

**COMMUNITY PERCEPTIONS AND PRACTICES REGARDING
TRANSMISSION AND MANAGEMENT OF HUMAN AND
PORCINE CYSTICERCOSIS IN ANGÓNIA RURAL DISTRICT,
MOZAMBIQUE**

By

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**A thesis submitted to the Institute of Anthropology, Gender and African Studies in
partial fulfilment of the requirements for the degree of Master of Arts in
Anthropology of the University of Nairobi**

March, 2010

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DECLARATION

This thesis is my original work and has not been presented for a degree in any other University.

Carlos Eduardo Cuinhane



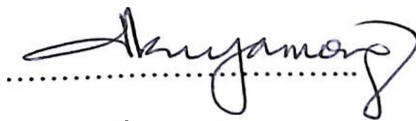
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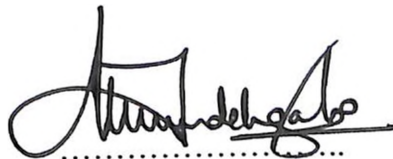


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DEDICATION

To my daughter, Carry.

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LIST OF ABBREVIATIONS

ASF	African Swine Fever
CESA	Cysticercosis in East and Southern Africa.
CWGESA	Cysticercosis Working Group in Eastern and Southern Africa.
ESA	East and Southern Africa.
FAO	Food and Agriculture Organization.
FGD	Focus Group Discussion
FRELIMO	Frente de Libertação de Moçambique
HIV	Human Immunodeficiency Virus.
IAF	Inquérito de Agregado Familiar (Family Aggregate Inquiry).
INE	Instituto Nacional de Estatística (National Institute of Statistic).
MAE	Ministério de Administração Estatal (Government Administration Ministry)
MISAU	Ministério de Saúde (Health Ministry)
RENAMO	Resistência Nacional de Moçambique
WHO	World Health Organization.

ABSTRACT

This study was designed to investigate the Community perceptions and practices regarding transmission and management of human and porcine cysticercosis in Angónia rural district, Mozambique. The main assumptions that guided the study were: people's knowledge influences their perceptions of the transmission of neurological disorders in humans and white nodules in pigs; local practices related to pig rearing, culinary and hygiene favour the transmission of neurological disorders in humans and white nodules in pigs and, that the way people understand the causes of neurological disorders in humans and white nodules in pigs determine the means that they employ to cope with the disease.

Data was obtained through survey, key informant interviews, narratives, focus group discussions and direct observations. Convenient sampling was used to obtain the sample size of 150 (100 pig keepers and 50 non-pig keepers) respondents. The study also included 5 traditional healers, 1 health worker and 5 people living with epilepsy. The quantitative data was analysed using SPSS and the information presented in tables of frequencies and figures. Qualitative data was analysed thematically.

The main findings of this study indicate that the community is familiar with porcine cysticercosis and epilepsy, but they have poor knowledge on the aetiology of the disease. Findings suggest that a number of factors may predispose the community and pigs to infection of *T. solium*. Factors, such as free range practices, lack of proper use of latrines and lack of veterinary field officers may contribute to the quick spread of white nodules in pigs; while, lack of knowledge on the *T. solium* life cycle, perceptions, home pig's slaughtering and lack of meat inspection, culinary practices and sanitary conditions may predispose people to infection of the disease. The study also found that there is a high prevalence of epilepsy, and this could be due to the high prevalence of porcine cysticercosis in the study area.

This study recommends that campaigns and education are needed to increase awareness of cysticercosis transmission and the implementation of measures for its prevention and, further studies are needed to investigate the association between the high epilepsy cysticercosis prevalence in the study area.

CHAPTER ONE: Introduction

1.1 Background information

Cysticercosis is a zoonotic disease caused by *Taenia solium* that infects both humans and pigs (García *et al.*, 2003; Tenzer, 2006). The disease is commonly found in South America, Africa and Asia (Phiri *et al.*, 2003; Wandra *et al.*, 2000; Rajshekhar *et al.*, 2003; Kraft, 2007), and it is estimated that 50 million people are infected worldwide (Kraft, 2007). Cysticercosis is a major public health and agricultural problem, especially in developing countries (Rajshekhar *et al.*, 2003), mainly in communities where sanitary conditions are poor (Ngowi *et al.*, 2004).

Humans become infected with *T. solium* by eating raw or undercooked infected pork containing tapeworm cysts (Love and Max, 1984) that then attach to the human gut and grow into adult tapeworms (Kraft, 2007). Usually a person only harbours a single adult worm. The disease caused by the adult tapeworm is called taenosis which generally creates little or no clinical signs or symptoms. The adult tapeworm excretes up to 50,000 eggs per day which if eaten by a pig develop into metacestodes in the gut. The metacestodes penetrate the intestinal wall and invade subcutaneous tissues, brain, eye, muscle, heart, liver, lung, and peritoneum, which lead to cysticercosis and neurocysticercosis if located in the brain (Kingondu and Nordberg, 2007). If humans accidentally eat the eggs, the tapeworm larvae develop as in pigs. In humans cysticercosis shows clinical symptoms ranging from mild headache to mental disorders, seizures, changes in behaviour, compromised vision and meningoencephalitis. However, some individuals with this disease remain asymptomatic for long periods (Vilhena *et al.*, 1999). Almost 50,000 deaths attributable to neurocysticercosis occur every year. Many more patients survive but are left with irreversible brain damage – with all the social and economic consequences that this implies. Seizures occur in up to 70% of patients (WHO, 2006:130).

Neurocysticercosis is the most common worldwide central nervous system infection and causes between 60 and 90% lesions in infected individuals (Osborn and Tong, 1996), which leads to epilepsy (Love and Max, 1984). Epilepsy is a chronic neurological disorder affecting both sexes and all ages, with worldwide distribution (WHO, 2006).

Although cysticercosis has been recognized as a major problem in many countries, in Africa it is still not well recognized (Carpio *et al.*, 2000) and no policy has been put in

place to deal with it. Cysticercosis affects mostly poor families, particularly in rural areas, where farmers keep pigs as their source of income.

In Africa, especially in Eastern and Southern Africa (ESA), cysticercosis has been reported to increase significantly in the past decade, and affects mostly rural farmers. According to Phiri *et al.* (2003), the prevalence of cysticercosis in the region is among the highest in the world and the disease is emerging as an important constraint to the nutritional and economic well-being of resources-poor smallholder farming communities. Ngowi *et al.* (2004) observe that infection of animals result in great economic losses as far as the livestock industry is concerned owing to partial or total condemnation of the affected carcass.

Data available from Eastern and Southern Africa reveal high prevalence of cysticercosis. For example, in Tanzania, the level of infection ranges between 17.4% in the north highland district of Mbulu and 5.1- 16.9% in the southern highlands (Phiri *et al.*, 2003). In western south Kenya, 10-14% of pigs have been found positive with cysticercosis (Onyango-Abuje *et al.*, 1996), while in Kampala, Uganda, surveys undertaken in 1998 and 1999 showed that the prevalence of porcine cysticercosis was between 0.12 and 1.2%. However, a rural survey in northern Uganda in 1999 indicated that 35% pigs were infected. A survey in Kampala in 2002 indicated that 33.7% of the pigs from Lira district were infected (Phiri *et al.*, 2003). In Zimbabwe, surveys from 1994 to 2001 reported a prevalence of 0.34%, but another survey carried out in 1999 showed that 28.6% of pigs from rural west Zimbabwe were infected (Boa *et al.*, 2006). In Lusaka, Zambia, inspection showed that 20.6% of pigs had cysticercosis, and other surveys indicated that 56.6% of pigs were found to have circulating antigens of *T. solium* (Phiri *et al.*, 2003). South Africa has the largest number of pigs and cysticercosis has been recognized as a problem in the country (Shasha and Pammenter, 1989; Mafojane *et al.*, 2003).

In Mozambique, records indicate that cysticercosis is present in all provinces of the country (Afonso *et al.*, 2001). A study in 11 districts of rural Tete province in the country showed that porcine cysticercosis seroprevalence ranged from 6.5 - 33.3% in pigs (Afonso *et al.*, 2001), while 20% of people were infected with cysticercosis (Vilhena and Bouza, 1994).

Reports have shown that the high prevalence of the disease is due to poor sanitary conditions such as poor water supply and poor or lack of toilet facilities (Vilhena *et al.*, 1999; Margono *et al.*, 2006), free range pig practices (Boa *et al.*, 2006), and lack of information and awareness about the problem (Carabin *et al.*, 2006).

The aim of this study was to explore community perceptions, attitudes and practices of the transmission and management of human and porcine cysticercosis in Angónia rural district, Mozambique. However, to collect data about the diseases, the study used white nodules in pigs as a proxy for the presence of porcine cysticercosis while epilepsy (neurological disorders) was used as a proxy to human cysticercosis.

Angónia rural district is predominantly inhabited by the Chewa ethnic group, but there are a few other ethnic groups from different provinces of Mozambique. The Chewa are traditionally matrilineal. Like other Chewa matrilineal ethnic groups in Malawi and Zambia, the property and land rights are inherited through the mother (Gough, 2004).

Like many other rural districts in Mozambique, Angónia is primarily agricultural. People farm and produce most of what they eat, especially maize, beans, peanuts, cassava, and vegetables such as tomatoes, cabbages and onions. The small scale farmers also farm cash crops such as tobacco and soya beans. The surplus of what is produced is sold to help in meeting the basic financial needs of the household, to buy food-stuffs produced outside of the locality or imported from abroad. The local community also keep cows, pigs, goats, sheep, chicken, ducks and rabbits. People keep pigs as any other animal such as goats and chickens in a mix system (husbandry and free-range system). Pigs are for consumption and selling to help with the financial needs of the household.

The availability of food for the majority of people in the district, like other many citizens of Mozambique, depends on good weather conditions. This means that if the rains fail or floods occur, crops will be destroyed, and the community faces famine (Ndege, 2006). The weather and lack of veterinarians influence negatively the development of livestock in the area.

1.2 Problem statement

Pig keeping and pork consumption have increased significantly in Eastern and Southern Africa (FAO, 2005) especially in rural smallholder communities. However, the growth of pig keeping and pork consumption has been accompanied by the appearance and

increase in occurrence of cysticercosis. In addition, the increased demand for pork in urban areas of the Eastern and South Africa region has resulted in the transportation of pigs from the rural smallholder communities to large population centres (Phiri *et al.*, 2003) and, therefore, the spread of cysticercosis.

Recent studies (Boa *et al.*, 2006; Carabin *et al.*, 2006; Margono *et al.*, 2006) suggest widespread presence of human tapeworm carriers and thus a high risk of human cysticercosis in both rural and urban areas of Eastern and Southern Africa (Phiri *et al.*, 2003). Cysticercosis is an important contributor to neurological morbidity in developing countries and is the major cause of acquired epilepsy in the world (García *et al.*, 2003). Lifestyle, religion, and socioeconomic aspects have been reported as important issues in the perpetuation and enhancement of endemicity of *T. solium* and cysticercosis (Margono *et al.*, 2006).

Cysticercosis is a threat to the economic stability in Angónia rural district because pigs are raised by poor small scale farmers to increase their incomes. However, such farmers cannot realize their profits when pigs are infected with cysticercosis. This leads to a local and national economic loss, since the pig industry is undermined by the disease. The disease is also a serious constraint for people's health and increases medical expenses to the infected poor families that cannot afford treatment of common diseases, such as malaria, cholera and tuberculosis. According to Carabin *et al.* (2006), neurocysticercosis leads to stigmatization, incapacitation and decreased work productivity. In addition, epileptic patients are frequently denied schooling, shunned by their peers, find it difficult to marry, and meet active discrimination when they seek employment (Kleinman, 1995).

Despite the fact that practices such as allowing pigs to roam freely, lack of hygiene and hygienic culinary practices are considered risk factors in the transmission of cysticercosis, some communities continue with these practices. Given the high spread of cysticercosis in the study area, it was important to explore the risk practices and attitudes that exposed the people to the risk of infection as well as the beliefs that they had about pigs and their relationship with the transmission of cysticercosis.

This study explored folk knowledge, attitudes and practices of the transmission and management of neurological disorders in humans and white nodules in pigs in Angónia

rural district of Mozambique. The study was, therefore, designed to answer the following questions:

1. What influences people's perceptions regarding the transmission of neurological disorders in humans and white nodules in pigs in Angónia rural district?
2. What practices favour the transmission of neurological disorders in humans and white nodules in pigs in the study area?
3. How do people in the study area manage the problem of neurological disorders in humans and white nodules in pigs?
4. What are people's attitudes regarding white nodules and neurological disorders associated risks?

1.3 Objectives

1.3.1 General objective

The main objective of this study was to explore community perceptions and practices of the transmission and management of neurological disorders in humans and white nodules in pigs in Angónia rural district of Mozambique.

1.3.2 Specific objectives

1. To establish peoples' perceptions regarding the transmission and management of neurological disorders in human and white nodules in pigs.
2. To determine the practices contributing to the transmission of neurological disorders in humans and white nodules in pigs.
3. To establish mechanisms of coping with neurological disorders in humans and white nodules in pigs.
4. To elucidate peoples' attitudes towards changing cysticercosis associated risks.

1.4 Justification of the study

Cysticercosis is a concern at the community, national and international levels, and it is becoming a challenge in the health and agricultural sectors because of lack of awareness and poor information about its transmission. Thus, a study of community perceptions and practices of the transmission and management of human and porcine cysticercosis

is important because the findings could be used by different organizations (the community, the Government as well as national and international organizations) to come up with policy guidelines to control the disease.

Behavioural aspects of cysticercosis should help health practitioners to understand how the disease affects the patient's relationship within the family and community, how people contextualized themselves, and what mechanisms have been developed to cope with the disease.

Since this was a study of folk knowledge regarding transmission of cysticercosis, it answered questions related to Medical Anthropology such as which diseases affected different populations, how disease was socially constructed, and how one treated the disease in effective and culturally appropriate ways. The findings should also stimulate debate on theories related to the socio-cultural context and implications of disease and illness.

1.5. Scope of the study

This study explored people's perceptions, attitudes and practices regarding the transmission and management of human and porcine cysticercosis in Angonia rural district of Mozambique. The study examined people's perceptions of the relationship between the presence of white nodules in pigs and the existence of *T. solium* cysticercosis, as well as the relationship between cysticercosis and neurological disturbances (epilepsy) in humans. It also examined people's knowledge, practices and attitudes related to the transmission and mechanisms developed to cope with the disease.

1.6. Limitations of the study

The study used proxies (white nodules in pigs and neurological disturbances in humans - epilepsy) to determine the existence of cysticercosis. Therefore, no laboratory tests were carried out to determine who were infected by cysticercosis. This procedure reduced the validity and reliability of the study findings because the presence of white nodules in pigs did not necessarily mean that they were infected with cysticercosis. This is because not all the white nodules are *T. solium* and cysticercosis was not the only cause of neurological disturbances (epilepsy) in humans. Therefore, the study cannot conclude categorically that people suffering from epilepsy in the study area are

suffering from epilepsy related to cysticercosis, and the finding cannot be generalized to other places beyond the study area.

CHAPTER TWO: Literature Review

2.1 Introduction

This chapter focuses on review of the literature related to the different aspects of cysticercosis. In addition, the theoretical orientations, which formed the framework for analysis, are presented and their relevance to the study explained. Assumptions are presented, and operational definitions of the concepts provided.

2.2 Cysticercosis

Taenia solium is a zoonotic tapeworm transmitted between humans and pigs. The cestode belongs to the family *Taeniidae* (Rickard and Williams, 1982). Humans are the only natural definitive host while pigs are the intermediate hosts. However, human beings may become an intermediate host from ingestion of eggs of the adult tapeworm (Phiri *et al.*, 2003; García *et al.*, 2003; Tenzer, 2006). The infection in humans with the adult tapeworm results in a condition known as taeniosis while the infection with the larval stage of the worm results in human cysticercosis, while in pigs, it results in porcine cysticercosis (Phiri *et al.*, 2003).

Humans acquire the tapeworm after eating raw or undercooked pork contaminated with cysticerci (larval form of *T. solium*), which develops into an adult tapeworm in the small intestine and produces eggs that are passed with faeces. After ingestion of eggs by either pig or accidentally by human, the developing larvae migrate through the gut wall and via the blood stream develop into larval cysts primarily in the muscles, subcutaneous tissues and brain (Carabin *et al.*, 2006). Humans most often acquire cysticercosis through faecal-oral contamination with *T. solium* eggs from tapeworm carriers. Thus, vegetarians and other people who do not eat pork can also acquire cysticercosis (García *et al.*, 2003). Although cysts may lodge in any organ, mostly disease results from brain involvement (Carabin *et al.*, 2006). When cysticercosis develops in the brain and spinal cord of humans, the condition that arises is known as neurocysticercosis (Mafojane *et al.*, 2003).

Cysticercosis is found in all age groups and equally in men and women. According to Mafojane *et al.* (2003), in South Africa, active infections suggested two peaks in prevalence, between 5-9 and 20-24 year age groups. Thus, infection may occur at an early stage. However, the time between infection and symptoms of neurocysticercosis depends on a number of things such as size, type, condition, and site of cysts in the

brain (Pal *et al.*, 2000). For example, in a case series of British soldiers infected in Asia, the median time from infection to appearance of first symptoms was 4 years (Bern *et al.*, 1999).

Clinical manifestations of neurocysticercosis in humans depend primarily on the number and location of cysticerci in the central nervous system and the host's immune response to infection. Serious pathologic findings of neurocysticercosis can include seizures, obstructive hydrocephalus, meningoencephalitis, vascular accidents, headache, and those within the cisterns may also cause serious vasculitis and stroke (Tenzer, 2006). Other central nervous system manifestations include asymptomatic infections, subarachnoid and ventricular involvement, and massive infection and encephalitis (Carabin *et al.*, 2006), nausea, vomiting, headache, ataxia, and confusion (Pal *et al.*, 2000), chronic meningitis, and also isolated non-neurological manifestations, such as ocular or dermal cysts (Bern *et al.*, 1999). But, neurocysticercosis may also be characterised by mild symptoms (abdominal pain, distension, diarrhoea, and nausea) or none at all (García *et al.*, 2003).

2.3 Transmission of cysticercosis

The transmission of *T. solium* occurs in a cycle process that begins from consumption of undercooked infected pork (Bern *et al.*, 1999). The life cycle of this zoonotic cestode includes the pig as the normal intermediate host (harbouring the larval vesicles or cysticerci), and humans as the definitive host (harbouring the adult tapeworm), as shown in Figure 2.1.

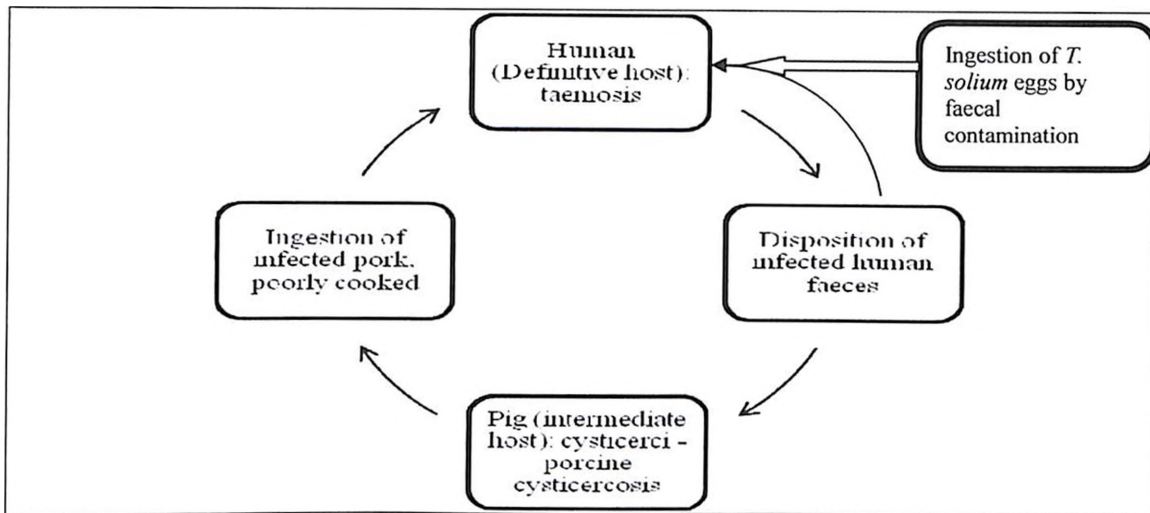


Figure 2.1: Life cycle of *Taenia solium* (source: Adapted from García et al., 2003).

