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Investigating Interpersonal and Community Drivers of *Taenia solium* Prevention to Reduce Acquired Seizure Disorders in Northern Peru: An Analysis of Social Networks, Social Capital, and Community-Identified Barriers and Facilitators

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by

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Abstract

Background: In Northern Peru and other low- and middle-income countries (LMICs) worldwide, the *Taenia solium* parasite causes an estimated 30% of acquired epilepsy – an entirely preventable disease burden. Sanitation development and pork production regulation would reduce infection risk in endemic communities, but large-scale systemic improvements are not likely to occur in the near future. In the meantime, communities can reduce infection risk by adopting protective behaviors. Social networks can provide role modeling and support for health-promoting behaviors, and deliver social capital in the form of trusting relationships, norms of reciprocity, and information exchange in support of *T. solium* control.

Methods: I estimated the contribution of head-of-households' informational and social support exchanges, within their social networks, to household *T. solium* prevention behaviors, using binomial logistic regression (aim 1). Next, I estimated the contribution of household social capital to community efficacy for *T. solium* control (aim 2). Finally, I thematically analyzed transcripts of focus group interviews conducted with community leaders and identified contextual, community-level, and individual-level factors that may support or hinder *T. Solium* control (aim 3).

Results: Participant heads-of-households who exchanged informational and emotional support with a higher proportion of their close social networks had higher odds of self-reported household action to prevent infections compared to those who rarely talk about the disease with their network alters. Being the provider of information and encouragement was more strongly associated with self-reported household *T. solium*

control action than being the recipient of information and encouragement. Effect estimates for social capital on community efficacy at baseline were indistinguishable from null, whereas at 20-month follow-up, higher social capital scores were associated with an increased odds of perceived community efficacy. In my qualitative analysis of community leader focus groups, the community-level barriers for *T. solium* control included inadequate infrastructure and gaps in community resources, while facilitators included municipal investments and supportive relationships among community members. Individual-level barriers included low risk perception, misconceptions about *T. solium* transmission, and pig-raising practice norms; facilitators included risk awareness, knowledge about *T. solium* transmission, and personal experience with human and pig infections.

Impact: Taken together, these studies illuminate who people are talking to about *T. solium* control, what types of topics are discussed, how people talk about *T. solium* in group settings, and community members' perspectives on their collective abilities to control the parasite's transmission and reduce infections. Future studies can employ the methods used in this dissertation, particularly analyses that include human and animal networks, to inform our understanding of how *T. solium* and other zoonoses move through social systems, and where to focus interventions for the largest potential impacts.

Acknowledgements

This dissertation would not exist without the contributions of many people, especially the participants who allowed me to learn about their lives and experiences.

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Dr. Michelle Beam lead the pilot study under which this dissertation data was collected. During that study, she lived in Tumbes and led a participatory process to develop new methods for community-based cysticercosis control. She generously invited me to collaborate and to collect dissertation data alongside the pilot study.

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List of Abbreviations

CGH	Center for Global Health
CLTS	Community-Led Total Sanitation
CT	Computerized Tomography
EITB	Enzyme-Linked Immuno-electrotransfer Blot
GSS	General Social Survey
ITFDE	International Task Force for Disease Eradication
LMICs	Low- and Middle-Income Countries
MDA	Mass Drug Administration
NCC	Neurocysticercosis
RS	Ring Screening
RT	Ring Treatment
SCAT	Social Capital Assessment Tool
SNT	Social Network Theory
WHO	World Health Organization

Chapter 1 Introduction and Research Aims

In Northern Peru and other low- and middle-income countries (LMICs) worldwide, brain infection with the larval-stage *Taenia solium* parasite causes an estimated 30% of acquired epilepsy – an entirely preventable disease burden. Sanitation development and pork production regulation would reduce infection risk in endemic communities, but large-scale systemic improvements are not likely to occur in the near future. In the meantime, communities can reduce infection risk by adopting protective behaviors, but many people remain unaware of how *T. solium* is transmitted and what can be done to reduce their chance of infection. Qualitative and quantitative studies have found that social networks may influence the uptake and maintenance of a variety of protective health behaviors. Social networks provide role modeling and social support for health-promoting behaviors, and boost self-efficacy for new behaviors. Social networks influence health via direct contact, and also by delivering social capital in the form of trusting relationships, norms of reciprocity, and information exchange. Social capital can contribute to collective efficacy for new behaviors and collaborative problem-solving. No prior work has explored how information or support for *T. solium* prevention is transmitted through social networks. Not knowing how people educate and influence their peers about this disease represents a critical knowledge gap for how to effectively work with communities to support cysticercosis prevention and control.

The long-term goal of this research is to investigate the social drivers of individual and collective behavior change for cysticercosis prevention. The objective of this study is to determine how social networks, social capital, and norms of Northern

Peruvian villages are associated with cysticercosis risk-reducing behaviors. To realize my objective, I conducted three studies, which are detailed in subsequent chapters.

The study presented in Chapter 3 addresses my first aim: To examine the association between social support exchanges and cysticercosis prevention control practices. I calculated social network size, stability, network tie strength, and types of support exchanges (e.g., informational, emotional) with network alters for heads-of-households. I then tested the estimated the contribution of head-of-households' informational and social support exchanges with household *T. solium* prevention behaviors using binomial logistic regression.

The study presented in Chapter 4 addresses my second aim: To estimate the contribution of household social capital to community efficacy and collective action for cysticercosis prevention. I measured social capital in the form of trust among village residents and norms of reciprocity, using a selected items from a social capital assessment tool. I used binomial logistic regression to estimate the effects of heads-of-households' social capital scores and perceived community efficacy for *T. solium* control.

The study presented in Chapter 5 addresses my final research aim: To describe community-identified barriers and facilitators for community-based cysticercosis interventions. I thematically analyzed focus group interviews conducted with community leaders and identified contextual, community-level, and individual-level factors that may support or hinder *T. Solium* control.

No prior work has explored how information or support for *T. solium* prevention is transmitted through social networks. Not knowing how people educate and influence their peers about this disease represents a critical knowledge gap for how to effectively work with communities to support *T. solium* prevention and control. Likewise, the relationships between social capital, collective efficacy, and collective/community actions for *T. solium* control have not been previously researched in the published literature.

Context for dissertation studies: This dissertation was conducted within a pilot study which was designed to apply participatory methods for capacity building, evidence sharing, and community mobilization to develop community-adapted approaches to implement a focal *T. solium* cysticercosis control intervention known as “ring strategy.”[1] The pilot study consisted of two phases: the first phase was formative and iterative, applying a range of community-engaged activities in order to co-design ring interventions adapted for each community. The second phase of the pilot study implemented the tailored ring interventions in each community. Seven villages were selected for the pilot study: four received the community mobilization intervention, which included organization and facilitation of community workgroups to develop adapted ring interventions; the other three villages received a comparison intervention consisting of health education but no additional engagement in community workgroups.

Chapter 2 Literature Review

2.1 Background

Taenia solium, commonly known as the pork tapeworm, has coexisted with humans for thousands of years. While tapeworms living in the human intestinal tract cause little discomfort to their human hosts, the tapeworm's microscopic eggs, when accidentally ingested via fecal-oral route, allow the nascent parasite to pass though the intestinal wall to cause cysticercosis (larval infection of soft tissue) and neurocysticercosis ([NCC] larval infection of the brain). NCC is a leading cause of epilepsy in endemic regions.

Beginning in the mid-to-late 17th century, scientists built on the discoveries of those who came before them to collectively assemble a substantial body of knowledge about how *T. solium* is transmitted; which drugs are effective in treating infection in humans and the parasite's intermediate host (pigs); and which interventions reduce the risk of human and porcine infection. Despite advances, there is still much to learn about how to transfer transmission knowledge to people living in endemic communities, how to motivate behavior change to reduce risk of infection, and how to control the parasite through feasible and sustainable interventions.

The World Health Organization (WHO) estimates there are 2.46 – 8.3 million people affected by NCC worldwide (based on epilepsy prevalence),[2] and an estimated 400,000 – 1.5 million people in Latin America are living with NCC.[3]

2.1.1 History of Discovery

The first known written references to human-infecting parasites are found in ancient Egyptian texts dating from 3000 to 400 BC.[4] Diseases that were likely caused by parasites were described in ancient Greek, Chinese, Indian, Roman, and Arabic texts.[4] The ancient Greeks noted the presence of cysts in pork, describing it as "measly."[5] Aristotle knew of intestinal worms, but attributed their origin to spontaneous generation.[5] In 1668, Fransesco Redi ran a series of experiments to refute spontaneous generation, hypothesizing that maggots and other worm-like organisms came from eggs being deposited in putrefying flesh. Redi placed the flesh of dead animals in open boxes and observed the development of maggots as the flesh decayed. He followed these experiments with another series of experiments where he placed decaying flesh in sealed and unsealed flasks and observed that no maggots appeared in the sealed flasks.[5] In 1683, Edward Tyson dissected *Ascaris* roundworms and discovered they had two sexes, leading him to conclude they reproduced sexually, but when he examined tapeworms, he could not find any sex organs.[5] Around the same time, the invention of the microscope allowed humans to observe previously-unseen phenomena, including a multitude of microorganisms, yet the belief in spontaneous generation persisted in the minds of many scientists for the next century. In 1758, *Taenia solium* and 5 other helminth worms were named and classified by Linnaeus, but after classification, almost a century passed before the tapeworm life cycle was observed and recorded.[6]

In 1851, Friedrich Küchemeister began a series of experiments where he collected the cysticerci (larvae) of bladder worms found in rabbits and mice, fed them to foxes, and recovered tapeworms from the foxes' intestines after 30 hours – 22 days.[5] He repeated these experiments with different parasites and hosts (e.g., cats, dogs, and sheep) and over time concluded that parasites were specific to certain hosts. In 1853, Pierre van Beneden fed *T. solium* eggs to a pig and found multiple larval cysts in the pig's muscle tissue upon slaughter four months later.[5,7] In 1855, Aloy Humbert infected himself by consuming *T. solium* cysticerci and subsequently found *T. solium* segments in his feces, and Rodolf Leuckart replicated this self-infection experiment in 1856 and got the same result.[5] Contemporaneously, in 1854, Küchemeister fed cysticerci to a prisoner who was going to be executed (without the prisoner's consent) and found tapeworms in the prisoner's intestine upon autopsy. Küchemeister repeated this experiment on another prisoner in 1860.[5] These studies, while unethical in the case of Küchemeister's experimentation on prisoners, established the link between cysticerci and *T. solium* intestinal tapeworms. The presence of cysts in the brains of humans with epilepsy was established though observations in autopsies dating back to the 1500s, but the link between *T. solium* and NCC would not be firmly established until the 1930s, when British troops who had been stationed in sub-Saharan Africa and India presented with epilepsy upon returning from their tours of duty.[8] Military physicians observed multiple brain cysts, made the connection to epilepsy, and hypothesized that the degeneration and calcification of viable cysts triggered inflammation that resulted in clinical symptoms such as seizures, headaches, dementia, and memory loss.[8] In the 1970s, infected pigs were imported into a previously tapeworm-free area of Papua New Guinea. A few years after the arrival of the infected pigs, there was a notable rise in epileptic seizures, caused by the presence of cysts in the brains of those affected.[9] In the early 1990s, four cases of NCC were observed in people who did not eat pork, living in a Jewish Orthodox community in the United States.[10] The most likely source of infection was determined to be housekeepers who were infected with *T. solium*, as one housekeeper tested positive for taenaisis and another tested positive for *T. solium* antibodies.[10] These cases helped establish that clinical neurological symptoms can take years to appear post-exposure, and that human-to-human infection is possible without the presence of pigs.[11]

2.1.2 Taxonomy

Taenia solium belongs to the *cestoda* class of parasitic flatworms and the *Eucestoda* (cestodes) subclass. Cestodes are endoparasitic to vertebrate animals in the adult stage, with a life cycle that requires an intermediate host (vertebrate or invertebrate) for the metacestode (larval) stage.[12] The cestode body is made up of segments, called proglottids, which mature and grow from the neck. Cestodes are hermaphrodites, and each proglottid contains a set of reproductive organs. *T. solium* belongs to the family *Taeniidae*, which has two genera: *Echinococcus* and *Taenia*. *Taeniidae* possess a head, known as a scolex, which is attached to the host's intestine in the adult stage, and a segmented body with no mouth or digestive tract.[12] As *T. solium* proglottids mature, they become filled with 50,000 – 60,000 fertile eggs (fig. 2.1).[13,14]

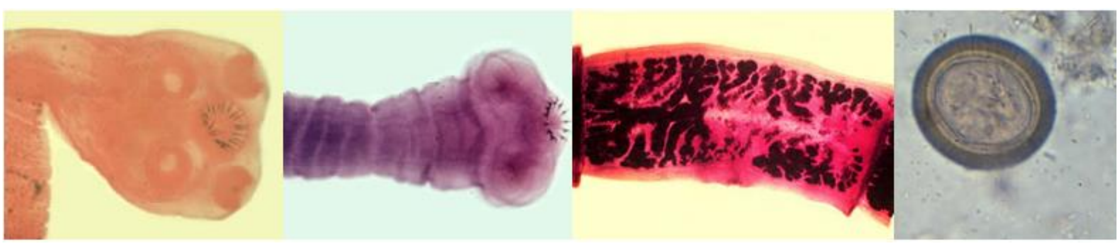


Figure 2.1 A. *T. solium* scolex, showing four suckers and rostellum with two rows of hooks. B. *T. solium* scolex. C. Mature proglottid (stained with carmine) D. *Taenia* species egg (unstained wet mount). Images from Centers for Disease Control Division of Parasitic Diseases and Malaria.

2.1.3 Life cycle/Transmission

Human intestinal infection of adult-stage *T. solium* is known as taenaisis. *T. solium* eggs are shed in the feces of infected humans, which may then be ingested to become larval cysts in the muscle tissue of people and pigs, a condition known as cysticercosis. Humans can then eat cyst-contaminated pork, which causes taenaisis (intestinal infection with tapeworms). As intestinal tapeworms mature and produce egg-containing proglottids, their eggs are shed in human feces and may be accidentally ingested, which can lead to brain infection when the nascent parasite (the oncosphere) travels through the blood stream and is deposited in brain and spinal tissue. Infection of the central nervous system with *T. solium* in the larval stage is NCC, a condition that may lead to severe headaches, seizures, other neurologic symptoms, and fatality. (Fig. 2.2)

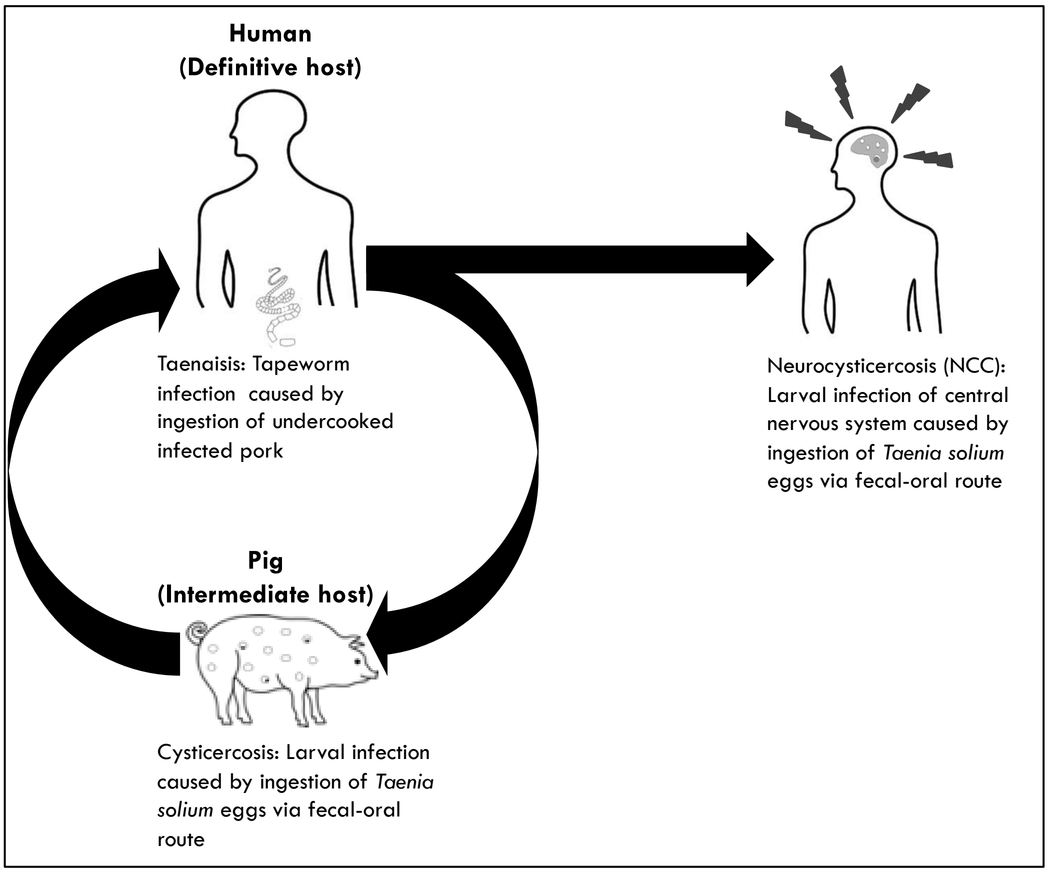


Figure 2.2 *Taenia solium* life cycle.

