$ 503 (95% CI: 414 – 592) and U.S.$ 438 (95% CI: 322 – 571) for patients without a history of hospitalization seen at the INNN and at the HE-IMSS, respectively (Table 8). In contrast, the annual average actual (level 5) direct costs were U.S.$ 2,506 (95% CI: 1,797 – 3,215) and U.S.$ 2,170 (95% CI: 1,303 – 3,037) for patients with a history of hospitalization seen at the INNN and at the HE-IMSS, respectively (Table 9). The average out-of-pocket expense was U.S.$ 242 (95% CI: 182 – 303) and U.S.$ 301 (95% CI: 228 – 375) for INNN patients without and with a history of hospitalization, respectively. The annual per patient cost charged to the social security administration was U.S.$ 571 and U.S.$ 3,109 for IMSS patients without and with a history of hospitalization, respectively. The total annual actual (level 5) direct cost for the 224 patients treating at INNN and HE-IMSS was U.S.$ 335,901. Figures 4 and 5 show the total per patient annual direct cost of treatment, by cost component and payer, for individuals enrolled with and without a history of hospitalization at the INNN and HE-IMSS respectively.

Table 8: Annual average actual (level 5) per patient direct costs for INNN and HE-IMSS patients with no history of hospitalization NCC in U.S. dollars (Values in brackets represent 95% CIs)

	Number of patients		Diagnostic tests		Consultations		Drugs		Total	
	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN
Epilepsy/seizure	16	34	356 (208 – 508)	248 (169 -329)	68 (54 – 82)	45 (38 – 53)	199 (109 – 290)	250 (170 – 332)	624 (426 – 822)	545 (440 – 650)
Hydrocephalus	5	7	124 (11 – 237)	254 (83 – 425)	49 (35 – 63)	46 (35 – 59)	56 (0 – 145)	151 (12 – 291)	230 (83 – 376)	452 (175 – 730)
Severe chronic headaches	14	3	153 (79 – 228)	71 (10 – 132)	39 (34 – 46)	23 (17 – 30)	170 (0 – 402)	28 (0 – 62)	363 (134 – 593)	122 (10 – 235)
Stroke	0	1	-	224	-	19	-	0	-	244
Dementia	0	1	-	83	-	78	-	195	-	357
Severe chronic headaches and hydrocephalus	2	7	61 (59 – 62)	330 (138 – 523)	26 (21 – 32)	46 (28 – 65)	0	135 (0 – 296)	87 (80 – 94)	512 (291 – 735)
Epilepsy/seizure and severe chronic headaches	6	5	291 (33 – 500)	172 (77 – 268)	53 (35 – 69)	43 (32 – 56)	188 (53 – 372)	224 (70 – 378)	532 (237 – 827)	441 (198 – 684)
Epilepsy/seizure, severe chronic headaches and hydrocephalus	2	0	106 (74 – 137)	-	15 (13 – 18)	-	132 (73 – 193)	-	254 (228 – 280)	-

Table 9: Annual average actual (level 5) per patient direct costs for INNN and HE-IMSS patients with a history of hospitalization for NCC in U.S. dollars (Values in brackets represent 95% CIs)

	Number of patients		Diagnostic tests		Consultations		Hospitalization		Surgery		Drugs		Total	
	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN
Epilepsy/ seizure	6	9	147 (77 – 217)	414 (255 – 573)	42 (37 – 48)	41 (24 – 58)	182 (81 – 283)	493 (0 - 1,060)	501 (38 – 965)	567 (26 – 1,109)	193 (103 – 284)	240 (146 – 335)	1,067 (440 – 1,694)	1,758 (616 – 2,900)
Hydrocephalus	19	11	222 (154 – 291)	330 (222 – 438)	53 (42 – 64)	52 (42 – 62)	442 (106 – 780)	740 (58 – 1,422)	778 (461 – 1,094)	689 (361 – 1,017)	93 (0 – 193)	60 (13 – 108)	1,590 (990 – 2,191)	1,872 (938 – 2,806)
Severe chronic headaches	4	13	571 (364 – 778)	478 (323 – 633)	56 (21 – 92)	53 (40 – 67)	486 (155 – 817)	397 (246 – 549)	695 (159 – 1,232)	234 (0 – 481)	129 (121 – 139)	187 (101 – 273)	1,939 (885 – 2,993)	1,351 (875 – 1,827)
Stroke	0	1	-	507	-	49	-	943	-	1,266	-	412	-	3,178
Severe chronic headache and hydrocephalus	14	24	297 (195 – 400)	428 (313 – 544)	44 (36 – 53)	66 (50 – 82)	454 (237 – 672)	361 (217 – 504)	1081 (342 – 1,820)	695 (370 – 1,021)	145 (34 – 255)	97 (54 – 141)	2,022 (1,141 – 2,904)	1,648 (1,117- 2,179)
Epilepsy/seizure and hydrocephalus	6	3	266 (127 – 405)	670 (186 – 1153)	20 (12 – 29)	63 (49 – 79)	180 (63 – 298)	890 (20 – 1,761)	675 (228 – 1,122)	1813 (65 – 3,563)	678 (0 – 1,558)	405 74 – 737)	1,821 (664 – 2,979)	3,844 (432 – 7,256)
Epilepsy/seizure and severe chronic headaches	1	4	226	660 (354 – 966)	53	66 (49 – 84)	136	790 (122 -1,459)	0	1120 (287 – 1,953)	168	162 (41 – 284)	585	2,504 (909 – 4,099)
Epilepsy/seizure, severe chronic headaches and hydrocephalus	4	3	168 (106 – 232)	402 (195 – 609)	24 (14 – 35)	40 (0 – 85)	222 (150 – 294)	658 (0 – 1,393)	263 (70 – 456)	965 (491 – 1,439)	96 (11 – 181)	272 (187 – 357)	775 (599 – 952)	2,338 (1,059 – 3,618)



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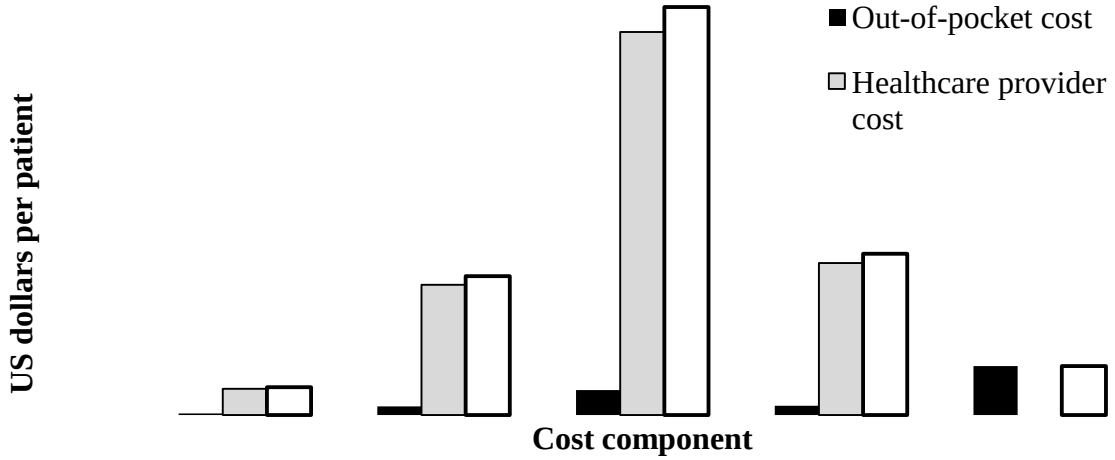
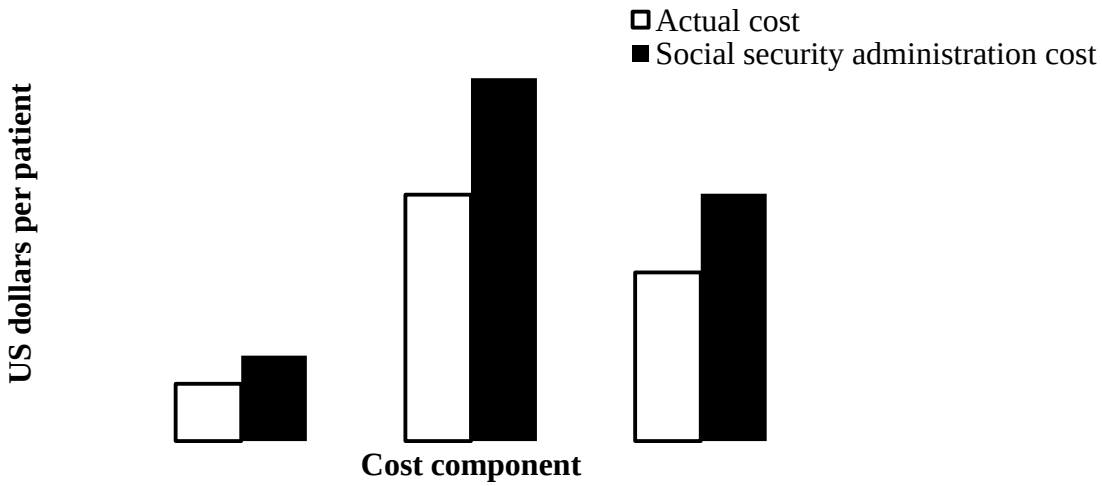


Figure 4: Average annual cost of treatment at the INNN per patient a) for 55 patients with no history of hospitalization NCC and b) for 68 patients with a history of hospitalization for NCC



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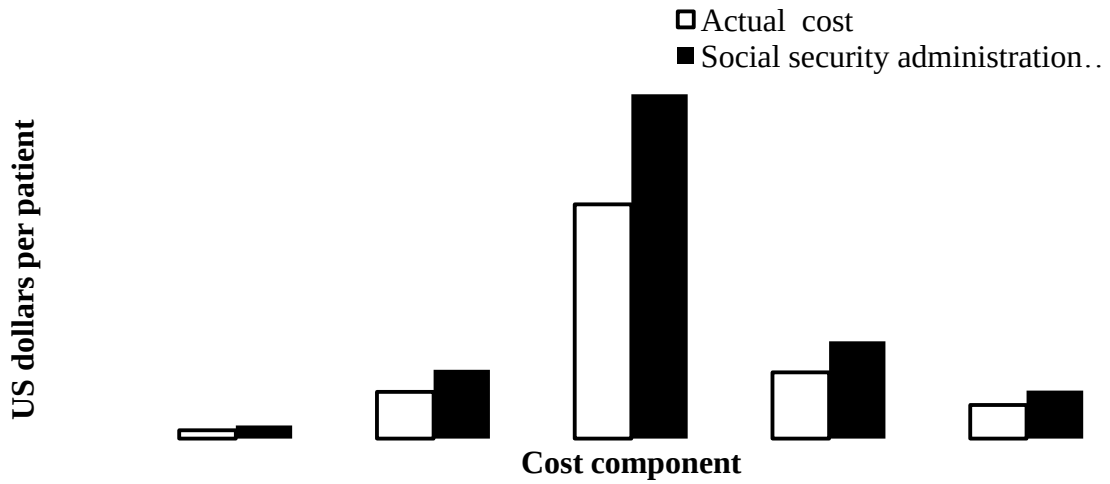

Figure 5: Average annual cost of treatment at the HE-IMMS per patient a) for 47 patients with no history of hospitalization NCC and b) for 54 patients with a history of hospitalization for NCC

II.3.5 Indirect costs

Forty percent of study patients were housewives and 16% were unemployed. Table 10 shows the average number of working days lost annually by enrolled NCC patients. Table 11 shows the total per patient annual cost of NCC-associated productivity losses and transportation costs using the opportunity cost method, the minimum wage approach, and the house cleaning wage approach for patients not officially employed outside of the home. The total annual indirect cost for the 224 patients treated at the INNN and HE-IMSS was U.S.$ 17,172 based on the opportunity cost method, U.S.$ 41,841 based on the minimum wage approach, and U.S.$ 44,406 based on the house cleaning approach.

Table 10: Average number of working days lost annually by NCC patients who were receiving treatment at the INNN and HE-IMSS

	Number of patients				Loss of working days due to the inability to work due to illness				Loss of working days due to visits to a health care provider			
	Without a history of hospitalization and/or surgery		With a history of hospitalization and/or surgery		Without a history of hospitalization and/or surgery		With a history of hospitalization and/or surgery		Without a history of hospitalization and/or surgery		With a history of hospitalization and/or surgery	
	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN
Hydrocephalus	5	7	19	11	0	0	8.85	17.71	2.62	2.63	8.89	15.01
Severe chronic headaches	14	3	4	13	0	16	0	3.28	2.39	1.03	13.12	9.28
Epilepsy/seizures	16	34	6	9	0.27	6.21	0	55	3.89	2.51	4.65	12.56
Stroke	0	1	0	1	-	0	-	0	-	1.50	-	18.57
Dementia	0	1	0	0	-	0	-	-	-	1.27	-	-
Seizures and hydrocephalus	0	0	6	3	-	-	0	0	-	-	5.00	16.87
Severe chronic headaches and hydrocephalus	2	7	14	24	0	35.83	0	16.25	1.53	2.81	9.06	10.10
Seizures, severe chronic headache and hydrocephalus	2	0	4	3	0	-	0	0	1.72	-	5.35	13.71
Seizures and severe chronic headaches	6	5	1	4	20	0	0	10	3.09	2.02	5.95	11.44

Table 11: Average annual indirect costs of NCC for INNN and HE-IMSS patients due to productivity losses and transportation costs to and from the hospital and doctor visits in U.S. dollars (Values in brackets represent 95% CIs)

Cost component	Per patient					
	Opportunity cost approach		House cleaning approach		Minimum wage approach	
	HE-IMSS	INNN	HE-IMSS	INNN	HE-IMSS	INNN
Transportation	7 (6 – 9)	7 (6 – 9)	7 (6 – 9)	7 (6 – 9)	7 (6 – 9)	7 (6 – 9)
Productivity losses due to treatment seeking behavior	42 (25 – 60)	27 (18 – 35)	56 (39 – 72)	50 (40 – 60)	57 (40 – 74)	48 (37 – 59)
Productivity losses due to symptoms without treatment seeking	22 (0 – 46)	42 (8 – 77)	50 (0 – 108)	214 (125 – 302)	50 (0 – 113)	190 (115 – 265)
Total	72 (41 – 103)	78 (41 – 112)	113 (51 – 175)	271 (184 – 349)	114 (51 – 178)	245 (165 – 324)

II.3.6 Total costs

The total annual actual cost for the 224 patients treated at the INNN and the HE-IMSS was U.S.$ 352,961 based on the opportunity cost method, U.S.$ 377,742 based on the minimum wage approach, and U.S.$ 380,307 based on the house cleaning approach. The total annual average actual costs per patient were U.S.$ 581 (95% CI: 455 – 704) and U.S.$ 510 (95% CI: 363 – 674) based on the opportunity cost method, U.S.$ 748 (95% CI: 579 – 916) and U.S.$ 552 (95% CI: 373 – 749) based on the minimum wage approach, and U.S.$ 774 (95% CI: 598 – 941) and U.S.$ 551 (95% CI: 373 – 746) based on the house cleaning approach for patients without a history of hospitalization seen at the INNN and at the HE-IMSS, respectively. This amount increased to U.S.$ 2,584 (95% CI: 1,838 – 3,327) and U.S.$ 2,242 (95% CI: 1,344 – 3,140) based on the opportunity cost method, U.S.$ 2,751 (95% CI: 1,962 – 3,460) and U.S.$ 2,284 (95% CI: 1,354 – 3,215) based on the minimum wage approach, and U.S.$ 2,777 (95% CI: 1,981 – 3,564) and U.S.$ 2,283 (95% CI: 1,354 – 3,212) based on the house cleaning approach for those with a history of hospitalization seen at the INNN and at the HE-IMSS, respectively.

II.4 Discussion

This is the first patient-based study to quantify the monetary losses of NCC-affected individuals in Mexico. In a study conducted in a reference center for neurological disorders in Peru from 1999 – 2002, a mean cost of U.S.$ 966 per NCC patient, including treatment costs and wage/productivity losses due to NCC over a two year treatment period, was estimated. In that study, treatment costs and wage/productivity losses were equivalent to 54% and 16% of an annual minimum wage salary during the first year and second year of treatment, respectively [63]. In the current study, the average annual treatment costs and wage/productivity losses for

patients with and without a history of hospitalization receiving care at tertiary referral hospitals were equivalent to 212% and 41% of an annual minimum wage salary, respectively. One difference between the Peruvian and Mexican studies is that the annual cost per NCC patient in the Mexican study was the average annual cost per patient over the documented course of treatment, whereas in the Peruvian study costs were stratified by year of initial diagnosis and the subsequent year of follow-up. Since most of the diagnostic tests are performed in the first year of treatment, the cost of treatment is likely to be higher in the first year compared to following years. When treatment costs for Mexican NCC patients were stratified by year, the first year costs for patients with and without a history of hospitalization were equivalent to 255% and 56% of an annual minimum wage salary, respectively, which is consistent with the Peruvian estimates.

A study conducted in India in 1997 estimated the cost of treating seizure disorders associated with solitary cysticercus lesions from the time of seizure onset until resolution of the lesion confirmed by CT scan was U.S.$ 174 per patient [62]. Although the actual estimated direct costs due to NCC-associated seizures was low in Indian patients compared to the Mexican patients with NCC-associated epilepsy (U.S.$ 1,482 and U.S.$ 570 for patients with and without hospitalization), the Indian patients were also spending a considerable proportion (50.9%) of their per capita gross national product on their disease to a level similar to that of the Mexican patients.

In the current study, among patients without a history of hospitalization, the annual direct costs for patients with epilepsy as the only clinical manifestation were higher than the costs for patients with any other clinical manifestation (single or combined). This difference was primarily due to the high cost of epilepsy drugs. In contrast, among patients with a history of

hospitalization, the annual direct costs were highest for patients with severe chronic headaches or hydrocephalus, primarily due to the high cost of surgery to treat hydrocephalus.

Three methods were used to value productivity losses of individuals considered not economically active or employed. Since more than 50% of the patients were housewives or unemployed, the estimated indirect costs ignoring losses for this group lead to the smallest estimates. This method clearly undervalues the time of homemakers. Therefore, the total costs estimated from the minimum wage approach or the house cleaning approach likely better represent actual productivity losses.

This study has some limitations. The study was conducted in two neurology reference hospitals in Mexico City and only represents a fraction of the total regional population with NCC, with an over-representation of more severe cases. Therefore, the overall cost per NCC case is not generalizable to all NCC cases in Mexico. However, the annual costs for such severe NCC patients were likely underestimated since opportunity costs of family members who accompany patients to treatment, the cost of over-the-counter medication, and the cost of treatment by traditional healers were not included. Since patients were selected at the time of an outpatient visit, estimates excluded patients who never returned to one of the hospitals for follow-up care and any patients who may have died due to NCC.

In conclusion, individuals with NCC treated at tertiary hospitals in Mexico City, Mexico had a significant economic loss due to NCC-associated clinical manifestations. Additional studies are needed to determine the treatment gap of NCC, losses associated with individuals with untreated NCC, and losses associated with patients treated at lower level care facilities in Mexico. This information can then be used to better define and estimate the total economic losses due to NCC for the entire country.

CHAPTER III

PRE-HOSPITALIZATION, HOSPITALIZATION, AND POST-HOSPITALIZATION COSTS OF NEUROCYSTICERCOSIS PATIENTS TREATED AT THE INSTITUTO NACIONAL DE NEUROLOGIA Y NEUROCIRUGIA (INNN) IN MEXICO CITY, MEXICO

III.1 Introduction

Neurocysticercosis (NCC) is caused by the larval stage of *Taenia solium.* The disease occurs when a human inadvertently ingests parasite eggs that have been shed in the feces of a person infected with taeniosis, with the eggs developing into larvae in the central nervous system. NCC is predominantly found and considered endemic in Latin American, Asian, and African countries where pigs are raised using traditional methods, veterinary meat inspection is insufficient, and sanitation is poor [1-3]. It has also been increasingly diagnosed in higher income areas such as the United States, Western Europe, and Canada due to immigrants from endemic areas who may have taeniosis or cysticercosis [6,7,66]. In Mexico and other Latin American countries, NCC is considered one of the leading causes of epilepsy [58,83].

In humans, NCC is associated with numerous clinical manifestations, including epilepsy, hydrocephalus, focal deficits, severe chronic headaches, increased intracranial pressure, dementia, vasculitis, and stroke [8]. These NCC-associated clinical manifestations have been shown to affect patients' quality of life leading to poorer physical and mental health and important economic consequences [13,16,17,84]. Studies conducted in India, Peru, and Mexico have estimated the average direct and indirect costs per NCC patient under care [62,63,84], while two studies from the United States and one from Chile evaluated hospital-associated charges for

NCC patients [64,65,85]. However, the per-patient costs associated with pre-hospitalization, hospitalization, and post-hospitalization for NCC have not been evaluated.

Period-specific cost estimates will be crucial for policy makers to comprehensively understand the true economic impact of the disease in order to prioritize and allocate resources. Therefore, this study was conducted to better define direct costs associated with pre-hospitalization, hospitalization, and post-hospitalization from a societal perspective for NCC patients seeking care at a referral hospital in Mexico City, Mexico.

III.2 Materials and methods

III.2.1 Study location

This study was conducted in a referral hospital for adult neurological cases in Mexico City, Mexico: the Instituto Nacional de Neurologia y Neurocirugia (INNN). The INNN only accepts patients who do not have medical insurance coverage through their employment. NCC patients with employer-provided medical insurance are seen at a different referral hospital in Mexico City and are, therefore, not represented in the current study.

III.2.2 Definition and study populations

NCC was defined based on the presence of compatible cerebral lesions on a computed tomography (CT) scan, magnetic resonance imaging (MRI), or both [23]. Outpatients diagnosed with NCC and with a clinical appointment at the INNN between July 17 and December 7, 2007 were eligible to participate. Eligible patients were identified using outpatient appointment books, which allowed a research assistant to explain the study and ask for patient consent at the time of the appointment. NCC outpatients were sequentially invited to participate until at least

100 patients were enrolled. The medical charts of consenting patients were reviewed by a trained member of the research team (i.e., a Mexican intern, resident, or social worker). Only patients alive at the time of recruitment and who were hospitalized for the treatment of NCC between January 2002 and August 2007 were included in this study.

III.2.3 Data collection

Four forms were used to gather information on presenting clinical manifestations, diagnostic tests performed, number of days hospitalized, surgical procedures, and treatments received by the patients, including prescription medications (Appendix C, D, E and F). An intake form was used to record information on the NCC-associated clinical manifestation(s) that resulted in the patient being referred to the hospital. A diagnostic and treatment form was used to record information on techniques employed for the confirmation of NCC and the medications and procedures used for its treatment. Inpatient and outpatient forms were used to record information on the number of times patients were hospitalized or had an outpatient appointment for the treatment and management of NCC.

III.2.4 Direct costs associated with pre-hospitalization, hospitalization, and post-hospitalization of NCC patients

Diagnosis and treatment-related costs were calculated for the pre-hospitalization, hospitalization, and post-hospitalization periods, beginning with the first NCC-associated visit to the INNN. The frequency of appointments with various healthcare providers (neurologists, neurosurgeons, psychiatrists, neurootologists, and general practitioners), prescription medication use, hospitalizations, surgical interventions, and diagnostic testing (CT scans, MRI,

cerebrospinal fluid (CSF) testing, enzyme-linked immunosorbent assays (ELISA), enzyme-linked immunoelectrotransfer blot (EITB), biopsies, electroencephalograms (EEG), and neurological examinations) performed before, during, and after hospitalization were obtained using the forms described above. Initial visits to the INNN prior to the first NCC-associated hospitalization were included in the pre-hospitalization cost estimation. Healthcare services received at the INNN between two hospitalizations contributed to post-hospitalization costs for patients hospitalized more than once.