The life cycle of *T. solium* seems to suggest that the disease caused by the parasite is a problem of pig producers and pork consumers; however, in reality, cysticercosis can infect and affect everyone. According to Mafojane *et al.* (2003) earlier studies (Heinz and MacNab, 1965) have revealed that non-pork eaters also have a high risk of getting cysticercosis.

The transmission of cysticercosis appears to be primarily a rural phenomenon, sustained by free-range pigs and poor sanitary conditions (Bern *et al.*, 1999), but water, wind, flies, and other indirect means of infection also play an important role in transmission (García *et al.*, 2003). In addition, migrants with tapeworms may import cysticercosis into unlikely settings, such as upper-class urban homes in non-endemic regions and industrialized countries. A striking instance of imported cysticercosis occurred in an Orthodox Jewish community in Brooklyn, New York, where 11% of people tested seropositive. This infection was associated with having a Latin American immigrant working in the home (Bern *et al.*, 1999). Other reports have shown infections in people who are vegetarians or who do not eat pork on religious grounds in India, Kuwait and United States of America (WHO, 2003).

Although the manner in which eggs are ingested is not usually known, the tapeworm carrier and close household contacts are at greatest risk, suggesting that person-to-person spread is important (Carabin *et al.*, 2006). Besides these means, the transmission of cysticercosis also takes part in food preparation, poor personal hygiene and lack of

proper sanitary conditions (Phiri *et al.*, 2003), lifestyle, religion, socioeconomic (Margono *et al.*, 2006) and cultural factors (Mafojane *et al.*, 2003).

2.4. Relationship between cysticercosis and epilepsy

Epilepsy is a group of symptoms caused by abnormal neuronal activity in the brain, which can perturb motor, sensory, dysfunction, infection, cognitive and mental function, consciousness, and it may be caused by idiopathic, trauma, cardiovascular stroke (Osborn and Tong, 1996), and cysticercosis (García *et al.*, 2003). It can become chronic neurological disorder but it may be treated (Boshes and Gibbs, 1972).

Neurocysticercosis is an important contributor to neurological morbidity in developing countries and presumably is the major cause of acquired epilepsy in the world (García *et al.*, 2003), especially in developing countries, but its relative contribution remains unknown (Pal *et al.*, 2000; Carabin *et al.*, 2006; Bern *et al.*, 1999). However, several studies have reported a close relationship between neurocysticercosis and epilepsy. A study in southern India, reported in 2000, found an association between neurocysticercosis and localization-related symptomatic epilepsy in 51% of patients (WHO, 2003). Serological studies in India, South Africa, Mexico, and Peru suggest that the higher rates of epilepsy are due mainly to neurocysticercosis (García *et al.*, 2003). In Eastern Cape Province, South Africa, for example, a study found that 95% of neurocysticercosis cases were associated with epilepsy (Carabin *et al.*, 2006; Mafojane *et al.*, 2003). In Harare, Zimbabwe, 12% of epileptic patients were found to be positive of *T. solium* on serological testing (Mason *et al.*, 1992, cited by Mafojane *et al.*, 2003). The prevalence was higher in men (18%) than in women (7%) (Mafojane *et al.*, 2003). These results confirm other studies (García *et al.*, 1993; Medina *et al.*, 1990) from Latin America, which have shown that infection of the brain by *T. solium* larvae is an important cause of epileptic seizures in endemic communities (Pal *et al.*, 2000).

In Angónia rural district, Tete Province in northwest Mozambique, a community-based survey of 1723 people indicated that 15.6% were epileptic while 14.5% were serologically positive for active cysticercosis infection (Assane, 2009 – personal communication). The same study found that epilepsy associated with cysticercosis was higher in children than adults (more than 15 years old), and the prevalence was higher in males (21.4%) than females (11.8%).

2.5 Treatment and control of cysticercosis

Cysticercosis is a preventable and curable disease, and the International Task Force has declared *T. solium* infection eradicable (Carabin *et al.*, 2006). For example, the disappearance of the disease in most European countries is important evidence of the potential eradication of this species in the long term. The strategy was based on development of environmental sanitation and pig husbandry and strict meat inspection (Sarti and Rajshekhar, 2003). However, human behaviour and socioeconomic obstacles may challenge the process of eradication of the disease in developing countries.

First of all, neurocysticercosis is diagnosed by using neuroimaging (Pal *et al.*, 2000), which is not available in many developing countries, especially in rural areas. Once the disease is detected, it can be treated using praziquantel and niclosamide, both of which are safe and efficient in the treatment of taeniosis (Sarti and Rajshekhar, 2003). In pigs, porcine cysticercosis can be treated using antiparasitic drugs, such as oxfendazole (Sarti and Rajshekhar, 2003; Ngowi *et al.*, 2007, 2008). Other measures and available tools that can be used to eradicate the disease are: improvements in sanitation, better pig husbandry (Bern *et al.*, 1999); and health education campaigns (Sarti and Rajshekhar, 2003; Ngowi *et al.*, 2007, 2008). However, in many developing countries, the rural poor use numerous ethno-veterinary plants for the treatment of worm diseases in livestock and in humans. For example, in Tanzania, “*lodwa*” (*Embelia schimperi*) is a plant used to remove the *T. solium* (Krecek, 2005).

Human behaviour plays an important role in the process of eradication of cysticercosis. For example, in Peru, small producers prefer to sell *T. solium* infected pigs clandestinely at a discounted price rather than take a complete loss; a practice which helps to maintain the parasite life cycle (Bern *et al.*, 1999). Human attitudes regarding the use of biomedical treatment are another challenge to eradication of the disease. Carabin *et al.* (2006) reported various community-based surveys on related issues. In Gambia, for example, 48% of active epilepsy patients had never sought biomedical treatments. The same behaviour was found in rural India where 38% of children with epilepsy had never sought allopathic health care. In Burundi, only 5% of patients with epilepsy had sought care in the hospital.

Unlike cysticercosis, epilepsy can be diagnosed, based on the history of the patient, parents or other witnesses; and the symptoms can be treated, using anti-epileptic drugs

such as phenobarbital, phenytoin, carbamezepine or valproate (Boshes and Gibbs, 1972).

Treatment seeking behaviour for epilepsy remains to be elucidated in most African countries. In Mozambique, for example, a study has reported that people frequently make use of a traditional spiritual care provider before seeking any medical advice (Vilhena *et al.*, 1999). Knowledge regarding traditional practitioners' treatment and people's perception and acceptance of their methods are also warranted in order to get a holistic picture of how to prevent and control cysticercosis.

2.6 Risk factors for transmission of cysticercosis

The life cycle of cysticercosis does not occur in a vacuum, but within an environment, where humans play an essential role in the process of transmission of the disease. Some of human's attitudes that may be regarded as potential risk factors in the transmission of cysticercosis are: culinary practices, poor sanitary conditions, pig rearing practices, cultural beliefs, and ignorance combined with lack of information and awareness about the disease. These risk factors are described below.

2.6.1 Culinary practices

Culinary practices refer to processes through which people prepare and consume food, especially pork, according to their habits and customs. Culinary practices regarding the transmission of cysticercosis include cooking process, time required to cook pork and personal hygiene in preparation of food.

It is important to note that what people eat and how they prepare it is often a crucial factor in determining what infections they suffer from and how prevalent the infections are in a particular community. Thus, inadequate cooking processes can fail to kill parasitic helminths and thus predispose humans to infection (Goldsmid, 2005). For example, humans acquire taeniosis and cysticercosis through consumption of uncooked infected pork and consumption of unclean vegetables and water contaminated with infected human faeces, respectively (Sarti and Rajshekhar, 2003).

According to Jimba *et al.* (2001), pork should be carefully cooked because cysticerci are killed at a temperature of 45 to 50° C, but can survive in the large piece of meat if the centre is inadequately cooked. However, cooking is not an easy task to control since it depends on where and how pork is prepared. For example, if the cooking is within the

households or restaurants, it may be possible to control, but in pork roasting centres (especially informal) cooking process may be influenced by the number and expectations of clients and expenditure of the fuel.

Poor hygiene in food preparation can be a source of infection. For example, the use of knives, which have been used to cut raw meat being used to carve the meat for serving after cooking (Goldsmid, 2005), could lead to infection of taeniosis. On other hand, poor personal hygiene, such as inadequate washing of hands before eating and after defecating (Sarti and Rajshekhar, 2003) contributes to infection with cysticercosis.

2.6.2 Sanitary conditions

Several studies (Pal *et al.*, 2000; Santamaría *et al.*, 2002; Phiri *et al.*, 2003; Sarti and Rajshekhar, 2003; García *et al.*, 2003) have reported that the spread of cysticercosis results from poor sanitary conditions, which include, among other things, poor infrastructures, lack of utilization of toilets, and poor hygiene in water. According to Pal *et al.* (2000), poor hygiene and living conditions allow pigs to access human faeces, and, therefore, put people at the risk of infection with cysticercosis.

Poor hygiene also includes lack of latrines, particularly in rural areas where pigs have easy access to human faeces (Santamaría *et al.*, 2002). This factor is responsible for the spread of the disease, since the life cycle of cysticercosis completes when pigs access human faeces (Santamaría *et al.*, 2002; Sarti and Rajshekhar, 2003). For example, a study in Maputo city, Mozambique, found that people who were living in poor sanitary conditions, such as poor water supply, poor or no latrine facilities, and poor housing had the highest seropositivity of cysticercosis (Vilhena *et al.*, 1999).

Lack of adequate water supply and hygiene has been described as a major means of the spread of the disease in general, and of cysticercosis in particular. According to Goldsmid (2005), lack of hygiene and sanitation generally results from a lack of available water or poor planning within a community. This brings problems since water contaminated with human or animal faeces may be the source of many human enteric infections. This contamination may be the result of simple runoff into a stream used for drinking water often affecting a “downstream” village or due to well contamination through the building of pit toilets too close to the well (Goldsmid, 2005), rivers or lakes.

2.6.3 Pig rearing practices

Pig rearing practice refers to a process of pig management in different countries and communities. There are two methods of pig management: the first is a confinement management, characterized by keeping pigs enclosed in fulltime, feeding and controlling. The second is a free-range management system (traditional management) in which pigs are not enclosed and controlled at all, but are allowed to scavenge for food and water. This practice is mostly dominant in rural areas, and it has been described as a major means of the spread of cysticercosis in developing countries (Pal *et al.*, 2000; Phiri *et al.*, 2003). In Africa, and particularly in rural areas, pig keepers use a mixed system (confinement and free-range), where they confine, but sometimes, allow them to roam freely, depending on the season.

Free range is practised by small scale farmers mainly in rural areas in Africa, Latin America and South East Asia where pigs are fed mostly on grass, brewery, and cereal by products or waste products/food remnants (Lekule and Kyvsgaard, 2003). Free range is practised by subsistence farmers who cannot afford enclosed pens or proper animal feed (Pal *et al.*, 2000). In addition, the lack of grazing land for ruminants and the recognition by farmers of quicker and higher returns on their investment (Phiri *et al.*, 2003) has contributed to an increase of this practice.

Although free ranging of pigs constitutes an advantage to the pig producers (little or no economic expenditure), this method is considered as one of the risk factors for porcine cysticercosis (Lekule and Kyvsgaard, 2003). For example, a study reported that Eastern Cape Province, South Africa, has the highest prevalence of cysticercosis/taeniosis probably due to the common practice of free-range pig farming and the lack of sanitation (Mafojane *et al.*, 2003).

Community-based survey in our study area, where the prevalence of cysticercosis is high (34.9% pigs positive), showed that free-range husbandry was significantly associated with cysticercosis (Pondja, 2009 – personal communication). In this community, pigs were only housed when there were crops in the fields, but after harvest, were allowed to graze freely (Gule, 2008).

Sometimes, free ranging of pigs may be increased due to people's perceptions regarding pigs. Kriel (1997), cited by Mafojane *et al.* (2003) reported that in some rural areas of Limpopo Province, South Africa, pigs were regarded as environmentally friendly

because of their neat habit of tidying up human faeces. This may be one of the reasons for people not enclosing the pigs.

2.6.4 Meat inspection

The lack of infrastructures such as meat inspection facilities and inspection of pork by professionals (Sarti and Rajshekhar, 2003) in rural areas, where domestic pigs are raised without veterinary control or surveillance systems, is a major risk factor (Mafojane *et al.*, 2003). In addition, lack of disease control measures (Phiri *et al.*, 2003) may also contribute to the spread of cysticercosis. For example, the disease is also widely prevalent in urban areas in endemic countries (Pal *et al.*, 2000).

A community-based survey in our study area found that there was a lack of and improper pork inspection. For example, the study found that 5.4% of inspected carcasses were positive for porcine cysticercosis (Gule, 2008).

2.6.5 Cultural beliefs

Human behaviour and cultural practices have a profound effect on the range and prevalence of diseases suffered by tropical communities, though this is considered as “the forgotten factor in the transmission of tropical disease”. However, while behaviour can often help in understanding the epidemiology of a disease and even in making a correct diagnosis, in particular, knowledge of human behaviour is essential in the planning of disease control programmes (Goldsmid, 2005).

Cultural beliefs embrace the worldview of the people and vary from a community to community. The way people of a certain community perceive and act towards certain phenomena is mostly influenced by their cultural beliefs (religion, customs, etc.). According to Goldsmid (2005), what people eat can be determined by their religion. For example, the restrictions of Jews and Muslims relating to the eating of pork and the burying of human faeces may protect them from such parasites as *T. solium*.

However, religious and traditional practices may have both positive and negative effects on health. They can have a marked influence on disease patterns through medical (public health) and social directives. Traditional medical practices, widely used in developing countries and the practitioners of scientific medicine may come into conflict. But, traditional medical practices do impact on the medical system in many countries/areas, particularly amongst remote rural populations (Goldsmid, 2005). For

example, in Mozambique, although medical care is available in health centres, a large number of people make use of faith healers (Vilhena *et al.*, 1999).

The practice of using faith healers may help to propagate certain diseases such as cysticercosis. In South Africa, for example, one of the modes of transmission is where self-trained healers use *Taenia* segments either for benevolent (in the treatment of severe intestinal tapeworm infections) or malevolent purposes (women 'poisoning' an unfaithful husband or lover by adding the contents of *T. solium* segments to beer) (Mafojane *et al.*, 2003).

Other practices and attitudes that may help the spread of cysticercosis include eating raw pork and use of human faeces as fertiliser for food plants (Goldsmid, 2005). Many of these practices continue to be used in many communities not only because they are part of their culture, but also because, probably, people are not aware of the risks of their actions regarding the transmission of the disease.

2.6. 6 Knowledge about cysticercosis

One of the key factors in the process of prevention and controlling of diseases is information and awareness. Studies (Prasad *et al.*, 2002; García *et al.*, 2003) have shown that very little is known about the natural history of *T. solium* infection at community level. This unawareness may lead to infection and re-infection of people and pigs in the target communities.

According to Carabin *et al.*, (2006), infection and disease remain uncontrolled because of lack of information and awareness about the problem, and the absence of suitable diagnostic tools and intervention strategies appropriately adapted to Africa. Thus, infection in pigs and meat is not recognised as something unusual or as a health hazard. In addition, Bern *et al.* (1999) concluded that in rural villages, seizure disorders are poorly understood. In many parts of Mozambique, for example, porcine cysticercosis is not yet recognized (Vilhena *et al.*, 1999); and in Angónia rural district, there is no information on the mode of transmission of cysticercosis among the key players in the trade (Gule, 2008).

A study in Chunya district, Tanzania (Boa *et al.*, 2001), found that 94% of the respondents were ignorant of the mode of transmission of *T. solium* taeniosis/cysticercosis and 45.2% allowed their pigs to roam about scavenging for food

especially in the post-harvest period (Mafojane *et al.*, 2003). Another study conducted in Lao regarding the relationship between epilepsy and pig consumption showed that 42% of the respondents viewed epilepsy as having a supernatural origin, while 60% of respondents associated it with pig consumption (Tran *et al.*, 2007).

Lack of awareness by the medical community is an important issue either in developing countries/endemic areas or developed countries. For example, in non-endemic industrialized countries, imported cases have been found in carriers of intestinal-stage *T. solium* infection who, through food-handling and other modes of contact, were responsible for locally-acquired cases of neurocysticercosis (WHO, 2003).

2.7 Theoretical framework

This study was guided by the ecological approach with cultural and biological parameters and Kleinman's explanatory model.

2.7.1 Ecological approach with cultural and biological parameters

Ecological model owes its basic lineaments to revolutionary theoretical syntheses in the biological sciences, specifically in evolutionary biology during the 1970s (Wellin, 1974). The approach was later developed by Eduard Wellin (1974). This author considers that there are three basic empirical generalizations in medical anthropology. The first is that disease, in some form, is a universal fact of human life, it occurs in all known times, places and societies; the second states that all known human groups develop *methods* and allocate *roles* congruent with their resources and their structure for coping with or responding to the disease; and the third considers that all groups develop some sort of *beliefs, cognitions and perceptions* consistent with their cultural matrix, for defining or organizing the disease.

However, Wellin (1974) notes that these assumptions have weakness and strength. The strength is anchored in the fact that they summarize and order a large number of specific time-place-people observations, thus they provide a rich empirical base and many points of departure for medical anthropology research. The weakness consists in that they can describe and observe regularities in nature, but they cannot explain them.

Wellin (1974) expands the ecological model from criticisms of these three assumptions. According to the author, the ecological model is concerned with dimension of the

disease. It deals with how biological factors, culture, and/or environmental pressure influence the process or distribution of the disease, and investigates socio-cultural factors, including the cognitive and consequences of given diseases in given particular groups.

The ecological model comprehends biological variables, viewing health and disease (whether as dependents or independent variables) as expressions of dynamic relationship between populations, their cultures, and their environment (Wellin, 1974). This model recognizes that people may change their environment drastically through the adaptive mechanisms of culture, and this changed environment then may influence people's physical structure and behaviour. This means that there is continuous interaction between disease and population variables.

The scope of ecological model includes societies and populations, the behaviour of human groups and of microbiota, perceptions of the environmental features, definitions of disease and disease itself, ethno-medicine (traditional system) and modern medicine (Wellin, 1974). Thus, this model acknowledges the influence of cultural environment in disease and its interaction with biologic factors and ecological system.

2.7.2 Kleinman's explanatory model

This study was also guided by Kleinman's explanatory model published in his book "*Patients and healers in the context of culture*" (Kleinman, 1980). This model suggests a way of studying the relationship between culture and medicine and provides a classification for healing activities in plural medical systems. The model proposes three health care sectors: popular sector, professional sector and folk sector.

The popular health sector consists of lay, non-professional, non-specialist domain of society, where ill-health is first recognized and defined and then health care initiated. It includes all the therapeutic options that people utilize without any payment and without consulting either folk healers or medical practitioners. Among these options are: self-treatment or self-medication, advice or treatment given by a relative, friend, neighbour or workmate, healing or mutual care activities in a church, cult or self help group (Kleinman, 1980).

Kleinman also notes that in all societies, the majority of sickness episodes are managed entirely within this sector, often at the household level and under the supervision of

mothers and other women. In this sector, healing is not the privileged activity of selected practitioners (Joralemon, 2005). This sector also includes a set of beliefs about *health maintenance*. These are usually a series of guidelines that are specific to each group about the “correct” behaviour for preventing ill-health in oneself, and in others. They include beliefs about the “health” way to eat, drink, sleep, dress, work, pray and generally conduct one’s life (Helman, 1994).

At the opposite extreme, Kleinman identifies professional health care sector, in which healing is carried out by persons with specialized training and knowledge, such as modern western medicine. Some of the defining features of a healing profession are: standardized and formal training based on an organized body of knowledge; credentials or licences required to practice; structured relationships among those in the profession (for example, mutual referrals, specializations, prestige/experience rankings); organizations that enforce standard of practice, share knowledge, and protect the profession from competitors (Joralemon, 2005; Helman, 1994).

In an intermediate position, between the popular and professional sectors, there is a folk sector, in which healing is performed by “non-professional, non-bureaucratic, specialists” (Kleinman, 1980). Folk healers typically undergo a non-formal education, often by apprenticeship, to learn their curing art (Joralemon, 2005). This sector is largely dominant in non-western societies, and folk healers use *sacred* or *secular*, or a mixture of two healing process. Most folk healers share the basic cultural values, and world views of the community in which they live, including beliefs about the origin, significance and treatment of ill-health (Helman, 1994).

Although each sector has its particular ways of healing, there is interaction of the three sectors. According to Joralemon (2005), though the populace as a whole may not be fully aware of the subtleties of the folk healer’s practice, the overlap between popular sector and folk concept of disease is greater than that between the popular and professional sectors.

