ESTIMATING THE BURDEN OF NEUROCYSTICERCOSIS IN MEXICO

A Thesis

by

RACHANA BHATTARAI

Submitted to the Office of Graduate Studies of
Texas A&M University
in partial fulfillment of the requirements for the degree of

MASTER OF SCIENCE

August 2010

Major Subject: Epidemiology

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Approved by:

Chair of Committee,	Christine Budke
Committee Members,	Hélène Carabin
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ABSTRACT

Estimating the Burden of Neurocysticercosis in Mexico. (August 2010)

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Chair of Advisory Committee: Dr. Christine Budke

Neurocysticercosis (NCC) is a parasitic disease caused by the larva of the zoonotic cestode *Taenia solium*. The objectives of this study were to evaluate the distribution of presenting clinical manifestations of NCC, to evaluate the socio-demographic characteristics of NCC patients, to compare quality of life of individuals diagnosed with NCC with an age and sex matched control population and to estimate the non-monetary burden of NCC in Mexico. In order to accomplish these objectives, a case series of NCC patients was conducted in two neurology referral hospitals in Mexico City, Mexico during 2007-2008. Information on clinical manifestations associated with NCC was obtained via medical chart reviews of NCC patients. Information on socio-demographic characteristics of NCC patients was obtained through the administration of questionnaires. In addition, a cross-sectional study was conducted to compare the quality of life of NCC patients to an age and sex matched control population using the short form 12 v2 (SF-12 v2) survey. Non-monetary burden of NCC in Mexico was estimated using disability adjusted life years (DALYs), incorporating morbidity due to both NCC-associated epilepsy and severe headache and mortality due to NCC-associated epilepsy.

NCC patients presented to the neurology referral hospitals with numerous clinical manifestations, with severe headache and epilepsy being the most common. Lack of knowledge of *T. solium* transmission was common among NCC patients, with 25% of patients not knowledgeable about tapeworm infections in humans. Of those that were aware that tapeworm infections do occur, 57% were not aware of how the worms were transmitted to humans. The SF-12 v2 general health survey showed that individuals with NCC had a significantly lower score for all eight domains of health evaluated (physical functioning, role physical, bodily pain, vitality, general health, social functioning, role emotional and mental health) compared with the age and sex matched population from the same region ($p< 0.05$). The mean total number of DALYs lost due to NCC in Mexico was estimated to be 99,866 (95% CR: 43,187 –189,182), with a mean of 0.95 (95% CR: 0.4–1.8) DALYs lost per thousand persons per year.

DEDICATION

I would like to dedicate this work to my parents; the late Mr. Chandra Raj Dhungel and Mrs. Geeta Dhungel, who have always been very supportive of my educational and personal development. All of the goals I accomplished were backed up by their support and motivation.

I would also like to dedicate this thesis to my son Robbie who missed much of my care during his first two years and to my husband Bikash who always supports me during stressful situations.

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R. Bhattarai

NOMENCLATURE

CI	Confidence Interval
CR	Credibility 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
MCS	Mental Component Summary
MRI	Magnetic Resonance Imaging
NCC	Neurocysticercosis
PCS	Physical Component Summary
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

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1. INTRODUCTION

Neurocysticercosis (NCC) is a major public health problem caused by the larva of the zoonotic cestode *Taenia solium*. Humans are the definite hosts of *T. solium*. The parasite needs two hosts to complete its life cycle. Pigs act as intermediate hosts and harbor cysticerci in different parts of the body, but mostly in the skeletal and cardiac muscles and the brain (cysticercosis). Humans become infected with the tapeworm form (taeniasis) by ingesting undercooked pork containing *T. solium* cysticerci. Eggs and/or mature proglottids of the tapeworm are regularly excreted by human tapeworm carriers. The tapeworm can shed up to 300,000 eggs daily [1]. Humans can also act as intermediate hosts after ingesting the eggs of *T. solium* leading to cysticercosis and/or NCC [2].

Neurocysticercosis occurs when immature *T. solium* larvae migrate to the central nervous system. When NCC manifests, it is most often in the form of acute seizures, epilepsy, severe progressively worsening headaches, or focal deficits. Less often it will present as cranial hypertension, hydrocephalus, stroke or dementia [3,4]. The condition is common in many developing countries, where sanitation and meat inspection infrastructure are lacking [5]. This disease is predominantly found and considered endemic in Latin American, Asian and African countries [6]. However, it is now being seen in other regions due to an increasing flow of immigrants from endemic areas who may have taeniasis [7,8]. Two previous studies conducted in Africa evaluated the

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socio-economic burden of cysticercosis and found it to be a serious public health problem causing morbidity as well as financial loss [9,10]. NCC is believed to be one of the main causes of late onset epilepsy in developing countries [11,12] and a recent meta-analysis of published studies estimated that 29.6% (95%CI: 23.5%-36.1%) of epilepsy cases in NCC endemic countries are associated with NCC lesions as identified by neuroimaging [13]. NCC may also act as a risk factor for stroke [14] and migraine-type headaches [15].

The Global Burden of Disease (GBD) Study was conducted to evaluate the non-monetary burden of a variety of infectious and non-infectious conditions on pre-defined regions of the world [16,17]. The approach combined estimates of mortality and morbidity for a population into a single measure of disease burden called the disability adjusted life year (DALY). The DALY is a summary measure of population health that assesses the disability and early age mortality associated with the condition of interest. DALYs measure the gap in years between age at death and some standard age before which death is considered premature, in addition to time lived in states other than excellent health; they are obtained by summing years of life lost (YLL) from premature death and healthy years lost due to disability (YLD). The DALY is a negative concept and one DALY is considered the equivalent of one year of healthy life lost. DALYs have been used to measure disease burden in both developed and developing countries [9,18]. Evaluation of the number of DALYs lost is then used to set health service and health research priorities, identify disadvantaged groups and target health interventions [16].

Although NCC is endemic in many areas of the world and believed to be associated with considerable economic losses, very few studies have been conducted to evaluate the burden of NCC and there are no estimates from Mexico. One study in Cameroon revealed that the number of DALYs lost due to NCC was higher than a number of other neglected tropical diseases in sub-Saharan Africa such as trypanosomiasis and schistosomiasis [9]. However, this estimate only evaluated disease burden due to NCC-associated epilepsy, therefore underestimating the true impact of the disease. In addition, this study used serology for the diagnosis of NCC, which has been shown to have a poor performance in detecting cases. Another study conducted in South Africa revealed high financial losses associated with cysticercosis [10]. This study also considered epilepsy as the only clinical manifestation of NCC and thus underestimated the impact of financial loss associated with the disease. The true health burden of NCC in endemic areas likely differs substantially from country to country. Therefore, more comprehensive studies are needed to estimate the actual burden of NCC in endemic areas and specific countries, such as Mexico, in order to allocate resources for health interventions. This study provides the first estimate of the non-monetary burden of NCC in Mexico using the DALY.

2. BACKGROUND AND SIGNIFICANCE

NCC and taeniasis have long been recognized. From 1100 - 1800 AD, the adult and larval stages of *T. solium* were not considered the same species. In the late 19th century, cysticercus, formerly known as *Cysticercus cellulosae*, was demonstrated to be the larval form of *T. solium*. Later, in 1973, after the development of improved neuroimaging techniques and other immunological diagnostic methods, the epidemiology of *T. solium* was better established [2].

NCC is still common in developing countries and is considered an emerging disease in many developed countries due to increased immigration from endemic areas [7,8]. In a study conducted in the United States in 2003, 84.6% of 221 NCC patients were foreign born and 62.0% had emigrated from Mexico [7]. The *T. solium* life cycle can rarely be completed in developed countries due to good environmental sanitation and highly regulated inspection of pig carcasses [19].

2.1. Life cycle, pathogenesis and transmission of *Taenia solium*

T. solium belongs to the phylum Platyhelminthes, class Cestoides, family Taeniidae. The adult *T. solium* has a scolex that consists of four suckers and a rostellum with a double crown of hooks, an unsegmented narrow neck and a large body formed by many proglottids. The entire body is called the strobila. The adult worm is found in the small intestines of humans where it attaches to the intestinal wall by its suckers and hooks and may measure up to 10 – 30 feet in length. Infected humans excrete thousands

of eggs and gravid proglottids, which are very resistant to adverse environmental conditions. It is believed that eggs can remain viable for up to two months in water, soil and vegetation in a humid and warm environment. The condition caused by adult *T. solium* infection is known as taeniasis [2].

Pigs, the intermediate hosts, become infected when they ingest eggs of *T. solium* 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 [2]. Pigs acquire cysticercosis mainly in endemic areas where they have access to human feces [20]. In some countries, human feces are fed directly to pigs believing that pigs fed human feces produce better quality pork [20,21].

Humans can become infected with *T. solium* in two ways (Figure 1). First, a person may act as a definitive host when ingesting raw or undercooked pork infected with viable cysticerci. The scolex of the larva emerges from the cyst and attaches to the wall of the small intestine. Within three months, an adult tapeworm develops and starts to produce proglottids. Humans can also act as intermediate hosts if they ingest the eggs of *T. solium* via contaminated food. 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. After reaching these sites, oncospheres evolve to the vesicular stage and are called cysticerci [4] (Figure 1).

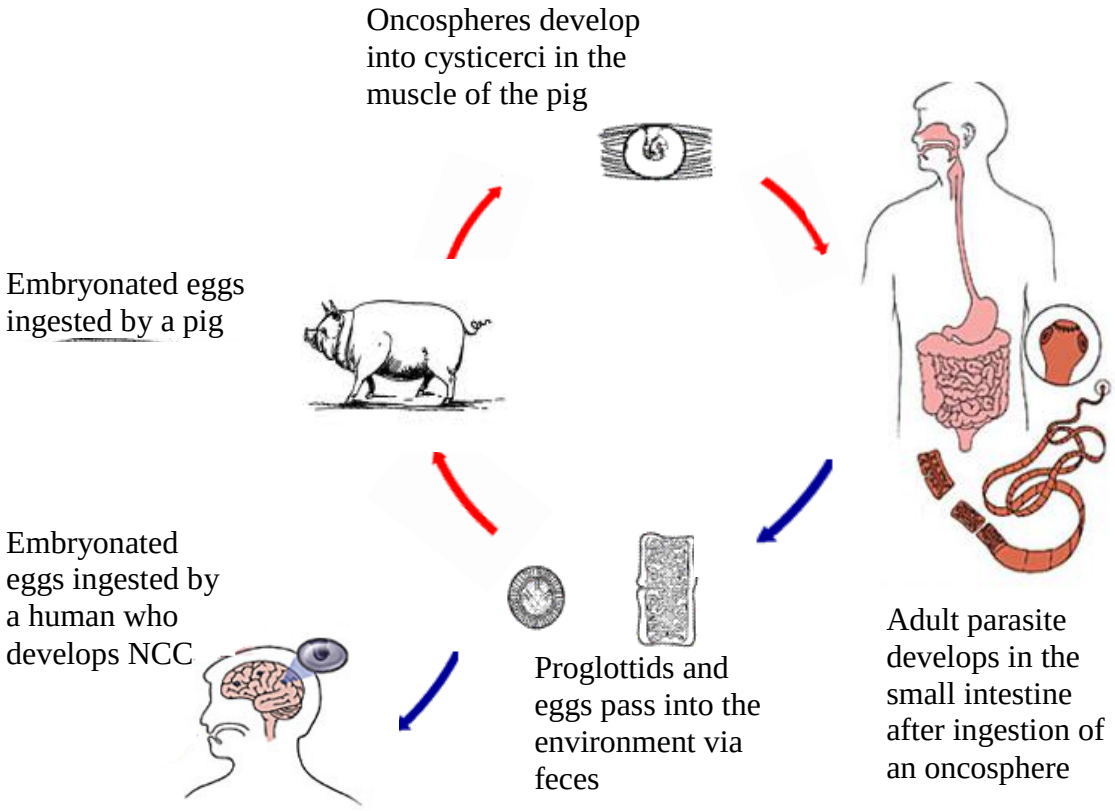


Figure 1: Life cycle of *Taenia solium*.

2.2 Pathological changes of the central nervous system due to NCC

Neurocysticercosis is the condition that occurs when cysticerci reach the brain parenchyma, the subarachnoid space, the ventricular system or the spinal cord and produces clinical manifestations. Cysticerci within the brain parenchyma usually measure around 1 cm and tend to lodge in the cerebral cortex or basal ganglia [4]. After the parasite enters the CNS, it changes into a viable stage (i.e., vesicular stage) where it stimulates the host's immunological response. Inflammatory reaction around cysticerci

appears due to the host's immunological response and is composed of lymphocytes, plasma cells and eosinophils. This reaction is usually associated with some degree of edema and gliosis, which varies according to the stage of the parasite [4,6]. The severity of the tissue changes depends on the stage of the parasites' development and their location within the central nervous system [2].

Meningeal cysticerci may cause an intense inflammatory reaction within the subarachnoid space, forming a dense exudate which is composed of collagen fibers, lymphocytes, giant cells, eosinophils and hyalinized parasitic membranes. This causes thickening of the leptomeninges at the base of the skull from the optochiasmatic region to the foramen region [2]. The exudate usually entraps the optic chiasm, as well as cranial nerves arising from the brain stem, producing visual defects and other nerve dysfunction. The thickened leptomeninges may occlude the foramen of Luschka and Magendie leading to hydrocephalus. Blood vessels may be affected by inflammatory reaction and the inflammatory cells may invade walls of small penetrating arteries leading to a proliferative endarteritis with occlusion of the lumen which may result in cerebral infarction [22,23].

Ventricular cysticerci also induce a local inflammatory reaction if they are attached to the choroid plexus or the ventricular wall. Ependymal cells may proliferate and block cerebrospinal fluid transit at the cerebral aqueduct or Monro's foramina causing obstructive hydrocephalus [24,25] resulting in increased morbidity and mortality compared to parenchymal cysticerci [26].

2.3 Clinical manifestations

Clinical signs depend on the number and location of cysts as well as the host's immune response to the cysts. Epilepsy, hydrocephalus, severe headaches, and increased intracranial pressure are among the most commonly reported clinical manifestations [3,4].

Epilepsy

NCC has been reported as a major cause of late onset epilepsy in *T. solium* endemic areas of the world [11,27]. Epilepsy may occur when a cyst is in an active form, (i.e., viable or degenerating) [11,28] or in a calcified form [29]. Seizures, due to NCC, are most commonly generalized tonic, clonic or simple partial. Few cases present with complex partial or myoclonic seizures [30,31]. Severity of seizures has not been correlated with intensity of infection [26] and single calcifications were often found in patients with seizures in a study conducted in India [28]. Parenchymal cysts appear to be common in patients with epilepsy [32].

Increased intracranial pressure/hydrocephalus

Increased intracranial pressure is another symptom of NCC due to obstructive hydrocephalus. Ventricular or cisternal cysts, and chronic cysticercus meningitis are common causes of hydrocephalus and increased intracranial hypertension [33]. Mobile deformable cysticercal cysts in the posterior portion of the third ventricle can cause intermittent intracranial hypertension due to a ball valve mechanism known as Bruns

Syndrome [25]. Massive cysticerci infections of the brain parenchyma can also increase intracranial pressure. However, the pathology is induced by an intense inflammatory immune response rather than by the physical presence of the cysts. A study conducted in Mexico in 1987 reported that cysticerci of the brain parenchyma were more common in young females and were characterized by sub-acute encephalitis associated with headaches, seizures, vomiting, diminution of visual acuity and papilledema [34].

Cerebrovascular complications

Cerebrovascular complications include transient ischemic attacks, lacunar infarcts, large cerebral infarcts and brain hemorrhage [29,35,36]. Occlusion of the small cortical or penetrating vessels at the base of the brain caused by arteriopathy has been reported as the most common mechanism of stroke among 31 NCC cases presenting with stroke in Mexico in 1985 [37]. Lacunar infarcts are frequently located in the area of the lenticulostriate branches of the anterior or middle cerebral artery and produce occlusive endarteritis within the subarachnoid space that is triggered by meningeal cysticerci [38]. This condition produces typical lacunar syndromes such as pure motor hemiparesis and ataxic hemiparesis, which is difficult to distinguish from those syndromes caused by atherosclerosis [39]. The most common vessels reported to be involved in cerebral infarcts among 28 NCC patients in Mexico in 1997 were the middle cerebral artery and the posterior cerebral artery [36]. Different types of intracranial hemorrhage, such as intracystic hemorrhage and subarachnoid hemorrhage, have also been documented with NCC [40].

Psychiatric disorders

Patients with NCC may present with psychiatric disorders. In a study conducted in Brazil between January 1993 and April 1994, depression syndromes were the most common clinical manifestations in 38 NCC patients presenting to a neurology referral hospital [41]. However, the primary study looking at these manifestations did not have a control group and did not take into account confounding variables such as illiteracy, high prevalence of seizures and use of anticonvulsant medications. Therefore, results might be biased. Other reported manifestations include poor performance on neuropsychological testing, dementia, psychotic episodes characterized by confusion, paranoid ideation, psychomotor agitation, and/or violent behavior [42]. Although dementia is a less common clinical manifestation of NCC, it can occur in patients with untreated NCC. NCC-related dementia was shown to be associated with older age, lower education level and increased number of parasitic lesions in the brain in a study conducted in 14 NCC patients in Mexico during 2005 [43]. However, the same test was used to evaluate dementia in educated and less educated NCC patients. Therefore, it might have overestimated the relationship between dementia and less educated people. NCC-associated dementia has been reported to be reversible by regular treatment of NCC with anticysticercal drugs, with patients experiencing noticeable recovery of cognitive functioning [43]. However, this conclusion must be interpreted with care since there was no placebo control group with which to compare the results.

Severe headache

Severe headache is also a common manifestation presented by NCC patients in neurological hospitals. Both abrupt and chronic obstruction of cerebral spinal fluid (CSF) can result in headache. Abrupt intermittent obstruction of the interventricular CSF flow by the cyst produces symptoms which can last several hours to days. Obstruction may occur in the foramen of Monro, the third ventricle, the aqueduct of Sylvius or the fourth ventricle [44].

2.4 Diagnostic techniques

Before the wide scale use of modern neuroimaging methods, radiological procedures such as plain roentgenograms, pneumoencephalograms, cerebral angiography and myelography were considered helpful diagnostic tools for NCC. Computed tomography (CT) and magnetic resonance imaging (MRI) are two neuroimaging techniques that have improved the accuracy of diagnosis in recent years [45]. Both of these techniques provide evidence concerning the number and topography of lesions, their stage of involution and the degree of host inflammatory response against cysticerci [46]. Cystic lesions showing the scolex in the nodule and multiple punctuated calcifications are pathognomonic of NCC. However, single or multiple enhancing lesions are not specific to NCC and may represent, for example, pyogenic brain abscesses, fungal abscesses, tuberculosis, *Toxoplasma* abscesses and primary or metastatic brain tumors [2].