The cost of physician office visits, diagnostic tests, a one-day stay in the hospital, and surgery were obtained from the year 2006 price list for healthcare services at the INNN [74]. Year 2006 tariffs were used due to their availability to study personnel and to be in line with previous studies looking at NCC-related costs in Mexico [84]. Services for all patients included in the study were costed in 2006 U.S. dollars (U.S.$) regardless of the date of hospitalization. The prices used in this study, are considered applicable to other healthcare facilities in Mexico. There are seven levels of payments at the INNN, where patients pay medical fees according to their household income. Patients with a very low household income (level 0) do not pay anything out-of-pocket, with all costs associated with treatment paid for by the healthcare provider (HCP). Level 1-6 patients pay increasing amounts for procedures and services. Based on discussions with hospital personnel, level 5 best represents the true cost to the healthcare system.

In order to estimate costs associated with prescribed medications, a list of drugs along with their dosages were extracted from the medical records. Brand name drugs were noted if specifically stated in the medical record. Otherwise, the active ingredient was recorded. Medication costs were obtained from pharmacies in Mexico City, Mexico. When only the active ingredient was available, pharmacy costs could represent either a brand name or generic drug. In

situations where more than one dosage was available, the dosage that best matched the dosage and formulation presented in the medical record was used. Table 12 shows a list of the drugs' active ingredients, dosages, and year 2006 pharmacy prices. Some of these combinations are known to represent specific brands, while others may represent generic drugs. Table 13 shows a list of surgical procedures performed for NCC patients. All patients seen at the INNN pay for prescription medications out-of-pocket. An exchange rate for the year 2006 of 10.80 Mexican pesos to 1 U.S. dollar was used [75].

Table 12: List of drugs prescribed for NCC patients treated at INNN between 2002 and 2006

	Dosage	**Pharmacy price per dose in U.S.$**
Acetaminophen	500 mg	0.08
Acetylsalicylic acid	100 mg	0.07
Albendazole	200 mg	0.69
Captopril	25 mg	0.02
Carbamazepine	200 mg	0.08
Cinnarizine	75 mg	0.83
Ciprofloxacin	500 mg	0.35
Clobazam	10 mg	0.46
Clonazepam	2.5 mg	0.04
Clonixin lysine-cyclobenzapine	100 mg/2 ml	0.5
Dexamethasone	8 mg/2 ml	0.27
Enalapril	10 mg	0.23
Fluoxetine	20 mg	2.4
Galantamine	4 mg	1.27
Ibuprofen	400 mg	0.75
Ketorolac	10/30 mg	0.12
Lamotrigine	100 mg	1.41
Metoclopramide	10 mg	0.03
Metronidazole	500 mg	0.19
Nimodipine	30 mg	0.96
Omeprazole	20/40 mg	0.04/3.50
Phenytoin	100/250 mg	0.16/1.40
Praziquantel	600 mg	5.86
Prednisone	5mg/50 mg	0.02/0.10

Table 12: Continued

	Dosage	Pharmacy price per dose in U.S.$
Primidone	250 mg	0.16
Propanolol	40 mg	0.13
Quetiapine	25 mg	0.77
Ranitidine	150/300 mg	0.10/0.15
Topiramate	100 mg	1.93
Valproic acid	200 mg	0.11
Vigabatrin	300 mg	0.53

Table 13: List of surgical procedures performed for NCC patients treated at the INNN between 2002 and 2006

Type of Surgery	Level 5 Cost in U.S.$
Close up ventriculostomy	71
Craniotomy	2,389
Cysticercosis removal/resection	1,535
Endoscopic exploration	307
Laminectomy	2,507
Replacement/removal of vericulo-peritoneal shunt	1,023
Valve replacement	1,023
Valvular dysfunction	1,023
Ventriculoperitoneal shunt placement	1,535
Ventriculostomy	511

III.2.5 Statistical analysis

Pre-hospitalization, hospitalization, and post-hospitalization costs were determined for each patient, with the average cost per period calculated for all patients. Pre-hospitalization costs were obtained by adding the actual (level 5) costs associated with physician office visits, diagnostic testing, and pharmacy costs for prescription medications prior to the first hospitalization. Similarly, hospitalization costs were obtained by adding actual (level 5) costs associated with diagnostic testing performed during hospitalization, a hospital stay in a private or

general ward, surgery, and pharmacy costs for prescription medications received during hospitalization. An individual patient's per day hospitalization cost was obtained by dividing the patient's total hospitalization cost by the number of days hospitalized. These costs were then averaged over the entire study population to obtain a mean per day hospitalization cost. Post-hospitalization costs were calculated by adding the actual (level 5) costs associated with physician office visits, diagnostic testing, and pharmacy costs for prescription medications received after the first hospitalization for NCC at the INNN.

Enrolled patients began receiving treatment for NCC at the INNN on various dates between 2002 and 2007. Therefore, at study commencement, patients had been followed for differing lengths of time. Annual costs were assessed for up to five years post-hospitalization based on the date of treatment initiation at the INNN. Only patients followed for at least 12 months after hospitalization were included in any post-hospitalization costs estimates. For patients with more than one recorded hospitalization, post-hospitalization out-patient costs were assessed from the date of first hospitalization for NCC until the date of data collection.

Average per-patient level 5 costs were calculated for the entire study population as well as stratified by presenting clinical manifestation(s). The average costs that patients paid out-of-pocket during the pre-hospitalization, hospitalization, and post-hospitalization periods were also obtained using patient payment levels and prescription medication costs. The average per-patient cost for each clinical manifestation grouping was then compared across the pre-hospitalization, hospitalization, and post-hospitalization periods using a repeated measures ANOVA, with post hoc pairwise comparisons made using Tukey's method. The above comparisons were made for all patients followed at least one year post-hospitalization. For patients followed at least 3 years post-hospitalization, the average treatment costs for the first, second, and third years post-

hospitalization were compared using a repeated measures ANOVA, with post hoc pairwise comparisons conducted using the Tukey method. A t-test was used to compare the average per-patient hospitalization cost for patients who had a history of surgery with those who did not receive surgery. As the number of observations was small after stratifying the patients based on clinical manifestation(s), the variances of the cost estimates were calculated using bootstrap techniques. The obtained variances were then used to calculate the 95% confidence intervals (95% CIs) for the average annual costs. All calculations were performed using Stata (Stata Statistical Software: Release 11.2. College Station, TX: StataCorp LP). A p-value <0.05 was considered statistically significant.

III.2.6 Ethical approval

This study received IRB approval from Texas A&M University (2006-0606 and 2014-0702) and the INNN.

III.3 Results

III.3.1 Patient demographics

Among the 123 outpatients recruited, 108 had been hospitalized between 2002 and 2007 and 18 of these patients were hospitalized more than once. Patients were primarily from the State of Mexico (41%) and Mexico City (25%). The demographic characteristics of the hospitalized patients are shown in Table 14. The median age at the time of first hospitalization for NCC at the INNN was 42 years old and ranged from 19 to 84 years old. Almost half of the hospitalized patients were males (48%). The number of hospitalized days ranged from 2 to 56 per patient. The lengths of time patients were treated at the INNN pre-hospitalization and post-

hospitalization ranged from 0 days to 5 years and 1 month to 5 years, respectively. Fifty percent of patients paid at level 2, with no patients assigned to level 0 (Table 14).

Table 14: Demographic features of 108 NCC patients hospitalized at the INNN from 2002 to 2007

	Level 1 (n=37)	**Level 2 (n=54)**	**Level 3 (n=9)**	**Level 4 (n=1)**	**Level 5 (n=3)**	**Level 6 (n=4)**	**Total (n=108)**
Number of patients who were hospitalized more than once	9	8	0	0	0	1	18
Number of patients who did not receive pre-hospitalization treatment at the INNN	16	11	4	0	1	1	33
Number of patients who received 1 to 30 days of pre-hospitalization treatment at the INNN	10	22	2	0	1	1	36
Number of patients who received 31 to 180 day of pre-hospitalization treatment at the INNN	5	7	2	1	0	0	15
Number of patients who received 181 to 365 days of pre-hospitalization treatment at the INNN	2	2	0	0	1	0	5
Number of patients who received 1 to 2 years of pre-hospitalization treatment at the INNN	1	3	1	0	0	1	6
Number of patients who received more than 2 years, but less than 3 years of pre-hospitalization treatment the INNN	1	3	0	0	0	1	5
Number of patients who received more than 3 years, but less than 4 years of pre-hospitalization treatment at the INNN	1	2	0	0	0	0	3
Number of patients who received more than 4 years, but less than 5 years of pre-hospitalization treatment at the INNN	1	4	0	0	0	0	5
Number of patients with records available for at least 1 year post-hospitalization	31	43	7	1	2	2	86

Table 14: Continued

	Level 1 (n=37)	Level 2 (n=54)	Level 3 (n=9)	Level 4 (n=1)	Level 5 (n=3)	Level 6 (n=4)	Total (n=108)
Number of patients with records available for at least 2 years post-hospitalization	19	25	7	1	2	1	55
Number of patients with records available for at least 3 years post-hospitalization	14	17	7	0	2	1	41
Number of patients with records available for at least 4 years post-hospitalization	8	12	5	0	1	0	26
Number of patients with records available for 5 years post-hospitalization	4	7	4	0	0	0	15

III.3.2 Clinical manifestations

The most common clinical manifestations reported were severe chronic headaches (21%), hydrocephalus (19%), and the combination of hydrocephalus and severe chronic headaches (29%) (Figure 6).

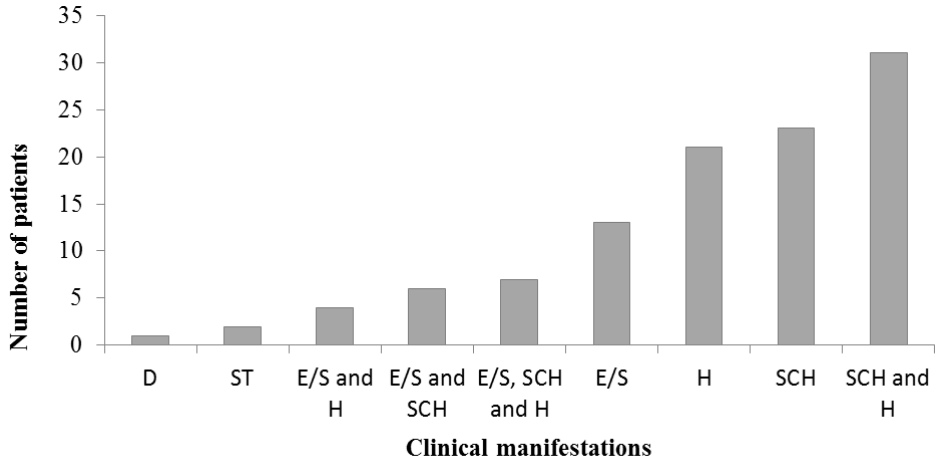

Figure 6: NCC-related clinical manifestations of study patients

E/S = Epilepsy/seizures, H = Hydrocephalus, SCH= Severe chronic headaches, ST= Stroke, D = Dementia

III.3.3 Estimation of pre-hospitalization, hospitalization, and post-hospitalization costs

Hospitalization costs were significantly higher compared to the costs incurred during the pre-hospitalization or complete post-hospitalization periods for all clinical manifestations except for epilepsy and stroke (Table 15).

Table 15: Comparison of average pre-hospitalization, hospitalization and total post-hospitalization costs for NCC patients treated at the INNN between 2002 and 2006 (2006 U.S.$) by clinical manifestation(s)

Clinical Manifestation(s)	Pre-hospitalization	Hospitalization	Post-hospitalization	P-value	Overall p value
Epilepsy/seizures (n=11)	191	1,397		0.00	0.00
	191		1,258	0.00	
		1.397	1,258	0.88	
Hydrocephalus (n=16)	155	1,983		0.00	0.00
	155		663	0.06	
		1,983	663	0.00	
Severe chronic headache (n=21)	306	2,089		0.00	0.00
	306		806	0.18	
		2,089	806	0.00	
Stroke (n=2)	269	4,007		0.38	0.36
	269		1,054	0.94	
		4,007	1,054	0.51	
Epilepsy/seizures and severe chronic headaches (n=6)	448	3,050		0.00	0.02
	448		872	0.7	
		3,050	872	0.01	
Epilepsy/seizures and hydrocephalus (n=4)	119	4,544		0.00	0.04
	119		711	0.85	
		4,544	711	0.01	
Severe chronic headaches and hydrocephalus (n=22)	290	3,022		0.00	0.00
	290		769	0.28	
		3,022	769	0.00	
Epilepsy/seizures, severe chronic headaches, and hydrocephalus (n=4)	213	3,488		0.00	0.03
	213		539	0.94	
		3,488	539	0.00	

Pre-hospitalization costs

The average actual (level 5) per-patient pre-hospitalization cost was U.S.$ 257 (95% CI: 185 – 329). Diagnostic testing made up 81% of this cost, followed by physician office visits (10%) and prescription medications (9%). The average out-of-pocket pre-hospitalization cost was U.S.$ 62 (95% CI: 32 – 92). Table 16 shows the average per-patient pre-hospitalization costs by presenting clinical manifestation(s). No significant difference was found in the per-patient pre-hospitalization costs for the various presenting clinical manifestation(s) (p=0.75). Overall, thirty-one percent of patients did not receive pre-hospitalization treatment. Since few patients received pre-hospitalization treatment for more than 30 days, stratification by the duration of pre-hospitalization care was not conducted.

Table 16: Average actual (level 5) per-patient pre-hospitalization costs (2006 U.S.$) for NCC patients treated at the INNN between 2002 and 2006 by clinical manifestation(s) (values in brackets represent 95% CI)

		Per-patient pre-hospitalization costs (95% CI)			
Clinical manifestation(s)	**Number of patients**	**Diagnostic tests**	**Physician office visits**	**Prescription medications**	**Total**
Epilepsy/seizures	13	156 (10 - 303)	12 (0 - 32)	28 (4 - 52)	196 (8 – 402)
Hydrocephalus	21	134 (44 -226)	10 (1 – 19)	7 (2 – 12)	152 (58 – 246)
Severe chronic headaches	23	239 (75 - 403)	24 (4 – 44)	24 (0 – 64)	287 (106 – 470)
Stroke	2	269 (181 – 356)	0	0	269 (181 – 356)
Dementia	1	0	60	0	60
Severe chronic headaches and hydrocephalus	31	270 (143 – 397)	49 (13 – 84)	12 (0 – 26)	331 (166 –495)
Epilepsy/seizures and hydrocephalus	4	108 (10 – 207)	5 (0 – 10)	6 (0 – 13)	119 (15 – 223)
Epilepsy/seizures and severe chronic headaches	6	263 (0 – 528)	46 (0 – 112)	139 (0 – 334)	448 (0 – 938)

Table 16: Continued

		Per-patient pre-hospitalization costs (95% CI)			
Clinical manifestation(s)	**Number of patients**	**Diagnostic tests**	**Physician office visits**	**Prescription medications**	**Total**
Epilepsy/seizures, severe chronic headaches, and hydrocephalus	7	183 (51 – 316)	17 (0 – 42)	0	200 (43 – 355)
Overall	108	210 (152 – 270)	26 (15 – 39)	21 (3 – 40)	257 (185 – 329)

Hospitalization costs

The average actual (level 5) per-patient hospitalization cost was U.S.$ 2,576 (95% CI: 2,244 – 2,908), with an average per-patient per-day hospitalization cost of U.S.$ 269 (95% CI: 218 – 320). The average total out-of-pocket hospitalization cost was U.S.$ 424 (95% CI: 247 – 602), with an average daily cost of U.S.$ 67 (95% CI: 6 – 128) (Table 17). Figure 7 shows the average per-patient per-day hospitalization cost by presenting clinical manifestation(s). No significant difference was found in the per-patient hospitalization costs for the various presenting clinical manifestation(s) ($p=0.13$). However, the cost of hospitalization was significantly higher in patients who had surgery (n=66) (U.S.$ 3,487) compared to those who did not have surgery (n=42) (U.S.$ 1,166) ($p<0.001$). While 67% of NCC patients with clinical manifestations other than epilepsy underwent surgical procedures during hospitalization, only 23% of epilepsy patients had surgery.

Table 17: Average actual (level 5) per-patient hospitalization costs (2006 U.S.$) for NCC patients treated at the INNN between 2002 and 2006 by clinical manifestation(s) (values in brackets represent 95% CI)

Clinical manifestation(s)	Number of patients (Number of hospitalizations)	Per-patient hospitalization costs (95% CI)				
		Diagnostic tests	Hospital stay	Surgery	Prescription medications	Total hospitalization
Epilepsy/ seizures	13(13)	177 (100 - 253)	1,026 (655 – 1,397)	429 (5 - 853)	107 (0 – 220)	1,739 (926 – 2,552)
Hydrocephalus	21 (24)	186 (99 – 273)	803 (570 – 1,037)	1561 (947 – 2,176)	13 (2 –24)	2,565 (1,787 – 3,342)
Severe chronic headaches	23 (25)	297 (198 – 396)	758 (585 – 930)	882 (382 – 1,382)	24 (7 – 42)	1,961 (1,427 – 2,496)
Stroke	2 (2)	229 (31 – 427)	2,416 (441 – 4,393)	1,278 (90 – 2,468)	82 (11 – 154)	4,007 (467 – 7,548)
Dementia	1 (1)	469	748	0	99	1,316
Severe chronic headaches and hydrocephalus	31(44)	197 (115 – 280)	874 (664 –1,084)	1,782 (1,245 – 2,318)	28 (10 – 47)	2,882 (2,265 – 3,499)
Epilepsy/seizures and hydrocephalus	4 (9)	481 (154 – 809)	1,276 (680 – 1,872)	2,771 (1,289 – 4,253)	14 (0 -33)	4,544 (2,241 – 6,847
Epilepsy/seizures and severe chronic headaches	6 (10)	433 (115 – 749)	1,316 (869 – 1,763)	1,279 (447 – 2,110)	22 (9 – 35)	3,050 (1,803 – 4,296)
Epilepsy/seizures, severe chronic headaches, and hydrocephalus	7 (12)	472 (310 – 634)	904 (531 – 1,277)	1,819 (451 – 3,187)	38 (24 – 52)	3,223 (1,866 – 4,579)
Overall	108 (140)	254 (206 – 302)	922 (689 – 1,155)	1,365 (797 – 1,933)	35 (19 – 51)	2,576 (2,244 – 2,908)

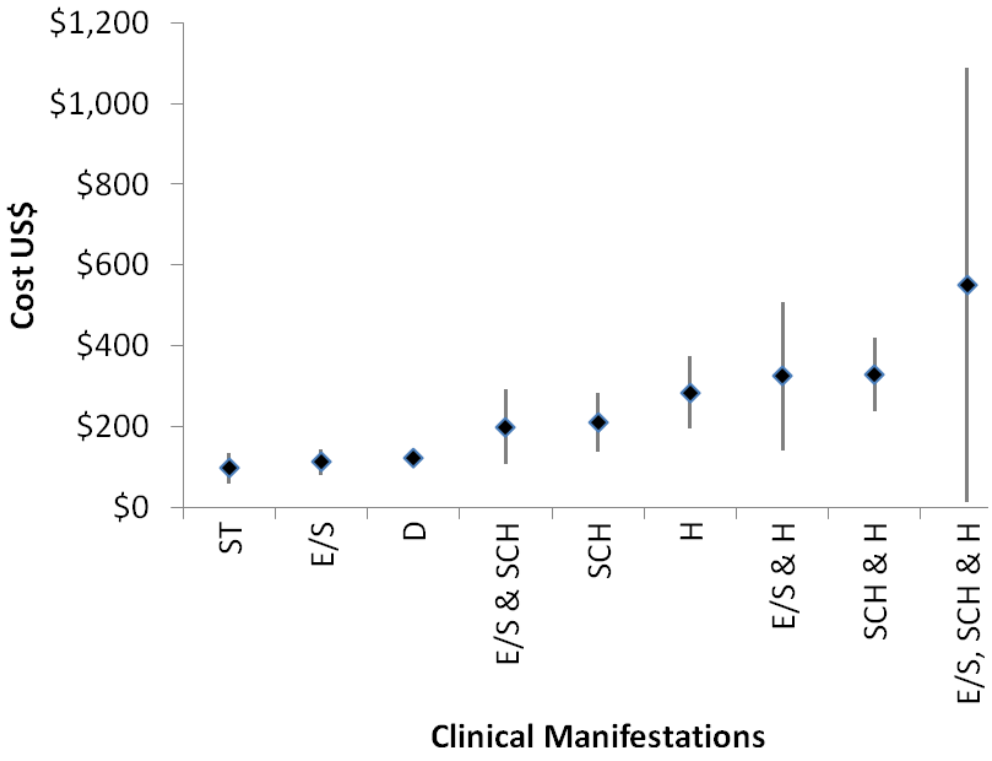

Figure 7: Average actual (level 5) per-patient per day hospitalization costs (U.S.$) for NCC patients treated at the INNN by clinical manifestation(s) (The plot whiskers extend to the upper and lower 95% confidence intervals)

E/S = Epilepsy/ seizures, H = Hydrocephalus, SCH= Severe chronic headaches, ST= Stroke, D = Dementia

Post-hospitalization costs

The average actual (level 5) per-patient costs for one to five years post-hospitalization were U.S.$ 475 (95% CI: 423 – 527), U.S.$ 228 (95% CI: 167 – 288), U.S.$ 157 (95% CI: 111 – 202), U.S.$ 150 (95% CI: 106 – 204), and U.S.$ 91 (95% CI: 27 – 154), respectively (Table 18 and Figure 8). For patients followed for at least 3 years post-hospitalization (n=41), the average cost for the first post-hospitalization treatment year (U.S.$ 445) was significantly higher than that for the second year post-hospitalization (U.S.$ 316) (p=0.05), which in turn was not

significantly higher than that of the third year post-hospitalization (U.S.$ 239) (p=0.35). No significant difference was found in the per-patient costs for the various presenting clinical manifestation(s) for the post-hospitalization period (p=0.37) (Table 18). Figure 8 shows the average post-hospitalization costs broken down by the cost components of diagnostic testing, visits to a healthcare provider, and prescription medications. The out-of-pocket costs for one to five years post-hospitalization were U.S.$ 114 (95% CI: 88 – 141), U.S.$ 56 (95% CI: 32 – 80), U.S.$ 47 (95% CI: 25 – 69), U.S.$ 45 (95% CI: 17 – 74), and U.S.$ 32 (95% CI: 0 – 66), respectively. Most of the out-of-pocket costs were due to prescription medications (Figure 9).