Kleinman (1995) also acknowledges that the boundaries between these three sectors are fluid and contested. Knowledge and practices from the professional sector can be adopted by the folk and popular sectors. In his book “*Writing in the margin*”, using a case study of epilepsy, he shows the possible relationship among the sectors. According to him, in ill-health, people develop social settings and interpersonal networks in the

local world, which help them to identify and take decisions about the condition. The social settings include both formal and informal sectors of health care, and network of connections that can mobilize needed resources, or further drain reserves. Interpersonal networks, work units, and the sectors of care may combine in one case of epilepsy to lighten financial and emotional burdens and to minimize the effects of bias so that disability is avoided. In another case, social experience about the disease in the community may deepen the suffering of patients and families. Epilepsy, in turn, can effect changes in those worlds, altering the experience of families, network, and work units, as, for example, when the social and financial relations of network members are placed under great pressure by a serious recrudescence of seizures such that reciprocity is broken and bitter resentment results (Kleinman, 1995).

Kleinman's explanatory model suggests a holistic study of a disease and it enables researchers to explain both biological and cultural aspects of the disease. It also represents the idea of an episode of sickness and its treatment in a certain culture. The explanatory model notation is presented in Figure 2.2.

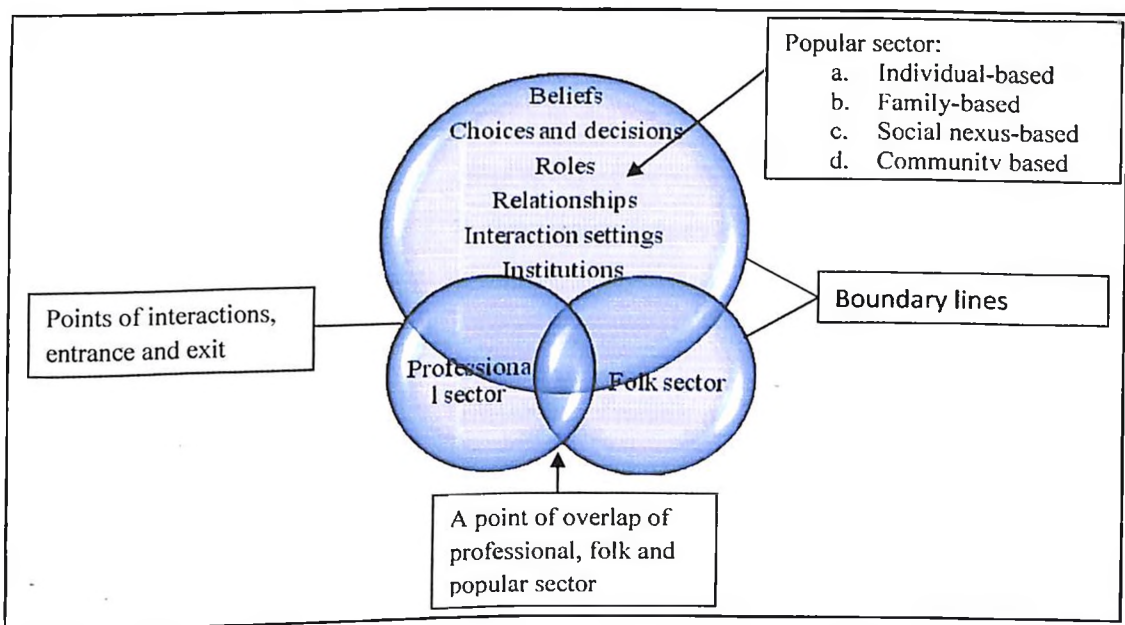


Figure 2.2: Kleinman's Explanatory model (Source: Kleinman, 1980).

The Kleinman's explanatory model notation shows how people interact within the three health sectors. For example, a sick person or her/his relatives seek treatment in the popular sector before opting for other sectors. In this sector healing is based on faith,

beliefs and cultural practices. If the outcomes are not satisfactory, then they move either to folk sector or professional sector, or combine both sectors. After patients receive a treatment, they turn to the popular sector to evaluate it and decide what to do next. The decision whether to choose the folk or professional sector is discussed with the family and friends in the popular sector. However, those who choose folk sector, if the problem is not solved, move to the professional sector. The same may happen to those who choose the professional sector as their second option. They may either move to the folk sector or decide to go back to the popular sector, especially in case of chronic disease. Sometimes, patients use the three health sectors at the same time for the treatment of the disease.

2.7.3 The relevance of the ecological approach and Kleinman's explanatory model to the study

The ecological model links biomedicine with biological culture and environment, resulting in important contributions to understanding health and disease as dynamic and adaptive in certain culture and environmental context. The model also presents a holistic perspective in studying health and disease because it considers that health and disease are part of a set of physical, biological, and cultural subsystems that continually influence one another. In this study, the model was used to describe and explain the relationship between presence of white nodules in pigs and people's practices, such as pig rearing practices and hygiene. It also enabled us to study how people perceive their environment in relation to health-disease and how they cope with the changing of the environment, such as the appearance of *T. solium*.

On the other hand, Kleinman's classification of health care sectors helps to organize the diversity of healing roles into a comparative framework in a certain cultural context. The model highlights the health system available and how people interact with it according to their perceptions and beliefs. Thus, in this study, the model allowed us to explain how people experience neurological disorders (epilepsy) and how the episode of sickness and its treatment are perceived and managed in Angónia rural district. It also enabled us to see the decisions that people take regarding the management of white nodules in pigs.

The explanatory model also enabled the study to examine the relationship between people's perceptions and knowledge of the disease. This allowed the analysis between

knowledge and beliefs and the decisions that people take to prevent or treat white nodules in pigs and neurological disorders in humans.

Although the two models present complementary elements for the analysis of cysticercosis, they have limitations. The ecological model provides a framework for the study of health in an environmental context, but it does not specify what factors maintain health within any given local system. The model does not also explain what actions people take to deal with the changed environment or when they are affected with the disease. On the other hand, Kleinman's explanatory model provides a framework for the analysis of what action people take to deal with the disease, but it does not provide elements for the study of health in an environment context. The two models were combined in one conceptual framework to facilitate the analysis of data on cysticercosis (Figure 2.3).

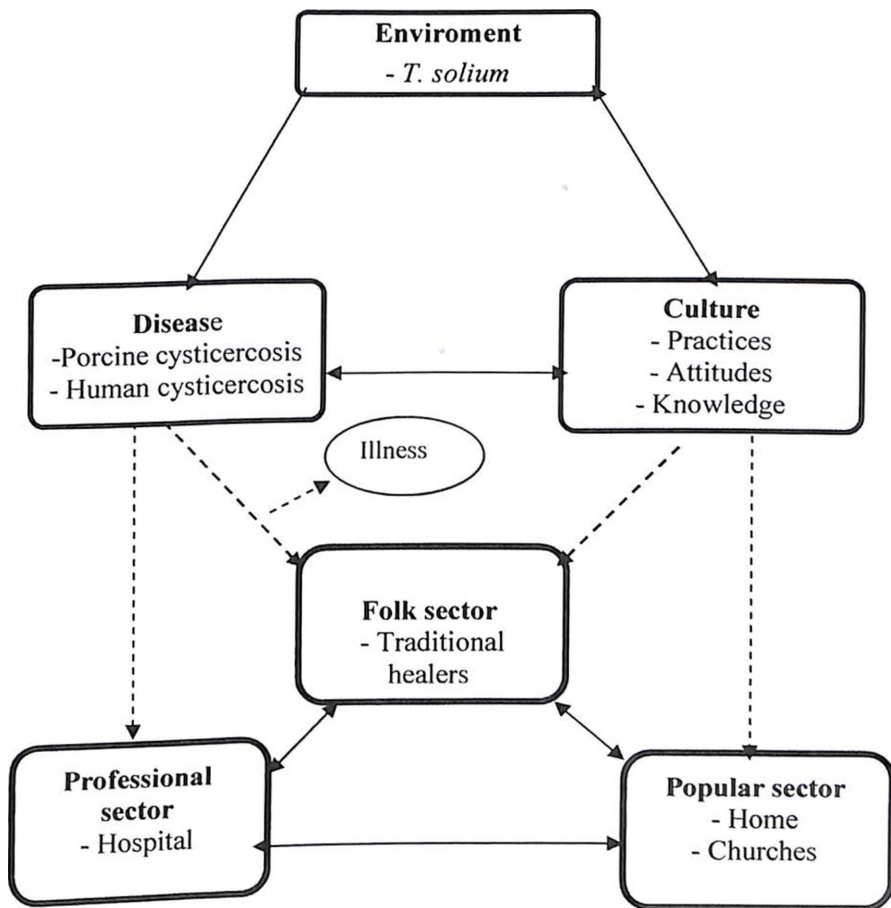


Figure 2.3: Conceptual framework of cysticercosis management

The conceptual framework shows the interaction among different components regarding porcine and human cysticercosis. Cysticercosis is an environmental disease transmitted between pigs and humans. However, humans can be infected through faecal transmission due to their practices, attitudes and lack of knowledge. Once humans are infected by cysticercosis they use different health sectors such as popular, folk and professional to manage the disease. When patients use popular and folk sectors to treat the disease, it is considered that they perceived it as illness and the causes are associated with cultural factors such as witchcraft. On the other hand, patients move to professional sector when they perceive that the causes of the disease are associated with biological factors, such as infected pork consumption.

In the health care system, patients may use or combine different sectors to treat the disease, depending on the outcomes of the treatment in one sector. The choice of health sector may be influenced by social network and beliefs. The first option is that patients may move from popular to folk or professional sectors. In the second option, patients may move in between popular and folk sectors and between popular and professional sectors. Third option is that, sometimes, patients may combine the three health sectors at the same time to treat the disease.

2.8 Assumptions

1. People's knowledge influences their perceptions of the transmission of neurological disorders in humans and white nodules in pigs in Angónia rural district.
2. Local practices related to pig rearing, culinary and hygiene favour the transmission of neurological disorders in humans and white nodules in pigs.
3. The way people understand the causes of neurological disorders in humans and white nodules in pigs determine the means that they employ to cope with the disease.
4. People can change their attitudes towards neurological disorders and white nodules associated risks if they know that their practices may expose them and pigs to diseases.

2.9 Definition of key terms

- Neurological disorders** are diseases of the central and peripheral nervous system. These disorders include, among others, epilepsy, alzheimer and stroke. In this study only epilepsy was investigated.
- Perception** is an image or feelings that people have according to the way they understand or see certain things. In this case, we asked the following question: how do you view white nodules in pigs? And how do you view epilepsy?
- Practice** is an action taken regularly to do certain things or solve a certain problem or event. In this case, we looked at local habits and customs such as cooking practices, hygiene and pig rearing used in the community. We also looked at actions taken to manage white nodules in pigs and neurological disorders in humans.
- Transmission** is a process of passing an infection from one individual to another.
- Knowledge** is the state of knowing about particular fact or situation. In this case it includes information through scientific knowledge of the disease (aetiology) or common sense (experience).
- Hygiene** refers to the state of a certain place. It includes practices of maintaining health such as food preparation, water conservation, and disposition of a home (condition of the house, toilets, domestic and personal cleanliness).
- Management** is an action taken in order to heal animals or people infected by a certain disease. In this case, we asked: what do you do treat white nodules in pigs? And what do you do to treat epilepsy?
- Health care system** is a system where healing activities take place. In this context we are talking about hospital (government and private hospitals), faith healers or herbalists (folk sector) and self-treatment (popular sector).

CHAPTER THREE: Methodology

3.1 Introduction

This chapter presents information on the research site, sample population and sampling procedures, as well as instruments of data collection and data analysis. Problems encountered and ethical considerations are also presented.

3.2 Study site

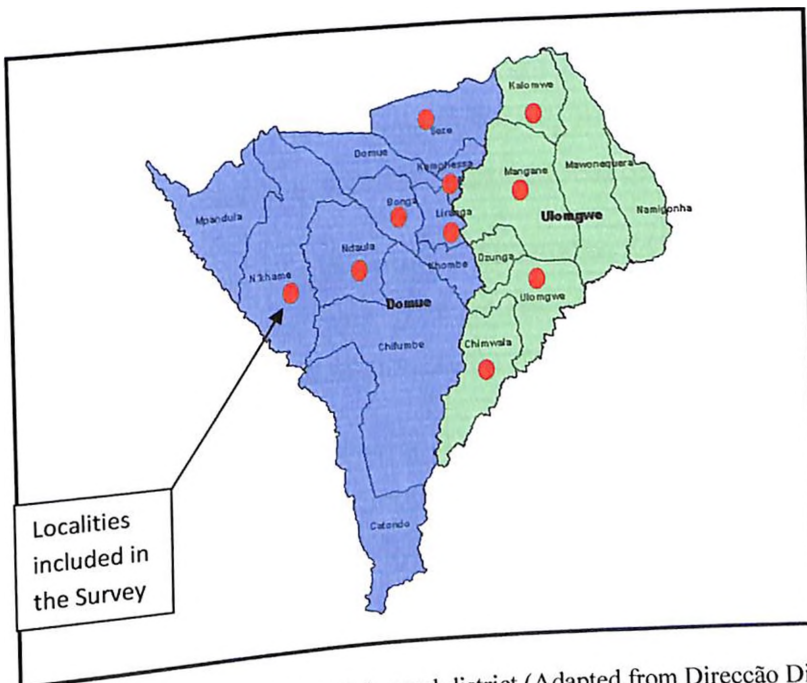
The study was conducted in Angónia rural district, Tete province, which is located in north-western Mozambique, between latitudes 14.46°S and longitude 34.45°E. The area borders Malawi to the north and east. The dominant vegetation is that of shrub land (Direcção Distrital de Agricultura de Angónia, 2006).

In 2007, there were 335,808 inhabitants in the district, with a density of 72,2 inhabitants/Km². The total number of households in the district is 1,080 (INE, 2007). The district is divided into 2 administrative posts: Ulongue and Domue. Ulongue administrative post has 6 localities and it has a population of 161,001 inhabitants, while Domue administrative post has 11 localities with a population of 174,807 inhabitants (INE, 2007; MAE, 2005). Ulongue was declared a district municipality in 2009. The main Government and private institutions are located in this administrative post.

The road network in the district is in a poor state, and people mostly use bicycles, motorbikes and cars as means of transport. However, only some cars with open cabs are used as public transport in the district, linking the two main administrative posts. During rainy season, many of the localities and villages are not accessible either by car or motorbike.



Map 3.1: Location of the study site in Mozambique (Source: Direcção Distrital de Agricultura de Angónia, 2006)



Map 3.2: Study localities in Angónia rural district (Adapted from Direcção Distrital de Agricultura de Angónia, 2006)

3.2. 1 Climate

The district is characterized by a humid climate that receives an annual rainfall ranging between 1100 and 1200 mm. The rainy season extends from October to mid-March and the dry period extends from April to September. Relative humidity is about 70% and the mean annual temperature ranges from 18° to 22°C (Direcção Distrital de Agricultura de Angónia, 2006).

3.2.2 Socioeconomic activities

The main economic activity in Angónia rural district is subsistence agriculture and the people practice mixed farming. They cultivate different crops such as maize, beans, cassava, potatoes, pumpkins, peanuts, as well as vegetables such as cabbages, spring greens, pepper, cucumber, carrots, lettuce, garlic, tomatoes, and onion. The community also cultivate cash crops such as tobacco and soya beans. Tobacco is supported by Mozambique Leaf Tobacco, an international enterprise based in Tete City, and it is the most dominant cash crop in the district. Almost every farmer cultivates tobacco, and it is considered the major means of income for many families.

The community also keep pigs. The total number of pigs in the whole district is about 3500 animals. Besides pigs, the people also keep cows, goats, sheep, chickens and ducks (MAE, 2005; Direcção Distrital de Agricultura de Angónia, 2006), rabbits and pigeons. Animals such as goats, chicken and ducks are generally for home consumption while pigs, cows, goats and sheep are for trading (MAE, 2005). Pigs are generally easier to sell than cows, and the revenue helps with financial needs of the household.

Pig keeping has been increasing in the district, but studies (Afonso *et al.*, 2001) have shown that some pigs are infected with cysticercosis. Porcine cysticercosis was 6.5 – 33.3% in pigs, and the number tends to increase due to free-range husbandry system.

In terms of gender labour division, women mostly sell bread and cakes, and they are engaged in activities such as ceramic production and distillation of traditional brew, while men are engaged in activities such as carpentry and ceramic production (MAE, 2005).

3.2.3 Education

The general level of education in the district is very low. Available data show that 81 % of the population is illiterate, and only 11.4 % of the population speak Portuguese (MAE, 2005). The low level of education in the district is due to, among other factors, the civil war between two competing political parties: FRELIMO and RENAMO. Like many other rural districts of Mozambique, Angónia was hit by the civil war from 1976 to 1992 (Young, 1991). Many people emigrated to Malawi and Zimbabwe as refugees and they were not offered any education. However, even after the civil war many children could not access education due to shortage of schools, lack of school fees and unavailability of teachers. It was not until 2005 that the Government implemented free primary education and increased education facilities.

The district has 145 schools, out of which 142 are primary, 2 are secondary and one is a technical school. There are also 86 community alphabetization centres for adult education (MAE, 2005). These alphabetization centres provide the basic writing and speaking skills to the adult population. The program is implemented by educated individuals (who at least completed class 7 or more) and local community radio programs.

3.2.4 Health

Angónia rural district has two types of health sectors. Traditional system composed of folk health practitioners, and the modern health system consisting of 1 rural hospital, 4 health centres and 3 health posts. The most common diseases in the district are malaria, cholera, diarrhoea, tuberculosis, and sexually transmitted diseases such as HIV and gonorrhoea (MAE, 2005; MISAU, 2006).

Although neurocysticercosis and epilepsy are not clearly documented in the local health care system, a study by Afonso *et al.* (2001) indicated that 20% of the people were infected by neurocysticercosis, and some cases of epilepsy were related to cysticercosis.

3.2.5 The socio-cultural setting and everyday life in the district

The socio-cultural characteristics and everyday life in the district were important in this study, since they revealed certain practices and the cultural environment that contribute to the spread of *T. solium*.

The majority of the inhabitants are the Chewa, an ethnic group that is matrilineal (Gough, 2004; MAE, 2005). Unlike the patriarchal societies, the Chewa practice matrilocality. However, before a man moves to his wife's parent's home, he must build a house, a latrine and a bathroom in his wife's compound. Traditionally, once a daughter is married, she and her husband are not supposed to share the same latrine and bathroom with the parents. The compounds are generally small and the houses are either square or circular in shape. Some houses are built of wood and sand, and covered with grass, while others are built of bricks. The houses are close to each other and in some compounds, pig pens are built close to the latrines.

Women have a special place in Chewa society's belief system. They are recognized as reproducers of the lineage, which is an extended family of people related to the same ancestor (Gough, 2004). Women do housework, undertook agricultural activities, took care of small animals such as chicken, rabbits, pigs, goats, and duck, and some of them participated in commercial activities, especially selling of vegetables and other agricultural products. Men participated in farming (farming and harvesting of tobacco), took care of cows and pigs, and other commercial activities, especially selling of tobacco and beans. Some men were involved in external commerce and they travel to Malawi to buy products, such as soft drinks, beer and clothes, to be sold in the community.

The commercial activities take place every day in many local markets, but there are also "market days", which take place along the two main roads (one road links Angónia and Tete City and another links Angónia and Malawi). Along these two roads, there are up to 55 markets. Each market has its own market day, and local business people keep rotating in the markets according to the market day. In these markets, people sell agricultural products, vegetables, crafts, clothes, food and drinks. Common foods include fried, roasted pork, goat and chicken and chips.

The dominant currency in many villages of the district is the Malawian Kwacha, especially in those villages bordering Malawi. Metical, the local currency is only dominant in the district head quarters.

Angónia rural district is also rich in religious diversity, but there are only a few Muslims. There are different churches in the district, such as Catholic, Protestant Reformed Church, Jehovah Witnesses, Presbyterian Church, Zambeze Evangelical

Church, Nazarene Church, Four Square Church, Water's Life church), Universal Church of the Kingdom of God, Abraham Church, God's Harvest Church, God's Miracles Church, God Assemble Church, Zion Church, Gule Church, Seventh Day Adventist Church, Islamic and Xitauara Church.

The most popular church in the district is the Roman Catholic Church. A census undertaken in 1997 showed that the Catholic Church was dominant with 43.2%, followed by Zion Church with 20.7%, Evangelical Church (3.4%), Jehovah Witness Church (3.4%) and other Churches with 28.2 % of followers (INE, 1997).

3.3 Study design

This study was exploratory and it adopted cross sectional design. The study collected qualitative and quantitative data on community perceptions and practices of the transmission and management of neurological disorders in humans and white nodules in pigs in Angónia rural district. The field work was carried out between the months of January and March 2009. The study was carried out in two different phases. The first phase entailed visiting the study site. It was in this phase that we contacted the main local stakeholders (Administrative officers, community leaders and community members) in order to obtain permission to conduct the research. The objectives of the study were explained, pig keeping administrative posts and villages were identified. In the second phase, we conducted the survey, key informant interviews, narratives, direct observations and focus group discussions.

