HEALTHCARE PROVIDERS' AND COMMUNITY LEADERS' KNOWLEDGE AND PERCEPTIONS OF NEUROCYSTICERCOSIS IN RURAL BOLIVIA

by

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Final approval and acceptance of this dissertation is contingent upon the candidate's submission of the final copies of the dissertation to the Graduate College.

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DEDICATION

This work is dedicated in loving memory to my father, Edward Alberts.

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ABSTRACT

Background: Neurocysticercosis (NCC) is a preventable infectious disease that is considered a major cause of epilepsy in developing nations. Bolivia is one of the least developed nations in Latin America and in rural Bolivia persons with epilepsy (PWE) go largely without treatment. Epilepsy is a devastating disease that has the capacity to significantly decrease the quality of life, not only for PWE, but for their families as well. The development and implementation of a self-sustainable program for the prevention and treatment of NCC and the consistent treatment of epilepsy is essential. However, research on epilepsy and NCC in Bolivia, whether in the urban or rural population, is extremely sparse. The central premise of this study is that rural Bolivian communities have the need for a self-sustaining program for the treatment of epilepsy and for the prevention of NCC.

Purpose: Using a qualitative descriptive design, the purpose of the proposed study is to determine the knowledge and their perceptions of community barriers and facilitators among health care providers and community leaders regarding NCC and epilepsy.

Sample: A sample of 12 health care providers and community leaders representing 14 communities in the Bajo Isoso district, El Chaco region, Bolivia were included.

Methods: Gatekeepers were identified and assisted with entry into the communities and identification of participants. A semi-structured interview format was used to elicit participant descriptions of knowledge of cysticercosis and epilepsy, and of their perceptions of community barriers and facilitators regarding cysticercosis and epilepsy. Individual interviews were audio-recorded, transcribed, coded manually, and analyzed using the content analysis method.

Findings: Data analysis revealed four major themes; Knowledge of Cysticercosis, Resource Availability Related to Cysticercosis, Perceptions of Responsibility for Addressing Cysticercosis, and Perceptions of Impact of Cysticercosis on the Community. Relating to the conceptual model PRECEDE-PROCEED used in this work, resource availability was an enabling factor, while the other themes were predisposing factors of the problem. Major findings of this study were that knowledge about cysticercosis and epilepsy was lacking, resources to address cysticercosis were severely limited, that community members perceived the problem as highly significant and needing to be urgently addressed, and that there were positive attitude toward accepting community responsibility for addressing the problem of cysticercosis.

Implications: This study suggests that lacking resources is a major factor impacting the problem of neurocysticercosis in the region, and that education to address gaps in knowledge, in collaboration with the community leaders, would be an appropriate and effective next step in working towards development of a self-sustaining program for the prevention and treatment prevention of NCC.

CHAPTER I: INTRODUCTION

Neurocysticercosis

Neurocysticercosis (NCC) is a preventable infectious disease that increases the prevalence rate of epilepsy by an estimated 30% in endemic nations (Bruno et al., 2013; Del Brutto, 2014a). It is caused by infection with *Taenia solium,* or tapeworm, in its larval state, and transmitted through consumption of eggs found in contaminated water, or passed through poor hygiene. Considered a major neglected tropical disease by the World Health Organization (WHO), it is endemic to most resource poor nations (Bruno et al., 2013; Del Brutto, 2014; WHO, 2016). Prevalence data varies widely and much of it is dated, particularly in low-middle income nations (Bruno et al. 2015). However, NCC is considered a major cause of epilepsy in developing nations (Coyle et al., 2012; Mewara, Goyal, & Sehgal, 2013). As one of the most frequent parasitic diseases of the central nervous system (CNS), NCC is regarded a biological marker of socio-economic development, since it is highly endemic in resource-poor areas, where conditions lead to its occurrence, for instance, where pigs have access to human feces for ingestion (Mewara, Goyal, & Sehgal, 2013).

Bolivia and NCC

Bolivia is a landlocked nation in South America that is among the poorest in the western hemisphere, and one of the least developed in Latin America, with 45% living below the poverty line (Central Intelligence Agency [CIA], 2017). In rural Bolivia persons with epilepsy (PWE) go largely without consistent treatment (Bruno et al., 2015). Significantly, its rural population

represents approximately 32% of its total population, and approximately 95% of these people live in deep poverty (CIA, 2017).

Virtually all of the prevalence statistics regarding epilepsy and NCC in Bolivia stem from a set of studies carried out by the Global Campaign Against Epilepsy in a joint initiative of the International League Against Epilepsy and WHO between 1998 and 2015 in the Santa Cruz region (Bruno et al., 2011; 2012; 2015; Nicoletti et al., 1998; 1999; 2000; 2002; 2005; 2009; 2017). In the epileptic population of the Santa Cruz region of Bolivia studied in 2001, 27.4% had evidence of probable NCC related seizures, and 90% of these did not receive consistent anti-epileptic treatment (Nicoletti et al., 2005). The follow up study of the same cohort helped describe the natural history of these patients. While a portion of epileptic persons goes into remission spontaneously, NCC increases the risk of death up to three times in the population they studied (Nicoletti et al., 2009).

Epilepsy is a devastating disease that has the capacity to significantly decrease the quality of life, not only for PWE, but for their families as well. The development and implementation of a self-sustainable program for the prevention and treatment of NCC and the consistent treatment of epilepsy is essential to their wellbeing. However, research on epilepsy and NCC in Bolivia, whether in the urban or rural population, is extremely sparse (Bruno et al., 2013; 2015).

To reach the goal of developing an intervention that will help this population create and maintain a sustainable treatment program for patients with epilepsy in rural areas, it is imperative to create and share data. Research and knowledge is vitally important to the creation and development of a working, sustainable disease control and health care system (WHO, 2012).

Preliminary studies establishing community needs are an important first step to achievement of the long-term goal.

Moreover, a sustainable intervention must have community buy-in. To achieve this stakeholder perspectives and needs must be assessed (Pelletier, Corsi, Hoey, Faillace, & Houston, 2011; Velasquez, Knatterud-Hubinger, Narr, Mendenhall, & Solheim, 2011). Community participation in the processes of planning and research builds sustainability and buy-in (Velasquez et al., 2011).

In summary, NCC significantly impacts epilepsy rates in developing nations, increasing them by as much as 30%. It is considered by the WHO and CDC to be a major neglected tropical disease. Bolivia's rural population is particularly susceptible since conditions there are ideal for disease proliferation, including low education levels, poverty, poor access to clean water and hygienic facilities, pig farming, and close contact with pigs. By studying this population, and assessing knowledge, needs, barriers, and facilitators to treatment, it was hoped that valuable information would be derivable, applicable, and generalizable to broader populations bringing us closer to the development of interventions that will be widely beneficial.

Exploratory Work

Important exploratory work related to the current study occurred in 2014-18 and is described here. Consistent with CBPR research (discussed in detail below) exploratory trips were undertaken to gather information about community structure, the health care system and cultural norms within the region of interest. The findings of our exploratory work and specific characteristics of the villages and people are described below and set the stage for the current study.

TABLE 1. *Exploratory work by visit, contacts made and outcomes.*

Visit	Contacts	Outcomes
1st - Accompanied Helping Hands, an American lead medical mission to Bolivian villages in the Chapare Province	Chief Executive Officer of Cup of Cold Water Ministries (CCWM) in La Paz, Bolivia and the gatekeeper for Helping Hands mission – CCWM is a group that organizes medical missions traveling to remote villages and providing basic healthcare, referrals and assistance to reach cities that can provide higher level care	Familiarity with Bolivian village life and cultures, as well as with infrastructures providing basic health care and sanitation services.
2nd - Travel with Helping Hands to another region of Bolivia, to remote villages in the Altiplano	Again – met with the above mentioned representative of local medical mission group	Deepening familiarity with specific villages in Bolivia that might be included in the current study as well as with the region of the Altiplano and variance of cultural/ethnic groups within Bolivia. Based on this visit Dept. of Santa Cruz, Cordillera Province was chosen.
3rd - Personal travel to the target region, the Dept. of Santa Cruz, the Cordillera Province	Met with some of the members of the research group that published the bulk of previous research on Epilepsy and NCC in Bolivia, and with an affiliated group providing medical care there, the Convenio de Salud. Also met with members of CCWM village nurses, teachers, and leaders (captains). In the nearby town of Camiri I met local nurses and physicians and different levels of care facilities were visited.	Chose the region El Chaco, and became familiar with the culture, infrastructure, and ethnic group. Deepened knowledge about the research done on NCC and epilepsy and the ongoing involvement of that group in the province. Deepened connection with a Cold Cup of Water and planning for future trips. After this trip a representative from CCWM traveled to the region in the name of this research project and met the mayor of a larger city near the rural area in question (Camiri). From there we were directed to the Asamblea del Pueblo Guarani (representatives of the tribe). From this trip we chose the territory of Isoso as the targeted territory.
4th - Travel to the territory of Isoso, the final targeted territory with a medical mission associated with a CCWM.	Village leaders, the Asamblea del Pueblo Guarani, Anthropologist/Guarani language teacher	Traveled to villages in the targeted territory of Isoso, met with leaders to ascertain interest and receive permission to return. Met with the Asamblea del Pueblo Guaraní representing the Guaraní tribe and including several of the abovementioned leaders to determine final route and to obtain permission for the research from the tribe.

Specific characteristics of the villages included in this study are listed below. With respect to community structure we found:

- Village leaders make most of the village decisions regarding events, and formal interaction with the community, including visiting health care workers
- Schools are the central gathering place for almost all events
- Visiting health care workers are revered
- Typically, the only running water (toilets & showers) is at the school; running water may not be available at all. Water may be delivered to the villages in barrels, hand pumped water from wells, collected in rain reservoirs or collected from natural ponds where animals (e.g., pigs) often gather
- Toileting is often done “in the air” or in public latrines
- There are no paved roads. Road conditions are subject to severe weather; rainy season is four months long, and travel in and out of villages is severely limited at this time
- Many people have cell phones; regional cell phone service only and service is patchy

With respect to the health care system:

- Health care access is extremely limited.
- There are no hospitals in any of the villages; the closest hospitals are hours or days away, weather and road conditions can severely lengthen travel time to healthcare access. Even to reach a small clinic with a nurse may take a villager all day. Not everyone has access to cars.
- Health care may be provided by a nurse in the village or villagers may need to travel to other nearby villages for assistance

- Visiting clinics arrive rarely, if ever, and when they do provide care, it is basic health care (provision of antibiotics, anti-parasitics, anti-inflammatories, basic assessments, and referrals)
- We also found that the communities in the Chaco region had initiated steps towards identifying and treating those with epilepsy. This work is carried out largely through the volunteer efforts of one neurologist from the city of Santa Cruz
- There remain problems with consistently attaining antiepileptic drugs (AEDs), compliance with treatment plans and assessment of patients in the area.
- There is not a local neurologist and there are no facilities appropriate for neurosurgery

With respect to cultural norms, we found that:

- In some villages that raise pigs, they roam freely, with access to human waste, and human living quarters, cooking areas, water, public spaces, etc.
- Cooking areas are often outside the homes which are very small
- Principle languages are Guaraní primarily, and Spanish secondarily
- The people have a strong oral communication style
- Decisions for the village are made in groups that include the community leaders
- The villagers appear to be reserved when approached by strangers

As a result of these exploratory trips the final advisory board, the village gatekeepers and translators for this study were identified:

- *The advisory board* was a member of the Asamblea del Pueblo Guaraní (APG), who is also a veterinarian and is from the territory of Isoso but lives in the city of Santa Cruz de la Sierra; the Chief Executive of a CCWM based in La Paz, Bolivia, and veteran clinic

organizer; a Bolivian neurologist that lives Santa Cruz and occasionally travels to the villages to provide volunteer neurologic services; and an anthropologist/teacher of Guaraní native to the territory of Isoso, now residing in the city of Santa Cruz de la Sierra.

- *The village gatekeepers* were members from CCWM (either the above noted chair or another group representative); and village residents appointed by the APG at a meeting upon arrival to Santa Cruz, prior to travel to the villages.
- *Translators* were volunteers from CCWM, native to Bolivia and fluent in English as well as Spanish.

In the naming of these group members it happened that persons served in multiple groups. In this dissertation, the terms *advisory board, gatekeepers,* and *translators* refer to those identified above.

In summary, the development and institution of a self-sustainable program for the prevention and treatment of NCC is essential to the wellbeing of PWE in this region and is a long-term goal of this researcher. Currently, research on epilepsy and NCC in this region is extremely limited (Bruno et al., 2013; 2015). Establishing community knowledge/beliefs, strengths and needs regarding epilepsy are an important first step to achieving the long-term goal. Similarly, a successful sustainable intervention requires community buy-in. To achieve this goal stakeholder perspectives, needs, and strengths must likewise be assessed (Pelletier et al., 2011; Velasquez et al., 2011). Importantly, community participation in the processes of planning and research builds sustainability and buy-in (Velasquez et al., 2011). This study hoped to build on the work done thus far (Bruno et al., 2011; 2012; 2015; Nicoletti et al., 1998; 1999; 2000;

2002; 2005; 2009). Through interviews with healthcare providers and community leaders regarding their knowledge of epilepsy and NCC, as well as their perceptions of community strengths and needs related to these challenges, guidelines for a future intervention for NCC may be designed.

Statement of Purpose and Specific Aims

The central premise of this study was that rural Bolivian communities have the need for a self-sustaining program for the treatment of epilepsy and for the prevention of NCC. As a first step toward meeting that need, *the purpose of the proposed study was to determine health care providers and community leaders knowledge and their perceptions of community barriers and facilitators regarding NCC.*

Specific aims of this project were as follows:

1. Determine health care providers and community leaders knowledge of NCC considering:
    - How NCC is acquired, treated, recognized, and prevented.
    - The degree to which they see NCC as a problem, including impact on quality of life, and understanding and appreciation of the long-term consequences of chronic untreated epilepsy from NCC.
2. Determine health care providers and community leaders perceptions of barriers and facilitators to NCC treatment and prevention, considering:
    - How they view resources, such as clean water, money for treatment and for travel to appropriate treatment facilities, availability of local facilities that can manage the problem, transportation, providers equipped to diagnose and manage the problem, medication, and specialized diagnostics.

- How they view the degree to which community knowledge (or lack thereof) and beliefs (such as traditional/spiritual views on etiology and meaning of epilepsy) affect treatment and prevention.
- How they view their community's desire and sense of urgency to address NCC and epilepsy.

Significance

The impetus of this study was the hope that the findings would add to the limited body of research done in Bolivia on epilepsy and NCC, along with related needs and potential interventions. It was meant as a starting point to building an intervention to prevent and treat NCC. The study assessed health care providers and community leaders knowledge and perceptions of needs, facilitators, and barriers that might impact future interventions to prevent and treat NCC. It was hoped that the findings of this study would have the potential to be generalizable to other regions in Bolivia, as well as to communities outside of Bolivia.

Theoretical Framework

Community Based Participatory Research

Rural Bolivia provides an ideal environment for the proliferation of NCC, because poverty is the norm, and clean water, sanitation infrastructure, healthcare, and education are limited. It can be argued that rural Bolivians are marginalized through economic standing, as well as through racial and lingual differences. Most of the people in these areas are indigenous, and often their first language is an indigenous one rather than Spanish. In the Department of Santa Cruz, the primary language in small communities is Guaraní. A modified community-based participatory research (CBPR) approach was taken, since the original topic was decided on

independently, and not in collaboration with the community. Gatekeepers from the community who speak Guaraní were included in the project for admission into the communities, for cultural translation, as well as for project design participation.

CBPR requires the research to be an equitable working partnership between the researcher and the community being evaluated, and requires community participation in the research process, expertise, and decision-making (Israel, Eng, Schulz, & Parker, 2013). Research is intentional, such that it follows a defined topic, while allowing for alteration in method as required by participants and the project itself (Chenail, St George, Wulff, & Cooper, 2012). The goal is to improve health and quality of life in the community through increased knowledge and understanding of the topic as defined, and subsequently through interventions developed from the knowledge gained (Israel, Eng, Schulz, & Parker, 2013). Inherent in the process is community ownership and responsibility for the problem through the work of changing the conditions leading to it (Chenail, St George, Wulff, & Cooper, 2012). CBPR seeks to understand problems in the context of health inequities, such as poverty, lacking access to care, racism, and exposure to toxic substances, within the cultural context of the partner community (Israel, Eng, Schulz, & Parker, 2013).

While the following principles may not apply to each situation, they represent the guiding tenets of CBPR as revealed through a literature review carried out by Israel et al., (2013). They include recognition of community as a unit of identity; building on communal strengths and resources; facilitation of equitable partnership in all phases of the work; shared learning and capacity building for all members; balance of knowledge gained and intervention benefiting participants; focus on local relevance of the problem; system development that incorporates all

phases of the project in a cyclical manner and draws from the knowledge gained; participant receipt of all results and inclusion in wider dissemination of results; and a commitment to long term sustainability (Israel, Eng, Schulz, & Parker, 2013).

The main phases of CBPR (Figure 1) can be regarded in a more circular than linear fashion, and include core components as follows: formation of partnership; assessment of community strengths and dynamics; identification of main community concerns; design of research and implementation of intervention; research findings presented to community and interpreted; dissemination and translation of findings; and maintenance and evaluation of the work (Israel, Eng, Schulz, & Parker, 2013).

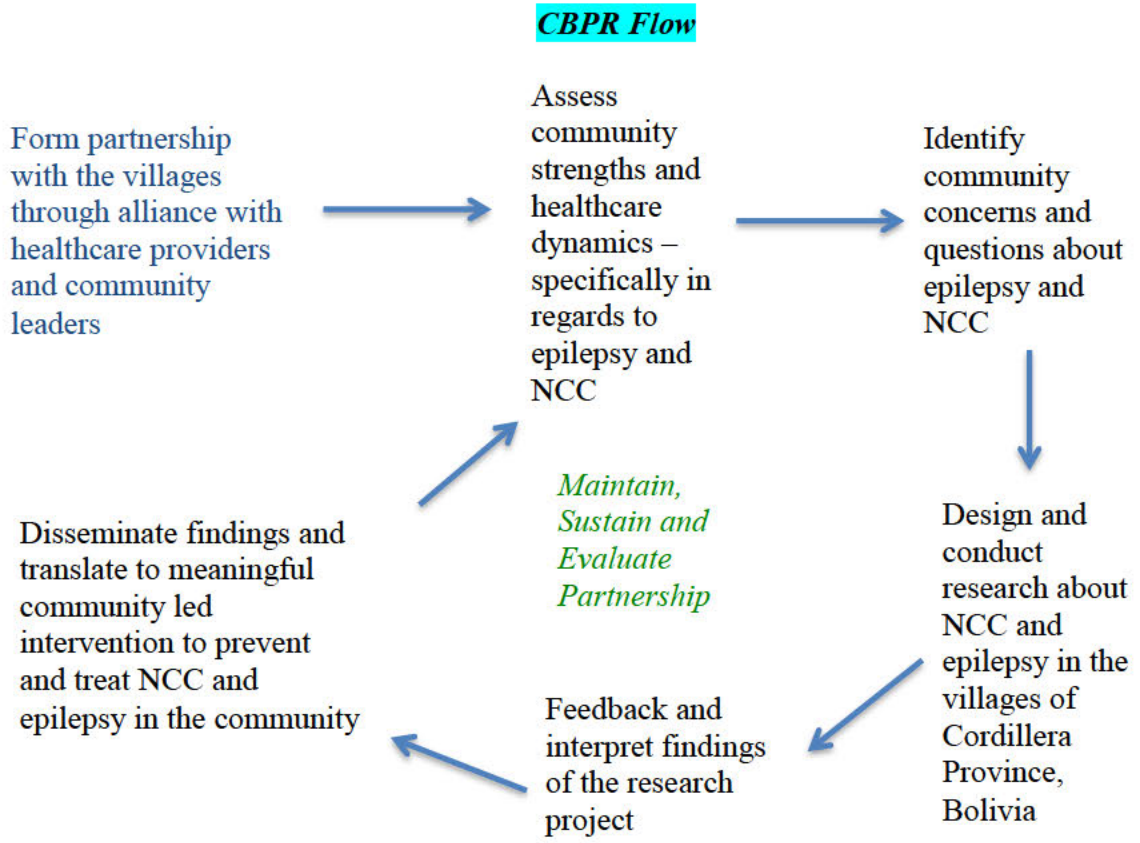


FIGURE 1. CBPR flow. (Adapted from Israel BA, Coombe C & McGranghan R. (2010). *Community-based participatory research: a partnership approach for public health* (CD-ROM). Available from http://sitemaker.umich.edu/cbpr/home)

Figure 1 depicts the CPBR flow specific to this study. The study began with the establishment of a partnership in the Santa Cruz region of Bolivia. Villages are very small so several rural locations in the region were appropriate to partner with in order to form an adequate sampling. It was important to identify members to the partnership, including those with expertise and interest in the issue. Original partners assisted in this determination, referring additional members. Equitable participation, appropriate group size, mutual trust, and shared leadership were concepts to consider in this process. The inclusion of gatekeepers was necessary. Gatekeepers included a Bolivian neurologist from the city of Santa Cruz who provides occasional care in the Cordillera province, and Guaraní health care facilitators and community leaders familiar with the communities, living now outside the communities, but with access to, and familiarity with them. These were separate from healthcare providers and community leaders within the villages.

Exploratory trips to Bolivia were carried out to establish familiarity with the culture, infrastructure and healthcare system (Table 1). The most recent trips in November 2017 and March 2018 were made to the Cordillera Province in the Department of Santa Cruz where the study took place, with the specific purpose of establishing contacts, finding potential gatekeepers, identifying key informants, and determining villages to target for the study. Villages were chosen and a route was decided upon in coordination with community leaders. This planning will be discussed in greater detail below.

It is a key principle of CBPR that partners participate in the research process even before the initial proposal is developed. During the 2017 trip community members as described above were contacted and the project was discussed with them. These included healthcare providers

involved in the Cordillera Province and in the specific assessment and treatment of epilepsy, as well as community leaders, as discussed above. Their considerations, suggestions and interests were taken into account in the preparation of this proposal and research questions to be considered, as was the work they have initiated in the area. For instance, they helped identify the region to target and potential key informants. Various hospitals and clinics in the region, along with a training facility for future were visited. Areas of interest to pursue, such as why patients were not compliant with medications, and factors that might make regular filtration of water more achievable, were discussed. This project was intended to build on and complement the work already being done in the Cordillera Province, and to provide additional data that serves to establish a greater foundation on which to extend the work to communities outside the defined study area, and into other Departments in Bolivia, where this work has not yet begun.

With the partnership established, the engagement work could begin. Partners participated in carrying out key components of research as defined above. The work was intentional, in that the purpose of examining the understanding of NCC, its effects and impact on the community and dissemination of knowledge surrounding the disease back to the community through the sharing of findings were explicit.