Table 18: Average actual (level 5) per-patient post-hospitalization costs (2006 U.S.$) for NCC patients treated at the INNN between 2002 and 2006 by clinical manifestation(s) (values in brackets represent 95% CI)

Clinical manifestations	**Per-patient post-hospitalization costs (95% CI), (number of patients)**				
	1st year	**2nd year**	**3rd year**	**4th year**	**5th year**
Epilepsy/ seizures	648 (421 - 874) (n=11)	319 (66 – 574) (n=9)	220 (65 – 376) (n=6)	207 (44 – 398) (n=4)	197 (n=1)
Hydrocephalus	480 (369 – 591) (n=16)	115 (51 – 180) (n=9)	187(54 – 320) (n=4)	159 (23 – 295) (n=3)	127 (5 – 245) (n=2)
Severe chronic headaches	474 (357 – 592) (n=21)	302 (173 – 432) (n=11)	176 (78 – 275) (n=8)	226 (99 – 353) (n=5)	151 (1 – 301) (n=4)
Stroke	506 (255 – 665) (n=2)	105 (0 – 218) (n=2)	238 (n=1)	304 (n=1)	209 (n=1)
Dementia*	-	-	-	-	-
Severe chronic headaches and hydrocephalus	461 (379 – 542) (n=22)	244 (136 – 352) (n=15)	145 (84 – 206) (n=13)	67 (16 – 118) (n=10)	20 (1 – 38) (n=6)
Epilepsy/seizures and hydrocephalus	450 (328 – 571) (n=4)	167 (46 – 291) (n=3)	134 (0 – 291) (n=2)	124 (0 – 275) (n=2)	20 (n=1)
Epilepsy/seizures and severe chronic headaches	376 (221 – 531) (n=6)	266 (46 – 487) (n=4)	114 (0 – 246) (n=4)	215 (n=1)	-

Table 18: Continued

Clinical manifestations	Per-patient post-hospitalization costs (95% CI), (number of patients)				
	1st year	2nd year	3rd year	4th year	5th year
Epilepsy/seizures, severe chronic headaches, and hydrocephalus	373 (161 – 585) (n=4)	122 (31 – 213) (n=2)	-	-	-
Overall	475 (423 – 527) (n=86)	228 (167 – 288) (n=55)	157 (111 – 202) (n=41)	150 (106 – 204) (n=26)	91 (27 – 154) (n=15)

* The dementia patient was followed for less than 12 months and was, therefore, not included in the estimation of post-hospitalization costs

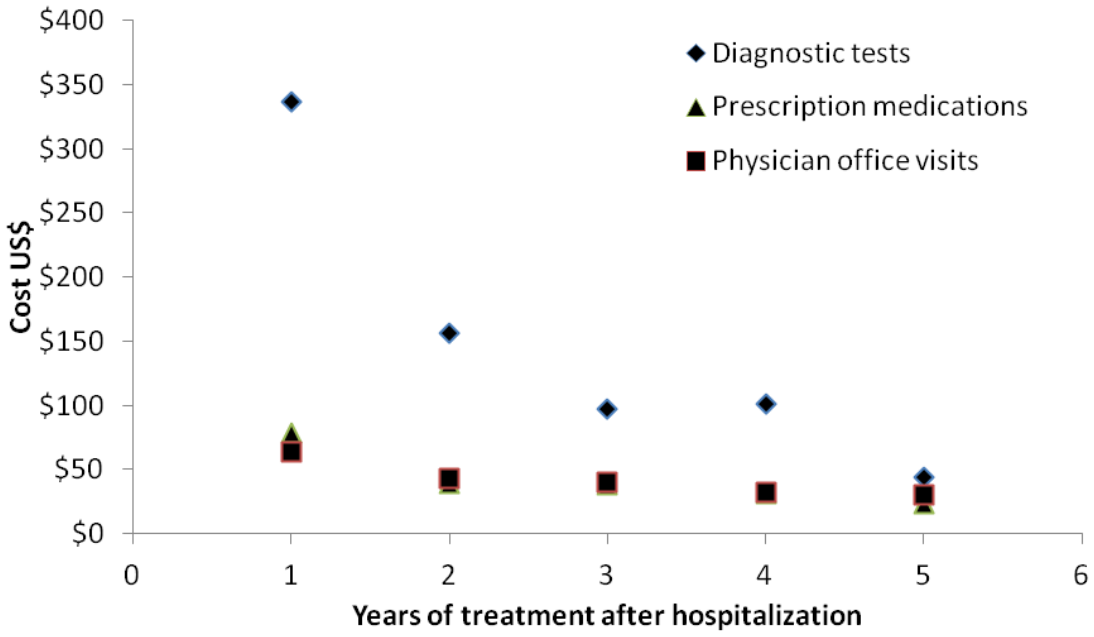

Figure 8: Average costs broken down by cost component and year of treatment post-hospitalization for NCC patients treated at the INNN

Note: There were 86, 55, 41, 26, and 15 patients who received treatment one, two, three, four, and five years post-hospitalization, respectively.

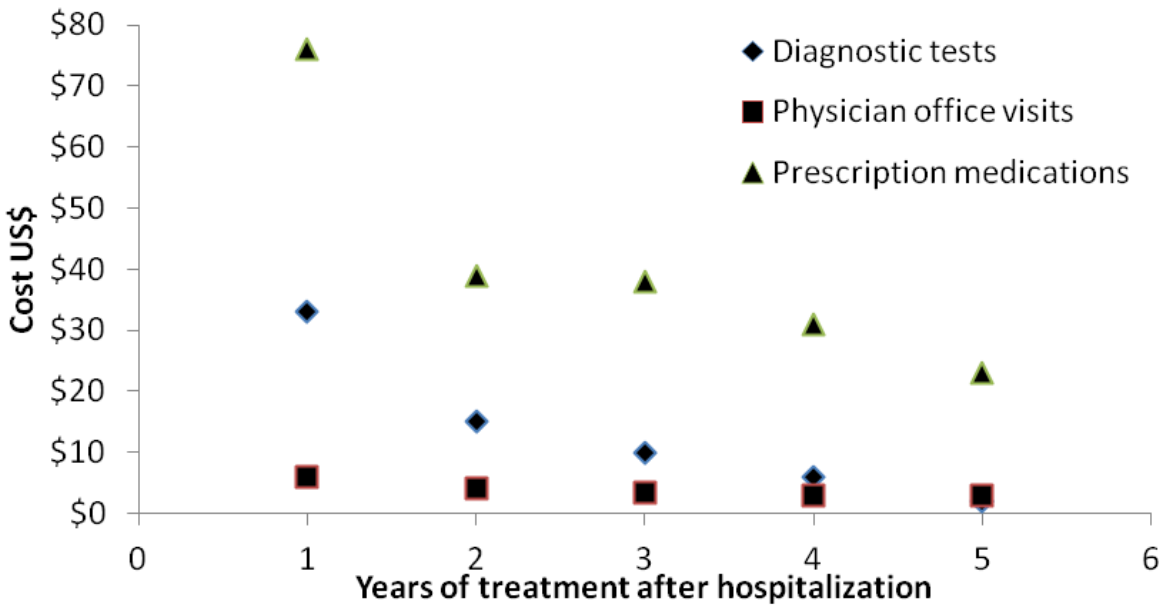

Figure 9: Average out-of-pocket costs breakdown by cost component and year of treatment post-hospitalization for NCC patients treated at the INNN

Note: There were 86, 55, 41, 26, and 15 patients who received treatment one, two, three, four, and five years post-hospitalization, respectively.

III.4 Discussion

This is the first patient-based study estimating the direct monetary losses associated with NCC-affected individuals in Mexico during the pre-hospitalization, hospitalization, and post-hospitalization periods. Overall, substantial costs were associated with patients requiring hospitalization for NCC, with this burden continuing years post-hospitalization. When all patients, regardless of having received pre-hospitalization care at the INNN, were included in the analysis, the direct economic losses pre-hospitalization, during hospitalization, and during the first year post-hospitalization were equivalent to 22%, 224%, and 42% of an annual minimum wage salary in Mexico (U.S.$ 1,145), respectively [80]. Overall, pre-hospitalization represented the least expensive cost period for patients. However, pre-hospitalization costs increased from

22% to 32% of an annual minimum wage salary when only those patients with pre-hospitalization treatment were included [80].

Very few studies have been conducted to estimate the cost associated with NCC patients. In the current study, patients incurred expenses equivalent to 64% of an annual minimum wage salary during the pre-hospitalization period plus one year post-hospitalization. In comparison, non-hospitalized Indian patients with NCC-associated epilepsy were shown to spend 51% of their per capita gross national product (GNP) on direct and indirect costs associated with their disease during their treatment period, which ranged from 1 to 14 months[62]. Unfortunately, direct comparison between these two studies is difficult. Not only did the Indian study use per capita GNP versus wage data, this study also restricted study participants to only those NCC patients with epilepsy. Since the cost of prescription medications tends to be higher for epileptic patients with NCC compared to non-epileptic NCC patients, it would be expected that epileptics would incur higher costs. In our study, epileptic patients were spending twice as much out-of-pocket for their prescription medications compared to non-epileptic patients. If we consider only the epileptic patients in our study, economic losses were equivalent to 72% of an annual minimum wage salary during pre-hospitalization plus the first year post-hospitalization. Another reason why these two studies are difficult to compare is that the Indian study also included indirect losses whereas the current Mexican study did not. Productivity losses accounted for 17% of total costs associated with the Indian patients.

In another study conducted in a reference hospital in Peru, NCC patients were spending 54% and 16% of an annual minimum wage salary on direct and indirect costs associated with their disease during their first year and second year of treatment, respectively [63]. This study included patients with and without epilepsy as well as hospitalized and non-hospitalized patients

whereas the current study only included hospitalized patients. Overall, 78% of the patients in the Peruvian study were hospitalized. The Peruvian patients spent a smaller proportion of a minimum wage salary on treatment costs compared to the Mexican patients. One possible reason for this difference is that 61% of the patients in the current study underwent surgery whereas none of the Peruvian patients underwent surgery. The pre-hospitalization, hospitalization, and post-hospitalization costs for the Mexican patients who did not have surgery were 16%, 100% and 66% of an annual minimum wage salary, respectively. Hospitalization and post-hospitalization values were, therefore, about 50% less than for the entire studied population. It should be noted that the Peruvian study also included productivity losses, which were not assessed in the current Mexican study. Productivity losses accounted for 10% of total costs in the Peruvian study.

In the current study, the hospitalization period incurred higher per-patient costs for all clinical manifestations when compared to the pre-hospitalization or entire post-hospitalization period. However, this cost was not significantly higher for patients with epilepsy or stroke as the sole presenting clinical manifestation. In comparison to patients with other clinical manifestations, fewer epilepsy cases had surgery and the number of patients with stroke was very small, explaining the lack of significant differences for these two groups. The post-hospitalization costs were highest in the first year post-hospitalization, which was likely due to the greater number of diagnostic tests performed in this year as compared to subsequent years. The average number of hospitalized days for patients whose records were evaluated after they had received only one year of treatment post-hospitalization (11 days) was similar to patients whose records were evaluated after they had received more than one year of treatment post-

hospitalization (13 days). Therefore, patient clinical severity at the time of hospitalization most likely did not greatly influence these values.

Although our results suggest that the actual cost to treat NCC is high compared to an annual minimum wage salary in Mexico, most of the patients in this study paid a reduced amount based on their income. The exception was for prescription medications. The vast majority (83%) of patients paid at level 2 or under, which is well below the actual costs to the healthcare system, indicating that they fell into a lower income bracket. Although they paid a reduced amount compared to the actual price of services, they were still spending a considerable proportion of an annual minimum wage salary out-of-pocket during the pre-hospitalization and hospitalization periods combined (43%), and during the first year post-hospitalization (10%). It should be noted that costs associated with treatment that were not paid by patients were absorbed by the hospital system and, therefore, society as a whole.

This study has some limitations. Data were collected from medical chart reviews, which limited assessed variables to those recorded as part of the standard medical charting process and those anticipated to be of value prior to commencement of this study. Therefore, type of NCC (intraparenchymal versus extraparenchymal), cyst viability, and actual wage data were not available for analysis. Our estimates are also an underestimate of the total costs associated with NCC among patients hospitalized at the INNN since indirect costs such as loss of working days due to visits to a healthcare provider or during hospitalization, cost of over-the-counter medication, cost of traditional medicine/treatment, reduction in productivity level, costs associated with transportation to and from medical treatment, and time lost by the patient's family to take care of them or to accompany them to treatment were not available for consideration[86]. In addition, this analysis excludes any costs incurred while receiving

treatment in a healthcare facility other than the INNN, which could especially affect the estimated pre- and post-hospitalization costs. Finally, this study was conducted in a neurology reference hospital, which likely sees many of the more severe cases. Therefore, the determined costs cannot be extrapolated to all NCC cases in Mexico.

While the actual costs associated with healthcare services may change over time, the relative proportion of costs associated with the pre-hospitalization, hospitalization, and post-hospitalization periods will likely remain more stable. Therefore, values presented in this study can be used by Mexico to better define the direct costs associated with NCC patients who are hospitalized at tertiary care hospitals, with the ultimate goal of better conveying the true economic impact of NCC to policy makers.

CHAPTER IV

THE MONETARY BURDEN OF CYSTICERCOSIS IN MEXICO

IV.1 Introduction

Cysticercosis is a public health and agricultural problem caused by the larvae of the zoonotic cestode *Taenia solium*. Humans are the definitive hosts of *T. solium*, with adult tapeworms found in the intestines after ingestion of undercooked pork containing cysticerci. Infection with the adult stage of the parasite is known as taeniasis. Pigs acquire cysticercosis when ingesting eggs shed in the feces of humans with taeniasis. Porcine cysticercosis results in the development of cysts in the muscles, including the tongue, and less commonly in the heart, diaphragm, brain, and other organ systems. When humans accidentally ingest eggs shed in the feces of an infected human, they develop larval cysts (cysticercosis) similar to infected pigs. Neurocysticercosis (NCC) occurs when *T. solium* cysticerci infect the central nervous system, which can result in symptoms such as epilepsy, severe chronic headaches, hydrocephalus, stroke, and dementia [8].

Porcine cysticercosis and NCC have important economic consequences. NCC incurs direct and indirect costs. Direct costs include fees associated with medical services, diagnostic procedures, surgical interventions, prescribed chemotherapeutic treatment, hospitalization, and traditional therapies. Indirect costs are associated with loss of working days due to visits to a healthcare provider or hospitalization, over-the-counter medication, loss of income due to reduced productivity, transportation to and from medical treatment, and time lost by the patient's family to take care of them or to accompany them to receive medical care [86]. In pigs,

cysticercosis can lead to partial or full condemnation of the carcass and economic losses in areas where meat is inspected [2].

NCC has been shown to result in a significant economic burden to people in Mexico requiring hospitalization [84]. However, no previous study has evaluated the burden of cysticercosis in Mexico incorporating both human and pig losses. NCC-associated monetary losses to both the human health and agricultural sectors have been evaluated in South Africa, Lao People's Democratic Republic, Cameroon, Tanzania, and India [16-20]. Studies are needed to estimate the burden of cysticercosis in endemic countries to facilitate comparisons with other locally important health conditions and to better prioritize disease control initiatives. The research presented here provides the first estimate of the monetary burden of human NCC-associated epilepsy and severe chronic headaches and porcine cysticercosis for the country of Mexico.

IV.2 Materials and Methods

IV.2.1 Study area

Mexico is the third largest country in Latin America, with a 2012 population of almost 114 million and an annual population growth rate of 1.2% [67]. It is the eleventh most populous country in the world, with 23% of the population living in rural areas [67]. Traditional pig rearing practices in *T. solium*-endemic areas allow pigs to have access to human feces in open fields facilitating the completion of the *T. solium* life cycle [68,69]. Confined pigs in yards next to dwellings may also have direct access to poorly maintained outdoor latrines [70].

IV.2.2. Estimation of the number of NCC cases with epilepsy and severe chronic headaches in Mexico

The exact number of NCC cases in Mexico is not known. The proportion of people with NCC who develop epilepsy, severe chronic headaches or other clinical manifestations is also unknown. Therefore, the numbers of cases of NCC-associated epilepsy and NCC-associated severe chronic headaches, in urban and rural areas of Mexico, were estimated based on the model used by Bhattarai el 2012 [58]. The number of epilepsy cases in Mexico was estimated by multiplying the age and rural/urban stratified population size from the 2010 Mexico census by the epilepsy prevalence estimates for Mexico [55]. The number of NCC-associated epilepsy cases was obtained by multiplying the estimated numbers of people with epilepsy in rural and urban areas by the respective proportion of people with epilepsy with NCC lesions based on a meta-analysis of NCC-frequency data from Latin America [83]. The results from this meta-analysis were also used to estimate the number of NCC-associated epilepsy cases receiving modern medical treatment in urban and rural areas. This was achieved by multiplying the numbers of NCC-associated epilepsy cases in rural and urban areas by the respective percentages seeking treatment [83].

The proportion of NCC cases with severe chronic headaches in Mexico was estimated using a multistep process. First, the total number of NCC cases presenting to a healthcare facility for any NCC-associated symptom (epilepsy, severe chronic headaches, focal deficits, stroke, dementia, etc.) was calculated. This was done by dividing the estimated number of NCC-associated epilepsy cases seeking treatment (see above) by the proportion of all symptomatic individuals with NCC who present to neurological clinics with epilepsy reported in a meta-analysis of clinical manifestations associated with NCC [8]. The number of people with NCC-

associated severe chronic headaches seeking care at a healthcare facility of any level was then estimated. The proportion of people with symptomatic NCC that have epilepsy or severe chronic headaches was assumed to be the same regardless of whether they were seen at a primary, secondary, or tertiary care facility, due to the lack of data for individuals treated at different levels in Mexico. The number of people with NCC-associated severe chronic headaches was obtained by multiplying the total number of NCC cases presenting to a healthcare facility for any NCC-associated symptom (stratified by urban/rural origin), by the proportion of NCC cases who seek care at a neurology referral hospital due to headaches based on the same systematic review [8]. The total number of people with NCC-associated severe chronic headaches, in urban and rural areas, was then calculated by dividing the total number of NCC-associated severe chronic headaches cases seen in healthcare facilities by the proportion of NCC cases with severe chronic headaches who received treatment in a neurology clinic based on Carabin et al. 2011 [8]. It should be noted that some individuals with NCC have both epilepsy and severe chronic headaches and these people contribute to the estimates for both NCC-associated epilepsy and NCC-associated severe chronic headaches. Table 19 shows the epidemiological parameters used to calculate the number of NCC-associated epilepsy and severe headache cases.

Table 19: Epidemiological parameters used to calculate the number of NCC-associated epilepsy and severe chronic headache cases

Parameter	Value or range of values	Distribution	References
2010 Population of Mexico ('000)			
Total	112,336,538	Fixed	[87]
Urban areas	86,287,410	Fixed	[87]
Rural areas	26,049,128	Fixed	[87]
Prevalence of epilepsy in 0-14-year-old males in Mexico (per 1,000)	Min:1.4 Max:12.5	Uniform (1.4 - 12.5)	[55]
Prevalence of epilepsy in 0-14-year-old females in Mexico (per 1,000)	Min: 0.8 Max: 10.0	Uniform (0.8 - 10.0)	[55]
Prevalence of epilepsy in 15-44-year-old males in Mexico (per 1,000)	Min: 1.4 Max: 17.2	Uniform (1.4 - 17.2)	[55]
Prevalence of epilepsy in 15-44-year-old females in Mexico (per 1,000)	Min: 1.4 Max: 11.7	Uniform (1.4 - 11.7)	[55]
Prevalence of epilepsy in 45-59-year-old males and females in Mexico (per 1,000)	Min: 0.1 Max: 13.2	Uniform (0.1 - 13.2)	[55]
Prevalence of epilepsy in males and females older than 60 years of age in Mexico (per 1,000)	Min: 0.3 Max: 30.8	Uniform (0.3 - 30.8)	[55]
Proportion of epilepsy cases associated with NCC in urban area of Mexico	Min: 0.21 Max: 0.37	Uniform (0.21 - 0.37)	[83]
Proportion of epilepsy cases associated with NCC in rural areas of Mexico	Min: 0.26 Max: 0.49	Uniform (0.26 - 0.49)	[83]
Proportion of NCC patients 0-14 years of age with epilepsy	Min: 0.70 Max: 0.86	Uniform (0.70 - 0.86)	[8]
Proportion of NCC cases older than 15 years of age with epilepsy	Min: 0.52 Max: 0.74	Uniform (0.52 - 0.74)	[8]
Proportion of people with epilepsy not receiving modern medical treatment in urban areas	Min: 0.10 Max: 0.46	Uniform (0.10 - 0.46)	[83]
Proportion of people with epilepsy not receiving modern medical treatment in rural areas	Min: 0.67 Max: 0.87	Uniform (0.67 - 0.87)	[83]
Proportion of people 0-14 years of age with severe chronic headaches presenting with NCC	Min: 0.21 Max: 0.35	Uniform (0.21 - 0.35)	[8]
Proportion of individuals older than 15 years of age with severe chronic headaches presenting with NCC	Min: 0.11 Max: 0.45	Uniform (0.11 - 0.45)	[8]

IV.2.3 Treatment seeking behavior of people with NCC in Mexico

People with NCC-associated epilepsy and severe chronic headaches were divided into two categories; 1) those who do not seek modern medical treatment, and 2) those who seek modern medical treatment. Modern medical treatment is defined as western medicine/allopathic medicine. These categories were further divided into sub-categories as explained in the next sections. A flowchart showing treatment end-points for Mexicans with NCC-associated epilepsy and severe chronic headaches is found in Figure 10.

Literature-based information on healthcare seeking behavior and treatment gaps was used to estimate the number of people with NCC in each of the above groups. A setting-specific questionnaire was developed in Spanish to obtain information not found in the published literature (Appendix G).

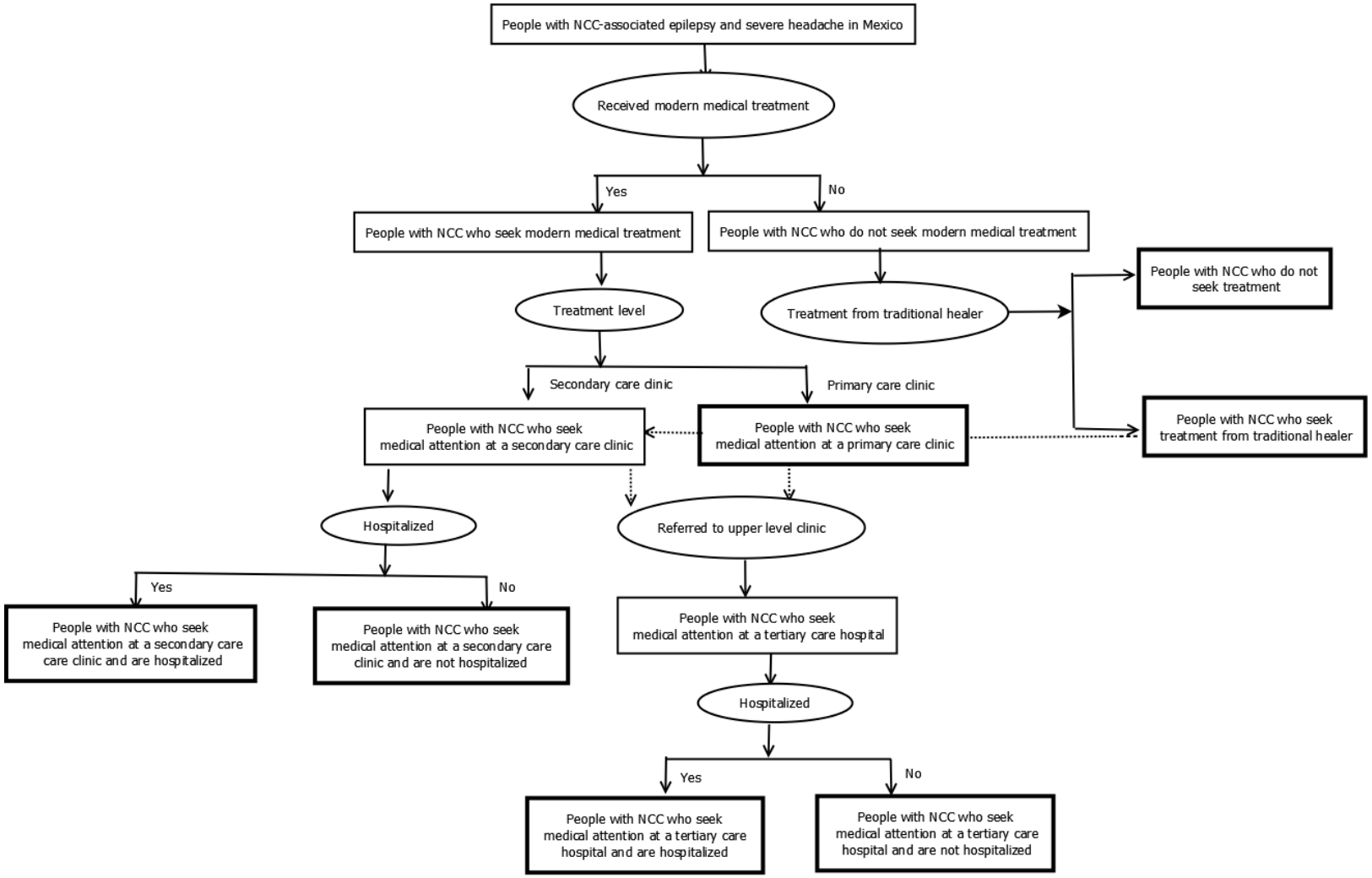

Figure 10: Flowchart showing categories of treatment-seeking behavior of people with NCC-associated epilepsy and NCC-associated severe chronic headaches in Mexico

Note: Please refer to table 19 for information concerning the uncertainty distributions associated with the specific parameters. All data were stratified by rural/urban residence. Localities of 2,500 or more inhabitants were considered urban (UN 2010).