3.4 Study population and unit of analysis

Population refers to the entire group of individuals, events or objects having a common observable characteristic and unit of analysis refers to those units that we initially describe for the purpose of aggregating their characteristics in order to describe some larger group. Therefore, units of analysis are the individuals units about which or whom descriptive or explanatory statements are to be made (Mugenda and Mugenda, 2003; Bernard, 2006). The population of this study consisted of all households in Angónia district with pigs or without pigs and with people suffering from epilepsy or not. However, the unit of analysis was the individual household head, whether a man or a woman who was 18 years old and above. We chose this unit of analysis because the household heads were considered central to individual perceptions and practices in the community.

3.5 Sample size and sampling procedure

The research adopted both probabilistic (simple random) and non-probabilistic (convenient) methods to obtain its sample. According to Nachmias and Nachmias (2005), simple random is a procedure that gives each of the total sampling units of the population an equal known nonzero probability of being selected. Simple random was applied to select 10 out of 17 localities (4 localities from Ulongue administrative post and 6 from Domue administrative post). To access the 10 localities, all names of the localities were written down on different pieces of paper. The different papers were folded, mixed and one local leader was requested to pick 10 pieces at random without reaping. Simple random was used to select the localities in two administrative posts because all localities kept pigs. The localities included in the survey were Mangane, N'kame, Chimuala, Seze, Bonga, Lilanga, Kalomue, Ulongue, Kampensa and Ndaula.

After the 10 localities were selected, one village was selected conveniently from each locality for the survey. In each village, 15 respondents were conveniently selected, 10 pig keepers and 5 non-pig keepers. Therefore, 150 respondents were selected for the survey. The respondents were identified with the help of village leaders. Local village leaders identified households with and without pigs while survey was taking place. If a respondent in the household was not present, the next household was picked.

The choice of 15 households in each village was made arbitrarily because there was no exact record of households with pigs and those without, and no accurate information on the number of the villages in each locality. Thus, we could not use the simple random methods.

Apart from the respondents, five traditional healers who had knowledge and experience regarding the treatment of the diseases were interviewed. One health worker who was a specialist in treatment of epilepsy in rural hospital of Ulongue was interviewed and five people suffering from epilepsy narrated their experience regarding the disease. These informants were selected conveniently with the help of local leaders and research assistant. A total number of 45 participants in the focus group discussion, of which 27 were pig keepers and 18 were non-pig keepers, were included in the study. The participants were selected from the surveyed population and were identified with the help of local leaders. A summary of sample population is presented in Table 3.1.

Table: 3.1: Summary of study population

Method of data collection	Gender of study population		
	Male	Female	Total
Survey	95	55	150
Focus group discussions	23	22	45
Key informants (Traditional healers)	5	-	5
Key informants (Health workers)	1	-	1
Narratives (people with epilepsy)	3	2	5
Total	127	79	206

Ten observations were made, five at local pork roasting centres and five at household level. Pork roasting centres were those that prepared pork in the open view of the customers and were conveniently selected. Hygiene in pork preparation and time of cooking were observed. At the household level, arrangements were made in order to access their acceptance. Only household that accepted the observation were included in the study. The researcher bought pork and delivered to the households and observations consisted on the time and preparation methods. The households were selected conveniently with the help of local leaders.

3.6 Methods of data collection

3.6.1 The Survey

Survey method was used to collect quantitative information about peoples' perceptions of the relationship between the presence of white nodules in pigs and neurological disorders in humans. The method was also used to identify local practices that favour the transmission of cysticercosis, and the methods used to manage white nodules in pigs and neurological disorders in humans. Thus, a questionnaire with close-ended and open-ended questions (Appendix 1) was directly administered to the 150 respondents.

3.6.2 Key informant interviews

Key informant interview is a type of personal interview that consists of a face-to-face situation in which an interviewer asks respondents questions designed to obtain answers pertinent to the research hypotheses (Nachmias and Nachmias, 2005). In this case we considered focused interview, which followed an interview guide specifying topics

related to the research. This instrument was used to collect qualitative information from key informants. The information was on causes of infection and transmission, changing attitudes towards cysticercosis associated risks and management of neurological disorders in humans and white nodules in pigs. The key informants were selected conveniently with the help of local leaders and research assistant, and consisted of traditional healers and one health worker in the local hospital. A total of 6 informants were interviewed, using a key informant interview guide (Appendix 2) and the information was recorded and taped.

3.6.3 Focus group discussions

Focus group discussion (FGD) is a form of qualitative research in which a group of people are asked about their attitude towards a product, service, concept, advertisement, idea, or packaging. Questions are asked in an interactive group setting where participants are free to talk with other group members (Rushkoff, 2005). This instrument was used to collect qualitative data on peoples' attitudes toward cysticercosis associated risks and methods of management of the disease. Five groups constituted with between 8–10 participants selected from surveyed population were involved in two localities of Ulongue administrative (Mangane and Ulongue) post and three localities of Domue administrative post (Bonga, Kampensa and Lilanga). Out of the five FGDs, three were for pig keepers and two were for non-pig keepers. In these FGDs, two were constituted by men, two comprised by women and one included both men and women. The information discussed was recorded and taped.

3.6.4 Narratives

Narrative is a construct created in a suitable format that describes a sequence of events about certain phenomena. This method was used to collect qualitative information concerning experience and suffering of people with epilepsy in their everyday life. In this issue, five key informants suffering from epilepsy at the household were given an opportunity to narrate their experience. These informants were selected conveniently with the help of local leaders and the information was recorded and taped with the permission of the informants.

To identify people suffering from epilepsy, a screening tool developed by Cysticercosis Working Group in Eastern and Southern Africa (CGWESA) was used. This screening tool consisted of a structured interview guide that contained indicators that enabled us to

access information regarding people suffering from epilepsy. However, for the purposes of this study, only some indicators were adopted according to the objectives of the study. Themes related to this matter included timing of the disease, causes, means of transmission and prevention, management, coping mechanism and challenges that they faced in their situation.

3.6.5 Direct observations

Direct observation method was used to generate qualitative information about pork preparation methods at the household and pork roasting centres. To access this information, five observations were made at household level and five observations at local pork roasting centres. The observations were made at least twice in each place. In this regard, issues such as hygiene in pork preparation, time of boiling or roasting pork were observed in the pork roasting centres and households. At the household, during survey, the technique also enabled us to collect information about pig management and environmental conditions in the study area. In pig management, it was observed pig rearing practices, type of pig pen and pig feed. In term of environmental conditions, hygiene in the household, presence and type of latrine were observed.

3.6.6 Secondary data

The research also relied on secondary data from authored books, journals, world organizations' reports and internet reports and non published reports on porcine cysticercosis and epilepsy.

3.7 Methods of data analysis

Qualitative and quantitative data were analysed separately. The content of qualitative information was analyzed thematically. This involved transcription of the information taped and recorded, organization, interpretation and analyzing information generated through focus group discussions, key informant interviews, narratives and direct observations. Quantitative data obtained through survey was coded, entered, cleaned and analyzed using the Statistical Package for Social Sciences (SPSS) computer software. This method helped to generate aggregate information, which was presented in measures of central tendency and dispersion such as mean and median. The information was described and presented in tables of frequencies as well as figures. To identify the scientific names of the plants used for pig's feeds and epilepsy treatment in Angónia rural district, photos and sample of the plants and leaves were taken to the

Faculty of Botany. Basing on the sample and characteristics of the plants and leaves, specialists in botany classified and identified the manes of the plants.

3.8 Problems encountered

During research, various problems were encountered, especially accessibility to the selected localities; since it was the rainy season and the roads in the district were poor. During rainy days, we could not go to the field and conduct survey, and sometimes we had to interrupt field work due to the rain. Some randomly selected localities could not be accessed either by car (even four wheel vehicles) or motorbike because when it rains, the sand turns into mud, which made it impossible to drive. To solve this problem, two localities that could not be reached were substituted conveniently. Accessing respondents was another problem, since at that time of the year, many farmers were busy with farming activities, such as harvesting beans and selling tobacco. In many cases, we had to go 2 times in each village in order to complete the survey. As a solution of this problem, the interviews were conducted in the afternoon, when many farmers would be coming from their fields.

Local language (*Chewa*) was another problem, since not all participants could speak Portuguese and the researcher did not speak the local language. To access the language of the respondents, a research assistant was hired and trained on the aspects and objectives of the research. This made the researcher depend on the research assistants that, sometimes, delayed the research process. To compensate for the time lost, the researcher sometimes worked with local leaders who could speak both Portuguese and Chewa as complementary alternatives. Local leaders who helped with the survey were first quickly trained on the aspect of the research. To ensure that they had understood the training, they were first interviewed and then they interviewed somebody else before they assist the researcher.

Some respondents had high expectations from the researcher, such as providing them with pigs or piglets, which could resist African swine fever or even treatment of their animals and children suffering from epilepsy. To deal with these expectations, the community members were explicitly told that the ongoing activity was purely research, which would provide accurate information about the situation in the district to the Government and other organizations, which could possibly help them to treat pig disease and provide medication to people living with epilepsy.

3.9 Ethical considerations

The research received all the necessary approvals from the relevant authorities. Thus, before the research started, the proposal was defended at the Institute of Anthropology, Gender and African Studies, and then submitted to the ethical and scientific committee of Eduardo Mondlane University for ethical clearance. The aim and benefits of the study were explained to the key community leaders and participants in the study area. Respondents were assured of privacy, anonymity, and confidentiality during the study. In order to ensure this privacy, respondents' names quoted in the text are pseudonyms.

Respondents had a right to accept or decline participation in the study. Before the interviews, respondents were asked whether they wanted to participate in the study or not. Only respondents who were willing to do so were included. However, all respondents had a right to drop out or not to answer certain questions if they wished to do so. Respondents also had a right not to give their names and any other information they did not wish to volunteer.

Results from this study will be communicated to the study community and CESA project since the project provided funds for undertaking this study, and later on, the findings will be presented to the scientific community.

CHAPTER FOUR: Pig husbandry in Angónia rural district

4.1 Introduction

This chapter presents demographic information of the study subjects and pig husbandry in Angónia rural district.

4.2 Demographic characteristics of the study population

The demographic characteristics of the respondents are shown in Table 4.1 below.

Table 4.1 Demographic characteristics of respondents (N = 150)

Characteristics	Pig keepers		Non-pig keepers		Combined	
	Number	Percentage	Number	Percentage	Number	Percentage
Gender						
Male	61	61	34	68	95	63.3
Female	39	39	16	32	55	36.7
Total	100	100	50	100	150	100
Age Group (Years)						
18-35	40	40	24	48	64	42.7
36-55	40	40	15	30	55	36.7
56 and above	20	20	11	22	31	20.6
Total	100	100	50	100	150	100
Education Level						
None	56	56	29	58	85	56.7
Primary (1-6 years)	42	42	16	32	58	38.7
Middle (18-10 years)	2	2	5	10	7	4.6
Total	100	100	50	100	150	100
Occupation						
Farmer	99	99	47	94	146	97.3
Teacher	0	0	3	6	3	2
Tailor	1	1	0	0	1	0.7
Total	100	100	50	100	150	100

4.2.1 Gender

Out of the 150 respondents involved in the survey, 95 (63.3%) were males and 55 (36.7%) were females (Table 4.1). Among pig keepers, 61% (61 respondents) were males and 39% (39 respondents) were females, while 68% (34 respondents) were males and 32% (16 respondents) were females among non-pig keepers.

4.2.2 Age

The age of the respondents ranged from 18 to 56 years old and above. Most of the respondents (42.7%) were between 18 and 35 years old (Table 4.1).

4.2.3 Education

More than half (56.7%) of the respondents had no formal education (Table 4.1). Although 38.7% of the respondents had attended primary school, findings suggest that many of those who had completed between 1-4 years of schooling could not speak, write and read Portuguese, the national language. Over 4.6% had education beyond primary.

4.2.4 Occupation

Angónia rural district is dominated by agricultural activities. The kind of farming practised in the study area is subsistence agriculture. Farmers mostly use hand hoes for tilling the land, but occasionally use oxen-plough. The main crops cultivated are maize, beans, cassava, potatoes, pumpkins, peanuts and vegetables. The vegetables include cabbages, pepper, cucumber, carrots, lettuce, garlic, tomatoes, and onion. The farmers also cultivate tobacco and soya beans, which were used as crop. Along with agriculture, small scale farmers keep animals such as cattle, pigs, goats, chicken, rabbits, ducks and pigeons. As expected, the majority of the respondents (97.3%) were small scale farmers (Table 4.1). The remaining respondents were teachers (2%) and tailor (0.7%).

4.3 Community perceptions of pig keeping

Most of the respondents (97.7%) viewed pig keeping as a good practice because pigs were considered as animals that multiplied quickly and brought in a lot of money. The remaining 2.3% perceived pigs as animals that were difficult to keep. It was among non-pig keepers that pigs were viewed as difficult to keep. This finding suggests that the underlining principle is the incomes that respondents may get from selling pigs.

Focus group discussions (FGDs) confirmed that pig keeping in Angónia rural district was perceived as good because of its benefits. During discussion with pig keepers, participants expressed their perceptions. One of the participants said:

“It is good to keep pigs because they can help. If you have pigs, you can sell and you can get manure for vegetables and field planting. You can also slaughter and use it to pay people who work in the field” (FGD with pig keepers).

Even among non-pig keepers, pig keeping was viewed as an activity that can add to family incomes. For example, in some FGDs, non-pig keepers discussed the potential profits one could get from keeping pigs. They considered pig keeping as good practice because they multiplied quickly and gave quick income and manure.

Respondents viewed pig keeping as a practice that improves family incomes in many households. They are used to provide extra income to the family, as payment for services rendered and they provide manure, which is used to improve crop fields. Information obtained through FGDs on the importance of animals kept in the community show that pigs were ranked between 1 and 3. Other animals such as chicken, ducks, rabbits, pigeons, goats and cattle were ranked between 1 and 6. Among pig keepers, 2 FGDs considered pigs as number 3 and chicken and ducks as number one, while cattle and goats were placed number 4 and 5, respectively. On the other hand, one FGD of pig keepers and 2 FGDs of non-pig keepers ranked pigs as number 1, and chicken and ducks as number 2, goats and cattle number 4 and pigeons and rabbits as number 5 and 6 respectively.

It is important to mention that the fact that respondents ranked cattle number 4 does not mean that they were not important to them. For example, participants used accessibility of animals, ease of management, markets to sell and profit to be accrued as the criteria in ranking the animals. Those that placed chicken, ducks and rabbits as number 1 stated that these animals provided them with meat, while pigs were number 3 because they multiply quickly and provide meat and money. Cattle and goats were considered numbers 4 and 5 respectively because they do not multiply quickly, and it is not easy to sell them. For example, in one of the FGDs with pig keepers, one participant stated:

“Pigs are number one because they are easier to keep, multiply quickly and you can sell them easily, while cows produce only one calf each time, and cannot be sold anytime. Chicken, ducks and rabbits are for consumption in the house, they give meat” (FGD with pig keepers).

4.4 Pig keeping

All the pig keepers interviewed keep native pigs. These pigs are obtained in three forms. First, they are purchased from the local villages, the second is “mutual help” and the third is in the form of loan. Mutual help is a situation in which a non-pig keeping neighbour assists a pig keeping neighbour with pig feeds. In return, when piglets are born, the pig keeper gives one female piglet to the helping neighbour. The third method is in the form of loan. In this case non-pig keeper borrows a female pig and manages it;

and when piglets are born, he or she keeps one female piglet and returns the mother and other piglets to the owner. Many small scale farmers use the second and third methods to obtain their pigs, since they do not require money.

4.4.1 Duration of pig keeping

Most of the small scale farmers (72%) had been keeping pigs for between 1 and 5 years (Figure 4.1).

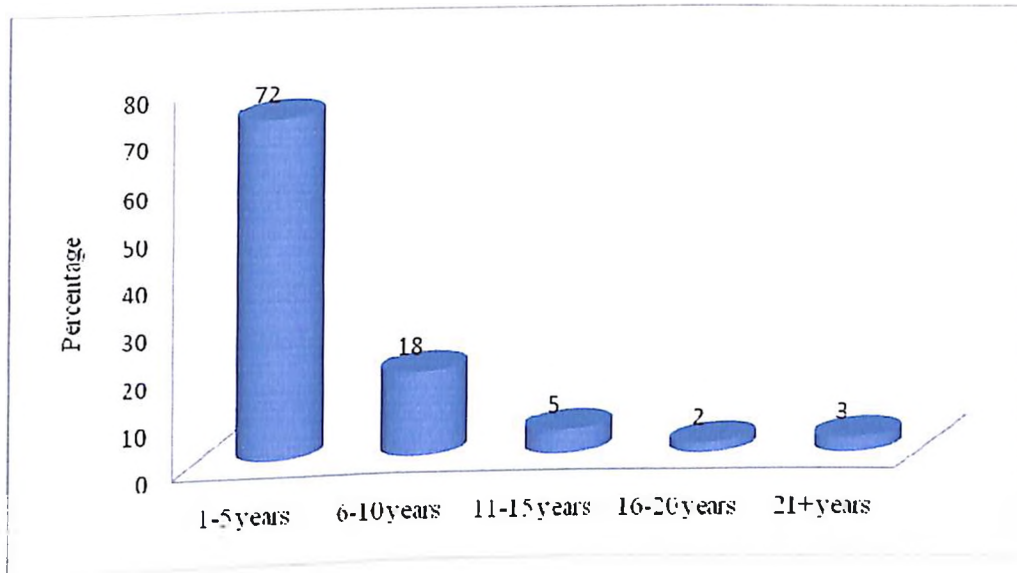


Figure 4.1: Duration of pig keeping (n = 100)

Although Figure 4.1 shows that small scale farmers had been keeping pigs for between 1 and 5 years, pig keeping is not a recent phenomenon in the study area. The duration of pig keeping might have been influenced by the fact that respondents gave up keeping pigs whenever they died due to disease. Respondents only reported the time they had been keeping pigs without interruption. They also said that pig keeping was a traditional and *normal* practice like keeping other animals such as goats, chicken and ducks.

4.4.2 Reasons for keeping and not keeping pigs

Most farmers (88%) reported that they kept pigs for money, meat and manure. Another 8% kept pigs as a source of meat and manure, while only 4% kept pigs as a source of meat only (Figure 4.2).

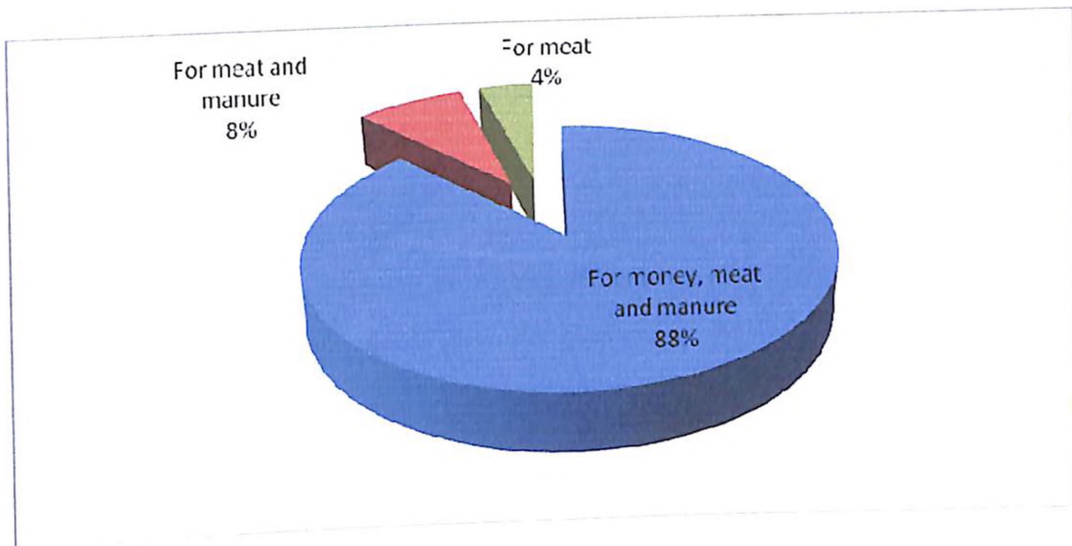


Figure 4.2: Reasons for pig keeping (n = 100)

On the other hand, non-pig keepers expressed their willingness to keep pigs, but they could not do so due to lack of capital (78%) (Figure 4.3). However, 10% of the respondents reported that they were not keeping pigs due to pig diseases such as *xigodola*, (African swine fever) ASF. 12% of non-pig keepers reported that pigs are difficult to keep.