Assessment of needs, barriers, facilitators, and knowledge of the disease comprise the findings. These results will be shared with community members and will inform the next phase of the work. The process will be dynamic and ongoing, meaning it will be amenable to alterations and will continue beyond this first phase of analysis. Changes will be made according to participant and project needs, such that flexibility within the project design will be required as the research proceeds.

PRECEDE-PROCEED Model

In addition to the CBPR framework, to guide the research, the PRECEDE-PROCEED model (PPM) was used for application and planning. The PPM is a nine-phase model based in principles of behavior change and community program planning and evaluation (Glanz, Rimer, & Vizwaneth, 2015). The PRECEDE portion includes the first three phases that guide the development of a logic model of the problem (Bartholomew, Markham, Mullen, & Fernandez, 2015). These include assessment of the (Phase 1) social, (Phase 2) epidemiological, behavioral and environmental, (Phase 3) educational and ecological influences. Phase 4 involves assessment of administrative and policy influences and determination of appropriate interventions, and considers whether these are aligned. This is the stage at which methods are chosen and theories continue to be implemented. After this movement to the next phases, the PROCEED portion, may occur. They include implementation and evaluation of process, impact, and outcome (Bartholomew, Markham, Mullen, & Fernandez, 2015).

According to Green et al. (1994) the *raison d'être* of the PPM is to systematically apply prior research and theory to the assessment of local needs, priorities, resources, established structures and pre-existing circumstance. Because this model does not specify theory or construct it can be used as a guide that begins with problems and works toward solutions, implementation, and evaluation. It is amenable to global problems and can be used to address issues involving health disparities (Bartholomew, Markham, Mullen, & Fernandez, 2015).

According to the model as described by Xin Qi Dong et al. (2010), local health problems can be improved by changing communal predisposing, reinforcing, and enabling factors. Predisposing factors are the antecedents that provide a rationale for behavior change and include

elements such as community values, beliefs, and perceptions affecting motivation for change. Enabling factors are external resources that facilitate behavior change and may include elements such as access to health services, sanitation infrastructure, clean water, or health education. Reinforcing factors are consequences of health behavior that determine whether actions are supported, such as decreased infection and seizure rates. (Xin Qi Dong et al., 2010)

Time constraints, economic resources, limited personnel (one researcher), and the international nature of this study limited the amount of work that could be accomplished during this cycle. It was therefore a short-term evaluation, as opposed to a long-term, cyclical one. Nevertheless, it was undertaken with the long-term goal of returning to the setting with the intentions of furthering it. This work was then, primarily situated in the first three phases of PRECEDE, touching on phase 4 to continue with phase 4 and the PROCEED phase in the future.

Summary

Neurocysticercosis is a potentially eradicable disease that greatly increases epilepsy in developing nations (Del Brutto, 2014a). This study adds to the sparse body of knowledge of the problem, especially specific to rural Bolivia, and serves to guide future interventions. It is felt that the findings are generalizable to other regions and communities in Bolivia, as well as to similar communities in other nations. By adding to the existing research, solutions to the problem of NCC and epilepsy are more attainable. The primary goal of the project was to assess knowledge, needs, and community strengths in rural communities located in the Gran Chaco, Cordillera Province in the Department of Santa Cruz, Bolivia. The research was guided by CBPR and PRECEDE-PROCEED frameworks. The perspectives of healthcare providers and community leaders were solicited with the help of community partners.

CBPR projects do not always implement direct interventions, but maintain a commitment to translation of findings into action strategies that benefit the community, while promoting co-learning and capacity building among partners (Israel et al., 2013). This project was an initial step towards informing interventions designed to prevent or treat NCC and to improve the quality of life in these villages by addressing NCC as it exists in rural Bolivia, specifically in Gran Chaco.

CHAPTER II: LITERATURE REVIEW

In this section, the pathophysiology of neurocysticercosis (NCC) will be discussed. Next, although literature pertaining directly to epilepsy and NCC in Bolivia is glaringly sparse at best, and is indeed absent for most of the country, there are some studies that provide a basis for this project. These studies will be examined here. The objective of this literature review is to not only systematically demonstrate the gaps in the literature, but more importantly, to find supportive work upon which to build future studies that might fill those gaps.

Literature Search Criteria

An attempt was made to include only the most current research, published in the last five years. However, due to the extreme paucity of literature, some articles were included that were older. In particular, regarding research on epilepsy and NCC specific to Bolivia, it was found that the work done is largely based on a study that was initiated by the Global Campaign Against Epilepsy (GCAE), a joint initiative between the International League against Epilepsy (ILAE) and the World Health Organization (WHO) region (Bruno et al., 2011; 2012; 2015; Nicoletti et al., 1998; 1999; 2000; 2002; 2005; 2009; 2017). Being seminal works in the field, these earliest studies were included. Current research done on epilepsy and NCC in Bolivia is largely based on and derived from these studies and their series of three door-to-door surveys carried out in the Cordillera Province of Bolivia, which initially estimate prevalence and incidence, and then follow up with longitudinal data.

Research on epilepsy was included only if it followed the ILAE guidelines defining epilepsy as two or more seizures at least 24-hours apart which were unprovoked, and used their definitions of lifetime and active prevalence (ILAE, 1993). Studies were excluded if they dealt

with acute seizures, or epileptic syndromes. Retrospective cross-sectional or prospective studies measuring prevalence and incidence, as well as treatment (or gaps), were eligible for inclusion.

Finally, research was included if it addressed the aforementioned topics and was pertinent to Latin American or South American countries, with environments similar to Bolivia. These were included to provide supportive evidence to the sparse literature that pertains directly to Bolivia.

Neurocysticercosis

In order to highlight the significance of the problem studied it is important to provide a brief description of the transmission, diagnosis and treatment of NCC. Of note, these three elements are relatively complex, contributing to the challenges of reaching elegant solutions, especially in the setting of poverty, limited resources, and cultural barriers present in rural Bolivia, and similar communities, where the disease is endemic and prevalent.

NCC is an infectious parasitic disease that is endemic to most of the developing world. Rural Bolivia provides all the conditions for NCC to proliferate. It is a disease of poverty, spread through poor hygiene and limited access to clean water and sanitation infrastructure. It is the larval form of infection with *Taenia solium* (*T. solium*), or tapeworm. As such its transmission and lifecycle are particularly interesting and complex. Discussion is significant in terms of prevention, treatment, and eradication.

Below (Figure 2) is a diagram of the lifecycle of *T. solium*. Humans are the only hosts of the adult form, while cysts can develop from the eggs or gravid proglottids in the tissues of pigs or humans. Humans may autoinfect themselves with the eggs or proglottids through poor hygiene after defecation. This form of infection would result in cysticercosis, rather than adult *T.*

solium infection in the intestines, which results from ingesting oncospheres in raw or undercooked infected meat. The cycle is further discussed below (Figure 2).

Life Cycle:

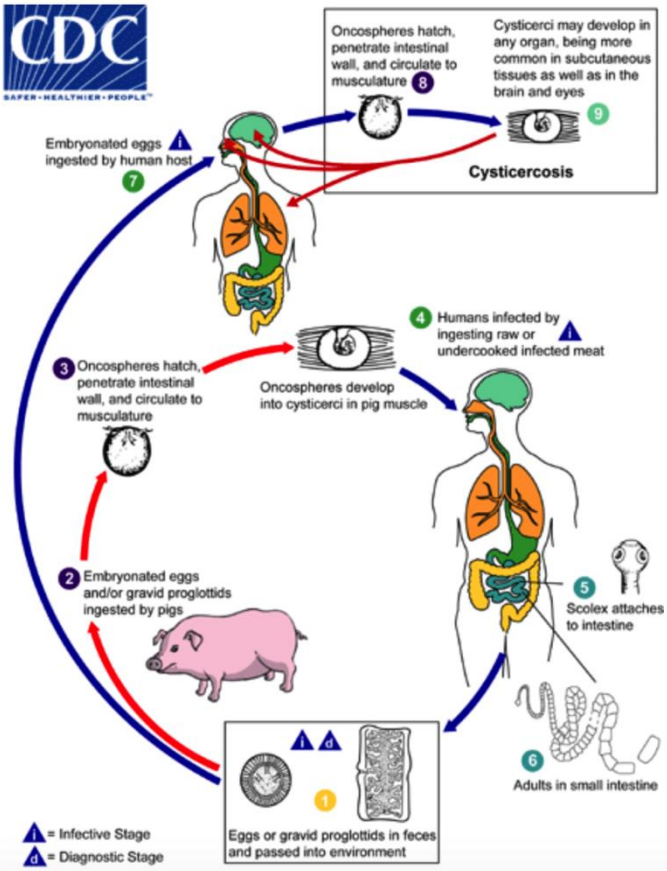


FIGURE 2. Life cycle of *Taenia solium*. (Website https://www.cdc.gov/parasites/cysticercosis/biology html Retrieved 09/02/2018.)

To reiterate, humans are the only definitive host to this organism, and swine are the natural intermediate hosts to the larval form. However, humans can also be intermediate hosts. The adult form is contracted when the larval form is ingested through consumption of under cooked pork. The worms reach adulthood in the intestines, where they reproduce and shed eggs excreted in feces (Del Brutto, 2014a). Poor sanitation and hygiene results in the spreading of these eggs. Pigs contract the disease when they are exposed to and ingest contaminated human

feces (Coyle et al., 2012). Water and even plants can become contaminated through poor sanitation. Ingestion of water that is contaminated or plants contaminated directly through exposure to feces or indirectly through irrigation can cause infection (Verbyla et al., 2013).

Additionally, humans can spread the disease through poor hygiene. Contaminated hands can spread eggs for accidental consumption through direct ingestion or contamination of food during preparation (Del Brutto 2014a). The eggs or cysts infect human tissues causing cysticercosis (CC). When it does not involve the CNS it is usually benign, although, infection can cause serious problems in organs such as the liver (Gonzales, Rivera, & Garcia, 2016).

When the CNS is infected the disease is known as NCC. CNS infection is sometimes asymptomatic, but it can have serious and sometimes fatal effects, and is thought to increase the incidence of epilepsy by as much as 30% in endemic regions (Nash, Mahanty, & Garcia, 2013). Moreover, epilepsy is the most commonly recognized symptom. Other consequences include stroke, spinal cord compression, encephalitis, headache, meningeal irritation, and depression, to name a few.

Variable presentation is related to host immunology, as well as to location and number of cysts within the CNS. Hippocampal sclerosis leading to development of mesial temporal epilepsy has also been suggested as an explication for NCC related chronic epilepsy (Del Brutto, 2014b). Finally, genetic variation may contribute to varied presentation and acuity of symptoms (White, 2010).

Diagnostics

Diagnostics for NCC can be problematic, especially in endemic areas that are generally resource poor and lacking in sophisticated diagnostic equipment (Anticona Huaynate et al., 2015;

Fogang et al., 2015). Even without the challenges rural communities face, diagnostics are not straightforward since disease presentation is not specific, nor is neuroimaging, and laboratory specimens have poor specificity and sensitivity (Del Brutto, 2012). In rural Bolivia there is no immediate access to neuroimaging or even laboratory testing. People do not have the money to afford tests, and even if they do, they have to travel long distances to one of the large cities to have them done. In the villages and small towns healthcare workers are generally not trained to interpret results of sophisticated examinations.

While NCC is infection of the central nervous system (CNS) by larval cysts of *T. solium*, these cysts may also infect other tissues throughout the body (Gonzales et al., 2016). Furthermore, the presence of the adult worm in the gastrointestinal tract can lead to autoinfection of NCC, or infection of others with NCC, especially family members, as the adult parasite yields eggs which are passed in stool and spread through poor hygiene practices and contaminated water (Fogang et al., 2015).

Because of this complexity, diagnosis is best established through multifactorial analysis. By combining evidence from multiple sources NCC can be determined, since the unique variables become most apparent through consideration of the results of the varied perspectives provided by neuroimaging, serology, epidemiological clues, and clinical manifestations (Nash & Garcia, 2011). According to Del Brutto (2012), in order to assist with the difficult diagnosis of NCC a set of criteria was developed in 2001 and is widely followed today. These include absolute, major, minor, and epidemiologic criteria, with definitive and probable degrees of certainty (Del Brutto, 2012). While these criteria form helpful diagnostic guidelines, they have

not been validated systematically (Nash & Garcia, 2011). Below is a list of the abovementioned criteria, taken from Del Brutto (2012).

TABLE 2. *Diagnostic criteria for neurocysticercosis.*

Absolute: • Histological demonstration of the parasite from biopsy of a brain or spinal cord lesion • Evidence of cystic lesions showing the scolex on neuroimaging studies • Direct visualization of subretinal parasites by fundoscopic examination
Major: • Evidence of lesions highly suggestive of neurocysticercosis on neuroimaging studies • Positive serum immunoblot for the detection of anticysticercal antibodies • Resolution of intracranial cystic lesions after therapy with albendazole or praziquantel • Spontaneous resolution of small single enhancing lesions
Minor: • Evidence of lesions compatible with neurocysticercosis on neuroimaging studies • Presence of clinical manifestations suggestive of neurocysticercosis • Positive CSF ELISA for detection of anticysticercal antibodies or cysticercal antigens • Evidence of cysticercosis outside the central nervous system
Epidemiological: • Individuals coming from or living in an area where cysticercosis is endemic • History of travel to disease-endemic areas • Evidence of a household contact with T. solium infection

TABLE 3. *Degrees of diagnostic certainty*.

Definitive: • Presence of one absolute criterion • Presence of two major plus one minor and one epidemiological criteria
Probable: • Presence of one major plus two minor criteria • Presence of one major plus one minor and one epidemiological criteria • Presence of three minor plus one epidemiological criteria

Treatment

Treatment of NCC is complex since clinical and pathological presentations are varied. Furthermore, treatment plans will be altered depending on the resources available. Chemotherapy and surgery are both viable options, with preference hinging on case specifics.

Anti-parasitic intervention will not always be indicated, and in fact will be contraindicated in particular cases, since cysticide may cause intracranial edema. Location of the cyst must therefore be considered. Additionally, use of anti-epileptics will depend on presentation, that is, whether or not the infected individual presents with chronic epilepsy. In rural Bolivia, where resources are lacking, as are providers trained in these therapies, treatment options become very limited. A notable challenge is the rampant and regular administration of anti-parasitic medications by NGOs providing medical relief in the villages, since the medications are strong and not without side effects, and documentation of administration is not always systematic or consulted. Villagers may take the approach that "more is better" without considering consequences of overmedication. A further complication is the difficulty in maintaining steady supplies of anti-epileptic medications, and lacking laboratory facilities available to monitor serum levels of these drugs.

Works describing the diagnosis and pathology of NCC are important to the understanding of the problem. Important work has been done describing the diagnosis and pathology of NCC, some that is specific to Latin America, and this literature is described below. Much of the literature pertaining to NCC comes out of countries where it is endemic. Every attempt has been made to update and use only the most current research.

Prevalence

NCC in Bolivia

As discussed above, the work done on epilepsy in Bolivia largely stems from the GCAE work carried out in the Cordillera Province, initiated in the 1990s and based on a series of three door-to-door surveys. Two of the articles on NCC in Bolivia are derived from this work

(Nicoletti et al., 2002; 2005). An additional article was included, although it is dated (Carrique-Mas et al., 2001), because of the paucity of literature and because it is providing research done in Bolivia by different authors.

The studies on NCC in Bolivia all gathered data from rural areas in the Cordillera Province of Bolivia. They are all somewhat dated, having been published in 2001, 2002 and 2005. Both studies by GCAE teams report that NCC is positively associated with epilepsy. The findings show that partial seizures are more highly correlated with NCC and that NCC is found to be more prevalent in the epileptic population. The findings suggest that NCC may explain the higher prevalence of epilepsy in developing nations (Nicoletti et al., 2002; 2005). The third study reports prevalence of cysticercosis in Bolivia that is similar to other Latin American countries (Carrique-Mas et al., 2001). It was also carried out in El Chaco region of Bolivia, although outside the Cordillera Province. Limitations of these findings are that they are derived from only two research teams and they are dated. Since the studies were only done in one region of Bolivia, transferability is not ensured. However, the work was carried out systematically and with good sample sizes. Results are supported by the findings in literature from other Latin American countries.

Epilepsy in Bolivia

Seven articles pertaining to epilepsy and its treatment in Bolivia were found. All of these were derived from the GCAE studies. As noted these works were carried out over a 20+ years span, and the results are longitudinal. All findings are based on door-to-door surveys along with neurological exams of those with seizures. Topics covered include prevalence, incidence,

treatment gaps, methods for the studies, and mortality (Bruno et al., 2011; 2012; 2015; Nicoletti et al., 1998; 1999; 2000; 2002; 2005; 2009; 2017).

Two papers analyze stigma associated with epilepsy, stating that this may be a factor impacting treatment (or gap). It is found that while there are belief systems that may inhibit reporting of epilepsy and treatment adherence, there is also the perception that combined biomedical and traditional treatment may be effective. It is found that education may increase treatment seeking, adherence, and understanding of epilepsy (Bruno et al., 2011; 2012).

The authors state that lifetime and active prevalence of epilepsy in their 2010 survey was similar to the findings in their original survey, with the population size remaining relatively stable. Lifetime epilepsy (with convulsive seizures) prevalence was estimated at 7.2/1000 and active epilepsy (with convulsive seizures) prevalence was estimated at 6.6/1000. They report that this is likely consistent with estimates in other parts of Latin America, considering that studies done in these areas have included non-convulsive seizures in their estimates. The studies also reveal a large treatment gap. The findings of the latest data show a treatment gap of 70% down from 90% of the original study. This difference might also be attributable to the inclusion of only convulsive epilepsy in the 2010 data. Since the studies are longitudinal there may be recall bias involved in the surveys. There may be some impact on findings from migration over the 10-year period. The treatment gap was consistently very large and NCC was found to increase the risk of death three-fold in the population (Nicoletti et al., 1998; 1999; 2000; 2009; Bruno et al., 2011; 2012; 2015).

The most recent work done by the group tested a Spanish-language screening tool for convulsive epilepsy, carried out in rural Bolivia where previous epidemiological work was

carried out. It was tested in the field and designed to test for convulsive epilepsy in rural settings (Nicoletti et al., 2017).

NCC and Epilepsy in Latin America (or Similar and Related Environments)

In this category eight articles were found that deal directly with the topic of epilepsy and NCC in Latin America. One of them was related to the GCAE work discussed above, and is a systematic review and meta-analysis examining the burden of epilepsy in Latin America and the impact of NCC on it (Bruno et al., 2013). Another systematic review addressing the burden of epilepsy in the region was published in 2005 (Burneo, Tellez-Zenteno, & Wiebe, 2005). These two works summarize older studies. Otherwise, only articles published in the last five years were included. The remaining five articles identified discuss neurocysticercosis in terms of prevalence, mortality, risks, and modifiable risks in Peru, Brazil, Ecuador, and Honduras (Gonzales et al., 2015; Kelvin et al., 2012; Martins-Melo et al., 2016; Medina et al., 2011).

The articles support the evidence found in the GCAE studies. The studies found higher epilepsy prevalence rates compared with the developed world were reported, along with an association with NCC. Treatment gaps were also associated with higher epilepsy prevalence. In Brazil NCC was found to increase mortality rates, consistent with findings in Bolivia. Education based intervention was found effective in decreasing NCC in highly endemic areas. Del Brutto, Arroyo, Del Brutto, Zambrano and García (2017), found through performing computed tomography scans of the brains of adult villagers in rural Ecuador, that people with PWE have three times the odds of having NCC than those without.

See Appendix A for tables regarding literature on NCC in Bolivia, epilepsy in Bolivia and NCC in Latin America.

NCC in Non-Endemic Countries

NCC is endemic to most of the developing world (Del Brutto, 2014a), and is classified as a major neglected tropical disease by the WHO (2012). While its impact is recognized in the developing world, it is receiving more attention in the non-endemic world as well, and is considered a leading contributor to acquired epilepsy, as well as the most common helminthic infection of the central nervous system (CNS) (Del Brutto & Garcia, 2012). In non-endemic countries the infection is usually found in immigrants from endemic areas, or less commonly in travelers from them, but it can be acquired locally as well (Del Brutto & Garcia, 2012; Garcia & Cysticercosis Working Group, 2012).

Prevalence appears to be increasing in non-endemic nations (Del Brutto & Garcia, 2012; Serpa & White, 2012). Climbing statistics may be related to increasing travel, as well as to growing recognition and diagnosis of the disease (Del Brutto & Garcia, 2012; Roman et al., 2000; Serpa & White, 2012). Heightened awareness of NCC in non-endemic nations may lead to decreased neglect in endemic regions (Roman et al., 2000).

Pathology

Taenia solium is a platyhelminth, of the class cestoidea (Ryan & Ray, 2014). Cysticercosis is contracted through ingestion of its eggs. Once *T. solium* eggs reach the intestines they release oncospheres that cross the intestinal wall and enter the bloodstream. They migrate to the tissues then develop into metacestodes and then into larvae, or cysticerci (Del Brutto, 2014a). NCC results when cysticerci enter the CNS. According to Krisstenson, Masocha, and Bentivoglio (2013), the mode of entry into the host defines how the parasite enters the CNS. *T. solium* eggs must first pass through the intestinal wall. They enter the blood stream through the

intestinal mucosa and lodge in the small blood vessels where they develop into cysts. It has not been determined whether or not they cross the blood brain barrier (BBB), although in a murine model, BBB permeability was disrupted in meningeal and brain parenchymal vessels as a result of inflammatory responses (Kristensson, Masocha, & Bentivoglio, 2013).

As noted above, some parasites are capable of inhibiting host immune responses. *T. solium* cysts are thought to release molecules capable of doing so. Conversely, when the larvae die, cytokines become uninhibited and immune response is triggered. Seizures may then occur as a result of changes in the brain caused by the immune response to the nonviable cyst (Kristensson et al., 2013).

According to Del Brutto (2014a; 2014b), cysts go through stages of involution in the CNS. Upon entry into the CNS they enter the vesicular stage during which they are viable. They may remain in this stage for years. As a result of immunologic attack they may begin to degenerate and lose viability and ultimately reach the calcified stage, at which point they become mineralized and are inert. Between these two stages are the colloidal and granular stages. Orderly and predictable progression through these stages is not ensured. Duration of these stages has not been determined, is likely variable, and may vary within the host as well as between individuals. Moreover, some hosts show evidence of multiple cysts at varied stages of involution (Del Brutto, 2014a; 2014b).

As noted above, degeneration of cysts may lead to inflammatory responses, and to seizures. According to Del Brutto (2014a), it is in the colloidal stage that inflammatory reaction is most pronounced. However, as degeneration progresses, astrocytic gliosis near the lesion may worsen, and epitheloid cells may appear and join to form multinucleated giant cells. Although

degeneration has been implicated in seizure activity as a result of inflammation due to immune response, seizures may initiate at any stage in the disease process, with epileptogenesis reflecting that stage. Viable cysts may induce seizure as a result of pressure on the brain parenchyma, while gliosis, exposure of the parenchyma to antigenic material and hippocampal sclerosis may be the etiology in calcified stages (Del Brutto, 2014b).