IV.2.4 People with NCC-associated epilepsy or severe chronic headaches not seeking modern medical treatment

A recent systematic review of epilepsy and NCC in Latin America was used to estimate the number of NCC-associated epilepsy cases receiving modern medical treatment in urban and rural areas of Mexico [83]. Due to limited data on the treatment gap for severe chronic headaches, the treatment gap was assumed to be 10% more than that of epilepsy due to the generally greater clinical severity of epilepsy. This estimate is consistent with treatment gaps reported in other countries. For example, studies conducted in the United Kingdom (U.K.) reported that the epilepsy treatment gap was 2%, whereas the migraine treatment gap was 14% [88,89] (Table 20).

It was assumed that some individuals with epilepsy or severe chronic headaches seek treatment exclusively from traditional healers. Questionnaire findings from employees at the Michoacán Office of the Ministry of Health estimated that an average of 23% (min: 0%, mode: 0%, max: 70%) and 26% (min: 0%, mode: 0%, max: 80%) of people with epilepsy and severe headaches from rural areas, respectively, seek medical attention exclusively from traditional healers. Questionnaire findings are in line with a study conducted in rural Mexico where 33% of people with epilepsy sought treatment from traditional healers after their first seizure [90]. There was no literature to support the proportion of people with severe chronic headaches seeking treatment from traditional healers in Mexico. However, questionnaire findings are similar to those of a study conducted in rural and urban Taiwan where 24.2% of people with migraines sought treatment from practitioners of traditional Chinese medicine [91]. Triangular distributions using the minimum, mode, and maximum values from the questionnaires were used to estimate

the number of NCC-associated epilepsy and severe chronic headache cases seeking treatment solely from traditional healers in rural areas of Mexico.

According to Hoeven et al. 2012, individuals residing in rural areas of South Africa were twice as likely to prefer treatment from a traditional healer compared to individuals residing in urban areas [92]. Since such data are not available from Mexico, the proportions of individuals with epilepsy and severe chronic headaches who seek medical attention exclusively from a traditional healer in rural areas of Mexico were multiplied by 0.5 to obtain the proportions of individuals who seek medical attention exclusively from a traditional healer in urban areas of Mexico. The numbers of NCC-associated epilepsy and severe chronic headaches cases seeking treatment solely from traditional healers were estimated by multiplying the number of NCC-associated epilepsy and NCC-associated severe chronic headaches cases in rural and urban areas by the proportion of people seeking treatment from traditional healers (Table 20).

The proportion of people with NCC-associated epilepsy or severe chronic headaches who do not receive any treatment was estimated by subtracting the proportion of people who only receive treatment from traditional healers from the proportion of people who do not seek modern medical treatment. These proportions were multiplied by the numbers of people with NCC-associated epilepsy and severe chronic headaches in rural and urban areas to obtain the respective numbers of people with NCC not receiving any form of treatment.

IV.2.5 People with NCC-associated epilepsy or severe chronic headaches seeking modern medical treatment

People with NCC receiving modern medical treatment were further broken down into six sub-categories representing the highest level of care obtained; i) those who receive medical

attention from a primary care provider, ii) those who receive medical attention from both a primary care provider and a traditional healer, iii) those who receive medical attention from a secondary care provider and are not hospitalized, iv) those who receive medical attention from a secondary care provider and are hospitalized, v) those who receive medical attention at a tertiary care hospital and are not hospitalized, and vi) those who receive medical attention at a tertiary care hospital and are hospitalized.

In Mexico, people with epilepsy or severe chronic headaches generally initially seek treatment at a primary care clinic. From there, a proportion of them are referred for further treatment at a secondary or tertiary care facility. Due to a lack of published data on the proportion of people with epilepsy, in urban areas, who are referred for upper level care in Mexico, data from a 2007 study conducted in Brazil and a 2010 study conducted in the U.K. were used. The Brazilian and U.K. studies reported that 59% and 23% of people with epilepsy who came to primary care clinics in urban areas were referred to upper level care, respectively [93,94]. The estimate was modeled as a uniform distribution between the U.K. study (23%) and the Brazilian study (59%). Similarly, the proportion of people with severe chronic headaches referred to upper level care in urban areas was assumed to follow a uniform distribution between an estimate from a study of people with migraine conducted in Latin America in 2005 (8%) and a study conducted in the United States (U.S.) in 1993 (30%) [95,96].

Since referral data based on a rural versus urban setting are not available from Mexico, it was assumed that the proportion of cases of epilepsy and severe chronic headaches referred in rural areas would be half that seen in urban areas. This estimate was based on a U.S. study showing that urban physicians are twice as likely to refer people for upper level care on the suspicion of hereditary breast cancer compared to rural physicians [97]. The proportion of

patients referred to a secondary care clinic directly from a primary care clinic was based on questionnaire responses provided by physicians working in a primary care clinic in Michoacán. The proportion of patients referred to a tertiary care hospital directly from a primary clinic was based on questionnaire responses provided by neurologists working in a secondary care clinic in Michoacán. The estimate was modeled as a triangular distribution using the provided values for minimum, mode, and maximum. Based on the assumption that the referral rate is double in urban areas, the values provided by the physicians were multiplied by two to estimate the proportions referred from primary to tertiary care in urban areas. The proportions of people with epilepsy or severe chronic headaches referred from a primary care provider to a secondary care provider were estimated by subtracting the proportion of people referred to a tertiary care hospital from all referred patients with epilepsy and severe chronic headache for both rural and urban locations. It was assumed that secondary care providers and tertiary hospitals are primarily located in urban areas; therefore, the proportions of patients that were referred to tertiary hospitals from secondary care clinics would be the same for both urban and rural areas.

Some people with epilepsy and severe chronic headaches seek medical attention from both a modern doctor and a traditional healer. This proportion (35% for epilepsy and 31% for severe chronic headaches) was based on questionnaire responses provided by employees of the Michoacán branch of Mexico's Ministry of Health (Appendix G). The estimate provided is consistent with findings from a study conducted in the Rio Grande Valley of Texas where 44% of Mexican Americans were found to use alternative medicine in addition to modern medicine [98]. Based on the assumption that individuals residing in rural areas are twice as likely to prefer treatment from a traditional healer compared to individuals residing in urban areas, the above

values were multiplied by 0.5 to estimate the proportion of people who seek medical attention from both a modern doctor and a traditional healer in urban areas.

Table 20: Human epidemiologic parameters used to estimate the monetary burden of cysticercosis in Mexico

Parameter	Value	Distribution	Reference
Proportion of people with epilepsy not receiving modern medical treatment in urban areas	Min: 0.10 Max: 0.46	Uniform	[83]
Proportion of people with epilepsy not receiving modern medical treatment in rural areas	Min: 0.67 Max: 0.87	Uniform	[83]
Proportion of people with severe chronic headaches not receiving modern medical treatment in urban areas	Min: 0.21 Max: 0.56	Uniform	[see text]
Proportion of people with severe chronic headaches people not receiving modern treatment in rural areas	Min: 0.78 Max: 0.97	Uniform	[see text]
Proportion of people with epilepsy who seek treatment exclusively from a traditional healer in urban areas	Min: 0 Mode: 0 Max: 0.35	Triangular	Appendix G
Proportion of people with epilepsy who seek treatment exclusively from a traditional healer in rural areas	Min: 0 Mode: 0 Max: 0.7	Triangular	Appendix G
Proportion of people with severe chronic headaches who seek treatment exclusively from a traditional healer in urban areas	Min: 0 Mode: 0 Max: 0.4	Triangular	Appendix G
Proportion of people with severe chronic headaches who seek treatment exclusively from a traditional healer in rural areas	Min: 0 Mode: 0 Max: 0.8	Triangular	Appendix G
Proportion of people with epilepsy in urban areas who seek medical attention at a primary care clinic and are referred to upper level care	Min: 0.21 Max: 0.59	Uniform	[93,94]
Proportion of people with epilepsy in rural areas who seek medical attention at a primary care clinic and are referred to upper level care	Min: 0.10 Max: 0.30	Uniform	[see text]
Proportion of people with severe chronic headaches in urban areas who seek medical attention at a primary care clinic and are referred to upper level care	Min: 0.08 Max: 0.30	Uniform	[95,96]
Proportion of people with severe chronic headaches in urban areas who seek medical attention at a primary care clinic and are referred to upper level care	Min: 0.04 Max: 0.15	Uniform	[see text]
Proportion of urban people with epilepsy referred to a tertiary hospital from a primary care clinic	Min: 0 Mode: 0 Max: 0.8	Triangular	Appendix G

Table 20: Continued

Parameter	Value	Distribution	Reference
Proportion of rural people with epilepsy referred to a tertiary hospital from a primary care clinic	Min: 0 Mode: 0 Max: 0.4	Triangular	Appendix G
Proportion of urban people with severe chronic headaches referred to a tertiary hospital from a primary care clinic	Min: 0 Mode: 0 Max: 0.2	Triangular	Appendix G
Proportion of rural people with severe chronic headaches referred to a tertiary hospital from a primary care clinic	Min: 0 Mode: 0 Max: 0.1	Triangular	Appendix G
Proportion of urban people with epilepsy referred to a tertiary care hospital from a secondary care clinic	Min: 0 Mode: 0 Max: 0.5	Triangular	Appendix G
Proportion of rural people with epilepsy referred to a tertiary care hospital from a secondary care clinic	Min: 0 Mode: 0 Max: 0.5	Triangular	Appendix G
Proportion of urban people with severe chronic headaches referred to a tertiary care hospital from a secondary care clinic	Min: 0 Mode: 0 Max: 0.25	Triangular	Appendix G
Proportion of rural people with severe chronic headaches referred to a tertiary care hospital from a secondary care clinic	Min: 0 Mode: 0 Max: 0.25	Triangular	Appendix G
Proportion of urban people with epilepsy who seek medical attention from a modern doctor and also receive treatment from a traditional healer	Min: 0.005 Mode: 0.025 Max: 0.5	Triangular	[see text]
Proportion of rural people with epilepsy who seek medical attention from a modern doctor and also receive treatment from a traditional healer	Min: 0.01 Mode: 0.05 Max: 1	Triangular	Appendix G
Proportion of urban people with severe chronic headaches who seek medical attention from a modern doctor and also receive treatment from a traditional healer	Min: 0 Mode: 0 Max: 0.475	Triangular	[see text]
Proportion of rural people with severe chronic headaches who seek medical attention from a modern doctor and also receive treatment from a traditional healer	Min: 0 Mode: 0 Max: 0.95	Triangular	Appendix G

IV.2.6 Parameters associated with use of healthcare resources

Parameters associated with the use of healthcare resources by people with NCC-associated epilepsy and NCC-associated severe chronic headaches in Mexico are shown in Tables 21 and 22. Frequency of doctor visits and prescribed medications taken by individuals seeking medical attention at a primary care clinic were based on data provided by primary care physicians in Michoacán. Frequency of doctor visits, medications, diagnostic tests such as computed tomography (CT) scans and magnetic resonance imaging (MRI), and hospitalization for people seeking medical attention at a secondary care clinic were based on data provided by neurologists working at a secondary care clinic in Michoacán. Data on frequency of electroencephalogram (EEG) and cerebrospinal fluid (CSF) testing for people who received treatment at a secondary care clinic were not available from study questionnaires and were assumed the same as for people seen in tertiary care facilities. Frequency of doctor visits, medications, hospitalizations, surgical intervention, and diagnostic tests, including CT scans, MRIs, CSF testing, EEGs, EITBs, and ELISAs were based on the results of a recent study conducted in two tertiary care hospitals in Mexico City, Mexico [84]. It was assumed that all NCC-related surgical interventions were performed at a tertiary care facility. For people referred to a higher level of care, a single consultation with a healthcare provider was attributed to the referring lower level facility or facilities. Since diagnostic tests, including CT, MRI, and serology, are not typically available at primary care clinics, it was assumed that anthelminthic treatment is only prescribed in higher level clinics.

Data on length of hospitalization in a secondary care facility were not available from the questionnaires and hospital stay length was assumed the same as that observed for non-surgical cases hospitalized at a tertiary care facility. Assuming that the same non-anthelminthic drugs are

available in both rural and urban areas, people with epilepsy and severe chronic headaches receiving care at primary and secondary care facilities were assumed to receive the same non-NCC specific medical treatment protocols as people treated in tertiary care hospitals [84].

It was assumed that people with epilepsy exclusively seeking traditional care visited a healer 4 to 6 times per year. Due to the lack of published data on this topic from Mexico, these values were chosen in light of cross-sectional data from India suggesting that individuals with epilepsy visited a traditional healer 1 to 8 times per year [99]. For severe chronic headaches, the number of visits was assumed to be only 2 to 3 times per year, due to lesser clinical severity. It was also assumed that the number of visits to a traditional healer would be less for those people who seek medical attention from both a modern doctor and a traditional healer (2 to 3 times and 1 to 2 times per year for people with epilepsy and severe chronic headaches, respectively).

Table 21. Parameters associated with the use of healthcare resources (per year) in people with NCC-associated epilepsy or severe chronic headaches in Mexico

Parameter	Value	Distribution	Reference
Number of visits to a traditional healer by an epilepsy patient who also receives treatment from a modern doctor	Min: 2 Max: 3	Uniform	[see text]
Number of visits to a traditional healer by a severe chronic headaches patient who also receives treatment from a modern doctor	Min: 1 Max: 2	Uniform	[see text]
Number of visits to a traditional healer by an epilepsy patient who exclusively seeks treatment from a traditional healer	Min: 4 Max: 6	Uniform	[see text]
Number of visits to a traditional healer by a severe chronic headaches patient who exclusively seeks treatment from a traditional healer	Min: 2 Max: 3	Uniform	[see text]
Number of visits to a physician by an epilepsy patient who seeks treatment at a primary care clinic	Min: 1 Mode: 2 Max: 12	Triangular	Appendix G

Table 21: Continued

Parameter	Value	Distribution	Reference
Number of visits to a physician by a severe chronic headaches patient who seeks treatment at a primary care clinic	Min: 1 Mode: 1 Max: 12	Triangular	Appendix G
Number of visits to a neurologist by an epilepsy patient who seeks treatment at a secondary care clinic	Min: 2 Mode: 3 Max: 20	Triangular	Appendix G
Number of visits to a neurologist by a severe chronic headaches patient who seeks treatment at a secondary care clinic	Min: 1 Mode: 3 Max: 8	Triangular	Appendix G
Proportion of people with NCC-associated epilepsy treated at a tertiary care facility that receive a surgical intervention per year	0.25	Fixed	[84]
Proportion of people with NCC-associated severe chronic headaches treated at a tertiary care facility that receive a surgical intervention per year	0.57	Fixed	[84]
Proportion of people with epilepsy receiving treatment at a secondary care clinic who are hospitalized	Min: 0.02 Mode: 0.2 Max: 1	Triangular	Appendix G
Proportion of people with severe chronic headaches receiving treatment at a secondary care clinic who are hospitalized	Min: 0.01 Mode: 0.2 Max: 0.5	Triangular	Appendix G
Length of a hospital stay (in days) for people with epilepsy who are hospitalized at a secondary care clinic	7	Fixed	[see text]
Length of a hospital stay (in days) for people with severe chronic headaches who are hospitalized at a secondary care clinic	4	Fixed	[see text]
Length of a hospital stay (in days) for people with epilepsy who are hospitalized at a tertiary care facility	10.96	Fixed	[84]
Length of a hospital stay (in days) for people with severe chronic headaches who are hospitalized at a tertiary care facility	7.56	Fixed	[84]

Table 22: Parameters associated with the use of diagnostic tests and prescription medications in people with NCC-associated epilepsy or severe chronic headaches in Mexico

Parameter	Value	Distribution	Reference
Proportion of people with epilepsy who seek medical attention at a primary, secondary or tertiary care clinic and are prescribed the anti-epileptic drug phenytoin	0.95	Fixed	[84]
Proportion of people with epilepsy who seek medical attention at a primary, secondary or tertiary care clinic and are prescribed the anti-epileptic drug carbamazepine	0.33	Fixed	[84]
Proportion of people with epilepsy who seek medical attention at a primary, secondary or tertiary care clinic and are prescribed the anti-epileptic drug valproic acid	0.20	Fixed	[84]
Proportion of people with severe chronic headaches who seek medical attention at a primary, secondary or tertiary care clinic and are prescribed the anti-inflammatory drug ketorolac tromethamine	0.37	Fixed	[84]
Proportion of people with severe chronic headaches who seek medical attention at a primary, secondary or tertiary care clinic and are prescribed the antipyretic drug acetaminophen	0.26	Fixed	[84]
Proportion of people who are diagnosed with NCC and prescribed the anthelmintic drug albendazole at a secondary or tertiary care clinic	0.36	Fixed	[84]
Proportion of people who are diagnosed with NCC and prescribed the anthelmintic drug praziquantel at a secondary or tertiary care clinic	0.02	Fixed	[84]
Proportion of people who are diagnosed with NCC and receive a CT scan and/or MRI at a secondary care clinic	0.18	Fixed	Appendix G
Proportion of people who are diagnosed with NCC-associated epilepsy and receive a CT scan at a tertiary care clinic	0.42	Fixed	[84]
Proportion of people who are diagnosed with NCC-associated severe chronic headaches and receive a CT scan at a tertiary care clinic	0.5	Fixed	[84]
Proportion of people who are diagnosed with NCC-associated epilepsy and receive an MRI at a tertiary care clinic	0.77	Fixed	[84]
Proportion of people who are diagnosed with NCC-associated severe chronic headaches and receive an MRI at a tertiary care clinic	0.76	Fixed	[84]

Table 22: Continued

Proportion of people who are diagnosed with NCC-associated epilepsy and receive an EEG at a secondary or tertiary care clinic	0.36	Fixed	[84]
Proportion of people who are diagnosed with NCC-associated severe chronic headaches and receive an EEG at a secondary or tertiary care clinic	0.09	Fixed	[84]
Proportion of people who are diagnosed with NCC-associated epilepsy and receive EITB testing at a tertiary care clinic	0.05	Fixed	[84]
Proportion of people who are diagnosed with NCC-associated severe chronic headaches and receive EITB testing at a tertiary care clinic	0.007	Fixed	[84]
Proportion of people who are diagnosed with NCC-associated epilepsy and receive CSF testing at a secondary or tertiary care clinic	0.33	Fixed	[84]
Proportion of people who are diagnosed with NCC-associated severe chronic headaches and receive CSF testing at a secondary or tertiary care clinic	0.45	Fixed	[84]
Proportion of people who are diagnosed with NCC-associated epilepsy and receive ELISA testing at a tertiary care clinic	0.33	Fixed	[84]
Proportion of people who are diagnosed with NCC-associated severe chronic headaches and receive ELISA testing at a tertiary care clinic	0.42	Fixed	[84]
Proportion of people who are diagnosed with NCC-associated epilepsy and receive surgery at a tertiary care clinic	0.25	Fixed	[84]
Proportion of people who are diagnosed with NCC-associated severe chronic headaches and receive surgery at a tertiary care clinic	0.57	Fixed	[84]

IV.2.7 Parameters associated with productivity losses in people with NCC

Table 23 shows the parameters associated with productivity losses in people with NCC. Information on loss of working days due to people with NCC-associated epilepsy and severe chronic headaches seeking medical attention at a primary care clinic was based on minimum,

mode, and maximum values provided by physicians at a primary care clinic in Michoacán. Information on loss of working days due to NCC-associated epilepsy and severe chronic headaches for people seeking medical attention at tertiary care hospitals was based on a study conducted in Mexico [84]. In the absence of available data, people seeking care in secondary healthcare facilities were assumed to lose 25% fewer working days than those seeking care at tertiary care facilities. Information on loss of working days due to NCC-associated epilepsy and severe chronic headaches for people not seeking modern medical treatment was based on values provided by employees of the Michoacán branch of Mexico's Ministry of Health.