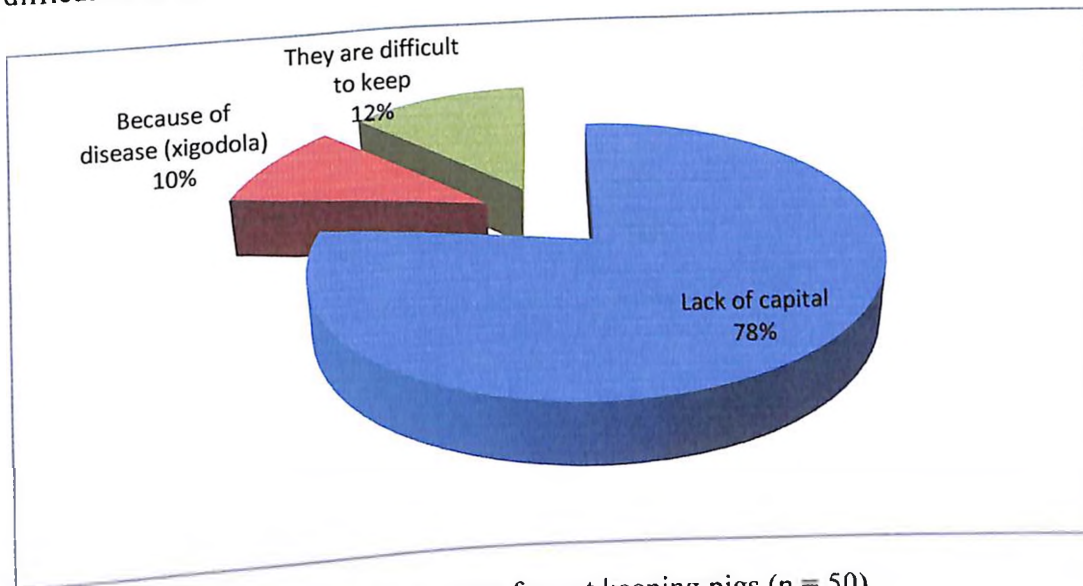


Figure 4.3: Reasons for not keeping pigs (n = 50)

FGDs revealed that many non-pig keepers who reported lack of money to buy pigs considered themselves as poor. This was summarized by a participant in one FGD with non-pig keepers who stated that:

“We don’t keep pigs because we are poor. We would like to keep pigs, but they are very expensive, and we have no money to buy them” (FGD with non-pig keepers).

However, some non-pig keepers, especially those who did not keep pigs because of diseases such as ASF, had given up after their pigs died. In one of the FGDs, a participant said:

“We used to keep pigs, but suddenly *xigodola* (ASF) appeared and killed all of them. We tried in the following year and they also died, and we gave up” (FGD with non-pig keepers).

Findings from the survey show that 92% of pig keepers used pig’s dung as manure in the cultivation of vegetables and maize, with 28.3% always doing so and 63.7% only occasionally. Pig’s dung was also used by non-pig keepers. In fact, more than half (58%) of non-pig keepers used it in their agricultural activities. Respondents reported that pig’s dung is very good fertilizer for growing vegetables and maize.

4.4.3 Reasons for selling pigs

Most pig keepers (82%) sold their pigs to get money to solve family problems (Figure 4.4). Other reasons for selling pigs were related to the age of pigs, disease and the large number of pigs a farmer had. If they were many, they got rid of some since they became difficult and expensive to feed.

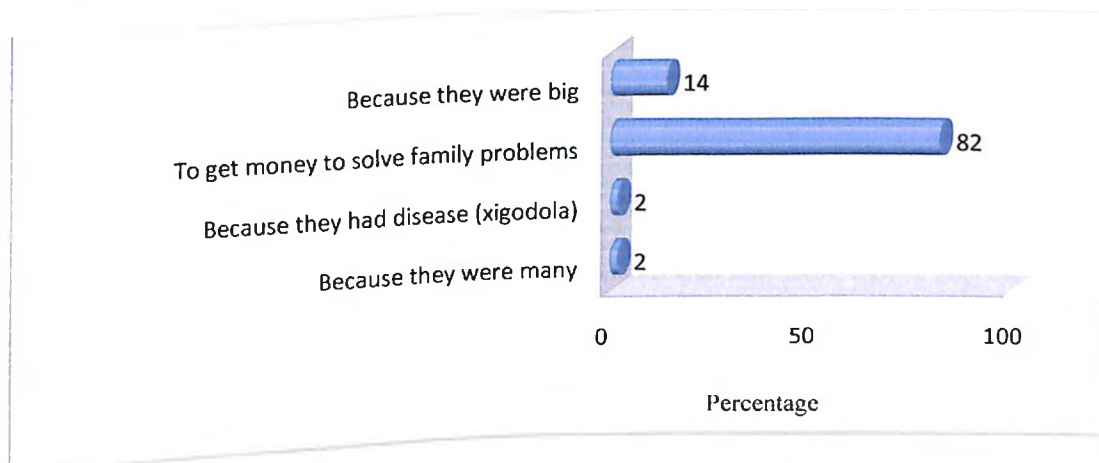


Figure 4.4: Reasons for selling pigs (n = 100)

There seems to be a relationship between the reason for keeping pigs and the reason for selling them. Many of the respondents who sold their pigs because they wanted money

to solve family problems belonged to the group of respondents who said that they were keeping pigs to help their families. Pig keepers sold pigs to buy food, fertilizers, seeds, clothes and school material for their children, as well as to pay casual labourers and when their children or relatives were sick.

4.4.4 Age and price of pigs

Most farmers (56%) sold their pigs alive and 43% sold the pigs either slaughtered or alive. However, 1% of the respondents sold only slaughtered pigs. Pigs were slaughtered or sold when they were at least 1 year old. Pig keepers (76%) sold their pigs when they were between 2 and 3 years (Table 4.2).

Table 4.2: Age and price of pigs (n = 100)

Price of pigs (USD)	Age of pigs (year)			Total	
	1	2-3	4 +	Number	Percentage
12-20	3	7	0	10	10
24-32	8	22	0	30	30
36-48	8	37	2	47	47
52-60	2	4	0	6	6
64-80	0	2	0	2	2
80 +	0	4	1	5	5
Total	21	76	3	100	100

The price of pigs ranged from 300 Meticals (12 American dollars) to more than 2000 Meticals (80 USD), with an average of 43 USD (the exchange rate at the study time was 1USD to 25 Meticals). Most pig keepers (47%) sold their pigs for between 36 and 48 USD (Table 4.2).

Survey data revealed that the age of pigs did not necessarily influence the price of pigs. However, information obtained from FGDs showed that the price of the pigs depended on the buyer and it seemed to be influenced by the pig's weight. In a FGD with pig-keepers, a participant said:

“There is no fixed price for pigs. People who come to buy pigs are the ones who determine the price of pigs. They always pay in low prices because they say the pigs are of low weight” (FGD with pig keepers).

Farmers living in the villages bordering Malawi sell their pigs in Malawian Kwacha, while those living near the district headquarters used the Metical (Mozambican currency). Those who were using Malawian Kwacha stated that they were doing so because it was the currency used in their everyday life to purchase goods. They were not

using the Metical because it was rare and they would need to go to the district headquarter to exchange it to Malawian Kwacha.

4.4.5 Trading channels of pigs

Pigs were sold to either local wholesalers or foreign customers. 39% of the respondents reported selling their pigs to their neighbours in the district, while 26% of the respondents sold their pigs to people from Malawi (Figure 4.5).

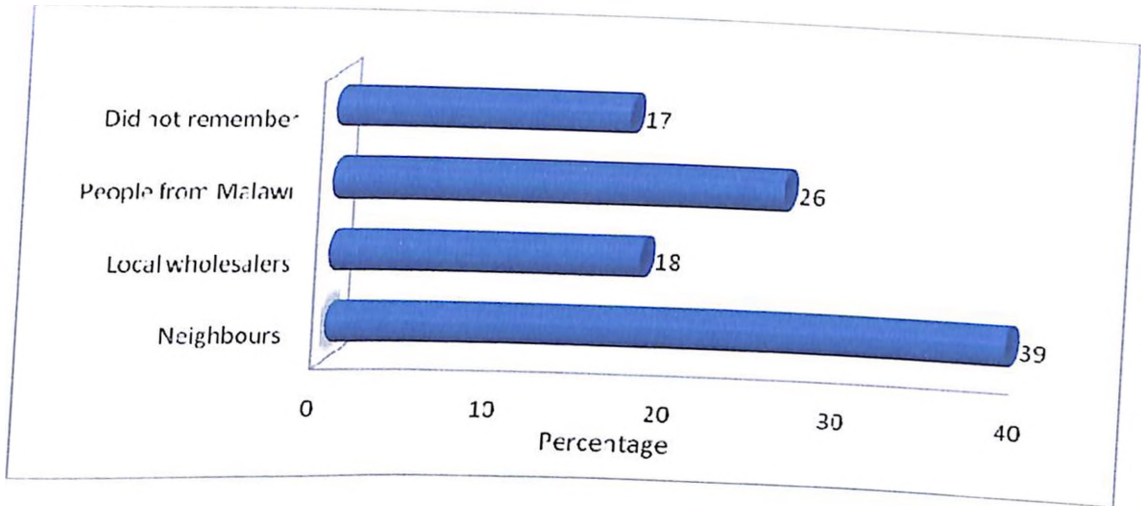


Figure 4.5: Trading channels of pigs (n = 100)

Neighbours bought pigs either for raising (reproduction) or consumption, while local wholesalers bought pigs for commercial purposes (selling them alive or slaughtered). However, there was no specific market where pigs were sold alive. Information gathered through FGDs revealed that local wholesalers, neighbours and people from Malawi go to the community searching for pigs. Farmers living in the villages bordering Malawi sold most of their pigs to people from that country. In one of the FGDs, a participant observed that:

“We do not have any problem in selling pigs, because customers come here from time to time looking for pigs to buy. They ask in each household whether there are pigs and if the owner is willing to sell them” (FGD with pig keepers).

Local wholesalers sell pork in the local butchery located at Ulongue in the district headquarters and at the local markets. The wholesalers slaughtered pigs at the household, and only the pork sold at the butchery was inspected by meat inspectors.

4.4.6 Pig management

Almost every member of the household takes care of the pigs when they are in pens. Pigs are managed by women (23%), men (7%), both men and women (41%), children (7%) and all members of the household (22%). Both male and female children (from 9 to 17 years old) are involved in pig management.

In terms of the decision to sell and how the profit is utilized, men (65%) made the decision on when to sell and 46% decided the use of pig profits. However, 34% reported that the decision about the use of pig profit was decided by both men and women (Figure 4.6).

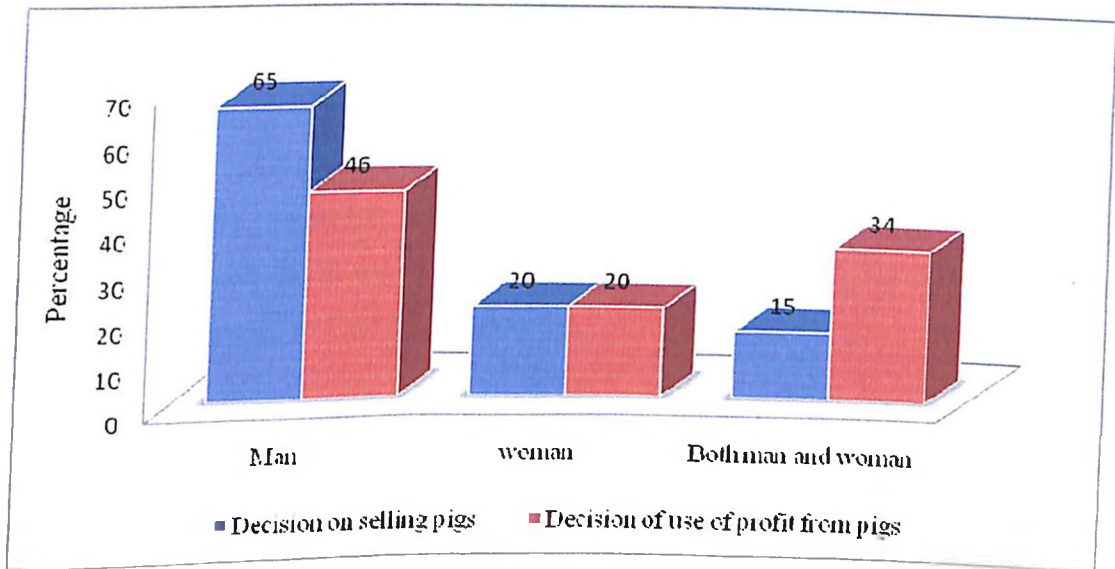


Figure 4.6: Decision making on selling and use of profits from pigs (n = 100)

A small number of women (20%) were allowed to make decision on whether to sell the pigs (Figure 4.6). They also decided on the use of the money. Some of these cases could be related to the situation where a woman was the household head.

Another reason for women's participation on selling and use of pig profit may be related to the ownership of pigs in the community. Information obtained through FGDs revealed that in many villages, pigs belonged to the women. Three of the five FGDs (1 with pig keepers and 2 with non-pig keepers) confirmed that pigs, chicken, ducks, rabbits and pigeons belonged to a woman, while cattle belonged to men. The remaining two FGDs (pig keepers) reported that pigs belonged to both women and men.

The ownership of pigs was determined by the responsibility in the management of animals. Both pig keepers and non-pig keepers reported that pigs belonged to women because they are the ones who mostly took care of them, while men were responsible for cattle.

4.4.6.1 Pig feeds

All pig keepers reported using maize bran as first option feed for their pigs when they were in pens. However, in case maize bran was not available or was not enough, 32% of pig keepers used sweet potato vines leaves to feed pigs, 26% used pumpkin leaves, 15% local herbs, such as *covane*, scientifically known as *celosia trigyna* and *tossa*, scientifically named *commelina benghalensis*, 5% mangoes and 5% and 9% used cabbage and kitchen leftovers, respectively. Only 8% of farmers fed their pigs on maize bran without adding other types of feed. Direct observation confirmed that pigs were fed on maize bran, local herbs, bananas leaves and kitchen leftovers. Local herbs, such as *tossa* and *covane* (Plate 4.1) were used as complementary feeds. These types of feed constituted not only pig feeds during famine, but also human food. For example, *covane* (Plate 4.1b) was used as food for humans too.

a) *Tossa (commelina benghalensis)*: pig's feed

b) *Covane (celosia trigyna)*: used as human and pig's feed)



Plate 4.1: Local herbs for feeding of pigs

4.4.6.2 Problems encountered in pig management

Pig keepers said that they faced many challenges in pig management when pigs were enclosed in pens. The common problems were pig feeds (73%), loss of weight (11%), pig diseases such as ASF, lice and fleas (7%) and time to manage the pigs (2%). The remaining 7% reported that they had no problem when pigs were in pens.

The most common pig disease in the study area was ASF, followed by cysticercosis, fleas and lice. ASF (48%) and both ASF and white nodules (31%) were the most reported diseases (Figure 4.7).

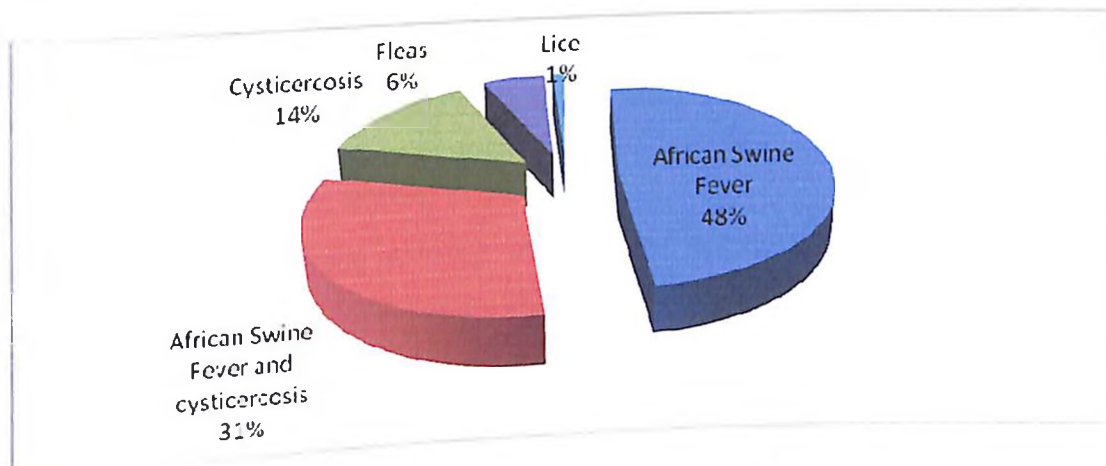


Figure 4.7: Diseases affecting pigs (n = 100)

Farmers explained that fleas were a problem because they made it difficult for female pigs to reproduce. In one FGD with pig keepers, it was noted that when pigs become sick due to lice, the piglets die because female pigs cannot produce enough milk to feed them.

However, pig keepers mostly feared ASF because when it appeared, it killed all the pigs. One participant in FGD stated that:

“*Xigodola* is the most dangerous pig disease, since it decimates all pigs and piglets, whether in pens or not. Sometimes, when you are lucky, you can remain only with one pig” (FGD with pig keepers).

CHAPTER FIVE: Community perceptions, knowledge and management of white nodules in pigs in Angónia rural district

5.1 Introduction

This chapter presents community perceptions and knowledge regarding white nodules in pigs. It also presents management of white nodules in pigs, as well as risk factors and changing attitudes towards porcine cysticercosis risks.

5.2 Perceptions of white nodules in pigs

Porcine cysticercosis (white nodules) was perceived as pig disease (85.3%). However, 2.7% perceived it as pig and human disease (Table 5.1). As one of the respondents stated:

“I have heard that people who eat pork infected by white nodules can also acquire white nodules” (Bill Veto, a non-pig keeper).

Table 5.1: Perceptions of white nodules (N = 150)

View of white nodules in pigs	Pig keepers		Non-pig keepers		Total	
	Number	Percentage	Number	Percentage	Number	Percentage
Normal condition of pigs	8	8	4	8	12	8
Between normal and pig disease	5	5	1	2	6	4
Pig disease	85	85	43	86	128	85.3
Pig and human disease	2	2	2	4	4	2.7
Total	100	100	50	100	150	100

Respondents who reported that white nodules in pigs were a condition in between normalcy and disease were of the view that not all white nodules in pigs indicated disease. They explained that only white nodules in pig's tongue were an indication of disease.

5.3 Folk knowledge regarding the presence of white nodules in pigs

The majority of the respondents (94.7%) had heard about white nodules in pigs. Only 5.3% were not aware about the disease. Among pig keepers, 94% of respondents reported to be aware of white nodules and 6% had not heard about it; whereas 96% of non-pig keepers said that they had heard about white nodules and the remaining (4%) were not aware of it. All respondents reported that the local name for white nodules was *massesse*.

Findings from the survey reveal that 86.7% of the respondents had seen a case of white nodules in pig, while 13.3% had never seen it. Among pig keepers, 69% of the respondents reported that their pigs had never been infected by white nodules, while 31% reported to have experienced the disease.

5.3.1 Sources of information about white nodules in pigs

Findings from the survey show that farmers got information about white nodules from neighbours (38%) and people who went to the community to buy pigs (37%) (Figure 5.1).

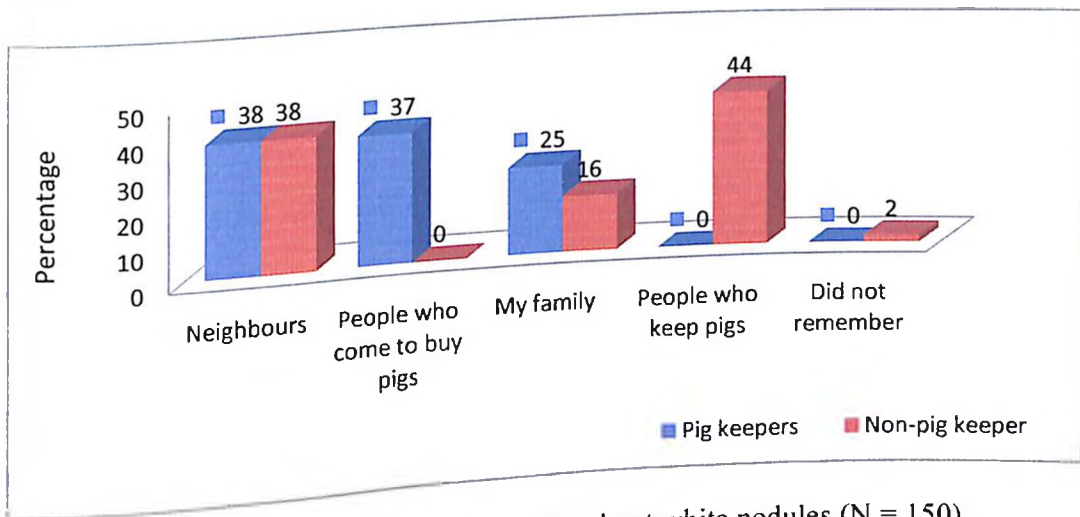


Figure 5.1: Sources of information about white nodules (N = 150)

The source of information about white nodules in pigs varied on whether one kept pigs or not. While pig keepers accessed information from neighbours, people who bought pigs in the community and families, non-pig keepers heard about white nodules from pig keepers, neighbours and their families (Figure 5.1).