White (2010) also discusses variation in symptomatic NCC and proposes that genetic variance may be responsible for some of the differences. The explication proposed is that polymorphisms in toll-like receptors (TLRs) may increase inflammatory response and hence seizure activity in some individuals (White, 2010). Verma et al. (2011) found that the TLR4 Asp299Gly and Thr399Ile genotypes were associated with as much as 4.5- and 3.3-fold increases in the development of symptomatic disease. They found that Th2 type response was associated with asymptomatic presentation, and alteration towards Th1 type was shown to lead towards symptomatic disease (Verma et al., 2011). These studies have important implications and are indicative that more research in the field is reasonable. Nash et al. (2015) concur that genetic factors may predispose some individuals to seizure as a result of NCC, possibly related to ability to control inflammatory response, but also as related to other predisposing factors. They further postulate that chronic epilepsy may be the result of a consequent inflammatory feedback loop and changes in brain excitability (Nash et al., 2015).

Diagnostic Criteria

The suggested framework and criteria developed for the assessment of NCC provide useful guidelines for its diagnosis. The preferred approach utilizes multiple tools, including neuroimaging, serology, clinical presentation, and epidemiology. Endemic areas often face

economic and human resource challenges that preclude the use of many of these technologies, so diagnostics must be altered accordingly. Researchers continue to search for more cost effective and easier to interpret alternatives.

According to Del Brutto (2012), assessment for NCC is complex and confident diagnosis usually requires a multi-modal approach (Table 2). As a result of this complexity, guidelines were created with criteria to facilitate the task. In addition to neurologic assessment, serological exams, and neuroimaging are generally required for definitive diagnosis (Del Brutto, 2012). In developed nations we have the equipment readily available for neuroimages and serological examinations. However, endemic areas frequently do not have the equipment, practitioners, and resources necessary for this type of approach (Lightowlers, Garcia, Gauci, Donadeu, & Abela-Ridder, 2016). Therefore, they may need to use more limited diagnostics, including serological tests that are less sensitive, and/or rely on clinical judgment. Furthermore, according to Garcia et al. (2012), serology is most informative when used along with neuroimaging. In its absence, resources are put to better use in the development of therapies than in investing in serological testing capabilities (Garcia, Rodriguez, Gilman, Gonzalez, & Tsang, 2012). Diagnostic criteria are further described below according to typology.

Del Brutto (2012), who worked on establishing this diagnostic framework, defines *absolute* criteria as including biopsy or excision of parasitic cells from brain or spinal cord lesions, imaging studies that show cystic lesions with visible scolex, and direct fundoscopic visualization of the parasitic cyst in the subretinal or retinal space. *Major* evidence includes neuroimaging studies demonstrating lesions with an appearance strongly consistent with those found in NCC, serum immunoblot positive for anticysticercal antibodies, intracranial cystic

lesions that resolve with the use of albendazole or praziquantel, and the spontaneous resolution of small single enhancing lesions. Included in the *minor* criteria are neuroimaging results that are suggestive of *T. solium* cysts, clinical presentation consistent with infection, cerebral spinal fluid (CSF) enzyme-linked immunosorbent assay (ELISA) that is positive for cysticercal antigens, or anticysticercal antibodies, and imaging results that show cysts elsewhere in the body. Finally, *epidemiological* criteria include either coming from or living in an endemic area or a history of travel to such areas, and family contact with infected persons. Definitive certainty is reached with either one absolute or two major, one minor and one epidemiological criterion. One major and two minor; one major, one minor and one epidemiological; or three minor along with epidemiological evidence is probable evidence (Del Brutto, 2012) (Table 2).

Clinical Manifestations

As noted above, clinical presentation is non-specific. The number of parasites present in the system, their location, size, and stage may all impact physical manifestations (Rodriguez, Wilkins, & Dorny, 2012). According to Fogang et al. (2015), NCC is known as "the great imitator" in endemic areas because it can present variedly as many other neurological disorders. It may be asymptomatic, devastating or deadly.

The most commonly recognized symptom is seizure activity, which may occur acutely or chronically. Various hypotheses attempt to explain the mechanisms behind this process. For instance, it has been suggested that atrophy and inflammatory responses to calcified cysticerci may trigger each other, in another feedback loop leading to seizure in NCC infected persons (Del Brutto & Del Brutto, 2012). Del Brutto (2014b) asserts that variable presentation is related to host immunology, as well as to location and number of cysts within the CNS. Hippocampal

sclerosis leading to development of mesial temporal epilepsy has also been suggested as an explication for NCC related chronic epilepsy (Del Brutto, 2014b). More research is needed to understand hippocampal sclerosis related to NCC, and to find clear explanations for variation in presentation of NCC overall.

Acute increased intracranial pressure is less common but life threatening. Other symptoms may include chronic headaches, focal neurological signs, meningeal signs, gait abnormalities, altered mental status, psychiatric symptoms, and spinal cord involvement (Fogang et al., 2015). NCC should be considered in the differentials with new onset seizures in healthy young people or middle-aged adults in endemic areas (Venkat, Aggarwal, Makhaik, & Sood, 2016).

Cysts have been associated with ischemic and hemorrhagic stroke, and when occurring in the subretinal or retinal area, decreased visual acuity (Gonzales et al., 2016). According to Gonzales et al. (2016), cysts outside the nervous system are usually asymptomatic, but can have deleterious effects in certain locations. For instance, those in the orbital space may cause gaze deviation and those in the vitreous may obscure fields of vision.

It is important to note the symptoms of intestinal infestation with the adult *T. solium* as well, as its presence can cause auto-infestation of the cystic larval form of the disease. While often asymptomatic, bloating, nausea, epigastric pain and distention, as well as dizziness, anxiety, urticaria, and headache may occur, and proglottids may be seen in stool (Leder & Weller, 2015). Malabsorption of unknown origin and anemia are additional causes to suspect taeniasis, especially within endemic areas or with recent travel to them (Canaval Zuleta, 2015).

Serology

There are several tests that can be used to examine blood serum for evidence of NCC. Although the ideal test has yet to be developed there is an ongoing effort to improve precision, accessibility to endemic populations, and ease of use (Rodriguez, Wilkens, & Dorny, 2012). The lentil lectin-bound glycoprotein enzyme-linked immunoelectrotransfer blot assay (LLGP-EITB) is considered the preferred serological test for diagnosis (Noh et al., 2014; Rodriguez, Wilkens, & Dorny, 2012). ELISA-based assays have been developed, that also show high sensitivity and specificity to NCC, although they have not been adopted in the field, because of the high resource requirements to prepare the antigen (Lightowlers, Garcia, Gauci, Donadeu, & Abela-Ridder, 2016). CSF samples tend to yield better results than serum, however both serum and CSF sensitivity and specificity are greatly decreased in cases of single lesions (Rodriguez, Wilkins, & Dorny, 2012; Noh et al., 2014). According to Lightowlers et al. (2016), costs for antibody detection tests vary greatly, depending on manufacturer and supplier. ELISA kits may range from $5 to $30 per test, and Western blot tests go as high as $347 per sample. Results may be transient, and viability of cysts cannot be distinguished with these studies (Lightowlers et al., 2016). Furthermore, while tests show high specificity and sensitivity, the purification process of standardization of natural cysts is difficult to achieve, and cross sensitivity in native samples may occur, therefore, in the field these tests are less effective (Noh et al., 2014).

While the above tests are considered to be the best available, antigen detection tests are being studied as possible effective alternatives (Garcia et al., 2012). These tests are also very costly, positive findings may be transient, and although they may be highly specific, sensitivity requires infection with two or more viable cysts (Lightowlers et al., 2016). Sensitivity and

specificity are still inferior to antibody tests, and antigen tests are currently most useful for follow-up of patients after intervention with anti-helminthic medications (Rodriguez, Wilkins, & Dorny, 2012).

Garcia et al. (2012), discuss the usefulness of serological tests on their own, or in the absence of neuroimaging. They state that for individual patients, they show no efficacy. However, they may be useful in establishing baseline prevalence rates within a population or region. Effective utilization may include screening asymptomatic groups in order to alert them to high or increased risk, with the goal of then reducing that risk through diagnostics and intervention. Application may also be effective in the assessment of need for control measures, although it is suggested that screening pigs in the target region may prove more efficient and cost effective than screening human populations (Garcia et al., 2012).

According to Rodriguez, Wilkins, and Dorny (2012), serological tests are effective in determining etiology, but do not distinguish infection with viable versus non-viable cysts. Results are dependent on interpretation. A strong response may indicate severity of infection, however, in the field, seroprevalence may be exaggerated since past exposure, as well as current infection will be detected. They concur that transience is an issue, that the tests may support diagnosis and referral to better-equipped facilities, and that prevalence studies may be best utilized for control programs (Rodriguez, Wilkins, & Dorny, 2012). Conversely, Garcia et al. (2012) assert that the primary usefulness of serology testing in individuals is of a complementary nature when combined with neuroimaging. In the absence of imaging, communities would benefit more from increasing abilities to treat symptoms, such as seizures, than from investing in and trying to interpret individual serologies. Longitudinal follow-up studies may yield valuable

information for the management of individual cases. However, in poor, rural endemic regions this is an unlikely scenario (Garcia et al., 2012). Finally, research and design in the field has developed some less expensive and portable options for use in rural settings, however, they have not been adopted or incorporated into these settings at this time, likely due to economic constraints and untrained practitioners (Biswa & Parija, 2011; Cortsjens et al., 2014).

Neuroimaging

Computed tomography (CT) imaging may assist in initial visualization of hydrocephalus or calcified lesions in the brain, however magnetic resonance imaging (MRI) is the most useful tool for diagnosing NCC (Venkat, Aggarwal, Makhaik, & Sood, 2016). Nevertheless, because cost and availability are often factors, CT scans may suffice diagnostically in certain situations and MRI may not be needed (Padma Srivastava, 2015). Furthermore, CT scans are suggested as screening tools (Verma & Lalla, 2012). CT is actually the preferred method for diagnosing calcifications (Nash & Garcia, 2011). Additionally, according to Padma Srivastava (2015), CT may be used to effectively diagnose NCC when lesions are solitary, enhance with contrast, are less than 20mm, and do not cause midline shift, along with patient presentation that includes seizures without evidence of persistent increase in intracranial pressure (ICP), progressive neurologic deficit, or systemic illness such as primary malignancy, or tuberculosis. According to Nash and Garcia (2011), further criteria may include living in, or coming from an endemic region, and that the cyst does not increase in size over time. Calcified cysts are usually round and small, however, they may be larger, chunky and irregularly shaped. The appearance of multiple calcifications adds to the likelihood of the diagnosis (Nash & Garcia, 2011).

MRI has been proposed as an essential diagnostic tool in evaluating etiology of seizure, since it can be utilized to identify epileptogenic substrates, and to find precise locations and the histological nature of lesions (Jennifer, Udayakumar, & Pushpalatha, 2015). While it is more expensive and less available than CT, it is widely considered the best diagnostic tool for NCC (Venkat, Aggarwal, Makhaik, & Sood, 2016). In diagnosing NCC the strength of the MRI is also its ability to aid in the visualization of brain structures and anatomy, as well as characteristics of lesions (Nash & Garcia, 2011). According to Verma and Lalla, (2012), CT may fail to capture NCC in the vesicular neurocysticercal stage and meningeal NCC, while MRI detects them. Furthermore, MRI helps visualize brainstem and subarachnoid NCC (Verma & Lalla, 2012). MRI is also the most useful to determine cysticercal staging, and whether or not there is degeneration (Nash & Garcia, 2011). Nevertheless, MRI can fail to detect cysts. Advanced MRI technology, such as fast imaging employing steady-state acquisition (FIESTA), can improve diagnostics by making thinner slices and using faster speeds (Fogang et al., 2015).

It is important to remember that although neuroimaging tools have greatly benefited diagnosis of NCC, they remain interpretive tools. For instance, there is variation among practitioners regarding what defines target lesions, and results from images found in MRI and CT are interpreted differently per practitioner as well (Stefanoni et al., 2014). Those not trained in neuroradiology may misinterpret results (Fogang et al., 2014). For this reason, even with neuroimaging, all available evidence must be included in diagnostics (Stefanoni et al., 2014). According to Fogang et al. (2015), challenges faced for accurately reading neuroimaging are exacerbated in developing nations. Furthermore, imaging equipment is frequently unavailable to resource poor endemic regions (Fogang et al., 2015).

Gastrointestinal Taeniasis

Diagnosis of taeniasis can be problematic, since it is often asymptomatic, and symptoms when present are nonspecific (Leder & Weller, 2015; Canaval Zuleta, 2015). According to Canaval Zuleta (2015), diagnosis has been largely based on the presence of proglottids in the stool. Serology may be used to assist diagnosis as well. However, both of these tests lack sensitivity and specificity. Gastroscopy has been suggested as a viable alternative for both diagnosis and attempted removal of the scolex when resources are available (Canaval Zuleta, 2015).

Treatment

Treatment of NCC is equally complex, owing to varied clinical and pathological presentations (Del Brutto, 2014a). Chemotherapeutic options might remain the same in developed and non-developed nations, in theory. Of note, there is not a set of clinical practice guidelines for the treatment of NCC in the US per se, but there is a paper outlining evidence-based practice (Baird et al., 2013). It simply addresses the use of antiparasitics, concluding administration is reasonable, along with co-administration of corticosteroids. Dosage is also noted. They further state that corticosteroid use alone is not recommended, and that anti-seizure medications should be administered at least until active lesions have subsided (Baird et al., 2013). Del Brutto (2014a) asserts that treatment must be individualized, but concurs with above recommendations and states that surgery may also be a reasonable option. He gives much more detailed recommendations on situation specific regimens and dosing (Del Brutto, 2014a).

Fogang et al. (2015) explain that in endemic nations anti-parasitic medication administration is not urgent, and should be initiated only in the stable patient. Chemotherapy

may be dangerous in the absence of neuroimaging, because it may induce or increase intracranial edema (Fogang et al., 2015). Anti-parasitic medications are generally available and inexpensive, although less expensive or less effective alternatives may be substituted when resources and availability are limited. They are administered over the short term and do not require extensive monitoring. However, endemic areas are resource poor, and some extremely so. All expenses might be prohibitive and access to care can be problematic (Fogang et al., 2015).

Another complication is that medications in resource poor nations may be substandard in quality (Caudron et al., 2008). Anti-seizure medications, particularly the older, more affordable ones, pose additional challenges, since they require not only ongoing and uninterrupted administration, but also continued laboratory monitoring for toxicity and therapeutic levels. It is extremely important to educate patients on the importance of compliance with these medications, since inconsistent dosing can worsen epilepsy.

In developed nations surgical excision, is a reasonable option for problematic lesions, and possibly for absolute diagnosis through histology (Del Brutto, 2012; 2014a). In endemic regions this is generally not an option. Finally, in areas where there is an absence of neuroimaging, treatment should be carried out in symptomatic patients only, and use of anti-parasitics have higher associated risks when images providing information on size, location and developmental stage of cysts are unavailable (Fogang et al., 2015).

Non-Endemic Nations

The finding that cases are increasingly found in non-endemic nations emphasizes the fact that we live in a global setting with increasing travel possibilities. This has significance since diseases thought to be isolated to particular regions are increasingly found outside their regional

boundaries. A neglected tropical disease becomes more significant outside its borders when cases are found to travel beyond them.

Epidemiological studies demonstrate that NCC is largely transmitted from person to person (Del Brutto, 2014a). Lescano et al. (2009) conducted a study in seven rural communities in Peru, to examine the relationship between cysticercosis (CC) seroprevalence, seizure activity, and close proximity to carriers of adult *T. solium.* Findings showed hotspots of seropositivity clustered around carriers of adult worms, and there was a gradient related to distance (Lescano et al., 2009).

Even more relevant and revealing to the discussion at hand are the results of an investigation carried out to explore the epidemiology of NCC cases in an Orthodox Jewish community in New York City (Schantz et al., 1992). Four unrelated persons in the community were diagnosed with epilepsy and NCC. These individuals and their families followed Orthodox dietary practices and did not eat pork. The study significantly concluded that the likely source of infection was exposure to carriers of primary *T. solium* infection who immigrated from endemic regions, and shed eggs and then spread the disease through poor hygiene and food handling practices (Schantz et al., 1992).

Additional research supports a high prevalence of infectious *T. solium* in migrant communities. A study of migrant farmworkers in California showed *T. solium* infection seroprevalence of 1.1%, about equal to that in endemic nations, while surveys of migrant farmworkers in North Carolina and Texas border communities showed evidence of tapeworm infection in 3% of stool samples, although the tests could not distinguish between *T. solium* and *T. saginata* in these latter samples (Sorvillo, Wilkins, Shafir, & Eberhard, 2011). *T. solium*

carriers are likely to be surrounded by clusters of NCC infection (Lescano et al., 2009), especially if they are unaware of their condition, are living in conditions of poverty, and are not practicing good hygiene.

Del Brutto and Garcia (2012) further explore likely means for autochthonous cases of NCC in non-endemic countries. While it is thought that most immigrants carry the infection with them from their homelands, some may acquire it locally through contact with other immigrants who spread the infection to them within the community. Travelers to endemic areas are most likely to acquire the disease through contact with food that was prepared by a *T. solium* carrier in a non-hygienic manner. The pattern of infection in these persons is revealing. Travelers generally present with a single cysticercus granuloma, which suggests limited exposure. In contrast, *T. solium* carriers that auto-infect, or those that ingest large quantities of eggs from environmental sources, will be more likely to develop disseminated infections (Del Brutto & Garcia, 2012). It has also been suggested that NCC infection can occur through consumption of contaminated vegetables, irrigated with contaminated water, or fertilized with contaminated human feces, especially since the eggs can survive for long periods (Sorvillo et al., 2011). However, there are no corroborating studies or substantiated cases documented.

There have been few studies on prevalence of NCC in the US, although the work is increasing (O'Keefe et al., 2015; Serpa & White, 2012). Serpa and White (2012) summarize existing data, stating that 2.1% of seizure patients who had neuroimaging were positive for NCC, while Hispanics presenting with seizure had a prevalence rate of 9% to 13.5% (Serpa & White, 2012). O'Keefe et al. (2015) found that all regions of the US show a large burden of hospitalizations related to NCC. Average yearly hospitalizations were 2,361 per year from 1998-

2011. Hispanics accounted for 62% of those admitted, however, a limitation of the study was that the database utilized did not reveal information about immigration, travel, or birth country (O'Keefe et al., 2015).

It is likely that cases of NCC remain undiagnosed and that even those detected are inappropriately treated (Cantey et al., 2014). Many physicians remain unfamiliar with the disease, its symptoms, transmission, diagnostics, and management (Del Brutto & Garcia, 2012). At this time NCC is reportable in Arizona, California, New Mexico, Oregon, Texas, and Alaska (O'Keefe et al., 2015). It is likely that the disease is underreported even in these states (Cantey et al., 2014; O'Keefe et al., 2015). An immediate benefit of the initiation of reporting in California was the accurate provision of information, but it also facilitated in locating sources, and identifying infectious carriers (Roman et al., 2000).

In non-endemic as in endemic nations, sources of infection with NCC should be taken seriously and new cases should be required to be reported at the local, the state, and the national level. Upon report efforts should be made to follow diagnosed cases, monitoring families, and searching for possible sources of infection (Roman et al., 2000; Sorvillo et al., 2011). Carriers and other infected persons should be identified and treated (Sorvillo et al., 2011). This task is made easier by the availability of sensitive and specific serologic tests for infection with adult tapeworms (Serpa & White, 2012) and the demonstrated existence of probable source among close contacts (Lescano et al., 2009). Health care providers should be made aware of new cases in their communities, as well as of NCC diagnostic and management techniques (Del Brutto & Garcia, 2012; Roman et al., 2000). Education on prevention should be disseminated to all communities exhibiting infection and increased risk (Cantey et al., 2014). Additionally, national

statistics should be made reportable on an international level. Such reporting assists with the accurate estimation of prevalence and incidence, and eventually facilitates control and eradication efforts (Roman et al., 2000). Further research regarding better serologic tests, dispersion mechanisms of *T. solium* eggs, and prevalence patterns would improve efforts to understand and control NCC infection (Lescano et al., 2009; Serpa & White, 2012).

Summary

The pathophysiology of NCC is well known and there are currently diagnostic tools and treatment plans available, though utilization of this knowledge in rural Bolivia remains sparse. There is very little published research on epilepsy in Bolivia and even less on NCC. The work that has been done is limited to the Chaco region, and the vast majority was done in the Cordillera Province of the Department of Santa Cruz, by one research team. Nevertheless, the findings of the studies are supported by studies done in other parts of Latin America, although there are limited published articles to be found there as well. NCC is considered a major neglected tropical disease, and the lack in research attests to this classification. Further work needs to be done in the Department of Santa Cruz, as well as in other regions of Bolivia to support the existing evidence on NCC in rural areas in order to establish transferability. This review of literature identifies studies upon which future research can be built. While this base is small in size, the studies are consistent and scientifically strong. The next logical step is to add to this body of work by providing an assessment of key informant knowledge, needs, and strengths that can then be used to guide future interventions.

CHAPTER III: METHODOLOGY

In this chapter the methodology of the research project, including the setting, sampling, methods and measures, and data collection are presented. Following will be discussions of data management and analysis, validity and reliability, ethics, human subject protection, and limitations of the study. The research design is qualitative, utilizing the PRECEDE-PROCEED model as a framework for questions guiding interviews.

NCC is a preventable disease spread through poor sanitation and hygiene (Ryan & Ray, 2014; Rote & Huether, 2010). It thrives in conditions of poverty, illiteracy, poor hygiene and sanitation, and pig farming co-occurring with poor sanitation. (WHO, 2016). All of these conditions are met in rural Bolivia. Literature on the problem in this region is minimal, but what does exist supports the findings of high prevalence of epilepsy relative to developed nations, with NCC as the major contributor to the higher numbers and to acquired epilepsy (Bruno et al., 2013; 2015).

It is proposed that the assessment of community perception and knowledge of the problem, along with assessment of facilitators and barriers to treatment and prevention in rural Bolivia, are important first steps in moving towards an intervention aimed at treating epilepsy, and preventing and treating NCC there. The study was conducted in El Gran Chaco region, in the Cordillera Province, Department of Santa Cruz, Bolivia. This location was chosen since a series of previous studies have been carried out there to establish epilepsy prevalence rates and gaps in treatment (Bruno et al., 2015). We visited villages outside the previous study area but still in El Chaco region, at the request of CBPR partners. The ethnic base was Guaraní. While findings were specific to the region, it is thought that at least some are generalizable to other regions

where the problem exists within Bolivia, within Latin America, and to small villages with similar conditions worldwide.

Setting

The setting for the study was rural villages in El Chaco region in Bolivia as described above. It was further limited to the territory of Isoso. The region was chosen since there have been epidemiological studies done there, and nowhere else in Bolivia. It was therefore hoped that this study would build upon the existing knowledge base and increase confidence that the work can be generalized outside this region. Since we have further defined the study area, for the purposes of this paper the geographic location of the study will be referred to as the territory, meaning the territory of Isoso. This lies within the region of El Chaco, within which lies the Cordillera Province. The Cordillera Province is within the Department of Santa Cruz, not to be confused with the City of Santa Cruz de la Sierra, also within the Department, but far to the north of the chosen territory. To further clarify, region is a geographic term while province is a governmental subdivision, as is department.