Table 23: Parameters associated with productivity losses in people with NCC-associated epilepsy or severe chronic headaches in Mexico

Number of working days lost per year by people with NCC-associated epilepsy who seek medical attention at a primary care clinic	Min: 0 Mode: 12 Max: 36	Triangular	Appendix G
Number of working days lost per year by people with NCC-associated severe chronic headaches who seek medical attention at a primary care clinic	Min: 0 Mode: 12 Max: 24	Triangular	Appendix G
Number of working days lost per year by people with NCC-associated epilepsy who seek medical attention at a secondary care clinic and are not hospitalized	18.75	Fixed	[see text]
Number of working days lost per year by people with NCC-associated epilepsy who seek medical attention at a secondary care clinic and are hospitalized	46.5	Fixed	[see text]
Number of working days lost per year by people with NCC-associated severe chronic headaches who seek medical attention at a secondary care clinic and are not hospitalized	12	Fixed	[see text]

Table 23: Continued

Parameter	Value/Range of values	Distribution	Reference
Number of working days lost per year by people with NCC-associated severe chronic headaches who seek medical attention at a secondary care clinic and are hospitalized	28.5	Fixed	[see text]
Number of working days lost per year by people with NCC-associated epilepsy who seek medical attention at a tertiary care hospital and are not hospitalized	25	Fixed	[84]
Number of working days lost per year by people with NCC-associated epilepsy who seek medical attention at a tertiary care hospital and are hospitalized	62	Fixed	[84]
Number of working days lost per year by people with NCC-associated severe chronic headaches who seek medical attention at a tertiary care hospital and are not hospitalized	16	Fixed	[84]
Number of working days lost per year by people with NCC-associated severe chronic headaches who seek medical attention at a tertiary care hospital and are hospitalized	38	Fixed	[84]
Number of working days lost per year by people with NCC-associated epilepsy who do not seek treatment from a modern doctor	Min: 12 Mode: 24 Max: 120	Triangular	Appendix G
Number of working days lost per year by people with NCC-associated severe chronic headaches who do not seek treatment from a modern doctor	Min: 12 Mode: 12 Max: 60	Triangular	Appendix G
Proportion of Mexican adults that are not considered economically active excluding retirees	0.41	Fixed	[100]

IV.2.8 Epidemiologic parameters for porcine cysticercosis

Epidemiologic parameters for porcine cysticercosis are presented in Table 24. The number of pigs slaughtered in Mexico was obtained from the United States Department of Agriculture (USDA) Foreign Agricultural Service for the year 2009 [101]. Year 2009 data were

used because this is the only year for which slaughter numbers were reported by facility type, namely federally inspected, municipal, and in-situ. In-situ facilities are those without inspection, including home slaughtering. The prevalence of porcine cysticercosis was assumed lower in federally inspected and municipal facilities because most pigs slaughtered there would come from industrialized establishments. The prevalence of porcine cysticercosis in pigs slaughtered at in-situ facilities was assumed to vary between 5% and 33% based on a study conducted in 13 villages located in the Sierra de Huautla region of Morelos, Mexico [68]. Due to limited data on cysticercosis in pigs slaughtered in federally inspected and municipal facilities, the prevalence of porcine cysticercosis was assumed to be between 0 and 0.05%. This value seems reasonable when compared with a study conducted in Brazil from 2008 to 2013 where the prevalence of porcine cysticercosis in pigs reared under an intensive management system was 0.009% [102]. The average reduction in the price of a cysticercosis-infected pigs, regardless of slaughter location, was estimated at 20 – 30% of market value based on information from the only identified study of its kind, which was conducted in Africa [2].

Table 24: Epidemiologic parameters used to estimate the monetary burden of porcine cysticercosis in Mexico

Parameter	Value/Range of values	Distribution	Reference
Number of pigs slaughtered at federally inspected facilities	5,812,675	Fixed	[101]
Number of pigs slaughtered at municipal facilities	4,726,933	Fixed	[101]
Number of pigs slaughtered at in-situ facilities	3,460,153	Fixed	[101]
Prevalence of porcine cysticercosis in pigs slaughtered at in-situ facilities	Min: 0.05 Max: 0.33	Uniform	[68]
Prevalence of porcine cysticercosis in pigs slaughtered at federally inspected and municipal facilities	Min: 0 Max: 0.0005	Uniform	[see text]
Percent reduction in the price of a pig with cysticercosis	Min: 20 Max: 30	Uniform	[2]

IV.2.9 Human and pig economic parameters

Table 25 contains the economic parameters used to estimate the monetary burden of cysticercosis in Mexico in 2012 U.S. dollars. The cost of doctor visits, diagnostic techniques and tests, a one-day stay in the hospital, and surgery were obtained from the 2006 standardized tariffs for healthcare services in Mexico [74]. Year 2006 tariffs were used due to their availability to study personnel and to be in line with previous studies looking at NCC-related costs in Mexico [84]. Although patients pay based on their income, the actual costs of products and services were used in order to estimate the societal costs incurred due to NCC. The costs of medications used by people with NCC were based on year 2006 prices obtained from several pharmacies in Mexico. All 2006 costs were converted to the 2012 value according to the Consumer Price Index for Mexico [82]. The cost for a visit to a traditional healer to treat epilepsy or severe chronic headaches was based on the minimum, mode, and maximum values provided by employees of the Michoacán branch of the Ministry of Health who completed the questionnaire. The 2015 median wage and 2012 minimum wage were applied to lost working days for those who were officially employed and those not employed outside of the home, respectively [103,104]. Median wage data were only availabe for 2015, therefore, the 2015 median wage was converted to the 2012 value according to the Consumer Price Index for Mexico [82]. To capture the productivity losses of the unemployed population, excluding retirees, the minimum wage approach was used where time lost was estimated at an 8-hour workday. The proportion of the population that was not economically active was obtained from Mexico's Instituto Nacional de Estadistica y Geografia [100]. It was assumed that losses for a child less than 15 years of age would be the same as for an adult since a parent would need to take time off work or would lose productivity while caring for the child.

The price of an average finished live pig (weighing 150 lb) in Mexico in 2012 was obtained from the Food and Animal Organization of the United Nations [105]. A 2012 exchange rate of 13.06 Mexican pesos for 1 U.S. dollar was used for all estimates [75].

Table 25: Economic parameters used to estimate the monetary burden of cysticercosis in Mexico (in 2012 U.S.$)

Parameter	Value/range of values	Distribution	Reference
Cost of a visit to a general practitioner/ neurologist/neurosurgeon	17	Fixed	[74]
Cost of a CT scan	173	Fixed	[74]
Cost of an MRI	178	Fixed	[74]
Cost of an EEG	87	Fixed	[74]
Cost of CSF testing	17	Fixed	[74]
Cost of an EITB test	88	Fixed	[74]
Cost of an ELISA	26	Fixed	[74]
Cost of a one-day stay in a hospital's general ward	58	Fixed	[74]
Cost of a one-day stay in a hospital's private ward	69	Fixed	[74]
Cost of surgery (ventriculoperitoneal shunt placement or cyst removal)	1,301	Fixed	[74]
Cost of a visit to a traditional healer to treat epilepsy	Min: 1 Mode: 2 Max: 8	Triangular	Appendix G
Cost of a visit to a traditional healer to treat severe chronic headaches	Min: 0.5 Mode: 2 Max: 8	Triangular	Appendix G
Minimum wage (per day)	5	Fixed	[104]
Median wage (per day)	20.2	Fixed	[103]
Price of an adult pig	106	Fixed	[105]

IV.2.10 Analysis

Economic losses due to NCC-associated epilepsy and severe chronic headaches, with 95% credible regions (95% CRs), were estimated using @Risk (Palisade Corporation, Ithaca,

NY, version 5.7). Latin Hypercube sampling was used for uncertain parameters. The model was run for 20,000 iterations to achieve convergence. Uncertain epidemiologic and economic parameters were modeled using normal, uniform, and triangular distributions. Regression sensitivity analysis was conducted in @Risk by varying the value of each parameter to estimate its correlation to the total cost estimate. The relative values of the regression coefficients indicate which parameters had the greatest impact on the total cost estimate.

IV.2.11 Ethical approval

This study received IRB approval from Texas A&M University (2006-0606 and 2014-0702), the Instituto Nacional de Neurologia y Neurocirugia (INNN), and the Hospital de Especialidades of the Instituto Mexicano del Seguro Social (HE-IMSS).

IV.3 Results

IV.3.1 Estimated number of people with NCC-associated epilepsy and NCC-associated severe chronic headaches

The estimated number of people with NCC-associated epilepsy and severe chronic headaches in Mexico in 2012, along with their treatment patterns, are shown in Table 26.

Table 26: Estimated number of NCC-associated epilepsy and NCC-associated severe chronic headaches cases in 2012 along with their 95% CRs

Estimate	Number	95% CR
Number of NCC-associated epilepsy and severe chronic headaches cases whose final level of care was received at a primary care clinic	158,967	86,116 - 243,398
Number of NCC-associated epilepsy and severe chronic headaches cases whose final level of care was received at a secondary care clinic		
Hospitalized	18,172	3,998 - 48,502
Not hospitalized	31,359	2,448 - 67,907
Number of NCC-associated epilepsy and severe chronic headaches cases whose final level of care was received at a tertiary care hospital		
Hospitalized	7,675	1,736 - 18,287
Not hospitalized	16,765	3,186 - 41,354
Number of NCC-associated epilepsy and severe chronic headaches cases that only received treatment from a traditional healer	74,452	18,335 - 153,714
Number of NCC-associated epilepsy and severe chronic headaches cases that received no treatment	144,972	43,837 - 259,860
*Total	452,362	274,158 - 628,833

***** Note: Of this total, 44,446 (95% CR: 12,173 – 94,209) people are estimated to have received care from both a modern medical facility and a traditional healer.

IV.3.2 Monetary losses due to people with NCC-associated epilepsy and severe chronic headaches who received modern medical treatment

Tables 27 and 28 show the total direct and indirect losses and the cost-per-patient associated with individuals with NCC-associated epilepsy and severe chronic headaches who received modern medicine treatment.

Table 27: Total direct losses and the cost-per-patient for people with NCC-associated epilepsy and NCC-associated severe chronic headaches who received modern medical treatment in 2012 along with their 95% CRs (in 2012 U.S. $)

Cost component	Total direct loss	Cost per patient
Direct cost of people with NCC-associated epilepsy who received treatment at a primary care clinic	14,769,004 (6,005,470 - 29,553,557)	146 (88 - 236)
Direct cost of people with NCC-associated severe chronic headaches who received treatment at a primary care clinic	4,592,473 (400,575 - 13,627,948)	79 (20 - 173)
Direct cost of people with NCC-associated epilepsy who received treatment at a secondary care clinic Hospitalized Not hospitalized	11,066,273 (1,542,767 - 33,230,824) 7,065,744 (1,057,012 - 19,263,910)	717 (622 - 867) 313 (245- 407)
Direct cost of people with NCC-associated severe chronic headaches who received treatment at a secondary care clinic Hospitalized Not hospitalized	1,062,161 (65, 231 - 3,230,748) 1,394,583 (122,135 - 3,633,475)	389 (348 - 440) 158 (105 - 199)
Direct cost of people with NCC-associated epilepsy who received treatment in a tertiary care hospital Hospitalized Not hospitalized	10,645,300 (1,856,578 - 26,599,973) 8,076,970 (1,408,652 - 20,182,344)	1,511 (245 - 3,046) 491 (388 - 603)
Direct cost of people with NCC-associated severe chronic headaches who received treatment in a tertiary care hospital Hospitalized Not hospitalized	1,059,954 (47,979 - 3,606,657) 136,658 (6,186 - 465,001)	1,628 (567 - 2,873) 408 (345 - 499)
Cost of a traditional healer for people with NCC-associated epilepsy who received treatment from both a traditional healer and a modern doctor	256,504 (27,620 - 858,696)	8 (2 - 18)
Cost of a traditional healer for people with NCC-associated severe chronic headaches who received treatment from both a traditional healer and a modern doctor	61,037 (1,203 – 242,689)	5 (1 - 11)

Table 28: Total indirect losses and the cost-per-patient for people with NCC-associated epilepsy and NCC-associated severe chronic headaches who received modern medical treatment in 2012 along with their 95% CRs (in 2012 U.S. $)

Cost component	Total loss	Cost-per-patient
Indirect cost of people with NCC-associated epilepsy who received treatment at a primary care clinic	20,757,603 (3,737,745 – 48,884,756)	205 (42- 403)
Indirect cost of people with NCC-associated severe chronic headaches who received treatment at a primary care clinic	8,973,618 (728,951 – 22,762,576)	154 (34- 274)
Indirect cost of people with NCC-associated epilepsy who received treatment at a secondary care clinic		
Hospitalized	9,226,230 (1,303,254 - 27,079,478)	598 (263 - 789)
Not hospitalized	5,435,671 (900.855 - 13,984,043)	241 (145 - 346)
Indirect cost of people with NCC-associated severe chronic headaches who received treatment at a secondary care clinic		
Hospitalized	1,002,332 (61,203 - 3,027,342)	367 (65 - 645)
Not hospitalized	1,364,949 (124,713 - 3,407.690)	154 (43 -307)
Indirect cost of people with NCC-associated epilepsy who received treatment in a tertiary care hospital		
Hospitalized	5,616,663 (979,566 - 14,034,657)	797 (635 - 903)
Not hospitalized	5,284,495 (921,635 - 13,204,651)	322 (289 - 387)
Indirect cost of people with NCC-associated severe chronic headaches who received treatment in a tertiary care hospital		
Hospitalized	318,141 (14,401 - 1,082,523)	489 (57 - 978)
Not hospitalized	69,007 (3,124 - 234,806)	206 (177 - 253)

IV.3.3 Monetary losses and the cost-per-case associated with people with NCC-associated epilepsy and severe chronic headaches who did not receive modern medical treatment

Table 29 shows the total monetary losses and the cost-per-case associated with people with NCC-associated epilepsy and NCC-associated severe chronic headaches who did not receive modern medical treatment in Mexico in 2012.

Table 29: Indirect losses and the cost-per-case for people with NCC-associated epilepsy and NCC-associated severe chronic headaches who did not receive modern medical treatment in 2012 along with their 95% CRs (in U.S. $)

Cost component	Total loss (95% CR)	Cost-per-case (95% CR)
Indirect cost of people with NCC-associated epilepsy who received no treatment	78,417,534 (22,736, 939 - 180,245,832)	669 (227 - 1,336)
Indirect cost of people with NCC-associated severe chronic headaches who received no treatment	36,800,776 (23,546 - 100,506,588)	360 (162 - 674)
Cost of a traditional healer for people with NCC-associated epilepsy who exclusively received treatment from a traditional healer	758,597 (99,074 - 2,191,523)	18 (8 - 35)
Cost of a traditional healer for people with NCC-associated severe chronic headaches who exclusively received treatment from a traditional healer	264,132 (32,453- 1,025,4844,)	8 (2 - 17)

IV.3.4 Pig losses

Monetary losses associated with porcine cysticercosis were estimated at U.S.$ 16,473,528 (95% CR U.S.$ 4,906,568 - U.S.$ 30,464,504) in 2012.

IV.3.5 Total economic losses

The total 2012 monetary losses associated with people with NCC-associated epilepsy and NCC-associated severe chronic headaches, in Mexico, along with losses to the agriculture sector,

was estimated to be U.S.$ 250,219,772 (95% CR U.S.$ 145,560,590 U.S.$ 384,051,262), with U.S.$ 521 (95% CR: 344 - 760) lost per patient.

IV.3.6 Sensitivity Analysis

Figure 11 shows how uncertain parameters influenced the total monetary burden estimate. Prevalence of epilepsy in 15-44 year-old males and females, number of working days lost due to untreated epilepsy and severe chronic headaches, and the proportion of individuals older than 15 years of age with severe chronic headaches presenting with NCC were the five parameters with the greatest effect on the total cost estimate.

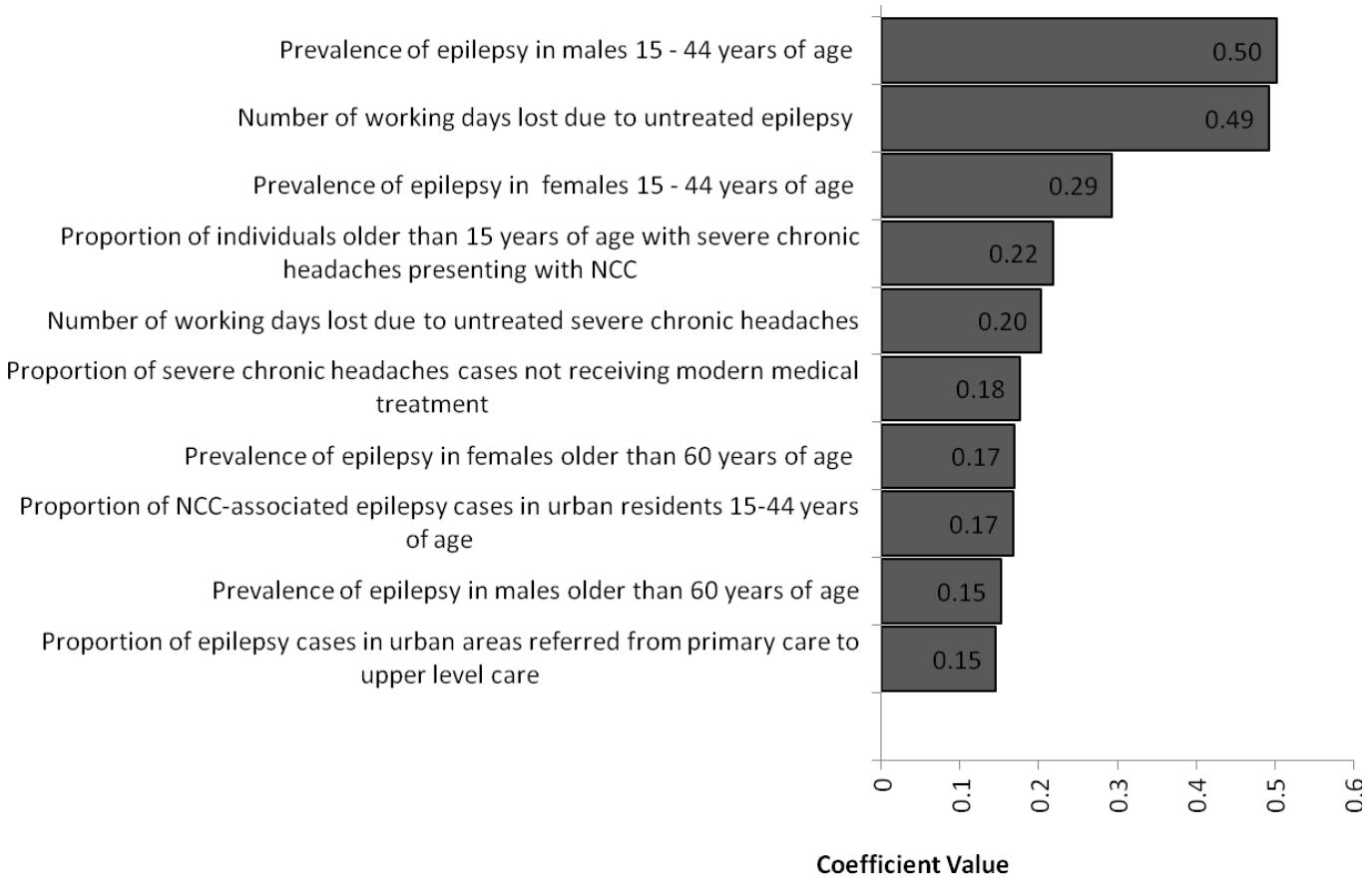

Figure 11: Sensitivity analysis for the estimated cost of cysticercosis in Mexico

IV.4 Discussion

This study is the first to estimate the monetary burden of cysticercosis due to people with NCC-associated epilepsy and severe chronic headaches, as well as pig-associated losses, in Mexico. Table 30 summarizes estimations of monetary losses due to *T. solium* cysticercosis in Mexico (the current study) and studies conducted in West Cameroon, the Eastern Cape Province (ECP) of South Africa, and Tanzania [16-18] .

The overall monetary burden reported in the current Mexican study was much higher than what was reported in the South African, West Cameroon, and Tanzanian studies. However, these studies only accounted for the disease burden due to human NCC-associated epilepsy and pig losses and not for severe chronic headaches. The estimated monetary burden of cysticercosis, in Mexico, when only NCC-associated epilepsy and pig losses are considered would be U.S.$ 193.9 million. Although the monetary burden due to NCC-associated epilepsy (U.S.$ 176.6 million) was higher in Mexico, the cost per epilepsy patient (U.S.$ 632) is similar to the estimate produced for South Africa and higher than the estimates for Cameroon and Tanzania. This may be due to lower salaries and treatment costs in Cameroon and Tanzania.

In the current study, the median wage was used to value productivity losses of all economically active individuals, and Mexico's minimum wage was used to value productivity losses of all economically inactive individuals. The minimum wage approach was used since these individuals do contribute to society even though they are not formally employed outside of the home and make-up about forty percent of the population. In contrast, the South African study used three approaches (the mean wage approach, opportunistic cost approach, and the generalist replacement costs approach) to calculate productivity losses whereas the Cameroon and Tanzanian studies used the minimum and maximum salary and applied either a uniform or

gamma distribution. In the Mexican study, a large proportion (65%) of the total costs was related to indirect costs, which is in line with the conclusions of the South African, Cameroon, and Tanzanian studies. Compared to Tanzania and West Cameron, the cost of a visit to the hospital, doctor or traditional healer was higher in Mexico. Traditional healer costs were not included in the South African study.

Table 30: Comparison of disease burden estimates due to *T. solium* cystercosis in Mexico with other countries

Estimate	**Mexico (This study)**	**Eastern Cape Province, South Africa [16]**	**West Cameroon [17]**	**Tanzania [18]**
Study year	2012	2004	2009	2012
Country population	112,336,538	7,088,000	5,065,382	44,928,923
Estimated number of NCC-associated epilepsy cases	201,897	34,662	50,326#	47,804
Overall monetary burden, including NCC-associated epilepsy losses and pig losses (in US dollars)	193.6 million	18.6 - 34.2 million**	14.9 million*	7.9 million
% due to porcine cysticercosis	6.8%	14.6 - 26.9%	4.7%	35.4%
Average cost per NCC-associated epilepsy patient (U.S. dollars)	635	632 - 844	240	106
Average cost per capita (U.S. dollars)	1.7	2.6 - 4.2	2.9	0.176

* based on a 2009 exchange rate of 1 U.S.$ = 0.69 Euro
** The range is due to the application of different calculation methods for wage and productivity losses (mean wage approach, generalist replacement costs, and opportunity costs).

The annual monetary loss per NCC–associated epilepsy patient was higher than the annual loss for an NCC-associated severe chronic headaches patient who received treatment at a primary or secondary care clinic in Mexico. This may be due to the higher costs associated with epilepsy drugs compared to drugs to treat severe chronic headaches. The annual monetary loss per hospitalized NCC–associated epilepsy patient was lower than the annual loss for a hospitalized NCC-associated severe chronic headaches patient who received treatment in a tertiary care facility. This was due to the lower number of patients with NCC-associated epilepsy who had surgery compared to the number with severe chronic headaches who had surgery. The annual monetary losses per untreated NCC–associated epilepsy or untreated severe chronic headaches case were higher than the annual losses for their counterparts who received treatment at a primary care clinic in Mexico. This was due to a greater number of lost working days for those people not receiving any form of treatment.

Based on the regression sensitivity analysis, the most influential parameters were prevalence of epilepsy in 15-44 year-olds and the number of working days lost due to untreated epilepsy. The epilepsy prevalence estimates were based on a single study that may not fully reflect the regional variation in epilepsy cases. Numbers of days lost due to untreated epilepsy were based on questionnaire responses obtained from people who worked in the Ministry of Health in Michoacán, with the obtained values having quite large ranges. Studies on the impact of NCC on productivity are needed for both treated and untreated individuals to obtain more accurate estimates of disease burden.

Our study has some limitations. The model most likely overestimated the costs associated with people manifesting both epilepsy and severe chronic headaches since the model assumes that costs associated with these two conditions were additive, which is most likely not the case.

However, the total estimated cost was most likely underestimated since only the NCC-associated clinical manifestations of epilepsy and severe chronic headaches were included. Other neurological manifestations of NCC, such as stroke and dementia may also carry a significant burden, but were not included due to the absence of valid frequency data. Costs associated with family members who may accompany adults with NCC to clinics or hospitals were also not included due to the absence of reliable data. To estimate monetary losses due to epilepsy and severe chronic headaches, this study relied on responses provided by physicians working in primary care clinics, neurologist working in secondary and tertiary care clinics, and employees at the Office of the Ministry of Health in Michoacán. Since these values come from a single endemic region, they may not be applicable to the entire country. The uncertainty placed around these parameters and the findings of the sensitivity analysis suggest that additional studies about healthcare seeking behavior and treatment gaps are needed. Due to the absence of data evaluating how infection affects the cost of pigs that are not slaughtered in formal settings, it was assumed that there would be a reduction across all settings. This was also the assumption for the South African and Cameroon study [6]. If only losses in inspected pigs were assumed, pig-associated losses would decrease from U.S.$ 16,539,552 to U.S.$ 66,024.