2.1.4 Taenaisis

Taenaisis is an infection of the small intestine with the adult egg egg-producing stage of *T. solium*, and is caused by eating raw or undercooked pork infected with larval-stage *T. solium* cysts (cooking pork at a sufficient temperature will kill viable cysts).[15] A single larval cyst is called a cysticercus. When the cysticercus reaches the human intestine, bile and other fluids trigger a process called evagination, in which the neck and scolex of the larval-stage tapeworm emerge from its protective bladder.[16] Within approximately 60 minutes, the scolex and neck are fully emerged and shortly thereafter will attach to the human host's small intestine.[16] The tapeworm primarily lives in duodenum of the small intestine, but moves frequently as food passes through the intestine.[17] The tapeworm matures after about two months, and adult tapeworms are thought to have a lifespan of approximately 3 years, growing to a length of 2-4 meters.[13,17] A mature tapeworm will have a scolex, neck, and a "strobila," which is made up of hundreds of proglottids, each with both male and female reproductive organs (Fig. 2.3).[17] As proglottids mature, they become larger and eventually develop into a rectangular-shaped segment called a gravid proglottid, which contains a uterus filled with eggs.[17] The gravid proglottids detach from the body of the tapeworm as they mature, and exit the host's body in feces.[13] Each proglottid may

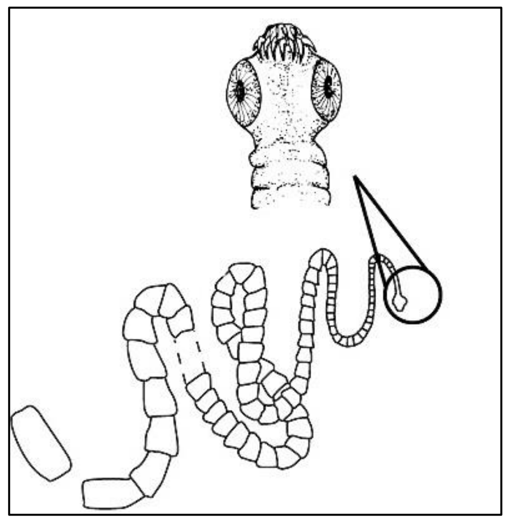


Figure 2.3 Line drawing of *T. solium* scolex, segmented body, and detached gravid proglottid. Image from Centers for Disease Control Division of Parasitic Diseases and Malaria.

contain up to 50,000 to 60,000 microscopic eggs.[13] Taenaisis infection is often asymptomatic, although some people may experience changes in appetite, abdominal discomfort, diarrhea or constipation. Infected people may notice proglottid segments in their feces.[18]

2.1.5 Cysticercosis

When the intermediate pig host ingests *T. solium* eggs, the pig may develop a condition known as cysticercosis. Upon contact with the host's intestinal tract, fertilized tapeworm eggs develop into oncospheres – early-stage larval forms of the parasite, which then pass through the intestinal wall and are carried by the bloodstream into the host's tissues, including muscles and organs. There they develop into cysticerci over the course of 60-70 days.[19] Both humans and pigs can develop cysticercosis via the ingestion of tapeworm eggs.

Free-roaming pigs spend much of their time foraging for food and actively seek out and consume feces. The presence of human taenaisis carriers, combined with outdoor/open defecation practices and pig raising practices that allow pigs access to feces (e.g., allowing pigs to freely roam) set the conditions for endemic cysticercosis in pig populations. The two-host transmission cycle is completed when humans consume cysticerci-infected pork.

2.1.6 Neurocysticercosis

T. solium oncospheres can travel via the blood stream in humans, in the same manner described above, to the brain and other parts of the central nervous system (CNS). CNS infection with cysticercerci is known as neurocysticercosis (NCC). NCC causes a range of sequalae, including headaches and seizures, and can be fatal. The location and number of cysts within the CNS will affect the patient's symptoms, treatment options, and clinical outcomes.

2.1.7 Prevalence and Geographic Distribution

Accurately measuring the prevalence of *T. solium* infections can be difficult, because taenaisis, cysticercosis, and NCC are often asymptomatic. Prevalence in both human and pig populations is typically estimated using enzyme-linked immuno-electrotransfer blot (EITB) assay of serum samples to detect antibodies for *T. solium*. However, being positive for antibodies indicates exposure to the pathogen, and does not necessarily indicate infection. In humans, taenaisis can be positively diagnosed by identifying *T. solium* eggs in stool samples, while diagnosis of cysticercosis or NCC require imaging to detect cysts within the body.[20] Porcine cysticercosis infections may be detected via tongue and eye examination, where cysts can be seen and/or palpated, but only heavily-infected pigs are likely to have cysts in these body regions; pigs with a lower cyst burden require necropsy and dissection of muscle tissue to confirm infections.[21–26]

T. solium is endemic in Latin America, Asia and Africa, especially in rural areas where pig raising is common.[1] It is most common in LMICs, but is also found in higher-income countries with a large number of immigrants from endemic countries.[28–30] In endemic areas, prevalence of *T. solium* antibodies in humans is between 10-25% of the general population.[31] Most studies in Latin American countries have found taenaisis prevalence in the range of 1-3% of the general population.[32–39]

In Peru, a 1993 study used EITB assays to detect serum antibodies in 498 neurology clinic patients, who were classified as epileptic (n=189) or non-epileptic (n=309). A high proportion of people diagnosed with epilepsy vs. people not diagnosed with epilepsy (12% vs 3%) were positive for *T. solium* antibodies.[40] A 2014 study analyzed data from two surveys containing data for 17,450 individuals in Northern Peru, and estimated that 17.25/1000 individuals had epilepsy during their lifetime, while 10.8/1000 participants had active epilepsy.[41] *T. solium* antibodies were found in 40% of individuals with epilepsy. CT scans were conducted on 282 individuals with epilepsy, and 109 (39%) had NCC-compatible images. Additionally, all the individuals with NCC-positive CT scans were also seropositive for *T. solium* antibodies.[41] A 2016 study in rural Northern Peru took blood samples from 385 individuals, and found 36.9% were positive for *T. solium* antibodies, but 79.6% of the seropositive participants reported no history of seizures or severe headache.[42] Follow-up computerized tomography (CT) scans of 256 participants found brain calcifications consistent with NCC in 48 (18.8%) of participants.[42]

In another region of Northern Peru, a study team carried out stool sampling with 2328 participants living in seven communities, which were analyzed with sedimentation and microscopy. *T solium* eggs were found in 49 (2.1%) of the samples.[43] Positive patients were treated with niclosamide, and 34 stool samples from these patients were obtained and tested with a polymerase chain reaction (PCR) followed by restriction enzyme analysis (REA) to identify the species of parasite, confirming *T. solium* in all 34 samples.[43] The overall prevalence of *T. solium* was 1.5%, with the highest community having a 2.9% prevalence.[43] In studies in Guatemala and Perú, taenaisis was found to be clustered within households.[38,44] Studies have also found seropositive pigs clustered around infected humans.[37,39,44]

2.1.8 Treatments for humans and pigs

There are three antiparasitic drugs available to treat taeniasis: niclosamide, albendazole, and praziquantel.[45,46] Of the three drugs, only niclosamide is not absorbed through the gastrointestinal tract, which means it can be administered to a person with taenaisis to kill tapeworms in the intestine, without concern for potential concurrent NCC infection and the possibility of triggering an inflammatory response in the brain due to death of a cyst or cysts located there.[46] Because albendazole and praziquantel are both absorbed into the bloodstream and pass the blood-brain barrier, they can be used to treat human cysticercosis and NCC.

NCC treatments are tailored to the individual patient, based on the location, condition, and number of cysts present. Viable (living) cysts, which are identified via imaging, are typically managed by using antiparasitic drugs (albendazole or praziquantel) to kill cysts, with or without co-administration of corticosteroids to reduce inflammation.[46] Surgical approaches, including excising cysts or inserting a ventricular shunt to address intracranial hypertension, are sometimes necessary.[46] Calcified (dead) or degenerating cysts do not require antiparasitic drugs. Other drugs are used to manage symptoms of infection, including analgesics for headache and anti-epileptic drugs for seizures.[46] People being treated for NCC require close monitoring by skilled medical professionals.

Porcine cysticercosis is treated with oxfendazole, an effective antiparasitic drug that typically eliminates viable cysts in pigs within 4 weeks post-treatment, but inflammation and subsequent degeneration of cysts can take up to 12 weeks.[46,47] Vaccines have also been developed to prevent pig infection, but widespread vaccination of pigs is severely limited by operational challenges, including the rural location of endemic regions and the frequent turnover of the pig population.[48–51]

2.1.9 Prevention and Control

T. solium cysticercosis was deemed one of six potentially eradicable diseases by the International Task Force for Disease Eradication (ITFDE) in 1993. In fact, *T. solium* is no longer endemic in many higher-income countries due to development of sanitation and food safety systems. It is an eradication candidate based on the life cycle, which can be interrupted by treating infections in the definitive and intermediate hosts, as well as practices that block transmission between the two hosts (Figure 2.2).[52,53] ITFDE based their conclusions on the existence of effective means of surveillance for *T. solium* and options for mass treatment of humans with safe and effective antiparasitic medications in endemic areas.

A feasibility study in Peru demonstrated that mass drug administration (MDA) with niclosamide for human taenaisis, coupled with pig immunizations (using the TSOL18 vaccine), could drive down transmission to near-zero levels in the short-term, but human migration and reintroduction of infected pigs into treated regions present substantial challenges to sustained regional elimination.[27] Subsequent research on geographic clustering of porcine infections and geospatial studies of pig movements in Peru provided the basis for targeted approaches to control transmission as alternatives to MDA.[37,43,54,55] In a head-to-head randomized controlled trial, two strategies “ring screening” (RS) and “ring treatment” (RT), which focus on providing antiparasitic treatment to humans who live in close proximity to infected pigs, were found to be equally efficacious to MDA for controlling infection, while treating 1.4% (RS) and 19.3% (RT) of the human population, vs. 88.5% treated in the MDA study arm.[56] The same study found that adding the antiparasitic treatment oxfendazole to the pig population provided no additional benefit for transmission control.[56]

While the MDA, RS, and RT interventions are each efficacious for controlling *T. solium* transmission, they require substantial human and material resources to conduct surveillance and provide treatments – resources not readily available in rural Peru. In addition to effective antiparasitic treatments, the World Health Organization recommends a combination of interventions to support control and elimination of the parasite, including health education, improved hygiene and sanitation, improved pig raising, and meat inspection to fight cysticercosis.[57] Many of the recommended interventions are not immediately feasible at large scale, due to cost, infrastructure, and sociopolitical barriers in endemic regions. In consideration of the low-resource environments in which cysticercosis is found, low-cost strategies with an emphasis on feasibility and community involvement are needed in order for prevention and control efforts to be successful.

2.1.10 Socio-behavioral Interventions

A number of studies have been conducted to test the efficacy of health education and behavior change interventions to support *T. solium* control. Health education has been shown to increase disease knowledge and actions that reduce risk of infection, but the link between knowledge increases and reduced transmission is less clear.[58–61] Researchers in Mexico found a statistically significant decrease in porcine cysticercosis prevalence before and after a health education program.[34] However, researchers in Peru found no change in porcine cysticercosis incidence during a health education intervention aimed at stimulating reports of pig infections.[62]

Qualitative studies have revealed social norms, including gender roles, pork consumption customs, hygiene and sanitation norms, stigma associated with pig infection, and trust of other community members or authorities may be factors affecting prevention and control behaviors.[59,63–67] Social systems are likely to affect peoples' knowledge and behaviors through the mechanisms such as social norms, social influences, and trust, as well as through interpersonal connections whereby knowledge can be transferred and new behaviors can be modeled.

Strategies that combine health education with efforts to change social norms have shown mixed results. Community-led total sanitation (CLTS) is a strategy to reduce open defecation that was first developed in Bangladesh.[68] CLTS focuses on building latrines and changing social norms related to latrine use. In Zambia, a CLTS intervention resulted in increased latrine coverage for the intervention communities, but not increased latrine usage, nor decreased *T. solium* transmission.[69] Strategies that include community members in the intervention planning and implementation are recommended. In Tanzania, an intervention developed using the PRECEDE-PROCEED planning model[70] was informed by focus groups and interviews with health promoters and people who raised pigs.[66] The researchers worked with community health services to implement the intervention, which included seminars, group training sessions, printed materials, and videos. There were eight key messages in the health education intervention to promote prevention and control. Care was taken to develop locally and culturally relevant educational materials. The intervention resulted in reduced reported pork consumption and decreased incidence of porcine cysticercosis in sentinel pigs, but only half of the farmers in the study raised sentinel pigs, which may have biased the results.[60,66]

During a One Health intervention that included mass drug administration for humans and vaccination and treatment for pigs in Lao People's Democratic Republic, researchers conducted an ethnographic study to learn about transmission dynamics, and locally-relevant control options.[63] The study conducted six focus groups, interviews, a latrine survey, a survey of latrine use, and participant observation. Few (16%) households had latrines. Most women understood the transmission cycle, but most men and children did not. Participation in drug administration was high, and attributed to trust between project staff and village leaders. In interviews, villagers noted gender differences in desire for and use of latrines (with latrines being more important/more desired by women than men). Participants reported that handwashing was not difficult technically, but did not fit in with the "farming lifestyle (p. 220)."[71] Poverty and religious norms played a role in pork consumption and preparation, and pig confinement was less desirable due to economic factors. People also reported hesitation to eat meat from corralled pigs due to the belief that it was unhygienic for pigs to have contact with their own feces. Latrines were viewed by some as dirty places, and open defecation was viewed as socially acceptable by many, especially men. The investigators concluded that social context was important for explaining epidemiologic findings and to understand how to develop interventions that are a good cultural fit for the local community. Interventions that were efficacious in a particular setting may not be successful in another setting due to social, cultural, and behavioral norms.[63]

Cultural and social norms are known to influence behaviors that place people at risk for, or protect them from, *T. solium* infection, but these norms are not always known or easily observable. Two studies in Zambia, using data from 21 focus groups (1 each for men, women, and children) in seven villages found that pig-raising played important economic, agricultural, and traditional roles in society.[65] Participants described how pig-raising labor was divided among family members, and how environmental factors affected decision-making for pig corralling. The study also found that women and children had a better understanding of the infection risk, but less decision-making power than men.[65] The same authors studied how social and cultural norms influenced latrine use in the same focus groups.[64] The researchers found that men and women both saw health and sanitation benefits to using latrines, including keeping pigs from eating human feces. Privacy was a commonly stated motivator both for and against latrine use, depending on the location and construction. The male focus group participants also discussed cultural taboos against men using the same latrines as their mothers-in-law or grown daughters.[64]

In New Guinea, communities within the country have differing practices with pork preparation and consumption.[72] In some regions, pig farmers take measures to domesticate their pigs, taming newborn piglets and teaching them to be comfortable being handled and tethered. In the middle altitudes, care is taken to keep pigs separated from sweet potato crops. Each of these pig-raising behaviors can affect the likelihood of pigs and humans being infected and passing the *T. solium* parasite among themselves.[72] Understanding why and how people raise pigs is an important element of designing effective interventions. The published intervention literature indicate there are complex cultural norms, economic issues, and social factors that influence the choices people make when raising pigs, preparing pork, and using latrines – choices which in turn influence their risk of *T. solium* infections.

2.2 The Potential Role of Social Capital in Cysticercosis Prevention and Control

Social capital is a product of individuals and their interpersonal social ties (networks), which enhances their collective problem-solving capabilities.[73] Social capital has a structural dimension, defined as the externally observable interactions among people, and a cognitive dimension, defined as trust, norms, and beliefs that influence the interactions among people in a society.[74] The term has roots in economics, with the term "capital" implying a good that can be exchanged for other goods or services. Social capital is an asset embedded within networks. Lin proposed that social networks, or the relationships through which social capital flows, affect outcomes by channeling and directing the flow of information, by activating social ties to people who have influence over other actors or decisions, by establishing "credentials" through the acknowledgement of formal or informal social connections, and by providing social support that reinforces an individual's inclusion in a network and thus their feelings of esteem and belonging.[75] However, social support is not inherently good, and social networks can create conditions that reinforce behaviors detrimental to health.

Summarizing his own and other theorists' perspectives, Lin defined social capital as, "resources embedded in social relations and social structure, which can be mobilized when an actor wishes to increase the likelihood of success in a purposive action" (p. 24).[76] Social capital as a resource, or set of resources, is differentiated from personal resources in that an individual does not own, or does not entirely control when and how to use or dispose of the resource(s).[75]

Bourdieu is generally credited with the modern concept of social capital, which he defined as "the aggregate of actual or potential resources" to which individuals have access via their social and institutional networks (p. 51).[77] Social capital is distinguished from human capital by being a product of interpersonal relationships, rather than a characteristic of individuals.[78] Coleman conceptualized social capital as an environmental factor influencing human behaviors and outcomes, exerting its effects alongside individual autonomous action.[79] Arguing against contemporaneous economists of the late 1980s, Coleman asserted that actors in an economic system do not act solely in their own self-interests, but also in accordance with contextual "norms, interpersonal trust, social networks, and social organization (p. S96)."[79] Coleman believed social capital was an antecedent to human capital and itself a "public good," meaning the benefits of social capital are extended beyond individual actors to the community, creating a resource greater than the sum of its parts. A decade later, Ostrom also criticized prevailing economic theories for assuming individuals act only as self-interested rational actors.[80] According to Ostrom, humans in complex adaptive economic systems create and enforce rules (including norms of reciprocity), based on prior knowledge and degrees of trust and trustworthiness of others.[72]

One element of social capital is "generalized reciprocity": the confidence that good (or bad) deeds will be reciprocated at an unspecified future time, not necessarily by the individual receiver of the good (or bad) deed.[81,82] This reciprocity constitutes a social norm that exerts pressure on the members of a community or social network to behave in a manner concurrent with the norm, or risk social exclusion and other negative consequences.[83]

There is reason to suspect social capital is of greater importance for health promotion in low-resource environments, where public health systems face lack of funding and infrastructure, than high-income countries. Hanibuchi and Nakaya speculate the bonding type of social capital, defined as “interpersonal relationships within homogenous groups” (p. 68), is not as important for people living in urban areas compared to people living in rural areas, because urban dwellers can get goods and services in the marketplace.[84] Although research on the role of social capital in LMICs has grown in the last two decades, the majority of research on social capital has been conducted in developed countries.