As discussed in Chapter I, during exploratory visits to the region in 2017 and 2018, several villages were identified, contacts were made and the partnering process was begun. Some of the villages chosen for this study were also villages included in studies done by the ILAE, or had been visited by affiliated caregivers from the Convenio de Salud, in the Province, as well as a neurologist from the city of Santa Cruz de la Sierra (a day's drive north of Camiri), and have had some NCC treatment and assessment initiated. The route for visiting the villages was determined in conjunction with the Asamblea del Pueblo Guaraní, the tribal committee based in Santa Cruz de la Sierra. The villages are in the territory known as Isoso, in the district of Bajo

Isoso. It was hoped that seven communities representing both Bajo and Alto Isoso would be visited. Due to weather conditions the route was necessarily altered. The villages included for this study were Rancho Nuevo, Yuki, and Kaurirenda, in the district of Bajo Isoso (Figure 3).

As noted above, some of the villages included in this route have been visited by healthcare providers, while others only very rarely so. Villagers have extremely limited access to health care. There are long travel times to cities that may have more health care and that care may be in very small hospitals. Travel from village to village can be significantly impacted by weather conditions, particularly in the rainy season. Furthermore, as is typical in these regions, although definitive appointments and events may be scheduled, there is a high degree of possibility that they may be changed, postponed, or canceled at the last minute. Therefore, while every attempt was made to visit the number of villages in the route identified above, plans had to be altered at the last minute and flexibility of location was ultimately required.

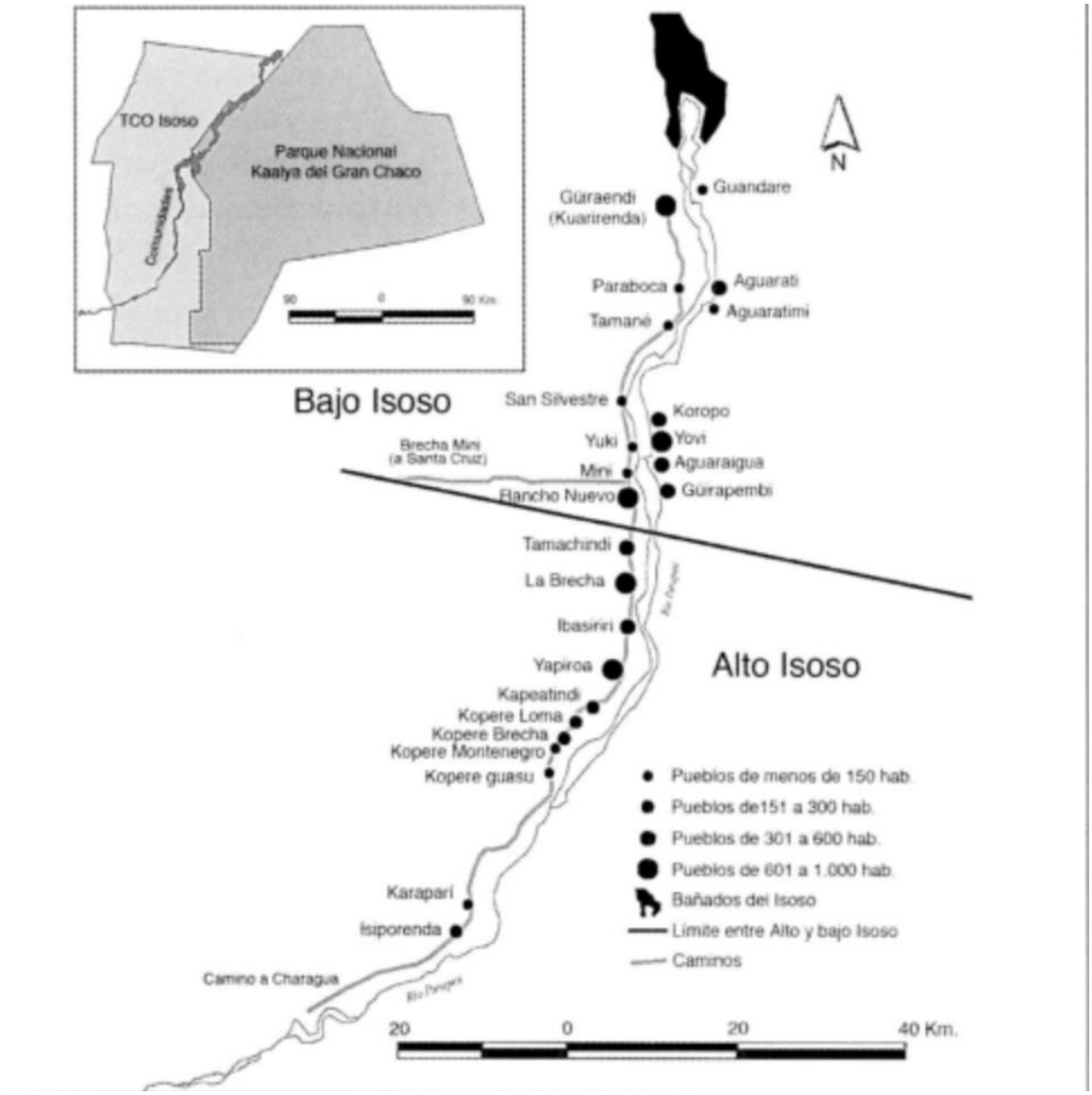


FIGURE 3. Route map. (Map adapted from: Combès, I. 2005. *Etno-historias del Isoso: Chané y chiriguanos en el Chaco boliviano (siglos XVI a XX).* La Paz: Institut français d'études andines. doi:10.4000/books.ifea.4752)

Sampling (Population)

Again, during exploratory visits to the region, gatekeepers were identified and they identified key informants. For this study, key informants included health care providers and community leaders in the villages. These key informants were selected because of the nature of this dissertation, which included time constraints and limited resources for data collection (the

principal investigator). Importantly, during exploratory trips to the region it was observed that while these key informants may serve as leaders and decision makers, they also function side by side as equals to other members of the community. Thus, for the purposes of this study, these key informants represented the community (see Study Limitations).

Recruitment of key informants occurred in alignment with CBPR principles which encourage researchers to enlist the help of community based organizations and gatekeepers (Minkler & Wallerstein, 2003). For this study, members of the ILAE, the Convenio de Salud, and the Asamblea del Pueblo Guaraní actively assisted with the choice of villages and assisted in identifying key informants. Members of the advisory board, including an anthropologist that speaks and teaches Guaraní, is very familiar with the communities, along with a neurologist from the city of Santa Cruz de la Sierra that visits the region and provides voluntary healthcare services in the form of neurological assessment and treatment assisted with determination of key informants.

As stated above, key informants included health care providers and community leaders from the rural villages that were selected. Exploratory visits to the region revealed that health care providers and community leaders live, or have lived in (and perhaps moved away from) the communities they serve and are familiar with health care practices in those villages. Health care providers included a nurses' aide, and a promoter of health. Community leaders included individuals known as "authorities" or "captains."

Key Informant Inclusion Criteria

- Health care provider or community leader in the El Chaco region in Bolivia.
- Over 21 years of age.

- Currently lived in or has previously lived in the villages in the region.
- Ability to understand and speak Spanish.

Methods

The aims of the project were to:

1. Determine health care providers' and community leaders' knowledge of NCC considering:
    - How NCC is acquired, treated, and prevented.
    - The degree to which they see epilepsy as a problem, including impact on quality of life, and understanding and appreciation of the long-term consequences of chronic untreated epilepsy.
2. Determine health care providers' and community leaders' perceptions of barriers and facilitators to NCC treatment and prevention, considering:
    - How they view resources, such as clean water, money for treatment and for travel to appropriate treatment facilities, availability of local facilities that can manage the problem, transportation, providers equipped to diagnose and manage the problem, medication, and specialized diagnostics.
    - How they view the degree to which community knowledge (or lack thereof) and beliefs (such as traditional/spiritual views on etiology and meaning of epilepsy) impact treatment and prevention.
    - How they view their community's desire and sense of urgency to address NCC and epilepsy.

For both Aims 1 and 2, data was obtained using individual semi-structured interviews with the key informants, specifically health care providers and community leaders in villages in the El Chaco region in Bolivia. In addition, field notes were generated throughout the entire project. Demographic data was also obtained.

Measures

Demographics

There were several questions aimed at gathering demographic data about the participants. These addressed age, gender, role in community, time in that role, level of education, and length of residency in the village.

Semi-Structured Interviews

Individual semi-structured interviews were conducted with key informants (health care providers and community leaders) using questions in the Interview Guide (Appendix C). Questions were developed using the PPM with a view to determining potentially predisposing, reinforcing, and enabling factors. There were a total of 57 open-ended questions. The entire Interview Guide (study introduction, informed consent, & interview questions) was submitted to the advisory board, as described in Chapter I, to achieve face validity. Interview Guide translation from English to Spanish was done by a professional certified translator, native to Bolivia.

Because the people of the region have a strong tradition of oral communication and in order to avoid the possibility of informants not being proficient in reading Spanish, the interview questions and answers were delivered in oral format. All interviews were conducted in the Spanish language by the researcher herself, who speaks fluent Spanish. A Bolivian resident

fluent in both English and Spanish accompanied the researcher to ensure translational accuracy and for language reference in the event of lacking clarity or understanding. All interviews were recorded on digital devices. The time for the interviews (study explanation, informed consent, & questions) took approximately one-half to three-quarters of an hour.

It was hoped that at least two key informants (ideally, one health care provider and one community leader) from each of seven communities would agree to participate in the study with more informants interviewed as time allowed. Thus, it was anticipated that a minimum of 14 participants (two per village for seven villages) would comprise the study sample. As noted above, changes were made in the proposed itinerary and the sample characteristics are described in the following section.

Field Notes

Field notes were taken throughout all processes by the researcher. These provided additional observational data for further evidence and aids in understanding cultural phenomena experienced. They provided thick, rich descriptions of the interviews and settings for further contextual data.

Data Collection

Once the study received approval from the University of Arizona (Appendix E), the researcher traveled to Bolivia; an attempt was made to travel during the dry (non-raining) season in order to ensure safe access to villages, however it was necessary for us to travel at the beginning of the rainy season. The route traveled and villages visited have been previously described. Because of weather conditions the trip was necessarily shortened to one week, with two to three days spent in each village visited.

Members of the group traveling to the villages included the researcher, accompanied by gatekeepers as described above in Chapter I from CCWM. The gatekeepers informed the village members and potential key informants prior to arrival in their village. Upon arrival at the village, the researcher and gatekeepers went to the village schools, which serve as a central meeting place for the villages. Members of the community at the school then informed the community health care workers and community leaders of the researcher's arrival (the villages are very small) and the informants then came to the school to meet the researcher. When the potential key informants arrived at the school, they scheduled an interview at a time of their choosing. Interviews occurred at the schools.

The Interview Guide was used to guide the semi-structured interviews (Appendix C). First, an introduction of the study was made (~ 5 min). Next, if the informant so chose, the informed consent was completed (~ 5 min). After the informed consent was completed, the interview questions were asked (~30 min). Approximately one half to three quarters of an hour of the participant's time was required.

As noted earlier some villages were unreachable due to weather conditions and unpredicted time constraints. Leaders were sometimes unavailable at the time the researcher was present, although all efforts were made to inform the potential key informants when the researchers would be in the village. Since certain villages were unreachable, continued sampling in villages that were reached was performed as described in the next chapter. Furthermore, leaders traveled to the communities we were able to reach in order to participate in our study, even when we were unable to reach their communities.

Data Management and Analysis

The interview questions were recorded; the recorded language was Spanish. The recordings were translated to English. All translations of survey responses were checked by at least one other person fluent in Bolivian Spanish and familiar with Guaraní in language and culture. An effort was made to glean cultural nuances from statements with the assistance of Bolivian persons' familiar with the regional culture.

Content analysis through coding was used for the qualitative data (Sandelowski, 2000). Manual coding was employed. The coding process of qualitative data (open ended questions) involved identifying themes directly related to the question as well as evaluating cultural and macro level social themes. Once again a process of checks with translation both involving language and cultural meanings was employed, utilizing committee members to evaluate and reevaluate meanings. This process is further described in Chapter IV.

All data was stored in a password-protected computer. Recordings were transferred daily from the recording device to the computer and then erased from the recording device. They were also saved to a secure password protected hard drive daily. All interviews were de-identified. Communities are very small and community leaders are known. Therefore, complete anonymity was challenging. However, according to CBPR tenets, this anonymity may not be required since those involved in the research are considered partners to it (Valade, 2012).

Deviant Case Analysis and Saturation

In the event that cases were found that appeared to be exceptions to the rule, these deviant cases were considered and an attempt was made to incorporate the new and different

data. All interviews were coded; saturation was identified when data was redundant and no new themes emerged.

Validity and Reliability

Validity was established through trustworthiness using the guidelines put forth by Lincoln and Guba (1985), and incorporating the criteria of credibility, dependability, confirmability, and transferability. Credibility speaks to the verity of the findings, dependability to the ability to repeat the findings and that they are consistent, confirmability that the findings reflect an accurate representation of the subjects, and are not impacted by research bias, and transferability, that the findings can be applied to other contexts (Lincoln & Guba, 1985).

These tenets were established by continuing to learn the culture and social setting, and by establishing a rapport with the people. A system of cross checks with members of the communities helped with this, as did speaking with a range of people. Trust was established through the use of gatekeepers and community member participation in the research process. Triangulation, comparing different types of data to enhance credibility and to confirm results was also employed. Since similar information was gathered through the varied means of interviews, observations, perspectives from different leadership roles, and field notes, triangulation occurred. Peer debriefing, or checking in with others for objectivity checks was also an active part of the data analysis; this was done on a frequent basis with the researchers committee members during the data analysis process. This included checking in with personal biases and attitudes towards the information collected and implications of data. As mentioned previously, an advisory board was formed with community providers and leaders who reviewed survey questions for face

validity. Data was reviewed and if there were findings that did not appear to support patterns these were also assessed and evaluated.

Reflexivity, the act of constantly reflecting back on preconceived notions in an effort to approach the partnership with fresh eyes was practiced diligently. Because we were approaching an unfamiliar culture or circumstance this was especially important. Evaluating problems without imposing preconceived notions and biases is always challenging, and it was in this situation that had many differences from familiar US settings. Thick description was utilized as a method to draw conclusions about transferability to other settings. This was especially useful within the region, and allowed for comparisons of similar communities in other locations (Lincoln & Guba, 1985).

The approach and methods were compared with similar studies in other regions to establish reliability. Transcripts were checked for translation and as well as for transcriptional accuracy. Coding of notes was analyzed for drift in definition of codes by constant comparing of data with codes throughout the process. Consistency of coding was monitored through multiple cross checks as described in Chapter IV.

Research Ethics

Mindfulness of cultural norms was central to this study and every effort was made to remain sensitive to community needs, beliefs and desires. Gatekeepers were used to gain access to community members and to achieve trust and partnership with the people of the villages. The Bolivian villages visited are very small. To gain access to the people in these communities it was necessary to be introduced by a trusted individual.

As noted earlier an initial investigatory trip to the region was made in October 2017 when the researcher met members of the ILAE in Camiri, as well as health care providers at the Convenio de Salud. They introduced the researcher to several villages and community members. A volunteer health care activist from Santa Cruz de la Sierra then went to the region to promote this project and further solidify our route. There she met the mayor of Camiri who was very interested in and supportive of the project. Through this contact we met a professor of Guaraní language native to the region that travelled with us during the March 2018 trip and introduced us further, acting as gatekeeper. We met many village authorities and leaders. Finally, we went to a gathering in Santa Cruz de la Sierra including many of the previously mentioned leaders and members of the Asamblea del Pueblo Guaraní. At this meeting an agreement was reached and the route was determined. See Appendix B for the document of this agreement.

In keeping with CBPR tenets, results will be shared with the community. This is an aspect of "giving back" to the people, as opposed to just studying them and leaving. Important ethical considerations include sensitivity to communities feeling further marginalized by research reporting, communities feeling stigmatized by results, communities feeling over researched, project that further academic goals at the expense of the community, and research that wastes limited community resources. Additionally, since representatives spoke for the communities it was important to consider potential dissent among community members (Flicker et al., 2007). The consent process therefore established widespread community support, where members agreed that the proposal was relevant and methods of evaluation were appropriate (Buchanan et al., 2006). This was in part established during the pre-research investigatory trip, where contacts were made and community input to the proposal was explored.

Human Subjects Protection

Human subjects protection involved basic tenets of CBPR including participation in research, explanation of the purpose of study, transparency, and shared results. CBPR is consciously flexible and adaptive in design, and includes prior contact with the participants, and group participation in research proposal, as well as informant recruitment. Community members are seen as partners rather than subjects. Approval for the study was obtained from the University of Arizona IRB. Findings incidental to the work and not described in the consent and IRB approval, was not utilized. Any risks and benefits for participation were discussed prior to initiation of any questioning or intervention. Confidentiality was maintained and participants had the right to withdraw participation at any time. Translators and culturally sensitive assistants to aid in explication of the above were employed. Since many participants spoke Spanish as a second language, Guarani translators were available. These were cultural as well as linguistic translators. Gatekeepers were involved and served to introduce the research team and help establish partnerships and in addition to frequently serving in the role of Guaraní cultural translator. See Appendix D for the Consent Form.

Summary

This work builds on the findings of Global Campaign Against Epilepsy group (Bruno et al., 2015; Nicoletti et al., 1999; 2005) in El Gran Chaco in the Department of Santa Cruz Bolivia to move towards development of an intervention addressing NCC in the region. The design is qualitative, and a semi-structured questionnaire with some open ended questions and a short survey was used for data collection. Key informants represented the communities and consisted of health care providers and community leaders. Topics discussed addressed perceived

community need for epilepsy treatment and NCC prevention. Surveys were conducted to ascertain knowledge about epilepsy in general, as well as about NCC and its prevention. An attempt was made to determine knowledge, beliefs and perceptions about hygiene, sanitation, clean water, cooking pork, and pig farming.

CHAPTER IV: RESULTS

Chapter IV describes nuances in the data collection process and analysis methods that, due to the changing nature of the people and communities involved in the study, were not wholly anticipated *a priori*. These processes are important to explain because they may inform future studies. This chapter also describes the sample and presents the content analysis of the qualitative data elicited from interviews with participants.

Data Collection

Although not ideal, data collection occurred at the beginning of the rainy season. In addition, it was planned that we would visit eight communities representing both Bajo and Alto Isoso, however we were only able to reach three due to weather conditions. All three communities reached were in the district of Bajo Isoso. We had planned to cross a river to reach the communities in La Banda, but the river was full and we were unable to cross. Furthermore, in spite of efforts to clearly communicate and coordinate travel plans and meeting times, there were difficulties reaching leaders and gatekeepers in the communities. Gatekeepers in the city of Santa Cruz attempted to contact community leaders in the rural communities in advance of our arrival. However we found that when we arrived there had been miscommunication and/or misunderstanding about arrival dates. It is not entirely clear how these misunderstandings between gatekeepers and their community occurred. Nevertheless, last minute alterations in the itinerary were required to accommodate for communities that were not prepared for our visit. These alterations included skipping planned communities on our list and visiting more accessible ones, where leaders from outlying communities would be able to meet us.

Through coordinated efforts with community leaders, representation of the communities we were unable to reach occurred nonetheless. For example, participants from La Banda walked and waded across the river to reach us in the community nearest them that we were able to visit. Similarly, participants from some of the other neighboring communities we did not reach traveled to us by road to meet us in communities we did reach. Finally, as noted above, the Zonal Captain of Bajo Isoso represented the communities of his district.

Before interviews were conducted consent forms were presented and permission to record interviews was obtained. After consent was obtained, the interviews were conducted in Spanish. Interviews were recorded on a cellular phone device, a portable recorder, and external and internal recording devices on a laptop computer. Multiple devices were used since electricity was not always available in the communities and recharging electronics was challenging. When one or another device lost power it was very useful to be able to rely on alternative. Additionally, we found that interviews were conducted either outside or in tiny buildings in open rooms with poor sound insulation, making sound quality another concern. Multiple devices allowed for multiple recordings in the event that portions from any one recording were inaudible. Since there was a great deal of background noise in the form of wind and sand storms, playing children, and insect sounds, which were extremely loud and proved most challenging with respect to background noise, the various modes of recording were invaluable.

Interviews were transcribed and translated by the professional agency Go Transcript (https://gotranscript.com), an international online agency, founded in Scotland and known for doing transcriptions of a similar nature. For cost savings, the agency was provided recordings from only one device, the computer recorder using an external microphone, chosen for the most

consistent sound quality. These translated versions were then reviewed by the researcher, with the consultation of two Spanish speakers familiar with the region. This was done in order to refine the translation process, for example, to correct for local accent and vernacular. When the translated versions were inaudible due to poor sound quality, the researcher used the alternate device recordings as described above, thus avoiding missing data.

Coding Process

Interviews were transcribed verbatim and translated into English. Based on the interview guide a codebook was created. Using the first iteration of the codebook, the researcher and one dissertation committee member reviewed one transcript to establish themes and subthemes. The codebook was adjusted as new themes emerged with continued review of the findings. A second transcript was coded to confirm use of the codebook and verified by the dissertation committee member. The researcher then coded all of the transcripts. Additionally, two dissertation committee members with experience in coding then coded 50% (n=6) of the transcripts, which were randomly chosen. Prior to submitting transcripts to committee members for coding they were de-identified. Codes were discussed among committee members until consensus (agreement) was achieved. Crosschecks were performed in order to assure consistency with the coding process between coders. Rather than using qualitative data analysis coding software as initially proposed, coding was done manually. It was determined that this process would be more efficient given the small sample size.

The following sections of this chapter describe the findings from qualitative data analysis of the interviews with the study participants. The sample characteristics will be reviewed first and then the findings will be described according to major themes and subthemes.

Demographic Data

Sample Characteristics

Twelve persons were interviewed representing the 14 communities of Bajo Isoso, Cordillera Province, in the Department of Santa Cruz Bolivia. Representation was achieved through participation of community leadership, including the Zonal Captain of Bajo Isoso. Community size in Bajo Isoso varies, ranging from less than 100 to nearly 2000 persons. In 2012 the census put the inhabitants of Bajo Isoso at 4828 persons (Gobierno Autónomo Guaraní Charagua Iyambae, 2016).

Participant demographics are described in Table 4. Ages of participants ranged from 27 to 72 years of age, 50% were in their 40s or 50s. Only two participants were female, one a nurse's aide and the other a school board president. Only two of the 12 had a high school education, and one is only now completing high school. The majority of those interviewed have lived in their communities since birth. The shortest residency in the community was stated to be "13 to 14 years."