Diagnostic criteria used for NCC is divided into absolute, major, minor and epidemiologic [47]. Parasite histologic examination from biopsy of a brain or spinal cord lesion, CT scan or MRI showing a scolex in a cystic lesions and direct visualization of sub-retinal parasites by funduscopic examination are considered pathognomonic and, therefore, absolute criteria for diagnosis of NCC. Major criteria are CT scan or MRI showing highly suggestive NCC lesions, the detection of anticysticercal antibodies by positive serum enzyme-linked immunoelectrotransfer blot assay (EITB), resolution of intracranial cystic lesions after therapy with albendazole or praziquantel and spontaneous resolution of small single enhancing lesions. Minor criteria are neuroimaging studies showing lesions compatible with NCC, clinical manifestations suggestive of NCC, positive CSF enzyme linked immunosorbent assay (ELISA) for detection of anticysticercal antibodies or cysticercal antigens and cysticercosis outside the CNS. Lastly, epidemiologic criteria are evidence of a household contact with *T. solium* infection, individuals coming from or living in an area where cysticercosis is endemic and history of frequent travel to disease-endemic areas.

According to Del Brutto et al. (2001), presence of one absolute criteria or presence of two major plus one minor and one epidemiologic criteria are definitive diagnostic criteria while presence of one major plus two minor criteria, presence of one major plus one minor and one epidemiologic criteria and presence of three minor plus one epidemiologic criterion are probable diagnostic criteria for NCC [47].

Immunological tests

Different immunological tests are available for the detection of anticysticercal antibodies and antigens in serum, saliva and CSF and are valuable for patients with suspected NCC, but should not be used alone as confirmatory tests. The antibody detection tests include the complement fixation test, hemagglutination, radioimmunoassay, enzyme linked immunosorbent assay (ELISA), dipstick-ELISA, latex agglutination and immunoblot techniques. Many of these tests (e.g., the complement fixation test, the ELISA and the immunoblot test) are highly sensitive for subarachnoid NCC [48]. However, sensitivity decreases when the lesions are inactive and are not in contact with the subarachnoid space. This is because large numbers of immunoglobulins are synthesized due to the contact of lesions with the subarachnoid space. Cross-reaction is known to occur with other helminth parasites for the ELISA [49]. Tsang et al., (1989) reported that the EITB has a 100% specificity and 70%-90% sensitivity in cysticercosis patients [50]. However, sensitivity of this test is low in patients with single cysts in the brain [51]. On the other hand, antibody detection has two major drawbacks. First, the test may be positive when a person has exposure to the parasite without the presence of viable infection and second, the antibodies may persist long after the parasite has been eliminated by immune mechanisms. Another type of immunological test is the antigen detection test. The sensitivity of antigen-detecting ELISA has been reported to be 85% for detecting NCC patients [52]. However, this study was only conducted on individuals who were seropositive on EITB.

Neuroimaging techniques

In subarachnoid NCC, CT and MRI findings may include hydrocephalus, abnormal enhancement of the leptomeninges, subarachnoid cystic lesions and cerebral infarcts [23]. Most of these findings are non-specific and may be observed in tuberculous meningitis, sarcomatous meningitis or fungal meningitis.

In NCC with ventricular cysticerci, CT and MRI findings show a distorted anatomy of the ventricular system, with cysts located in the ventricles. Due to the same radiodensity of lesions and CSF, these lesions cannot be seen clearly on a CT scan [53]. MRI is more sensitive and is superior to CT scans in finding multiple cystic lesions, protoscoleces and differential ring enhancements [46]. However, one important shortcoming of MRI is its failure to detect parenchymal calcification [54].

2.5 NCC in Mexico

Mexico is the third largest country in Latin America, with a 2008 population of almost 109 million and an annual population growth rate of 1.1%. The official literacy rate is 89.6%. CIA World Fact book reports that health care personnel and facilities are generally concentrated in urban areas and infections, including parasitic diseases, still are responsible for numerous deaths [55].

NCC is present in Mexico, with literature-reported prevalences of 4.9% - 10.8% in endemic areas [20,56,57,58]. However, not all of the diagnostic criteria used in these studies are uniform and reliable. In Xoxocotla, Morelos state of south-central Mexico, the reported seroprevalence was 10.8% in 1988 [20] . However, this study was

conducted twenty years ago and might not represent the present situation in this region of Mexico. In addition, a person can be seropositive if he or she has a cyst in another part of the body. In Tepetzezintla, Puebla state in central Mexico, a prevalence of 9.1% was confirmed by CT in 2003 [56]. All of the cases from Tepetzezintla had silent calcified lesions. In the 1970s, at the Instituto Nacional de Neurologia y Neurocirugia in Mexico City, a substantial number of patients admitted were diagnosed with NCC, with NCC representing the third most common reason for admission [2]. In addition, NCC was found in 1.3-3.1% of autopsies performed in four large hospitals in Mexico City for the years 1942-1974 [2].

Two studies have shown that NCC cases tend to be numerous in those areas where *T. solium* carriers are present [20,59]. In 1988, the prevalence of tapeworm carriers was 1.3% and 5.8% in La Curva, Sinaloa state of Mexico and in Xoxocotla, Morelos state of Mexico, respectively [20,59]. However, this prevalence may include cases of *T. saginata* since the eggs of these tapeworms are only differentiable by PCR.

In a study conducted in 2007, *Taenia* eggs were found in 24.2% of sampled areas (backyard, washboard, bucket, coral and kitchen) in the State of Puebla, Mexico, with the highest prevalence found in the spring [60]. Significantly higher numbers of *Taenia* eggs were found in kitchen samples compared to other places that were sampled. This indicates a high risk of infection with *Taenia* species within the household [60]. This study did not, however, identify the species of *Taenia* involved. Most animal species can carry *Taenia*, making the interpretation of those data in regard to *T. solium* difficult.

2.6 Quality of life associated with NCC infection

Quality of life assessment is used to measure changes in physical, mental and social health due to conditions and interventions that are influenced by a person's experiences and perceptions. It can also be used to plan and evaluate the services needed for people with disabilities [61]. Among numerous quality of life surveys, the short form 12 v2 health survey (SF-12 v2) (Quality Metric Inc., Lincoln, RI) is a short and easy to use tool to assess the quality of life of an individual. Ware et al. (2002) examined the validity and reliability of the SF 12v2 survey at the time of its development. They compared the results of the SF-12 v2 to that of the 1998 National Survey of Functional Health Status and 2000 Medical Outcomes Study [62]. Later, another study conducted by Cheak-Zamora et al. (2009) also evaluated the validity and reliability of the survey in the 2003-2004 Medical Expenditure Panel Survey [63]. Both studies found that the validity and reliability of the survey was high.

The SF-12 v2 survey is considered a generic health survey because it can be used across age, disease and treatment groups. The survey is specifically designed for adults 18 years of age and older and is available in multiple languages. The SF-12 v2 uses twelve questions to measure eight domains of functional health and well being. The eight domains of health assessed are physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional and mental health. A brief description of each domain is found in Table 1.

Table 1: Descriptions of the health domains used in the SF-12 v2 quality of life survey [64].

Domain	Description
Physical functioning	Degree to which health limits everyday physical activities
Role physical	Degree to which physical problems interfere with usual daily activities such as work or school
Bodily pain	Degree of bodily pain
General health	Ratings of current health in general
Vitality	Ratings of energy level
Social functioning	Degree to which health interferes with social activities
Role emotional	Degree to which emotional problems interfere with usual daily activities such as school or work
Mental health	Degree to which health limits emotional well being, including depression, anxiety and positive well being

The eight domains can be aggregated into two summary measures: the Physical Component Summary (PCS) and the Mental Component Summary (MCS). PCS weights more heavily physical functioning, role physical and bodily pain and MCS gives greater weight to mental health, social functioning and role emotional. General health and Vitality load fairly evenly on both component summaries [65].

The SF-12 v2 is a useful tool to compare the health scores of patients with an age and sex matched population from the same region[62]. Numerous studies have used the SF-12 v2 survey to compare different populations for conditions such as echinococcosis and migraine [66,67]. However, no previous studies have used this health survey to compare NCC patients with a comparison group.

2.7 Global Burden of Disease (GBD) Study

Prior to the 1990s, available information on mortality and health related problems in populations were largely incomplete and inconsistent. Thus, a framework for integrating, validating, analyzing and disseminating such information was needed to assess the comparative importance of diseases and injuries causing premature death, loss of health and disability in different populations. Therefore, the Global Burden of Disease (GBD) Study was initiated by the World Health Organization (WHO) and World Bank in 1993 to generate comprehensive and internally consistent estimates of mortality and morbidity by age, sex and region. The goal of this study was to measure the total loss of health resulting from diseases and injuries worldwide in a comparable way [68]. The GBD Study was the first large scale initiative to emphasize non-fatal health outcomes, which had not previously received much attention from health policy makers. This information could then be used to set health service and health research priorities, identify disadvantaged groups and target heath interventions [17]. The first GBD Study (GBD 1990) assessed the burden of 107 diseases and injuries and ten selected risk factors for the world. This and subsequent GBD studies used a common metric, the disability adjusted life year (DALY), for burden of disease assessment.

Disability adjusted life years (DALYs)

A new metric, the disability adjusted life year (DALY), was introduced by the GBD Study to assess the burden of disease consistently across diseases, risk factors and regions. DALYs are used to help quantify the burden of disease and the effectiveness of

health interventions. The DALY is a time based measure, which combines years of life lost due to premature mortality (YLL) and years of life lost due to time lived in a disability state (YLD). This metric calculates the years of life lost due to premature mortality by comparing study population life spans to the average life expectancy of the population of Japan, which has one of the longest known life expectancies. Therefore, it is a measurement of the gap between current health status and the ideal situation where everyone is free of disease and disability [68]. The formulas used for the calculation of YLL and YLD are described below:

$$YLL = N * L \quad \text{Eq. 1}$$

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

$$YLD = I * DW * D \quad \text{Eq. 2}$$

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

Discounting

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 [69]. The subject of discounting is complex and several papers have been published in favor and against its use in the context of DALYs [69,70] and health outcomes. Figure 2 illustrates the effect of time on

discounting using the discrete discounting function $(1/(1+r))^t$ where t denotes time in years and the discounting rates (r) values are 3%, 6% and 10%.

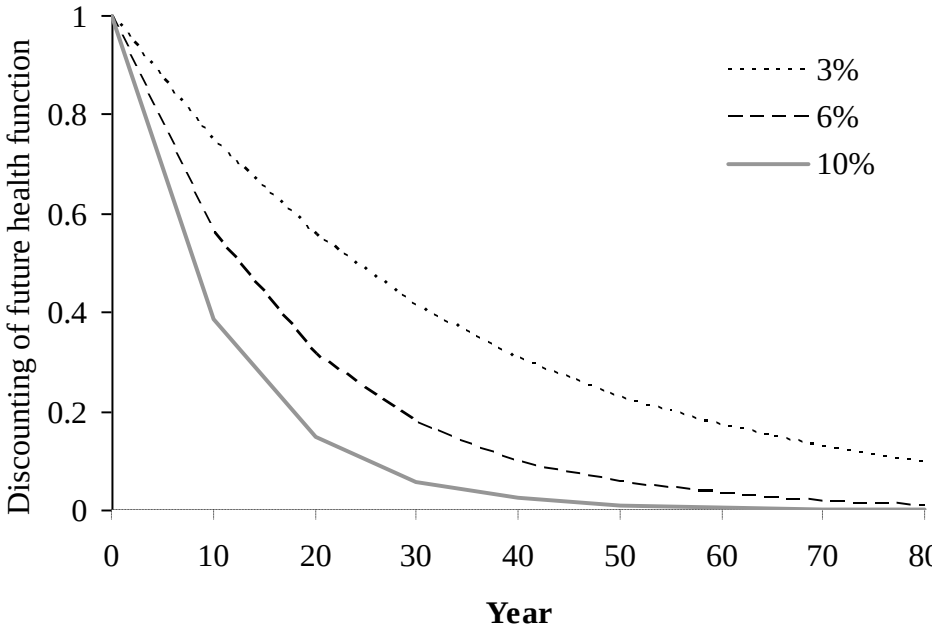


Figure 2: Effect of time, in years, on the discrete discounting function.

Figure 2 shows that a 3% discount rate implies a year of healthy life gained in ten years is worth 26% less than one gained now and a 10% discount rate implies a year of healthy life gained in 10 year's time is worth 61% less than one gained now. If we use a 0% discount rate, the future is valued exactly as the present.

Age weighting

The GBD Study incorporated social preferences for the value of life lived during adulthood over life lived during childhood or later years. For DALYs used for the GBD Study, the value of life peaks at age 24.5 years when an age weighting value of 0.04 is used. Age weighting is based on the belief that there is a social preference to greater value the lives of young adults versus individuals in other age categories. This may be due to the belief that young adults have reached maturity, have been trained and are ready to contribute economically and productively to society for a greater amount of time. The GBD Study [16] assumed an arbitrary continuous age weighting function F(C, age, β) for the weights at each age in the form:

$$F(C,age,\beta) = C*age*e^{-\beta*age} \quad \text{.....Eq. 3}$$

where β determines the importance of age weights and C is an adjustment constant. Only a narrow range of β provides reasonable age patterns (0.03 to 0.05). In the GBD Study, β was set to 0.04 and C set to 0.1658. The constant C was chosen because introducing unequal age weights does not change the global estimated burden of disease from the total and thus produces the same values as that of uniform age weights. Therefore, this constant should be changed if the age weighting function were to be changed. Figure 3 illustrates the effect of age on weighting without the influence of C. The new Global Burden of Diseases Study, (the GBD 2010 Study) will not include age weighting in the DALY calculations. Therefore, the influence of age weighting will be eliminated.

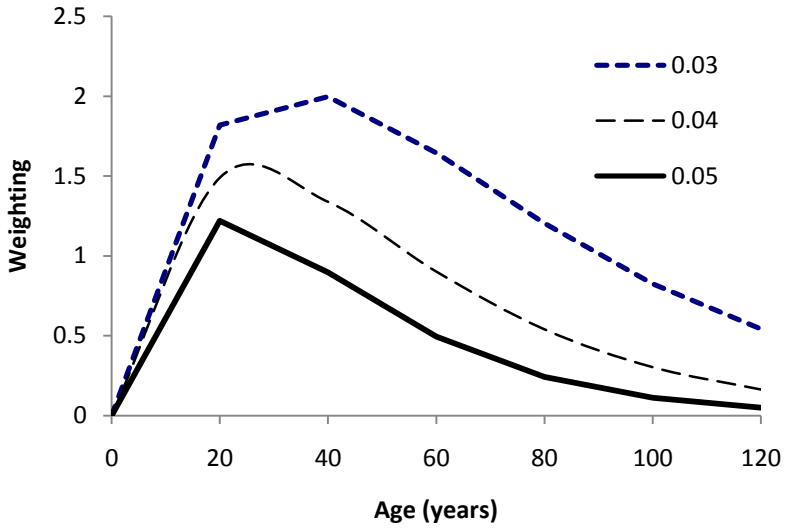


Figure 3: Shape of age weighting function for β in the set (0.03, 0.04, 0.05).

Disability weights

The DALY metric measures disability through reduction in human functioning. Disability weights are allocated according to the opinion of experts on the ability to perform certain activities such as learning, working, feeding oneself, etc of people affected by a disease. Disability is placed on a uni-dimensional scale between 0 (perfect health) and 1 (death). Disability classes were defined between 0 and 1, with each subsequent class representing more severe disease. Disability weights of clinical manifestations were determined for the GBD Study by the person trade-off (PTO) method [69]. The PTO method is a way of estimating social preferences for different health states by asking people how many outcomes of one kind they believe are equal in social value to a certain number of outcomes of another kind. The GBD 2010 Study will

not use the PTO method for determining disability weight of clinical manifestations. Three major data collection activities proposed for determining disability weight are community assessment of selected sequelae using discrete choice methods, assessment by health professionals of all sequelae using ranking and visual analog scale methods and multimethod studies among highly educated respondents [71].

Pros and cons of DALYs

The use of DALYs remains a controversial issue. According to Anand (1997), DALYs understate the burden of disease of females relative to males if the gender gap of life expectancy is high as it uses the standard expectation of life at birth for a developed country which has a very small gender gap [70]. DALYs also measure the burden of disease without considering cultural or socioeconomic differentiation of tested populations so that it underestimates the disease burden in developing countries [72]. The GBD 2010 Study will try to take into account some of the disparity between regions. Even with these controversies, the DALY remains a widely used summary measure of population health.

DALYs have been used to measure disease burden in both developed and developing countries [9,18]. However, only one study has been conducted to evaluate the burden of NCC. In that study conducted in Cameroon, a high non-monetary and monetary burden due to cysticercosis was found, with an estimated 9.0 (95% CR 2.8 to 20.4) DALYs lost per thousand person years and 194€ (95% CR 147 to 253) lost per case of NCC [9]. However, the total number of DALYs lost and total estimated cost

were most likely underestimated in the study, because the estimations were based on epilepsy as the only symptom of cysticercosis. On the other hand, it could have also been an overestimation since the authors used serology alone to diagnose NCC, which can lead to large numbers of false positives. This study also used prevalence data to estimate incidence which may or may not be appropriate and used disability weights from the GBD Study for epilepsy which also may not be appropriate for NCC.

3. MATERIALS AND METHODS

3.1. Study population and design

Source population

The source population included adults (>18 years old) in Mexico who have access to a formal health care system irrespective of social security coverage.

Study population

This study was conducted in the two major 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 (IMSS). The INNN is a referral institute that accepts patients who do not have medical coverage through their employment. The IMSS is the largest social security institution in Mexico and provides medical services to patients with social security coverage.

Study design

This study is a case series of NCC patients representative of those seen in two neurology reference hospitals in Mexico City, Mexico. Consecutive NCC outpatients presenting with epilepsy, symptomatic recurrent acute crises, hydrocephalus, dementia, vasculitis, EVC and / or severe headache for more than 3 days were invited to participate in the study. Those patients consenting to participate represented the case series of NCC

patients. General and pig ownership questionnaires were administered to NCC outpatients in order to evaluate socio-demographic characteristics and knowledge about *T. solium* transmission. In addition, a cross-sectional study was conducted to compare SF-12 v2 health scores of the NCC outpatients included in the case series to an age–sex-hospital-date matched comparison group of people accompanying neurological patients without NCC.