Svendsen and Svendsen described social capital as trustworthiness of others, networks, and institutions which establish trust as a foundation for collective action.[73] This definition of social capital ties together the elements of social capital of interest in this study, because it builds on the previous conceptualizations and links social capital to collective action, which can be mobilized for community-engaged *T. solium* control. The study described in subsequent chapters is based on this conceptualized link between social capital and collective action, with collective efficacy added as a precursor to collective action (Figure 2.4).[73]

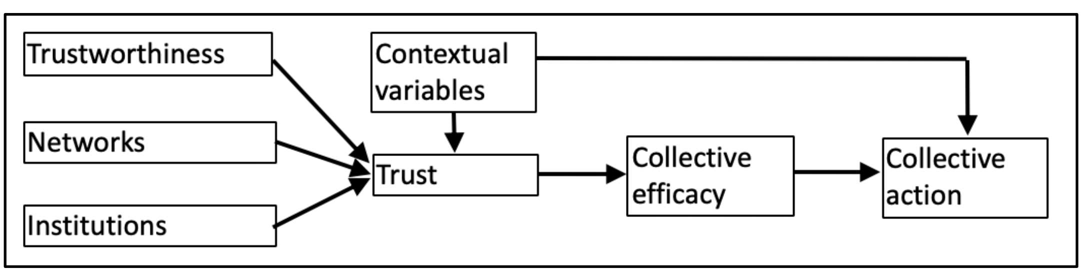


Figure 2.4 Relationship of social capital to collective action

2.3 The Role of Social Networks in Transmitting Knowledge and Promoting Health Behaviors

Social networks influence health via direct contact, and also by delivering social capital in the form of trusting relationships, norms of reciprocity, and information exchange. Social networks provide the structure for social capital to be accessed by community members.[85] The cohesion that exists in social networks can positively affect health, but can also exert pressure to conform to norms that have negative health effects.[84] The initiation and maintenance of protective behaviors may occur through social networks, which could potentially be leveraged to improve the design of community-based interventions.[86–93]

Social network theory (SNT) has foundations in sociology, psychology, anthropology and social epidemiology.[94–97] Social networks have structural and compositional attributes. Structure is defined as way that social relationships are linked within a network (e.g., network size, number of connections within a network), whereas composition is defined as the attributes of the individuals who make up the network (e.g., family/kin, friends, schoolmates, etc.).[98] According to SNT, health beliefs and behaviors are dependent on the structure and composition of social networks, which provide access to resources, information and other forms of social capital, such as trust and norms of reciprocity.[99–101] Berkman and Krishna conceptualized the pathways through which social networks, embedded within ecological and cultural contexts, affect individual psychosocial mechanisms which, in turn, affect health behaviors and exposures (Fig. 2.5). At the macro level, "social structural conditions determine the extent, shape, and nature" of mezzo-level social networks which are a source for micro-level social capital (informational and instrumental support), interpersonal interaction, and social reinforcement of behaviors (p. 241). Finally, micro-level mechanisms impact health via behavioral, psychological, and physiological pathways.[102]

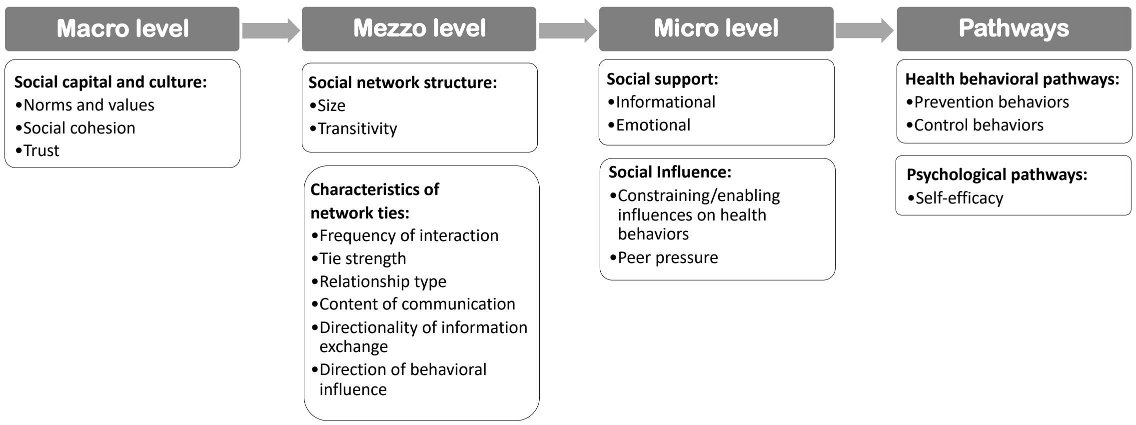


Figure 2.5 Selected elements of conceptual model of mechanisms by which social networks affect individual health (Berkman and Krishna, 2014)

Social networks are known to influence health behaviors both directly (e.g., HIV and other infectious disease transmission)[103] and indirectly (e.g., peer modeling and reinforcement of social norms).[93,99,102,104] Social norms around pork consumption, hygiene and sanitation, and stigma associated with infection can influence behaviors that, in turn, affect *T. solium* transmission.[59,63–67] Especially in low-resource environments, where public health systems face lack of funding and infrastructure, social networks play a critical role in health promotion.[105] People are more likely to adopt new behaviors if the behaviors are compatible with existing norms and if people they know and trust adopt the new behavior.[106] Social networks provide role modeling and social support for normative behaviors, and boost self-efficacy for new behaviors.[94,101,107] In LMICs, social network influences have been linked to health behaviors as varied as contraception use,[92,108] bed net use for malaria prevention,[109] and Chagas disease prevention behaviors.[110]

2.4 Summary

The *T. solium* parasite causes an estimated 30% of acquired epilepsy worldwide – an entirely preventable disease burden. Increased screening and treatment, sanitation development and pork production regulation would reduce infection risk in endemic communities, but large-scale systemic improvements are not likely to occur in the near future. In the meantime, communities can reduce infection risk by adopting protective behaviors, but many people remain unaware of how *T. solium* is transmitted and what can be done to reduce their chance of infection. Qualitative and quantitative studies have found that social networks may influence the uptake and maintenance of a variety of protective health behaviors. Social networks provide role modeling and social support for normative behaviors, boost self-efficacy for new behaviors, and influence health via direct contact, in addition to providing a delivery mechanism for social capital. Social capital can contribute to collective efficacy for new behaviors and collaborative problem-solving.

No prior work has explored how information or support for *T. solium* prevention is transmitted through social networks. Not knowing how people educate and influence their peers about this disease represents a critical knowledge gap for how to effectively work with communities to support cysticercosis prevention and control. Likewise, the relationships between social capital, collective efficacy, and collective/community actions for *T. solium* control have not been previously researched in the published literature.

Chapter 3 Cysticercosis prevention and control in Peru: The role of social networks in sharing knowledge and promoting behavior change.

3.1 Background

In LMICs worldwide, *Taenia solium,* commonly known as pork tapeworm, is the cause of an estimated 30% of acquired epilepsy, due to brain infection with the parasite in its larval-stage (neurocysticercosis [NCC]).[13] The parasite's definitive hosts are humans, who acquire intestinal infections (taenaisis) by eating pork contaminated with *T. solium* larva (fig. 3.1).

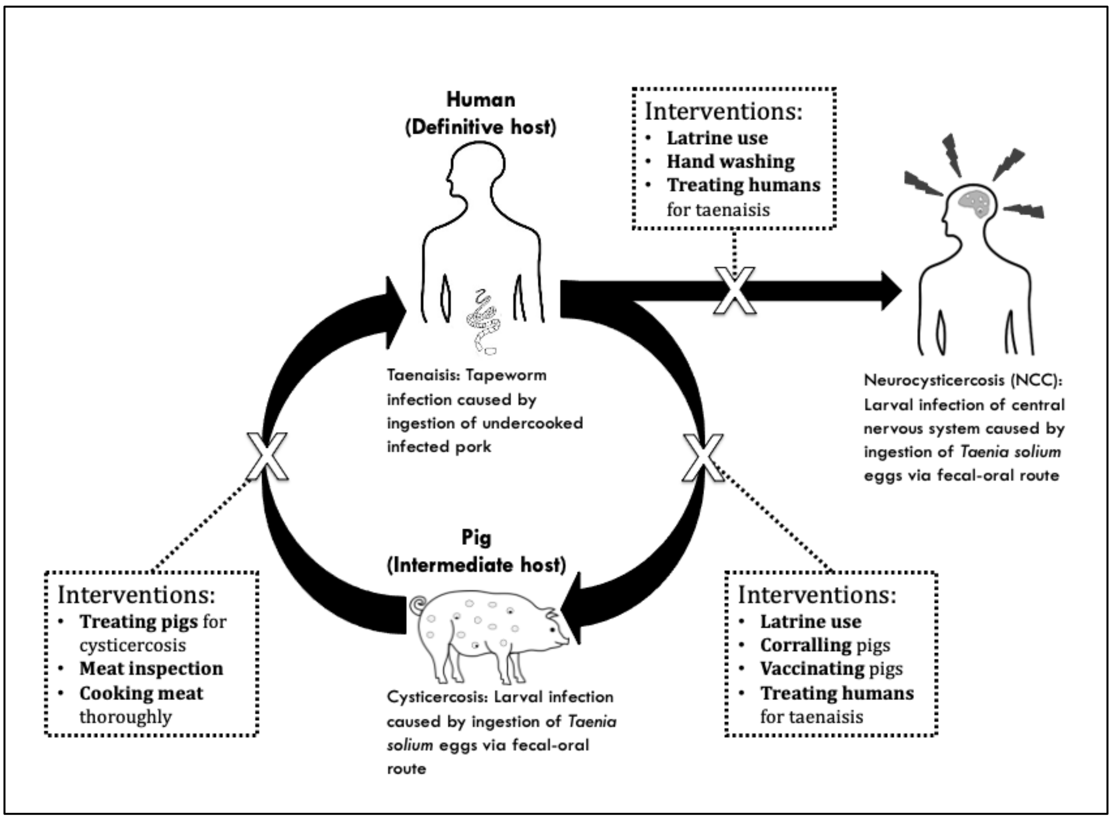


Figure 3.1 *Taenia solium* life cycle and points of intervention

This neglected tropical zoonosis is endemic to Latin America, Asia, and Africa, and is most prevalent in rural areas where pig raising is common. In addition to the toll NCC takes on human health, quality of life, and livelihood, there are substantial economic harms incurred by farmers due to pig infections (cysticercosis). In 1993, the International Task Force for Disease Eradication (ITFDE) evaluated 29 infectious diseases on their potential for eradication, and declared *T. solium* cysticercosis one of six diseases that "could potentially be eradicated."[52,53] The ITFDE based their conclusions on the existence of effective means of surveillance for *T. solium* and options for mass treatment of humans with safe and effective antiparasitic medications in endemic areas. In Northern Peru, three different approaches to delivering antiparasitic drugs for human taeniasis have been shown to be effective for controlling transmission: mass drug administration (MDA), and "ring screening" (RS) and "ring treatment" (RT), which focus on providing antiparasitic treatment to humans who live in close proximity to infected pigs.[56] These interventions have been tested with mass or targeted delivery of antiparasitic drugs for pig cysticercosis, as well as with or without immunizations to prevent cysticercosis in pigs.[27,56]

While the MDA, RS, and RT interventions are each efficacious for controlling *T. solium* transmission, they require substantial human and material resources to conduct surveillance and provide treatments – resources not readily available in rural Peru. In addition to effective antiparasitic treatments, the World Health Organization recommends a combination of interventions to support control and elimination of the parasite, including health education, improved hygiene and sanitation, improved pig raising, and meat inspection to fight cysticercosis.[57] Many of the recommended interventions are not feasible at large scale, due to cost, infrastructure, and sociopolitical barriers in endemic regions. In consideration of the low-resource environments in which cysticercosis is found, low-cost strategies with an emphasis on feasibility and community involvement are needed in order for prevention and control efforts to be successful.

Socio-behavioral interventions can be coupled with medical and epidemiologic interventions to educate people about their risks of *T. solium* infection, and facilitate behavior changes both on the individual/personal level, and via the influence of social relationships on social norms. Social networks are known to influence health behaviors both directly (e.g., infectious disease transmission)[103] and indirectly (e.g., peer modeling and reinforcement of social norms).[93,99,102,104] Social norms around pork consumption, hygiene and sanitation, and stigma associated with infection can influence behaviors that, in turn, affect *T. solium* transmission.[59,63–67] Especially in low-resource environments, where public health systems face lack of funding and infrastructure to influence social norms, social networks play a critical role in health promotion.[105] People are more likely to adopt new behaviors if the behaviors are compatible with existing norms, and if people they know and trust adopt the new behavior.[106] Social networks may also enable network members to provide role modeling and social support for changing normative behaviors, and boost self-efficacy for adopting new behaviors.[94,101,107] In LMICs, social network influences have been linked to health behaviors as varied as contraception use,[92,108] bed net use for malaria prevention,[109] and Chagas disease prevention behaviors.[110]

This study explores the network-based mechanisms by which people learn about the causes and health effects of *T. solium* infection, and how social relationships promote behaviors that reduce infection risk. It is informed by social network theory (SNT), which has foundations in sociology, psychology, anthropology and social epidemiology.[94–97]

According to SNT, health beliefs and behaviors are dependent on the structure and composition of social networks, which provide access to resources, information and other forms of social capital, such as trust and norms of reciprocity.[99–101] This study uses an adaptation of Berkman's and Krishna's conceptual framework[102] (Figure 3.2; see Appendix 3.A for full framework) to describe the pathways through which social networks, embedded within ecological and cultural contexts, affect individual psychosocial mechanisms which, in turn, affect health behaviors and exposures. At the macro level, "social structural conditions determine the extent, shape, and nature" of mezzo-level social networks, which are a source for micro-level social capital (e.g., informational and instrumental support), interpersonal interaction, and social reinforcement of behaviors" (p. 241). Micro-level mechanisms, including social support and social influences, impact health via behavioral, psychological, and physiological pathways.[102] The descriptive study described here explores the relationships between the elements of the behavior change model shown below (Figure 3.2). At the mezzo level, we asked participants about the content and directionality of their exchanges; at the micro

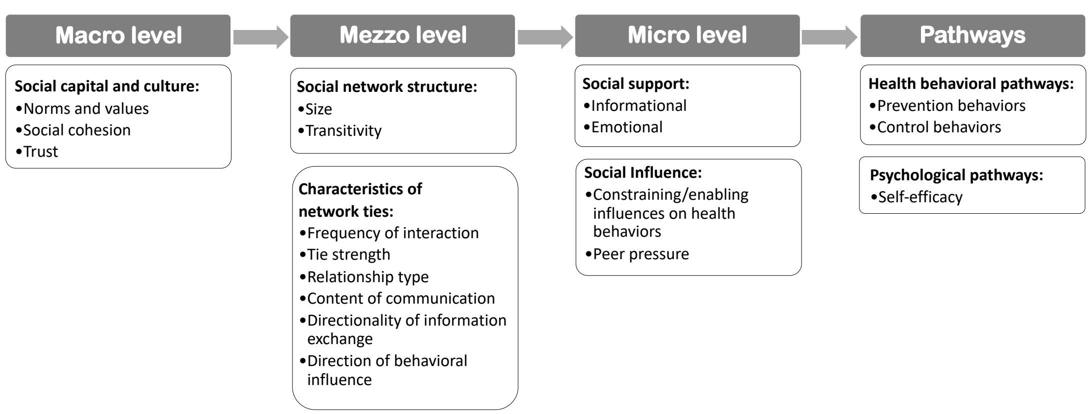


Figure 3.2 Conceptual model of mechanisms by which social networks affect individual health. (Berkman and Krisha, 2014)

level, we constructed variables to represent social supports, and explored the relationship of that social support to behaviors for *T. solium* control.

Social networks are the source of multiple kinds of social support, which have been classified by social scientists as informational, socialization, emotional, material, instrumental.[111,112] Lin proposed that social networks affect outcomes by channeling and directing the flow of information, by activating social ties that have influence over other actors or decisions, by establishing "credentials" through the acknowledgement of formal or informal social connections, and by providing social support that reinforces an individual's inclusion in a network and thus their feelings of esteem and belonging.[75]

This study uses an egocentric social network analysis approach, which can track connections to and/or from a single person, who is referred to as the "ego," and can examine how an ego's embeddedness in their social network affects health and other outcomes.[113] In egocentric network analyses, compositional (e.g., types of relationships) and structural (e.g., number of connections) attributes of social networks are treated as individual-level variables, or analyzed within multilevel models.[114]

3.2 Materials and Methods

3.2.1 Study site

Staff from the University Peruana Cayetano Heredia's Center for Global Health (CGH), located in Tumbes, Peru, carried out all field activities and data collection for this study. Participating villages were located in the Piura region of Northern Perú, an arid area near the Pacific coast and Perú-Ecuador border, where *T. solium* is endemic. Four of the villages had participated in previous cysticercosis education studies: two participated in primary school-based education activities in 2010-2011; those two along with two others participated in a study designed to promote screening and reporting of infected pigs in 2014-2015.[115]

This study was nested within a pilot study conducted from 2016-2018 to develop methods for a combined health education and community organizing intervention to support community-based *T. solium* surveillance and control (Beam, manuscript in preparation). At the beginning of the pilot study in November 2016, we conducted a community census, which found there were 1665 individuals living in 428 households in the seven study villages. Pig raising was common, with over half of the households (61%) owning pigs. The majority of households had outdoor latrines for feces disposal, but coverage varied among the villages: in five of the villages, more than 86% of households had a latrine, while the other two villages had latrine ownership rates of 68% and 31%. On average, 15% of the households reported regularly practicing outdoor defecation; however, in the village with the lowest latrine coverage, the rate of outdoor defecation was 50%. Additional community characteristics are included in Table 3.1.

3.2.2 Recruitment

We invited all heads-of-households to participate in knowledge, attitudes, and practices surveys via door-to-door visits every four months for the pilot study's 20-month duration (Nov. 2016 – Aug. 2018). Social network data described was collected during the final three waves of surveys: Dec. 2017, April 2018, and August 2018. There were no incentives given for survey participation.

3.2.3 Data collection

Survey data were collected via door-to-door in-person interviews using paper surveys. Household visits were scheduled for early morning and late afternoon, to accommodate participants' schedules, which typically made them unavailable during mid-day. Peruvian study team members conducted the interviews in Spanish. On average, each interview lasted 20-30 minutes. Information from the paper forms was double-entered into databases and checked for errors.

Table 3.1 Characteristics of participating villages

	N*	%
Number of villages	7	
Number of individuals	1665	
Female	809	49%
Age median in years	24	
<18	686	14%
18-49	610	37%
≥50	369	22%
Household characteristics		
Number of households	428	
Water source		
Piped	378	88%
River/stream	24	6%
Other	26	6%
Feces disposal		
Latrine	349	88%
Open field	66	15%
Bathroom/indoor	13	3%
Energy source		
Electricity	377	88%
Battery/motor	10	2%
None	41	10%
Pig owners	263	61%
Mean number of pigs per owner (SD)	3.9 (3.6)	

* Except where mean or median indicated.