Pork is not eaten in all communities, and largely this is dependent on whether or not pigs are raised in the immediate community. While seemingly unrelated, this data was included with demographics because in this context it may be considered a characteristic that may have had some bearing on participant responses.

TABLE 4. *Participant demographics.*

Interviewee	Age	Gender	Education	Role in Community	Years in Role	Time in Community	Pigs in Community/ Pork Eaten
A	51	M	6th grade	1st Captain	2	Since birth	No
B	41	M	Just now finishing high school	Health promoter	8	Since birth	No
C	42	M	"3rd, 4th, 5th grade (Multiple responses)	2nd Captain	2	13-14 years/ wife born here	Very little Not raised here
D	39	F	Grade school	School board president	3	Since birth	Very little
E	48	M	6th grade	Over captain (Region)	1.25	Since birth	Yes/some Other meats more
F	48	M	Grade school	Agricultural tech (Prior advisor to board)	1	Since birth	Yes
G	63	M	5th grade	(Prior Captain) Secretary	(15)	38 years, since inception of community	Yes
H	38	M	5th grade	Captain	4	24 years	Little/ not raised here/ brought in
I	62	M	2nd or 3rd grade	Counselor To board	4	Since birth	Yes
J	35	M	6th grade	Co captain	New elect: 1-week	Since birth	Yes
K	72	M	7th grade	Counselor (Prior captain)	(Several years)	Since birth	Yes
L	27	F	High School	Nursing Assistant	5	Since birth	Some

Qualitative Data

Major Themes and Subthemes

Analysis of the qualitative data revealed four major themes. These were Knowledge of Cysticercosis, Resource Availability Related to Cysticercosis, Perceptions of Responsibility for

Addressing the Problem of Cysticercosis, and Perceptions of Impact of Cysticercosis. Several subthemes were then identified. In relation to the PPM, Resource Availability is an enabling factor, while the remaining three major themes are predisposing factors to the problem. Major Themes and Subthemes and their relation to PPM are summarized below in Table 5.

TABLE 5. *Summary of major themes and subthemes.*

Major Themes	Subthemes	Relation to PPM
Knowledge of Cysticercosis	• Disease in Humans • Disease in Animals • Knowledge of Epilepsy • Porcine Risk Factors • Human Risk Factors • Disease Prevention and Management	Predisposing factor
Resource Availability Related to Cysticercosis	• Money • Providers • Medication • Facilities • Water • Sanitation	Enabling factor
Perceptions of Responsibility for Addressing Cysticercosis	• Leaders • Family • Community • External Assistance	Predisposing factor
Perceptions of Impact of Cysticercosis	• Significance of Problem • Urgency to Address • Need for Research and Teaching	Predisposing factor

Major theme: Knowledge of cysticercosis. The first major theme identified was Knowledge of Cysticercosis, a predisposing factor. In these communities, it was found that there is some knowledge of cysticercosis, although it is primarily known under the umbrella term "triquina." In English this translates to trichina, or *Trichinella spiralis*, which is a different parasite that infects pigs as well as other mammals, migrating from the intestines and forming cysts in the muscles. This is a factor that will be discussed more fully in the following chapter. In

spite of the potential of this overlapping terminology for impacting the results, knowledge of triquina was accepted as of knowledge of cysticercosis for the purposes of this study. The subthemes under knowledge of cysticercosis are discussed below.

Subthemes under the major theme Knowledge of Cysticercosis (predisposing factor) were identified as Disease in Animals, Disease in Humans, Knowledge of Epilepsy, Porcine Risk Factors, Human Risk Factors, and Disease Prevention and Management. The subthemes Disease in Animals, and Disease in Humans include findings regarding community knowledge about the disease in humans and in animals, including description of the disease, symptoms, diagnosis, and prevalence in both species. Perceptions of community knowledge and learning about cysticercosis will be discussed within these subthemes. The subtheme Knowledge of Epilepsy, the most common symptom of the disease in humans, includes all findings related to knowledge of that disease, including familiarity with the disease, descriptions of seizures, potential etiologies of seizures, perceptions of community knowledge and learning about epilepsy, and prevalence of epilepsy in the community. Last, the subtheme Disease Prevention and Management includes findings related to knowledge of preventative measures and treatment of cysticercosis and epilepsy. Within this subtheme, attitudes and habits regarding hygiene, meat handling, and water treatment are discussed.

Subtheme: Disease in animals. Among participants, there was greater knowledge about the disease in animals than in humans. There was some understanding about how to identify infected animals yet descriptions were frequently vague, if not fanciful and/or contradictory. Although several participants had a clear understanding of how the animals contract the disease, they did not seem to feel the community members as a whole shared this knowledge.

Two participants were able to describe the disease in animals somewhat comprehensively and with some accuracy as well as to identify relationship to human infection. They recognized pigs as carriers, eating human excrement as a risk factor for pigs, were familiar with some signs of infection in the animals and had some idea about prevalence. These two participants asserted that not all community members recognize signs or symptoms of cysticercosis in meat, nor do they understand or acknowledge consequences of eating infected meat. While providing the most comprehensive information, the descriptions provided by these two participants were nevertheless incomplete, with some contradictory information.

For instance, in evaluating one of the above noted participant interviews as a whole, knowledge of the relationship between cysticercosis and humans with the disease was denied, but later in the interview there was recognition that separating pigs from latrines and restricting their access would be a preventative measure. The participant stated, *"We always tell the community that they need to build their latrines so that there isn't any contact. If they have pigs, they need to be in a pen and not inside their homes. They need to be 100 or 150 meters away in their own place."* However, at a later time the participant denied there was a relationship between hygiene and infection. In addition, signs seen in pigs were described incompletely, noted as, *"The owner checks inside their mouths because they have it inside their teeth. That is how we know they have that disease."* This participant also initially denied knowledge of symptoms in humans but later describes them in a relative, stating, *"He has it inside of his brain. The trichina disease makes him faint. It will get worse."*

The same participant closed the interview expressing the urgent need for a solution to the disease in the community. The related quote is seen in the discussion below on description of the

disease in humans. Taken as a whole the interview illustrates imperfect understanding of cysticercosis but reveals that knowledge is not completely lacking.

Other than these two participants, respondents were largely unable to describe cysticercosis in animals, or gave very partial and/or conflicting versions. None of the participants were able to provide a complete description of the disease in animals, or in humans, as will be discussed below. Five participants identified pigs as the only animals infected with "triquina." Three stated other animals might also carry it. One stated fish have it, *"Once, about two years ago, the fish would come with trichina from the water, and we've seen a few of them. You grab it, open it up, and it has trichina worms in its blood. I don't know about other animals."* Another stated cows might also have the disease, and another generalized that it is mostly but not exclusively carried by pigs, while four people did not know.

While the participant may well have observed parasitic infection of one sort or another in these fish, it was not with *Taenia solium* or *Trichinella spiralis* for that matter, since these do not infect fish. The statement, then illustrates a lack of differentiation between parasitic organisms, the animals they infect and the diseases they cause.

Two participants described most clearly how to identify when a pig is infected. Five described signs and symptoms either incompletely, such that it is difficult to discern with certainty that they are truly familiar with signs, or they did so with the addition of incorrect information. For example, one participant stated that cysts are seen in the meat of the infected animal, but continued with, *"I think that, according to what I've heard, when dogs bite them, it's because the pig is healthy. I've heard that. I don't know if it's true because we haven't had studies done about that."* This statement reveals the idea that the bite of a dog might be used to

rule out infection in a pig. There was also clear acknowledgement in this statement that there is a lack of knowledge regarding signs and symptoms of cysticercosis.

Another individual stated that infection is seen in the open mouth of a pig, inside their teeth. While this is not necessarily untrue, in that a cyst might be seen in the gums of a pig or in other tissues, it will not be seen "in their teeth." Furthermore, cysts might reside in tissues other than in the mouth, such that absence from the mouth does not rule out infection. Another individual listed cysts in the flesh as a sign and also cited hairiness, snoring, and being fat as signs of the disease. In fact, two people stated that if a pig is very fat it is a sign of "triquina."

Most participants did not claim to know about prevalence of cysticercosis in pigs in their region. Two thought that there was some occurrence but that it was not very common. Two others gave conflicting or uncertain responses. Of course, without formal studies it is hard to know exactly what the prevalence is. One participant stated that it was very common, and later stated it was not very common. Another stated it was completely eliminated in pigs without any supportive evidence.

Most participants did not acknowledge any formal teaching in the community about cysticercosis. Two thought most community members knew that pigs have this disease. One said that some community members know pigs have it and some don't. Two thought the children learned about it at school. Most felt children learn about the disease through family teaching. Half of the participants said children do not know about it until they learn it from family. Four people thought children and adults learned about the disease in the same manner.

Subtheme: Disease in humans. The vast majority of participants interviewed were unfamiliar with cysticercosis as a human disease. If there was knowledge it was vague and

uncertain. A few people made the link between eating infected pork and contracting the disease. No one had a clear understanding of how the disease impacts humans or what the symptoms are. Only three respondents were able to provide a few factors about the disease in humans. One participant cited dizziness and fainting, as symptoms, stating that, *"I don't know. That might be the cause. We don't know for sure."* Of note, in these communities the word "fainting" is sometimes used to refer to seizures. One participant acknowledged a lack of understanding of the impact or risk factors of cysticercosis, but also thought some symptoms might be dizziness or fainting. It was acknowledged by this participant that humans might contract it by eating infected meat.

Another participant similarly listed headaches, dizziness, and fainting as potential symptoms, and noted that there is no knowledge about how to diagnose cysticercosis in humans. This participant also stated that eating infected pork was a risk factor. Finally, a participant denied knowledge of human symptoms but then went on to state that infected pork could cause it, and described how a relative had the infection in his brain, causing seizures. This was the most clearly illustrated connection made throughout all the interviews between cysticercosis and seizures. Finally, one participant described a disease caused by pigs that makes people "lose their minds," and was related to pigs roaming freely. This participant later stated that only pigs contract the disease.

Two persons ventured statements on prevalence of cysticercosis in humans, as opposed to the prevalence in pigs. One initially "imagined that many, many" in the communities have the disease, but ended by stating it is not that common. Another stated cysticercosis exists but is not common. All others denied any knowledge of prevalence of cysticercosis in humans.

Although not the focus of this study, general knowledge of parasites was also evaluated. Knowledge of variation in types was touched on in the cysticercosis section of the interview as it relates to that disease. About half the participants clearly stated that there are different types of parasites, but no further description or information was provided. Several noted gastrointestinal effects from parasites. These were the only symptoms identified independently of prompting. One stated that diarrhea and vomiting are the biggest health issue in the area, and related these conditions to parasitic infection. On the subject of parasites in general, one participant acknowledged that there are many different types of parasites, infecting all different animals. When asked how infection occurs this participant responded, *"Just imagine. We are in the woods. There is no cleanliness in the woods."*

Subtheme: Knowledge of epilepsy. Most participants had some familiarity with prevalence of epilepsy. Only two said they did not have any experience with epilepsy, but both of these recognized that it exists in other communities in the district. Only one participant denied knowing someone with the disease or having had some degree of exposure to it. Two participants had family members with the disease. Some of the experiences were remote. Four described ongoing and current experience within their communities. One participant stated, *"That disease has always been around. We are worried that it will continue."* The majority felt that while epilepsy exists in their district it is not common. Three people declined to comment on prevalence.

In contrast to familiarity with the prevalence of epilepsy, most participants did not know its etiologies and none directly identified cysticercosis or any other infectious process as a potential cause. Most participants were able to discuss impact on the person with epilepsy and on

the family/community to some degree. When asked open-ended questions about causes of epilepsy, cysticercosis was not mentioned.

Two participants that discussed causes of epilepsy both stated that sometimes people are born with it. One thought that they get it from the mother or the father. One participant also thought that fear causes this condition, stating, *"Those people that have this, they say that whoever has this thing has been scared since being little. They started getting worse with that problem. Society and families have it, and that's where it starts. The problem is that they don't take care of their children; they frighten them. Unfortunately, that child is traumatized."* One person treated epilepsy as a common or generalized illness and felt it was caused by weakness secondary to malnutrition, stating, *"Some people are weak because they don't eat enough. Some people have lunch at 12:00 PM, and some others don't. Some people have breakfast, but some others don't. That's the situation we have here. I think it makes it all complicated and that's why people get sick, doctor. People are weak."*

Interestingly, in response to a closed ended question where participants were asked if they thought parasites might cause epilepsy, about half thought they might. Some stated all types of parasites might cause epilepsy. One participant, when prompted to describe which parasite might cause epilepsy revealingly stated, *"At the moment, I'm starting to understand the trichina worms, because I didn't know before, let's say, yesterday."*

Most participants were also able to describe seizures. Only two respondents were unable to describe seizures at all. One participant provided a description that was somewhat vague and sounded more like stroke than seizure symptoms. This participant had endorsed having seen seizures in neighboring communities but not locally. Six respondents provided very good

descriptions noting the intermittent and unpredictable character of events. Two respondents thought that events occur with the new moon.

Subtheme: Porcine risk factors. Two participants clearly identified at least some risk factors related to cysticercosis in pigs. Four provided uncertain, incorrect or conflicting responses, and six had no knowledge of risk factors related to pigs. The two that most clearly identified risk factors recognized that pigs contract the disease through eating human excrement. One stated that exposure to hygiene waste products was also a risk factor of porcine cysticercosis. The other acknowledged the impact of allowing pigs to roam free. This participant went on to state that places for defecating should be separated from where pigs are allowed to go. However, it was additionally asserted that the pigpen should be placed where the "wind runs," so that pig waste can be taken away by the wind.

Another participant stated that pigs contract cysticercosis by standing in puddles. In response to repetition of the question "how do pigs contract cysticercosis?" this participant repeated this assertion and added that they might contract it by eating human feces, explaining:

> *"Like I told you earlier, that's what I understand, more or less. It also happens when pigs go and touch some-- How shall I tell you? Some people go and relieve themselves there out in the open. This happens where there are no bathrooms, and people don't have a bathroom, surely, right? They relieve themselves out in the open, and they throw their paper. Apparently, that happens too. I heard that."*

Another participant stated that pigs contract cysticercosis through eating garbage of any kind. Of interest, one participant that was unable to answer most questions with any substantive information did make a connection between the disease that pigs carry and allowing them to roam freely, stating that this was dangerous practice. One participant thought it was contracted

when dogs from the wilderness come into the community and bite the pigs, and another thought that they are born with it.

Subtheme: Human risk factors. Three participants identified eating infected pork as a human risk factor for cysticerosis, although one of those participants was not certain that humans contract the disease. Three respondents gave incorrect or vague answers, one thought it was related to luck, and unrelated to age, the other two were not certain that humans contract the disease. One respondent thought that people might get the disease "through animals" but had no further explanation. Another participant thought it was related to pigs roaming free. This same participant thought the disease makes people lose their minds but in the end stated that only pigs contract the disease.

Nobody linked cysticercosis with tapeworm. None discussed tapeworm cysts as a source of infection, other than through eating infected meat, which would actually result in intestinal tapeworm, rather than cysticercosis. Thus, the life cycle of *T. solium* appears completely unfamiliar to those interviewed.

Subtheme: Disease prevention and management. As noted above, pork is not eaten in all communities. This is largely determined by whether or not pigs are raised locally. Five participants stated pork was eaten in their communities, five more said some was eaten but not very much, two participants stated pork was not eaten at all in their community. Regarding meat, one participant explained, ***"****We could have meat here, but the thing is that there's no work here, there's no money. If we want meat, we have to go to the woods, to hunt. Some people, who have resources, go to Santa Cruz to sell and buy meat or chicken. It's difficult; there are not many people eating meat."* Later this participant added, *"Not everybody likes pork, not even for*

Christmas or New Year's dinners. Spanish speakers are the ones that eat pork; they cook it with potatoes and all that for New Year. Here people don't do that; they just eat boiled chicken, baked goat meat, beef but not pork."

Meat may or may not be evaluated for cysts. Four participants stated confidently that if infection is detected the meat is not eaten. Another participant asserted that personal practice would be to reject infected meat, but that there was no knowledge what the actions of others might be.

Conversely, three participants stated that when contamination in meat is detected, it might be eaten anyway or given away, noting, *"Sometimes, they give away pieces of meat with trichina for free. Since it's rare to see meat around here, sometimes, we cook it-- We cook it and eat it."*

It was felt that some people are unaware of cysticercosis infection in pigs. For example, one participant stated, *"Some people know. I know it, but my son doesn't know it yet. My sister doesn't know that there are trichina worms in the meat and that they carry the disease. It's very complicated."* Seven participants identified checking meat for cysts and then refusing to eat it as an important health measure, although effects of eating it were unknown or unclear. One participant stated simply that eating it is "nasty." Two participants thought that cooking the meat would not kill the cysts. In contrast, one respondent said, *"They have to cook it really well in the oven. They have to season it so it has a delicious smell. If they cook it really well, they will be fine and safe, but it has to be really well cooked."*

One participant thought clean water was an important preventative measure for cysticercosis, along with the availability of medicines and specialists. Another participant also

felt the availability of doctors would be contribute to prevention, as would education of communities, since the community members are lacking in knowledge. Another participant thought studies to determine prevalence, along with education on prevention is needed. Two respondents listed the importance of separating pigs and human living quarters. One respondent felt veterinarians and treatment of animals was necessary for elimination of the disease.

One participant stated it would be important to build latrines. *"I would suggest every society and every family take care of themselves and that they keep their animals where they belong. They have to do it themselves. They need to build latrines for that illness not to spread."* One respondent emphasized hygiene as important in preventing parasitic infections. Another simply stated that clean houses were important to disease prevention.

Treatment for parasitic infection (referring to intestinal infection as familiar to the people) was covered in the previous section. No one was able to describe knowledge or treatment of cysticercosis. There was complete consensus that when using medications a physician's instructions (or nurse/nurse's aide's) should be followed. A few participants noted concern that parents might not comply or might be reluctant to give their children medications. None of the participants questioned dosage, overlapping prescribers or instructions. That is to say, anyone with the authority to give medications was given full faith and trust in dosing and frequency.

In contrast to treatment for parasitic infection, regarding treatment for epilepsy, several participants felt that medications and care by medical doctors provided no relief. They felt traditional healers were more effective. Of note, some of the participants related stories of seeing providers in nearby cities, which, while offering larger facilities and the availability of medical doctors, do not have specialists. There are no neurologists closer than Santa Cruz, which is a

very large city, and a full day's drive away, weather permitting. As such, several participants noted that in order to treat epilepsy, local specialists were necessary. The requirement to travel was noted.

Two participants said there were local herbal remedies and ointments for epilepsy, but no medical cures. Two participants noted "secret" cures for epilepsy provided by traditional healers. One participant describes a traditional cure for epilepsy involving a fox, explaining:

> *"People say that you have to kill it and grill it well, let it dry, extract the fat, and when the moon is full, your mother or parents, your whole family, have to fry that meat with that same fat. At 12:00 AM, you have to feed that to them. That's what they say is the cure for that."*

None of the participants felt that medical treatment for epilepsy was available in the district of Bajo Isoso, or even readily in the Cordillera province. Antiparasitic medications, on the other hand, are familiar to the community members and given routinely to children under 5 years old. Although children are treated routinely according to a schedule provided to the health posts, adults may not receive any treatment or evaluation for parasites as participants agreed that health care is available for children less than five years old because the government provides assistance for them, but that it is more difficulty for people between the ages of 5 and 60 to receive care. This is discussed in the resources section. Participants all agreed that when prescribed medications are taken as directed. None of the participants had heard of any possible negative effects of overlapping this type of medication or of taking too much of it.

An attempt was also made to gauge knowledge of the relationship of hygiene, water, food, and sanitation to epilepsy and cysticercosis. Sanitation as it relates to pigs and cysticercosis was noted above. For the most part, participants did no identify direct relationships between sanitation and seizure, except two participants who indirectly related sanitation, cysticercosis and

seizure, but without full explanation or apparent understanding of the details of how they were related.

Regarding water and epilepsy, one participant thought contaminated water might be a causative factor of the disease but could not explain how. Otherwise food and water were related to disease only in terms of general health. For example, several participants stated that a healthy diet keeps a person healthy, while too much sugar and/or malnutrition can weaken a person. One respondent stated that windy conditions deposit dust in food and this might be contaminated with organisms. Two respondents related drinking contaminated water with intestinal parasites.

Two participants expressed generational differences in understanding/beliefs about prevention and management of disease in general, epilepsy and cysticercosis. Regarding general healing one of these participants felt that their own generation learned more about traditional healing and plants than the younger generation. The other participant stated that their elders thought cooking meat with cysts killed them, while their own generation knew this to be untrue.

The vast majority of participants stated that hygiene was deficient. Only one participant stated it was “fine,” continuing with an assertion that community members are continually taught about hygienic practices at community meetings, and that part of their role in the community was also to teach this. This participant went on to state that houses were not typically clean. In fact, a common theme was that the participants, as community leaders, were continually teaching about hygiene. Participants cited lacking resources, especially lacking water and sanitation infrastructure as part of the problem. Not only are toilets lacking but many have no latrine either, and defecate in the open. These conditions make good hygiene difficult according to several participants. Some also cite disinterest, irresponsibility, lack of follow through regardless of

repeated instruction, and lacking education about consequences of poor hygiene as contributors. Two participants acknowledged improvement with the recently improved access to water and increased numbers of latrines. One participant stated, *"There are some people who keep their places clean; they sweep and clean up. However, there are some others who never clean, and we, as the authority, have to give them a warning because we can't allow them to cause the spread of diseases. We set meetings in the community to talk to people about hygiene."*

The majority of participants denied treatment of water before consumption. One participant thought chlorine was added to the tanks in the community, in contradiction to three other respondents, one stating it used to be added, and another noting there was no money for the chlorine. One respondent stated that they boiled their family's water but did not know what other community members practice. Another participant felt that 10% of the water in their community was boiled water prior to use.

Several participants were uncertain about water quality, while others felt it was unclean. A few participants thought the water was potable as available. Most respondents felt access to clean water was limited. Although water was largely felt by respondents to be contaminated, some participants stated they did not treat it either because they lacked education, knowledge or guidance, or because "that is not our culture". One participant stated that although they were instructed to boil their water they do not do so. Another participant noted that tablets for water purification were recently provided to the community but they were not in use. This participant felt it would be easy for community members to adopt this practice, and that they would be willing to do so. Of note, this participant also that stated water treatment was outside of cultural

practices. Estimates of water quality and access will be further discussed in the section on resources.

Major theme: Resource availability related to cysticercosis. Resource availability related to cysticercosis, an enabling factor, was also identified as a major theme. Subthemes identified were Medical Providers and Healthcare Facilities, Medication and Diagnostics, Water, Sanitation Infrastructure and Money.

Subtheme: Medical providers and facilities. All (100%) of those interviewed agreed that there are no local permanent doctors. Participants described that occasionally doctors visit the communities but this is seldom. Specialists are never available locally, or even in nearest cities. For this kind of care, the closest availability is in the city of Santa Cruz, a full day's drive away at best.