5.3.2 Means of identification of white nodules in pigs

Respondents (42%) recognized white nodules through inspecting the pig's tongue. On the other hand, 20% of respondents did not know how to identify white nodules in pigs (Table 5.2).

Table 5.2: Means of identification of white nodules in pigs (N = 150)

Means of identification of white nodules in pigs	Pig keepers		Non-pig keepers		Total	
	Number	Percentage	Number	Percentage	Number	Percentage
Under the tongue	48	48	16	32	64	42
Under the tongue and skin	26	26	4	8	30	20
Under the skin	3	3	10	20	13	9
Whole pig's body	4	4	3	6	7	5
Impossible to find in a live pig	5	5	1	2	6	4
Did not know	14	14	16	32	30	20
Total	100	100	50	100	150	100

Most pig keepers (48%) and non-pig keepers (32%) used pig's tongue to identify the disease (Table 5.2). Although most of the non-pig keepers (32%) did not know how pigs get white nodules, it was among pig keepers that had 5 out of 6 respondents who stated that it was not possible to find white nodules in a live pig.

The pig keepers who have experienced white nodules in their pigs, 23 (74.2%) out of 31 respondents used the pig's tongue to identify the disease, while others (3.2%) used pig's skin. The remaining (16.1%) used pig's tongue and pig's skin and 6.5% stated that it was not possible to find white nodules in live pigs.

5.4 Causes and transmission of white nodules in pigs

The findings from the survey show that 92% of the respondents did not know how pigs got white nodules. Both pig keepers (94%) and non-pig keepers (88%) did not know how pigs got white nodules (Table 5.3).

Table 5.3: Knowledge of white nodules in pigs (N = 150)

Do you know how pigs get white nodules?	Pig keepers		Non-pig keepers		Total	
	Number	Percentage	Number	Percentage	Number	Percentage
From another infected pig	3	3	2	4	5	3.3
When they are free and eat dirt	2	2	2	4	4	2.7
By eating human faeces	1	1	2	4	3	2
Did not know	94	94	44	88	138	92
Total	100	100	50	100	150	100

Findings from the survey show that there was lack of knowledge about how pigs got white nodules. Even among 31 pig keepers that had experienced the disease, 29 of them did not know the cause of white nodules. However, one pig keeper said that the disease was from another infected pig and another one recognized that when pigs eat human faeces they could get white nodules. Information gathered from FGDs confirmed that both pig keepers and non-pig keepers did not know the causes of white nodules in pigs. One of the participants in a FGD with pig keepers stated that:

“White nodule is a disease that suddenly appears in pigs and we do not know where it comes from and its causes” (FGD with pig keepers).

5.5 Period of appearance of white nodules in pigs

More than half of respondents (51.3%) said that white nodules in pigs appeared any time of the year, while 22.7% did not know about the time of appearance of the disease. The remaining respondents, 11.3% said that white nodules appeared during harvesting, 10.7% during fallowing period, 3.3% throughout dry season and 0.7% in the rainy season. Most of the pig keepers (62%) noted that white nodules appear all over the year, 11% said that white nodules appear during harvesting period, 7% reported fallowing period, 4% mentioned dry season, and 16% did not know the period of appearance of white nodules. On the other hand, 36% of non-pig keepers did not know the time of appearance of the disease in pigs, while 30% mentioned whole year, 18% fallowing period, 12% harvesting period and 4% dry season. FGDs showed that white nodules infected pigs anytime of the year. One participant in a FGD observed that:

“White nodules appear anytime of the year, whether it is hot or cold, you can realize that your pigs have the disease” (FGD with pig keepers).

Among pig keepers (31 respondents) that had experienced white nodules in pigs, 54.8% indicated that white nodules appeared any time of the year (whole year). They also appear during harvesting (22.6%) and fallowing period (9.7%). However, 12.9% did not know the period of appearance of white nodules.

5.6 Management of white nodules in pigs

Pig keepers used various methods to deal with white nodules in pigs. However, 62% of the respondents did not know what to do if a pig got infected (Figure 5.2).

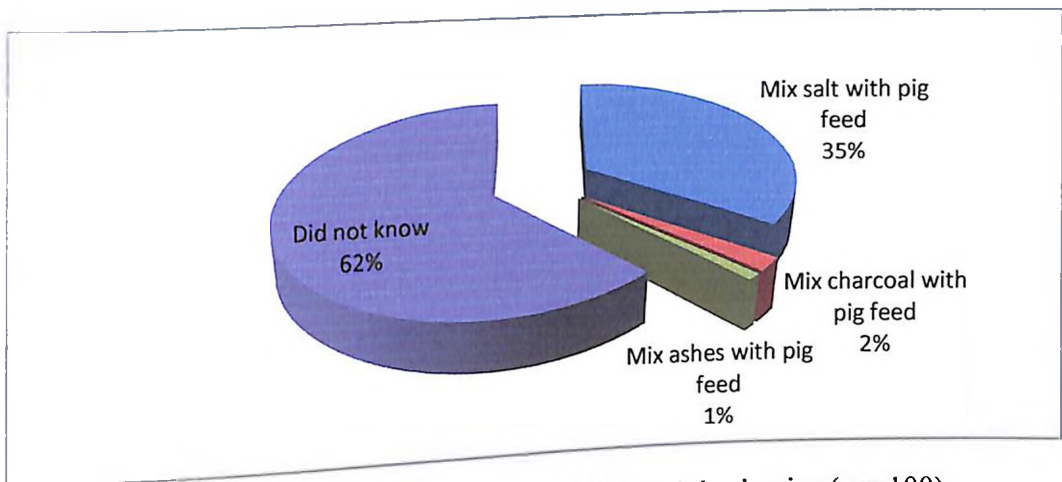


Figure 5.2: Methods used to treat white nodules in pigs (n = 100)

Among 31 pig keepers that had experienced white nodules in pigs, 32.3% mixed salt with maize bran, 3.2% mixed coal with maize bran and 64.5% did not do anything to treat the nodules. However, 5 out of the 31 respondents separated infected pigs from others not infected with white nodules. The remaining 26 mixed infected and non-infected pigs in the same pig pen.

Pig keepers who have attempted some actions such as mixing salt, charcoal or ashes with maize bran to treat white nodules in pigs, reported that the methods were not effective. While some pig keepers who had experienced these methods said that if you mix salt with maize bran, white nodules disappear, all participants of FGDs reported that the methods could not bear positive results. One participant captured this view when he said:

“We try to mix salt or charcoal with maize bran, but it does not give an effect. The white nodules do not disappear in the pigs” (FGD with pig keepers).

Some pig keepers who had tried all the mentioned methods and failed concluded that there was no cure for white nodules. In a FGD with pig keepers, one participant noted that:

“We have tried all possible methods to treat white nodules and still they do not disappear. There is no cure for white nodules” (FGD with pig keepers).

5.7 Difference between white nodules and African swine fever

White nodules were always mentioned alongside ASF as the main pig diseases in the study area. It was important, therefore, to assess people’s knowledge regarding the difference between white nodules in pigs and ASF. FGDs revealed that both pig keepers and non-pig keepers recognized the difference between the two types of pig diseases.

To distinguish the difference between white nodules and ASF in pigs, participants in FGDs were asked to describe the pig's "behaviour" when it is infected. The difference between the two diseases according to pig keepers and non-pig keepers is presented on Table 5.4.

Table 5.4: Difference between white nodules and ASF as expressed by pig keepers and non-pig keepers

FGD	White nodules	ASF
Pig keepers	<p>Infected pigs eat without any problem</p> <p>Pigs do not die;</p> <p>You cannot easily see white nodules manifestation;</p> <p>Pigs loose strength.</p>	<p>Pigs do not eat;</p> <p>Pigs' feet are paralyzed;</p> <p>Pigs get sick and die within few days;</p> <p>Pigs get weak and bend the head;</p> <p>Pig tilts the head;</p> <p>Pigs have fever.</p>
Non pig keepers	<p>Infected pigs eat without any problem;</p> <p>Pigs do not die;</p> <p>You cannot easily see white nodules manifestation ;</p> <p>You can only see white nodules infection when you slaughter it;</p> <p>It is not transmissible from pig to pigs.</p>	<p>Pig's feet are paralyzed;</p> <p>Pigs get sick and die within few days;</p> <p>When a pig is infected, it does not eat;</p> <p>It is visible that pigs are infected;</p> <p>It is transmissible from pig to pig.</p>

Non-pig keepers also recognized the difference between white nodules and ASF in pigs (Table 5.4). The knowledge of non-pig keepers about the difference between white nodules and ASF may be related to the fact that some of them had kept pigs in the past but died due to ASF and also may be influenced by their neighbours who are pig keepers.

Unlike white nodules, ASF was a pig disease that was easy to tell from the pig's behaviour. As one pig keeper put it:

"Xigodola appears like wind and it does not give you time to think about treatment. It kills all the pigs and piglets" (Alton Buda, a pig keeper).

However, both pig keepers and non-pig keepers did not know the causes of ASF. They reported that ASF appears between June and December (hot season). Some pig keepers confined their pigs as a method of preventing infection from ASF, but still they got

"This time there is no food even to feed humans. We buy maize bran, which is normally for pigs, to feed ourselves" (FGD with pig keepers).

However, other factors such as the belief that pigs would grow big quickly and fat when they are not enclosed, lack of time for proper management of pigs and free range as a normal practice influenced free roaming pig practices.

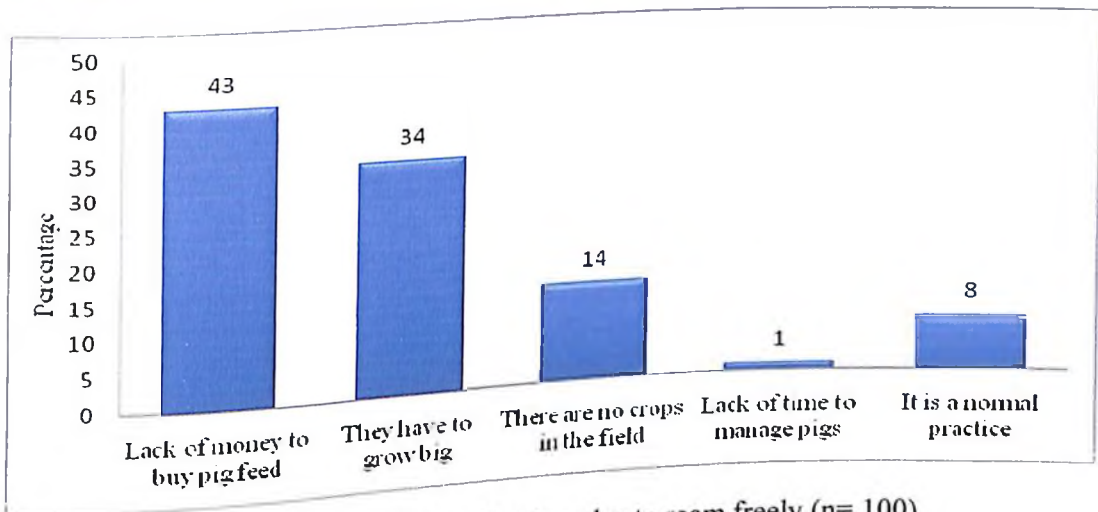


Figure 5.4: Reasons for allowing pigs to roam freely (n= 100)

Perceptions, beliefs and normal practices influenced directly the type of pig management system (free range). Farmers believed that when pigs are free, they become fat and grow quickly, and when they are confined, they do not grow big and loose weight. In one FGD with pig keepers, a participant noted that:

"When you keep pigs confined, they get slim/lose weight, but when you leave them free they get fat and they grow quickly" (FGD with pig keepers).

The perception that pigs grow bigger when they are free than when confined is very important, since the price of pigs was determined by its weight. Thus, many pig keepers would prefer to let their pigs roaming freely to get high profit. Information obtained from FGDs showed that pig keepers confined their pigs during planting and growing seasons (December to March/April), the time which people were facing famine because they had already sold their agricultural products, and practiced free range during harvesting and fallowing seasons (April to October/November), when people had enough food to feed themselves and their animals.

5.8.2 Type of pig pens

Free range system was also influenced by the type of pig pens used. Direct observations showed that 54% of pig pens were constructed using wood and grass and 46% using a mixture of stone and wood or grass (Plate 5.3).

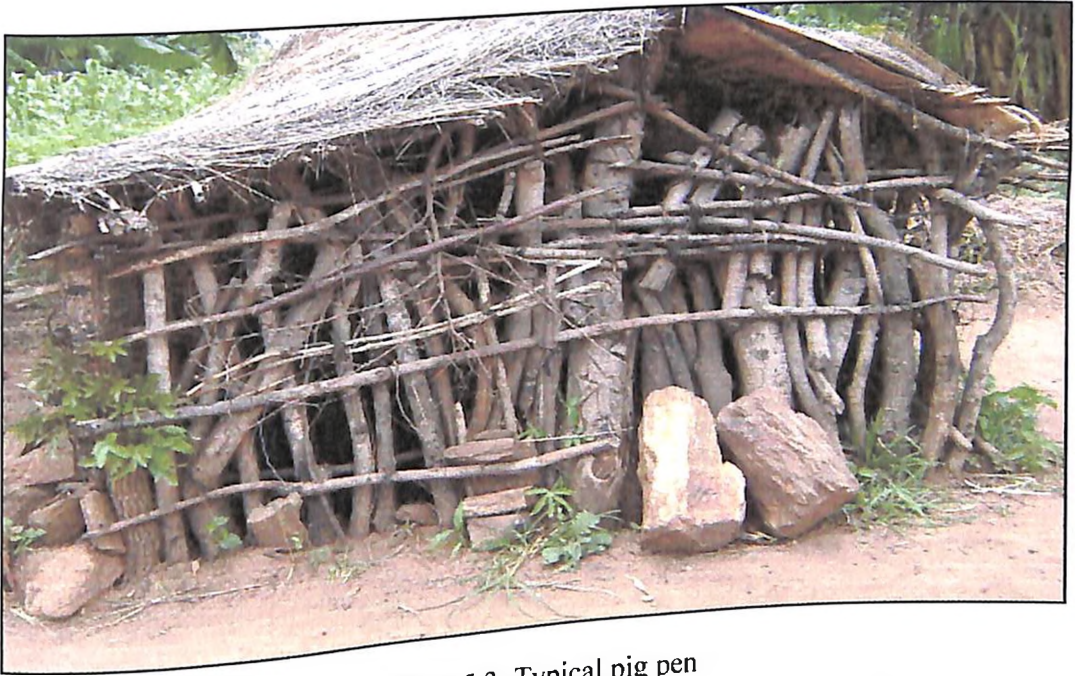


Plate 5.3: Typical pig pen

Although all pig keepers' households visited in the study area had pig pens, their condition were poor (Plate 5.4). Many of the pig pens were made of old material and were damaged. This condition allowed piglets to escape and roam freely without being allowed intentionally by pig keepers.

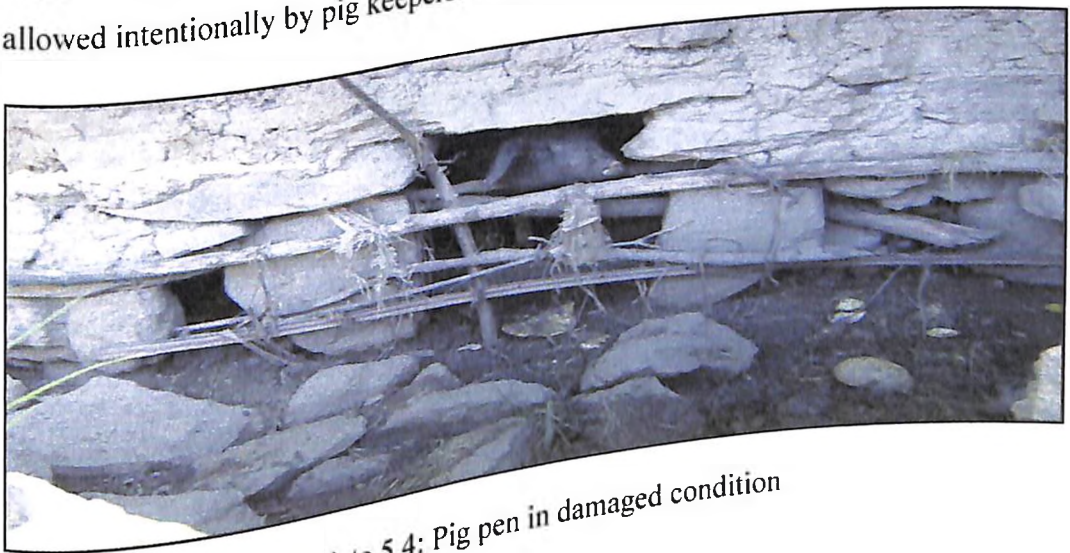


Plate 5.4: Pig pen in damaged condition

5.8.3 Latrine coverage in the study area

The majority of respondents (95.3%) owned latrines. Only 4.7% reported that they had no latrines. Direct observations confirmed presence of latrines in the households visited during the survey. However, 85.3% of latrines had no doors, while 14.7% of them were closed. Respondents without latrines said that theirs had been destroyed by rain and wind; and they were trying to build new ones. As one pig keeper put it:

“I had a latrine, but the rain which fell a few days ago destroyed it, and I haven’t had time yet to rebuild it” (Patrick Damo, a pig keeper).

Respondents were using pit latrines, and 58% of them were constructed using stone and grass, while 42% were built on wood and grass.

Latrines were mostly used by all members of the household. This accounted for 97% of the respondents. The remaining 3% reported that they were mostly used by adults. Out of the 150 respondents, 91% always used latrines and 9% said that they used it occasionally.

In most of the households (90%) latrines were situated far from the pig pens. The remaining 10% of the households, latrines were close to the pig pens. Respondents, whose latrines were near the pig pen, said that they did not have enough space to build latrines far from the pig pen and others said that the land was too stony for the construction of latrines.

Latrine coverage in the community was influenced by local health workers from the local centre. Local health centre had promoted campaigns to build latrines in the study area. More than half of the respondents (66%) reported that local health centre had told them to build latrines to avoid cholera and diarrhoea. However, 34% said that no organization had told them to build latrines.

Another factor that contributed to the presence of latrines in the study area was the perceptions that people had about human faeces. The majority of the respondents (85%) perceived human faeces on the ground as dirty and 14% viewed it as very bad. One percent of the respondents said that faeces on the ground would not bring health problem. As one respondent put it:

“Human faeces around the household or community are very bad because they bring many flies that pose in the food, and may bring diseases such as diarrhoea and cholera” (Maria Fata, a pig keeper).

The perceptions on human faeces may be influenced by the implication it may have in the community, especially during the rainy season. Almost all respondents (99%) said that human faeces could cause health problems in the community, such as diarrhoea (62%), cholera (27.3%) and malaria (10.7%). These perceptions might have influenced the household environ. Out of the 150 households visited, 98% were clean and only 2% of them were dirty as evidenced by presence of grass and pods of beans.

5.8.4 Lack of animal specialists and measures for disease control

Lack of veterinary field officers and measures to control animal diseases favoured the spread of cysticercosis in the community. It was observed that there were no animal specialist in the study areas and pig keepers had no specialist to report to in case of outbreak of pig disease. Information available in the local butchery, recorded by meat inspectors, showed the quantity of pork (in kg) that had been rejected since 2006 due to cysticercosis. For example, in August 2006, 30 kg of pork was rejected due to the disease, but in May 2008, 52.5kg were rejected due to the infection of cysticercosis (Direcção distrital de Agricultura de Angonia, 2008). Despite the increase of rejection of infected pork due to cysticercosis, no measures were put in place to deal with the disease in pigs.

5.9 Changing behaviour towards porcine cysticercosis risks factors

This study probed on changing attitudes towards porcine cysticercosis risks that could be identified in the study area. This section analyzes the attitudes of respondents towards risk factors such as allowing pigs to roam freely and use of latrines in the study area.