Definition and selection of NCC cases

NCC patients were identified by the hospital staff from their databases. The diagnosis of NCC was that of the physicians who had taken care of the patient. All patients had at least one CT-scan of the brain and/or and MRI. An attempt was made to ask all NCC outpatients presenting with the symptoms mentioned above and who came to the INNN from July 17, 2007 to December 7, 2007 and to the IMSS from June 2, 2008 to August 12, 2008 for their consent to participate in the study. All patients who provided written consent 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.

Definition and selection of non-NCC group (Controls)

An individual (e.g., a caregiver or close relative) who accompanied an outpatient to either the INNN or the IMSS who had not been diagnosed with NCC was considered as a possible control. To avoid confounding, controls were selected from individuals who accompanied non-related patients and paired with an NCC patient seen at the clinic

on the same day by sex, age (± 5 years) and hospital. This 1-to-1 matched control group was selected and interviewed in the hospital's waiting area by a member of the research team after obtaining written consent.

3.2 Description of manifestations associated with NCC cases

Intake forms were completed via medical chart reviews of all consenting NCC outpatients from the INNN and IMSS. Intake forms were also completed via chart reviews for consenting NCC patients who had been hospitalized at the INNN during 2006 and 2007, but who did not have an outpatient appointment during the study dates (July 17, 2007 to December 7, 2007). The intake forms [Appendix A (English version) and D (Spanish version)] were used to obtain information on the medical problem(s) associated with NCC that caused the patient to be referred to the tertiary care hospital. Chart reviews took place between July 17, 2007 and December 7, 2007 at the INNN and between June 2, 2008 and August 12, 2008 at the IMSS, with data abstracted from January, 2002 to the date of abstraction by trained members of the research team (e.g., a Mexican medical student, intern, or resident). The forms were prepared in English, translated into Spanish and back translated into English by two independent persons. All forms were piloted prior to use**.** In addition to the information on medical problems, age distribution and geographical distribution of patient residences were also evaluated using information obtained through chart reviews.

3.3 Description of socio-demographic characteristics of NCC cases

Two questionnaires [Appendix B and C (English version) and E and F (Spanish version)] were completed via patient interviews. A general questionnaire was completed by all consenting NCC outpatients and an additional pig questionnaire was completed by those individuals who raised pigs. The general questionnaire focused on socio-demographic factors, knowledge about the life cycle of *T. solium*, as well as questions on care received by NCC patients. The second questionnaire focused on pig ownership and use. Both questionnaires were translated into Spanish, back-translated into English by two independent persons and pilot tested locally prior to use.

The general questionnaire contained questions about the patient's knowledge of the transmission of *T. solium*, socio-demographic factors of NCC cases and the cost related to care received by NCC patients with epilepsy in Mexico. This questionnaire contained 29 questions, with some questions having multiple sub-parts. Questions related to patient's knowledge and socio-demographic characteristics were closed ended and cost related questions were open ended. The pig questionnaire contained information on breeds of pig raised by the patient, the purpose and/or use of these pigs and costs related to lost economic value due to cysticercosis. The questionnaire consisted of 11 questions, with all questions, except for cost-related questions, closed ended.

3.4 Measurement of outcome (Quality of life)

The Short Form 12 version 2 generic quality of life survey (SF-12 v2) was completed by participating NCC outpatients and controls. The SF-12 v2 survey

(Mexican Spanish version) was used to compare the health scores of NCC patients with an age (± 5 years) and sex matched control population from the same region [Appendix H (Spanish version)]. Twelve questions were used to assess eight domains of health in the survey: physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional and mental health.

All domains were checked for missing data for each patient. If more than four health domains were missing for any case or control, that case/control along with his or her matched control/case were not included in the analysis. Data were rescored for uniformity (i.e., positive health responses received higher scores) according to Quality Metric guidelines [62]. Raw scores were then transformed to a 0-100 scale in accordance with standard procedures [62]. This transformation converts the lowest and highest possible scores to zero and 100 and scores between these values represent the percentage of the total possible score achieved. Health scores for the NCC positive and control groups were compared for the overall population, for males and females separately, for long (diagnosed 6 or more years prior) and short (diagnosed less than 6 years prior) duration of NCC, for epilepsy and severe headache separately and across different age groups.

The Physical Component Summary (PCS) and Mental Component Summary (MCS) were calculated by aggregating the eight domains of the SF-12 v2, transformed to z-scores and multiplied by their factor score coefficients, and standardized as t scores with a mean of 50 and standard deviation of 10 according to Quality Metric guidelines [62]. Due to lack of information on factor score coefficients for Mexico, mean, standard

deviation and factor score coefficients used to calculate the component scores were based upon the U.S. population. While using U.S. based norms may not be optimal, it does provide a basis of uniformity for cross-national comparison [73]. A higher score on both summary scales represents better functional health.

3.5 Data management of chart review and health survey data

Information obtained from the chart reviews, questionnaires and SF-12 v2 survey forms was captured in paper form. Later, the information was entered into the Select Survey program (ClassApps Com., Overland Park, KS) and then exported into Excel (Microsoft Corp., Redmond, WA) spreadsheets for analysis. Paper copies of the completed chart reviews were kept in a locked filing cabinet at Texas A&M University, with access provided only to members of the research team.

3.6 Statistical analysis of chart review and health survey data

Descriptive analyses of the data were performed using means, medians and proportions. Normality of the SF-12 v2 data was analyzed by the Shapiro-Wilk method. SF-12 v2 data was not normal. Therefore, the Mann-Whitney test was used to compare the health scores of the two populations. The distribution of health scores of NCC patients and controls were visually compared by drawing box plot graphs.

3.7 Ethical approval of chart review and health survey data

This study received IRB approval from Texas A & M University (2006-0606), the INNN and the IMSS. The licensed (28408) SF-12 version 2 health survey (Mexican Spanish version) was used for the comparison of quality of life of NCC patients and controls.

3.8 Non-monetary burden of NCC in Mexico

Disability adjusted life years (DALYs)

For the calculation of years of life lost due to premature mortality (YLL), standard life expectancies (life expectancy of 82.5 years at birth for women and a life expectancy of 80.0 years at birth for men) were used [16]. As in past GBD studies, 3% discounting and non uniform age weighting ($\beta = 0.04$ and $C = 0.1658$) were used [16]. These values were chosen so that the socioeconomic impact of NCC determined in this study can be compared with previous burden of disease estimates for other conditions.

For the calculation of years of life lost due to premature NCC-associated epilepsy mortality (YLL), WHO 2004 mortality estimates for epilepsy were used [74]. Of these deaths, 30% were assumed to be associated with NCC, based on the findings of a recent systematic review of the association of NCC with epilepsy [13]. There is no published literature on NCC-associated severe headache deaths. Therefore, we assumed that no deaths occurred due to NCC-associated severe headache. For the calculation of years of life lost due to time lived in a disability state (YLD), annual incident cases of NCC-associated epilepsy and severe headache were needed. However, incidence of epilepsy

and severe headache due to NCC is not known in Mexico. Therefore, these parameters were estimated by dividing the prevalence of epilepsy and severe headache associated with NCC by the reported duration of epilepsy from GBD studies [75] and mean duration of NCC-associated severe headache from chart reviews. Prevalence of epilepsy and severe headache were obtained from available literature [76,77].

Disability weights

Disability weights for NCC were not included in the original GBD Study or its subsequent updates. Therefore, to calculate the morbidity component of DALYs lost due to NCC, disability weights for treated and untreated groups for different clinical manifestations of NCC were estimated. Clinical manifestations reported by patients with NCC, in this study, included severe headache/migraine, epilepsy, stroke, dementia, hydrocephalus and increased intracranial pressure. Hydrocephalus and increased intracranial pressure were included in the severe headache category as headache is often a result of both hydrocephalus and increased intracranial pressure. Disability weights for severe headache were not included in previous GBD studies. Therefore, published disability weights for migraine were used as a surrogate for severe headaches. Disability weight for severe headache was not divided into age categories because of limited available data. Due to the limited data on stroke and dementia, these manifestations were not included in the estimation of DALYs. Hence, only two manifestations (epilepsy and severe headache) were used to estimate the DALYs. Disability weights for epilepsy and severe headache used in this study are listed in Tables 2 and 3.

Table 2: Age specific disability weights (DWs) for treated and untreated forms of epilepsy.

Parameter	Mean	95% CI	Distribution	References
DW for people between 0 and 4 years of age not receiving an appropriate treatment	0.099	0.021-0.225	Beta(3,27.3)	[9,75]
DW for people between 0 and 4 years of age receiving an appropriate treatment	0.041	0.003-0.124	Beta(1.5,35)	[9,75]
DW for people older than 5 years of age not receiving an appropriate treatment	0.15	0.033-0.331	Beta(3,17)	[9,75]
DW for people older than 5 years of age receiving an appropriate treatment	0.065	0.004-0.192	Beta(1.5,21.6)	[9,75]

Table 3: Disability weights (DWs) for treated and untreated forms of migraine/ severe headaches.

Parameter	Mean	95%CI	Distribution	References
DW for people not receiving an appropriate treatment	0.0275	0.025-0.03	Uniform (0.025,0.03)	[78]
DW for people receiving an appropriate treatment	0.007	0.0063-0.0077	Uniform (0.0063,0.0077)	[78]

Duration of disease

Mean duration of disease varies according to the clinical manifestation associated with NCC. Therefore, duration of disease was considered separately for epilepsy and severe headaches stratified by age and sex. Due to the lack of published data on the duration of NCC-associated epilepsy and severe headache, duration provided by GBD studies for epilepsy and chart reviews data for severe headache was used. Chart reviews

captured information on duration of NCC-associated severe headache from the time of diagnosis to the date when data was abstracted. Mean duration of NCC-associated severe headache was calculated from those data for each age group. Due to lack of information on duration of severe headache for the 0-14 years age group, duration used for the 15-44 years age group was used for both groups. Mean durations of the clinical manifestations used in this study are listed in Tables 4 and 5.

Table 4: Age and sex specific mean duration of epilepsy in years.

Parameter	Mean* (years)	References
Mean duration of disability in males between 0 and 4 years of age	0.82	[75]
Mean duration of disability in males between 5 and 14 years of age	2.64	[75]
Mean duration of disability in males between 15 and 44 years of age	5.14	[75]
Mean duration of disability in males between 45 and 59 years of age	2.33	[75]
Mean duration of disability in males older than 60 years of age	1.16	[75]
Mean duration of disability in females between 0 and 4 years of age	1.27	[75]
Mean duration of disability in females between 5 and 14 years of age	3.41	[75]
Mean duration of disability in females between 15 and 44 years of age	6.83	[75]
Mean duration of disability in females between 45 and 59 years of age	6.73	[75]
Mean duration of disability in females older than 60 years of age	3.5	[75]

*Distribution: fixed.

Table 5: Age and sex specific mean duration of migraine/severe headaches in years.

Parameter	Mean* (years)	References
Mean duration of disability in males and females between 0 and 4 years of age	4.28	Chart reviews
Mean duration of disability in males and females between 5 and 14 years of age	4.28	Chart reviews
Mean duration of disability in males and females between 15 and 44 years of age	4.28	Chart reviews
Mean duration of disability in males and females between 45 and 59 years of age	2.90	Chart reviews
Mean duration of disability in males and females older than 60 years of age	4.75	Chart reviews

*Distribution: fixed.

Literature search strategy for prevalence of epilepsy in Mexico

The available literature was reviewed to estimate the prevalence of epilepsy in Mexico [76,77]. Those studies that used advanced imaging, standardized previously validated questionnaires, door to door surveys and/or interviews with parents for data collection were included. The adult epilepsy prevalence estimates used in this study were based on epilepsy incidence and prevalence estimates for Mexico found in a systematic review of the literature on epilepsy frequency for Latin America [76]. This review reported prevalence estimates for Tepatitlan, Jalisco, Mexico and a representative subsample living in urban areas of Mexico during the first National Survey on Drug Abuse. Therefore, we took the mean of the two available prevalence estimates for adult males (0.83% and 3.4%) and females (0.55% and 4.8%) and modeled the uncertainty with a triangular distribution. For the prevalence of epilepsy in children, an estimate

from nine year old children was used [77]. This study reported minimum, maximum and mean values of epilepsy prevalence in 9 year old Mexican school children from Tlalpan, Mexico. Therefore, we modeled the uncertainty with a triangular distribution. Due to the absence of data for children of other ages, this estimate was used for the entire 0-14 year age group. The epidemiological parameters used to calculate DALYs lost due to NCC in Mexico are provided in Table 6.

Table 6: Epidemiological parameters used to calculate DALYs associated with NCC in Mexico.

Parameter	Value	95%CI	Distribution	Reference
2005 Population of Mexico (‘000)	105,329		Fixed	[79]
Mortality due to epilepsy in Mexico	1500		Fixed	[74]
Prevalence of epilepsy in 0-14 year old males and females in Mexico (%)	4.2	2.2 – 4.3	Triangular (1.8, 4.2, 4.4)	[77]
Prevalence of epilepsy in males older than 15 years of age in Mexico (%)	2.15	1.1 – 3.1	Triangular (0.83,2.1,3.4)	[76]
Prevalence of epilepsy in females older than 15 years of age in Mexico (%)	2.7	1.0 – 4.3	Triangular (0.55,2.6,4.8)	[76]
Proportion of epilepsy associated with NCC in individuals 0-14 years of age in Mexico	0.22	0.18 - 0.26	Uniform (0.18,0.26)	[13,80]
Proportion of epilepsy associated with NCC in individuals older than 15 years of age in Mexico	0.23	0.18-0.29	Uniform (0.18,0.29)	[13,80]
Proportion of epilepsy in people with NCC (all age groups combined)	0.58	0.14 – 0.96	Normal (0.58,0.22)	[81]
Proportion of individuals with severe headache presenting with NCC	0.22	0.16 – 0.29	Normal (0.22, 0.03302)	[81,82]
Proportion of epilepsy patients receiving treatment	0.45	0.4-0.5	Uniform (0.4,0.5)	[75,83]
Proportion of severe headache patients receiving treatment	0.60	0.525-0.69	Uniform (0.525,0.69)	[84,85]

Estimation of the number of NCC cases with epilepsy in Mexico

The number of cases of epilepsy in Mexico was estimated by multiplying the size of the population of Mexico in 2005 [79] by the prevalence of epilepsy in Mexico reported in Burneo et al., (2005) for adults and Garcia-a-Pedroza et al., (1983) for children [76,77]. The 2005 population of Mexico was chosen because age and sex stratified data for Mexico could only be found up to this year. In addition, the GBD 2010 Study will use 2005 estimates. In a recent meta-analysis of the literature, it was estimated that 29% of adults and 26% of children 0-19 years of age with epilepsy had NCC lesions in endemic areas [13]. However, since all regions of Mexico are not equally endemic for NCC, an estimate from urban areas of India was assumed to be similar to urban areas of Mexico. Therefore, the estimate from urban areas of India was used as the lower bounds and meta-analysis data was used as the upper bounds, with uncertainty modeled with a uniform distribution. Hence, the numbers of adults and children with epilepsy in Mexico were multiplied by the respective proportion of people with epilepsy (PWE) with NCC lesions to obtain the number of NCC-associated cases of epilepsy in adults and children in Mexico. The 1996 GBD Study estimated that 40% of total epilepsy cases receive treatment in Mexico [75] and Meyer et al., (2009) estimated that 50% of total epilepsy cases receive treatment in lower middle- and upper middle-income countries [83]. Therefore, the proportion of NCC-associated epilepsy cases receiving treatment was estimated by multiplying the number of NCC-associated epilepsy cases in Mexico by the percentage seeking treatment, modeling the uncertainty with a uniform distribution with 40% as the lower bounds and 50% as the upper bounds.

A flowchart depicting how incidence of NCC-associated epilepsy in Mexico was determined is shown in Figure 4.

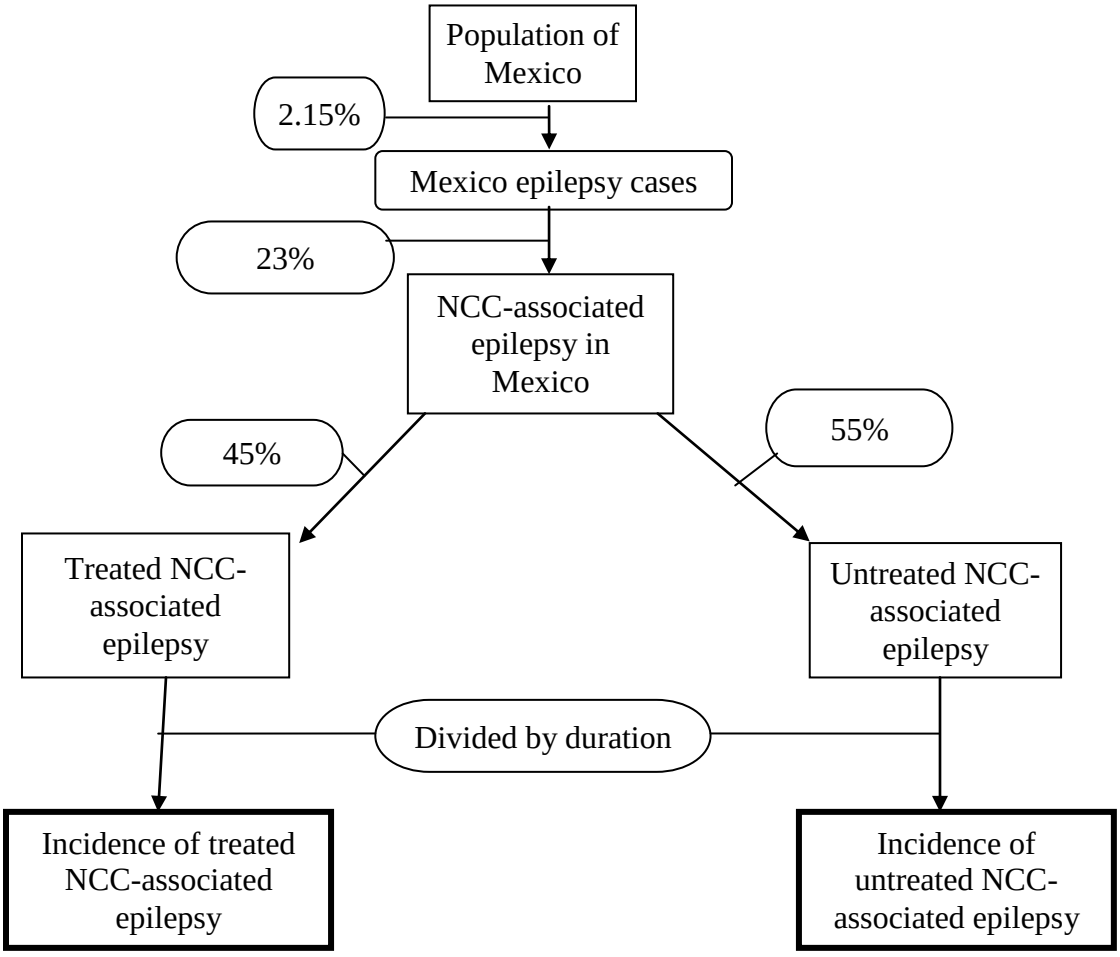


Figure 4: Flowchart for estimating the incidence of NCC-associated epilepsy in Mexico (for adults).