Participants also described that local providers are limited to nurses or nurse's aides. They noted that occasionally there is an NGO nurse at these facilities to assist with care. Participants noted further that nursing is not always available. They do not reside in the communities and when not working there is no health care coverage. Further, they described that nurses are present at the Health Centers, (two in the district) which might be some distance away and difficult for community members to reach, depending on the community. There are small hospitals that are event farther away, also depending on the community.

Participants described that health centers have only the most basic medications, including over the counter analgesics, a few antibiotics, and antiparasitics. They also described that healthcare is provided for children under 5 years and adults 60 and over, as noted above. Others must pay for medications and services. One participant emphasized the point, stating, *"Well, we*

don't have any doctors here. There are no doctors in this place. There are doctors at hospitals in another community. However, they tell you the truth at the health center; they don't have any doctors. Only the aides and nurses see people. From there, they refer you to the hospital, but sometimes, not even the hospital has medication. There isn't any."

One participant stated that there is plenty of health care in the form of traditional healers. Other participants noted that since there is no medical care, people search for alternatives in the form of traditional healers. Several noted that some community members prefer traditional healing methods to allopathic medicine.

One participant stated that there is a need for a veterinarian and vaccines to prevent cysticercosis, noting, *"All we need is a person, a human resource such as a veterinarian, to vaccinate pigs for all the things they have. They need that treatment not to have that bug. That way, we eliminate the trichina disease, but there has to be a veterinarian."*

Subtheme: Medications and diagnostics. Similarly, and in relation to the above, there was 100% agreement among participants that medications are unavailable except in the most basic form, and diagnostics tools are absent. Participants stated that it is difficult for people to get prescriptions because there are no medical doctors. If they do have prescriptions it is difficult to fill them because medications are scarce. Participants stated that there are no specialized medications available, no pharmacies, and assistance is only available for children under five years old and adults over 60 years old.

Subtheme: Water. Responses regarding water access were more varied and complex. Most participants acknowledged at least some limit to accessibility and some question about water quality. Several participants felt there was no potable water, but it was used anyway, and

without treatment. For instance, a participant stated, *"I know that other communities have controlled access to water, so they have very clean spaces. The situation is different here. I think that's why there are so many illnesses in this community. We seldom clean the water tank, and it's probably dirty, with bugs and stuff. That's why people suffer from diarrhea and vomits all the time. That's the reason."*

Several participants compared current to past access, asserting it was much improved from then. One of these respondents described drinking water from the river, (very shallow and sometimes dry) and having to wait until the sand settled in order to drink it. Compared to that this participant stated their well provides very good water. Another participant stated that sometimes community members go to the river for their water (a running river), and they have a process for cleaning the water involving branches for removing large contaminants. They add seeds to the water and when these are settled they are able to drink the water. This method is used in supplementation to water in tanks.

One participant discussed recently improved access to water with some publicly accessible faucets. Another participant stated plans for improvement were underway. One participant stated that the water engineer told them their water was clean. Several respondents stated that water quality studies were deficient. Varying accounts are in part due to conditions that vary by community.

Subtheme: Sanitation infrastructure. Sanitation was discussed to some degree in an earlier section. In addition, participants stated that many communities have no toilets. Others have limited toilets and limited access to water limits use of these. Many have limited latrines (a communal or privately owned hole in the ground). There are community members without

latrines and many people in the communities defecate in the open. Garbage and waste is not always disposed of. Respondents described that leaders attempt to educate community members and that they desire to improve conditions. There was no disagreement regarding estimations of these conditions and the need for improvement among respondents.

Subtheme: Money. As noted earlier, all participants felt that the lack of financial resources was central to their other problems. Participants stated that they require money for medications, travel to adequate facilities, improved local facilities, human resources, diagnostic capabilities, water, housing, food, sanitation and healthy food.

Major theme: Perceptions of responsibility for addressing cysticercosis. Another major theme identified was *perceptions of responsibility for addressing cysticercosis*. While talking about related issues statements were made regarding whose responsibility it is to manage and prevent health problems in the community. Subthemes were Leaders, Family, Community as a Whole and External Assistance. Frequently mixed responsibility was cited.

Subtheme: Leaders. Leaders frequently noted educating their community members and reminding them about healthy habits and actions. For instance, in discussing what pigs have access to one participant stated, *"We (leaders) always tell the community that they need to build their latrines so that there isn't any contact."* And later, regarding meat handling, this same participant stated, *"That's why we always ask that they watch what they need to watch."* Another participant described daily responsibilities of community authorities eloquently noting,

> *"The captain has to visit every house in the community and support people. The captain has to want to do this kind of work during the whole day, no matter if he's hungry. When school starts, I have to go every two days and check the condition of the bathrooms, see if they're dirty or smell bad, ask them to clean them, and to have water. I think it's part of our responsibility, to make everything be better for the community well-being."*

Subtheme: Family. Many respondents felt family was responsible for teaching and providing role models to the children, as well as for making sure family members were cared for appropriately and took medications as required, when available. For example, one respondent stated, *"Children don't know about the diseases people catch, but adults do, and adults have to explain to their child, to their woman, 'This is how this disease is. It's like this. Therefore, don't touch it,' 'Don't smell it; otherwise —'so that they learn."*

Regarding knowledge of cysticercosis in particular, another respondent noted that education begins at home, noting, *"For example, that has to be born in the home, and it has to start there. Since I'm a father and an old man, and I know when a pig has trichina disease, I know that, for example, the little ones must be warned. They need to know that that one is sick and cannot be eaten. It is not good. We can start warning that generation in that way, and we can start teaching them."*

When asked about adopting healthy habits a participant asserted the parent's responsibility as role model stating, *"The more I practice it, my child will practice it."* And regarding management of epilepsy one participant stated that because families were *"giving their children the opportunity"* to heal, there was an improvement in symptoms, later noting, *"Thank God, their mothers are helping them to learn about natural medicine and about the medication from doctors."*

Subtheme: Community as a whole. When discussing hygiene and its lack in communities, most participants implied or stated directly that community members need to participate and be responsible for maintaining cleanliness. One community leader, while describing his own role as educator, stated that everyone in the community must be involved,

saying, *"We need to do what it takes to keep the environment cleaner. Yesterday, I had to talk to people and demand them to keep everything clean here; they don't take care of their spaces; hygiene depends on each of us. We have to take care of our spaces, keep them cleaned. We also have to keep ourselves cleaned and take a shower. I was hard on them yesterday."*

Subtheme: External assistance. Participants frequently cited doctors and healthcare providers from outside the communities as responsible for educating community members. Regarding lack of hygiene in the communities, one participant stated it was deficient, "*Because of a lack of training. They were supposed to come from the hospital to give us a course and some training on hygiene, but they don't do it. People learn to be clean and clean things in their own homes. Usually, from their families."*

Similarly, regarding the importance of keeping pigs separated from human living spaces and latrines, and why it is not commonly practiced, a respondent stated, *"Perhaps there is no training. For example, doctors don't have any plans to come here and explain to us the different diseases that attack us. Some people know, but most of us need a doctor or nutrition aide to explain things to us. That's why. People forget, and they don't know which diseases will attack us."*

Additionally, participants and other community members openly and frequently expressed their hope for external assistance. This researcher, over the course of multiple trips, was asked for assistance for many things including training, medications, assistance building housing and schools, diagnoses, and assistance establishing access to permanent healthcare in the districts. While these are not realistically attainable by the researcher single-handedly, they nonetheless, instill a desire to assist the community in finding solutions.

Major theme: Perception of impact of cysticercosis. The next theme identified was *perceptions of impact of cysticercosis*, a predisposing factor. This theme deals with the perceptions of the impact of the disease on persons afflicted, on their families and on the community as a whole. The impact of epilepsy is included under this theme, since it is the primary presenting symptom. The urgency to address NCC similarly falls under this theme. Finally, under this major theme is the frequently cited need for further studies that unexpectedly came out in interviews. Subthemes are Significance of the Problem of Cysticercosis, Urgency to Address Cysticercosis, and Need for Studies on Cysticercosis in the Communities.

***Subtheme: Significance of the problem of cysticercosis*.** Two participants acknowledge an impact of cysticercosis on humans, although with uncertainty. One was the participant quoted previously who acknowledged that a relative had contracted the disease, and another was a participant who thought many were affected but was unable to describe or quantify this. That assertion may have been a guess based on the knowledge that this researcher was in the community to study the disease, but this cannot be known with certainty. The remaining participants could not address the question about impact of this disease on the community.

On the other hand, most participants were able to discuss impact of epilepsy on those with the disease. Emphasis was placed on intermittent and unpredictable nature of seizures making daily life difficult and creating potentially hazardous situations. Other descriptors about the impact of epilepsy on the person afflicted were “scary,” “huge” and “total.” One respondent stated that epilepsy insidiously weakens the individual. The danger of being alone and the inability to work or live independently was noted. One participant explained, *“That hinders their (the person with epilepsy) freedom to go to work on their own because, sometimes, they may fall*

into the water, or when they're burning garbage, they might fall into the fire. It's an issue. They don't have much freedom to work by themselves on the farm anymore."

Similarly, almost all participants were able to discuss the impact of the disease on family and community members. Only two participants failed to comment claiming unfamiliarity. One participant thought the responsibility fell largely on the mother, as primary caretaker. Others respondents emphasized the need to continuously monitor the afflicted person, keeping them from going off on their own. Several participants commented that the continued stress of trying to keep the person with epilepsy safe was huge. There was again the acknowledgement that it is scary for family/community members, and that they cannot be at peace. One participant noted that related continual stress drains family and community members. One participant described the effects of one witnessed event, *"I got scared. I thought it was going to kill him, but no. He got better, overall."*

Subtheme: Urgency to address cysticercosis. An attempt was made to assess the importance of addressing cysticercosis and epilepsy to the communities represented. Participants were asked directly if they thought addressing cysticercosis and epilepsy was important, urgent, and a priority to the community. 100% of respondents answered affirmatively to these questions. One participant simply but revealingly stated, *"It's complicated and urgent."* Another participant asserted, *"The number one priority is that it has to be eliminated."* One participant expressed the urgency to address cysticercosis stating, *"It's very urgent because we didn't know about that kind of disease. When you came last year you spoke about cysticercosis. We saw that a lot of people would faint sometimes, but we didn't know why."*

Another participant described the urgency of the problem relating it to personal experience, stating, *"For example, my uncle has that disease in his head now. If we don't explain this to our children, they may eat pork with trichina disease. If the trichina worms don't die, they damage the body. That's why my uncle has this disease … That's why we need to eliminate it as soon as possible; we need to do it so that it doesn't hurt anybody else."*

Subtheme: Need for research and teaching. One third of respondents brought up the need for studies within their communities to determine the extent of the disease there. These suggestions were spontaneous and not in response to prompting by the researcher. That is to say, there were no questions asking whether or not the participants thought research was needed. Rather, the suggestions came out in discussion. Illustrating this, in response to questioning about resources needed in the community, one participant stated, "*For example, studying diseases. Here in the countryside, with so much poverty, we need human resources. We need professionals in that specialty. Because there are people have that disease."* Another participant responded to questioning about prevention of cysticercosis by stating it could be prevented by, "*Making all the necessary studies, so that we can detect it and take preventive measures."*

Several participants also noted the need for education in the communities. Lacking knowledge was frequently cited as a problem contributing to poor habits. As noted above, responsibility for this was assigned variously to leaders, who frequently take it upon themselves to educate community members, family, who are thought of as primary educators of children, teachers in the schools and educated persons from outside the community. When asked if change required for the adoption of new habits for health and wellness was easy for community members, one participant stated, *"Sure. You start by giving out training sessions."* One

participant went farther, stating that the young people in the community need to be trained so that they can become future healthcare providers for their communities. This respondent repeated the need for a permanent doctor or nurse in the community.

Summary

Twelve community leaders were interviewed and asked to discuss their community's knowledge of cysticercosis and epilepsy. Four major themes were identified: Knowledge of Cysticercosis (predisposing factor), Resource Availability Related to Cysticercosis (enabling factor), Perceptions of Responsibility for Addressing the Problem of Cysticercosis (predisposing factor), and Perceptions of Impact of Cysticercosis (predisposing factor). Subthemes under each of the major themes were identified and comprehensively represented.

The findings revealed some striking information about the communities visited. First, knowledge of cysticercosis was lacking. Most participants were not aware that humans might contract cysticercosis or what the symptoms are. Most participants did not know potential etiologies of epilepsy, including cysticercosis, nor did they have comprehensive knowledge of prevention or treatment. Second, it was most apparent that resources to address the problem of cysticercosis are severely limited. There is no consistent access to medical providers or medications. No specialized medications are available in these areas and most people with epilepsy go untreated, or are treated with traditional medications. Third, participants perceived the problem to be highly significant and expressed urgency in addressing the issues. They seemed to sense that there was more to the problem than what they were aware of, and expressed an urgent desire to learn more and to prevent and treat cysticercosis and epilepsy. Fourth, perceptions of responsibility in addressing the issue were positive. Participants wanted to be

educated, and they are more than willing to participate in collaborations to achieve their goals in acquiring greater access to care. A striking finding was the keen interest in more research in their communities, in order to gain understanding of diseases present there.

In summary, we successfully conducted interviews of leaders in a variety of communities in rural Bolivia. The following chapter will discuss the study findings and unanticipated findings in the context of the specific aims of the study and in the context of other literature in the area, the study limitations and strengths, transferability and recommendations for future study.

CHAPTER V: DISCUSSION

NCC increases epilepsy by as much as 30% in endemic areas, such as rural Bolivia, where conditions are ripe for the disease to flourish. Research is limited regarding the problem in general, and even more so specific to rural Bolivia. Moreover, a study aimed at determining the knowledge of cysticercosis, along with facilitators and barriers to addressing the problem, and the perception of need in the communities to do so, has not been done in this region. This study was undertaken to address the gap in knowledge. Interviews with 12 healthcare providers and community leaders representing 14 communities were successfully obtained. These provided rich data, allowing us to answer stated research questions and to fulfill the goals of this project.

We identified four major themes from the interviews, Knowledge of Cysticercosis, a predisposing factor, Resource Availability Related to Cysticercosis, an enabling factor, Perceptions of Responsibility for Addressing Cysticercosis a predisposing factor, and Perceptions of Impact of Cysticercosis on the Community, a predisposing factor. Specifically, we found that there was a lack of knowledge of cysticercosis, that resources to address cysticercosis were severely limited, that community members perceive the problem as highly significant and needing to be urgently addressed, and that there is positive attitude toward accepting community responsibility for addressing the problem of cysticercosis.

In this chapter, the findings will be related to the study purpose and specific aims of the project. Unanticipated findings will be discussed. Findings from this work will be related to previous research results as applicable. Finally, significance and limitations of the study, along with recommendations for future research will be addressed.

Relationship of Findings to Study Purpose and Specific Aims

The purpose of this study was to determine healthcare providers' and community leaders' knowledge and perceptions of community barriers and facilitators regarding NCC. The first specific aim was to determine healthcare providers' and leaders knowledge of NCC, considering how NCC is acquired, treated, recognized and prevented, and the degree to which NCC is seen as a problem in the communities. The major themes Knowledge of Cysticercosis and Perceptions of Impact of Cysticercosis on the Community relate to the first specific aim. The second specific aim was to determine healthcare providers' and community leaders' perceptions of barriers and facilitators to treat and prevent NCC, considering how they view their resources, the degree to which community knowledge and beliefs impact treatment and prevention, and how they view their community's desire and sense of urgency to address NCC and epilepsy. The major themes Resource Availability Regarding Cysticercosis and Perceptions of Responsibility for addressing Cysticercosis relate to the second specific aim.

First Specific Aim: Knowledge of Cysticercosis (Predisposing Factor)

Specifically, we found that there was a lack of knowledge of cysticercosis, and that community members perceive the overall problem as one that is highly significant and needing to be urgently addressed. In general, knowledge was found to be much greater about the disease in pigs than in humans. Those that eat pork appeared to have more knowledge about porcine cysticercosis than those that do not. A surprising finding was the degree of separation between communities in this regard. It was expected that community characteristics would be more homogenous given the small area covered and the size of the population, as well as the cultural homogeneity of the people (all are Guaraní). Specifically, it was surprising to find such

delineation in diet per community. The degree of variation in diet as well as in knowledge based on this characteristic was unexpected. Also somewhat surprising was the finding that although there was more knowledge about the disease in animals, it was imperfect at best. There was little acknowledgement that there was any relationship between the disease in humans and the disease in pigs.

It was found that there was minimal knowledge about the disease in humans, and what was known was imperfect and vague. The lifecycle of *Taenia solium* seemed to be completely unfamiliar, as did its relationship of cysticercosis to intestinal tapeworm. There was no evidence of understanding of transmission of cysticercosis. While a few participants were able to relate seizures to cysticercosis most did not make the connection between the two. Once again, it must be noted that the use of the term trichina to discuss cysticercosis might be a confounding factor at the least. Since *Trichinella spiralis* was found to be present in the Cordillera province in 1999 (Bartoloni et al.), this is especially true. What clearly emerged from the data is that there appears to exist a lack of distinction between the two forms of cystic infection in pork. The distinction is important because disease prevention, impact, and treatment vary according to organism of infection.

Other factors that may contribute to lack of knowledge of the disease may be the education level of the participants. Most of the participants had only a grade school education and none had a college education. In addition, all participants lived in the same community for most if not all their lives, and travel to urban areas is difficult. These factors might limit the extent of exposure to facts other than what is known in the community. Finally, the lack of health

care providers in the region and the education they may bring may also contribute to the overall lack of knowledge regarding these diseases.

In contrast to the above, most people had some familiarity with and exposure to epilepsy, and it was understood to a greater degree than cysticercosis, but understanding of potential etiologies of epilepsy was lacking and no one directly cited cysticercosis as a possible cause. There was also lacking knowledge about treatment and management of chronic seizures. Porcine risk factors for cysticercosis were largely unknown, and what knowledge was present was incomplete and vague. Most of those who were interviewed did not recognize the disease in humans at all.

There was minimal recognition that pigs might become infected because of poor sanitation. Furthermore, there was little recognition that NCC might be contracted through eating infected pork, and there was no recognition that it might be contracted through poor hygiene, contaminated water or food contaminated by cysts. There was no knowledge about management of cysticercosis. Again, epilepsy seemed to be better understood. It was stated that epilepsy medications were hard to come by and many preferred natural to allopathic treatment, or chose natural treatment as a more accessible option.

These findings highlight the fact that knowledge of cysticercosis in these communities is incomplete at best. Furthermore, large gaps in knowledge were identified, specifically regarding human infection, modes of transmission, treatment and effective methods for prevention. Cysticercosis was not related with tapeworm and the life cycle of *T. solium* appeared completely unfamiliar to those interviewed. As a result of this lack of knowledge, it stands to reason that knowledge of prevention will also be deficient. Interestingly, while lack of knowledge of the

disease was apparent, perceptions of the severity of the problem in the community was evident and an urgency to address the problem existed.

Since few identified cysticercosis as a disease that impacts humans it was difficult for participants to state significance of the problem per se. However the significance of epilepsy was easier for participants to understand, and there was agreement that epilepsy, when present, has a huge impact on individuals, family, and the community.

An interesting finding was that when asked through closed ended questions, all participants stated that *both* cysticercosis and epilepsy were urgent problems that need to be addressed, in spite of the lack of knowledge of cysticercosis. This finding might be explained by several factors. First, the presence of this researcher likely influenced these findings. In order to obtain permission from the tribe to conduct the research, information regarding the study had to be provided. Leaders were involved in this process, and therefore had some prior introduction to the topic on this basis alone. That a researcher from the United States would travel to their communities to study the disease likely provided an indication that the disease is a significant problem in their region.

In addition, prior to this study, other studies on epilepsy, NCC and *T. spiralis* were conducted in the area; these studies occurred intermittently between 1998 and 2017 and were carried out by the Global Campaign Against Epilepsy in a joint initiative of the International League Against Epilepsy and WHO (Bruno et al., 2011; 2012; 2015; Nicoletti et al., 1998; 1999; 2000; 2002; 2005; 2009; 2017).1998-2017 (Nicoletti et al., 1998; 2002; 2005; 2015). Researchers from these studies conducted door-to-door surveys to establish prevalence of epilepsy in the Cordillera province, although the extent to which education was provided within

the communities is not known, either from the literature or from communication with community members or participants in the project. During preparatory trips this researcher had the opportunity to discuss the interventions related to this project with several members its research team, and it appears that they did surveys Bajo Isoso, but education and treatment were minimal due to the remoteness of these communities. Of significant note is that in spite of the sum of research activities that may have affected knowledge of the disease, we found that for the most part, knowledge specific to cysticercosis is still lacking and further, interventions for education, prevention and community programs have not occurred.

Second Specific Aim: Resource Availability for Addressing Cysticercosis (Enabling Factor) and Perceptions of Responsibility for Addressing Cysticercosis (Predisposing Factor)

The major themes that related to the second specific aim were Resource Availability Regarding Cysticercosis and Perceptions of Responsibility for addressing Cysticercosis. Specifically, we found that resources for the disease were severely lacking and that there were positive attitudes about their own responsibility for the disease.

There was complete agreement among all participants about the lack of resources available to these communities. Poverty was the primary concern of the participants and was said to impact all aspects of daily living. They agreed that lack of resources included medical providers and healthcare facilities, medications and diagnostics and sanitation infrastructure. The participants all agreed that the lack of resources played a large role in distracting them from good health-related behaviors, including good hygiene, pursuit of medical care and appropriate sanitation. There was some variation in responses related to water, in that some felt there was plenty of good quality water available to them. Most participants, however, questioned water

quality and felt that this resource was also severely lacking. Some variation in the perceptions on water quality and availability is attributable to variation in accessible water per community.

Participants readily acknowledged that they lacked education and knowledge about the disease. Of significance is that there were strong positive attitudes about addressing the problem including collaborating with outside sources. In addition, who owned responsibility for the disease and its impact was addressed at more than one level. Family was described as being responsible for teaching and providing role models, as well as for managing care of the individual. Community was ascribed responsibility for caring for the environment and following good health practices so as to keep everyone safe. Leaders seemed to feel responsible for educating the community and providing alerts and reminders of duty. External assistance was relied on for bigger problems, such as access to medicine, infrastructure issues, research and education going beyond the capacity of the community. There was a sense of disappointment that while doctors have come in to teach or do research occasionally, they have not returned. It appeared that while knowledge reached the community from outside sources at times, there was currently no in-depth teaching or implementation of programs that could be self-sustaining. Taken together, these findings have bearing on the implications for interventions and future studies.