Social network data:

Participants responded to a name-generating prompt, modified from the General Social Survey (GSS) to establish network members (alters).[116] Participants could name as many alters as they wanted, and were asked to describe the alters' relation to participants. For the first five alters named, a series of follow-up questions was asked about the frequency of interactions with alters, and informational and social support exchanges related to *T. solium* prevention and control. Participants were also asked if they had communicated with any health workers or health promoters about *T. solium* in the last four months. (Social network survey questions, translated from Spanish to English, and constructed variables are provided in Appendix 3.B). We constructed independent variables representing the proportion of the participants' networks with whom they exchanged informational support or emotional support related to *T. solium* transmission and control.

Dependent variable data collection:

For the dependent variable, we asked participants to respond with a *yes* or a *no* to the question asking if their household had taken any action to avoid human or porcine *T. solium* infection in the past 30 days. If yes, they were asked to describe the actions with an open-ended response, which we classified into types of prevention and control behaviors.

3.2.4 Analysis

First, we conducted a cross-sectional analysis of each wave of data. Based on an observed reduction in named alters at each round of surveys, we elected to estimate the following models: a cross-sectional analysis of the network variables at time one; a panel that included the individual heads-of-households who participated in all three waves of network interviews; and a panel of pig-farmers. Results for these three approaches are described here.

For the Time 1 panel and pig farmer subsets of data, we used binomial regression with a logit link to estimate the odds of taking an action to control *T. solium* as a function of network size, informational support exchange, and emotional support exchange with members of the respondent's close network (defined as the first five alters named by the survey respondent / ego). These models were adjusted for likely covariates including age (in years), sex (dichotomous male / female), and education (in years), as well as a village-level variable indicating if the respondent lived with an intervention or control village. Pig ownership was used as a stratification variable to explore relationships for all respondents and then among pig farmers exclusively. Model coefficients were exponentiated to yield odds ratios (OR) and corresponding 95% confidence intervals (95% CI). For the panel data, we incorporated cluster robust standard errors at the individual/head-of-household level to account for having three interviews for each participant. The low number of villages participating in this study prevented us from being able to account for clustering at the village level.[117] We conducted all analyses with Stata 16 statistical analysis software (Stata Corporation, College Station, Texas, USA).

3.3 Results

There were 419 heads-of-households surveyed at time one; 409 at time two; and 424 at time three. There were 359 individually-matched heads-of-households who participated in all three data collection points. The majority (65% and 67% respectively) were female, and the median age was 48 years for the cross-section and 49 years for the panel (range 18 to >89). Pig ownership varied over the three waves of data collection therefore pig farmers are not included in the participant summary table, but were similar to the cross-sectional and panel participants in household and individual characteristics (Table 3.2).

Table 3.2 Participant characteristics at time 1

	Cross-Sectional		Panel	
	N	%	N	%
Number of individual heads-of-households	419		359	
Household characteristics				
Mean number of household residents (SD)	3.5 (1.2)		3.5 (1.2)	
Pig owners	259	61.8%	229	63.8%
Number of pigs	967		862	
Mean number of pigs per owner (SD)	3.7 (3.5)		3.8 (3.5)	
Number of pigs	967		862	
Pigs corralled	374	38.7%	325	37.7%
Pigs tied up	143	14.8%	128	14.8%
Pigs roaming freely	436	45.1%	402	46.6%
Corral present at home (all households)	143	34.1%	125	34.8%
Participant characteristics				
Female	274	65.4%	242	67.4%
Age median in years	48		49	
Years of education mean (SD)	6.3 (4.1)		6.2 (4.0)	
Education Level				
None	40	9.6%	36	10.0%
≤ Primary completion	255	60.9%	216	60.2%
Some secondary to secondary completion	99	23.6%	89	24.8%
Some post-secondary education to college completion	25	6.0%	18	5.0%

* Except where mean, median, or standard deviation indicated.

Network composition and tie strength

For the cross-section of participants from time one, mean network size (the total number of network alters named by each participant divided by the total number of participants) was 2.76. For the panel, mean network size was 2.78 at time one, 2.22 at time two, and 1.35 at time three; and for pig farmers, mean network size was 2.9 at time one, 2.44 at time two, and 1.45 at time three (Table 3.3).

Table 3.3 Network size, composition, close networks, tie strength

	Cross section	Panel			Pig farmer panel		
Time	t1	t1	t2	t3	t1	t2	t3
No. of participants	419	359	359	359	233	216	225
Net Degree							
Mean network size (SD)	2.76 (1.58)	2.78 (1.49)	2.22 (1.42)	1.35 (1.31)	2.90 (1.49)	2.44 (1.43)	1.45 (1.32)
Total number of alters named	1157	1002	799	483	675	527	327
Network Composition							
Kin	496 (43.5%)	435 (43.8%)	321 (40.3%)	185 (38.3)%	279 (41.3%)	207 (39.3%)	113 (34.6%)
Neighbor or Friend	590 (50.2%)	504 (49.7%)	427 (53.2%)	272 (56.3%)	351 (52.0%)	287 (54.5%)	192 (58.7%)
Health Worker	2 (0.2%)	2 (0.2%)	3 (0.4%)	0	1 (0.1%)	3 (0.6%)	0
Teacher or Religious Advisor	9 (0.8%)	9 (0.9%)	2 (0.3%)	15 (3.1%)	4 (0.6%)	1 (0.2%)	0
Leader	36 (3.2%)	32 (3.3%)	39 (5.0%)	9 (1.9%)	28 (4.1%)	26 (4.9%)	20 (6.1%)
Other	24 (2.1%)	20 (2.0%)	7 (0.9%)	2 (0.4%)	12 (1.8%)	3 (6.1%)	2 (0.6%)
Multiplex relationships							
>1 type of relationship	158 (13.7%)	140 (14.0%)	142 (17.8)	58 (12%)	104 (15.4%)	95 (18.0%)	45 (13.8%)
Kin + Neighbor	48 (4.1%)	43 (4.3%)	32 (4.0%)	13 (2.7%)	23 (3.4%)	18 (3.4%)	10 (3.1%)
Tie Strength							
Total number close alters	1116	972	784	480	656	512	325
Frequency communication with close alters:							
Every day	405 (36.3%)	357 (37.1%)	545 (33.7%)	70 (32.9%)	237 (37.1%)	163 (31.8%)	96 (29.5%)
Weekly	622 (55.7%)	264 (56.1%)	474 (60.5%)	46 (58.5%)	372 (56.7%)	320 (62.5%)	199 (61.2%)
Less than weekly	89 (8.0%)	158 (7.2%)	281 (5.9%)	41 (8.5%)	47 (7.2%)	29 (5.7%)	30 (9.2%)

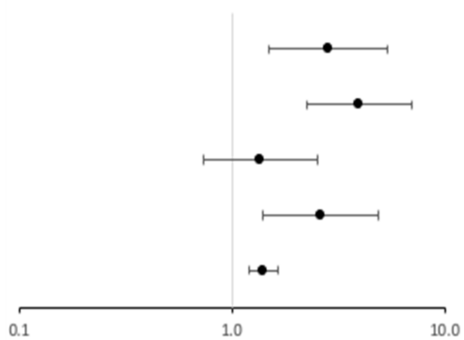
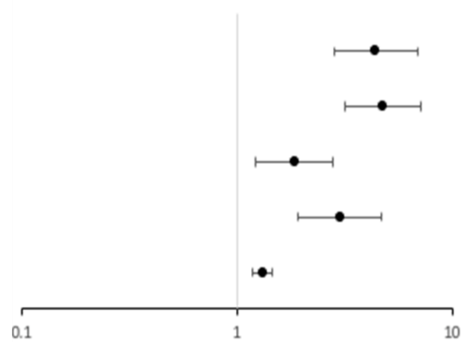
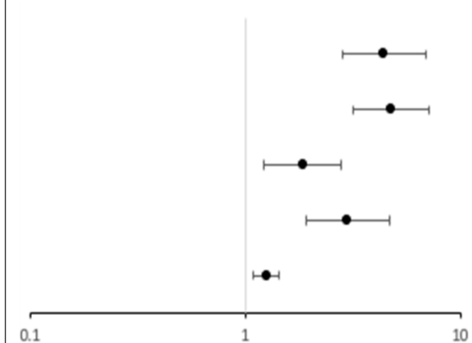
Half of the alters were neighbors, and between 35-44% were kin. Among members of the close network (first five alters named), participants communicated with over 90% of alters at least weekly, and over 30% communicated with their close alters daily.

In our first round of data collection, 17.9% of participants (n=419) reported their household had taken any action to control *T. solium* transmission over the last month. For the panel (n=359), household action was reported by 18.4% of participants at time one, 14.9% at time two, and 15.6% at time three. The most frequently-mentioned *T. solium* control actions were avoiding pork altogether, checking pork for cysts prior to eating, corralling pigs, and handwashing.

In binomial regression analyses conducted using the first round of network surveys, providing informational support (OR 2.95, 95% CI 1.62, 5.39) and encouragement (OR 4.11, 95% CI 2.59, 6.52) to a higher proportion of alters was associated with increased odds of household action to control *T. solium* (Table 3.4). Participants for whom a higher proportion of alters provided them with informational support (OR 1.64, 95% CI 0.91, 2.93) and encouragement (OR 2.9, 95% CI 1.59, 5.27) also had increased odds of taking action for *T. solium* control. Pig ownership (OR 1.99, 95% CI 1.14, 3.51), years of education (OR 1.07, 95% CI 1.01, 1.14), and net degree (network size) independent of the type of support provided or received (OR 1.41, 95% CI 1.22, 1.65) were also associated with increased odds of taking action for *T. solium* control. These results were consistent for cross-sectional and panel analyses.

For the panel, adjusted for age, years of education, inclusion in pilot study intervention communities, and pig ownership, the largest effect estimates were for providing information (OR 3.79, 95% CI 2.27, 6.34) and encouragement (OR 4.11, 95% CI 2.59, 6.52) to alters, while receiving encouragement from alters was associated with strongly increased odds of action (OR 2.98, 95% CI 1.69, 5.27), and the effect estimate for receiving information from alters was modest (OR 1.58, 95% CI 0.94, 2.4). The same analyses applied to the subset of participants who were current pig farmers at the time of the network surveys resulted in similar effect estimates as non-pig farmers (Table 3.4). When a village-level identifier was included as a fixed effect in both cross-sectional and panel models, effect estimates and 95% CI remained unchanged and the rho associated with the village variable was near 0. Therefore, we presented the most parsimonious models here.

Table 3.4 Odds Ratio for self-reported action to control *T. solium* over the last 30 days

	Time 1	Panel	Pig-Owner Panel
N	413	354	229 *time 1*; 213 *time 2*; 221 *time 3*
Participant:			
Gave information			
Gave encouragement			
Received information			
Received encouragement			
Net Degree			

3.4 Discussion

Our study indicates that people who exchange information and encouragement with higher proportions of their close social networks are more likely to take action to prevent infections than those who rarely talk about the disease with their alters. We also observed that being the provider of information and encouragement was more strongly associated with taking action than being the recipient of information and encouragement. These findings are consistent with research on how inhabiting social roles (for example being a source of information or being known as having expertise in the care and raising of pigs for food consumption), can reinforce behaviors that are consistent with those social roles.[111,112,118]

A number of studies have been conducted to test health education and behavior change interventions, designed to help communities reduce their risk of cysticercosis infection, prevent transmission, and to seek treatment for infected humans and pigs. Health education has been shown to increase disease knowledge and actions that reduce risk of infection, but the link between knowledge increases and reduced transmission is less clear.[58–61] Although this study did not measure incidence or prevalence, the results indicate that receiving information is not sufficient to motivate prevention and control actions that would ultimately drive down transmission.

We observed an increase in odds of self-reported household action with increased network size (total number of network alters named). This held true over the three waves of data collection, despite the total number of network alters named by participants reducing by nearly half between the first and final surveys. It stands to reason that people with larger networks have more people to with whom to exchange information, and given the large number of pig farmers in the study communities, there are likely many opportunities to discuss the topic of pig raising.

We found that pig farmers were more likely to report recent *T. solium* control activities than people who don't raise pigs. Pig farmers have more opportunities to act on the transmission cycle, because they can intervene on pigs via restricting their access to feces, regularly screening their pigs for infections, treating infections, and properly disposing of contaminated pork. Pig farmers have financial incentives, in addition to health incentives, to raise clean, cyst-free pork and to be known as someone who raises healthy animals. Education specifically developed for pig farmers has the potential to motivate farmers to adopt practices that decrease incidence of infections, but more research is needed to determine the most effective strategies for farmer education, as well as better understanding of how the presence of the research team influences farmers' knowledge as the team goes about activities – especially if those activities involve testing or treating pigs.[51,60,119,120] Providing outreach, education, and organizing support to pig farmers can build on their existing opportunities and motivations for raising clean, healthy pigs. Further research could also explore the social networks of pig farmers specifically, to both understand trade networks and movement of pigs and pork via commercial exchanges,[121,122] and to understand how pig farmers share information and pig-raising practices with one another, which may, in turn motivate changes in practices.[123]

Inclusion in the pilot study, which was conducted concurrently with this study, was not a significant predictor of self-reported action at months 12, 16, and 20, of the pilot when we collected social network data. This held true in both our unadjusted models and covariate-adjusted models. The pilot study included activities that raised awareness about pig infections and engaged pig farmers and community members in dialogue with community facilitators about *T. solium* and the need for controlling infections. The content of informational and social support exchanges may have been related to activities within the pilot study that occurred prior to this study, particularly activities that were designed to educate community members and encourage participation in community workgroups.[124]

3.4.1 Limitations

This study had several limitations. First, the timing of our first round of social network data collection prevented us from being able to measure social networks and support exchanges at the beginning of the pilot study. While our analysis included inclusion in the intervention villages as a covariate, we were unable to assess potential effects of the intervention on the volume and content of informational and emotional support exchanges related to *T. solium* control. Adding the pilot study intervention inclusion as a covariate has the potential to introduce spurious results due to the problem of multiple comparisons (family wise error rate). However, there was no association with the pilot study invention and action in bivariate analysis, ruling out the potential error of conditioning on an antecedent variable.

We used self-reported behavior for our dependent variable data, which has the potential to be unreliable. Participation in pilot study activities may have been under-reported by participants in the intervention communities. Further exploration of the data is warranted, including an analysis of participation in pilot study activities compared to self-reported behaviors, which may provide a more complete understanding of the prevention and control behaviors taken by participants during this study.

We suspect the decrease in named alters at each wave of data collection was due to survey fatigue.[125] The social network questions were embedded within a larger knowledge, attitudes, and practices survey that was collected every four months during the 20-month-long parent pilot study. In addition to adding time to the total length of the survey (relative to the prior versions before the social network questions were asked), each named alter in the participant's network added 15 questions to the survey. For this reason, we analyzed the cross-sectional data collected when we asked our first round of social network questions (time 1) separately, under the assumption that survey responses were most accurate at the participants' first encounter with those questions.

Due to the design of our social network survey questions, we did not collect data on alters such as alters' sex, age, and alter-alter relationships. Additional data on alters would have enabled us to construct more complex and complete social network models, and to calculate the homogeneity-heterogeneity and density of the participants' networks. This limitation is tempered by the need to keep the number of questions on the survey low in order to reduce the potential for participant and interviewer fatigue. Additionally, the alter-name-generating prompt we used (people with whom the ego frequently shared "support or important information") can be open to interpretation, as opposed to questions like "who have you spoken with in last 7 days."[125,126] More specificity in our questions, especially by adding a recall time period to the alter-naming questions or using the previous list of alters in subsequent data collection waves, would have allowed us to direct that questioning in a way that better guarded against recall bias and/or forgetting.[125]

3.4.2 Strengths

Collecting three waves of social network data allowed us to better understand the stability of relationships (given the limitations described above), and the consistency of conversations on the topic of *T. solium* transmission and control. It is worth noting the high proportion of network composition that are neighbors, suggesting that the social ties are concentrated in geographic areas and neighbors are communicating frequently. This information can be used to design interventions that encourages neighbors to work together to create environments and promote practices that create healthy homes, families, and animals.

Including a sub-analysis of pig farmers allowed us to examine their specific networks and behaviors. Pig farmers may be more invested in learning and taking steps to prevent infections than population at large, due to the economic consequences they incur when their animals are infected. Given that pig farmers have multiple opportunities to intervene and interrupt the transmission cycle, the information from this study provides a basis for further research and development of interventions designed to develop pig farmer networks, such as providing accurate information about the diseases that can affect pigs and the strategies to maintain healthy animals.

3.5 Conclusion

Many people who live in *T. solium*-endemic areas are unaware of their sources of exposure as well as the actions they can take to reduce their risk of infection. Previous research on the effectiveness of health education has shown that educational interventions developed and delivered by formal sources (e.g., governmental organizations, health professionals, and trained paraprofessionals) can improve peoples' knowledge of the disease.[59,60,124] However, increased knowledge does not necessarily result in measurable prevention practices or reductions in incidence of pig and human infections.[69] Few studies have examined how people exchange knowledge and social support on the topic of *T. solium* via interpersonal relationships, or how these exchanges may support or discourage infection control. This descriptive study adds to the body of knowledge about the way *T. solium* is talked about in the social realm, and what types of transmission-related topics are most commonly discussed.

The initiation and maintenance of protective behaviors may occur through social networks, which could potentially be leveraged to improve design of community-based interventions.[86–93] However, people need to be knowledgeable and enthusiastic enough to become providers of information to others. Our study's results suggest that social network interventions to support *T. solium* control might be useful, but also that a high of level of training is needed to get people to become support providers.

There are a number of future studies that could build upon this research. Whole networks studies that identify the social connections of entire communities, as opposed to egocentric studies, could identify influential people and inform the design of interventions that seek to leverage that influence to shift social norms around pig-raising, infection surveillance, reporting, and other control activities. Given the relatively small size of the rural communities where the study was conducted, whole network studies are feasible, but require careful design to mitigate limitations like those we met in this study. Strategies to address those limitations include developing a study that is solely focused on networks and thus limited to network survey questions, excluding additional questions such as knowledge, attitudes, and practices that were collected in this study's questionnaire for other purposes. New mobile technologies and tablet-enabled software have been developed to facilitate whole network data collection and improve the accuracy of data entry. When designing future studies, these technologies should be employed where appropriate in order to reduce the burden of data collection, and recall for both the participants and the study team.