Note: The flowchart provides the mean values of the model parameters. Please refer to Table 6 for information concerning distributions applied to the various parameters.

Estimation of the number of NCC cases with severe headache in Mexico

A recent meta-analysis of the literature indicated that approximately 58% and 22% of symptomatic NCC cases seen in neurological clinics have epilepsy and severe headaches as a clinical manifestation, respectively [81]. Therefore, we assumed that 58% of NCC cases who are seen at neurology clinics in Mexico is equivalent to the number of NCC-associated epilepsy cases in Mexico who receive treatment (45% of total NCC-associated epilepsy cases). The total number of clinical cases of NCC was calculated by dividing the number of NCC-associated epilepsy cases who go to neurology clinics by 58%. The number of people in Mexico with NCC-associated severe headache who go to neurology clinics was calculated by multiplying the total number of NCC cases who go to neurology clinics by the proportion of NCC cases in neurology clinics who have severe headache as a clinical manifestation. Morillo et al. (2005) estimated that 52.5% of total migraine cases receive treatment in Mexico [84] and Lipton et al. (2002) estimated that 69% of total migraine cases receive treatment in the USA [85]. The estimate from the USA was considered the maximum proportion of severe headache cases that receive treatment in Mexico and the Mexican value considered the minimum value, with uncertainty modeled using a uniform distribution. Therefore, the total number of people with NCC-associated severe headache was calculated by dividing the total number of NCC cases presenting to neurology clinics with severe headache by these values. A flowchart depicting how incidence of NCC-associated severe headache in Mexico was determined is shown in Figure 5.

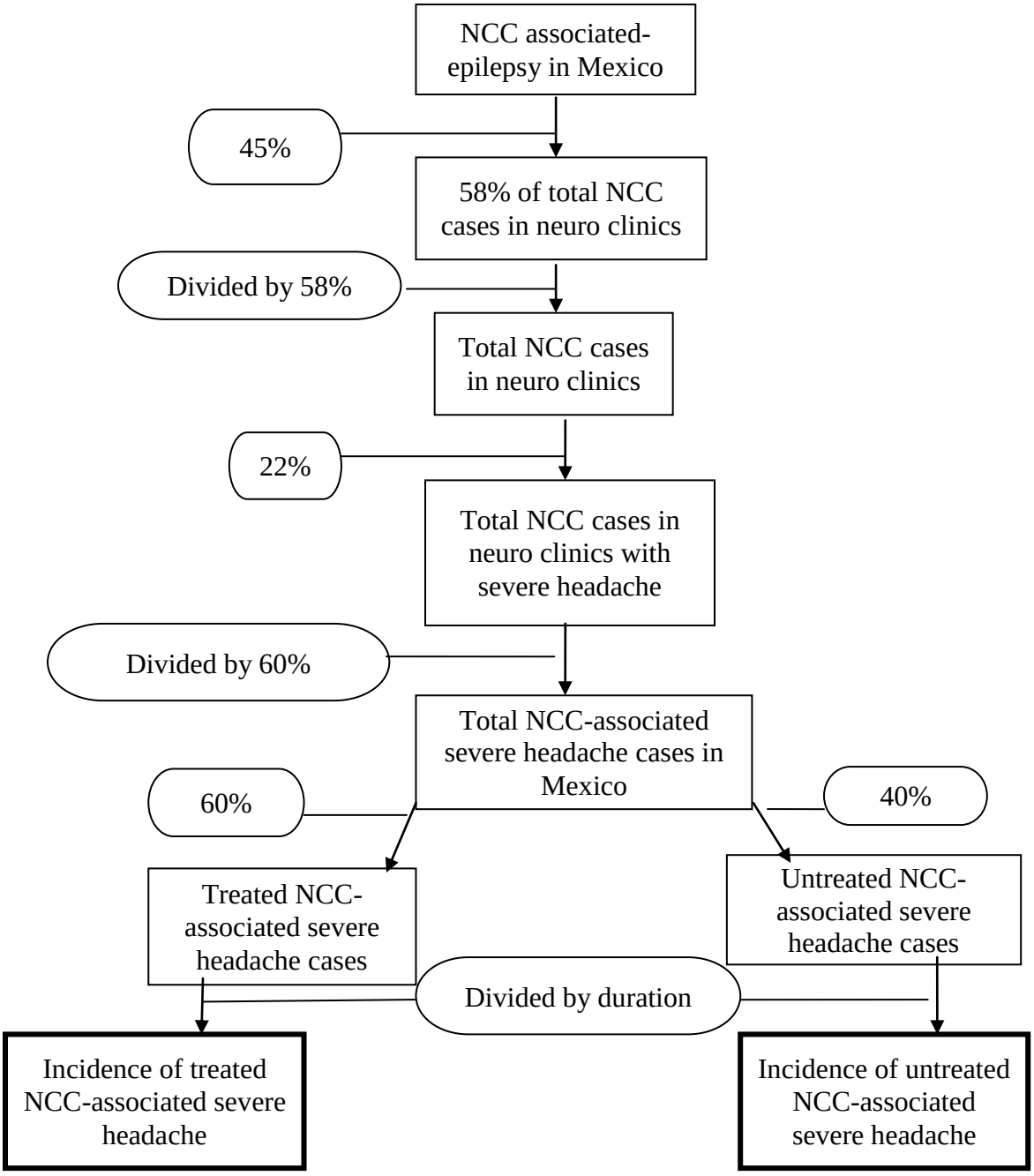


Figure 5: Flowchart for estimating the incidence of NCC-associated severe headache in Mexico.

Note: The flowchart provides the mean values of the model parameters. Please refer to Table 6 for information concerning distributions applied to the various parameters.

Analysis

A spreadsheet model using @Risk software (Palisade Corporation, Ithaca, NY, version 4.5) was used to estimate the number of DALYs lost due to NCC. Monte Carlo methods were employed to simulate the data and to calculate 95% credibility intervals. The model was run for 20,000 iterations. Different distributions were used according to the type of information available for each of the included parameters. In addition, regression sensitivity analysis was performed to identify which parameter had the greatest effect on the total DALYs estimate.

4. RESULTS

4.1 Patients descriptive data from chart reviews

Chart reviews were conducted for 101 patients from the IMSS and 177 patients from the INNN. There were slightly more female patients (144) than male patients (134). Patient ages ranged from 19-88 years, with a mean of 47 years and a median of 46 years (Figure 6).

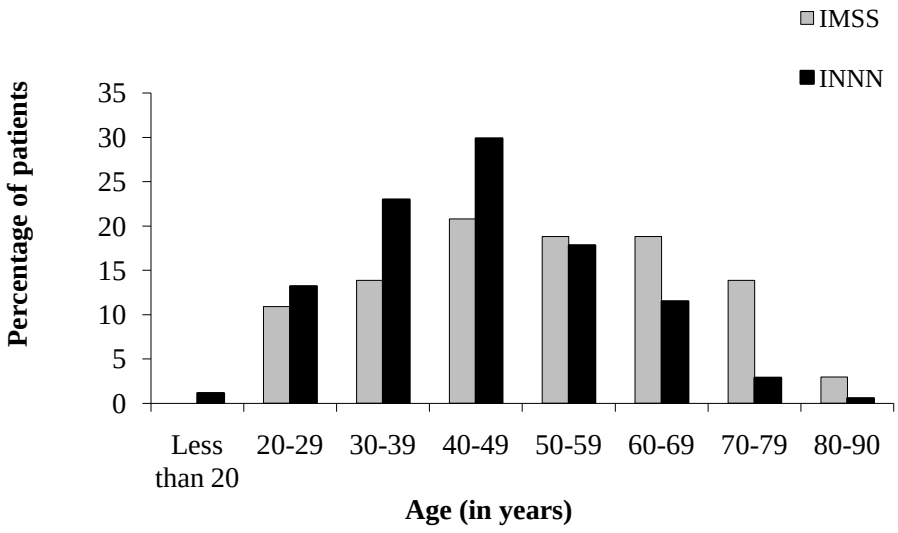


Figure 6: Age distribution of NCC patients presenting to the INNN and the IMSS.

Most of the patients (82%) attending the IMSS were from Ciudad de Mexico (Mexico DF (Distrito Federal)). Patients attending the INNN were primarily from Estado de Mexico (37%) and Mexico DF (26%) (Figure 7).

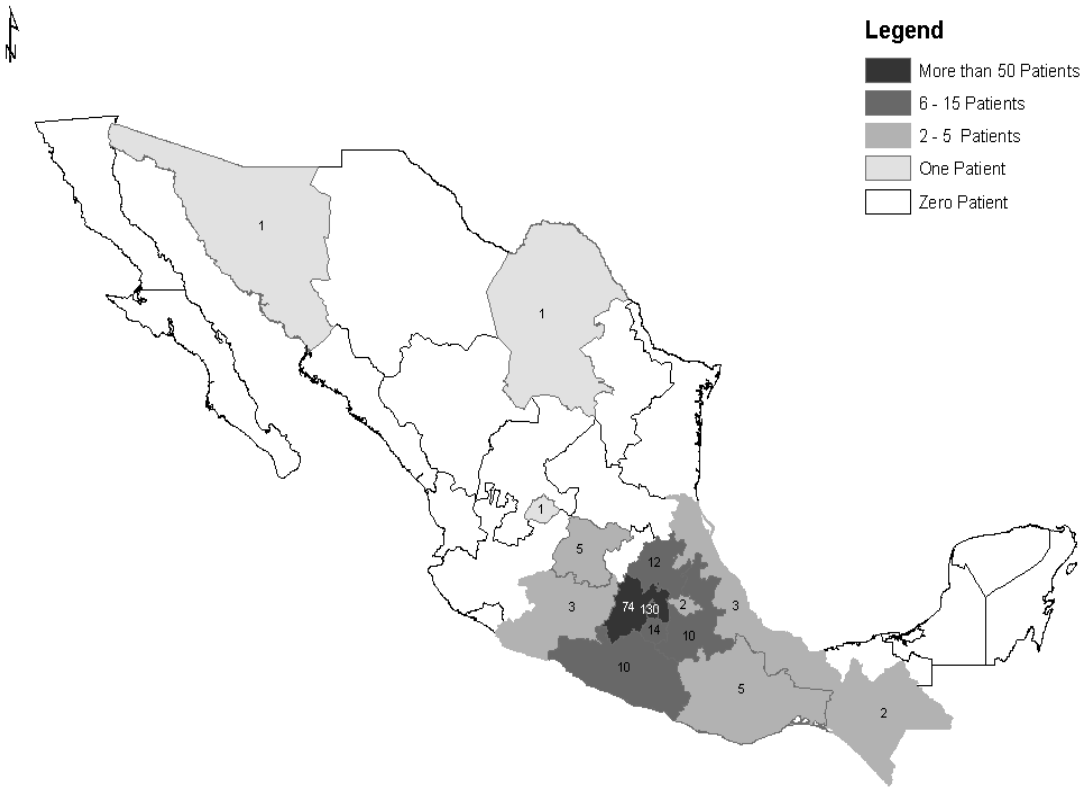


Figure 7: Distribution of patients according to their state of residence (number of patients attending the IMSS = 101, number of patients attending the INNN = 177).

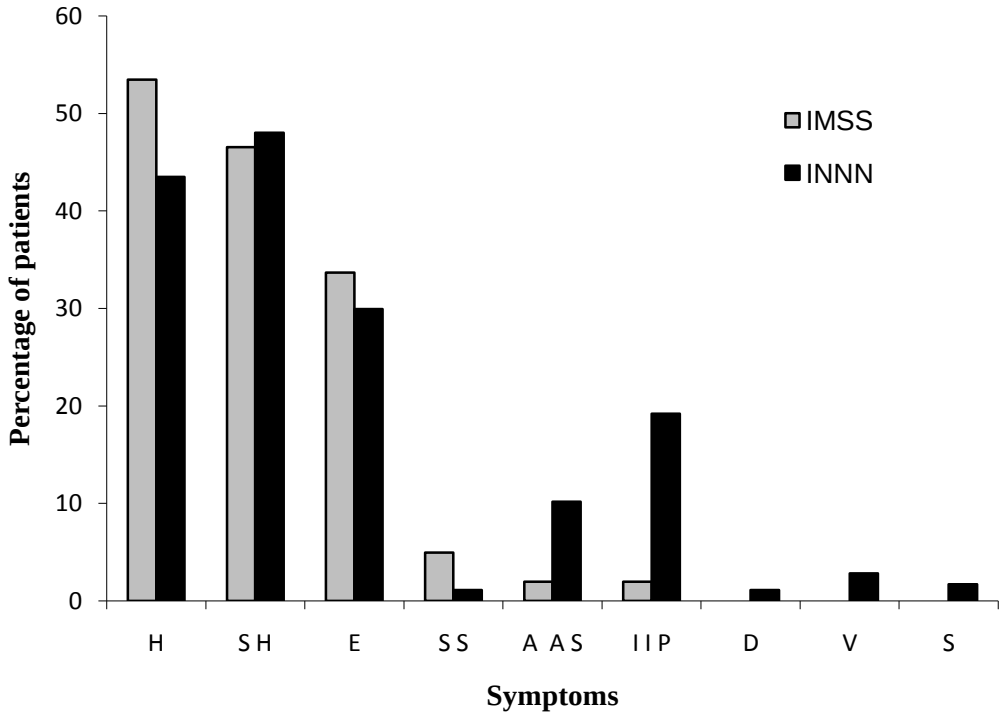
4.2 Clinical manifestations associated with NCC cases

NCC (in and out) patients reported numerous clinical manifestations throughout the course of disease (Table 7 and Figure 8), with severe headache being the most common. In some patients, more than one symptom was present such as epilepsy and severe headache; epilepsy, hydrocephalus and severe headache; hydrocephalus and epilepsy. The most common combination was hydrocephalus and severe headache (15%) (Table 8). Of the cases evaluated in this study, 50% had a long clinical history of NCC (diagnosed 6 or more years prior to the date of the patient's last appointment at the neurology clinic).

Table 7: NCC related manifestations of patients seeking treatment at the INNN or IMSS (n=278).

Symptoms	Number	Proportion
Severe headaches	132	0.48
Hydrocephalus	131	0.47
Epilepsy	87	0.31
Increased intracranial pressure	34	0.12
Acute symptomatic seizures	20	0.07
Single seizures	7	0.03
Vasculitis	5	0.02
Stroke	3	0.01
Dementia	2	0.01

Note: The percentages sum to more than 100% because patients could present with more than one symptom.



H = Hydrocephalus, SH = Severe headache, E = Epilepsy, SS = Single seizure, ASS = Acute symptomatic seizures, IIP= Increased intracranial pressure, D = Dementia, V = Vasculitis, S = Stroke

Figure 8: NCC related clinical manifestations of patients seeking treatment at the INNN or the IMSS.

Table 8: Different combinations of clinical manifestations in NCC patients seeking treatment at the INNN or the IMSS (n=278).

Combinations	Number	Proportion
Epilepsy and hydrocephalus	18	0.06
Severe headache and hydrocephalus	43	0.15
Severe headache, hydrocephalus and epilepsy	12	0.04
Epilepsy and severe headache	26	0.09
Increased intracranial pressure and hydrocephalus	19	0.07
Increased intracranial pressure and severe headache	26	0.09
Increased intracranial pressure, severe headache and hydrocephalus	13	0.05
Epilepsy alone	52	0.19
Acute symptomatic seizures alone	9	0.03
Single seizure alone	3	0.01
Hydrocephalus alone	26	0.09
Severe headache alone	33	0.12
Increased intracranial hypertension alone	2	0.007

4.3. Socio-demographic characteristics of NCC cases

Of the 278 NCC cases whose medical charts were reviewed, 224 (80.6%) were outpatients who consented to be interviewed. Of these, 101 sought treatment at the IMSS and 123 sought treatment at the INNN. Of the total interviewed NCC patients, 71.4% were pork consumers, while 28.6% never ate pork. Of those who ate pork, 53.0% reported only eating well done pork while 16.0% reported consuming undercooked pork. Only three (1.3%) patients currently owned pigs whereas 51% had owned pigs one to five years prior. Present pig owners lived in Puebla, Acapulco and Edo, Mexico. A total of 20% of present or former pig owners had a history of seeing cysts in their pigs. Of the interviewed NCC patients, 24.0% had a history of seeing tapeworms in their feces and 9.0% of patients' near relatives were known tapeworm carriers (Table 9).

Table 9: Pig ownership and taeniasis history among NCC patients (n = 224).

	IMMS	INNN	Total	Proportion
Currently or previously owned pigs	51	67	118	0.52
Currently or previously ate pork	65	95	160	0.71
Ate undercooked pork	6	20	26	0.16
Had a history of taeniasis	36	18	54	0.24
Relative of a known tapeworm carrier	13	8	21	0.09

Only two (0.9%) NCC patients did not currently have a toilet in their home and always defecated outdoors, while 11 (5.0%) sometimes defecated outdoors. In addition, 70.9% of the patients drank bottled water and 12.9% drank water from a well. Of the total NCC patients interviewed, 28.6% were unaware of cysts occurring in pigs. Among 160 patients who had heard about cysts, 75.6% did not know how pigs acquired the cysts. Similarly, 25.0% of patients did not know about tapeworm infections in humans. Among people who did know about human tapeworms, 57.1% were not aware of how the worms were transmitted to humans (Table 10). Of those patients who knew about tapeworms, 28.3% of patients got their information from physicians and the remainder obtained their information from radio/newspaper, friends/families or a traditional healer.