5.9.1 Free roaming pig practices

Free roaming pig practice is a risk factor for infection and transmission of cysticercosis in pigs. Findings from the survey show that 92% of the pig keepers allowed their pigs to roam freely during harvesting and fallowing seasons, while only 8% kept their pigs enclosed. Among the 92% pig keepers that reported practicing free range, 82% said they would confine their pigs if they have enough food to feed the pigs and 10% rejected the possibility of enclosing their pigs because they believe that even if there were sufficient food for pigs, they could not grow fat. As one pig keeper stated:

“Pigs need to get air and breathe adequately, so that they can grow bigger. Even if you give enough food, if you do not let them free, they will not grow. Pigs need to be free for some period and should not always be enclosed” (Zita-ba, a 35 years old man).

Information gathered from FGDs revealed the possible changing attitudes towards cysticercosis risk factors. Participants revealed that besides lack of pig feeds, they had challenges on the type of pig pens because they were very small and this was another reason why pigs were not growing fat and quickly. They also said that they did not know how to build an adequate pig pen for their pigs. In one FGD, a participant said that:

“We have enough materials such as stones and wood that could be used to build the pig pens. but we do not know how we can construct better pig pens, which will enable the pigs to grow fat quickly without allowing them to be free” (FGD with pig keepers).

5.9.2 Use of latrines

Proper use of latrines in the study area is important since it would curb the spread of cysticercosis among humans and pigs. Most respondents (91.3%) said that they were always using latrines. However, those who had no latrines said that they would have always used it if they knew that defecating on ground could bring disease.

Traditions related to accessibility of latrines favoured the presence of latrines. According to the respondents, each couple should have own particular latrine, even if there are other latrines in the same compound. Latrines were mostly close to the house of each couple. However, whether they used it properly or not, was difficult to measure during the survey. It is important to mention that the study took place during the rainy season and the community had information about the implication of spreading faeces (diarrhoea, cholera) in the community. Participants in FGDs confirmed that latrines were used every season. However, direct observation in the study area revealed that people spent long time in the field doing agricultural activities than in their homes. This may influence the proper utilization of the latrines. This is because the latrines are located in the homes closer to the houses and not in the fields. This may be a risk factor because if pigs access the infected human faeces, they may get cysticercosis.

CHAPTER SIX: Community perceptions, knowledge, practices and management of epilepsy in Angónia rural district

6.1 Introduction

This chapter analyzes data on perceptions, knowledge and management of human cysticercosis among pig keepers and non-pig keepers, as well as risk factors and changing attitudes regarding risks favouring transmission of the disease. Data presented in this chapter were gathered from survey, in-depth interviews with health workers, traditional healers and people suffering from epilepsy, FGDs and direct observations. In this study, epilepsy was used as proxy to the presence of human cysticercosis.

6.2 Perceptions of epilepsy

Out of the 150 respondents, 91.3% of respondents perceived epilepsy as sickness (Table 6.1).

Table 6.1: Perceptions of epilepsy (N =150)

View on epilepsy	Number	Percentage
Sickness	137	91.3
Normal condition	12	8.0
Between normal and sickness	1	0.7
Total	150	100

A majority of pig keepers (97%) as well as non-pig keepers (80%) viewed epilepsy as sickness. The remaining (2%) of the pig keepers perceived the disease as normal condition and 1% viewed it as being between normal and sickness. On the other hand, 20% of non-pig keepers considered it as a normal condition. Respondents who reported that epilepsy was a condition in between normalcy and sickness were of the view that only when a person has frequent seizures could it be considered sickness.

6.3 Folk knowledge regarding epilepsy

The majority of the respondents (98%) knew or had heard about someone suffering from epilepsy and 36% had a case of epilepsy. Only 2% of the respondents had never heard about the disease and 64% did not have relatives suffering from it. The disease is locally known as *matendacugua* or *gala gala*, which means epilepsy.

Epilepsy was not a disease only to pig keepers, but also to non-pig keepers. Among 54 (36%) respondents that reported having at least someone suffering from epilepsy in their households, 40 (74%) were pig keepers and 14 (26%) were non-pig keepers.

Although 98% respondents had heard about epilepsy, close to 93% did not know how people get it. Most of pig keepers (96%) and non-pig keepers (86%) did not know the causes of epilepsy (Figure 6.1). Only a small number of respondents mentioned that epilepsy was due to witchcraft, pork consumption and malaria.

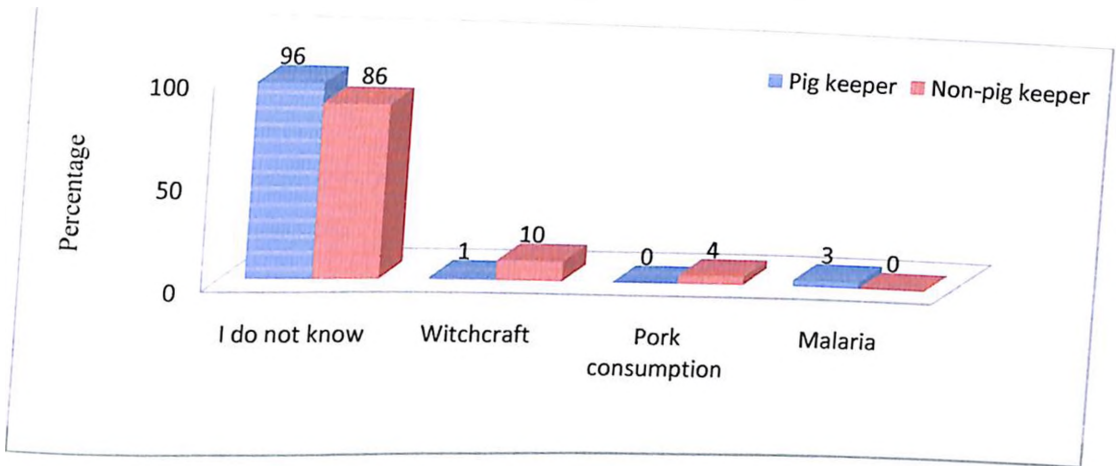


Figure 6.1: Causes of epilepsy (N = 150)

The causes of epilepsy were viewed in different ways by pig keepers and non-pig keepers. Pig keepers considered witchcraft and malaria as the cause of the disease, while non-pig keepers attributed it to both witchcraft and eating infected pork (Figure 6.1).

Among 54 (36% of the 150) respondents that reported having someone suffering from epilepsy in their households, 95% did not know the causes of epilepsy, 4% attributed it to witchcraft and 1% to eating infected pork.

6.4 Transmission of epilepsy

More than half (52%) of the respondents said that epilepsy was not contagious (that is, transmission from one person to the next through contact). On the other hand, 41.3% did not know whether one could get epilepsy through contact or not, and 6.7% reported that the disease was contagious. Among the 10 (6.7%) respondents that said epilepsy was contagious, 7 were pig keepers and 3 were non-pig keepers.

Respondents (54 out of the 150) who said they had people suffering from epilepsy in their households, 65% reported that the disease was not contagious, 20% did not know and 15% thought that the disease was contagious.

Epilepsy was perceived as contagious disease that could be spread through saliva, breathing and when people get in contact with the epileptics. Among the 10 (6.7% out of 150) respondents who reported epilepsy as contagious disease, 6 respondents said that the transmission was through saliva, 2 said breathing and 2 said that one could get epilepsy if one gets in contact with epileptic people. Pig keepers mentioned saliva and when the people get in contact with the epileptics as the means of contagion, while non-pig keepers considered breathing. People living with the epileptics in their households noted that one could get epilepsy when they got into contact with the epileptics and breathing. Participants in FGDs said that the disease could affect anybody at anytime, but it was not contagious. In a FGD session, a participant captured this view when he said:

“If epilepsy was contagious, then everybody in the community would have this disease. But it happens that you can find one person suffering from this disease in one household and other members of the household are fine” (FGD with pig keepers).

6.5 People suffering from epilepsy

The 54 (54 of the 150) households with epileptics had 63 patients. The respondents stated that there were cases of some families having 1-4 patients.

People suffering from epilepsy were of both gender albeit with more men than women and of all ages. In terms of gender, 70% were males and 30% were females. More than half (55.6%) were children (1-17 years), while 22.2% were between the ages of 18 and 35 years (Table 6.2).

Table 6.2: Age and gender of people suffering from epilepsy

Age of people suffering from epilepsy	Gender of people suffering from epilepsy				Total	
	Male (n = 44)		Female (n =19)		Number	Percentage
	Number	Percentage	Number	Percentage		
1-17	28	63.6	7	36.8	35	55.6
18-35	7	16	7	36.8	14	22.2
36-55	6	13.6	3	15.8	9	14.3
56 +	3	6.8	2	10.6	5	7.9
Total	44	100	19	100	63	100

Respondents living with epileptic people mentioned that 46% of epileptics began experiencing epileptic seizures in their childhood (8 months -17 years old), while 37% were adults (18 and more years) (Figure 6.2).

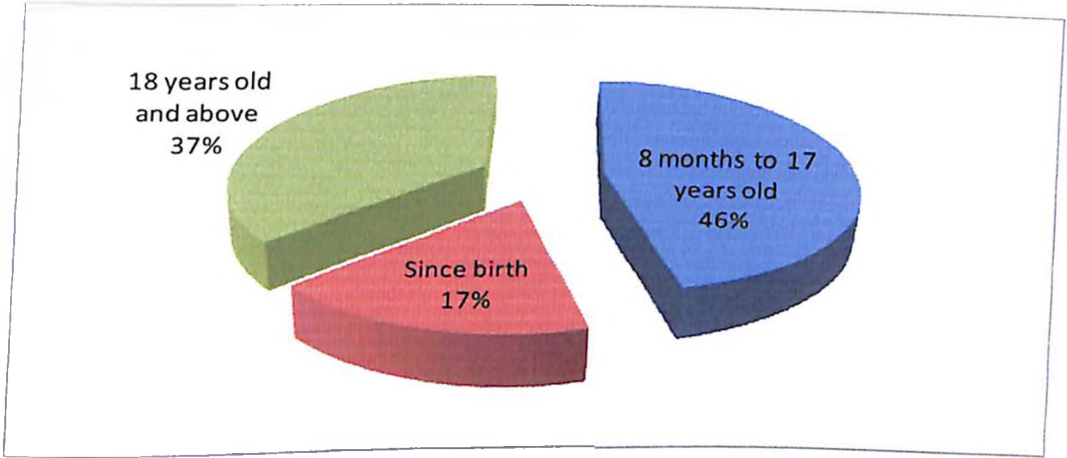


Figure 6.2: Age at appearance of the epileptic seizures

Many respondents who reported having epileptics in their households said that they had never experienced such cases in their families before. As one respondent living with an epileptic stated:

“She began to suffer from epilepsy when she had 2 children. She is the only one in the family. None of the family members suffered from this disease before” (Belta Malta, a respondent living with an epileptic).

Information obtained through narratives with people suffering from epilepsy in the study area showed that, sometimes, the disease starts from nowhere. It changes people’s health status and creates panic to the victim, as narrated by an epileptic:

“The disease started suddenly last month (January, 2009) when I was sitting on the chair. I felt dizzy and suddenly lost breath and fell down, crumbling. I felt something like convulsions in my stomach. I lost consciousness and do not know what happened later.... My father, who took care of me, said that I started grinding my teeth and he put a small cloth in my mouth, between upper and lower teeth, to prevent me from biting my tongue. When I regained consciousness, I was disturbed; nobody could understand what I was saying. After going through the same experience seven times, I started seeking help in the hospital. My father took me to hospital and while there, I experienced seizures 3 times. Since I began treatment last month (February 2009), I am feeling better and I rarely faint. I do not know where it comes from. Nobody in the family had this disease before.... I have never had an accident or cerebral malaria.... I used to eat pork, but I gave up as soon as I became sick and began treatment because people in the hospital told me to stop eating pork, but they did not explain the reasons” (Rito-Bajo, 29 years old man suffering from epilepsy).

6.6 Management of epilepsy

Epilepsy was considered a disease that required treatment in the health sectors available in the community. Responses of those surveyed regarding epilepsy show that 33% did not know how it could be treated, 26% reported that one should go to hospital and traditional healers, 21% to traditional healers, 16% to hospital, 3% said it was untreatable and 1% used herbs (see Figure 6.3).

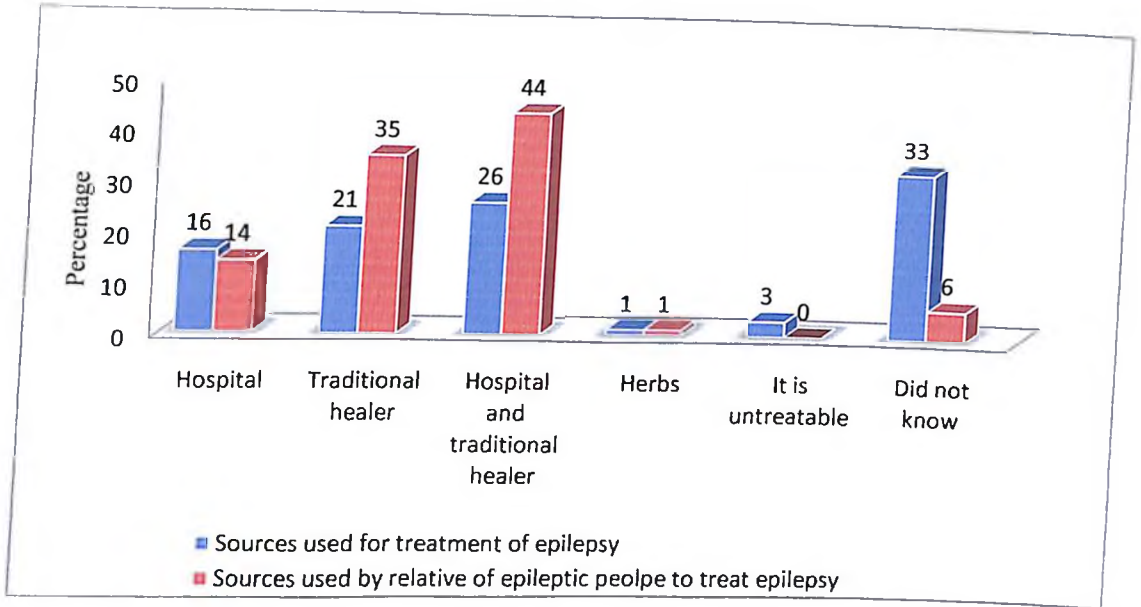


Figure 6.3: Sources of treatment of epilepsy

Respondents living with epileptic people ($n = 54$) reported to have used various health sectors to treat the disease. Most of them (44%) consulted both hospital and traditional healers, 33% went to traditional healers, 14% visited the hospital, 1% used herbs and 6% did not take any action (Figure 6.3).

The choice of therapy was influenced by the way one perceived the causes of the disease. Informants that perceived witchcraft as the cause of the disease consulted traditional healers. One of the informants narrated thus:

“Epilepsy can appear suddenly. It can be a natural disease, but sometimes it is due to witchcraft. When you suspect that it may be witchcraft, you must to go to a traditional healer, because if you go to hospital, you will not get cured. If you do not get a cure from the traditional healer, then the disease may be natural and you have to go to hospital” (Jen-Babo, a 28 years old man suffering from epilepsy).

However, informants that perceived epilepsy as disease but did not know its causes, tended to consult both traditional healers and hospitals, or using herbs for relief from epileptic seizures. As one informant put it:

“When the disease started, we consulted a traditional healer. He gave us medicine, but did not tell us what the patient was suffering from. After some months, the disease continued and we took him to hospital, but up to now he is still suffering from the disease” (Frade-Nab, a 48 years old woman living with an epileptic).

Three percent of the respondents who considered epilepsy as untreatable had gone for treatment in the hospital and to a traditional healer, but failed to get cured. One respondent living with an epileptic said:

“I took him to hospital in 1994 and they told me that it was cerebral malaria. The Doctor gave him tablets and he became better, but it started again in 2008. This time, I took him to a traditional healer, who gave us some medicine, but he did not tell us what the patient was suffering from. However, the disease was not cured, and he is still suffering. That is why it is untreatable” (Afra-Mat, a 40 years old woman living with an epileptic).

Most of the relatives (44%) used both hospital and traditional healers to treat epilepsy (see Figure 6.3). However, findings from the survey show that 53% of respondents consulted traditional healers before seeking advice from hospital, while 47% sought solutions in the hospital and later shifted to traditional healers.

The choice of whether to seek for treatment in the hospital or visit a traditional healer was influenced by neighbours that had experienced the disease and options available in the community, as narrated by an informant living with an epileptic:

“When the disease started, I went to a traditional healer, but it was not cured. I have never gone to hospital because people say that this disease is not treatable in the hospital. Now and then, I stay home and I don't know what to do” (Bil-Jo, a 35 years old man living with an epileptic).

Some informants reported that they got better after consulting a traditional healer. This may be the reason why they did not seek another option, such as hospital treatment.

This is captured by an epileptic sufferer who said:

“I went to a traditional healer seeking for treatment, and it has been a year now since. but it has never happened again. I have never sought advice in the hospital because some people who have experienced the disease advised me to go to a traditional healer” (Jen-Babo, a 28 years old man suffering from epilepsy).

In some cases, consultation with a traditional healer was used as an alternative after the hospital had failed to yield positive results. As one of the informants living with an epileptic put it:

“When epileptic seizures began, I took her to hospital, but the nurses told me that there was no medication in the hospital to treat the disease. I came back home and when the situation worsened, I took her to a traditional healer. However, despite the fact that she took medicine from the traditional healer, she has not been cured” (Mata-Gat, a 40 years woman living with an epileptic).

Some (6%) respondents did not seek for treatment at all. The reason for this decision is due to the fact that the respondent did not know what should be done.

The use of herbs for epilepsy treatment was based on local knowledge inherited from parents. This option was used without consulting a traditional healer. One percent of the respondents reported using a plant leaf locally known as *chipwetepumbwa* (Plate 6.1). The scientific name of the plant is *convolvulus*.

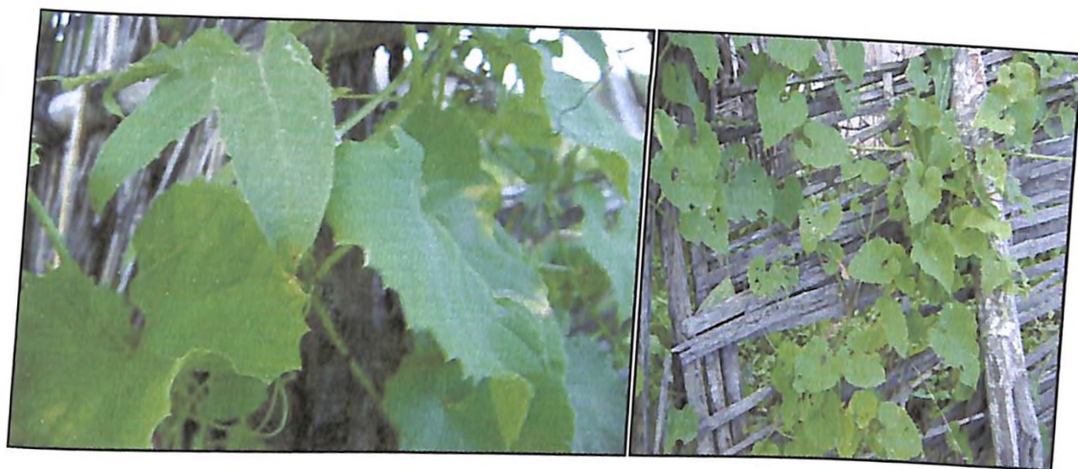


Plate 6.1: Leaves used for treatment of epileptic seizures

These leaves were used to prevent or to relieve epileptic seizures. Informants who used this plant said that one should collect the leaves, rub them in the hands and then put in a cup, add water and drink the resulting mixture. One of the epileptic people said:

“I have been suffering from epilepsy since childhood. I had never sought treatment in the hospital or traditional healer because my parents had never taken me there. They taught me to use these leaves whenever epileptic seizures occurred. Whenever I feel that seizures are coming, I ask my husband to collect the leaves. He prepares them and gives me to drink the concoction. However, though they relieve pain and stop seizures from occurring, they do not cure the disease” (Gida-Fate, 79 years old woman suffering from epilepsy).

Informants shifted from one health sector to another to seek treatment for epilepsy. This happened whenever the disease was not cured by the sector consulted. However, informants were sometimes advised in the hospital to seek treatment from traditional healers. This oscillation is captured by one sufferer who said:

“When epileptic seizures started, I went to hospital but, the nurses did not tell me what I was suffering from. They instead advised me to seek treatment from a traditional healer” (Rido-Alto, an epileptic).