It is important to take into account the socioeconomic situation in the Peruvian communities where *T. solium* is endemic. Pig farming is a source of income for a large number of families who depend on it for basic supplies and for food. Asking farmers to shoulder the burden of infection control neglects to acknowledge the substantial infection control gains that can be achieved through municipal investments, and regional/national programs that facilitate human, animal, and environmental health professionals to work with farmers and communities. One Health programs can bring together people around the shared goals of healthy people and animals to create community-led strategies that seek not only to control *T. solium*, but prevent and control other zoonoses and support healthy food systems.[51,63]

Appendix 3.A Conceptual Model of Social Networks and Health

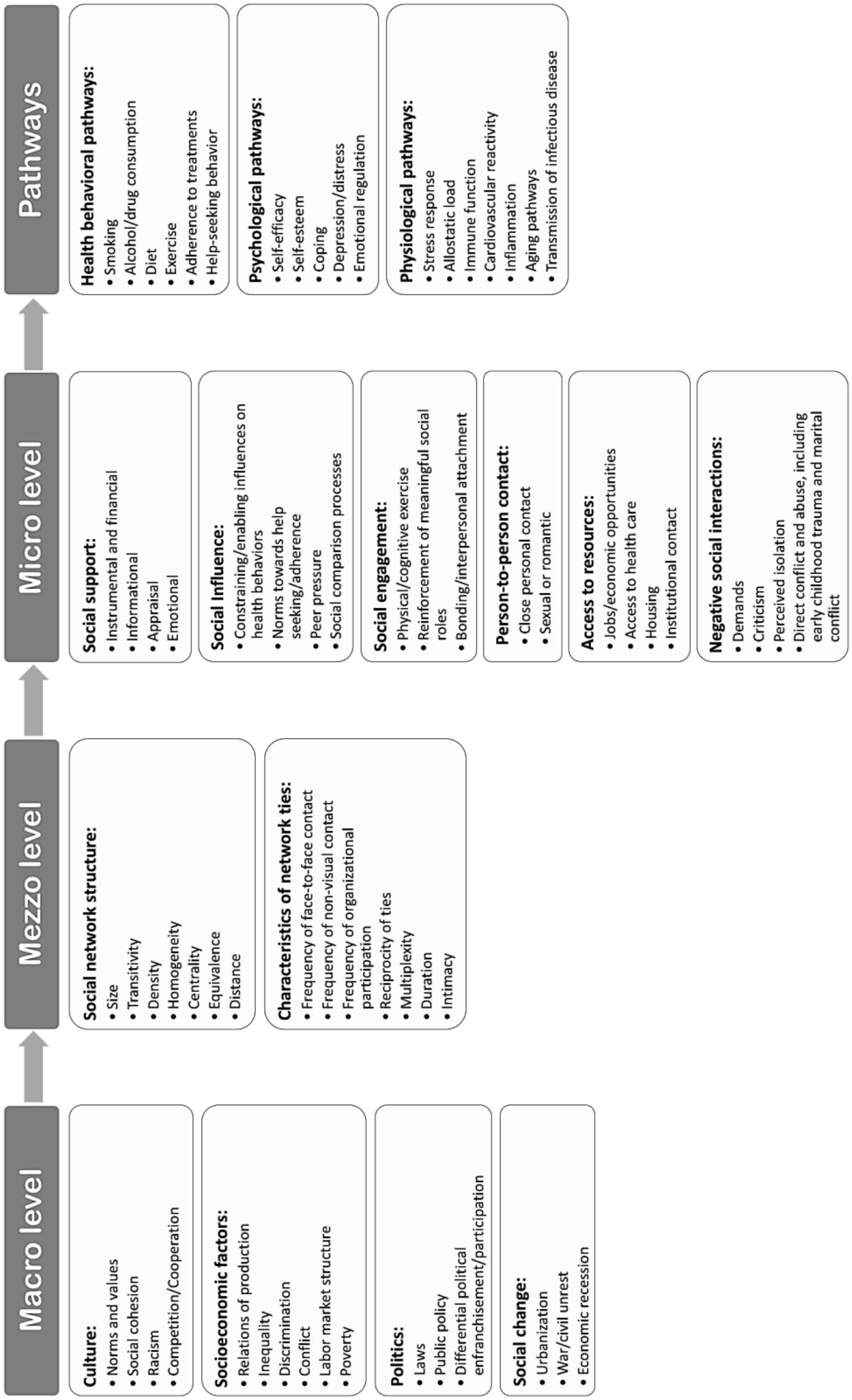


Figure 3.3 Berkman and Krishna (2014) Conceptual Model of Social Network Pathways to Health Outcomes[102]

Appendix 3.B Social network survey questions

Table 3.5 Social network survey questions and constructed variables for descriptive statistics and analysis

Question	Response options		Constructed variable(s)
1) In the last 4 months, who are the people you most trust to talk to receive support or share important or frequent information? List names of alters			Network size; stability over waves
2) What is your relationship with each person named:	Friend Neighbor Professor/teacher Religious leader/advisor	Health worker Leaders Store vendor Other (specify)	Network composition
For the first 5 people you mentioned, how often have you spoken in the last 4 months?	Every day 2 to 3 times a week Once a week	Every 15 days Once a month Less than once a month	Tie strength
For the first 5 people you mentioned, from whom you RECEIVE support or important or frequent information, please let us know: (Yes/No)	[Alter] has talked to [Ego] about… how people get sick from the pork tapeworm how people get sick with "trichina" in the brain how pigs get sick with "trichina" how to identify "trichina" in a live pig or pork meat how to notify or report when a pig comes out with "trichina"		Informational support received from alter re: transmission; detecting infection; reporting
	[Alter] has encouraged [Ego] to take some action… so that the pigs do not get sick of "trichina" to prevent the tapeworm in people		Emotional support received from alter re: human and pig infection prevention
For the first 5 people you mentioned, with whom you SHARE support or important or frequent information, please tell us: (Yes/No)	[Ego] has talked with [Alter] about… how people get sick from the pork tapeworm how people get sick with "trichina" in the brain how pigs get sick with "trichina" how to identify "trichina" on a live pig or pork how to notify or report when a pig comes out with "trichina"		Informational support provided to alter re: transmission; detecting infection; reporting
	[Ego] has encouraged [Alter] to… carry out some action so that the pigs do not get sick of "trichina" take some action to prevent tapeworm in people		Emotional support provided to alter re: human and pig infection prevention

Chapter 4 Cysticercosis control in Northern Peru: Estimating the contribution of household social capital to collective efficacy.

4.1 Background

In Northern Peru and other LMICs worldwide, brain infection with the larval-stage *Taenia solium* parasite causes an estimated 30% of acquired epilepsy – an entirely preventable disease burden. The parasite is transmitted via a two-host cycle, in which pigs act as the intermediate host of larval-stage *T. solium* (figure 4.1).[13]

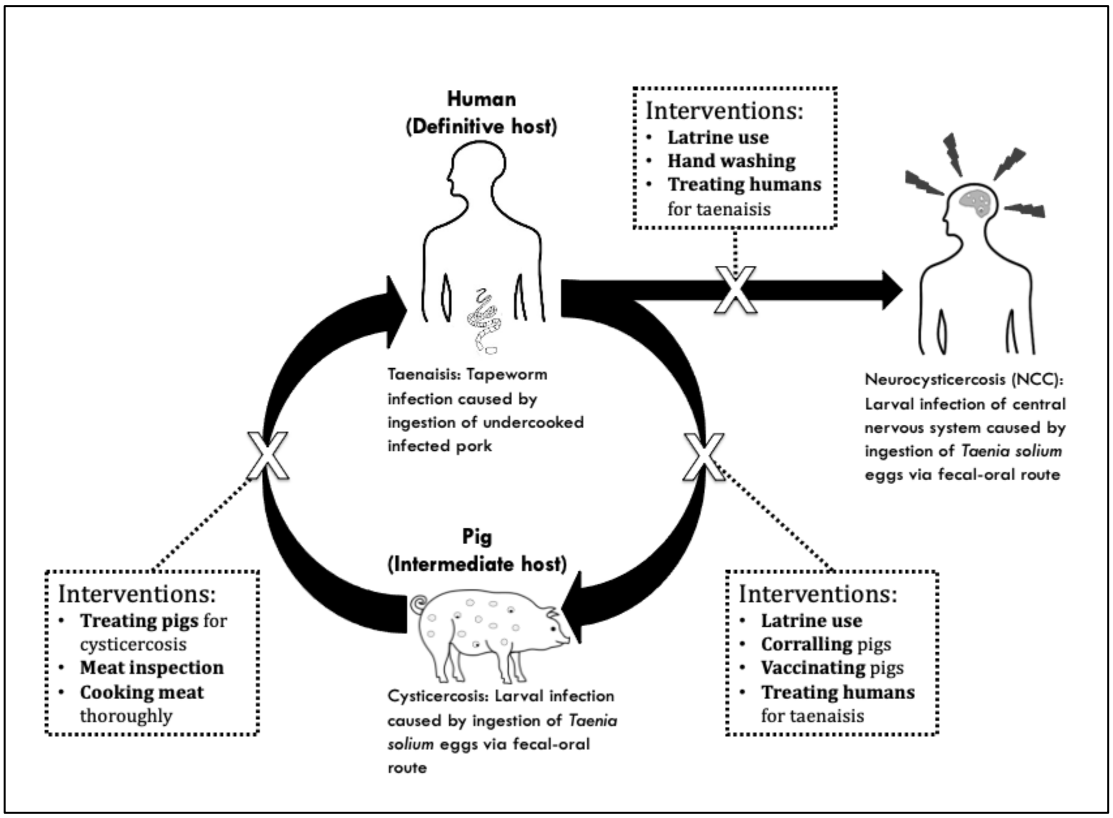


Figure 4.1 *Taenia solium* life cycle and points of intervention.

Humans with intestinal tapeworm infection (taenaisis) pass tapeworm eggs in feces which, if ingested via fecal-oral route, can develop into larval cysts in human or pig muscle tissue (cysticercosis), or in the central nervous system (neurocysticercosis), causing seizures and other neurologic complications. In addition to adverse health effects, *T. solium* infection causes substantial economic harms, both to farmers who lose income due to infected pigs, and to people living with neurocysticercosis who incur treatment costs and lost wages.[127–129] *T. solium* is endemic in Latin America, Asia and Africa, especially in rural areas where pig raising is common.[1,27] It is most common in LMICs, but is also found in higher-income countries, primarily among immigrants from endemic countries.[28–30] In Latin America, an estimated 400,000 – 1.5 million people are living with neurocysticercosis.[3] Sanitation development and pork production regulation would reduce infection risk in endemic communities, but large-scale systemic improvements are not likely to occur in the near future. In the meantime, communities can reduce risk by adopting protective behaviors, but many people remain unaware of how *T. solium* is transmitted and what can be done to lower their chance of infection.

The study reported here used data collected from household surveys during a pilot health education and community mobilization intervention conducted from 2016-2018 in seven villages in rural Northern Peru, where *T. solium* is endemic (Beam, manuscript in preparation). Within this context, we sought to understand how social capital, defined as trust and norms of reciprocity among members of a community, could be related to collective actions for *T. solium* control.

This study uses Lin's definition of social capital: *"resources embedded in social relations and social structure, which can be mobilized when an actor wishes to increase the likelihood of success in a purposive action"* (p. 24).[76] Social capital has a cognitive dimension, defined as trust, norms, and beliefs that influence the interactions among people in a society.[74] Social capital is a product of individuals and their interpersonal social ties (networks), which has the potential to enhance their collective problem-solving capabilities.[73]

Our conceptual model builds on Svendsen and Svendsen's presentation of the relationship between the trust component of social capital and collective action, to which we added collective efficacy as a probable precursor to collective action.[73] We define collective efficacy as the belief, among members of a group or community, that they can work together to solve problems or achieve a common goal (Figure 4.2).

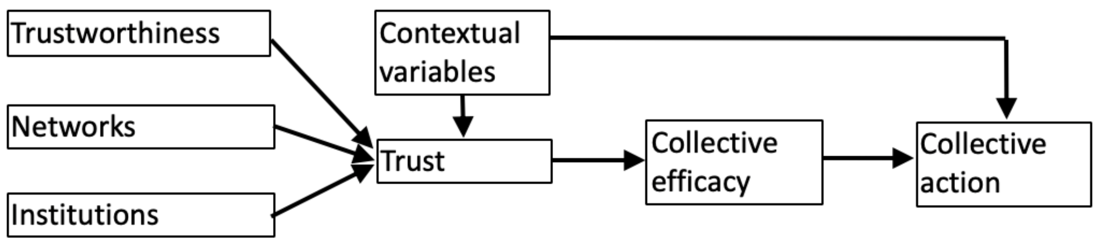


Figure 4.2 Relationship of social capital to collective action

There is reason to suspect social capital plays an important role in health promotion efforts within low-resource environments, where public health systems face lack of funding and infrastructure. In these environments, residents may need to depend on one another to build community infrastructure and support each other during times of crisis and in daily activities that contribute to community health. In this way, social capital is thought to compensate for comparatively lower levels of human resources or institutional support accessible to people in low-resource areas.[130–132] Social capital contributes to sense of community identity, and can be the foundation for access to information and tangible resources, such as interpersonal financial assistance.[133]

Social capital has also been defined according to its function.[134] "Bridging" social capital appears when there gaps or "holes" in the social network that allow an individual to become a bridge, connecting two previously unconnected others.[78] This study focused on "bonding" social capital, which consists of trust and reciprocal relationships between two or more members of a social network who are similar in terms of social identity and positions of power or authority.[135] Hanibuchi and Nakaya speculate that bonding social capital is more important for people living in rural areas compared to those living in urban areas, because urban dwellers can get goods and services in the marketplace, whereas they may be neither accessible or available to rural peoples.[84]

Although research addressing the role of social capital in LMICs has grown in the last two decades, the majority of research on social capital has been conducted in high-income countries. This study describes elements of social capital in a rural, low-resource area of Peru, and examines the relationship between social capital, collective efficacy, and collective action for *T. solium* prevention.

4.2 Materials and Methods

4.2.1 Study site

Participating villages were located in the Piura region of Northern Perú, an arid area near the Pacific coast and Perú-Ecuador border, where *T. solium* is endemic. Four of the villages had participated in previous cysticercosis education studies: two participated in primary school-based education activities in 2010-2011; those two along with two others participated in a study designed to promote screening and reporting of infected pigs in 2014-2015.[115] These four communities, along with three negative comparison communities, were the setting of a 2016-2018 community mobilization pilot intervention, alongside which this study of social capital was conducted. Results from the pilot intervention are reported elsewhere (Beam, manuscript in preparation).

Table 4.1 Characteristics of participating villages		
	N*	%
Number of villages	7	
Number of individuals	1665	
Female	809	49%
Age median in years	24	
<18	686	14%
18-49	610	37%
≥50	369	22%
Household characteristics		
Number of households	428	
Water source		
Piped	378	88%
River/stream	24	6%
Other	26	6%
Feces disposal		
Latrine	349	88%
Open field	66	15%
Bathroom/indoor	13	3%
Energy source		
Electricity	377	88%
Battery/motor	10	2%
None	41	10%
Pig owners	263	61%
Mean number of pigs per owner (SD)	3.9 (3.6)	
* Except where mean or median indicated.		

At the beginning of the study in November 2016, the study team conducted a community census. Pig farming was common, with over half of households (61%) raising pigs. The majority of households had outdoor latrines for feces disposal, but coverage varied among the villages: in five of the villages, more than 86% of households had a latrine, while the other two villages had latrine ownership rates of 68% and 31%. On average, 15% of the households reported regularly practicing outdoor defecation; however, in the village with the lowest latrine coverage, the rate of outdoor defecation was 50%. Additional community characteristics are included in Table 4.1.

4.2.2 Recruitment

We invited all heads-of-households to participate in knowledge, attitudes, and practices surveys every four months for the pilot intervention's 20-month duration (Nov. 2016 – Aug. 2018), and over 95% participated at baseline and 20-month follow-up. The survey items used in this study are described in detail later in this section. Social capital data was collected during first and final waves of the surveys (Nov. 2016 and August 2018), and we matched responses for individual heads-of-household to create a dataset of 336 participants who had been interviewed at both timepoints. There were no incentives given for survey participation.

4.2.3 Data collection

Survey data were collected via door-to-door in-person interviews using paper surveys. Peruvian study team members conducted the interviews in Spanish. Household visits were scheduled for early morning and late afternoon, to accommodate participants' schedules, which typically made them unavailable during mid-day. Surveys were typically conducted outside the front door of the participant's home. Although the interviews were most often conducted with only the study team and participants present, occasionally other members of the participant's household were present for the interviews. On average, each interview lasted 20-30 minutes. Data were double-entered into databases and checked for errors.

Social capital data collection:

Questions measuring social capital were modified from the World Bank's Social Capital Assessment Tool (SCAT) (Table 4.2).[136,137] Each item on the scale was coded with a numeric point score, and points were then summed to create a total social capital score for each participant. The total (continuous numeric) social capital score was our independent variable.

Table 4.2 Social capital survey questions

Question	Response options	Score
The neighbors in the community are reliable.	Strongly agree	1
	Agree	0.5
	Disagree	0
	Strongly disagree	0
If a community project does not benefit you directly, but has benefits for many other people in your town, what would you help with?	Time	1
	Money	1
	Both	2
	Nothing	0
In your opinion, do you trust leaders in your community?	Yes	1
	No	0
How would you rate the work of the municipality within this community?	Good	1
	Regular	0.5
	Bad	0
	Don't know	0
How would you rate the work of health personnel within this community?	Good	1
	Regular	0.5
	Bad	0
	Don't know	0
In this community, how often do neighbors help each other?	Always	1
	Sometimes	0.5
	Never	0

Dependent variable data collection:

Perceived community efficacy was assessed during the same survey administration described above and constructed with one question to which respondents could either agree or disagree (Table 4.3). For community action, we asked respondents if there had been any actions taken in the community to avoid pork tapeworm infection in the past 30 days. If the respondent answered yes, they were asked to describe the community actions with a text response, which we could classify into types of prevention and control behaviors.

Table 4.3 Community efficacy and community action survey items

Outcome	Survey question
Community efficacy	In your opinion, can this community avoid "trichina" and tapeworm on its own?
Collective action	In this community, in the last 30 days, has any action been taken to avoid "trichina?" If yes: What was done?