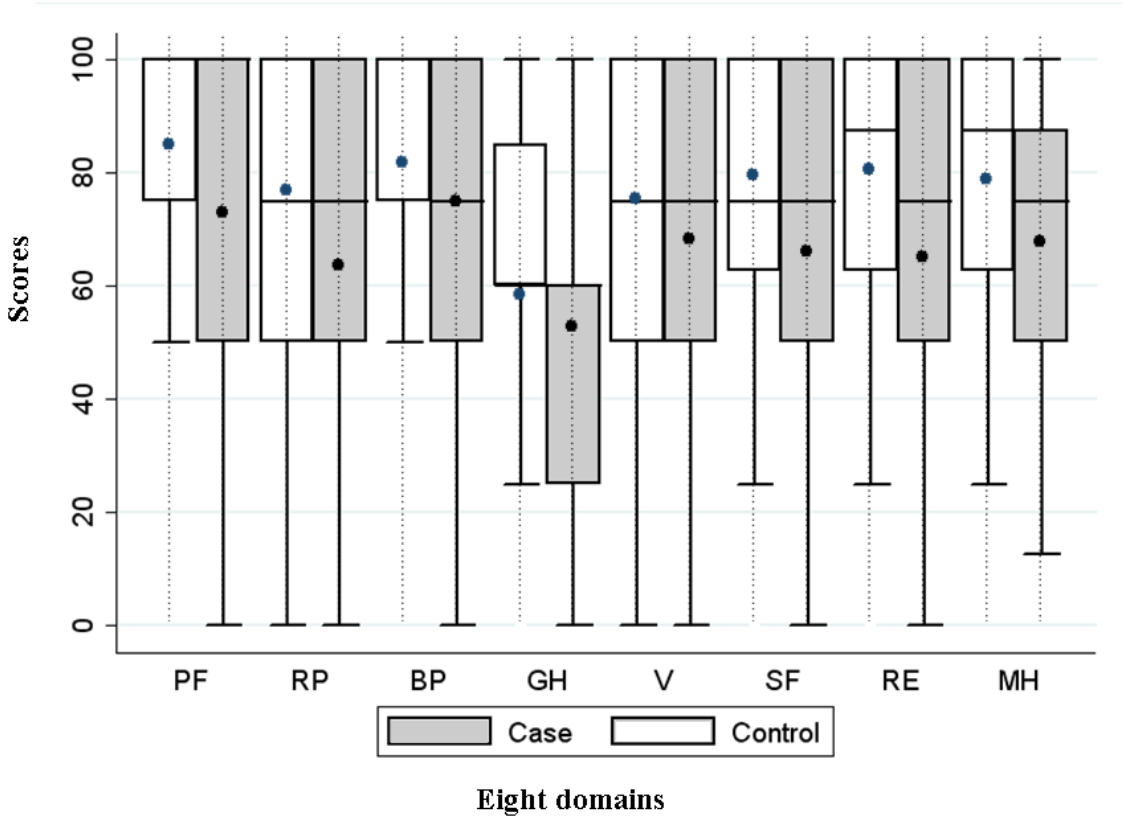
Table 10: Hygienic behavior and knowledge of *T. solium* transmission (n = 224).

	IMMS	INNN	Total	Proportion
Did not have a toilet in their homes and defecated outdoors	0	2	2	0.01
Did not know about cysts in pigs	36	28	64	0.29
Knew about the cysts, but did not know about transmission	47	73	121	0.76
Did not know about the tapeworm in humans	12	44	56	0.25
Knew about the tapeworm, but did not know about transmission to humans	62	34	96	0.57

4.4. Measurement of outcome (quality of life)

Of the 278 NCC patients whose medical charts were reviewed, 224 (80.6%) were outpatients who consented to complete the SF-12 v2 quality of life survey. Four pairs of cases and controls were not used for the analysis due to missing data.

The Shapiro-Wilk test indicated that the SF-12 v2 data were not normally distributed. Therefore, health scores for NCC patients and the comparison group were compared using the Man-Whitney test. Individuals with NCC had a significantly lower score for all eight domains of health (physical functioning, role physical, bodily pain, vitality, general health, social functioning, role emotional and mental health) compared with the age and sex matched population ($p < 0.05$) (number of cases and controls pairs = 220) (Figure 9).



PF = Physical functioning, RP = Role physical, BP = Bodily pain, GH= General health V = Vitality, SF = Social functioning, RE= Role emotional, MH= Mental Health.

Figure 9: Health scores from the SF-12 v2 health survey for NCC patients versus their matched control group (Overall population).
Note: Dot in the box plot represents the mean of the health scores.

Male NCC outpatients had significantly lower scores in role physical, social functioning, role emotional and mental health compared with their matched controls from the same source population ($p<0.05$) (n=104 pairs) (Figure 10).

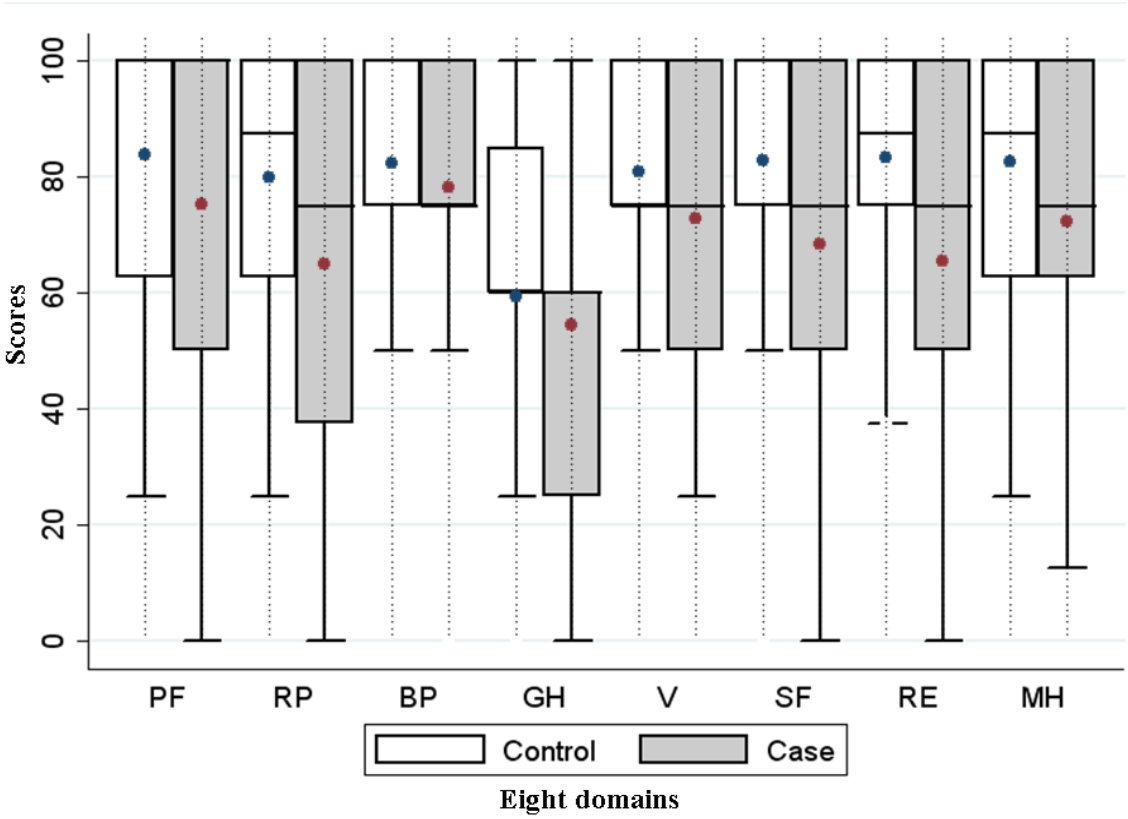


Figure 10: Health scores from the SF-12 v2 health survey for NCC patients versus their matched control group (Males).
Note: Dot in the box plot represents the mean of the health scores.

Except for general health, female NCC outpatients had significantly lower scores in all domains compared with their matched controls ($p<0.05$) (n=116 pairs) (Figure 11).

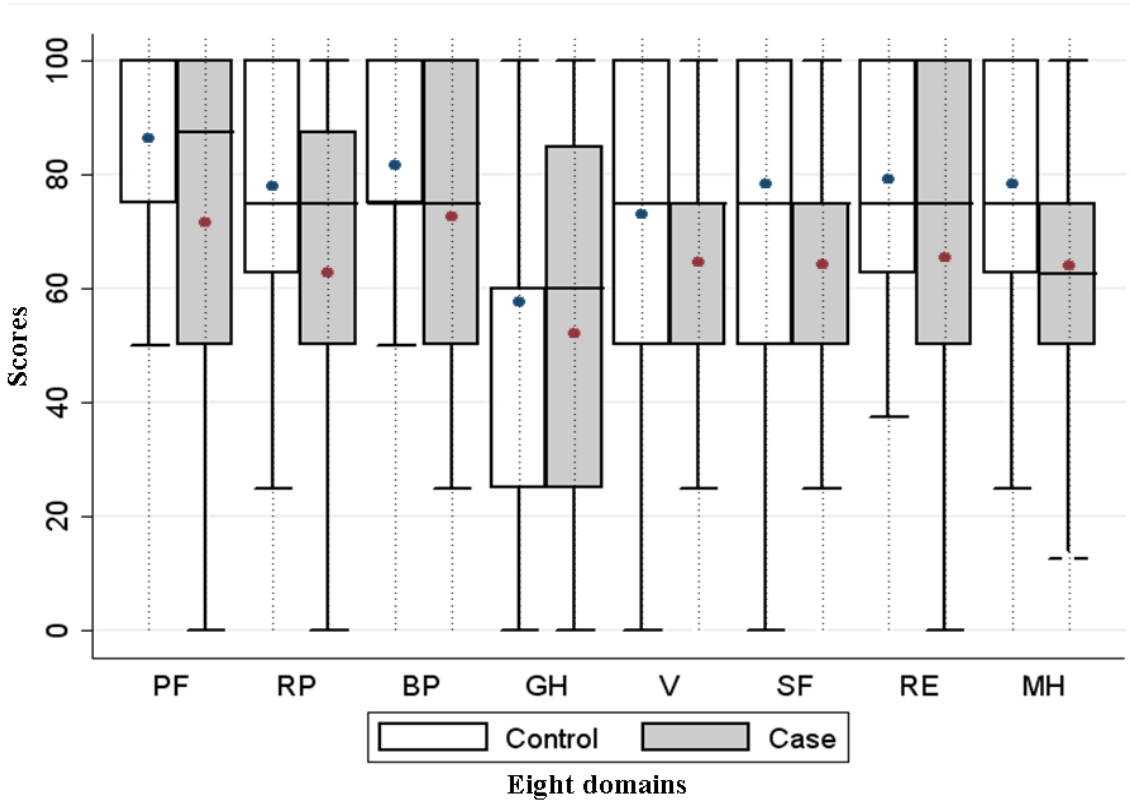


Figure 11: Health scores from the SF-12 v2 health survey for NCC patients versus their matched control group (Females).
Note: Dot in the box plot represents the mean of the health scores.

To assess the possible effect modification of age on the difference in scores, a stratified analysis was conducted using an age cut off of 45 years old. Forty-five years was chosen since the median age of the NCC cases was 46 years. Younger individuals (≤ 45 years of age) with NCC had lower health scores in all eight domains compared to their matched controls (n=100 pairs) (Figure 12). However, for the older individuals (>45 years of age), four domains (physical functioning, bodily pain, general health and

vitality) were not significantly different between the two groups (n=120 pairs) (Figure 13).

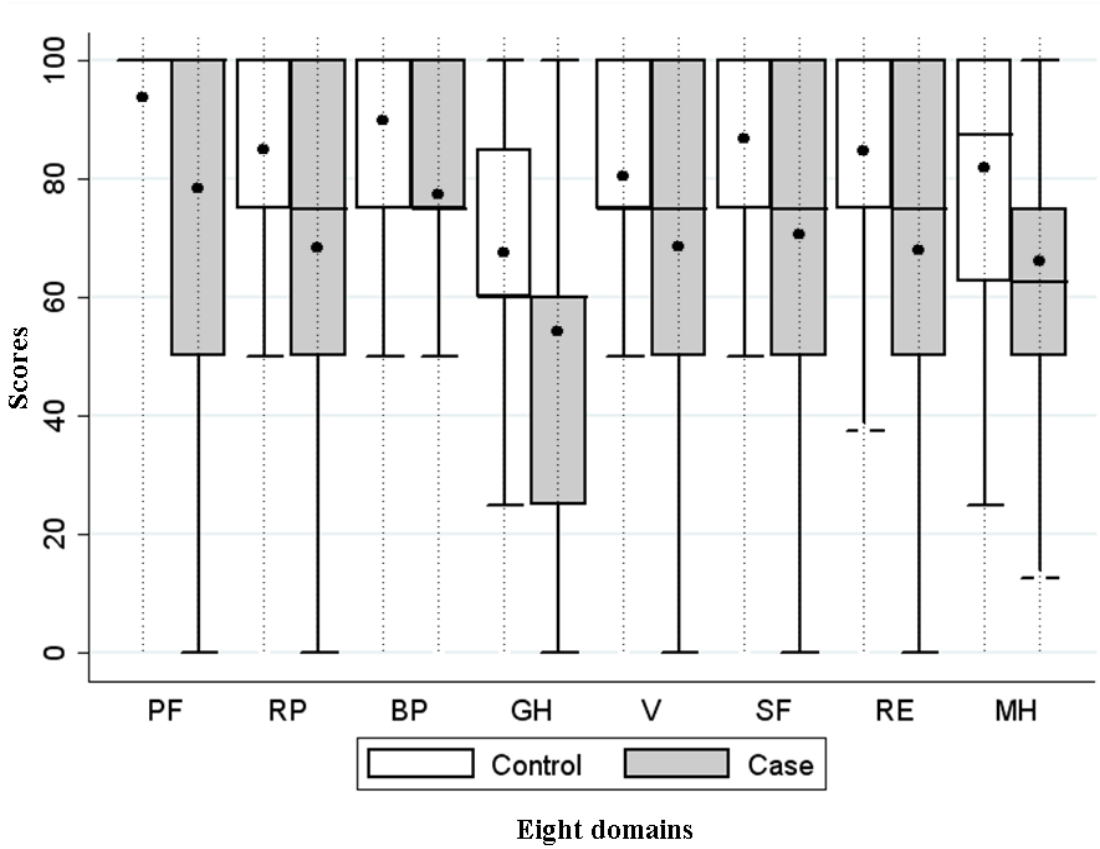


Figure 12: Health scores from the SF-12 v2 health survey for NCC patients versus their matched controls (Younger (<=45 years) group).
Note: Dot in the box plot represents the mean of the health scores.

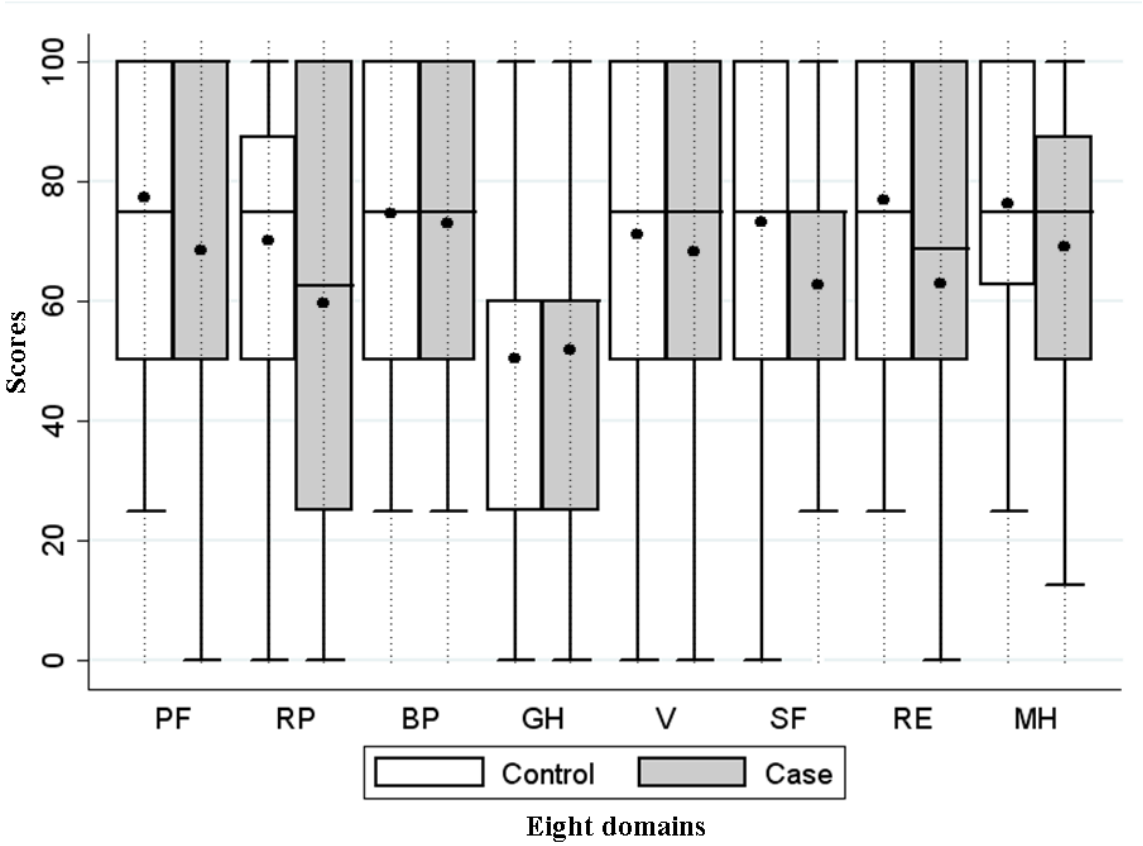


Figure 13: Health scores from the SF-12 v2 health survey for NCC patients versus their matched controls (Older (>45 years) group).
Note: Dot in the box plot represents the mean of the health scores.

Similarly, the comparison between the NCC cases and their matched controls was stratified by the time since diagnosis. A cut-off point of five years was chosen as the cutoff since the median time since diagnosis of the NCC outpatients was 5 years. Thirty-six cases did not have time of diagnosis documented in their medical charts and were, therefore, not included in this comparison. NCC cases diagnosed less than 6 years ago had lower health scores in all eight domains compared with their matched controls

(n=102 pairs) (Figure 14). However, three domains (bodily pain, general health and vitality) were not significantly different for NCC cases diagnosed more than six years ago and their matched controls (n=82 pairs) (Figure 15).