This preliminarily estimate suggests that *T. solium* cysticercosis results in considerable monetary losses in Mexico even when compared to other diseases. For example, a study showed that the monetary burden of dengue in Mexico was U.S.$ 170 million in 2010. Although the estimated number of people affected by dengue was three times lower than the estimated number with cysticercosis, the cost was similar because surveillance and vector control accounted for 48.9% of the total economic burden of dengue [106]. In conclusion, this is a first study to estimate the monetary burden of cysticercosis in Mexico. The methodology developed here can

be applied to estimate the monetary burden of cysticercosis in other regions in order to better prioritize disease control initiatives.

CHAPTER V

SUMMARY AND CONCLUSIONS

Taenia solium cysticercosis is considered a public health and agricultural problem in many low and middle-income countries where health education, sanitation, pig management practices and meat inspection infrastructure are insufficient. Cysticercosis affects both human and animal health and has important economic consequences. Very few studies have been conducted to evaluate the monetary burden of cysticercosis. The monetary impact of NCC has been reported as the average treatment cost per patient under care for patients in India and Peru [62,63]. Direct costs associated with treatment of NCC have also been assessed in California [65]. NCC-associated monetary losses to both the human health and agricultural sectors have been evaluated in South Africa, Lao PDR, Cameroon, Tanzania and India [16-20]. While there are studies concerning the economic impact of cysticercosis in other countries, this dissertation evaluates the socioeconomic impact of cysticercosis in Mexico.

Mexico is the third largest country in Latin America where about twenty percent of the population lives in rural areas. Traditional pig rearing practices in rural *T. solium*-endemic areas allow pigs to have access to human feces in open fields, facilitating the completion of the parasite's life cycle [68,69]. The findings presented from our study will be crucial for policy makers to comprehensively understand the true economic impact of the disease in order to prioritize and allocate resources.

NCC produces a variety of clinical manifestations such as severe chronic headaches, epilepsy, hydrocephalus, stroke and other neurological symptoms [8]. Severe headaches, epilepsy and hydrocephalus were the most common clinical manifestations reported in this study.

The total annual cost for patients who had and had not been hospitalized and/or undergone a surgical procedure for the diagnosis or treatment of NCC in a tertiary care hospital corresponded to 212% and 41% of an annual minimum wage salary, respectively. Among patients without a history of hospitalization, the annual direct costs for patients with epilepsy as the only clinical manifestation were higher than the costs for patients with any other clinical manifestation (single or combined). In contrast, among patients with a history of hospitalization, the annual direct costs were highest for patients with severe chronic headaches or hydrocephalus, primarily due to the high cost of surgery to treat hydrocephalus.

We also attempted to estimate the direct monetary losses associated with NCC-affected individuals in Mexico during the pre-hospitalization, hospitalization, and post-hospitalization periods. Overall, substantial costs were associated with patients requiring hospitalization for NCC, with this burden continuing years post-hospitalization. When all patients, regardless of having received pre-hospitalization care at the reference hospital, were included in the analysis, the direct economic losses pre-hospitalization, during hospitalization, and during the first year post-hospitalization were equivalent to 22%, 224%, and 42% of an annual minimum wage salary in Mexico (U.S.$ 1145), respectively [80]. The hospitalization period incurred higher per-patient costs for all clinical manifestations when compared to the pre-hospitalization or entire post-hospitalization period. However, this cost was not significantly higher for patients with epilepsy or stroke as the sole presenting clinical manifestation because, in comparison to patients with other clinical manifestations, fewer epilepsy cases had surgery and the number of patients with stroke was very small, explaining the lack of significant differences for these two groups. The post-hospitalization costs were highest in the first year post-hospitalization, which was likely due to the greater number of diagnostic tests performed in this year as compared to subsequent years.

The final part of this study evaluated the overall socioeconomic impact of *Taenia solium* cysticercosis in humans and pigs in Mexico. The estimated cost of human NCC took into consideration direct and indirect losses due to NCC-associated epilepsy and NCC-associated severe chronic headaches. The estimated cost of porcine cysticercosis took into consideration losses due to the reduction in the price of cysticercosis-infected animals. The total 2012 monetary losses associated with people with NCC-associated epilepsy and NCC-associated severe chronic headaches, in Mexico, along with losses to the agriculture sector, was estimated to be U.S.$ 250,219,772 (95% CR U.S.$ 145,560,590 - U.S.$ 384,051,262), with U.S.$ 521 (95% CR: U.S.$ 344 - U.S.$ 760) lost per patient. Monetary losses associated with porcine cysticercosis were estimated at U.S.$ 16,473,528 (95% CR U.S.$ 4,906,568 - U.S.$ 30,464,504).

The sensitivity analysis indicated that the input parameters with the most influential impact on the total estimated losses associated with *T. solium* cysticercosis were prevalence of epilepsy in 15-44 year-olds and the number of working days lost due to untreated epilepsy. The epilepsy prevalence estimates were based on a single study that may not fully reflect the regional variation in epilepsy cases. Numbers of days lost due to untreated epilepsy were based on questionnaire responses obtained from people who worked in the Ministry of Health in Michoacán, with the obtained values having quite large ranges. Studies on the impact of NCC on productivity are needed for both treated and untreated individuals to obtain more accurate estimates of disease burden.

Our study has some limitations. Data were collected from medical chart reviews, which limited assessed variables to those recorded as part of the standard medical charting process and those anticipated to be of value prior to commencement of this study. Therefore, type of NCC (intraparenchymal versus extraparenchymal), cyst viability, and actual wage data were not

available for analysis. Our estimates are also an underestimate of the total costs associated with NCC patients hospitalized at the reference hospital since cost of over-the-counter medication, cost of traditional medicine/treatment, and time lost by the patient's family to take care of them or to accompany them to treatment were not available for consideration [86]. In addition, this analysis excluded any costs incurred while receiving treatment in a healthcare facility other than the reference hospital, which could especially affect the estimated pre- and post-hospitalization costs.

Similarly, the economic model most likely overestimated the costs associated with people manifesting both epilepsy and severe chronic headaches since the model assumes that costs associated with these two conditions were additive, which is most likely not the case. However, the total estimated cost was likely underestimated since only the NCC-associated clinical manifestations of epilepsy and severe chronic headaches were included. Other neurological manifestations, such as stroke and dementia may also carry a significant burden, but were not included due to the absence of valid frequency data. Costs associated with family members who may accompany adults with NCC to clinics or hospitals were also not included due to the absence of reliable data. To estimate monetary losses due to epilepsy and severe chronic headaches, this study relied on responses provided by physicians working in primary care clinics, neurologist working in secondary and tertiary care clinics, and employees at the Office of the Ministry of Health in Michoacán. Since these values come from a single endemic region, they may not be applicable to the entire country. The uncertainty placed around these parameters and the findings of the sensitivity analysis suggest that additional studies about healthcare seeking behavior and treatment gaps are needed.

In conclusion, this is the first attempt to obtain an estimate of the monetary burden of cysticercosis in Mexico. The disease tends to affect rural socioeconomically disadvantaged populations and creates health disparities and significant economic losses. This parasitic disease should be prioritized for preventive measures because the disease is, in essence, 100% preventable.

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APPENDIX A

GENERAL QUESTIONNAIRE FOR PATIENTS AT THE INNN AND IMSS

Patient study code_____

Last name : _____ First name : _____

Questionnaire number _____

District _____

Village _____

Hut (house) number _____

How long have you lived in this village? (yrs.)

1 How old are you? _____ (years)

2 What is your date of birth?____ Day _____ Month _____ Year

3 Sex ☐1 Male ☐2 Female

4 What is the highest schooling grade you have completed?

☐1 None ☐2 Primary school

☐3 High School ☐4 College

5 What further education have you completed?

☐1 None ☐2 Technical school

☐3 University ☐4 Aprentice diploma

6 What is your occupation?

☐1 Self-employed (crafts) ☐2 Self-employed (farmer)

☐3 Housewife ☐4 House maid

☐5 Employed by someone else (specify occupation) _____

6.1 What is your income (per month): _____

7 How many days of work have you missed in the past month because of illness? ____days

7.1 If you are not employed outside the home (i.e. house wife), how many days in the past month have you been unable to attend to your daily chores because of illness? _____ days

8 How many days of work have you missed in the past year because of illness? _____ days

8.1 If you are not employed outside the home, how many days in the past year have you been unable to attend to your daily chores because of illness? _____ days

9 Where do you usually get your drinking water?

☐1 River ☐2 Bore-hole

☐3 Well ☐4 Other [*Specify*] _____

10 How often do you boil your drinking water?

☐1 Always ☐2 Almost always

☐3 Sometimes ☐4 Never

11 How often do you eat pork?

☐1 At least once a month ☐2 Less than once a month but at least once a year

☐3 Less than once a year ☐4 Never [*Skip to Q13*]

12.1 How is the pork that you eat prepared? [*Check all that apply*.]

☐1 Boiling ☐2 BBQ

☐3 Fried ☐4Others[*Specify*]_____

12.2 Have you ever eaten [Read list and c*heck all that apply*.]

☐1 Raw pork meat ☐2 Rare pork meat

☐3 Medium cooked pork meat ☐4 Well done pork meat

☐5 Cannot remember, do not know

13 Do you have a toilet at home?

☐1 Yes ☐2 No [*Skip to Q14*]

13.1 How often do you use a toilet when you have to defecate?

☐1 Always ☐2 Sometimes ☐3 Never

14 Do you keep pigs?

☐ Yes [*please fill in the pig questionnaire*] ☐ No

15. Have you ever owned pigs? *[If they answer "yes", ask when they owned pigs]*

☐ Yes [*please fill in the pig questionnaire*] ☐ No

18 Have you ever heard of tapeworm infection in humans?

☐1 Yes ☐2 No [*Skip to Q 19*]

18.1 How did you learn about it?

☐1 From a doctor ☐2 From a friend or family member

☐3 From a traditional healer ☐4 From the radio / newspaper

☐5 Other [*Specify*] _____

18.2 How does a person know if they have a tapeworm?

☐1 They can see it in their faeces ☐2 They have diarrhoea

☐3 They have fever ☐4 Other [*Specify*] _____

☐5 I don't know

18.3 Have you ever had a tapeworm or seen small parts (segments) of worms that look like rice grains in your faeces? (*Show photographs of proglottids*)

☐1 Yes ☐2 No [*Skip to Q 18.4*]

☐3 I don't know/cannot remember [*Skip to Q 18.4*]

18.3.1 When that happened, what did you do? [Read list and *check all that apply*]

☐1 Went to a primary health care provider (hospital, clinic, dispensary)

☐2 Went to the pharmacy to get a drug to treat it

☐3 Went to a traditional healer

☐4 Did nothing

☐5 I cannot remember, I do not know

18.4 How does a person get tapeworm infection?

☐1 They do not wash their hands ☐2 They eat undercooked pig meat

☐3 They are in contact with an infected person ☐4 Other [*Specify*] _____

☐5 I don't know

19 Have you ever had skin nodules or hard lumps under the skin? [*Show photograph of person with subcutaneous cysticercosis nodules*]

☐1 Yes, currently has ☐2 Yes in the past year, but not currently

☐3 Yes, one year or more ago, but not currently ☐4 No

☐5 Cannot remember, do not know

24 Have you ever hurt yourself when you lose consciousness or during a seizure?

☐1 Yes ☐2 No

☐3 I do not lose consciousness or have seizures [*Skip to Q 25*]

☐4 Cannot remember [*Skip to Q 25*]

24.1 If yes, how did you hurt yourself?

☐1 Fell in the fire ☐2 Fell in the water

☐3 Fell off your bicycle ☐4 Fell while walking along the road

☐5 Cut yourself ☐6 Other [*Specify*] _____

25 Is there someone in your household with epilepsy or seizures?

☐1 Yes, currently is ☐2 Yes in the past year, but not currently

☐3 Yes, one year or more ago, but not currently ☐4 No

25.1 (If yes) Who in your household has epilepsy or seizures? [*check all that apply*]

☐1 Mother ☐2 Father

☐3 Brother/sister ☐4 Child (how many) _____

☐5 Other relative (how many) _____ ☐6 Other [*specify*] _____

(Interviewer: Read the following statement)

Now I want to ask you a few questions about your treatments for *[insert name of symptom or condition they reported having in question 21.1-21.6]*

26 Before you came to this hospital, had you ever consulted a health provider because of this condition?

☐2 No [*Skip to Q 26.6*] ☐3 Cannot remember [*Skip to Q 26.6*]

☐1 Yes

26.2 Before you first came to this hospital for treatment, when was the last time you had consulted a health provider for your condition?

☐1 Within the previous month ☐2 Within the previous year

☐3 From one (1) to five (5) years before ☐4 More than five (5) years before

☐5 Cannot remember, not sure

26.3 Before you first came to this hospital for treatment, what kind of health provider(s) had you consulted and how many times in the past 5 years [*check any that apply*]?

☐1 A physician /_____ times (26311)

☐2 A neurologist/_____times (26322)

☐3 A nurse/_____ times (26331)

☐4 A herbalist/_____ times (26341)

☐5 A traditional healer /_____times (26351)

☐6 A psychiatrist/psychologist/ __ times (26361)

☐7 Other (specify _____)/_____ times (26371)

☐8 Cannot remember, not sure

26.4 Before you first came to this hospital, how much did it cost each time you consulted with one health provider [*specify the currency used*]?

☐1 A physician/ (26411)_____

☐2 A neurologist/(26421)_____

☐3 A nurse/ (26431) _____

☐4 A herbalist _____

☐5 A traditional healer/(26451)

☐6 A psychiatrist / psychologist/(26461) _____

☐7 Other (specify _____)(26471) _____

☐8 Cannot remember, not sure

☐9 I never pay because the government covers my health expenses

26.5 Before you came to this hospital, how far did you have to travel to go to the health provider from your house and how did you get there (1 foot, 2 bicycle, 3 bus, 4 train, 5 taxi, 6 car, 7 other)?

☐1 Physician at/ _____ km reached by___

☐2 Neurologist at ____ km reached by___

☐3 Nurse at ____ km reached by____

☐4 Herborist at ____ km reached by____

☐5 Traditional healer at _____ km reached by_____

☐6 A psychiatrist / psychologist at _____ km reached by_____

☐7 Other (specify _____) at _____ km reached by_____

☐8 Cannot remember

26.6 How far is this hospital from your house? _____km

26.7 How do you usually come to this hospital? [*Check all that applies*]

and how do you get here (1 foot, 2 bicycle, 3 bus, 4 train, 5 taxi, 6 car, 7 other)?

☐1 By foot ☐2 by bicycle

☐3 By bus ☐4 By train

☐5 By taxi ☐6 by car

☐7 Other (specify _____)

26.8 Are you currently being followed by a health provider outside of this hospital for this condition?

☐2 No [*Skip to Q 28*] ☐3 Cannot remember [*Skip to Q 28*]

☐1 Yes

26.9 When was the last time you consulted with that health provider for your condition?

☐1 Within the past month ☐2 Within the past year

☐3 From one (1) to five (5) years ago ☐4 More than five (5) years ago

☐5 Cannot remember, not sure

26.10 What kind of health provider(s) is currently seeing you outside of this hospital and how many times have you seen him/her in the past 5 years [*check several boxes if appropriate*]?

☐1 A physician /_____ times(26311)

☐2 A neurologist/_____times(26322)

☐3 A nurse/_____ times(26331)

☐4 A herbalist/_____times(26341)

☐5 A traditional healer /_____times(26351)

☐6 A psychiatrist/psychologist/ __ times(26361)

☐7 Other (specify _____)/_____ times (26371)

☐8 Cannot remember, not sure

26.11 How much does it cost each time you consulted with that health provider (outside of the hospital) for this condition [*specify the currency used*]?

☐1 A physician/ (26411)_____

☐2 A neurologist/(26421)_____

☐3 A nurse/ (26431) _____

☐4 A herbalist _____

☐5 A traditional healer/(26451)

☐6 A psychiatrist / psychologist/(26461) _____

☐7 Other (specify _____)(26471) _____

☐8 Cannot remember, not sure

☐9 I never pay because the government covers my health expenses

26.12 How far do you have to travel to go to the health provider from your house and how do you usually get there (1 foot, 2 bicycle, 3 bus, 4 train, 5 taxi, 6 car, 7 other)?

☐1 Physician at/ _____ km reached by___

☐2 Neurologist at ____ km reached by___

☐3 Nurse at ____ km reached by____

☐4 Herborist at ____ km reached by____

☐5 Traditional healer at _____ km reached by_____

☐6 A psychiatrist / psychologist at _____ km reached by_____

☐7 Other (specify _____) at _____ km reached by_____

☐8 Can not remember

29. Before you came to this hospital, were you ever treated with drugs for this condition?

☐2 No (the interview is finished)

☐3 Can't remember, do not know (interview is finished)

☐1 Yes

29.4 What medication was it and how much did it cost (check several boxes if appropriate)?

☐1 Carbamazepine/Tegretol_____ ☐2 Phenytoin/Dihydan_____

☐3 Valproic acid/Dépakin_____ ☐4 Phenobarbital/Gardénal _____

☐5 Traditional medicine _____ ☐6 Other (specify _____) _____

☐7 Can not remember, not sure

THIS IS THE END OF THE INTERVIEW

THANK YOU VERY MUCH FOR YOUR COOPERATION

INTERVIEWER: _____

APPENDIX B

ESTUDIO DE NEUROCISTICERCOSIS HUMANA (NCC)

CUESTIONARIO GENERAL

Número de expediente _____

Municipio _____

Comunidad _____

Número de casa (lote, manzana, etc.) _____

¿Cuántos años ha vivido en esta comunidad?_____

¿Tiene seguro médico? ☐ Si ☐ No ☐ No sabe

Tipo de seguro médico ☐ Popular ☐ IMSS ☐ ISSSTE ☐ Privado

1 ¿Qué edad tiene? _____ (años)

2 ¿Cuál es su fecha de nacimiento?____ Día _____ Mes _____ Año

3 Género ☐1 Hombre ☐2 Mujer

4 ¿Cuál es el último grado de escolaridad que terminó?

☐1 Ninguno ☐2 Primaria

☐3 Secundaria ☐4 Preparatoria

5 ¿Qué otro tipo de educación ha terminado?

☐1 Escuela técnica ☐2 Licenciatura

☐3 Posgrado

6 ¿Cuál es su ocupación? _____

6.1 Si trabaja, cual es su salario mensual?

7 ¿Puede calcular cuántos días ha faltado a su trabajo por enfermedad en el último mes?

_____ ☐2 No puede calcular

7.1 Si no tiene un empleo oficial, ¿Puede calcular cuántos días no ha podido realizar sus tareas diarias en el último mes? _____ ☐2 No puede calcular

8 ¿Puede calcular cuántos días ha faltado a su trabajo por enfermedad en el último año? _____

☐2 No puede calcular

8.1 Si no tiene un empleo oficial, ¿Puede calcular cuántos días no ha podido realizar sus tareas diarias en el último año? _____ ☐2 No puede calcular

9 ¿Por lo general de dónde obtiene su agua para beber?

☐1 Río ☐2 Pipa ☐3 Pozo ☐4 Embotellada

☐5 Otro [*Especifique*] _____

10 ¿Hierve su agua para beber?

☐1 Siempre ☐2 Casi siempre

☐3 A veces ☐4 Nunca

11 ¿Con qué frecuencia come cerdo?

☐1 Por lo menos una vez al mes ☐2 Menos de 1 vez al mes pero por lo menos 1 vez al año

☐3 Menos de una vez al año ☐4 Nunca [*Pase a la P13*]

12.1 ¿Cómo se prepara el cerdo que usted come? [*Marque todas las que se apliquen.*]

☐1 Carnitas ☐2 Chorizo

☐3 Embutidos ☐4 Otro

[*Especifique*]_____

12.2 ¿Alguna vez ha comido [*Marque todas las que se apliquen.*]

☐1 Carne de cerdo cruda ☐2 Carne de cerdo poco cocida

☐3 Carne de cerdo medio cocida ☐4 Carne de cerdo bien cocida

☐5 No recuerdo, no sé

13 ¿Tiene un baño o letrina en su casa?

☐1 Sí ☐2 No [*Pase a la P14*]

13.1 ¿Con qué frecuencia usa un excusado cuando tiene que defecar?

☐1 Siempre ☐2 A veces ☐3 Nunca

13.2 ¿Con qué frecuencia defeca en el campo o en las milpas?

☐1 Siempre ☐2 A veces ☐3 Nunca

14 ¿Cría cerdos?

☐ Sí (por favor conteste el cuestionario de cerdos) ☐ No

15 ¿Alguna vez ha tenido cerdos? *[Si la respuesta es "sí", pregunte cuándo]*

☐1 Sí, el año pasado ☐2 Sí, hace de 1 a 5 años

☐3 Sí, hace más de 5 (cinco años ☐4 No [*Pase a la P 17*]

15.1 ¿Qué tipo de cerdos eran?

☐1 Europeos (blancos) ☐2 Criollos (oscuros)

☐3 Europeos y criollos ☐4 No recuerda, no sabe

16 ¿Alguna vez le dijeron que sus cerdos tenían grano, granillo o tomate (cisticercosis)?

☐1 Sí ☐2 No [*Pase a la P 17*]

16.1. ¿Cuándo le dijeron que sus cerdos tenían grano, granillo o tomate (cisticercosis)?
☐1 El año pasado ☐2 Hace de 1 a 5 años ☐3 Hace más de 5 años
☐4 Nunca me dijeron (Pase a la P 17) ☐5 No recuerdo, no sé (Pase a la P 17)

16.1.1 ¿Pudo vender sus cerdos después de que le dijeron que tenían grano, granillo o tomate?

☐1 Vendí todos ☐2 Vendí algunos ☐3 No pude venderlos [*Pase a la P 17*]
☐5 No recuerdo, no sé [*Pase a la P 17*]

16.1.2 Cuando sucedió eso, ¿a qué precio vendió sus cerdos adultos (Especifique la forma de pago, puede ser dinero o trueque)? _____

16.1.3 Cuando sucedió eso, ¿a qué precio vendió sus cerditos de 4 meses de edad o menos (Especifique la forma de pago, puede ser dinero o trueque)? _____

17 ¿Alguna vez ha visto o escuchado grano, granillo o tomate en la canal de cerdo?

☐1 Sí ☐2 No [*Pase a la P 18*]

17.1 ¿Dónde se pueden encontrar grano, granillo o tomate en un cerdo vivo?

☐1 No es posible encontrarlos en un cerdo vivo

☐2 Debajo de la piel ☐3 Debajo de la lengua

☐4 No sé ☐5 En algún otro lugar [*Especifique*] ____

17.2 ¿Por qué sale grano, granillo o tomate a los cerdos?

☐1 Por comer excremento humano ☐2 Por comer excremento de cerdo

☐3 De otro cerdo infectado ☐4 Otro [*Especifique*] _____

☐5 No sé

17.3 ¿Qué haría si descubriera que su cerdo tiene grano, granillo o tomate?

☐1 Lo vendería ☐2 Lo trataría con hierbas

☐3 Picar los granos ☐4 Otro [*Especifique*] _____

☐5 No sé

18 ¿Alguna vez ha escuchado de una infección por solitaria o tenia en humanos?