4.2.4 Analysis

We created a dataset of individual heads-of-households who participated in both waves of data collection. We calculated descriptive statistics for all variables in our model and tested the differences in social capital between comparison groups and from baseline to follow-up using independent sample and paired t-tests, respectively, with a significance p-value of 0.05. We used binomial regression with a logit link to estimate the odds of perceived community efficacy and the odds of recent community action to control *T. solium* as a function of the participant's social capital score. The binomial regression models were adjusted for likely covariates including age (in years), sex (dichotomous male / female), education (in years), inclusion in the pilot intervention communities, and pig ownership. Model coefficients were exponentiated to yield odds ratios (OR) and 95% confidence intervals (95% CI). We conducted all analyses with Stata 16 statistical analysis software (Stata Corporation, College Station, Texas, USA).

4.3 Results

There were 336 individual heads-of-households who participated in both baseline and 20-month follow-up data collection points. The majority (64%) were female, and the median age was 48 (range 18 to >89) (Table 4.4). Slightly more than half of the participants were pig farmers, raising an average of 3.7 pigs per farmer.

Table 4.4 Participant characteristics

	All		Pilot		Comparison	
	N	%	N	%	N	%
Number of individual heads-of-households	336		193		143	
Household characteristics						
Mean number of household residents (SD)	2.76 (1.8)		2.28 (1.95)		3.42 (1.30)	
Pig farmers	182	54.2%	96	49.7%	86	60.1%
Mean number of pigs per farmer (SD)	3.7 (3.5)		5.72 (7.76)		3.41 (3.31)	
Total number of pigs	843		549		294	
Pigs corralled	320	38%	232	42.3%	88	29.9%
Pigs tied up	186	22.1%	108	19.7%	78	26.5%
Pigs roaming freely	351	41.6%	223	40.6%	128	43.5%
Corral present (all households)	121	36.1%	76	39.4%	45	31.5%
Participant characteristics						
Female	216	64.3%	126	65.3%	90	62.9%
Age median in years [range 18 - >89] (SD)	48 (16.5)		48 (16.5)		49 (16.6)	
Years of education mean (SD)	6.0 (4.0)		6.82 (3.95)		4.97 (3.69)	
Education Level						
None	32	10.4%	11	5.7%	24	16.8%
≤ Primary completion	212	63.1%	117	60.6%	95	66.4%
Some secondary to secondary completion	74	22.0%	53	27.5%	21	14.7%
Some post-secondary education to college completion	15	4.5%	12	6.2%	3	2.1%

Social capital and community efficacy

Average social capital and self-efficacy scores, and the changes in scores from baseline to follow-up, are shown below (Table 4.5).

Table 4.5 Social capital and collective efficacy scores

Metric	**All (n=336)**	**Pilot (n=193)**	**Comparison (n=143)**
SC baseline	3.78	3.65	3.97
SC month 20	3.68	3.70	3.65
Mean change	-0.1	0.05	-0.32
Efficacy baseline	33.04%	37.31%	27.27%
Efficacy month 20	44.64%	53.89%	32.17%
Mean change	11.6	16.58	4.9

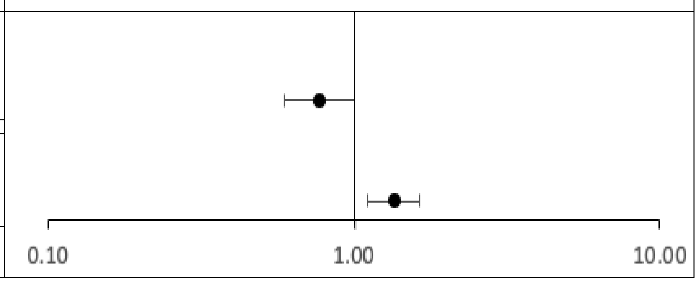
Participants from intervention communities had a lower average social capital score at baseline (3.65, range 0-6.5, SD 1.31) compared with participants from the comparison communities (3.97, range 1-7, SD 1.12). At 20-month follow up, the intervention and comparison residing participants had similar social capital scores (3.70, SD 1.24; and 3.65, SD 1.27, respectively). A two-sample t-test found a statistically-significant difference in the social capital changes comparing the pilot intervention and non-intervention communities from baseline to follow-up (p=0.02).

Average social capital scores for all participants were 3.78 (range 0-7, SD 1.24) at baseline and 3.68 (range 0.5-7, SD 1.25) at follow up. In unadjusted binomial regression analyses conducted using baseline data, the estimated odds of perceived community efficacy as a function of social capital were indistinguishable from null (OR 0.95, 95% CI 0.79, 1.14). In models adjusted for continuous age (OR 1.00, 95% CI 0.80, 1.16) continuous years of education (OR 1.03, 95% CI 0.95, 1.11), dichotomous pig ownership

(OR 0.75, 95% CI 0.47, 1.19), and dichotomous residence in an intervention community (OR 1.45, 95% CI 0.87, 2.41), the effect estimates for social capital on community efficacy at baseline remained indistinguishable from null (OR 0.96, 95% CI 0.80, 1.16). At 20-month follow-up in unadjusted models, higher social capital score was associated with an increased odds of perceived community efficacy (OR 1.37, 95% CI 1.14, 1.64); inclusion of covariates did not change the effect estimates or 95% CIs at the 20-month time point (OR 1.35, 95% CI 1.12, 1.63). We then tested inclusion in the pilot intervention as a mediator of the relationship between social capital and community efficacy at 20-month follow-up and we found no significant interaction effects (p = 0.19).

Table 4.6 Odds Ratio for perceived community efficacy for *T. solium* control, Adjusted for sex, age, education, pig ownership, and pilot study inclusion

n=336	OR (95% CI)	Log odds, 95% CI
Baseline	0.77 (0.59, 1.00)	
Month 20	1.35 (1.11, 1.63)	



Community action

At baseline, participants in the pilot intervention communities reported a high level of community action within the last 30 days (39.4%) compared to the non-pilot communities (2%). Upon inspection of the open-text comments used to describe the actions taken in the intervention communities, however, it was clear that some participants in the pilot communities were reporting actions taken by the research team, such as taking blood samples from pigs to check for *T. solium* antibodies, rather than actions taken by community members. Comments from the comparison communities were focused on avoiding, or disposing of, contaminated pork. At follow-up, nearly a quarter of the intervention community participants (23.3%) reported recent community actions; they most frequently described the recent distribution of promotional materials by the study team to motivate reports of pig infections. Comparison community participants (8.3%) mostly described the study team's medication administration to treat humans for *T. solium* following the report of a local pig infection.[1,56] The reports of community actions at follow-up could be viewed as community-driven or research-team driven, depending on the interpretation of the participant and the specifics of the action (e.g., promotional materials in the pilot study were often co-designed by community members and study research team members, making it difficult to separate community actions from the research team's activities). Therefore, the question soliciting actions taken by community members was not effective at clearly identifying non-study personnel actions, and for this reason we did not include community action as an outcome in our final analyses.

4.4 Discussion

The components that made up our measure of social capital – trust, working together, and reciprocity – are useful when communities need to self-organize, or work together with institutions and formally-organized programs, to address a common need or problem.[138] In communities with low social capital, community organizing activities for *T. solium* control may face greater barriers to participation compared to those with high social capital.

We also observed an increase in both social capital and community efficacy for the pilot intervention participants; yet when we controlled for the estimated effects of the pilot in our models, social capital remained statistically significantly associated with increased odds of community efficacy at follow-up. This suggests that community mobilization activities of the pilot intervention may not have been the sole drivers of increased community efficacy, although the mechanisms of that relationship are not observable with our study design.

Researchers in Bolivia found that social capital, in the form of participation in formal group activities, in a healthy village intervention was associated with higher levels of self-efficacy, compared to negative controls.[139] A study using nationally-representative data in Colombia found that, for rural populations, cognitive social capital was associated with higher odds of better health, but the interpersonal trust and reciprocity dimensions of social capital were not associated with better or worse health.[140] We measured cognitive social capital, which included items rating trust levels among neighbors, and found it positively associated with perceived community efficacy in our second round of data collection, but not at baseline. As Shiell and colleagues concluded, in their summary of 28 systematic reviews linking social capital to health, the health effects of social capital are likely dependent on context, and more specificity is needed when conceptualizing and measuring the components of social capital.[141]

4.4.1 Limitations

This study attempted to measure social capital as a contributor to collective efficacy for *T. solium* control. We were challenged by the limitations of our study design, which included a relatively small number of questions in our social capital assessment, and our inability to estimate the effect of social capital on community actions.

One of the most fundamental limitations was the design of our question regarding community action. Participants understandably reported on the highly visible activities of the study team in the pilot intervention communities. Constructing our questions differently, and making a distinction between research team-led activities and community-generated control actions, would have helped us better understand what actions community members were motivated to take independently. However, in small, rural communities, such as those in which this study was conducted, research teams are conspicuous. In addition, the nature of the pilot intervention, which involved working with community members for mobilizing control activities, made it difficult to decouple pilot intervention activities from those being driven by community members independently. Additional research is needed to explore the relationship between pilot study activities and community actions. Besides rephrasing the community action question, our surveys could have been conducted prior all other study activities to guard against the study team's activities being reported as baseline community actions.

Prior work in the pilot intervention communities may have been the reason for their higher community efficacy at baseline, even though social capital scores for these communities were lower than the scores for participants in the comparison communities. This limitation could have been avoided by conducting the study in naïve communities, but a fundamental component of community-based research is long-standing commitment to working with communities, which is the context within which the study exists.[142] The difference between the pilot intervention and comparison communities' baseline social capital scores could also be attributable to unobserved factors, such as municipal programs or community resources and services (Spencer, manuscript in preparation).

Our measure of social capital also had limitations. Because our set of social capital questions were embedded in a larger community survey, we included only a small subset of social capital questions that focused on the cognitive dimensions of social capital.[74] We could have better measured social capital using a validated tool that includes other dimensions of social capital, such as bridging connections between people from different social groups and participation in formally-organized and informally-organized groups and civic institutions.[138]

4.4.2 Strengths

This study included data collection at baseline and 20-month follow-up, which allowed us to understand the stability of social capital in the participating communities. Because of this design, we were able to observe that social capital was relatively stable within the participating communities. Trust and sense of community take time to develop, and are not likely to be changed quickly, even when outside forces are introduced.

Another strength of our study was the inclusion of open-ended text responses to be able to understand the types of control actions people were reporting. Collecting these data allowed us to recognize that study activities, led by the research team were among the actions being reported, and prevented us from making false conclusions about the role of social capital in relation to collective action in the participating communities. The design of the pilot study included community mobilization that may be reflected in the participants' descriptions of community actions at follow-up, therefore additional research is needed to cross-reference the pilot study's activities in the intervention communities with the actions reported by participants.

4.5 Conclusion

Social capital is an element of community life that is theorized to be an important contributor to individual and community health. In low resource settings, social capital may play a larger role in community health than in high resource settings. Likewise, social capital may be more influential in rural communities compared to urban communities. The links between social capital and health could justify developing interventions that build social capital in low resource settings, but social capital should not be a substitute for municipal investments, infrastructure development, and infusion of resources.

Before developing any interventions that seek to create or leverage social capital, it is important to be clear about what is being measured, as well as the theory of change that would support the intervention's success. In this study, we were unable to draw actionable conclusions about the relationship between social capital and community actions for *T. solium* control. Future studies exploring the role of social capital in similar situations or settings would benefit from using participatory methods to include community members in developing locally-relevant definitions of social capital and measurement tools.

Chapter 5 Barriers and facilitators for community-based cysticercosis control in rural Northern Peru

5.1 Background

Taenia solium, commonly known as pork tapeworm, is the causal agent for an estimated 30% of acquired epilepsy worldwide.[143] The parasite is transmitted via a two-host cycle, in which pigs act as the intermediate host of larval-stage *T. solium* (figure 5.1).[13]

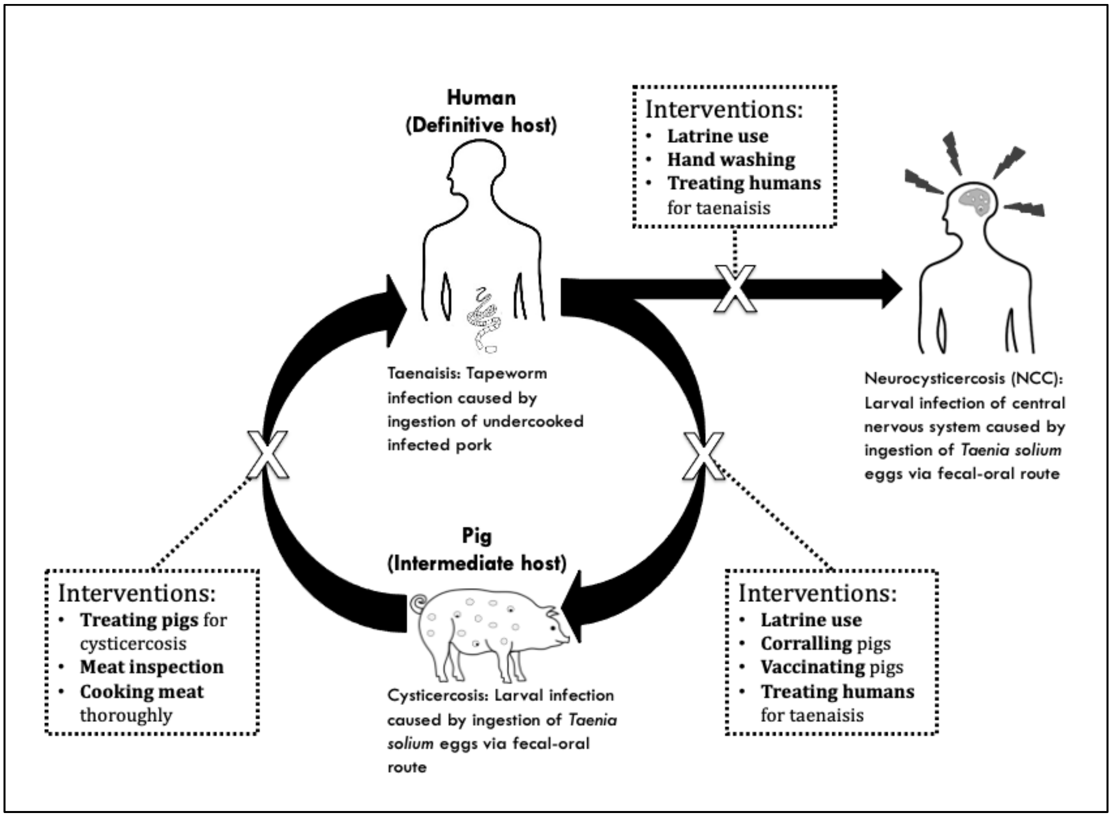


Figure 5.1 *Taenia solium* life cycle and points of intervention

Human intestinal tapeworm infection is called taenaisis. Humans with taenaisis can pass microscopic tapeworm eggs in their feces which, if ingested via fecal-oral route, can develop into larval cysts in human or pig muscle tissue (cysticercosis), or in the central nervous system (neurocysticercosis), causing seizures and other neurologic complications. In addition to adverse health effects, *T. solium* infection causes substantial economic harms, both to farmers who lose income due to infected pigs, and to people living with neurocysticercosis who incur treatment costs and lost wages.[127–129] *T. solium* is endemic in Latin America, Asia and Africa, especially in rural areas where pig raising is common.[1,27] It is most common in LMICs, but is also found in higher-income countries, primarily among immigrants from endemic countries.[28–30] In Latin America, an estimated 400,000 – 1.5 million people are living with neurocysticercosis.[3]

A recent review of *T. solium* control strategies found that health education programs and tools that are developed with community input and engagement may contribute to effective control programs, especially when combined with investment in sanitation, and treatment of infected humans and pigs.[144] Qualitative studies have informed intervention designs by revealing how gender roles, pork consumption customs, hygiene and sanitation norms, stigma associated with pig infection, and trust within communities may affect prevention and control behaviors.[59,63–67]

Within a larger study to optimize a focal control intervention in Perú,[56] we conducted a pilot study from 2016-2018 to develop methods for a combined health education and community organizing intervention to support community-based *T. solium* surveillance and control (Beam, manuscript in preparation). We held workshops in four participating villages to teach participants about *T. solium* transmission and its effects, using local physical, economic, and epidemiologic evidence.[124] We then organized a series of focus groups, and monthly “work groups” to discuss different methods and ideas for community-based *T. solium* control activities, and to develop locally-acceptable interventions. The objective of the research presented in this manuscript was to understand community resources, barriers, and facilitators for community-based *T. solium* surveillance and control, using data collected from focus groups conducted in the pilot study.

5.2 Methods

5.2.1 Study design

This study used thematic analysis to classify text segments from focus group transcripts into quotations representing barriers and facilitators for community-based *T. solium* control.

5.2.2 Study site

Participating villages were located in the Piura region of Northern Perú, an arid area near the Pacific coast and Perú-Ecuador border, where *T. solium* is endemic. The total population of the four villages was 838 people, living in 235 households. Small-scale pig raising is common, with 62% of households owning pigs, and an average 3.8 pigs per pig-owning household. While the majority of households (73%) reported having a latrine, coverage varied among the villages: in two of the villages, >90% of households reported having latrines, while 68% and 49% of households in the other two villages reported having latrines. Open defecation followed an inverse pattern, with 1% and 10% of households in the two villages with the highest latrine coverage reporting open defecation, and 32% and 50% of the others regularly practicing open defecation.

All of the villages had participated in previous cysticercosis education studies: two participated in primary school-based education activities in 2010-2011, and all four participated in a study designed to promote screening and reporting of infected pigs in 2014-2015. In the latter study, an increase in reports of pig infections was observed, compared to villages in a comparison group, but there was no difference in prevalence of human taenaisis or porcine cysticercosis at the end of the study.[62]

At the beginning of the health education and community organizing pilot study (November 2016), we asked 226 heads-of-households three open-ended questions about the *T. solium* transmission cycle.[124] We then classified the answers according to their accuracy in describing the transmission cycle. Fewer than half of the participants (38%) were able to explain the dynamics of human-to-pig transmission and 13% accurately described pig-to-human transmission. Only 4% had a correct understanding of human-to-human transmission, the causal path for neurocysticercosis. Shortly after the baseline survey, we conducted participatory education and evidence workshops in each of the participating villages, which resulted in significant improvement in workshop attendees' knowledge of the transmission cycle, but in 4-month follow up surveys post-workshop, a minority of heads-of-households accurately described the complete transmission cycle.[124] The focus groups described here were conducted between 3-12 days after the community workshops. Staff from the University Peruana Cayetano Heredia's Center for Global Health (CGH), located in Tumbes, Perú, carried out all field activities and facilitated the focus groups for this study.