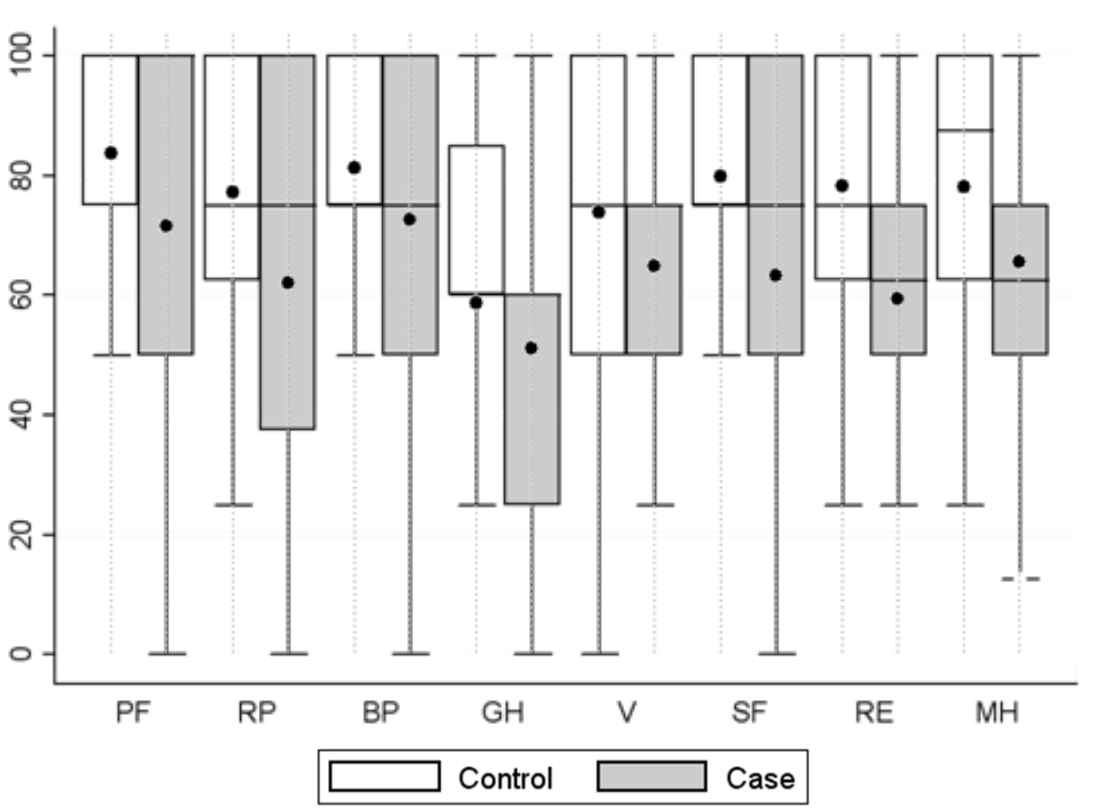


Figure 14: Health scores from the SF-12 v2 health survey for NCC patients versus their matched controls (Diagnosed less than 6 years ago).
Note: Dot in the box plot represents the mean of the health scores.

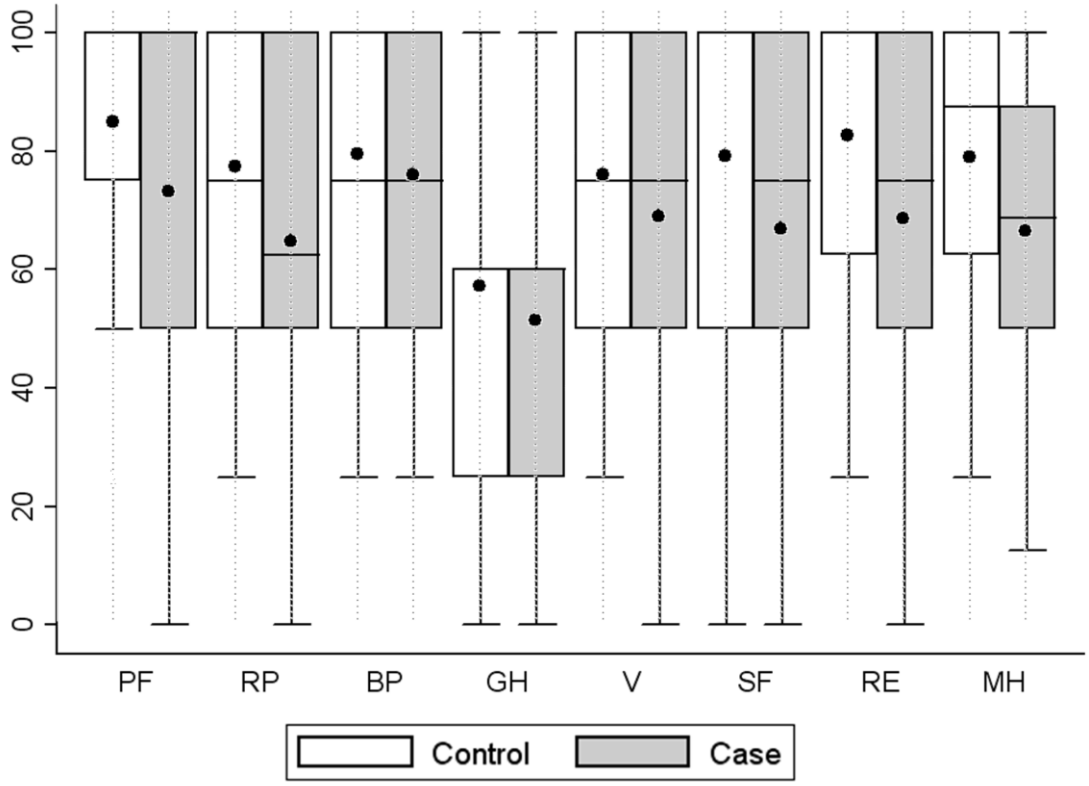


Figure 15: Health scores from the SF-12 v2 health survey for NCC patients versus their matched controls (Diagnosed 6 or more years prior).
Note: Dot in the box plot represents the mean of the health scores.

The comparison between the NCC cases and their matched controls was also stratified by symptoms. Except for physical functioning and bodily pain, NCC-associated epilepsy outpatients had significantly lower scores in all domains compared to their matched controls ($p<0.05$ pairs) (n=63) (Figure 16).

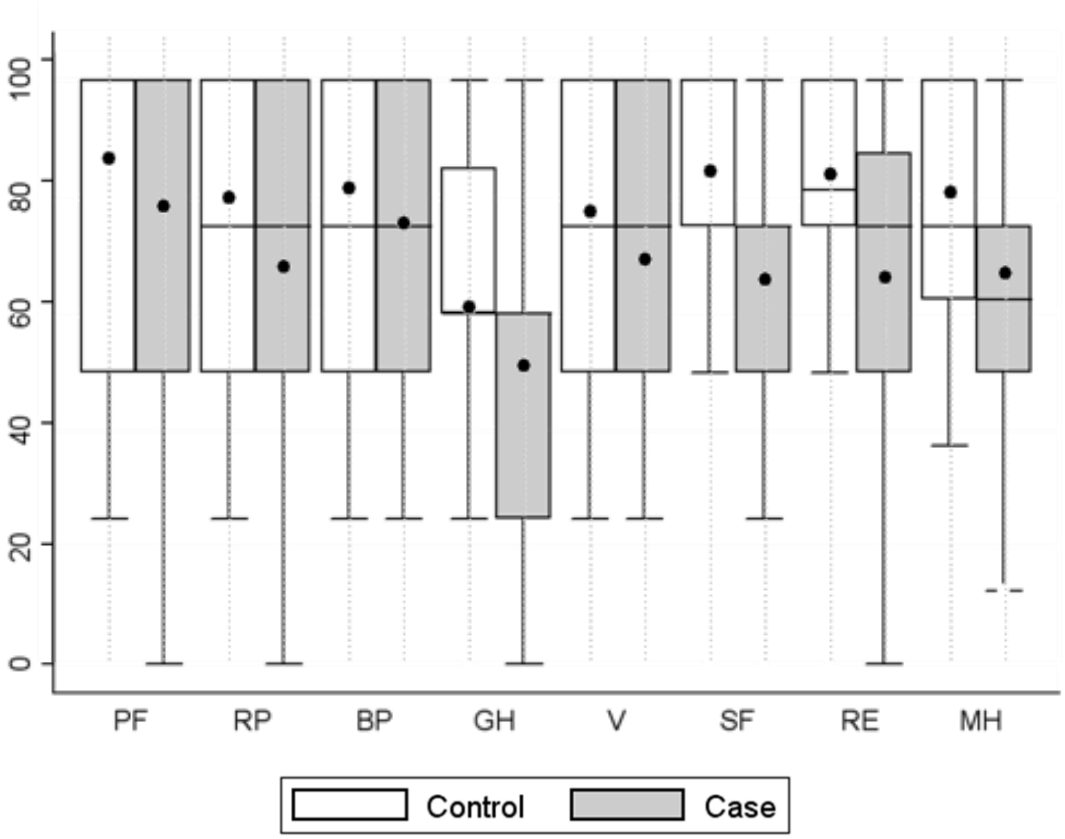


Figure 16: Health scores from the SF-12 v2 health survey for NCC patients versus their matched controls (Epilepsy group).
Note: Dot in the box plot represents the mean of the health scores.

Except for general health, NCC-associated severe headache outpatients had significantly lower scores in all domains compared to their matched controls ($p<0.05$) (n=100 pairs) (Figure 17).

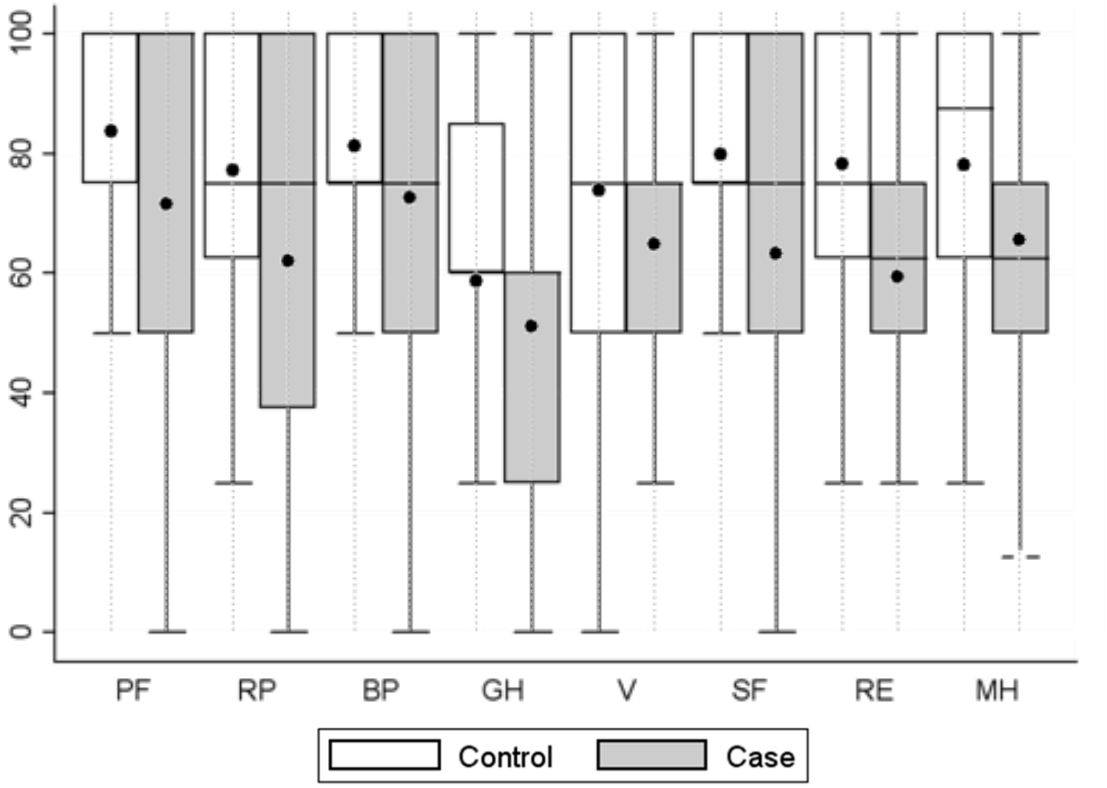


Figure 17: Health scores from the SF-12 v2 health survey for NCC patients versus their matched controls (Severe headache group).
Note: Dot in the box plot represents the mean of the health scores.

Physical and Mental Component Summary scores

From the results of norm based Physical and Mental Component Summary scores, calculated using U.S. norm factor score coefficients, both summary scores for NCC cases were lower than that of the U.S. norms. In norm based scoring, values are considered lower than the comparison group if the value is less than 50. Physical and mental component summary scores for different sub groups are shown in Table 11.

Table 11: Physical Component Summary (PCS) and Mental Component Summary (MCS) scores for different sub groups compared to U.S. norms.

	PCS		MCS	
	Mean	**Median**	**Mean**	**Median**
All NCC patients	45.9	47.7	45.8	47.2
Male NCC patients	46.1	48.2	47.2	47.7
Female NCC patients	45.7	48.2	44.7	47.7
Younger (<45 years) NCC patients	47.8	48.8	42.9	43.5
Older (>= 45 years) NCC patients	44.4	45.7	48.2	50.1
NCC-associated epilepsy patients	46.4	47.2	43.2	42.1
NCC-associated severe headache patients	45.8	47.7	46.7	47.7
Diagnosed less than 6 years ago	45.3	47.6	45.4	47.3
Diagnosed 6 or more years ago	45.8	46.8	45.7	45.9
Controls	48.5	50.5	51.8	52.6

4.5. Non-monetary burden of NCC in Mexico

Prevalence and annual incidence cases of NCC-associated epilepsy and severe headache in Mexico

Approximately 0.7% of the total population of Mexico was estimated to have NCC-associated epilepsy and 0.2% was estimated to have NCC-associated severe headaches. The estimated numbers of people in Mexico with NCC-associated epilepsy and NCC-associated severe headaches are given in Table 12.

Table 12: Estimated number of people with NCC-associated epilepsy and severe headaches in Mexico.

	Mean	Median	95% CR
People in Mexico with NCC-associated epilepsy	740,404	739,854	574, 207 – 903,967
People in Mexico with NCC-associated severe headache	209,337	207,592	151,608– 276,947

Percentages of annual incident cases of NCC that are associated with epilepsy and severe headache were 0.3 and 0.05, respectively. The mean estimated number of annual incident cases of NCC-associated epilepsy and severe headaches and their 95% credibility region are provided in Table 13.

Table 13: Estimated annual incidence cases of NCC-associated epilepsy and severe headache in Mexico.

	Mean	Median	95% CR
Annual number of incident cases of NCC-associated epilepsy	268,496	269,057	224,122 – 310,531
Annual number of incident cases of NCC-associated severe headaches	51,055	50,655	37,072 – 67,398

DALYs due to NCC-associated epilepsy and severe headaches in Mexico.

The total number of DALYs lost due to NCC in Mexico was estimated to be 99,866 (95% CR: 43,187 – 189,182), with a mean of 0.95 (95% CR: 0.4 – 1.8) DALY

lost per thousand persons per year. Estimated numbers of DALYs lost due to epilepsy and severe headaches are given in Table 14.

Table 14: Estimated annual number of DALYs lost due to NCC-associated epilepsy and severe headache in Mexico.

Source of DALYs	Mean	Median	95%CR	Percentage of total DALYs
DALYs due to epilepsy	96,450	90,408	40,012 – 185,223	96
DALYs due to severe headache	3,416	3,341	2,155 – 5,047	4
Total	99,866	93,824	43,187 – 189,182	100

Thirteen percent of DALYs lost due to NCC was attributed to YLL and the remaining 87% was due to YLD. Estimated number of YLL and YLD due to NCC in Mexico are shown in Table 15.

Table 15: Estimated annual number of YLL and YLD associated with NCC-associated epilepsy and severe headache in Mexico.

Source of DALYs	Mean	Median	95%CR	Percentage of total DALYs
YLL	12,252	12,322	10,329 – 13,938	13
YLD	87,614	81,583	31,061 – 176,586	87

Number of DALYs lost in different age groups

The estimated number of DALYs lost was highest in the 15-44 year age group and lowest in those greater than 60 years of age. The numbers of DALYs lost for males and females were similar for all age groups. The distributions of DALYs lost for males and females in different age groups are shown in Figure 18.

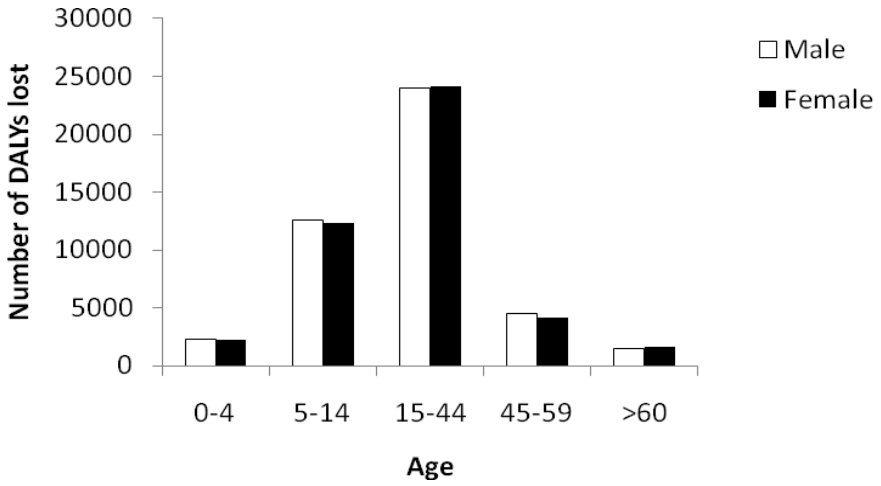


Figure 18: Estimated mean number of DALYs lost due to NCC for males and females in different age groups in Mexico.

Uncertainty analysis

The epilepsy disability weight for untreated people older than 5 years of age, the epilepsy disability weight for treated people older than 5 years of age and the total number of NCC patients who go to neurology clinics were the three parameters with the

greatest effect on the total DALYs estimate. Parameters which had the greatest effect on the number of DALYs lost due to NCC in Mexico are shown in Figure 19.