☐1 Sí ☐2 No [*Pase a la P 19*]

18.1 ¿Cómo supo de ella?

☐1 Por un doctor ☐2 Por un amigo o familiar

☐3 Por un curandero ☐4 En la radio / periódico

☐5 Otro [*Especifique*] _____

18.2 ¿Cómo sabe una persona si tienen una solitaria?

☐1 Lo puede ver en su excremento ☐2 Tiene diarrea

☐3 Tiene fiebre ☐4 Otro [*Especifique*] _____

☐5 No sé

18.3 ¿Alguna vez ha tenido una solitaria o visto pequeñas partes (segmentos) de gusanos que parecen como tallarines planos en su excremento? (*Muestre fotografías de proglótidos*)

☐1 Sí ☐2 No [*Pase a la P 18.4*]

☐3 No sé / no recuerdo [*Pase a la P 18.4*]

18.3.1 Cuando sucedió eso, ¿qué hizo? [*Marque todas las que se apliquen*]

☐1 Fui al centro de salud, hospital, clínica o dispensario

☐2 Fui a la farmacia para comprar la medicina y tratarlo

☐3 Fui con un curandero ☐4 No hice nada

☐5 No recuerdo, no sé

18.4 ¿Cómo se infecta una persona con solitaria?

☐1 No se lava las manos

☐2 Come carne de cerdo que no está bien cocida

☐3 Está en contacto con una persona que tiene solitaria

☐4 Otro [*Especifique*] _____

☐5 No sé

18.5 ¿Sabe si algún familiar o persona que vive en su casa tiene o ha tenido una solitaria?

☐1 Sí ☐2 No [*Pase a la P 19*]

18.5.1 ¿Hace cuanto tiempo la tuvo?

☐1 En los últimos 6 meses ☐2 Hace 1 a 2 años

☐3 Hace 3 a 5 años ☐4 Hace más de 5 años

☐5 No recuerdo, no sé

19 ¿Alguna vez ha tenido nódulos en la piel o bolitas duras debajo de la piel? [*Muestre la fotografía de la persona con nódulos subcutáneos por cisticercosis*]

☐1 Sí, actualmente los tengo ☐2 Sí, el año pasado pero ahora no

☐3 Sí, hace como un año o más, pero no ahora ☐4 No

☐5 No recuerdo, no sé

20 ¿Alguna vez ha tenido dolores de cabeza graves que duran varios días?

☐1 Sí, actualmente los tengo ☐2 Sí, el año pasado pero ahora no

☐3 Sí, hace como un año o más, pero no ahora ☐4 No

☐5 No recuerdo, no sé

21 ¿Alguna vez ha tenido alguno de los siguientes casos?

21.1 Pérdida repentina de la conciencia y episodios de incontinencia o espuma en la boca o morderse la lengua

☐1 Sí, actualmente los tengo ☐2 Sí, el año pasado pero ahora no

☐3 Sí, hace como un año o más, pero no ahora

☐4 No [*Pase a la P 21.2*] ☐5 No recuerdo, no sé

21.1.1 (Si la respuesta es sí) ¿Cuántas veces le ha sucedido esto?

☐1 Solamente una vez ☐2 Más de una vez

21.1.2 ¿Qué edad tenia cuando esto le sucedió por primera vez? [*Indicar el edad si lo se*]

☐1 Cuando era niño (menos de 15 anos) y tenia _____años

☐2 Cuando era joven (15-19 anos) y tenia _____años

☐3 Desde que soy adulto (20 anos o mas) y tenia _____años

☐4 No recuerdo, no se

21.1.3 Cuando le sucedió esto por primera vez?

☐1 Durante el año (12 meses) pasado

☐2 De 1 a 2 años

☐3 De 3 a 4 años

☐4 Al menos 5 años

☐5 No recuerdo, no se

21.2 Un período breve de ausencia o pérdida de contacto con sus alrededores que empieza de repente

☐1 Sí, actualmente lo tengo ☐2 Sí, el año pasado pero ahora no

☐3 Sí, hace como un año o más, pero no ahora

☐4 No [*Pase a la P 21.3*] ☐5 No recuerdo, no se [Pase a la P 21.2.1]

¿Cuántas veces le ha sucedido esto?

☐1 Solamente una vez ☐2 Más de una vez

21.2.2 ¿Qué edad tenia cuando esto le sucedió por primera vez? [*Indicar el edad si lo se*]

☐1 Cuando era niño (menos de 15 años) y tenia _____ años

☐2 Cuando era joven (15-19 años) y tenia _____ años

☐3 Desde que soy adulto (20 años o mas) y tenia _____años

☐4 No recuerdo, no se

21.2.3 ¿Cuando le sucedió esto por primera vez?

☐1 Durante el año (12 meses) pasado

☐2 De 1 a 2 años

☐3 De 3 a 4 años

☐4 Al menos 5 años

☐5 No recuerdo, no se

21.3 Sacudidas o tirones (alferecias) o movimientos anormales incontrolables de una o más extremidades (convulsiones) que empiezan de repente y duran algunos minutos

☐1 Sí, actualmente los tengo ☐2 Sí, el año pasado pero ahora no

☐3 Sí, hace como un año o más, pero no ahora

☐4 No [*Pase a la P 21.4*] ☐5 No recuerdo, no sé [*Pase a la P 21.4*]

21.3.1 ¿Cuántas veces le ha sucedido esto?

☐1 Solamente una vez ☐2 Más de una vez

21.3.2 ¿Qué edad tenia cuando esto le sucedió por primera vez? [*Indicar el edad si lo se*]

☐1 Cuando era niño (menos de 15 años) y tenia _____ años

☐2 Cuando era joven (15-19 años) y tenia _____ años

☐3 Desde que soy adulto (20 años o mas) y tenia _____años

☐4 No recuerdo, no se

21.3.3 ¿Cuando le sucedió esto por primera vez?

☐1 Durante el año (12 meses) pasado

☐2 De 1 a 2 años

☐3 De 3 a 4 años

☐4 Al menos 5 años

☐5 No recuerdo, no se

21.4 Inicio repentino de un período corto de oír u oler o ver cosas que no existen o tener sensaciones raras en el cuerpo

☐1 Sí, actualmente lo tengo ☐2 Sí, el año pasado pero ahora no

☐3 Sí, hace como un año o más, pero no ahora

☐4 No [*Pase a la P 21.5*] ☐5 No recuerdo, no sé [*Pase a la P 21.5*]

21.4.1 ¿Cuántas veces le ha sucedido esto?

☐1 Solamente una vez ☐2 Más de una vez

21.4.2 ¿Qué edad tenia cuando le sucedió esto por primera vez? [*Indicar el edad si lo se*]

☐1 Cuando era niño (menos de 15 años) y tenia _____ años

☐2 Cuando era joven (15-19 años) y tenia _____ años

☐3 Desde que soy adulto (20 años o mas) y tenia _____años

☐4 No recuerdo, no se

21.4.3 ¿Cuando le sucedió esto por primera vez?

☐1 Durante el año (12 meses) pasado

☐2 De 1 a 2 años

☐3 De 3 a 4 años

☐4 Al menos 5 años

☐5 No recuerdo, no se

21.5 ¿Alguna vez le dijeron que tenía epilepsia o que había tenido una convulsión epiléptica?

☐1 Sí, durante el mes pasado ☐2 Sí, durante el año pasado pero no el mes pasado

☐3 Sí, hace como un año o más ☐4 No

☐5 No recuerdo, no sé

21.5.2 ¿Qué edad tenia cuando le sucedió esto por primera vez? [*Indicar el edad si lo se*]

☐1 Cuando era niño (menos de 15 años) y tenia _____ años

☐2 Cuando era joven (15-19 años) y tenia _____ años

☐3 Desde que soy adulto (20 años o mas) y tenia _____años

☐4 No recuerdo, no se

21.5.3 ¿Cuando le sucedió esto por primera vez?

☐1 Durante el año (12 meses) pasado

☐2 De 1 a 2 años

☐3 De 3 a 4 años

☐4 Al menos 5 años

☐5 No recuerdo, no se

21.6 ¿Alguna vez ha tenido convulsiones o ataques?

☐1 Sí, actualmente los tengo ☐2 Sí, el año pasado pero ahora no

☐3 Sí, hace como un año o más, pero no ahora

☐4 No [*Pase a la P 22*] ☐5 No recuerdo, no sé [*Pase a la P 22*]

21.6.1 ¿Cuántas veces le ha sucedido esto?

☐1 Solamente una vez ☐2 Más de una vez

21.6.2 ¿Qué edad tenia cuando le sucedió esto por primera vez? [*Indicar el edad si lo se*]

☐1 Cuando era niño (menos de 15 años) y tenia _____ años

☐2 Cuando era joven (15-19 años) y tenia _____ años

☐3 Desde que soy adulto (20 años o mas) y tenia _____años

☐4 No recuerdo, no se

21.6.3 ¿Cuando le sucedió esto por primera vez?

☐1 Durante el año (12 meses) pasado

☐2 De 1 a 2 años

☐3 De 3 a 4 años

☐4 Al menos 5 años

☐5 No recuerdo, no se

[Si el entrevistado ha contestado "no" a las preguntas 21.1-21.6, la entrevista ha terminado. Vaya a la última página y conteste las preguntas 30 y 31 tomando como base sus observaciones]

MUCHAS GRACIAS POR SU COOPERACIÓN

[De lo contrario, por favor continúe con el cuestionario]

[Entrevistador: Si contestaron "sí" a cualquiera de las preguntas 21.1-21.6, pregunte lo siguiente. De lo contrario, pase a la P. 25.]

22 ¿Ha tenido alguno de los siguientes casos?

22.1 Lesión en la cabeza por la que perdio la conciencia?

☐ 1Sí ☐2 No [*Pase a la P 22.2*]

22.1.1 Si la respuesta fue afirmativa, ¿cuándo empezaron sus síntomas de convulsiones?

☐1 Antes de la lesión en la cabeza

☐2 Pronto después de la lesión en la cabeza

☐3 Mucho tiempo después de la lesión en la cabeza

☐4 No recuerdo, no sé

22.2 ¿Meningitis (infección cerebral) durante la infancia?

☐1 Sí ☐2 No

22.2.1 Si la respuesta fue afirmativa, ¿cuándo empezaron sus síntomas de convulsiones?

☐1 Antes de la meningitis

☐2 Pronto después de la meningitis

☐3 Mucho tiempo después de la meningitis

☐4 No recuerdo, no sé

23 ¿Qué le pasa cuando tiene una convulsión o un ataque? _____

24 ¿Alguna vez se ha lastimado cuando pierde la conciencia o durante una convulsión?

☐1 Sí ☐2 No

☐3 No pierdo la conciencia ni tengo convulsiones [*Pase a la P 25*]

☐4 No recuerdo [*Pase a la P 25*]

24.1 Si la respuesta fue afirmativa, ¿cómo se lastimó?

☐1 Caí en el fuego ☐2 Caí al agua

☐3 Me caí de la bicicleta ☐4 Me caí mientras caminaba en la calle

☐5 Me corté ☐6 Otro [*Especifique*] _____

25 ¿Hay alguien en su hogar que tenga epilepsia o convulsiones?

☐1 Sí, actualmente ☐2 Sí, el año pasado pero ahora no

☐3 Sí, hace como un año o más, pero no ahora ☐4 No

25.1 (Si la respuesta fue sí) ¿Quién tiene epilepsia o convulsiones en su hogar? [*Marque todas las que se apliquen*]

☐1 Madre ☐2 Padre

☐3 Hermano / hermana ☐4 Hijo (cuántos) _____

☐5 Otro pariente (cuántos) _____ ☐6 Otro [*Especifique*] ____

(Entrevistador: Lea la siguiente declaración)

Ahora voy a hacerle unas preguntas sobre sus tratamientos para *[diga el nombre del síntoma o condición que dijeron tener en la pregunta 21.1-21.6]*

26 ¿Alguna vez ha consultado a un proveedor de atención médica (médico, neurólogo, enfermera, herbolario, curandero, psiquiatra o psicólogo) por esta condición?

☐2 No [*Pase a la P 27*] ☐3 No recuerdo [*Pase a la P 27*]

☐1 Sí

26.2 ¿Cuándo fue la <u>última</u> vez que consultó a un proveedor de atención médica por su condición?

☐1 El mes pasado ☐2 El año pasado

☐3 Hace de 1 (uno) a 5 (cinco) años ☐4 Hace más de 5 (cinco) años

☐5 No recuerdo, no estoy seguro

26.3 ¿Qué tipo de proveedor o proveedores de atención médica consultó y cuántas veces en los últimos 5 años? [*marque varias casillas, según sea el caso*]

☐1 Un médico /_____ veces (26311) ☐2 Un neurólogo /_____ veces (26322)

☐3 Una enfermera/____ veces (26331) ☐4 Un herbolario /___ veces (26341)

☐5 Un curandero /_____ veces (26351)

☐6 Un psiquiatra / psicólogo / __ veces (26361)

☐7 Otro (Especifique _____)/_____ veces (26371)

☐8 No recuerdo, no estoy seguro

26.4 ¿Cuánto le costó cada vez que consultó a un proveedor de atención médica [*Especifique la forma de pago*]?

☐1 Un médico/ (26411)_____ ☐2 Un neurólogo/(26421)_____

☐3 Una enfermera / (26431) _____☐4 Un herbolario _____

☐5 Un curandero /(26451)

☐6 Un psiquiatra / psicólogo /(26461) _____

☐7 Otro (Especifique _____)(26471) _____

☐8 No recuerdo, no estoy seguro

☐8 Nunca pago porque el gobierno cubre mis gastos médicos

26.5 ¿A qué distancia está el proveedor de salud de su casa y cómo llegó allí? (anote si fue: a pie 1, en bicicleta 2, en autobús 3, por tren 4, en taxi 5, en coche 6, otro 7)

☐1 Médico a / ___ km y llegué ___

☐2 Neurólogo a ____ km y llegué___

☐3 Enfermera a ____ km y llegué__

☐4 Herbolario a ____ km y llegué____

☐5 Curandero a _____ km y llegué_____

☐6 Psiquiatra / psicólogo _____ km y llegué_____

☐7 Otro (Especifique _____) a _____ km y llegué_____

☐8 No recuerdo

27 ¿Alguna vez ha sido hospitalizado por esta condición?

☐2 No [*Pase a la P 28*] ☐3 No recuerdo [*Pase a la P 28*] ☐1 Sí

27.2 ¿Cuántas veces lo han hospitalizado en los últimos 5 años? _____veces

27.3 ¿Cuándo fue su <u>última</u> hospitalización? _____(meses)

27.3.1 ¿Cuántos días se quedó en el hospital? _____ (días)

27.3.2 ¿Cuánto le costó (Especifique la unidad monetaria) _____

27.3.3 ¿A qué distancia está el hospital de su casa? _____ km

27.3.4 ¿Cómo llegó al hospital?

☐1 A pie ☐2 En bicicleta ☐3 En autobús ☐4 En taxi

☐5 En coche ☐6 Por tren ☐7 Otro [*Especifique*] _____

28. ¿Alguna vez le han hecho exámenes médicos por esta condición?

☐2 No [*Pase a la P 29*] ☐3 No recuerdo, no sé [*Pase a la P 29*] ☐1 Sí

28.2 ¿Qué tipo de examen fue (marque todas las casillas que se apliquen)?

☐1 Examen de sangre para cisticercosis ☐2 Tomografía del cerebro

☐3 Rayos X del cerebro ☐4 Resonancia magnética del cerebro

☐5 Electroencefalograma (EEG) ☐6 Otro [*Especifique*] _____

☐7 No recuerdo, no estoy seguro

28.3 ¿Cuándo se le hizo el último examen médico para esta condición?

☐1 El mes pasado ☐2 El año pasado

☐3 Hace de 1 a 5 años ☐4 Hace más de 5 años

☐5 No recuerdo, no estoy seguro

28.4 ¿Cuánto le costó cada examen [*Especifique la unidad monetaria*]?

☐1 Examen de sangre para cisticercosis_____

☐2 Tomografía del cerebro _____

☐3 Rayos X del cráneo _____

☐4 Resonancia magnética del cerebro _____

☐5 Electroencefalograma _____

☐6 Otro [*Especifique*] _____

☐7 No recuerdo, no estoy seguro

28.5 ¿Qué distancia tuvo que recorrer desde su casa para hacerse este examen y cómo llegó allí? (anote 1 a pie, 2 en bicicleta, 3 en autobús, 4 por tren, 5 en taxi, 6 en coche, 7 otro)?

☐1 Examen de sangre para cisticercosis a _____ km y llegué_____

☐2 Tomografía a _____ km y llegué_____

☐3 Rayos X a _____ km y llegué_____

☐4 Resonancia magnética a _____ km y llegué_____

☐5 Electroencefalograma a _____ km y llegué_____

☐6 Otro (Especifique _____) a _____ km y llegué_____

☐7 No recuerdo, no estoy seguro

29. ¿Alguna vez lo han tratado por esta condición?

☐2 No (se termina la entrevista)

☐3 No recuerdo, no sé (se termina la entrevista)

☐1 Sí

29.2 ¿Cuándo fue la última vez que usó medicamentos para su condición?

☐1 El mes pasado ☐2 El año pasado

☐3 Hace de 1 a 5 años ☐4 Hace más de 5 años

☐5 No recuerdo, no estoy seguro

29.3 ¿Qué medicamento usó y cuántas veces ha usado algún medicamento en el último año (marque varias casillas, según sea el caso)?

☐1 Carbamazepina/Tegretol____ veces

☐2 Fenitoína/Dihydan_____ veces

☐3 Ácido valpróico/Dépakin_____ veces

☐4 Fenobarbital/Gardénal _____veces

☐5 Medicina tradicional _____ veces

☐6 Otro (Especifique _____) ___veces

☐7 No recuerdo, no estoy seguro

29.4 ¿Cuánto pagó cada vez que compró este medicamento (Especifique la unidad monetaria usada)?

☐1 Carbamazepina/Tegretol _____ ☐2 Fenitoína/Dihydan _____

☐3 Ácido valpróico/Dépakin _____ ☐4 Fenobarbital/Gardénal _____

☐5 Medicina tradicional _____

☐6 La recibí gratis del proveedor de atención médica (No la pagué yo) _____

☐7 Otro (Especifique _____) _____

☐8 No recuerdo, no estoy seguro

ÉSTE ES EL FINAL DE LA ENTREVISTA

MUCHAS GRACIAS POR SU COOPERACIÓN

ENTREVISTADOR: _____ FECHA DE LA ENTREVISTA_____

APPENDIX C

Neurocysticercosis Health Study (intake form)

Individual ID ☐☐☐☐☐

Abstractor ID ☐☐

Hospital/Clinic ID ☐☐

Today's Date ☐☐☐☐☐☐
(d d m m y y)

Date of Birth ☐☐☐☐☐☐
(d d m m y y)

Gender: ☐ (male) ☐ (female)

State of Residence: ☐ (Mexico City) ☐ (Mexico State) ☐ (Michoacan) ☐ (Guerrero)
☐ (Morelos) ☐ (Other_____)

Village of Residence _____

Postal Code ☐☐☐☐

Highest Education Level Completed: ☐ None ☐ Elementary school
☐ High school ☐ Some college
☐ Technical degree ☐ Graduate degree
☐ University degree

Insurance Type: ☐ (IMSS) ☐ (SSA) ☐ (no insurance) ☐ (ISTEE) ☐ (Not reported/unknown)

Payment Classification: (for SSA) ☐ (levels 0 - 6)

NCC/seizure-associated reason(s) for today's visit. Follow-up for: (check all that apply)

1. Epilepsy (>1 afebrile seizure not associated with an acute CNS process) ☐
2. Acute symptomatic seizures ☐
3. Single seizure ☐
4. Dementia ☐

5. Hydrocephalus ☐
6. Vasculitis/stroke ☐
7. Increased intracranial pressure ☐
8. Severe headaches lasting more than 3 days ☐
9. Other _____ ☐

Medical History:

HIV Status: ☐ Positive ☐ Negative ☐ Not reported / unknown

AIDS Status: ☐ Positive ☐ Negative ☐ Not reported / unknown

Has the patient ever been diagnosed with any of the following? (check all that apply)

		If yes, date of 1st diagnosis (d d m m y y)	**Information Source**	
1. Epilepsy ☐ Other record	☐		☐ History	☐ File
2. Acute symptomatic seizures ☐ Other record	☐		☐ History	☐ File
3. Single seizure ☐ Other record	☐		☐ History	☐ File
4. Dementia ☐ Other record	☐		☐ History	☐ File
5. Hydrocephalus ☐ Other record	☐		☐ History	☐ File
6. Vasculitis/stroke ☐ Other record	☐		☐ History	☐ File
7. Increased intracranial pressure ☐ Other record	☐		☐ History	☐ File
8. Severe headaches (>3 days) ☐ Other record	☐		☐ History	☐ File

Seizure types: (check all that apply)

1. Atonic ☐

2. Absence ☐
3. Tonic/clonic ☐
4. Myoclonic ☐
5. Simple partial ☐
6. Complex partial ☐
7. Partial seizures with secondary generalization ☐
8. Other type_____ ☐
9. Type not specified ☐
10. Never had seizures ☐

APPENDIX D

Neurocysticercosis Health Study (clinic visit/hospitalization form)

Individual ID ☐☐☐☐☐

Abstractor ID ☐☐

Hospital/Clinic ID ☐☐

Today's Date ☐☐☐☐☐☐
(d d m m y y)

Diagnostic testing record (2002-present): (list oldest to most recent)

Test	**Date** (dd/mm/yy)	**Findings** (list for each test performed)	**Testing Location** (name of hospital or clinic)
EITB		(1=neg, 2=pos, 9=NR)	
1.			
2.			
3.			
Ag-ELISA		(1=neg, 2=trace, 3= +, 4= ++, 9=NR)	
1.			
2.			
3.			
Ab-ELISA		(1=neg, 2=trace, 3= +, 4= ++, 9=NR)	
1.			
2.			
3.			
CSF study		(1=normal, 2=*T. solium* cysticerci Ab pos, 3=other abnormal, 9=NR)	
1.			
2.			
3.			
EEG		(1=normal, 2=abnormal, 9=NR)	
1.			
2.			

3.			
Skull x-rays		(1=normal, 2=calcifications, 3=other abnormal, 9=NR)	
1.			
2.			
3.			
Neurological exam		(1=normal, 2=abnormal, 9=NR)	
1.			
2.			
3.			
4.			
5.			
Examination for subcutaneous nodules		(1=present, 2=absent, 9=NR)	
1.			
2.			
3.			
Subcutaneous nodule biopsy		(1=normal, 2=cysticerci, 3=other abnormal, 9=NR)	
1.			
2.			
CT		(list primary findings)	
1.			
2.			
3.			
MRI		(list primary findings)	
1.			
2.			
3.			
Dementia evaluation (list testing method)		(1=normal, 2=abnormal, 9=NR)	
1.			
2.			
3.			
Other _____		(1=normal, 2=abnormal, 9=NR)	
1.			
2.			
3.			

Medications (2002-present) (re-list medication if dosage changes)

Name of medication	Dosage (units)	Times/day	Start date (dd/mm/yy)	Stop date (dd/mm/yy)	Reason for stop/change
1.					
2.					
3.					
4.					
5.					
6.					
7.					
8.					
9.					
10.					

Continue list on extra medication form

NCC-related surgery record (2002-present) (list oldest to most recent**):**

Type of Surgery	Surgery date (dd/mm/yy)	Hospital where surgery was performed
1.		
2.		
3.		
4.		