5.2.3 Recruitment and participants

During the pilot study's baseline household surveys (November 2016), we asked participants a series of questions about which people or groups were considered community leaders and/or change agents (Appendix 5.A). The study team generated a list of nominated individuals to invite to focus group discussions to inform the design of community-based surveillance programs. We conducted eight focus groups, with a total of 54 participants. The groups ranged in size from 5-10 participants, with a median size of 7. Participant ages ranged from 29-72 years. Most of the participants (63%) owned pigs, with an average of 5.4 pigs per household (range 1-30). Owing to the social norms, we conducted separate focus groups with men and women in each village. In the men's group, most participants were agricultural workers, but each men's group also included community leaders, such as the village's lieutenant governor and presidents of local agricultural cooperatives or volunteer community security patrols. In the women's groups, the majority of participants managed households; attendees also were educators, merchants, and leaders of local organizations.

5.2.4 Data collection

We conducted all focus groups in February 2017. The focus groups were scheduled for late afternoon to accommodate participants' schedules and were held in central locations, primarily in community multipurpose rooms, except for in one village, where the groups were held in a local school's classroom. Sex-concordant staff from the Center for Global Health, trained in facilitation and group observation, conducted the sex-specific focus groups. For each group, one team member facilitated the group discussion, while the other recorded observations, including the seating arrangements and the general disposition of participants. Each group was audio-recorded and lasted between 90-120 minutes. The focus group guide asked questions about the local economic situation, the advantages and disadvantages of raising pigs, the role of the municipality, and the community's formal and informal strengths (Appendix 5.B).

5.2.5 Analysis

Focus groups were transcribed in Spanish by a professional transcriptionist and transcripts were reviewed for accuracy by one of the facilitators. Transcripts were then analyzed using ATLAS.ti (versions 8 and 9, ATLAS.ti Scientific Software Development GmbH). The analysis team consisted of the principal investigator (for whom English is a first and Spanish is a second language) and three research assistants (two first language Peruvian Spanish speakers, and one bilingual first language Spanish and English speaker).

Our research goal was to describe barriers and facilitators that may affect community-based cysticercosis surveillance and control activities**.** We used thematic analysis to identify themes and concepts in the transcripts,[145] specifically community- and individual-level barriers and facilitators that may influence the implementation of community-based programs to control *T. solium*. We also noted contextual factors, which we defined as neither barriers nor facilitators, but as elements of the environmental and societal systems within which the participating communities are nested. The principal investigator created the initial set of 25 codes, based on the focus group interview guide. From the initial codebook, the principal investigator and another coder analyzed three transcripts using a combined deductive and inductive approach, where notable quotations were flagged, discussed, and used to develop version 2 of the codebook, which contained 54 codes. Codebook version 2 was used to analyze all transcripts, after which the study team compared coding and reviewed memos to develop the third and final version of the codebook, with 68 codes, in 8 groups, including groups of barriers and facilitators. The transcripts were then recoded using the final codebook.

5.2.6 Ethics statement

The original study protocols were approved by the Comité Ética at Universidad Peruana Cayetano Heredia and the Institutional Review Board at Oregon Health & Science University. The secondary analysis of focus group data described in this paper was approved by the Institutional Review Board at Portland State University. Participants reviewed an information sheet describing the purpose, risks, and benefits of participating in the focus groups, and subsequently provided written informed consent to participate. Participant names were removed from the transcripts prior to analysis.

5.3 Results

Results are presented with contextual factors described first, followed by community-level barriers and facilitators, then individual-level barriers and facilitators, with quotes selected to illustrate the most salient themes. Unless otherwise specified, the themes presented here were reported in all groups (Table 5.1).

A note about language: In Northern Perú, the common term used to refer to cysticercosis and neurocysticercosis is "*triquina*." Even though this term typically describes trichinosis, another parasitic disease, the term is understood widely in the participating communities to refer to pork tapeworm larval cyst infection, and will therefore be reported in the manner consistent with community usage.

5.3.1 Contextual factors

Contextual factors are defined as neither barriers nor facilitators, but rather circumstances within which peoples' lives are lived. Contextual factors exist beyond the community level, and extend to the regional or national levels. These factors are likely to structure choices people and communities make related to pig raising.

Table 5.1 Presence of themes among groups

Theme	N groups with theme present (%)
Contextual factors	
Economy	8 (100%)
The role of pork in nutrition	8 (100%)
Natural resources	8 (100%)
Community-level Barriers	
Inadequate infrastructure	7 (86%)
Gaps in community resources	8 (100%)
Community-level Facilitators	
Municipal investments	8 (100%)
Community organizations	8 (100%)
Relationships among community members	8 (100%)
Individual-level Barriers	
Low risk perception	8 (100%)
Misconceptions of transmission cycle	7 (86%)
Unawareness of health effects	6 (75%)
Low interest in the topic of T. solium	6 (75%)
Benefits of free-range pigs	6 (75%)
Pig-raising practice norms	8 (100%)
Individual-level Facilitators	
Risk awareness	8 (100%)
Knowledge of transmission cycle	8 (100%)
Financial incentives for clean pork	8 (100%)
Personal experience with NCC	6 (75%)
Personal experience with infected pigs	8 (100%)

Contextual factor: Economics

T. solium is endemic mainly in low-income regions, where many people do not have a steady income and instead rely on seasonal work and agricultural activities for their livelihood. This precarious economic situation motivates people to raise pigs for income and sustenance. "Nobody here… 100% do not have a… safe job… that you are going to get paid monthly. Here we are temporary, here we wait, sow the corn, sow the rice, to find money, raise the pig, sell the pig, raise your cow to have a baby, sell your cow."

Many agricultural workers do not own the land on which they work. Instead, they rent space from land owners to plant their crops. "The people do not have land to cultivate, there are few who have their farms, which the river washed away years ago ... Then came the shortage, because people have nowhere to go to work… We rent."

The overall economic situation makes raising pigs for both income and nutrition an appealing enterprise. Keeping pigs in a corral, with no access to human feces, is an important element in controlling *T. solium* transmission, but it requires investment of money, labor, and time to build and maintain a corral, and to feed pigs. If a pig can roam free, gain weight, and not be infected with cysticercosis, the pig's owner can make a profit and/or can feed themselves and others when the pig is sold. If the pig is infected, the owner loses money. Specific barriers and facilitators related to confining pigs, verses allowing them to roam free, are described in subsequent sections.

Contextual factor: The role of pork for nutrition and sustenance

Pigs play an important role in the economy and in peoples' lives as a source of food and materials. According to a recent market analysis, 76% of the estimated 600,000 pork farmers in Peru are raising pork for self-consumption or rural local trade.[146] In addition to daily diet, pork is often served on holidays or special occasions:

> "When we raise a pig, we make it fat and… we sentence it from the moment we started feeding it, we are going to eat this by October… My children are going to come. I already invited them, such a date, they come, we are going to eat the pig. And it would be so painful if they arrive and [we have to] sacrifice the pig because it is triquinous."

Post-slaughter, very little of the animal's parts go unused: "The pig is the animal that gives us the most benefit, because we do not waste not only it's hide, everything is used… their skins, their legs, everything is used by the person who raises it."

Contextual factor: Natural resources

The climate of the participating villages cycles between rainy and dry seasons. During the rainy season, there is plentiful natural forage for animals, but flooding may also occur, which negatively affects the animals' health. Nevertheless, people consistently viewed the natural environment as one of the best things about their home villages, citing fresh air and room for animals as important features. "The population here benefits from the rain, because there are people who don't have their land with water [for irrigation]. They wait for the rain to plant a plant… And for them it is beautiful, it is a blessing. It rains so that in that way there can be crops, fruits."

The natural cycles of rainy and dry seasons, along with the rural locations of the participating villages, results in a set of conditions that may encourage people to allow their pigs to forage for food. There is plenty of range for the pigs to roam throughout the year, and plenty of sustenance for the pigs during the rainy season.

5.3.2 Community-level barriers and facilitators

Barrier: Inadequate infrastructure

Most homes are not connected to sewage systems, and 22% of households in the study communities do not have a latrine or bathroom. This makes it difficult for people to follow *T. solium* prevention guidelines, including eliminating outdoor defecation and practicing consistent hand-washing. “It was [once] said that there would be sanitation, sewerage, but they say that because of the distance, according to the engineer, the sanitation cannot come out [to our village].”

Several participants viewed local government resources as undependable or unreliable. The level of investment in infrastructure varied among the 4 villages.

> “[The municipality] have made [other villages] very nice multipurpose rooms, but we have always had the very bad luck that they have never supported us with anything in [our village]… We are forgotten, always forgotten for a long time, I don't know why the authorities don't really do anything.”

Facilitator: Municipal investments

While some participants stated their communities had been left behind, or could not rely on the municipality to provide resources or make development improvements (see above), others described public investments or campaigns dedicated to developing infrastructure.

> “There have been leaders from here, and they have gone to the municipality. The municipality always comes… to meetings… and they

> give you ideas of what you need in your locality… for example, one of the benefits is that we made drinking water, we managed to get the services in [our community] 100%."

In addition to larger scale community investments, participants described occasions where the municipality provided basic supplies to families or individuals in need: "Sometimes [workers from the municipality] come to visit the houses where they are most in need, they give them corrugated iron, a bag of cement, sometimes plywood."

Facilitator: Community organizations

Every participating community had formal and informal groups or organizations whose purposes are to respond to residents' needs and improve daily life. Each of the villages had public spaces to gather, such as a community multipurpose room or school classroom. It is common to hold community meetings to discuss problems or issues of concern.

One of the most prominent organizations is the Ronda Campesina (literally translated as "peasant patrol"), commonly referred to as the Ronda. The Ronda is a civilian patrol unit, made up of local resident men. Often, it is the responsibility of the Ronda to address disagreements, petty crimes, and enforce social norms. "Any problem comes to us in the village, we have the Ronda… and we meet to solve those problems… Unless it is a serious case… Which is taken to the [appropriate] authority."

Other community organizations support the community's health and wellbeing in various ways, including through nutrition programs, children's development, and elder supports. Those organizations help to establish a sense of community and mutual aid.

Participants frequently mentioned organizations that provide supports to families with school-age children.

Community members also self-organize around projects that will benefit the community:

> "There are classes in [rural] society, for example, there is a class of breeding, agriculture, sectors ... [For example, in the agriculture sector], between 2, 3, 4, 5 farmers come together, and they consider that they have a need, for example, to improve an [irrigation] ditch, they make the request at the initiative of the residents of a certain sector... And many of the times it does not necessarily go through the assembly, the assembly occurs when it is a case of greater magnitude, for example, fixing this communal premises… [For larger projects], there is the general assembly. But if… farmers want, for example, a drinking fountain, a corral, we do that individually, via association, or finally we form a group and make a document and present it [to the local sector leaders]."

Facilitator: Relationships

Community members frequently help one another in times of need. While there are organizations that can provide material support in times of illness or financial crisis, neighbors also step in to organize aid to those in need:

> "Here it is customary, sometimes when a neighbor gets sick we make him a 'parrillada,' that is, a [fundraiser] is organized and we go out to sell there, and then they gather a thousand soles [Peruvian currency], whatever is left... And it's something common that we do here in our village and it's a way for me to solve the neighbor's problem, help him financially."

5.3.3 Individual-level barriers and facilitators

One of the most important elements of controlling *T. solium* transmission is preventing pigs from consuming human feces, which puts them at risk of ingesting *T. solium* eggs and becoming infected with cysticercosis. This can be accomplished by corralling pigs and eliminating human outdoor defecation. To prevent human taenaisis, the most important control actions are to avoid eating cyst-contaminated pork whereas to prevent human neurocysticercosis, the most important control actions are handwashing and treatment for taenaisis.

Even though many effective control strategies are relatively straightforward, there are multiple barriers to their uptake, including inaccurate understanding about the risks and mechanisms of transmission, lack of latrine access and sewage systems, and longstanding norms related to pig raising and outdoor defecation.

Barrier: Low risk perception

The prevalence of taenaisis is estimated at 1-3% in Latin American countries.[32–36,38] The prevalence of neurocysticercosis is difficult to estimate, due to lack of easily accessible diagnostics, but is estimated to affect 0.6 - 1.8% of the population in endemic areas.[57] Because both of these conditions can be asymptomatic, many people do not realize they are infected. A recent study in one small rural village in Northern Perú found that 19% of adult residents in a region with high *T. solium* endemicity had brain calcifications, but the majority were asymptomatic.[42] With other infectious diseases like dengue fever, Zika virus, influenza, and SARS-CoV-2 taking a much higher public profile, *T. solium* is not generally considered a major health concern. The relatively low prevalence, as well as the length of time that can pass between initial brain infection and symptoms of neurocysticercosis may contribute to the low risk perception described by participants. When discussing the perceived risk of human infection, one woman commented, “Since it doesn't happen to us, we don't mention it. [Pork with cysts have] been eaten long before and nobody has died with that.”

Likewise, many people do not view their pigs as susceptible to infection: “In winter time, my pigs go to the field, but they have not [been infected with cysts]. But my dad’s [pigs] had triquina. It may be that they get sick because they eat anything out there ... But not me, I have not gotten triquinous pigs.”

Low risk perception was a prominent theme in all of the focus groups. As to why this low risk perception exists, one participant reflected:

> “Perhaps because they do not give us… symptoms quickly…. That is, they catch us in the long term… the older people, they have always eaten [pork with cysts], and there have always been loose pigs, and the ones that come out [infected] will be rare, and well, since we don't have that knowledge that the triquina is something terribly serious… that's why we don’t think it is very important.”

Barrier: Misconceptions about the T. solium transmission cycle

In our focus groups, conducted shortly after the community evidence-sharing workshops, community members elaborated on the ways they and their neighbors may have misunderstood *T. solium* transmission. “Before we knew how we infect the pig with triquina, all of us, even I thought it was [the pig’s] breed, actually.”

The quotation above reflects a belief held by many that porcine cysticercosis is a hereditary condition in pigs, or a condition more common in certain breeds of pigs. In our baseline surveys, when asked the primary reason pigs become infected with *T. solium* cysts, 36 of 226 (16%) heads-of-households said the pig’s breed was the reason (unpublished data).

Barrier: Lack of knowledge about health effects of transmission

In addition to not understanding the full transmission cycle, many people are unaware of the human health consequences of *T. solium* infection. "The problem is that… children, young people, adults, who live here, do not give importance to this triquina, this disease… perhaps because we do not have the knowledge of how it affects us, what this disease is."

Barrier: T. solium not prioritized as a health problem

Perhaps related to low-levels of risk perception, participants noted that many of their fellow community members are not able or willing to attend health education talks or programs. They described previous efforts on the part of health educators to teach prevention practices, but expressed frustrations that long-term changes in behaviors did not seem widely adopted.

> "We have been doing that for years, which we never put into practice… It's not that they never told us anything, we always do or if we invite the people, we have always done trainings here with the health center, how many of us arrived? 3, the rest none from around here. The lady, the agents, doctors, came… and they give the talks and the talks are good. The main one is the hand washing that they do, but we never put it into practice, and then we say: they never told us anything. It is not like that they never tell us anything. The problem is that we do not put it into practice, we do not listen to it, we do not take interest in it, and that is the health problem we have, we infect our family, our children, we get sick."

Barrier: Advantages of free roaming pigs (and disadvantages of corrals)

There are few incentives for people to keep their pigs corralled at all times. The rural nature of the villages, plentiful forage (especially in the rainy season), combined with the expense of corral building, maintenance, and pig feed, creates a strong incentive to allow pigs to roam free and forage, at least part of the time.

> "We take [the pig] out to the country, I say that this pig is healthier. In winter, they go to the country, they live there. And around the country they are healthier than around here walking around town… In the winter, the corral gets ugly. It is difficult for [people] to lock their pigs in the corral, because the pig in the corral needs maintenance."

Barrier: Longstanding norms related to pig-raising

Longstanding norms for pig-raising, including allowing pigs to forage freely for food, present barriers to controlling *T. solium* transmission. Generations of families have raised pigs and passed on traditions for how to care for their animals. Similarly, people have been eating contaminated pork for generations, and employed preparation methods to attempt to kill cysts prior to consumption:

> "My parents say that they used to eat triquinous pigs earlier, and nothing happened to them, that is, people fried them… they added a lot of salt and with that [the cysts] fell off and that's it… and they did not get sick. You hear [people discussing the risk of brain infection] now, and they say that you did not hear that before... Why is that? This disease did not exist earlier or what?"

Facilitator: Risk awareness and concern

Concerns about the risks of *T. solium* infection and fear of the consequences, such as epilepsy or economic loss, can be a powerful motivator to act in order to mitigate these risks. Many of these concerns were heightened after the educational workshops held in the communities prior to the focus groups, where participants were able to view larval cysts from contaminated pork under the microscope, and see the living parasites become mobile in a bile solution.[124]

> "It is a very sad disease, because of the way [people with neurocysticercosis] convulse, lose consciousness and for that reason, we [are afraid]... Previously, here… in the community it has not occurred until now, I have not heard [of people with neurocysticercosis]... But pigs with triquina? Yes, there have been quite a few, and the people here have consumed it, when they had no knowledge. We had no knowledge; we did not know how dangerous it really is."

In addition to health concerns, as people learned more about the prevalence of pig infections and the health effects of human infections from the workshops and other education activities, they began to re-assess their current situations. Several people described new worries about the possibility of having undiagnosed NCC or taenaisis, and the possibility that human-to-human transmission was occurring in the community:

> "Since we know that this parasite exists, at some point we may have eaten [contaminated pork] without knowing if the pig was fine, right? Or someone else contaminated us... I always have a medication in my house for headaches, [as do] most people... Some of us think [our headaches are caused by] high blood pressure… I, for my part, I think I'm stressed, I have stress and that's why my head hurts, but now that I know that the parasite may be in here, I'm suddenly thinking that I [could] have triquina...Where does my headache come from?... A tremendous concern has entered me, that I think I am going to lose some time of my time that I have to go to a doctor, and leave everything, close my store, and go and have a CT scan taken to see if I do not have the parasite inside."