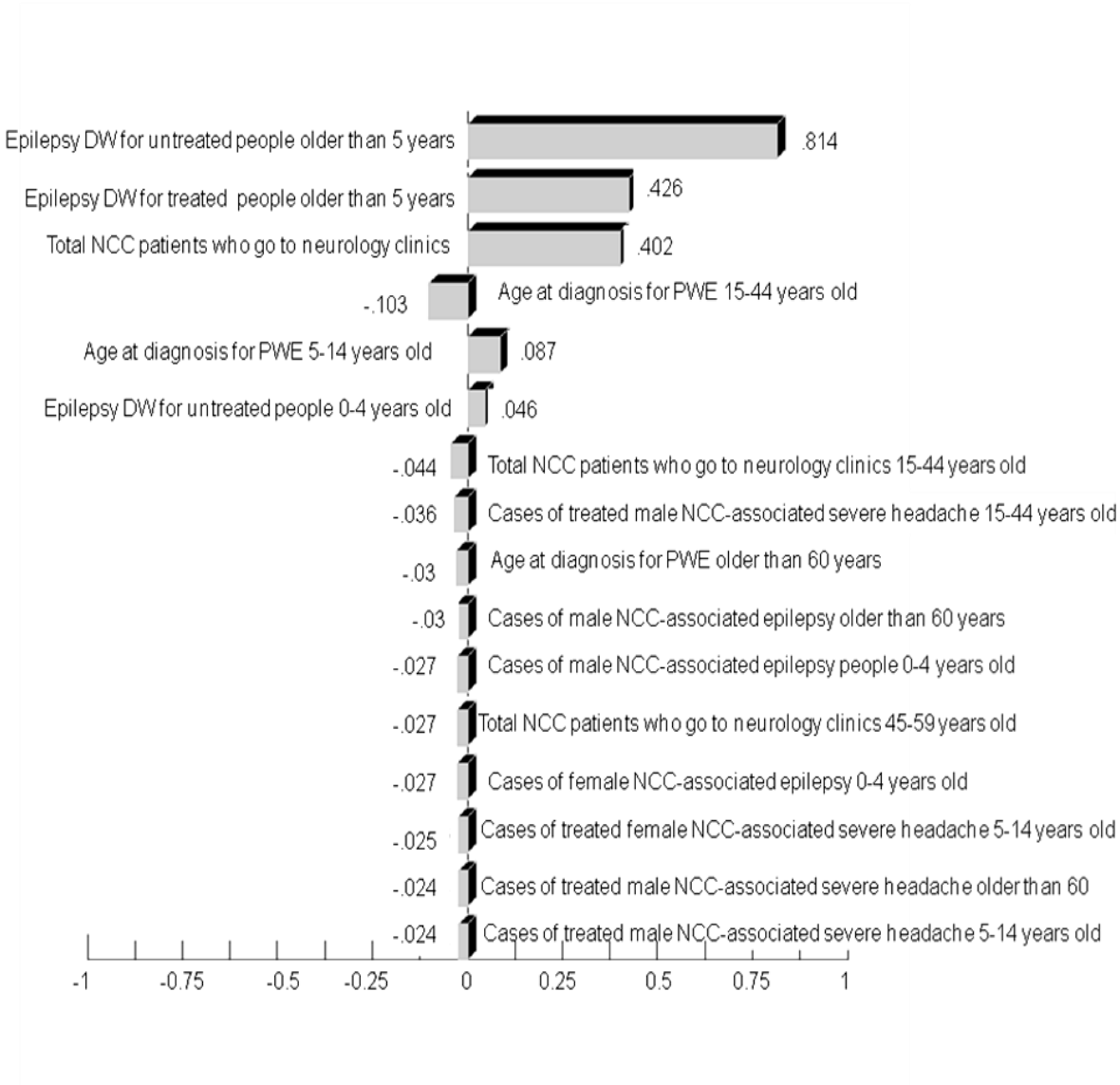


Figure 19: Sensitivity analysis of the total NCC-associated DALYs estimate for Mexico.

5. DISCUSSION

Neurocysticercosis (NCC) is a public health problem in Latin America and developing countries of Asia and Africa [6]. Prevalence of NCC in endemic areas of Mexico, including asymptomatic cases, was found to be as high as 10.8% by computed tomography in certain villages [56,58]. In our study, most patients were from the vicinity of Mexico City suggesting that people from the endemic regions may not commonly travel to referral hospitals or that NCC cases moved closer to the hospital following their diagnosis. Therefore, the numbers of patients treated in neurology referral hospitals most likely only represent a fraction of the total regional population with NCC, with less severe cases remaining unreported or treated in regional hospitals.

5.1 NCC-associated clinical manifestations

Clinical manifestations associated with NCC were found to be pleomorphic. Manifestations can be neurologic as well as psychiatric and include severe headache, epilepsy, seizures, stroke, dementia, and depression [3,41]. This variability is related to the number and location of lesions as well as the extent of the host's immune response to the parasites [4]. In this study, severe headache was the most common clinical manifestation presented by NCC patients in two neurological hospitals in Mexico City. This conclusion differs somewhat from other available literature. For example, a recent systematic review found that epilepsy was the most common clinical manifestation of NCC (58%) followed by severe headache (22%) in neurology clinics in endemic regions.

[81]. However, distribution of clinical manifestations at the community level is unknown.

5.2 NCC socio-demographic characteristics

Humans are exposed to eggs of *T. solium* by autoinfection, by direct contact with another tapeworm carrier, or indirectly by ingestion of food or water contaminated with infected human feces. In this study, 24% of surveyed patients had a history of tapeworms in their feces, indicating that they may have acquired NCC through autoinfection. Others might have acquired the disease from their taeniasis carrier relatives, with 9.0% of patients indicating that they had a relative with taeniasis. However, reports of taeniasis were self reported and therefore, the tapeworms could have been *T. saginata* instead of *T. solium*.

According to the information obtained from this study's questionnaires, 1% of patients reported that they did not currently have a toilet in their home. In some rural areas, even though people have toilets in their homes, they are built in such a way that pigs have direct access to human excrement [86]. Easy access of swine to human feces helps to complete the life cycle of *T. solium* and increase the risk of disease transmission in Mexico. Most of the patients in this study did not know about *T. solium* in pigs or humans and were unaware of the parasite's life cycle. These people were diagnosed with NCC and should be educated about the condition as well as its mode of transmission. While the medical profession is one of the best sources of disease information, it appears that physicians do not always adequately discuss the transmission of *T. solium* with their

patients. Although 59.7% of patients knew about the tapeworm, only 28.3% of these individuals acquired this information from a physician. Physicians should realize that they are not only responsible for treating their patients, but also for providing information about the disease and its mode of transmission. Findings from this study indicate that people in endemic areas of Mexico need better education about the disease and its mode of transmission. Therefore, it is important to find effective methods of providing information to the public to correct this deficit in knowledge.

5.3 Quality of life survey

The SF-12 v2 health survey was chosen to evaluate quality of life of NCC patients compared to an age and sex matched control population due to its brevity and ease of use. Other studies have used this health survey to show a reduction in quality of life due to echinococcosis and migraine [66,67,87]. However, no previous study has compared quality of life of NCC patients with a control population.

When the overall study population was considered, NCC patients scored significantly lower in all eight domains of health compared to controls. In addition, the PCS and MCS were also low compared to the U.S. norms. Findings from this study suggest that NCC not only affects the physical health, but also the mental health of patients. Different clinical manifestations associated with NCC may lead to deteriorated quality of life and, therefore, lower health scores. Various studies have shown that clinical manifestations such as epilepsy, stroke, and migraine reduced the quality of life

of individuals using the SF-12, the Comprehensive Quality of life Scale and the EuroQol Group Index [87,88,89].

This study showed that males with NCC had significantly lower scores in role physical, social functioning, role emotional and mental health. From these findings, it appeared that males were more impaired in mental domains. However, the MCS and PCS were found to be equally lower when compared to US norms. In female patients, all domains, except for general health, were significantly lower compared to an age matched control population. PCS and MCS scores of females compared to U.S. norms were found to be equally affected suggesting that women affected with NCC are impaired similarly in the mental and physical domains. PCS and MCS were low in females compared to males, which suggests that females with NCC are more impaired mentally as well as physically.

This study also compared the quality of life of NCC patients by separating the entire group by age (i.e., younger (≤ 45 years old) versus older (>45 years old)). Younger individuals had significantly lower health scores in all eight domains compared with an age and sex matched control population. MCS scores were more affected than PCS scores when compared to U.S. norms. PCS and MCS scores verified that younger individuals with NCC are more affected mentally. However, in the older group, four domains were not significantly different from the sex and age matched control population. Those domains which were different also did not vary greatly in their actual values. This may be due to the general population of older individuals already having a lower quality of life due to other conditions or circumstances. Mean time since diagnosis

of NCC patients was similar in both the younger and older categories (5.7 and 4.9 years, respectively) suggesting that this difference is not due to acclimatization to their conditions due to the long duration of disease. From norm based summary scores findings, older individuals were more affected physically when compared to U.S. norms.

This study compared the quality of life of those patients who had epilepsy and severe headache as a clinical manifestation separately to the age and sex matched control population. NCC-associated epilepsy outpatients scored significantly lower in all domains except physical functioning and bodily pain. The mean MCS score (43.2) was lower than the mean PCS score (46.4). These findings suggest that NCC patients with epilepsy are more affected in the mental domains. However, NCC-associated severe headache patients were significantly lower in all domains except general health compared to the control population. Their MCS and PCS scores also indicated that they were affected similarly in mental and physical health domains. The mean MCS score of NCC-associated severe headache patients (46.7) was low compared to that of NCC-associated epilepsy patients (43.2) indicating that NCC patients with epilepsy were more affected mentally than NCC patients with severe headache.

Those individuals who were diagnosed more than 6 years ago did not score significantly different in bodily pain, general health and vitality compared to the age and sex matched control population. However, those individuals who were diagnosed less than 6 years ago were significantly different in all eight domains. This may suggest that individuals who were diagnosed longer ago have somewhat acclimated to their situation or that their quality of life has improved due to the treatment they received. However,

PCS and MCS scores were similar in both individuals who were diagnosed less than 6 years ago and more than 6 years ago compared to general U.S. norms suggesting that the mental and physical health states are not associated with the time since diagnosis.

When we compared our findings with another study conducted for people with severe mental illness in the U.S., the mean PCS scores for NCC-associated epilepsy and severe headache (46.4 and 45.8, respectively) were found to be similar to the bipolar group (46.1). However, the mean MCS scores for NCC-associated epilepsy and severe headache (43.2 and 46.7, respectively) were higher compared to the bipolar group (39.6). The mean MCS score for NCC-associated epilepsy was similar to schizophrenia (42.4) whereas the mean PCS score was higher for schizophrenia (48.2). On the other hand, the mean MCS score for NCC-associated severe headache was higher and the mean PCS score was lower compared to schizophrenia.[90] However, these comparisons need to be made with care since the mental illness study was based on the U.S. population and not on the Mexican population. In addition, U.S. norms were used to calculate the PCS and MCS for Mexican NCC patients, which may not be optimal if Mexican and U.S. norms are found to differ substantially.

In order to get an idea of how well the U.S. norms fit the control group, PCS and MCS score for controls were compared to the U.S. norms. The mean PCS score for controls (48.5) was lower compared to U.S. norms whereas the mean MCS score for controls (51.8) was higher suggesting that PCS score for Mexican NCC patients might be overestimated and MCS scores for Mexican NCC patients might be underestimated.

In order to limit information bias in this study, the Mexican Spanish version of the SF-12 v2 was administered to NCC patients by a native Spanish speaking interviewer. However, persons administering the questionnaire were not blinded, which may have resulted in information bias. Similarly, to avoid age as a confounder, controls were matched and were selected from individuals who accompanied non-related patients and could be paired with an NCC patient by sex and age (± 5 years). However, the controls were taken from hospitals and might not represent the general population of Mexico. In order to calculate the PCS and MCS summary scores, factor score coefficients for the U.S. were used due to lack of information specific to the Mexican population. However, using U.S. norms provides a basis of uniformity for cross-national comparisons. This study was also hospital-based, with all NCC patients sampled clinically affected. This will most likely overestimate the overall difference between health domains of NCC patients and the age and sex matched control population.

5.4 Non-monetary burden of NCC in Mexico

This study represents the second study to estimate the burden of NCC using DALYs. The first study, which was conducted in Cameroon, estimated the burden of *T. solium* cysticercosis by calculating human non-monetary burden of disease and both human and animal-associated monetary disease burden [9]. The Cameroon study estimated human NCC burden based on epilepsy alone and used serology to diagnose NCC which has been shown to have poor performance in detecting cases. However, the estimated number of DALYs lost per thousand persons per year was higher in Cameroon

compared to Mexico, since NCC is more prevalent in Cameroon than in Mexico. Although the estimated mean number of DALYs lost per thousand persons per year is higher in Cameroon, the number of NCC-associated epilepsy cases is higher in Mexico compared to Cameroon. This occurs because of the difference in the percentage of NCC patients that receive treatment, with people in Mexico estimated to be four times more likely to receive treatment for epilepsy than people in Cameroon, and the difference in the population size of the two countries [75].

According to 2004 GBD estimates, 1.7 DALYs per thousand persons per year were estimated to be lost due to epilepsy in Mexico, with approximately the same number of DALYs lost due to migraine. Estimated DALYs lost per thousand persons per year for other parasitic diseases in Mexico include ascariasis: 0.05, trichuriasis: 0.10 and hookworm: 0.03 [74]. Compared to these parasitic diseases, DALY estimates for NCC were much higher because NCC not only causes morbidity but also mortality in humans. However, when estimates from the 2004 GBD Study are compared with other independent studies, estimates from the GBD Study tend to be lower. For example, a study conducted in Cameroon estimated 9 DALYs lost per thousand persons per year due to NCC-associated epilepsy [9]. However, according to the 2004 GBD estimate, only 2.45 DALYs per thousand persons per year were lost due to all cases of epilepsy in Cameroon [74]. This suggests that the GBD Study estimates were most likely underestimates. However, the Cameroon study also has to be interpreted with care since it used serology as a diagnostic method and could have potentially overestimated the number of NCC-associated epilepsy cases at the country level.

Numerous studies have tried to evaluate the prevalence of NCC in endemic regions of Mexico [20,56,57,58]. However, none of them have attempted to assess the socio-economic burden of NCC. This study was the first to report an estimate of the non-monetary burden of clinical NCC in Mexico. DALY estimates only incorporate human health losses. However, NCC not only causes losses to human health, but also to the local swine industry. Therefore, NCC causes socio-economic losses which are not accounted for by DALYs. Hence, the total societal burden is higher than that estimated by the number of DALYs lost. Therefore, the monetary burden of *T. solium* in Mexico is currently being estimated as part of a larger project, with the data to be presented in a later publication.

Morbidity of NCC is high compared to mortality [91]. Most of the clinical manifestations associated with NCC cause disability rather than death. The NCC-associated DALYs estimate for Mexico only included two clinical manifestations (severe headache and epilepsy). There were no publications reporting NCC-associated severe headache mortality. Therefore, YLL was calculated using only one clinical manifestation of NCC (epilepsy). This is likely the reason why our study has high YLD and low YLL estimates. A similar study conducted in Cameroon also showed high YLD and low YLL due to NCC-associated epilepsy [9].

Results from this study showed that DALYs lost due to NCC were highest in the 15-44 year age group. Sensitivity analysis results indicated that DALY estimates were mostly affected by disability weights for treated and untreated people who were older than 5 years of age. The number of cases of NCC associated headache and epilepsy were

also highest in the 15-44 year age group, which is similar to other published studies which showed that the peak age of incidence of NCC is in middle aged groups [92]. Therefore, NCC appears to affect those people who are often considered by society to be the most productive.

Since disability weights for NCC were not included in the original GBD studies, it was necessary to use disability weights and duration of clinical manifestations associated with NCC. However, all clinical manifestations (e.g., hydrocephalus, increased intracranial pressure) associated with NCC do not have GBD disability weights. Therefore, further studies are needed to evaluate the disability weights associated with all clinical manifestations associated with NCC.

This study has some limitations. The total estimated number of DALYs lost is most likely underestimated since only the NCC clinical manifestations of epilepsy and severe headache were included. Other symptoms such as stroke and dementia have not been taken into account because very little information is available about these clinical manifestations. Due to the lack of information on NCC-associated severe headache and epilepsy in the original GBD Study, disability weights or epilepsy and migraine were used, with migraine a surrogate for severe headaches. Similarly, information about incidence of epilepsy and severe headaches was not available. Therefore, number of incident cases was calculated using prevalence and overall duration estimates for epilepsy and severe headaches. As the duration of these conditions is not case specific, estimates may lack precision. In addition, mean duration of NCC-associated severe headache was calculated from chart reviews data. This will underestimate the duration

and therefore overestimate the incidence of NCC-associated severe headache. Due to limited country specific data, parameters used for calculating the proportion of NCC patients with epilepsy and the proportion of NCC patients with severe headaches were based on a systemic review of the NCC literature [13,81]. Therefore, additional studies are needed to obtain precise estimates of the socioeconomic impact of NCC in Mexico.

6. SUMMARY AND CONCLUSIONS

NCC continues to be a public health problem in Mexico, with an estimated 0.95 (95%CR: 0.4 – 1.8) DALYs lost per thousand persons per year. NCC produces a variety of clinical manifestations such as severe headache, epilepsy, hydrocephalus, stroke and other neurological symptoms. Severe headaches, epilepsy and hydrocephalus were the most common clinical manifestations reported in this study.

Individuals with NCC had a significantly lower score for all eight domains of health (physical functioning, role physical, bodily pain, vitality, general health, social functioning, role emotional and mental health) measured by the SF-12 v2 health survey compared with an age and sex matched population from the same region. Therefore, NCC appears to impact patients' overall health and their ability to perform daily tasks.

Many of the NCC patients in this study did not know about *T. solium* in pigs or humans. They were unaware of the parasite's life cycle. People in endemic areas of Mexico need better education about the disease and its mode of transmission.

In conclusion, this is first attempt to obtain an estimate of the non-monetary burden of NCC in Mexico using the DALY. These estimates suggest that healthy years of life continue to be lost annually in Mexico, with a continued effort needed to control this parasitic disease in endemic regions.