Comparison of Findings with Previous Literature

Research on NCC and specifically research examining knowledge, attitudes and health habits related to NCC in endemic areas is extremely limited. Three studies were identified and results were compared with those of this study. One population based study looking at a rural community in Mexico, Sarti et al. (1997) evaluated knowledge before and after an educational

intervention about NCC. In that study 1931 persons from 386 households were interviewed. The study found that only 10% of those interviewed had heard of NCC. None of the participants were able to identify the causative agent prior to the educational intervention. Knowledge of symptoms of cysticercosis in humans was low, while knowledge of symptoms in pigs was found to be higher because of experience related to raising pigs, or being close to someone that does. Modes of transmission were not known (Sarti et al. 1997). These findings on knowledge of cysticercosis were consistent with results found in Bajo Isoso. In contrast to this qualitative study, the project in Mexico included seroprevalence testing, in both community pigs and humans, and implemented an educational intervention with evaluation comparing results before and after the intervention. The population evaluated was similar in that the community is rural and Latin American. Differences in the studies are also found in that a much larger number of people were interviewed, and individuals represented themselves as opposed to being represented by a community leader or healthcare provider.

Girotra et al. (2011) compared knowledge about NCC in those who have been diagnosed with the disease, with those who have not. They found that knowledge of the disease was low in the control group of persons without NCC, but slightly higher in those with diagnosis and treatment of NCC. Neither the group with NCC, nor the control group was able to identify causative agent or modes of transmission. Knowledge of prevention and treatment of NCC was similarly low in both groups (Girotra et al.). This was a hospital-based quantitative study set in urban Northern India where 214 persons were interviewed. The sample characteristics were quite different from those of this study, which did not have a control group. Numbers of people interviewed was also significantly higher. No one in our study was diagnosed with NCC or knew

anyone with the diagnosis. Nevertheless, findings are similar to those of this study, especially in regards to the control group of persons without NCC.

Kungu, Dione, Ejobi, Ocaido, and Grace (2017) carried out a study in rural Uganda where pigs are raised, examining knowledge of cysticercosis and hygiene practices. It was found that knowledge of taeniasis was higher than knowledge of porcine or human cysticercosis. Men had more knowledge about cysticercosis than women. Understanding of parasites and treatment was limited and misunderstood. Hygiene practices were deficient, with only one third of the population practicing hand washing, and with failure to use latrines, and defecation in the open occurring commonly (Kungu et al. 2018). Again, the study was quantitative, and seroprevalence testing was performed as part of the study. The population sample was taken from pig farming communities in Uganda. Although in Africa, communities were small and rural. Findings were again similar to those of this study. It is interesting that male and female respondents differed in knowledge in the Uganda study. This comparison was not made in our study, since the participants interviewed were overwhelmingly male (83%). Future studies might benefit from evaluating gender differences in the rural Bolivian population as well.

Comparison with the literature above shows that findings were consistent with findings from this study. All were carried out in endemic areas but none of the studies were done in Bolivia. The results of this study add to the limited body of research looking at knowledge, perceptions and practices related to NCC in endemic areas, and strengthen the findings that gaps in knowledge point to the need for programs for education, prevention and treatment in these areas.

Strengths and Limitations

The limitations of this work must be acknowledged. The work is based on the assumption that the leaders and healthcare providers are likely the representatives of their people. This assumption is based on the observation that these individuals served as *both* leaders (health care providers & community leaders) and equal members of the community. It may be that these leaders do not, in fact, represent the community members. It is beyond the scope of this study to interview individual community members and future studies may be needed to capture this data. Another limitation to this study is related to gender bias. There were significantly more males than females in the population sampled and therefore the female perspective may not be captured. Results might have been different if more women were in leadership positions. As noted above, to truly reflect the community including female voices, it might be necessary to do a study of community members as opposed to leaders. Future studies might be conducted to determine whether gender plays an important role in the problem at hand.

Furthermore, this study was necessarily focused on a very specific region and ethnic population in rural Bolivia. Nevertheless, it is thought that findings are transferrable to similar small communities within Bolivia as well as extra- nationally. This is an exploratory study meant to advance research and also to establish need and desire for further intervention, along with working towards interventions that will provide self-sustaining solutions for the prevention and treatment of NCC.

Another limitation is that, as noted above, the results were likely influenced by the knowledge that this researcher was in the region specifically to study cysticercosis. The leaders of the communities held a meeting with this researcher in the city of Santa Cruz prior to the

study to discuss permission to conduct the research. They were informed of the topic at that time and had some introduction and information provided about it through this interaction. This may have encouraged more learning on the topic prior to my arrival, as well as leading participants to state its significance in their area.

Additionally, since the communities visited were all in close proximity to one another, after the first session there may have been some coaching or preparation of participants by other community members. This concern arose in part through the observation that the most incomplete responses occurred in interviews done at the first community visited. While incomplete results in the first community could be related to the fact that little pork is eaten in this community, the incomplete responses may in fact represent the most un-coached responses. It is also possible that probing for more complete responses was better accomplished after the first set of interviews.

The majority of those interviewed were community leaders, or captains. It is also possible that there was communication between leaders in the interval between sessions (from one community to the next) in an effort to provide more satisfying or "correct" responses to the researcher. Leaders traveled to neighboring communities, visiting the community while interviews were conducted, making sharing of interview questions likely and coaching possible. Some responses became progressively more eloquent as we traveled from one community to the next. It was also note that bits of knowledge that were correct were mixed with incorrect, vague or contradictory statements, supporting the idea that the topics may have been discussed to some degree. Furthermore, there were comments by participants suggestive of very recent education and discussion about cysticercosis.

Participants may have hoped to provide appropriate responses in efforts to gain future assistance. For this reason, they may have coached each other and expressed an interest in future research in their communities. Research might be associated with assistance, since these communities have prior experience of research and assistance going hand-in-hand.

The presenting order and nature of the questions themselves may have been leading at times, allowing participants to piece together relationships or desired responses. For example, to ask about neurocysticercosis, then about hygiene, and then about the relationship between the two, might be leading. It is proposed that improvement would include restructuring of the Interview Guide, such that questions would not be leading. This might be accomplished by beginning with a section on epilepsy, then on water, then sanitation and hygiene, then on to NCC and finally to parasites in general. Individual questions would be reworded such that they are not closed-ended, and prompts would be included in the guide to help encourage more detailed response. The question that asked, “Do adults and children learn in the same way?” would be taken out, in favor of questions directly geared towards understanding how community members gain knowledge about important issues that impact their lives. Nonetheless, we are confident that when all of the responses of a particular participant were analyzed, the identified themes held true.

It is again noted that when analyzed as a whole, interviews revealed consistencies and/or contradictions that showed less than perfect understanding of the topics discussed. It is nevertheless felt that the interviews provided rich information that is useful to those interested in addressing the problem of NCC. Specifically, overall the findings indicate lacking knowledge. It

was therefore important to analyze not only individual questions, but also entire interviews, considering the overall features they illustrate when taken as a whole.

It is possible that limited exposure to some of the communities may have limited the true nature of the participant responses. Even though the researcher traveled to rural Bolivia five times (to the Cordillera province three times and to the district of Bajo Isoso twice, two to three weeks at a time), some of the communities were visited for the first time during this project due to weather challenges. It is acknowledged this is very limited exposure to the communities, the people and their culture. Unfamiliarity with the researcher may have colored perceptions of statements and experiences.

The strengths of this study reside largely in the collaborative nature of the planning for community visits and interviews. Within the project a community was formed. Gatekeepers were identified and with each trip their numbers grew. The researcher's growing familiarity with the culture and repeated visits to the community helped inspire the trust of the community leaders. Investing time in getting to know the community before approaching partnerships is useful in building confidence (Duran et al., 2013). A result of this process of returning to communities several times, the researcher was able to establish contact with the Guaraní tribal government. The Asamblea del Pueblo Guaraní participated in planning of the communities to be visited and were interested in involving their communities in the study. The willingness of the leaders of the communities to learn, teach and collaboratively plan is the greatest strength of this work.

Transferability

This study hoped to evaluate knowledge about NCC and epilepsy, as well as community facilitators and barriers to prevention and treatment as a preliminary step in creating a self-

sustaining program designed with community participation to address these issues. It is thought that the findings are readily transferrable to other communities in the district as well as to communities in neighboring districts minimally. Of course, community participation in development of programs is necessary for this type of program. However, this study may serve as an a priori replacement of formal studies of this type in other communities in order to expedite intervention planning.

Recommendations for Future Studies

It was found that knowledge regarding cysticercosis as it presents in humans is lacking, as is understanding of the causative agent, modes of transmission, preventative measures and treatment. Epilepsy is understood to a greater degree, but understanding of potential etiologies is lacking, as is treatment and management of chronic seizures. It was also found that the community has a great interest in learning and taking action to prevent disease and to acquire access to treatment. Their willingness and enthusiasm to participate makes them perfect partners for Community Based Participatory Research (Yonas et al., 2013) and for a collaborative intervention aimed at achieving self-sustaining programs for treatment and prevention of these conditions.

As discussed previously, according to the PRECEDE-PROCEED, planning phases guide the development of a logical model of the problem. The model was used to inform the Interview Guide, and to questions that might reveal predisposing, enabling and reinforcing factors to the problem. The results revealed four major themes related to enabling and predisposing factors as previously illustrated in Table 5.

In this study initial phases of the PPM were explored, including (Phase 1) social, (Phase 2) epidemiological, behavioral and environmental, (Phase 3) educational and ecological influences. Phase 4 was not explored in this study. Phase 4 involves both assessment of administrative and policy influences and determination of appropriate interventions and considers whether these two factors are aligned (Bartholomew, Markham, Mullen, & Fernandez, 2015). Following the model, this would be the next appropriate stage to undertake in this project. It is the stage at which methods are chosen and theories continue to be implemented. After Phase 4 is completed, movement to the next phases, the PROCEED portion, can be considered. This portion includes implementation, and evaluation of process, impact and outcome (Bartholomew, Markham, Mullen, & Fernandez, 2015). The findings of the current study indicate that at minimum, the communities would benefit from education programs to include descriptions, etiologies and prevention and treatment of cysticercosis. The development and implementation of an education program that involves the community might be a next step.

Clearly, lacking resources create great obstacles for many aspects of health care in these communities. It was evident that they lack medical care overall, and that epilepsy and cysticercosis form a small percentage of diseases requiring evaluation and treatment in the communities. Permanent and consistent access to care and medications is required. The participants expressed the desire and need for guidance regarding how to achieve these goals. It is proposed that an intervention to help them achieve these goals in coordination with the Asamblea del Pueblo Guaraní would be extremely beneficial. It is proposed that partnerships with Bolivian and United States Universities, including Colleges of Medicine and Public Health, but be formed in order to beginning brainstorming to find solutions to the problem of lacking

access to care, and in potentially providing interim care by university students. Partnerships regarding access to clean water might be sought with water filtration companies and also with Bolivian government agencies and university personnel.

Nevertheless, while the grand and overarching goals of permanent and consistent access to care and medications are not immediately attainable, prevention of NCC is. Therefore, in keeping with CBPR tenets, this researcher intends to loop back to the community. Specifically, an executive summary of the findings of this study will be presented to the APG in English and in Spanish. It will make note of the willingness for future partnerships with the community. Furthermore, a simple brochure outlining preventative measures for NCC and *T. solium* infection will be prepared for presentation to the communities visited. These will be very brief, utilizing imagery, and written in Spanish with Guaraní translations if possible. Finally, an executive summary of the findings of this study will be presented to the Bolivian Ministry of Health (Ministerio de Salud - Plaza del Estudiante esq. Cañada Strongest s/n, La Paz – Bolivia), once again noting willingness for future partnerships with the communities and with Bolivian government agencies. These follow up statements and brochures will be provided within six months of finalization of the current study.

Summary

This chapter provided a discussion of the findings, which were largely anticipated except that there was less homogeneity amongst communities than expected. The researcher also expected to find somewhat more knowledge regarding the diseases investigated than was found. Study limitations were discussed. While several factors may have confounded the results, rich and valuable information was acquired, providing a strong basis for future work. The findings of

this study were similar to research in other endemic areas. The case for transferability was made and recommendations of future projects emerging from this work were made.

Conclusion

NCC is thought to greatly increase the prevalence of epilepsy, which can lead to devastating sequelae including, physical injury, inability to work or function independently, stress in relationships and decreased quality of life. NCC is preventable and even potentially eradicable yet it remains endemic in areas such as rural Bolivia where conditions support its transmission. This study evaluated community leaders' knowledge, and perception of community strengths and barriers regarding NCC in rural communities of Bajo Isoso, Cordillera Province, in the Department of Santa Cruz Bolivia. The major findings of the study were that there was a lack of knowledge of cysticercosis, that resources to address cysticercosis were severely limited, that community members perceive the problem as highly significant and need to be urgently addressed, and that there is positive attitude toward accepting community responsibility for addressing the problem of cysticercosis.

This study is significant because it adds to the extremely limited body of knowledge on cysticercosis in rural communities. It is novel in that it uses a qualitative approach, describing the problem of NCC from the perspective of community leaders in rural Bolivia. As a result of this study, an intervention involving community education to address gaps in knowledge, in collaboration with the community leaders, would be an appropriate and effective next step in working towards development of a self-sustaining program for the prevention and treatment prevention of NCC. Through these types of programs, it is hoped that the devastating effects of NCC can be significantly reduced in endemic areas.

APPENDIX A:

LITERATURE REVIEW

Neurocysticercosis in Bolivia

Title	Author and Year	Purpose of Study	Design and Methodology	Sample	Findings
An epidemiological study of *Taenia solium* cysticercosis in a rural population in the Bolivian Chaco	Carrique-Mas, J., Iihoshi, N., Widdowson, M.-A., Roca, Y., Morales, G., Quiroga, J, Cejas, F, Caihuara, M, Ibarra, R, & Edelsten, M. (2001)	Quantifying the extent of human and porcine taeniasis and cysticercosis in the Chuquisaca department of Bolivia and to investigate risk factors.	Cross-sectional study using structured interviews. Validated questionnaires -family heads or other present adults. Pigs were sampled when present, and blood samples from humans. Indirect ELISA for detection of antibodies.	Seven randomly selected families within each of 17 randomly determined block of the village. 100 households sampled.	Prevalence in humans similar to that across Latin America. Hyperendemic - In an area typical of rural Bolivia. human cysticercosis is potentially a serious problem. Links to poor sanitary practices, low education levels. 53% of families had at least one positive for human cysticercosis and 75.5% of herds were positive for porcine cysticercosis in at least one animal
Epilepsy, cysticercosis, and toxocariasis: A population-based case-control study in rural Bolivia	Nicoletti, A, Bartoloni, A, Reggio, A, Bartalesi, F, Roselli, M, Sofia, V, Rosado Chavez, J, Gamboa Barahona, H, Paradisi, F, Cancrini, G, Tsang, V. C.W, & Hall, A. J. (2002)	Assess the relationship between epilepsy and *Taenia solium* and *Toxocara canis* infection with a case-control study in Cordillera Province, Bolivia.	Following two phase door-to-door prevalence survey that found prevalence and identified cases and control subjects, these were assessed serologically for *T canis* and *T solium*	113 case-control subjects identified with epilepsy and 233 control subjects were tested..	T solium and epilepsy were associated positively with an OR of 1.85, partial epilepsy and later onset (over 15 yrs old) were more strongly associated with OR of 3.66. Also positive association with *T canis*. Conclusion: NCC and toxocariasis may explain higher prevalence of epilepsy in developing nations
Epilepsy and neurocysticercosis in rural Bolivia: A population based survey	Nicoletti, A., Bartoloni, A., Sofia, V., Bartalesi, F., Chavez, JR., Osinaga, R., … Hall, AJ. (2005)	Evaluate frequency of NCC in a well-defined, previously studied, cohort of epilepsy patients in rural Cordillera Province, Bolivia.	Two phase door-to door survey, standard screening survey with positive subjects given complete neurologic exam. CT and serology.	Of total sample of 10,124 subjects of rural Cordillera Province, Bolivia, 124 identified with active epilepsy. 105 of these had CT, and 112 had serology. 97 had both.	27.4% tested positive for NCC and of these 70.6% had partial seizures. Conclusion: Higher frequency of NCC confirmed in this population

Epilepsy in rural Bolivia

Title	Author and Year	Purpose of Study	Design and Methodology	Sample	Findings
Epilepsy-associated stigma in Bolivia: A community-based study among the Guaraní population-- An International League Against Epilepsy / International Bureau for Epilepsy / World Health Organization Global Campaign Against Epilepsy Regional Project	Bruno, E., Bartoloni, A., Sofia,V., Rafael, F., Magnelli, D., Padilla, S., … Nicoletti, A. (2012).	Assess stigma perception among Guaraní population of Cordillera Province, Bolivia.	Stigma Scale of Epilepsy questionnaire. Part of greater study in region spanning over 15 years, Global Campaign Against Epilepsy.	132 people living in Guaraní communities invited. July - August 2010. A group of persons with epilepsy, relatives and healthcare personnel in the Guaraní communities.	Main determinants of stigma: fear related to loss of control, feelings of sadness and pity toward those with epilepsy, difficulties faced by those with epilepsy in professional and relationship, level of education and type of seizure.
Sociocultural dimension of epilepsy: An anthropological study among Guaraní communities in Bolivia—An International League Against Epilepsy / International Bureau for Epilepsy /World Health Organization Global Campaign Against Epilepsy Regional Project.	Bruno, E., Bartoloni, A., Sofia, V., Rafael, F., Magnelli, D., Ortiz, E., … Nicoletti, A. (2011).	Analyze sociocultural beliefs about epilepsy among Guaraní communities in Bolivia.	People with epilepsy, family members, general population and local health care personnel were interviewed about the meaning of epilepsy, beliefs, feelings and practices concerning epilepsy.	People living in the Guaraní communities at the time of the study, Cordillera Province, Santa Cruz. January to March 2009, part of the greater epilepsy project performed in the region over a period of more than 15 years. Global Campaign against Epilepsy.	Termed mano-mano, epilepsy is considered a constant passage between life and death, attributed to a failure to observe a fasting period and to other eating habits. Natural remedies recommended. Half report thinking that AEDs may be effective. Not seen as a threat. Favor biomedical and tradition care combined
Prevalence and incidence of epilepsy associated with convulsive seizures in rural Bolivia. A global campaign against epilepsy project.	Bruno, E., Quattrocchi, G., Crespo Gómes, E. B., Sofia, V., Padilla, S., Camargo, M., …	Three stage of door-to-door survey to estimate incidence and prevalence of epilepsy in rural Bolivia, Cordillera Province – follow up	Door to door survey. Stage I screened for epilepsy associated convulsive seizures – those positive were included in stage II which was a	114 rural communities with 18,907 inhabitants in Cordillera Province, Dept of Santa Cruz, Bolivia included. Three stages	136 with epilepsy associated convulsive seizures. Lifetime prevalence 7.2/1000. Active prevalence 6.6/1000. Crude incidence risk 55.4/100,000. 105 had

Title	Author and Year	Purpose of Study	Design and Methodology	Sample	Findings
	Nicoletti, A. (2015).	from original survey conducted in 1999	questionnaire, and positive subjects went on to stage III - complete neurological exam, incidence risk evaluated for 10 year period from January 2000 to December 2010	progressively screening for epilepsy	onset during 10-year study period. Conclusion: considerable burden similar to other low to middle income countries, indicating need for treatment programs.
A neuroepidemiological survey in rural Bolivia: background and methods	Nicoletti A1, Reggio A, Bartoloni A, Failla G, Bartalesi F, Roselli M, Gamboa H, Salazar E, Paradisi F, Tempera G, & Hall AJ. (1998)	Initial survey assessing the most common neurologic conditions in rural Cordillera Province, Bolivia, was done. The background and methods of the door-to-door survey and the characteristics of the population are discussed.	Door-to-door survey to screen for neurologic conditions, with positive subjects continuing on for neurologic examination.	10,124 inhabitants rural areas of the Cordillera Province, Dept of Santa Cruz, Bolivia, screened for positive neurologic conditions. 1,130 were positive and continued to phase II.	Discussion of the background, methods and characteristics of the population
Prevalence of epilepsy in rural Bolivia: A door-to-door survey.	Nicoletti, A, Reggio, A.,Bartoloni, A.,Failla, G., Sofia, V., Bartalesi, F., Roselli, M., Gamboa, H., Salazar, E, Osinaga, R., Paradisi, F., Tempera, G.,	Door-to-door survey in rural Bolivia (Santa Cruz) to determine epilepsy prevalence, as well as, stroke, parkinsonism and peripheral neuropathy.	Health workers administration of a standard screening instrument for neurologic diseases, slightly modified from WHO protocol. Positive subjects underwent neurologic examination.	Approximately 10,000 inhabitants of the Cordillera Province of the Department of Santa Cruz in Bolivia.	1,130 positive, 1,027 examined by neurologists. 124 epileptic, prevalence 12.3/1000 with 112 active epilepsy, prevalence 11.1/1000. Most common partial seizures. Only 10.5% had received treatment for more than 2 months of their life. Conclusion: epilepsy is a major problem in rural

Title	Author and Year	Purpose of Study	Design and Methodology	Sample	Findings
	Dumas, M., & Hall, A. J. (1999)				areas of developing countries.
Natural history and mortality of chronic epilepsy in an untreated population of rural Bolivia: A follow-up after 10 years	Nicoletti, A., Sofia, V., Vitale, G., Bonelli, S. I., Bejarano, V., Bartalesi, F., Tran, D.-S., Preux, P.-M., Zappia, M. and Bartoloni, A. (2009)	Evaluate the natural history and mortality of chronic epilepsy in an untreated prevalence cohort of people with epilepsy in rural Bolivia	Revisit, 10 years later, the cohort of people with epilepsy from the 1994-96 epidemiologic survey in the Cordillera Province of Bolivia. Standardized questionnaire – characteristics of seizures, AED, cause of death, etc.	103 (87.3%) of original 118 persons with epilepsy identified in original study. Cordillera Province, Dept of Santa Cruz, Bolivia.	93 still living. 71 provided adequate seizure information. Of these 43.7% remained seizure free for more than 5 years, and only 3 of these had taken AEDs for more than 1 year. 3 of 10 subjects that passed in the interim died of possible epilepsy related causes. Most common cause NCC (71%). And NCC increased risk of death more than 3 fold in this population. Only 11.6% had taken an AED for more than one year.

NCC in Latin America (Similar and Related Environments)

Title	Author and Year	Purpose of Study	Design and Methodology	Sample	Findings
Epilepsy and neurocysticercosis in Latin America: A systematic review and meta-analysis	Bruno, E., Bartoloni, A., Zammarchi, L., Strohmeyer, M., Bartalesi, F., Bustos, J. A., … the COHEMI Project Study Group. (2013)	To define the burden of epilepsy in Latin American countries and to examine the strength of the association between it and NCC	Systematic review and meta-analysis of the literature. Meta-regression models used to determine impact of NCC on epilepsy prevalence. Association between epilepsy and NCC through additional meta-analysis performed on case-control studies.	Studies up to 2012. Inclusion criteria – lifetime epilepsy prevalence, active epilepsy prevalence, incidence, mortality, treatment gap, proportion with NCC	Median lifetime prevalency 15.8/1000. Median active prevalency 10.7/1000. Median incidence 138.2/100,000. Overall standard mortality ration 1.4. Median proportion NCC in those with epilepsy 32.3%. Higher NCC and treatment gaps associated with higher epilepsy prevalence. Association between NCC and epilepsy significant ($p<0.001$) with common odds ratio 2.8.
Understanding the burden of epilepsy in Latin America: a systematic review of its prevalence and incidence.	Burneo JG, Tellez-Zenteno J, Wiebe S. (2005).	To understand epidemiological and clinical characteristics of epilepsy in this region.	Search of MEDLINE, IMBIOMED, and LILACS to find community based studies reporting on the prevalence and incidence of epilepsy in Latin America.	33 studies that fulfilled eligibility criteria. English, Spanish and Portuguese studies included. Retrospective or prospective community based exploring prevalence and incidence of epilepsy using standardized previously validated questionaires, door-to-door surveys and interviews	Median lifetime prevalence was 17.8 (range 6 – 43.2) per 1000, and the range for incidence was 77.7 -190 per 100,000. No difference between rural and urban areas, gender, age groups, methods or year of study. Conclusion: Higher prevalence and incidence rates compared to northern hemisphere.