Facilitator: Knowledge of transmission cycle

In our baseline survey of heads-of-households, the majority of respondents did not have an accurate understanding of the *T. solium* transmission cycle. Comments from the focus group participants, indicated that some of the participants understood the mechanisms of *T solium* transmission:

> "They say… be careful not to eat those meats, take care of your piglets in the corral, so that they are more protected, and also have more hygiene with yourself, because [after] you go to the bathroom, you have to wash

> your hands well. Sometimes it infects animals, and even oneself, one's family, right? They get infected."

Facilitator: Knowledge of T. solium's effects on human health

Understanding the consequences of tapeworm infection allows people to make informed decisions. Many people view taenaisis (intestinal infection with a tapeworm) as a common and benign condition, without understanding the associated risk of accidental ingestion of *T. solium* eggs, which can cause neurocysticercosis. As one participant noted, this knowledge caused them to re-assess their past and future choices: "It brings us to the brink of death… because a person who is infected with this [parasite] no longer lives a quiet life, is having seizures… it would be a miracle or long treatment to be able to heal."

Facilitator: Personal experience with neurocysticercosis

Some people learn about neurocysticercosis via education, while others have seen its effects personally. In each participating village, there were focus group participants who either had experience with NCC themselves, or had family, friends, or acquaintances who had NCC. Knowing people who are impacted can also be a powerful motivator for people to take actions to reduce their own risk of infection.

> "I have a sister [whose condition is] quite serious… she has brain pain… She says that they have detected that triquina in her brain, and since she is low on resources, she has no way [to treat it]. She is holding on with pills, like this, from pain... And she says, her brain drives her crazy..."

Facilitator: Experience with infected pigs

During the study period, we received and confirmed 22 cases of infected living pigs or contaminated pork from recently slaughtered pigs (unpublished data [Beam, et al., manuscript in progress]). Among the focus group participants, experiences with discovering infections in their own pigs was common. Cysts in pork are visible without magnification, although they may be missed if there are only a few cysts within a large cut of pork. In live pigs, an examination of the tongue can reveal cyst infection.

> "I checked [a 5-month-old pig's tongue]…, it was beautiful, the pig had nothing. So, I began to feed it… and kept it. The pig was 1 year old…getting fat… One day, we checked it and it has three [cysts] on its tongue. But when they killed it, it had quite a lot. More of the triquina, it was in the shoulder, neck, and arms. It had quite a lot. So that's why the animal must be checked."

We consider this kind of experience to be a facilitator, because it indicates people know how to detect infections in live pigs and pork meat, and can also teach others how to identify pig infections. If this experience is combined with knowledge of the health risks associated with porcine cysticercosis, and an appropriate response (e.g., treating the pig infection or removing the pork from the food supply, plus treating the human who infected the pig), the transmission cycle can be interrupted.

Likewise, personal experience with the financial loss associated with selling a pig that turns out to be infected can be a motivator to prevent future infections and a cautionary tale to others.

Facilitator: Financial benefits to raising clean pigs

People raise pigs for income, and often will sell their pigs or pork when they need money for expenses such as school supplies or uniforms for their children, or for medications. If they learn, at the time of sale or slaughter, that their pigs are infected with cysticercosis, the loss of anticipated income can be devastating. At times, a live pig is sold to a pork buyer, only to have the buyer return to the seller post-slaughter, after discovering the pork to be infected, and the seller must refund the buyer for the cost of the infected pig.

> "Say I have 2, 3 piglets, I say with these 3 pigs I'm going to buy my television. At the time [the pig turns out to be infected], not even a portable radio [can be purchased] ... One always has expectations of something… with this pig I will buy [supplies] for planting, or with this pig I will buy my son's clothes, or with this pig I will solve the problem [of paying for] school."

5.4 Discussion

T. solium presents an ongoing risk to community health, because it causes acquired epilepsy and also produces economic harms. There are several effective interventions to control transmission, including mass drug administration[27] and targeted drug administration,[56] but implementing these interventions at a scale large enough to have a broad impact is challenging. Most experience with control interventions to date comes from small research studies with narrow objectives, while large scale public health programs are rare. Translating advances in the research setting into applied public health programs requires deeper understanding and consideration of contextual factors including barriers and facilitator to implementation.

T. solium has been present in endemic communities for generations, therefore people have longstanding ideas about the mechanisms, risks, and consequences of infection. The disease exists within the larger context of economic hardship and other threats to health and livelihood, including dengue fever, SARS-CoV-2, malaria, influenza, and multiple conditions that affect animals, plus environmental threats like drought and flooding. *T. solium* is just one of many concerns that people are living with every day. Even though it is a serious health problem, *T. solium* is not as prevalent as many other infectious diseases, and other important concerns are competing for people's attention. Therefore, one of the best ways forward may be to connect *T. solium* control to other issues of concern – both in terms of economic development and to health. As much as possible, we can draw connections between individual-level behaviors and community-level interventions that can meet other needs in addition to *T. solium* control, for example handwashing as a behavior that reduces risk of neurocysticercosis along with many other diseases. Emphasizing clean and healthy communities as a whole, which includes healthy people and pigs, may help motivate communities to act.

In the absence of effective education about *T. solium*, community members frequently do not understand how *T. solium* is transmitted, and what they can do to prevent infections. Often, they have a partial understanding of the disease, and believe they are taking steps to reduce their risk, but in actuality their actions are not effective. For example, many people think taenaisis is a common and benign condition – not realizing it can cause neurocysticercosis. People often employ traditional remedies, such as salting pork to kill cysts. These ideas are worth studying with collaborative, community-engaged research, because these methods have been passed down over generations, and the community would benefit from knowing if those interventions are effective or not.

Effective education about the parasite, its modes of transmission, and the importance of prevention and control is needed to increase community knowledge. Evidence workshops and other participatory education initiatives should be provided on a regular basis, with assertive outreach to increase participation. While ongoing surveillance is an important component to monitor disease trends and program effectiveness, it can also provide opportunities to directly control transmission. When infected pigs are detected, they can be removed from the food supply, and humans living near infected pigs can be treated for taenaisis.[1,56] The Ministry of Health can respond to reports of pig infections by locating the people who live in close proximity to infected pigs and providing screening and treatment for taenaisis, a control strategy shown to be effective in reducing incidence of pig and human infections.[56] The agricultural ministry could play a more active role in educating people about detecting pig infections and treating pigs for cysticercosis. However, both agencies have funding and staffing shortages that present barriers to their ability to maintain ongoing outreach activities in the community. Therefore, local farming cooperatives or other community organizations could be leveraged to implement programs to control transmission or prevent disease. Other organizations support community health in various ways, including through nutrition and children's health, helping to establish a sense of community and mutual aid. These organizations would likely not be primary leaders for cysticercosis surveillance, but they could be ancillary supports.

In addition, understanding existing programs' organizational structures, and how they established trust (or lack thereof), might provide insight into the characteristics that are needed for an acceptable community surveillance campaign. Finally, recruiting local champions, who have personal connections to people impacted by neurocysticercosis or strong concerns about the health of people and pigs in the community, to lead community control efforts may help to raise awareness of the risks associated with *T. solium*.

To prevent infection in pigs, sanitation – including greater access to latrines and indoor plumbing - would reduce pig access to human feces. However, large-scale infrastructure investments take time and require significant financing and labor from governments or other entities. Given the economic situation in the region, infrastructure development is unlikely in the near future, therefore corralling pigs, promoting latrine use and handwashing, and creating ongoing surveillance systems to detect infections in pigs and humans, so that appropriate antiparasitic treatment can be provided, remain the most viable near-term interventions.

Responsibility for *T. solium* control should not be left solely to individuals or the local communities. While there are many community strengths upon which to build (e.g., social connections, people willing to share their stories, people willing to share their expertise, and people willing to pay a higher price for clean pork), much progress can be made with municipally-run and government-run programs. The provision of public health infrastructure cannot be left to individuals, especially those individuals who are struggling to maintain their livelihoods and provide for their families. Legislators can enact policies related to food safety, such as requiring pig corralling and meat inspections. National and provincial governments can invest in infrastructure, and support health systems to provide outreach and treatment for people with taenaisis and neurocysticercosis, and support animal health through ongoing surveillance and treatment of infected pigs. New resources and programs need to be developed in consultation with the community and adapted to local contexts. Community members typically don't have the time, energy, resources, or expertise to develop everything on their own – especially when effective interventions are already known, but are not implemented. However, they are experts with regard to the specific needs and circumstances of their own communities, and many community leaders are willing and able to participate in the design and adaptation of interventions.

5.4.1 Limitations

While informative, this study is not without limitations. We did not ask questions about latrines or defecation practices, which are known affect transmission. Our questions were mainly focused on pig raising, because our parent study was focused on a control strategy based on surveillance for pig infections. Because we recruited community leaders to participate, our focus groups did not represent the community as a whole, and may have included people who are more knowledgeable about the issues affecting the communities than the general population due to their more prominent roles. Data from focus groups are not generalizable, but can provide important information about the circumstances in the communities where the study was conducted, and provide ideas for follow up quantitative studies using representative sampling.

5.4.2 Strengths

The study's limitations are far outweighed by its strengths, which included the study team, whose members have worked in the participating communities for several years. The focus group facilitators were Peruvian researchers who were trained in facilitation by a Peruvian anthropologist, and understood the local language and social context. The analysis team included two of the facilitators and three analysts whose first language is Spanish. The focus group participants were nominated by fellow community members who recognized their leadership roles within the communities, indicating a degree of confidence in their ability to represent their communities in this setting.

5.5 Conclusion

The study provides perspectives from people who live with the threat of taenaisis. cysticercosis, and neurocysticercosis in their communities. Within the context of a larger study to develop community-based surveillance for infected pigs and implement control strategies, the participants discussed the strengths within their communities, shared their experiences, and described the barriers that stand in the way of reducing *T. solium* transmission. These findings informed our subsequent work in exploring community-engaged adaptations of targeted control interventions, and our ongoing efforts to implement surveillance and control activities. Engaging community members in conversations about the strategies that will be implemented within their communities allows for mutual learning opportunities among researchers, health practitioners, and community members, and can increase the likelihood of finding acceptable community solutions for taenaisis and cysticercosis.

Appendix 5.A Focus group recruitment questions from baseline household survey.

(Asked only of pilot intervention community participants.)

- Who is the person who helps most in this community? (Option to cross-question: Who is the person who cares most about your community?)
- What people or community groups, do you consider have made positive changes in your community?
- In this community, who are the people most involved in community activities, such as community clean-up?
- In the last two years, was there any good change in this community? If yes, who managed it?
- What people in your house participate in community groups or associations? If no, did you participate in the past?

Appendix 5.B Focus group interview questions and prompts

1. Tell me, in this rainy season, how are things going?
    a. How does the rain affect the raising of animals?
    b. How does the rain affect pig farming?
2. And in general, what are the benefits of raising pigs?
3. What kind of diseases can pigs have?
    a. What are the consequences of trichina?
4. People do not want trichina in the community, but when asked about health issues, they do not mention it as a major problem. Why do you think there is this difference?
5. When we surveyed the community, more than half said they had serious financial problems in the last 12 months. Why did this economic problem occur?
    a. How did they survive this crisis?
    b. What measures did you take or are you taking to face/solve this problem?
6. In our survey we found that trichina in pigs can be expensive (up to S/ 500). If your family had a pig with trichina, how has trichina affected your economic situation or that of other families in the community?
    a. How does this disease affect daily life?
    b. How does this impact peoples' ability to get food or basic necessities?
    c. How does this impact pig farming?
    d. What are other consequences of the disease?
7. How are problems solved here in the community?
    a. Where do people go for help?
    b. How does the municipality help in this community?
8. What are the strengths of the community?
    a. Where do people get information about projects, public works and other situations?
    b. What steps do you take to achieve this?

Chapter 6 Synthesis of Research

6.1 Overview

For this dissertation, I used multiple analytic methods to explore elements of social relationships in rural Peruvian communities, and how those relationships may support or deter *T. solium* control. I studied structural elements of social capital in the form of social networks, and the reciprocal support exchanges within those networks (aim 1). I found that exchanging information and emotional support on topics related to *T. solium* transmission and control were associated with increased odds of self-reported *T. solium* control actions, and that being the giver of support to others was more strongly associated with self-reported control actions than being the receiver of support. I then studied elements of cognitive social capital, including interpersonal trust and reciprocity within participating communities, and its relationship to collective efficacy (aim 2), but obtained mixed results on the association between these constructs. Finally, I studied the words of community leaders from focus group interviews, and summarized the contextual, community-level, and individual-level barriers and facilitators they described in relation to *T. solium* control. Taken together, these studies illuminate who people are talking to about *T. solium* control, what types of topics are discussed, how people talk about *T. solium* in group settings, and community members' perspectives on their collective abilities to control the parasite's transmission and reduce infections.

6.2 Significance and future directions

Over 20 years ago, Kawachi and colleagues suggested that social capital in the form of per capita rates of group membership and social trust may have a protective effect on all-cause mortality.[147–149] Since then, researchers have developed several different operational definitions of social capital, including participation in voluntary community organizations and professional associations, trust in neighbors and institutions, and social cohesion.[141] These elements of social capital have been positively associated with health outcomes including lower rates of heart disease, cancer, mental illness, and increased life expectancy.[141] However, the research on social capital has also shown that increased participation in social activities can be negatively associated with health in certain settings.[141,150] After summarizing 28 systematic reviews of social capital in the published literature, Shiell and colleagues concluded that the health effects of social capital are likely dependent on context, and that researchers should develop interventions with community involvement, along with clearly defined and specified components of social capital. The three studies described in this dissertation, taken together, represent a potential multi-method approach, where social networks and social capital are measured with survey tools, and group interviews with community members provide important context to the survey data.

While my study design prevented the collection of social network data, social capital data, and focus group data simultaneously, future studies designed to collect these data contemporaneously could be beneficial in a number of ways. First, collecting baseline data on existing social networks and levels of social capital, along with focus group interviews to further explore the community context and interpretations of social capital elements (e.g., trust, norms of reciprocity), could inform the design of interventions that seek to increase social capital or social connections by elucidating the levels at which elements of social capital are present or absent. For example, an intervention that requires community members to share information or ask for assistance from municipal authorities is unlikely to be successful in a community where trust in the municipality is low. Furthermore, in this example, researchers would do well to explore *why* trust levels are low in a community (via qualitative methods) before proceeding with implementing an intervention. Lack of trust in authorities may be a sensible and relatively immutable community characteristic if governments have acted in ways that harm communities.

Future studies could also develop interventions that seek to build on social capital within existing social networks. My study of networks (aim 1) showed that neighbors made up half of participants' social networks. This information is useful in the context of *T. solium* control, because focal control interventions, like ring strategy, deliver treatment interventions to people living in homes with infected pigs and their nearest neighbors.[1,56] Studies in Peru have shown that free-roaming pigs generally stay near their homes, meaning neighbors' behaviors that effect transmission (e.g., outdoor defecation, allowing pigs to roam freely) can have a substantial impact on the risk of exposure to *T. solium* for nearby people and animals.[54] The findings in my social network study indicate that people in rural Northern Peru are communicating frequently with their neighbors about *T. solium*, and are influencing one another's behaviors. Interventions that build on the existing relationships among neighbors and create opportunities for increasing social capital in the form of mutually beneficial activities and reciprocity (e.g., facilitating the design and installation of shared corrals, or teamwork among neighbors to routinely examine pigs for infections), could bolster control efforts.

In my study of barriers and facilitators for community-based *T. solium* control (aim 3), I identified themes of trust and reciprocity in focus groups with community leaders. While the focus groups were only conducted in 4 of the 7 communities studied in my first two aims, the findings from this thematic analysis provided important context to the behaviors measured in my other two studies. In each of the focus groups, participants described the ways community members worked together for the benefit of the entire community, and the ways people helped one another when an individual or family needed extra assistance. Participants also described the various ways municipal and other organizations could help or hinder community development and health. Future studies could be designed to collect baseline social network and social capital measurements, which could then be shared and discussed with community members during focus group discussions to better understand how social capital exists and is defined within the local context. These data could then be used to create interventions aimed to enhance social capital and increase collective actions for *T. solium* control. Finally, interventions developed in this iterative manner can be measured using the community-defined conceptualizations of social capital, alongside standard epidemiologic analyses.

While this dissertation investigated interpersonal and community drivers of *T. solium* prevention, it is important to recognize that interpersonal relationships exist within larger regional and national contexts. Poverty is a primary reason that *T. solium* is circulating primarily in LMICs as opposed to high-income countries. Large scale investments in sanitation systems and infrastructure for regulating pork production/processing would certainly reduce *T. solium* transmission.[151] These types of interventions are typically not feasible at local levels, and instead require governmental implementation and oversight. Asking farmers to shoulder the burden of infection control neglects to acknowledge the substantial infection control gains that can be achieved through municipal investments, and regional/national programs that facilitate human, animal, and environmental health professionals to work with farmers and communities.

Finally, it is important to recognize that humans are in relationships not just with one another, but also with animals and the rest of the natural world. Globally, there are hundreds of known and emerging zoonoses (diseases with suspected or known animal-human transmission links). A recent review of 1407 species of human pathogens found that 58% were zoonotic.[152] In addition to known zoonoses, emerging infectious diseases - 60% of which are zoonotic - pose ongoing threats to public health.[153,154] Recent outbreaks of zoonoses such as Ebola and SARS-CoV-2, have motivated leaders in healthcare and government to renew the call for expanded research and action on One Health.[155] One Health is an approach that mobilizes human, animal, and environmental health professionals to work together.[156,157] The One Health perspective is hardly novel. In fact, many Indigenous communities have held this worldview for millennia, viewing interdependence among humans, animal, and ecosystems as a given.[158,159] The rationale for the importance of tending to animal and environmental health is rooted in both a sense of responsibility as well as our reciprocal relationships with plants and animals.[160,161] One Health programs can bring together people around the shared goals of healthy people and animals to create community-led strategies that seek not only to control *T. solium*, but prevent and control other zoonoses and support healthy food systems.[51,63] One Health studies can employ the methods used in this dissertation, particularly network analyses that include human and animal networks, to inform our understanding of how *T. solium* and other zoonoses move through social systems, and where to focus interventions for the largest potential impacts.

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