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APPENDIX A

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	☐	☐☐☐☐☐☐	☐ History ☐ File ☐ Other record
2. Acute symptomatic seizures	☐	☐☐☐☐☐☐	☐ History ☐ File ☐ Other record
3. Single seizure	☐	☐☐☐☐☐☐	☐ History ☐ File ☐ Other record
4. Dementia	☐	☐☐☐☐☐☐	☐ History ☐ File ☐ Other record
5. Hydrocephalus	☐	☐☐☐☐☐☐	☐ History ☐ File ☐ Other record
6. Vasculitis/stroke	☐	☐☐☐☐☐☐	☐ History ☐ File ☐ Other record
7. Increased intracranial pressure	☐	☐☐☐☐☐☐	☐ History ☐ File ☐ Other record

8. Severe headaches (>3 days) ☐ ☐☐☐☐☐☐ ☐ History ☐ File ☐ Other record

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 B

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

15.1 What kind of pigs were they?

☐1 Europeos ☐2 Criollos

☐3 Europeos y Criollos ☐4 Don't know

16. Were you ever told that your pigs or piglets were infected with cysts (cysticercosis)?

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

16.1 When were you told that your pig or piglets were infected with cysts (cysticercosis)?

☐1 In the past year ☐2 One to five years ago

☐3 More than 5 years ago ☐4 Never told

☐5 Don't know

16.1.1 When that happened, were you able to sell your pigs?

☐1 Sold all ☐2 Sold more

☐3 Could not sell ☐4 Don't know

16.1.2 When this happened, at what price did you sell your pigs (aged more than 4 months)? _____

16.1.3 When this happened, at what price did you sell your pigs (aged 4 months or less)? _____

17 Have you ever seen or heard of white nodules (rice) in pig carcasses?

☐1 Yes ☐2 No

17.1 Where can you find nodules on a live pig?

☐1 It is not possible to find them on a live pig

☐2 Under the skin

☐3 Under the tongue

☐4 Don't know

☐5 Somewhere else, please specify_____

17.2 How do pigs get these nodules?

☐1 By eating human feces ☐2 By eating pig feces

☐3 From another infected pig ☐5 Don't know

☐4 Other, please specify_____

17.3 What would you do if you discovered that your pig had nodules?

☐1Sell the pig ☐2 Treat it with herbs

☐3 Pierce the nodules ☐5 Don't know

☐4 Other, please specify_____

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

20 Have you ever had bad headaches that lasted more than a few days?

☐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

21 Have you ever had any of the following?

21.1 Sudden loss of consciousness and episodes of incontinence or foaming of the mouth or tongue biting?

☐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

21.1.1 If yes, how often has this happened?

☐1Only once ☐2 More than once

21.1.2 How old were you when this happened for the first time?

☐1 When I was a child (less than 15 years old)

☐2 When I was juvenile (15-19 years old)

☐3 When I was an adult (more than 20 years old)

☐4 Don't know

21.1.3 When did this occur for the first time?

☐1 In the last twelve months ☐2 One to two years ago

☐3 Three to four years ago ☐4 More than 5 years ago

☐5 Don't know

21.2 A brief period of absence(s) or loss(es) of contact with the surroundings that starts suddenly?

☐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

21.2.1 If yes, how often has this happened?

☐1Only once ☐2 More than once

21.2.2 How old were you when this happened for the first time?

☐1 When I was a child (less than 15 years old)

☐2 When I was juvenile (15-19 years old)

☐3 When I was an adult (more than 20 years old)

☐4 Don't know

21.2.3 When did this occur for the first time?

☐1 In the last twelve months ☐2 One to two years ago

☐3 Three to four years ago ☐4 More than 5 years ago

☐5 Don't know

21.3 Uncontrollable twitching or jerking or abnormal movements of one or more limb(s) (convulsions) that starts suddenly and lasts for a period of a few minutes?

☐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

21.3.1 If yes, how often has this happened?

☐1Only once ☐2 More than once

21.3.2 How old were you when this happened for the first time?

☐1 When I was a child (less than 15 years old)

☐2 When I was juvenile (15-19 years old)

☐3 When I was an adult (more than 20 years old)

☐4 Don't know

21.3.3 When did this occur for the first time?

☐1 In the last twelve months ☐2 One to two years ago

☐3 Three to four years ago ☐4 More than 5 years ago

☐5 Don't know

21.4 Sudden onset of a brief period of hearing or smelling or seeing things that are not there or feeling strange body sensations?

☐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

21.4.1 If yes, how often has this happened?

☐1Only once ☐2 More than once

21.4.2 How old were you when this happened for the first time?

☐1 When I was a child (less than 15 years old)

☐2 When I was juvenile (15-19 years old)

☐3 When I was an adult (more than 20 years old)

☐4 Don't know

21.4.3 When did this occur for the first time?

☐1 In the last twelve months ☐2 One to two years ago

☐3 Three to four years ago ☐4 More than 5 years ago

☐5 Don't know

21.5 Were you ever told that you had epilepsy or that you had an epileptic seizure?

☐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

21.5.2 How old were you when this happened for the first time?

☐1 When I was a child (less than 15 years old)

☐2 When I was juvenile (15-19 years old)

☐3 When I was an adult (more than 20 years old)

☐4 Don't know

21.5.3 When did this occur for the first time?

☐1 In the last twelve months ☐2 One to two years ago

☐3 Three to four years ago ☐4 More than 5 years ago

☐5 Don't know

21.6 Have you ever had seizures or fits?

☐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

21.6.1 If yes, how often has this happened?

☐1Only once ☐2 More than once

21.6.2 How old were you when this happened for the first time?

☐1 When I was a child (less than 15 years old)

☐2 When I was juvenile (15-19 years old)

☐3 When I was an adult (more than 20 years old)

☐4 Don't know

21.6.3 When did this occur for the first time?

☐1 In the last twelve months ☐2 One to two years ago

☐3 Three to four years ago ☐4 More than 5 years ago

☐5 Don't know

If the interviewee has answered "no" to questions 21.1-21.6, the interview is finsished. Otherwise, please continue with the questionnaire.

22 Have you had the following?

22.1 Head injury that made you lose consciousness?

☐1 Yes ☐2 No

22.2 Meningitis (brain infection) during childhood?

☐1 Yes ☐2 No

22.2.1 If yes, when did your seizure symptoms start?

☐1 Before meningitis ☐2 Soon after meningitis

☐3 Long time after meningits ☐4 Don't know

23 What happens to you when you have a seizure or fit?_____

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 <u>last</u> 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

27. Have you ever been hospitalized because of this condition?

☐2 No ☐3 Cannot remember

☐1 Yes

27.2 How many times have you been hospitalized in the past 5 years?_____

27.3 When were you last hospitalized (in months)?_____

27.3.1 How many days did you stay in the hospital?_____

27.3.2 How much did it cost?_____

27.3.3 How far is the hospital from your house (in km)?_____

27.3.4 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 _____)

28. Did you ever have any medical tests because of this condition?

☐2 No ☐3 Cannot remember

☐1 Yes

28.2 What kind of test was it (check all that are appropriate)?

☐1 Blood test for cysticercosis ☐2 CT scan of the brain

☐3 X-ray of the brain ☐4 MRI of the brain

☐4 EEG ☐5 Cannot remember, do not know

28.3 When was the last time you had a medical test for this condition?

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

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

☐5 Don't know

28.4 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 Blood test for cysticercosis_____ ☐2 CT brain scan_____

☐3 Skull X-ray_____ ☐4 MRI of the brain_____

☐5 EEG_____ ☐6 Other _____

28.5 How far from your house did you have to travel for this test and how did you get there?

☐ Blood test for cysticercosis / _____ km reached by___

☐2 CT brain scan ____ km reached by___

☐3 Skull X-ray ____ km reached by____

☐4 MRI of the brain ____ km reached by____

☐5 EEG _____ km reached by_____

☐6 Other _____ km reached by_____

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

29.2 When was the last time you used medication 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

29.3 What medication was it and how many times per year did you have to use some?

☐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

29.4 How much did it cost each time you bought this medication?

☐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 C

PIG QUESTIONNAIRE

District _____

Village _____

Hut (house) number _____

Last Name : _____ First Name _____

What is your position in the household?

☐1 Household head (mother) ☐2 Household head (father)

☐3 One of the daughters ☐4 One of the sons

☐6 Other [*Specify*]_____

[*Interviewer: If the person currently keeps pig, go to Q2, if the person owned pigs in the past, go to Q12]*

2. How many of each type of pig do you keep? [mark all that apply]

☐1 Foreign _____ ☐2 Native _____

☐3 Doesn't know type, but total number is _____

☐4 Does not know number or type_____

3. How many of these pigs are owed by your household? _____

[*indicate a number*]

4. How many pigs do you keep for each of these reasons? [*Read each option and indicate the number kept for that reason*]

☐ Home eating _____ ☐ Sell live animals (not to abattoir)

☐ Sell the meat to someone else _____ ☐ Sell the pig to the abattoir _____

☐ Raise pigs _____ ☐ Other [*Specify*]_____

5. How do you keep your pigs? [*read questions 5.1 to 5.4 one by one*]

5.1 During seeding season

☐ In a pen ☐ Free range

☐ Tethering (tied up?) ☐ Other [*Specify*]_____

5.2 During growing season

☐ In a pen ☐ Free range

☐ Tethering ☐ Other [*Specify*]_____

5.3 During cropping season

☐ In a pen ☐ Free ranged

☐ Tethering ☐ Other [*Specify*]_____

5.5 During fallowing season

☐ In a pen ☐ Free ranged

☐ Tethering ☐ Other [*Specify*]_____

6. What do your pigs eat? [*check all that apply*]

☐ Pasture ☐ Kitchen leftovers

☐ Commercial feeds ☐ Other [*Specify*]_____

7. How often do you slaughter pigs at home?

☐ Never [*Skip to Q 8*]

☐ Cannot remember, do not know [*Skip to Q8*]

☐ At least once a month

☐ Less than once a month but at least once a year

☐ Less than once a year

7.1 If ever, how often was the meat inspected by a meat inspector?

☐ Always ☐ Almost always

☐ Sometimes ☐ Never

☐ Cannot remember, do not know

8. What price do you usually sell your pigs when they are ready to be slaughtered [*specify the currency used, this can be money or barter*]? _____

8.1 What price do you usually sell your live pigs to someone else to raise [*specify the currency used, this can be money or barter – specify prices at different pig weights if necessary*]? _____

8.2 What price do you usually sell mature sows to someone else for raising? [*specify the currency used, this can be money or barter]*

_____

9. What price do you usually sell your piglets (aged 4 months or less) [*specify the currency used, this can be money or barter*]? _____ [*Skip to Q11*]

10. For what do you use the profits from selling your pigs ? *[check all that apply]*

☐ To send children to school ☐ To buy food

☐ To invest in a business ☐ For savings

☐ Other [*Specify*] _____

11. Have you ever seen or heard of white nodules (rice) in pig carcasses?

☐ Yes ☐ No [*Interview is over*]

11.1 Where can you find nodules on a live pig?

☐ It is not possible to find them on a live pig

☐ Under the skin ☐ Under the tongue

☐ I don't know ☐ Somewhere else [*Specify*]_____

11.2 How do pigs get these nodules?

☐ By eating human faeces ☐ By eating pig faeces

☐ From another infected pig ☐ Other [*Specify*] _____

☐ I don't know

11.3 What would you do if you discovered that your pig had these nodules?

☐ Sell the pig ☐ Treat it with herbs

☐ Pierce the nodules ☐ Other [*Specify*] _____

☐ I don't know

11.4 What price could you sell a pig with nodules when they are ready to be slaughtered [*specify the currency used, this can be money or barter*]?

_____

11.4.1 What price would you sell a live pig with nodules to someone else for raising?

_____

11.4.2 What price would you sell a mature sow with nodules to someone else for raising?

_____

11.5 What price could you sell piglets with nodules (aged 4 months or less) [*specify the currency used, this can be money or barter*]?

_____

THIS IS THE END OF THE INTERVIEW

THANK YOU VERY MUCH FOR YOUR HELP

INTERVIEWER: _____DATE OF INTERVIEW:_____

APPENDIX D

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)

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_____ ☐

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 E

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 F

Cuestionario sobre cerdos para la gente que cría cerdos

Municipio_____

Comunidad _____

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

Apellido _____ Nombre _____

Número de expediente_____

[*Entrevistador: Si la madre dijo que ella se encarga de los cerdos, lea lo siguiente*]:

Como usted está encargada de los cerdos nos gustaría hacerle algunas preguntas sobre sus cerdos.

[*Entrevistador: Si la persona que se encarga de los cerdos no es la madre, lea lo siguiente*]:

El ama de casa nos dijo que usted se encarga de los cerdos, nos permite hacerle algunas preguntas sobre ellos.

¿Cuál es su posición en el hogar?

☐1 Jefe del hogar (madre) ☐2 Jefe del hogar (padre)

☐3 Una de las hijas ☐4 Uno de los hijos

☐6 Otra [*Especifique*]_____

2. ¿Cuántos cerdos de cada tipo tiene?

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

☐3 No sabe el tipo, pero el número total es _____ ☐4 No sabe el número o tipo

3. ¿Cuántos de estos cerdos son propiedad del hogar? _____ [*indique un número*]

4. ¿Para qué cría cerdos? [*Lea cada opción e indique el número que se cría por esa razón*]

☐ 1. Para comer en casa _____

☐ 2. Vender animales en pie (no en rastro)_____

☐ 3. Vender la carne _____ ☐ 4. Criar cerdos _____

☐ 5. Otra razón [*Especifique*]_____ ☐ Vender el cerdo al rastro_____

5. ¿Cómo cría a sus cerdos? [*Lea las preguntas 5.1 a 5.4 una por una*]

5.1 Durante la temporada de siembra:

☐ En un corral ☐ Libres

☐ Amarrados ☐ Otro [*Especifique*]_____

5.2 Durante la temporada de siembra y/o del crecimiento de sus sembradíos:

☐ En un corral ☐ Libres

☐ Amarrados ☐ Otro [*Especifique*]_____

5.3 Durante la temporada de cosecha:

☐ En un corral ☐ Libres

☐ Amarrados ☐ Otro [*Especifique*]_____

5.5 Durante la temporada de barbecho o rastrojo:

☐ En un corral ☐ Libres

☐ Amarrados ☐ Otro [*Especifique*]_____

6. ¿Qué comen los cerdos? [*Marque todas las que se apliquen*]

☐ Pasto ☐ Sobras de la cocina

☐ Alimentos comerciales ☐ Tortillas

7. ¿Con qué frecuencia sacrifica a los cerdos en casa?

☐ Nunca [*Pase a la 8*] ☐ No recuerdo, no sé [*Pase a la 8*]

☐ Por lo menos una vez al mes ☐ Menos de una vez al año

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

7.1 El cerdo que sacrifica, lo revisa un inspector o un veterinario?

☐ Siempre ☐ Casi siempre

☐ A veces ☐ Nunca

☐ No recuerdo, no sé

8. Por lo general, ¿a qué precio vende sus cerdos cuando están listos para ser sacrificados? [*Especifique la unidad monetaria que usa, puede ser dinero o trueque*]?

_____

8.1 Por lo general, ¿a qué precio vende sus cerdos pequeños (cuando ya no maman) para que alguien mas los críe o los coma?

8.2 Por lo general, ¿a qué precio vende sus pies de cria?

9. Por lo general, ¿a qué precio vende sus cerditos de 4 meses o menores [*Especifique la unidad monetaria usada, puede ser dinero o trueque*]?

10. ¿Para qué usa las ganancias de la venta de sus cerdos? *[Marque todas las que se apliquen]*

☐ Para enviar a los niños a la escuela ☐ Para comprar comida

☐ Para invertir en un negocio ☐ Para ahorrar

☐ Otro [*Especifique*]

_____

11. ¿Ha visto o escuchado alguna vez sobre el grano, granillo o tomate de los cerdos?

☐ Sí ☐ No [*Termina la entrevista*]

11.1 ¿En que partes del cerdo vivo se pueden encontrar el grano, granillo o tomate?

☐ No es posible encontrarlos en un cerdo vivo

☐ Debajo de la piel ☐ Debajo de la lengua

☐ En la carne ☐ En los ojos

☐ En algún otro lugar [*Especifique*]_____ ☐ No lo sé

11.2 ¿Cómo le salen el grano, granillo o tomate a los cerdos?

☐ Por comer excremento/heces humanas ☐ Por comer excremento/heces de cerdo ☐ De otro cerdo infectado ☐ Otro [*Especifique*] _____

☐ Por comer semillas de jitomate ☐ No lo sé

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

☐ Lo vendería ☐ Lo trataría con hierbas

☐ Picaría los granos ☐ Otro [*Especifique*] _____

☐ No lo sé

ÉSTE ES EL FINAL DE LA ENTREVISTA, MUCHAS GRACIAS POR SU AYUDA

ENTREVISTADOR: _____FECHA DE LA ENTREVISTA:_____

APPENDIX G

Su Salud y Bienestar

Esta encuesta le pide su opinión acerca de su salud. Esta información permitirá saber cómo se siente y qué tan bien puede hacer usted sus actividades normales. ***¡Gracias por contestar estas preguntas!***

Por cada una las siguientes preguntas, por favor marque con una ☒ el cuadrito que mejor describa su respuesta.

1. **En general, ¿diría usted que su salud es:**

Excelente	Muy buena	Buena	Regular	Mala
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

2. **Las siguientes frases se refieren a actividades que usted podría hacer durante un día normal. ¿Su estado de salud actual lo/la limita para hacer estas actividades? Si es así, ¿cuánto?**

	Sí, me limita mucho	Sí, me limita un poco	No, no me limita en absoluto
a. Actividades moderadas, tales como mover una mesa, barrer, trapear, lavar, jugar béisbol, montar bicicleta	☐ 1	☐ 2	☐ 3
b. Subir varios pisos por la escalera	☐ 1	☐ 2	☐ 3

3. **Durante las <u>últimas cuatro semanas</u>, ¿cuánto tiempo ha tenido usted alguno de los siguientes problemas con el trabajo u otras actividades diarias normales <u>a causa de su salud física</u>?**

	Siempre	Casi siempre	Algunas veces	Casi nunca	Nunca
a. <u>Ha logrado hacer menos</u> de lo que le hubiera gustado	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b. Ha tenido limitaciones en cuanto al <u>tipo</u> de trabajo u otras actividades	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

4. **Durante las <u>últimas cuatro semanas</u>, ¿cuánto tiempo ha tenido usted alguno de los siguientes problemas con el trabajo u otras actividades diarias normales <u>a causa de algún problema emocional</u> (como sentirse deprimido/a o ansioso/a)?**

	Siempre	Casi siempre	Algunas veces	Casi nunca	Nunca
a. <u>Ha logrado hacer menos</u> de lo que le hubiera gustado	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b. Ha dejado de hacer su trabajo u otras actividades <u>con menos cuidado</u> de lo usual	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

5. **Durante las <u>últimas cuatro semanas</u>, ¿cuánto el <u>dolor</u> le ha dificultado su trabajo normal (incluyendo tanto el trabajo fuera de casa como los quehaceres domésticos)?**

Nada	Un poco	Más o menos	Mucho	Demasiado
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

6. **Estas preguntas se refieren a cómo se ha sentido usted durante las últimas cuatro semanas. Por cada pregunta, por favor dé la respuesta que más se acerca a la manera como se ha sentido usted. ¿Cuánto tiempo durante las últimas cuatro semanas…**

	Siempre	Casi siempre	Algunas veces	Casi nunca	Nunca
a. se ha sentido tranquilo/a y sosegado/a?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b. ha tenido mucha energía?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
c. se ha sentido desanimado/a y triste?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

7. **Durante las últimas cuatro semanas, ¿cuánto tiempo su salud física o sus problemas emocionales han dificultado sus actividades sociales (como visitar amigos, parientes, etc.)?**

Siempre	Casi siempre	Algunas veces	Casi nunca	Nunca
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

¡Gracias por contestar estas preguntas!

VITA

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