Individual ID ☐☐☐☐☐

Abstractor ID ☐☐

Hospital ID ☐☐

INPATIENT ADMISSIONS RECORD (2002-present): (Use a separate sheet for each admission)

Admission number (number sequentially from oldest to most recent) _____

Admission Date ☐☐☐☐☐☐ (d d m m y y) Discharge Date ☐☐☐☐☐☐ (d d m m y y)

Type of room: ☐ (private) ☐ (2 beds) ☐ (3 beds) ☐ (other_____)

Admitting hospital: ☐ (INNN) ☐ (IMSS) ☐ (INNN pediatric) ☐ (IMSS pediatric)
☐ (SSA hospital-Uruapan) ☐ (Other_____)

Services consulted during this admission: (check all that apply)

1. Neurology ☐
2. Cardiology ☐
3. Oncology ☐
4. Infectious disease ☐
5. Psychiatry ☐
6. General/Internal medicine ☐
7. Other_____ ☐

Karnofsky score at admission ☐☐☐
(999 = not reported)

Reason for this admission: (check all NCC/seizure-associated conditions that apply)

10. Epilepsy (>1 afebrile seizure not associated with an acute CNS process) ☐
11. Acute symptomatic seizures ☐
12. Single seizure ☐

13. Dementia ☐

14. Hydrocephalus ☐
15. Vasculitis/stroke ☐
16. Increased intracranial pressure ☐
17. Severe headaches lasting more than 3 days ☐
18. Other _____ ☐

Individual ID ☐☐☐☐☐

Abstractor ID ☐☐

Clinic ID ☐☐

OUTPATIENT RECORD (2002-present): (Use a separate sheet for each outpatient visit)

Outpatient visit number (number sequentially from oldest to most recent) _____

Date of outpatient visit ☐☐☐☐☐☐
(d d m m y y)

Hospital/clinic visited: ☐ (INNN) ☐ (IMSS) ☐ (INNN pediatric) ☐ (IMSS pediatric)

☐ (SSA hospital- Uruapan) ☐ (Other_____)

Services consulted: (check all that apply)

1. Neurology ☐
2. Cardiology ☐
3. Oncology ☐
4. Infectious disease ☐
5. Psychiatry ☐
6. General/Internal medicine ☐
7. Other_____ ☐

Reason for this visit: (check all NCC/seizure-related conditions that apply)

1. Epilepsy (>1 afebrile seizure not associated with an acute CNS process) ☐
2. Acute symptomatic seizures ☐
3. Single seizure ☐
4. Dementia ☐
5. Hydrocephalus ☐
6. Vasculitis/stroke ☐
7. Increased intracranial pressure ☐
8. Severe headaches lasting more than 3 days ☐
9. Other _____ ☐

APPENDIX E

Estudio de neurocisticercosis (NCC)

Formato para registro de la primera vez que se diagnosticó NCC

No. Expediente ☐☐☐☐☐

Identificación del encuestador ☐☐

Hospital/Clínica: ☐ (INNN) ☐ (CMNSXXI) ☐ (INPed) ☐ (SSA Uruapan)
☐ (Otro) (Nombre:_____)

Fecha de hoy ☐☐☐☐☐☐
(d d m m a a)

Fecha de nacimiento ☐☐☐☐☐☐
(d d m m a a)

Género: ☐ (hombre) ☐ (mujer)

Estado de residencia: ☐ (México DF) ☐ (Estado de México) ☐ (Michoacán) ☐ (Guerrero)
☐ (Morelos) ☐ (Otro) (especifique_____)

Comunidad o ciudad de residencia _____

Código Postal ☐☐☐

Nivel de estudios concluido
☐ Ninguno ☐ Primaria
☐ Secundaria ☐ Preparatoria
☐ Escuela técnica ☐ Licenciatura
☐ Posgrado

Tipo de seguro médico: ☐ (Popular) ☐ (IMSS) ☐ (ISSSTE) ☐ (no asegurado) ☐ (no sabe)
☐ (Privado) (Nombre:_____) ☐ (Otro) (Nombre:_____)

Nivel de cuota de recuperación en la SSA: (0 a 6) ☐

Visita de hoy debida a NCC/convulsiones. Causa de seguimiento: (marcar las necesarias)

19. Epilepsia (>1 convulsión no febril y no asociada a un proceso agudo del SNC) ☐
20. Convulsiones agudas sintomáticas ☐
21. Convulsión única ☐
22. Demencia ☐
23. Hidrocefalia ☐
24. Vasculitis ☐
25. EVC ☐
26. Hipertensión intracraneana ☐
27. Cefalea grave con duración mayor a 3 días ☐
28. Otra causa, especifique_____ ☐

Historia Médica:

VIH: ☐ Positivo ☐ Negativo ☐ No reportado / desconocido

SIDA: ☐ Positivo ☐ Negativo ☐ No reportado / desconocido

El paciente ha sido diagnosticado alguna vez con: (marcar las necesarias)

	En caso afirmativo, fecha del Dx (d d m m a a)	**Fuente de información**
9. Epilepsia	☐ ☐☐☐☐☐☐	☐ Historia ☐ Archivo ☐ Otra especifique_____
10. Convulsiones agudas sintomáticas	☐ ☐☐☐☐☐☐	☐ Historia ☐ Archivo ☐ Otra especifique_____
11. Convulsión única	☐ ☐☐☐☐☐☐	☐ Historia ☐ Archivo ☐ Otra especifique_____
12. Demencia	☐ ☐☐☐☐☐☐	☐ Historia ☐ Archivo ☐ Otra especifique_____
13. Hidrocefalia	☐ ☐☐☐☐☐☐	☐ Historia ☐ Archivo ☐ Otra especifique_____
14. Vasculitis	☐ ☐☐☐☐☐☐	☐ Historia ☐ Archivo ☐ Otra especifique_____

15. EVC ☐ ☐☐☐☐☐☐ ☐ Historia ☐
Archivo ☐ Otra
especifique_____

16. Hipertensión intracraneana ☐ ☐☐☐☐☐☐ ☐ Historia ☐
Archivo ☐ Otra
especifique_____

17. Cefalea grave (>3 días) ☐ ☐☐☐☐☐☐ ☐ Historia ☐
Archivo ☐ Otra
especifique_____

Tipo de convulsiones: (marcar las necesarias)

11. Atónica ☐
12. Ausencias ☐
13. Tónico/clónica ☐
14. Mioclónica ☐
15. Parcial simple ☐
16. Parcial compleja ☐
17. Convulsión parcial con generalización secundaria ☐
18. Otro tipo, especifique_____ ☐
19. Tipo no especificado ☐
20. Nunca ha tenido convulsiones ☐

APPENDIX F

Estudio de neurocisticercosis (NCC)

Formato para Dx y Tx en consulta externa o eu hositalización

No. Expediente ☐☐☐☐☐

Identificación del encuestador ☐☐

Hospital/Clínica: ☐ (INNN) ☐ (CMNSXXI) ☐ (INPed) ☐ (SSA Uruapan)

☐ (Otro) (Nombre:_____)

Fecha de hoy ☐☐☐☐☐☐
(d d m m a a)

Registros de pruebas diagnósticas (del 2002 a la fecha de hoy): (enlistar de la más vieja a la más nueva, si requiere mas espacio utilice otra hoja)

Prueba	**Fecha** (dd/mm/aa)	**Hallazgos** (enlistar para cada prueba realizada)	**Sitio en donde se realizó la prueba** (nombre del hospital, clínica o laboratorio)
Estudio del líquido cefalorraquídeo		(1=normal, 2= positivo a anticuerpos contra el cisticerco de *T. solium*, 3=otro dato anormal, 9=NR)	
1.			
2.			
3.			
Electroencefalograma		(1=normal, 2=anormal, 9=NR)	
1.			
2.			
3.			
Rayos X simples de cráneo		(1=normal, 2=calcificaciones, 3=otro dato anormal, 9=NR)	
1.			
2.			
3.			
Examen neurológico		(1=normal, 2=anormal, 9=NR)	
1.			
2.			
3.			
4.			
5.			
Tomografía computada		(enliste hallazgos primarios)	

1.			
2.			
3.			
Resonancia magnética		(enliste hallazgos primarios)	
1.			
2.			
3.			
Evaluación de demencia (enliste método de estudio)		(1=normal, 2=anormal, 9=NR)	
1.			
2.			
3.			
4.			
5.			
Otro _____		(1=normal, 2=anormal, 9=NR)	
1.			
2.			
3.			
EITB o Western Blot para cisticercosis		(1=neg, 2=pos, 9=NR)	
1.			
2.			
3.			
ELISA para anticuerpos		(1=neg, 2=dudoso, 3= +, 4= ++, 9=NR)	
1.			
2.			
3.			
Búsqueda de nódulos subcutáneos		(1=presentes, 2=ausentes, 9=NR)	
1.			
2.			
3.			
Biopsia de nódulos subcutáneos		(1=normal, 2=con cisticercos, 3=otro dato anormal, 9=NR)	
1.			
2.			
3.			

Medicinas tomadas (del 2002 a la fecha de hoy): (enlistar de la más vieja a la más nueva, si requiere mas espacio utilice otra hoja y vuelva a anotar si cambió la dosis de la medicina)

Nombre de la medicina	Dosis (en unidades)	Veces/día	Fecha de inicio (dd/mm/aa)	Fecha de conclusión (dd/mm/aa)	Razón por la que se concluyó o cambio el medicamento
1.					
2.					
3.					
4.					

5.					
6.					
7.					
8.					
9.					
10.					
11.					
12.					

Registro de neurocirugías para NCC (del 2002 a la fecha de hoy): (enlistar de la más vieja a la más nueva, si requiere mas espacio utilice otra hoja)

Tipo de cirugía	**Fecha de la cirugía (dd/mm/aa)**	**Hospital en donde se realizó la cirugía**
1.		
2.		
3.		
4.		

Estudio de neurocisticercosis (NCC)
Formato para costeo de hospitalización

No. Expediente ☐☐☐☐☐

Identificación del encuestador ☐☐

Hospital/Clínica ☐ (INNN) ☐ (CMNSXXI) ☐ (INPed) ☐ (SSA Uruapan)
☐ (Otro) (Nombre:_____)

Fecha de hoy ☐☐☐☐☐☐
(d d m m a a)

REGISTRO DE HOSPITALIZACIONES (del 2002 a la fecha de hoy): (Use una hoja separada para cada admisión)

Número de la admisión (número secuencial de la admisión más vieja a la más nueva) _____

Fecha de ingreso ☐☐☐☐☐☐ (d d m m a a) Fecha de alta ☐☐☐☐☐☐ (d d m m a a)

Tipo de habitación: ☐ (privada) ☐ (2 camas) ☐ (3 camas) ☐ (otro_____)

Hospital: ☐ (SSA) ☐ (IMSS) ☐ (ISSSTE) ☐ (Privado)
(Nombre:_____)

Servicios consultados durante la admisión (marcar las necesarias)

8. Neurología ☐
9. Cardiología ☐
10. Oncología ☐
11. Infectología ☐
12. Psiquiatría ☐
13. Medicina general/Interna ☐
14. Otros (especifique) ☐
_____

Calificación de Karnofsky en la admisión ☐☐☐

Causa de esta admisión (marcar todas las condiciones asociadas a NCC/convulsiones que se apliquen)

29. Epilepsia (>1 convulsión no febril y no asociada a un proceso agudo del SNC) ☐

30. Convulsiones agudas sintomáticas ☐
31. Convulsión única ☐
32. Demencia ☐
33. Hidrocefalia ☐
34. Vasculitis ☐
35. EVC ☐
36. Hipertensión intracraneana ☐
37. Cefalea grave con duración mayor a 3 días ☐
38. Otra causa, especifique_____ ☐

Estudio de neurocisticercosis (NCC)
Formato para costeo de consulta externa

Identificación del encuestado ☐☐☐☐☐

Identificación del encuestador ☐☐

Hospital/Clínica: ☐ (INNN) ☐ (CMNSXXI) ☐ (INPed) ☐ (SSA Uruapan)

☐ (Otro) (Nombre:_____)

REGISTRO DE PACIENTE DE CONSULTA EXTERNA (del 2002 a la fecha de hoy) (Use una hoja separada para cada consulta externa)

Fecha de consulta externa ☐☐☐☐☐☐
(d d m m a a)

Hospital o clínica visitada ☐ (SSA) ☐ (IMSS) ☐ (ISSSTE) ☐ (Privado)

(Nombre:_____)

Número de la consulta externa (número secuencial de la consulta más vieja a la más nueva)
_____

Servicios consultados (marcar las necesarias)

1. Neurología ☐
2. Cardiología ☐
3. Oncología ☐
4. Infectología ☐
5. Psiquiatría ☐
6. Medicina general/Interna ☐
7. Otros, especifique_____ ☐

Causa de la visita de seguimiento de hoy (marcar todas las condiciones asociadas a NCC/convulsiones que se apliquen)

10. Epilepsia (>1 convulsión no febril y no asociada a un proceso agudo del SNC) ☐
11. Convulsiones agudas sintomáticas ☐
12. Convulsión única ☐
13. Demencia ☐
14. Hidrocefalia ☐

15. Vasculitis ☐

16. EVC ☐

17. Hipertensión intracraneana ☐

18. Cefalea grave con duración mayor a 3 días ☐

19. Otra causa, especifique_____ ☐

APPENDIX G

Date: _____

Name of Respondent: _____

Organization/Hospital of Respondent: _____

Cysticercosis in Mexico

Questions for Michoacan Ministry of Health (or other Ministry of Health in an endemic region)

For the questions below, please fill in the blank or circle your response.

1. In rural areas, what proportion of epilepsy patients do you believe consult a traditional healer before consulting a physician? _____% I DON'T KNOW

2. Do you believe that some epilepsy patients that seek treatment by a traditional healer never see a doctor? YES NO I DON'T KNOW

    a. If yes, what proportion of epilepsy patients do you think sees a traditional healer without ever consulting a modern doctor? _____% I DON'T KNOW

3. In rural areas, what proportion of severe chronic headaches patients do you believe consult a traditional healer before consulting a physician?_____% I DON'T KNOW

4. Do you believe that some patients with severe chronic headaches that seek treatment by a traditional healer never see a doctor? YES NO I DON'T KNOW

    a. If yes, what proportion of patients with severe chronic headaches do you think sees a traditional healer without ever consulting a modern doctor? _____% I DON'T KNOW

5. How much does a traditional healer typically charge to treat epilepsy? (The answer may include non-monetary payments such as a chickens, eggs, or services.)

   Monetary payment: _____

   Non-monetary payments: _____

   I DON'T KNOW

6. How much does a traditional healer typically charge to treat severe chronic headaches? (The answer may include non-monetary payments such as a chickens, eggs, or services)

   Monetary payment: _____

   Non-monetary payments: _____

   I DON'T KNOW

7. How many days of work (or school) do you think a person with untreated severe chronic headaches misses every month (you can provide a range of values)? _____
   I DON'T KNOW

8. How many days of work (or school) do you think a person with untreated epilepsy misses every month (you can provide a range of values)? _____ I DON'T KNOW

9. What proportion of epilepsy cases do you believe is currently not receiving any treatment for their seizures?
   Between 0 and 10% Between 11% and 20% Between 21% and 30%

   Other: _____ I DON'T KNOW

10. What proportion of severe chronic headaches cases do you believe is currently not receiving any treatment for their headaches?

Between 0 and 10% Between 11% and 20% Between 21% and 30%

Other: _____ I DON'T KNOW

Date: _____

Name of Respondent: _____

Organization/Hospital of Respondent: _____

Cysticercosis in Mexico

Questions for physicians at a primary care clinic (preferably from a rural area where NCC is endemic)

For the questions below, please fill in the blank or circle your response.

1. What proportion of your patients with epilepsy consulted a traditional healer before coming to you? _____% I DON'T KNOW

2. Do you believe that some epilepsy patients that seek treatment by a traditional healer never see a doctor? YES NO I DON'T KNOW

    a. If yes, what proportion of epilepsy patients do you think see traditional healers without ever consulting a modern doctor? _____% I DON'T KNOW

3. What proportion of your patients with severe chronic headaches consulted a traditional healer before coming to you?_____% I DON'T KNOW

4. Do you believe that some patients with severe chronic headaches that seek treatment by a traditional healer never see a doctor? YES NO I DON'T KNOW

    a. If yes, what proportion of patients with severe chronic headaches do you think see traditional healers without ever consulting a modern doctor? _____% I DON'T KNOW

5. How much does a traditional healer typically charge to treat epilepsy? (The answer may include non-monetary payments such as a chickens, eggs, or services.)

    Monetary payment: _____

Non-monetary payments: _____

I DON'T KNOW

6. How much does a traditional healer typically charge to treat severe chronic headaches? (The answer may include non-monetary payments such as a chickens, eggs, or services.)

   Monetary payment: _____

   Non-monetary payments: _____

   I DON'T KNOW

7. What proportion of epilepsy patients seeks medical attention at a primary care clinic? _____% I DON'T KNOW

8. What proportion of your patients with epilepsy is referred to a secondary care provider (for example, a neurologist)? _____% I DON'T KNOW

9. What proportion of your patients with epilepsy is referred directly to a tertiary care hospital? _____% I DON'T KNOW

10. What proportion of patients with epilepsy that seek treatment at your clinic is hospitalized at your clinic? _____% I DON'T KNOW THERE ARE NO HOSPITAL BEDS IN THIS CLINIC

11. What are the principal drugs provided to/used by patients with epilepsy who are seen at your clinic? If possible, please include dosages.

    Prescribed drugs:

    Drug: _____ Dosage: _____

    Drug: _____ Dosage: _____

    Drug: _____ Dosage: _____

    Over the counter drugs:

Drug: _____ Dosage: _____

Drug: _____ Dosage: _____

Drug: _____ Dosage: _____

12. How many times per year do you think patients with epilepsy consult medical doctors at a primary care clinic? _____ I DON'T KNOW

13. What proportion of patients with severe chronic headaches seeks medical attention at a primary care clinic? _____% I DON'T KNOW

14. What proportion of your patients with severe chronic headaches is referred to a secondary care provider (for example, a neurologist)? _____% I DON'T KNOW

15. What proportion of your patients with severe chronic headaches is referred directly to a tertiary care hospital? _____% I DON'T KNOW

16. What proportion of patients with severe chronic headaches that seek treatment at your clinic is hospitalized at your clinic? _____%
    I DON'T KNOW THERE ARE NO HOSPITAL BEDS IN THIS CLINIC

17. What are the principal drugs provided to/used by patients with severe chronic headaches who are seen at your clinic? If possible, please include dosages.

    Prescribed drugs:

    Drug: _____ Dosage: _____

    Drug: _____ Dosage: _____

    Drug: _____ Dosage: _____

    Over the counter drugs:

    Drug: _____ Dosage: _____

    Drug: _____ Dosage: _____

Drug: _____ Dosage: _____

18. How many times per year do you think patients with severe chronic headaches consult a medical doctor at a primary care clinic? _____ I DON'T KNOW

19. What tests are available at your clinic for the diagnosis of NCC? (Circle all that apply)

    None X-ray CT-scan MRI

    ELISA test to detect antibodies EITB test to detect antibodies

20. How many days of work (or school) do you think a person treated at your clinic for severe chronic headaches misses every month (you can provide a range of values)? _____ I DON'T KNOW

21. How many days of work (or school) do you think a person treated at your clinic for epilepsy misses every month (you can provide a range of values)? _____ I DON'T KNOW

22. What proportion of patients with epilepsy do you believe is currently not receiving any treatment for their seizures?

    Between 0 and 10% Between 11% and 20% Between 21% and 30%

    Other: _____ I DON'T KNOW

23. What proportion of patients with severe chronic headaches do you believe is currently not receiving any treatment for their headaches?

    Between 0 and 10% Between 11% and 20% Between 21% and 30%

    Other: _____ I DON'T KNOW

Date: _____

Name of Respondent: _____

Organization/Hospital of Respondent: _____

Cysticercosis in Mexico

Questions for physicians at a secondary care clinic (for example, neurologists)

For the questions below, please fill in the blank or circle your response.

1. What proportion of epilepsy patients seeks medical attention at your clinic without previously consulting with a primary care provider? _____% I DON'T KNOW

2. What proportion of your epilepsy patients is referred to you by a primary care physician? _____% I DON'T KNOW

3. What proportion of your epilepsy patients do you refer to a tertiary care hospital? _____% I DON'T KNOW

4. What proportion of your patients with epilepsy is hospitalized at your facility? _____% I DON'T KNOW THERE ARE NO HOSPITAL BEDS IN THIS CLINIC

5. What are the principal drugs provided to/used by your epilepsy patients? Please provide dosages if available.

   Prescribed drugs:
   Drug: _____ Dosage: _____
   Drug: _____ Dosage: _____
   Drug: _____ Dosage: _____

   Over the counter drugs:
   Drug: _____ Dosage: _____
   Drug: _____ Dosage: _____

Drug: _____ Dosage: _____

6. What are the principal drugs prescribed for your patients with NCC-associated epilepsy? Please provide dosages if available.

   Prescribed drugs:
   Drug: _____ Dosage: _____
   Drug: _____ Dosage: _____
   Drug: _____ Dosage: _____

7. How many times per year do you think patients with epilepsy consult a medical doctor at a secondary care clinic? _____ I DON'T KNOW

8. What proportion of patients with severe chronic headaches seeks medical attention at your clinic without previously consulting with a primary care provider? _____% I DON'T KNOW

9. What proportion of your patients with severe chronic headaches is referred to you by a primary care physician? _____% I DON'T KNOW

10. What proportion of your patients with severe chronic headaches do you refer to a tertiary care hospital? _____% I DON'T KNOW

11. What proportion of your patients with severe chronic headaches is hospitalized at your facility? _____% I DON'T KNOW THERE ARE NO HOSPITAL BEDS IN THIS CLINIC

12. What are the principal drugs provided to/used by your patients with severe chronic headaches? Please provide dosages if available.

    Prescribed drugs:
    Drug: _____ Dosage: _____
    Drug: _____ Dosage: _____

Drug: _____ Dosage: _____

Over the counter drugs:

Drug: _____ Dosage: _____

Drug: _____ Dosage: _____

Drug: _____ Dosage: _____

13. What are the principal drugs prescribed for your patients with NCC-associated severe chronic headaches? Please provide dosages if available.

Prescribed drugs:

Drug: _____ Dosage: _____

Drug: _____ Dosage: _____

Drug: _____ Dosage: _____

14. How many times per year do you think patients with severe chronic headaches consult a medical doctor at a secondary care clinic? _____ I DON'T KNOW

15. What tests are available at your clinic for the diagnosis of?

None X-ray CT-scan MRI

ELISA test to detect antibodies EITB test to detect antibodies

16. How many days of work (or school) do you think a person treated at your hospital for severe chronic headaches misses every month (you can provide a range of values)?

_____ I DON'T KNOW

17. How many days of work (or school) do you think a person treated at your hospital for epilepsy misses every month (you can provide a range of values)? _____

I DON'T KNOW

18. What proportion of patients with epilepsy do you believe is currently not receiving any treatment for their seizures?

Between 0 and 10% Between 11% and 20% Between 21% and 30%

Other: _____ I DON'T KNOW

19. What proportion of patients with severe chronic headaches do you believe is currently not receiving any treatment for their headaches?

Between 0 and 10% Between 11% and 20% Between 21% and 30%

Other: _____ I DON'T KNOW