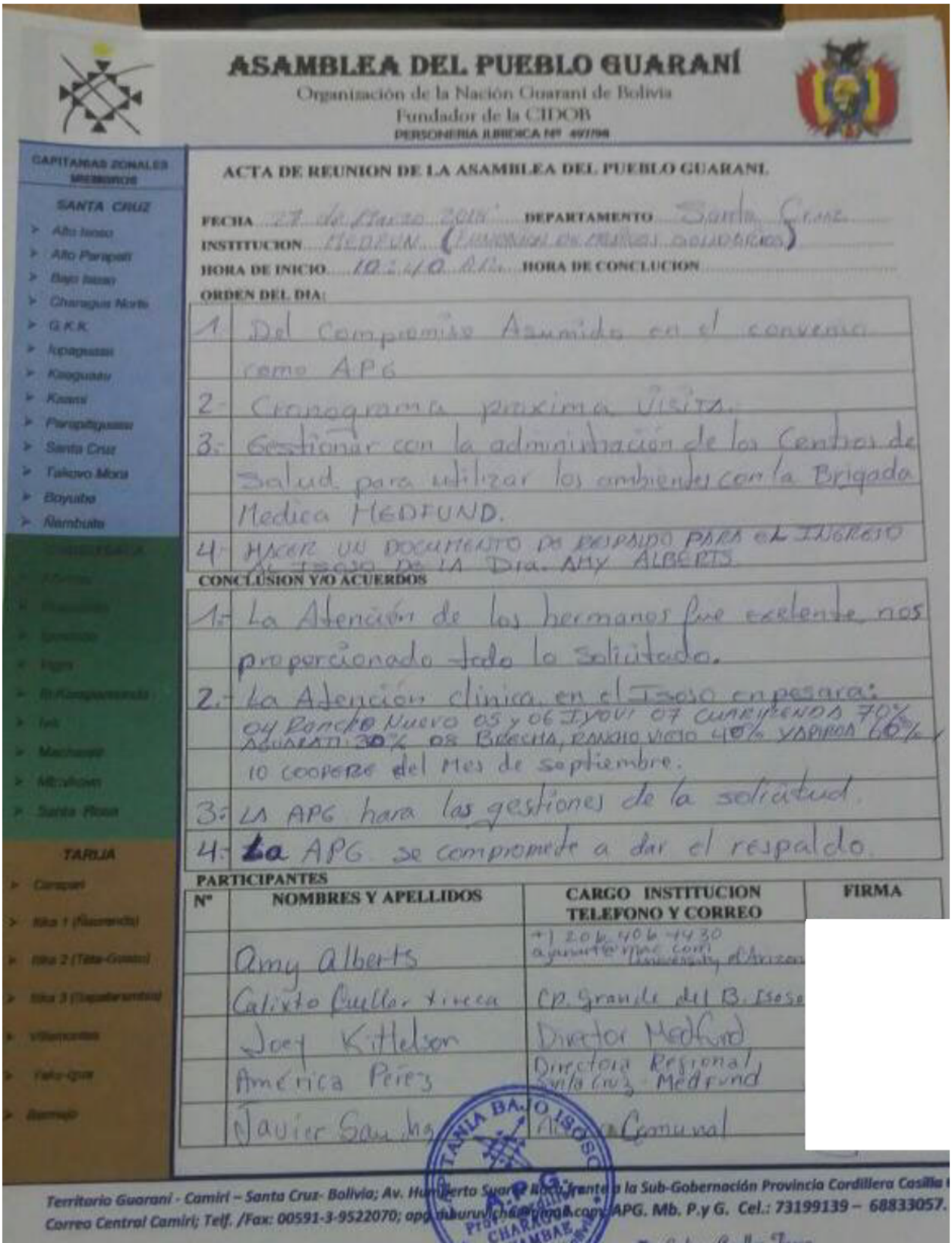
Title	Author and Year	Purpose of Study	Design and Methodology	Sample	Findings
Seizures, cysticercosis and rural-to-urban migration: the PERU MIGRANT study.	Gonzales, I., Miranda, J. J., Rodriguez, S., Vargas, V., Cjuno, A., Smeeth, L., … Garcia, H. H. (2016).	Examine the prevalence of seizures, epilepsy, and seropositivity for cysticercosis in rural villagers of endemic area, rural-to-urban migrants into non-endemic urban shanty town and urban inhabitants of the non-endemic shanty town	All from parent study screened for epilepsy and those identified received neurologic exams. 981/985 serum samples processed for cysticercosis antibodies on immunoblot	Single stage random sampling. 3 Peruvian populations from a parent study (n=985) recruited into a study about chronic disease and migration. 200 rural inhabitants from endemic region, 589 long-term rural-to-urban migrants and 196 inhabitants of the urban setting.	Epilepsy prevalence per 1000 was 15.3 in the urban group, 35.6 in the migrant group, and 25 in rural group. Cysticercosis antibody seroprevalence 2% in urban, 13.5% in migrant, 18% in rural groups (P=0.05). In rural villager's strong association between positive serology and seizures (P=0.011) and in entire population those with strong antibody reaction were more likely to have epilepsy (P<0.001).
The association of living conditions and lifestyle factors with burden of cysts among neurocysticercosis patients in Ecuador.	Kelvin EA, Yung J, Fong MW, Carpio A, Bagiella E, Leslie D, Leon P, Andrews H, & Allen Hauser, W. (2012).	Identify predictors of burden of cysts.	154 symptomatic patients for NCC in Ecuador, ran logistic regression models with the burden of cysts as outcome, defined as number of cysts in the brain, and having cysts in all three stages of evolution. Predictors examined – living in rural area, living on a dirt road, living in an adobe or wood house, no running water in the house, no bathroom in the house, having a domestic employee cook in the home, eating most meals at restaurants or street	172 participants in a clinical trial of treatment (albendazole v placebo) for NCC conducted between 2003 in 6 hospitals in Quito, Cuenca and Guayaquil, Ecuador. Those with new onset symptoms associated with NCC within past two months, active and/or transitional NCC cysts seen on imaging were eligible.	Multiple NCC cysts associated with working manual labour, and having cysts in all three stages with eating most meals outside the home. Burden of cysts may be a useful outcome when looking to identify exposure risk factors in the absence of an uninfected control group. Cysts in all three stages associated with no bathroom in home.

Title	Author and Year	Purpose of Study	Design and Methodology	Sample	Findings
			vendors, working a manual labour job.		
Neurocysticercosis-related mortality in Brazil, 2000–2011: Epidemiology of a neglected neurologic cause of death	Martins-Melo, FR, Ramos Jr. AN, Cavalcanti, MG, Carlos Henrique Alencar, CH, & Heukelbach, J. (2016)	A systematic assessment of the epidemiological patterns, time trends and spatial distribution of NCC related mortality in Brazil from 2000 - 2011	Mortality data obtained from the nationwide Mortality Information System (SIM) of the Brazilian Ministry of health. Population data obtained from the Brazilian Institute of Geography Statistics based on two censuses 2000 and 2011. Variables included gender, age, race, place of death, date of death and causes of death – both underlying and associated. Time trend analysis and spatial distribution.	2000-2011 12,491,280 deaths in Brazil recorded and analyzed.	Average NCC related deaths 152.4 per year (range 132-177). 2007/12,491,280 deaths identified cysticercosis (0.016%). NCC important but neglected and preventable cause of death in Brazil. May be underestimated. Higher mortality rates in regions highly endemic.
Reduction in rate of epilepsy from neurocysticercosis by community interventions: The Salamá, Honduras study	Medina, M. T., Aguilar-Estrada, R. L., Alvarez, A., Durón, R. M., Martínez, L., Dubón, S., Estrada, A. L., Zúniga, C., Cartagena, D., Thompson, A., Ramirez, E., Banegas, L., Osorio, J. R., Delgado-Escueta,	Evaluate impact of 8 year public health and intervention program in reducing symptomatic epilepsies in rural Salamá, Honduras.	Capture and recapture method, chart reviews, previous data bases, informants from the community, follow up house-to-house survey for epilepsy. Positive subjects offered neurologic evaluation. New data compared to pre-intervention data from initial 1997 baseline data.	33 of 36 patients found with active onset of epilepsy after baseline testing agreed to neurologic examination. Outcomes of 90 patients identified in baseline study evaluated.	Symptomatic etiology found in 58.3% with NCC most frequent cause (13.9%). Epilepsy secondary to NCC reduced significantly from 36.9% in 1997, but prevalence and incidence of epilepsy not significantly reduced. Conclusion: appears to indicate that health and community education can significantly reduce

Title	Author and Year	Purpose of Study	Design and Methodology	Sample	Findings
	A. V., Collins, J. S. and Holden, K. R. (2011)				epilepsy from NCC in a hyperendemic low resource developing country

APPENDIX B:

DOCUMENT OF PERMISSION FROM THE ASAMBLEA DEL PUEBLO GUARANÍ



ASAMBLEA DEL PUEBLO GUARANÍ

Organización de la Nación Guaraní de Bolivia
Fundador de la CIDOB
PERSONERIA JURIDICA Nº 497/98

CAPITANIAS ZONALES MIEMBROS

SANTA CRUZ
- Alto Isoso
- Alto Parapetí
- Bajo Isoso
- Charagua Norte
- G.K.K.
- Iupaguasu
- Kaaguasu
- Kaami
- Parapitiguasu
- Santa Cruz
- Takovo Mora
- Boyuibe
- Ñambuite

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TARIJA
- Carapari
- Itika 1 (Ñacarandá)
- Itika 2 (Tilita-Gosto)
- Itika 3 (Tapatarambia)
- Villamontes
- Yaku-Igua
- Bermejo

ACTA DE REUNION DE LA ASAMBLEA DEL PUEBLO GUARANI.

FECHA 27 de Marzo 2018 DEPARTAMENTO Santa Cruz
INSTITUCION MEDFUN (Fundación de Médicos Solidarios)
HORA DE INICIO 10:40 A.M. HORA DE CONCLUCION

ORDEN DEL DIA:

1. Del Compromiso Asumido en el convenio como APG
2. Cronograma proxima visita.
3. Gestionar con la administración de los Centros de Salud para utilizar los ambientes con la Brigada Medica MEDFUND.
4. HACER UN DOCUMENTO DE RESPALDO PARA EL INGRESO AL ISOSO DE LA Dra. AMY ALBERTS

CONCLUSION Y/O ACUERDOS

1. La Atención de los hermanos fue exelente nos proporcionado todo lo solicitado.
2. La Atención clinica en el Isoso empesara: 04 Rancho Nuevo 05 y 06 Iyovi 07 Cuarirenda 70% Aguarati 30% 08 Brecha, Rancho Viejo 40% Yapiroa 60% y 10 Coopere del Mes de septiembre.
3. LA APG hara las gestiones de la solicitud.
4. La APG se compromete a dar el respaldo.

PARTICIPANTES

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	América Pérez	Directora Regional Santa Cruz - Medfund	
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CAPITANIA BAJO ISOSO A.P.G. Prov. Cordillera CHARAGUA ÑAMBAE

ASAMBLEA DEL PUEBLO GUARANÍ

Organización de la Nación Guaraní de Bolivia
Fundador de la CIDOB
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CAPITANIAS ZONALES MIEMBROS

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- Alto Parapetí
- Bajo Isoso
- Chiaragua Norte
- G.K.K.
- Kaapuasu
- Kaaguasu
- Kaami
- Parapitiguasu
- Santa Cruz
- Takovo Mora
- Boyuiba
- Gamboa

TARIJA
- Caraguatá
- Mbo 1 (Bermejo)
- Mbo 2 (Villa Guaraní)
- Mbo 3 (Caraparicito)
- Chamorro
- Yaku Igua
- Kamiri

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CAPITANIA BAJO ISOSO A.P.G. Prov. Cordillera CHARAGUA IYAMBAE Santa Cruz - Bolivia

Territorio Guaraní - Camiri - Santa Cruz- Bolivia; Av. Humberto Suarez Roca frente a la Sub-Gobernación Provincia Cordillera Casilla 60 – Correo Central Camiri; Telf. /Fax: 00591-3-8522070; apg.mburuvicha@gmail.com; APG. Mb. P.y G. Cel.: 73199139 – 68833057.

APPENDIX C:

INTERVIEW GUIDE

Healthcare Providers' and Community Leaders' Knowledge and Perceptions of Neurocysticercosis in Rural Bolivia

Interview Guide

Amy Alberts

Intro to Study

Thank you for agreeing to speak with me, and for considering participation in my study. Prior to beginning the interview there is a consent form for you to review and sign. You may decline participation if you wish.

Should you agree to participate, the interview will take about an hour, it will be recorded and you may stop at any time during the interview if you wish.

I will now present you with the consent form explaining the study, asking if you agree to participate in it and granting consent for use of the information gathered during the interview. Please read the form and if you agree to the terms sign it.

Do you have any further questions about the consent form or the study?

Thank you for agreeing to participate.

The interview is going to start now.

Demographic information

What is your age?

What is your gender?

How long have you lived in the village?

What is your level of education?

What is your role in the community?

How long have you been in this role?

Short Answer Questions

Some questions are appropriate to more than one category.

1. *Determine health care providers' and community leaders' knowledge of NCC considering:*
    - *How NCC is acquired, treated, and prevented.*

How would you describe cysticercosis?

What are the symptoms/ How can you tell someone has it?

How can it affect people?

How do people get NCC?

Do you know anyone in your village with seizures?

If so, what is it like?

Do you think there is a connection between seizures and NCC?

Do animals get cysticercosis?

If so, which animals can get it?

How do you know if animals have it?

Is there a connection between animals with cysticercosis and people with it?

How do pigs get cysticercosis?

Do you think most people in the community know what NCC is?

If so, how do they talk about it amongst themselves?

Do you think adults and children learn about NCC the same way?

Has anyone taught community members about cysticiercosis?

What did they teach?

How common is cysticercosis?

How common is epilepsy?

What causes epilepsy?

Can it be prevented?

How?

How is cysticercosis treated?

How is epilepsy treated?

How can NCC be prevented?

Can parasites cause seizures?

If so, which ones?

Is there a relationship between hygiene and cysticercosis?

What is it?

Can medications help a person with seizures?

What happens if a PWE does not always have or take their medication, but take it only periodically?

- *The degree to which they see epilepsy as a problem, including impact on quality of life, and understanding and appreciation of the long-term consequences of chronic untreated epilepsy.*

What is the impact of NCC on this community?

What is the impact of epilepsy on a PWE?

What is the impact on the family of the PWE?

How do seizure events impact their daily lives?

Does a PWE need medical care?

What type of care do they require? What happens if they do not receive care? What happens if care is inconsistent?

Is there a relationship between water and epilepsy?

What is it?

Is there a relationship between food and epilepsy?

What is it?

2. *Determine health care providers' and community leaders' perceptions of barriers and facilitators to NCC treatment and prevention, considering:*
    - *How they view resources, such as clean water, money for treatment and for travel to appropriate treatment facilities, availability of local facilities that can manage the problem, transportation, providers equipped to diagnose and manage the problem, medication and specialized diagnostics.*

Are there enough providers to diagnose and treat epilepsy?

Are there enough resources to diagnose and treat NCC?

If not, what resources are needed?

Is medical management carried out on a consistent basis?

Do people have consistent access to medications?

Do people with epilepsy consistently take their AEDs?

If not, why?

What kind of assistance is available to people to ensure receipt of needed medications?

What kind of access is there to clean water?

How is a high level of hygiene maintained?

Is meat handled safely?

If not, why?

Is water treated before consumed?

If not, why? If so, how?

Have perspectives changed towards epilepsy in recent years?

How?

How have they changed towards treatment?

How?

How important is it to the community to prevent cysticercosis?

How important is it to the community to prevent epilepsy?

- *How they view the degree to which community knowledge (or lack thereof) and beliefs (such as traditional/spiritual views on etiology and meaning of epilepsy) impact treatment and prevention.*

What is the perspective on anti-parasitic medications?

How are they used?

How often?

Do people find change easy?

Is it easy to adopt new routines, such as hygiene practices?

What are attitudes about clean water?

What are attitudes about sanitation?

What are attitudes about where pigs go and what they have access to?

What causes seizures and is it important to treat them?

- *How they view their community's desire and sense of urgency to address NCC and epilepsy.*

Does the community think epilepsy is an important health issue?

Do they feel there is a need to address it?

How important is the need?

How urgent?

Would they consider this a priority need?

Does the community think NCC is an important health issue?

Do they feel there is a need to address it?

How important is the need?

How urgent?

Would they consider this a priority need?

APPENDIX D:

THE UNIVERSITY OF ARIZONA CONSENT TO PARTICIPATE IN RESEARCH

The University of Arizona Consent to Participate in Research

Study Title: Healthcare Providers' and Community Leaders' Knowledge and Perceptions of Neurocysticercosis in Rural Bolivia

Principal Investigator: Amy Alberts, MS, AGACNP-BC

This is a consent form for research participation. It contains important information about this study and what to expect if you decide to participate. Please consider the information carefully. Feel free to discuss the study with your friends and family and to ask questions before making your decision whether or not to participate.

Why is this study being done?
This study is being done to determine health care providers and community leaders knowledge and their perceptions of community barriers and facilitators regarding neurocysticercosis.

What will happen if I take part in this study?
If you choose to participate in this study, you will be asked to do the following:

1. Answer a few short questions about yourself and your role in the community.
2. Participate in an interview answering short answer questions about your know of neurocysticercosis and your understanding and perceptions of community needs regarding this disease.
3. Allow me to record your responses.

How long will I be in the study?
For each participant it is estimated that it will take approximately 60 minutes to complete the interview.

How many people will take part in this study?
Approximately 20 participants will be enrolled in this study

What are the costs of taking part in this study?
There are no costs to you as a potential participant in this study.

Will I be paid for taking part in this study?
This is a volunteer activity and there will be no compensation for participation.

Can I stop being in the study?

Your participation is voluntary. You may refuse to participate in this study. If you decide to take part in the study, you may leave the study at any time. No matter what decision you make, there will be no penalty to you and you will not lose any of your usual benefits. Your decision will not affect your future relationship with The University of Arizona.

What risks or benefits can I expect from being in the study?

There is no direct personal benefit for you to participate in this study; however, as a participant you may gain personal satisfaction in contributing to knowledge leading to improved prevention and treatment of neurocysticercosis in rural Bolivia and similar environments.

There are no physical, psychological, social, legal, and/or economic risk associated with this research.

What happens if I am injured because I took part in this study?

Not applicable.

Will my study-related information be kept confidential?

All interviews will be anonymous. There will be no names attached to interviews. They will instead be numbered.

Interviews may be reviewed by the following groups:

- The University of Arizona Institutional Review Board
- Office for Human Research Protections or other federal, state, or international regulatory agencies
- The dissertation committee and or faculty at the University Of Arizona College Of Nursing supporting the primary investigator

Who can answer my questions about the study?

For questions, concerns, or complaints about the study you may contact **Amy Alberts** at (206) 406-4430.

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact the Human Subjects Protection Program at 1 520-626-6721 or online at http://rgw.arizona.edu/compliance/human-subjects-protection-program.

An Institutional Review Board responsible for human subjects research at The University of Arizona reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

Signing the consent form

I have read (or someone has read to me) this form and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form**.**

Printed name of subject	**Signature of subject**	**Date**

Investigator/Research Staff

I have explained the research to the participant or the participant's representative before requesting the signature(s) above. There are no blanks in this document. A copy of this form has been given to the participant or to the participant's representative.

Printed name of person obtaining consent	**Signature of person obtaining consent**	**Date**

APPENDIX E:

THE UNIVERSITY OF ARIZONA INSTITUTIONAL REVIEW BOARD APPROVAL LETTER

THE UNIVERSITY OF ARIZONA
Research, Discovery & Innovation

Human Subjects Protection Program

1618 E. Helen St.
P.O. Box 245137
Tucson, AZ 85724-5137
Tel: (520) 626-6721
http://rgw.arizona.edu/compliance/home

Date:	November 06, 2018
Principal Investigator:	Amy Jeanne Alberts
Protocol Number:	1810050346
Protocol Title:	Healthcare Providers' and Community Leaders' Knowledge and Perceptions of Neurocysticercosis in Rural Bolivia
Determination:	Approved
Expiration Date:	November 04, 2023

Documents Reviewed Concurrently:

Data Collection Tools: *Interview Guide sept26 2018.docx*
Data Collection Tools: *TRADUCCION Interview Guide sept26 2018.docx*
HSPP Forms/Correspondence: *Confirmation for Scientific Review and Department Review.pdf*
HSPP Forms/Correspondence: *IRB with revisions3.pdf*
HSPP Forms/Correspondence: *list_of_research_personnel 9 26 2018.pdf*
Informed Consent/PHI Forms: *Informed Consent 11 5 2018.doc*
Informed Consent/PHI Forms: *Informed Consent 11 5 2018.pdf*
Informed Consent/PHI Forms: *TRADUCCION Informed Consent 11 5 2018.docx*
Informed Consent/PHI Forms: *TRADUCCION Informed Consent 11 5 2018.pdf*
Other Approvals and Authorizations: *Advisor Confirmation Email.pdf*
Other Approvals and Authorizations: *Amy Alberts - Travel.pdf*
Other Approvals and Authorizations: *APG.DOCX*
Other Approvals and Authorizations: *COI Certification Complete for 1810050346.msg*

Regulatory Determinations/Comments:

- The project is not federally funded or supported and has been deemed to be no more than minimal risk.
- The project listed is required to update the HSPP on the status of the research in 5 years. A reminder notice will be sent 60 days prior to the expiration noted to submit a 'Project Update' form.

This project has been reviewed and approved by an IRB Chair or designee.

- The University of Arizona maintains a Federalwide Assurance with the Office for Human Research Protections (FWA #00004218).
- All research procedures should be conducted according to the approved protocol and the policies and guidance of the IRB.
- The Principal Investigator should notify the IRB immediately of any proposed changes that affect the protocol and report any unanticipated problems involving risks to participants or others. Please refer to Guidance Investigators Responsibility after IRB Approval, Reporting Local Information and Minimal Risk or Exempt Research.

- All documents referenced in this submission have been reviewed and approved. Documents are filed with the HSPP Office.

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