However, traditional healers also advised their clients to seek treatment in hospital when they realize that they cannot treat the disease. One traditional healer noted thus:

“When people come to consult me, I give them “security” and then I advise them to go to hospital, where they get tablets for the disease. The security is to make sure that the disease is diagnosed and then treated. This is because even if it is a natural disease, it may not be properly diagnosed when there is something else such as witchcraft” (Arad-Sat, 60 years old man, traditional healer).

Traditional healers identified three causes of epilepsy. The first is natural, where people get the disease from their parents (hereditary), especially the mother (if she is infected during pregnancy), the second was consumption of infected pork, and the third cause was witchcraft, in which people are bewitched and become sick. Epilepsy due to natural causes is likely to attack children, whereas that caused by witchcraft would mostly hit adults. However, they admitted that adults can also suffer from epilepsy caused by natural causes, such as eating pork. One traditional healer explained thus:

“When epilepsy is due to witchcraft, the person gnashes his teeth and he or she does not open the mouth, while if it is due to natural causes, the patient foams at the mouth and his or her eyes are white” (Mamad-Mussa, a traditional healer).

Traditional healers also said that sometimes the causes of the disease might be both natural and due to witchcraft. In this case, it requires treatment from both the traditional healers and in hospital. Thus, epilepsy was treated in different ways, depending on its perceived causes. As one traditional healer put it:

“When the disease is due to natural causes, I give medicine only, but when it is related to witchcraft, I give medicine and incisions in the skin. If the patient does not get better, I advise him or her to go to hospital” (Allan-Alban, a traditional healer).

Interviews with the health workers in the hospital revealed that epilepsy in the study area was caused by eating infected pork, heredity and delivery by traditional midwives. Health workers said that there were many cases of children as young as 2 or 4 weeks suffering from epileptic seizures. As one of them put it:

“Many cases of epilepsy in children are caused by lack of knowledge and management of delivery process in the community. Many cases of birth occur in the household and they are managed by non-trained people, such as traditional midwives and some of them do not have enough experience on how to manage the baby’s head. Mismanagement of births causes injuries in the brain and may lead to the development of epileptic seizures” (Bido-Haja, a 50 years old man, health worker).

6.6.1 Efficiency of the methods used to manage epilepsy

The respondents ($n = 54$) who reported living with epileptic patients in their households, were asked about the condition of these patients after they had taken them to the hospital or to a traditional healer for treatment. Out of the 48 respondents who said that their relatives had experienced treatment, 34 reported that they still suffer from epilepsy, while 14 believed that they were better and perhaps were cured, out of which 9 reported that they got better after consulting a traditional healer and the remaining 5 did so after visiting the hospital.

Visit to hospital and traditional healers appear to result in relief of epileptic seizures. However, it was difficult to evaluate and authenticate these claims. Out of the 14 respondents who said that their relatives were better but did not know whether they were totally cured, 4 of them sought treatment in hospital, but the patient got better when they shifted to a traditional healer. On the other hand, 3 got better in hospital after they had sought treatment from the traditional healers.

Findings from the narratives reveal that people spend long time seeking treatment from the traditional healers before seeking help in the hospitals. One of the epileptic narrated the way epileptic seizures occurred and action that she took to treat the disease as follows:

“The disease started suddenly. It started like I was going crazy and I started fainting frequently. It started like malaria, I felt headache, dizzy and I fainted. I lost consciousness and when I woke up, I started destroying things like a crazy person, and then I became calm. After seizures, I stayed for a week while very weak and I could not do anything at all. I had never had cerebral malaria or accident. Nobody suffered from this disease before in the family. When seizures were frequent, we consulted a traditional healer. We went to several traditional healers. I took different medication, but the disease persisted.... I used to eat pork, but when I started suffering from epileptic seizures, a traditional healer told me not to eat pork, but he did not explain to me the reasons. He did not also tell me what I was suffering from. After almost five years, my mother decided to take me to hospital. Since I began treatment from the hospital, I am feeling better. Before, I used to faint between 2 to 4 times per month, but now, I faint once a month” (Cela-Nute, a 25 years old woman suffering from epilepsy for the last 6 years).

Some experience of people suffering from epilepsy showed that the solution lay in traditional sector than hospitals. However, all depended on personal experience and perceptions. People, who got better in the hospital after undergoing treatment from the traditional healers, said that hospital was better. On the other hand, those who did not get better after hospital treatment tended to see traditional sector as a better option for epilepsy treatment. An informant suffering from epilepsy said:

“I started fainting while I was young. I recall that my parents took me to hospital and for several years I followed hospital treatment, but the seizures did not stop to occur. But after some times, my parents were advised to seek treatment in the traditional sector. I began to take medication from a traditional healer and I became better. I could not faint anymore. I took medicine from a traditional healer for almost 2 years. Now I think I am cured because I have not experienced epileptic seizures for 7 years” (Jen-Babo, a 28 years old man suffering from epilepsy).

6.7 Discrimination against people suffering from epilepsy

People with epilepsy in the study area experience discrimination due to their condition. Although information gathered from FGDs indicated that epileptics were treated like other people without the disease (epileptic children were allowed in school and mixed freely with others), there were cases where parents did not allow their relatives to go to

school or to marry due to frequent seizures. There was a case of an epileptic girl whose parents did not allow her either to go to school or to have a boyfriend.

The discrimination seemed to be more likely within the family than from outsiders. A key informant interview with a health worker revealed that women were more likely to be discriminated against marriage than men. He stated thus:

“Many cases that I have attended to, I have noticed that when a man is sick, he is always accompanied by his wife, but when it is a woman, she comes here alone and some say that their husbands have abandoned them due to the seizures” (Bido-Haja, a 50 years old man, health worker).

In fact, findings from the narratives with epileptics reveal that some of them had experienced some discrimination in the community, especially in marriage. One of the epileptics narrated as follows:

“The seizures began 6 years ago before I was married to my first husband. Before, he was committed to the marriage, I explained to him that I was suffering from the disease. He said that there was no problem and he would help and be by my side in whichever situation. We married and I became pregnant. However, before the baby was born, I got seizures and he did not help me. My mother took care of me. After that event, he abandoned me and he has never come back. My first child was born while I was alone. I supported the child and he is now three years old, but his father has never come to see him and does not give financial support. Only his family, sometimes, give some support to the child. I heard that now he is already married to another woman. After one year and a half, I got married to another man. I also explained my health status to the second man. I told him that my son’s father abandoned me because of epilepsy, but he said that that was not a problem. He guaranteed that he would support me and would help in any situation. We married and I become pregnant with my second child. Unfortunately, before I gave birth, I got seizures and my second husband disappeared until today. The child was born while I was alone and now he is one half year old. Now and then, I live alone with my mother and I support two children without fathers. All my children’s fathers abandoned me because I suffer from epilepsy” (Cela-Nute, a 25 years old woman suffering from epilepsy for the last 6 years).

6.8 Risk practices favouring transmission of *T. solium*

Epilepsy, specifically the one related to cysticercosis, is caused by consumption of raw or undercooked infected pork. However, other factors such as drinking non-boiled infected water, consumption of unclean vegetables have also been described as means of transmitting cysticercosis. This section analyzes risk factors that could favour the transmission of cysticercosis in the study area.

6.8.1 Pork consumption

Direct observation revealed that pigs and goats were slaughtered and sold every day of the week, while cattle were slaughtered every Wednesdays and Saturdays at the local butchery.

Findings from the survey indicate that both pig keepers and non-pig keepers consumed pork. Out of the 150 respondents, 124 (82.7%) reported eating pork, while 26 (17.3%) did not eat pork. Among the pork consumers, 80% said they only ate it when they had money to buy it, while 2.7% stated they always ate pork. Most (80%) of the respondents (n = 54) living with people suffering from epilepsy reported that their relatives were pork consumers, while 20% said their relatives did not eat pork

The reasons for not eating pork were related to sickness and other personal reasons. Out of the 26 (17.3%) respondents who did not eat pork, 22 said that they became sick (suffered from diarrhoea, vomiting and quick pulse whenever they consume pork), 2 had never eaten and 2 said they did not like it. On the other hand, 20% of the respondents living with people suffering from epilepsy said their relatives did not eat pork because they have never eaten.

Apart from the availability of pork, the price charged among the 3 types of meat seemed to favour pork consumption. While beef was sold at 2.8USD and goat meat at 2.4USD, per kg, respectively; pork was sold at only 2 USD per kg. The pork roasting centres split pork into small pieces and sold it at 0.2USD a piece. This practice allows almost everybody to access and eat pork. Pork consumption might have also been influenced by religion. Angónia rural district is dominated by Christianity, a religion which does not forbid pork consumption.

Trading in and consumption of infected pork could also predispose people to infection of *T. solium*. Findings from the survey reveal that pork infected with cysticercosis was traded in the area. Out of the 31 respondents who had experienced white nodules in their pigs, 22 managed to sell them, while the remaining 6 said that they slaughtered and ate, one farmer slaughtered and used the meat as payment for casual labour, while 2 said that they buried the carcass. Information from FGDs also revealed that people consume infected pork. In a FGD, one participant said:

“Pigs infected by white nodules are slaughtered and eaten in the community. However, even if you cook for a long time, white nodules are not eradicated at all. It produces sound in the source pan, and the pork does not taste as good as non-infected pork” (FGD with pig keepers).

Sometimes, wholesalers return the carcass to the pig keeper when it is found to be infected at the local slaughter. When this happens, pig keepers give back the money to the wholesaler in exchange for the carcass. However, if they just give half of the money,

they will not get the carcass. Pig keepers who have received back the carcasses, said that they consumed the pork and distributed some of it to their neighbours.

6.8.2 Home slaughtering of pigs and lack of meat inspection

During the survey, it was observed that pigs were mostly slaughtered at home either for sale or for consumption. Out of the 100 pig keepers, 48 slaughtered pigs at home, while 52 sold their pigs alive.

Among the 48 respondents who slaughtered their pigs at home, 73% slaughtered pigs at least once a year, 21% two times a year and 6% slaughtered pigs 3 or more times a year. When pigs were slaughtered at the household, the pork was not always subjected to the meat inspection. Out of the 48 pig keepers who slaughter pigs at home, 4 reported having pork inspected and only 2 said their pork was always inspected by meat inspectors. The remaining 44 of the respondents said that their pork was not inspected because there were no meat inspectors or they did not know where to find them.

Direct observation revealed that pigs were likely to be slaughtered at home and then sold in the street either raw or cooked. The price of raw pork in the community or street was 2.USD per kg.

6.8.3 Pork preparation methods

Respondents reported using 3 ways of preparing pork: boiling, roasting and frying. All respondents stated that they boiled the pork, while 88% also roasted it and 12% combined boiling and frying. In terms of duration of boiling, 47% of the pork consumers reported boiling their pork for between 30 minutes and 1 hour, 22% for less than 30 minutes, 15% for more than one hour, while 16% did not remember how long it took them to cook the pork. The least time, that is, less than 30 minutes, mostly applied to roasting and frying.

However, direct observations in 5 households revealed that the average time of boiling pork was 35 minutes. People prepared their pork using intensive heat. In all the observed cases, water was added 3 times before the meat was considered ready. The Respondent reported that pork from that area (Ulongue locality) was hard and, therefore, required intensive fire and adding of water to ensure that it was properly cooked. At pork roasting centres, the average time of roasting or frying pork was 10

minutes. However, at some roasting centres, it took between 5 to 7 minutes, depending on the intensity of the fire.

6.8.4 Water sources and treatment of drinking water

Lack of adequate water supply and hygiene in water has been described as a major means of the spread of *T. solium*. Findings from the survey show that 54.7% of the respondents used a well (Plate 5.2) as their source of water, 37.3% fetched water from borehole and 8% from the rivers. Out of the 150 respondents, 26% boiled drinking water, out of which 10% reported always boiling their water and 16% boiled only during rainy season. The remaining 74% did not boil their drinking water. Respondents who fetched water from the well, 32.9% boiled water, while 21.8% did not boil the water. On the other hand, respondents who used rivers, only 3 out of 12 boiled their drinking water.

Type of wells used in the village

Type of well used at the local market (Ulongue)



Plate 6.2: Types of wells used in Angónia rural district

Plate 6.2 shows that wells were not properly covered. The kind of object used to cover the wells could not prevent pollution of the water. This could lead to health problem in the community since most people did not boil their drinking water. Wells in the local markets were not properly covered. This could expose wells to pollution.

6.8.5 Lack of health facilities in the study area

Lack of health facilities and specialized personnel presented a serious challenge to the treatment of epilepsy in the study area. Among the facilities that were in the district, 1 rural hospital, 4 health centres and 3 health posts, only the rural hospital located in Ulongue administrative post could deal with cases of epilepsy. At this rural hospital,

there was only one health worker specialized in epilepsy. However, even here, there was sometimes shortage of tablets (Phenobarbital) to treat the disease. Consultation and treatment of epilepsy is free.

Apart from these factors, it is important to mention the distance between the hospital and the community. Many people lived very far from the hospital and it required money for transport to get to the hospital. Some respondents noted that they were not seeking treatment in the hospital because it was far and they had no money for transport. The general distance between villages and the hospital is about 50 to 120 kilometres. A return ticket in a private car cost between 2.USD to 4.USD.

Despite the fact that treatment of epilepsy is free, community behaviour regarding modern health facility played a very important role in the treatment process. One health worker revealed during the interview, that epilepsy requires a long process of treatment and it was difficult to determine the duration. However, many patients did not adhere strictly to prescription instructions. Once they noticed that they were getting better and epileptic seizures no longer occurred, they gave up taking medication and any form of regular consultation. As he put it:

“Many patients do not follow the treatment process, despite the fact that I always inform them about the long duration required. Once they notice that they no longer have seizures for 2 or 3 months, they give up and they do not come back to the hospital. Last week (last week of February 2009), I received a patient who had began treatment in 2006 and gave up after 4 months because she thought that she was cured. She never came back to the hospital to take the tablets. Now (first week of March, 2009), she came back because she is convulsing again” (Bido-Haja, a 50 years old man, health worker).

This behaviour of epileptic patients, regarding the use of health facilities might be influenced by the lack of knowledge on causes of epilepsy. Although 91.3% of the respondents perceived epilepsy as a sickness, 93% of them lacked knowledge on causes of epilepsy and information about its transmission. Lack of knowledge and information has a great impact on the risk factors that could favour the transmission of the disease and choice of health sector for its treatment.

6.9 Changing behaviour towards *T. solium* risks

This study also probed on changing attitudes towards *T. solium* risks that could be identified in the study area. This section highlights changing attitudes of respondents towards risk factors such as home pig slaughtering and pork inspection, pork preparation methods and water treatment.

6.9.1 Home slaughtering of pigs and pork inspection

All pig keepers who reported slaughtering pigs in their households said that they would accept a meat inspector to inspect their pork. FGDs revealed that participants wanted veterinary officers in the study area to treat their pigs and inspect the pork because they had been cheated by wholesalers in determining the prices of pigs. In one of the FGDs with pig keepers, a participant observed that:

“We would like to have Veterinarians in the community to teach us how to raise pigs and treat pig’s disease because some wholesalers force us to sell out pigs at lower prices alleging that the pigs are infected by white nodules” (FGD with pig keepers).

Wholesalers had been purchasing pigs at a lower price, and the reason for that was related to the health of pigs. Since, pig keepers could not easily tell whether pigs were infected by white nodules or not, wholesalers might have taken the opportunity to purchase the pigs at a lower price. Participants reported that veterinary officers would teach and assist them in determining the health of the pigs.

6.9.2 Pork preparation

The 22% of the respondents who said that they cooked their pork for less than 30 minutes and those who did not remember (16%) mentioned that they would cook the pork for a longer time if they knew that there was a problem with it. All the 31 pig keepers that reported selling infected pigs and consuming infected pork said that they would stop doing so, if they knew that they could be infected. FGDs also revealed that participants did not know that if they consumed infected pork, they would get epilepsy or any other disease. However, they also said that they were willing to have a slaughter house in the village, so that the pork could be inspected before it was consumed.

6.9.3 Water preparation

The preparation of drinking water in the study area is important as a result of the possibility of pollution. All respondents who fetched water from the wells and did not boil it said that they would start doing so if they knew that this would protect them against diseases. Information gathered from FGDs indicated that participants were willing to boil the water if they were informed about any danger of drinking non-boiled water. As one participant put it:

“We can always boil our drinking water if we know that we may get disease when drinking non-boiled water from the wells” (FGD with pig keepers).

CHAPTER SEVEN: Discussion, Conclusion and Recommendations

7.1 Introduction

This chapter presents the discussion of the findings. The discussion concerns pig keeping practices, perceptions and knowledge regarding porcine and human cysticercosis, as well as practices favouring the spread of the disease in pigs and humans in Angónia rural district and action taken to treat the disease in pigs and health seeking behaviour in relation to epilepsy.

7.2 Pig rearing practices

Findings of this study suggest that pig keeping in Angónia rural district is a practice that adds income to families. Respondents viewed pigs in terms of their returns. Majority (97.7%) of the respondents perceived pigs as animals that multiplied quickly and bring in a lot of money.

Small scale farmers practiced pig keeping along with agriculture. Farmers kept pigs to help with the basic financial needs of the household, such as meat and money. Similarly, pig keeping had been perceived as an income generation activity in North of Vietnam and pigs/pork also fulfilled social obligations and were used in connection with customs and for special occasions like weddings, funerals, worshipping (Phama *et al.*, 2007). Although, pigs in Angonia rural district were used in ceremonies, such as wedding and funerals, respondents reported that they were using pigs like any other animals to access meat.

Pigs also appeared to be a means of saving. Pigs were sold when the families were facing problems such as starvation, lack of money to buy seeds, fertilizers or when their relatives were sick. In fact, finding shows that 82% of farmers sold their pigs to solve family problems, including buying food, fertilizers, seeds, clothes, school equipment and paying medical bills.

The outbreak of pig diseases, such as porcine cysticercosis and African swine fever could hinder pig keepers from getting an additional income. According to Ngowi *et al.* (2004), when pigs are infected by cysticercosis, it results in economic losses, since it can lead to a partial or total condemnation of the carcass. Boa *et al.* (2006) suggested that the economic losses due to porcine cysticercosis in Mbulu district, Tanzania may be estimated at 60% of the carcass value.

Although this study did not probe on economic loss, the results suggest that pig keepers experienced loss of the carcass value due to cysticercosis. Some respondents reported that they sold their pigs at half price and other did not succeed in selling them because they were infected. This is a clear indication that cysticercosis is a threat to the economic stability of small scale farmers.

7.3 Perceptions and knowledge regarding white nodules and epilepsy

In this study, it was assumed that people's knowledge influenced their perceptions of the transmission of neurological disorders (epilepsy) in humans and white nodules in pigs in Angónia rural district.

Findings regarding knowledge and perceptions on white nodules reveal that 85.3% of the respondents perceived white nodules as pig disease. However, this perception does not mean that respondents knew about the cause of the disease. Despite the fact that 94.7% of the respondents had heard about white nodules in pigs and 87.7% had seen a case of the disease, the majority (92%) of respondents did not know how pigs get the disease. Out of the 150 respondents, only 4% recognized the causes of white nodules in pigs (free range practice and by eating human faeces). There was no significant difference between pig keepers and non-pig keepers in terms of knowledge regarding cysticercosis.

Respondents (42%) used pig's tongue as a means of identification of white nodules in pigs. This knowledge was based on information obtained from pig traders and neighbours, and not from animal specialists. This suggests that pig traders used pig's tongue to examine the pigs before purchasing them from the farmers. Similarly, a study in Mbulu district, Tanzania (Ngowi *et al.*, 2004), found that pig traders were examining the pigs carefully before purchasing them from the farmers, using pig's tongue.

Although pig traders appeared to be an important source of information on cysticercosis in the community, they did not disseminate complete information on how pigs get the disease, and therefore, how the community could prevent the infection of their animals. This suggests that the community (pig keepers and non-pig keepers) in Angónia rural district lack knowledge on transmission of white nodules in pigs, and this could expose them and their animals to infection of the disease.

Findings of the study suggest that there is a high prevalence of epilepsy in the study area. Results from the survey reveal that out of the 150 respondents, 54 (36%) reported that they had someone suffering from epilepsy at their households. The high prevalence of epilepsy may be related to cysticercosis. According to Garcia *et al.* (2003), neurocysticercosis is the major cause of acquired epilepsy in developing countries, such as India, Mexico and Peru, suggesting that the higher rates of epilepsy were due mainly to neurocysticercosis. Besides, several studies have reported a close relationship between neurocysticercosis and epilepsy. A study in South India, reported in 2000, found an association between neurocysticercosis and epilepsy in 51% of patients (WHO, 2003). In Eastern Cape Province, for example, a study found that 95% cases of neurocysticercosis were associated with epilepsy (Mafojane *et al.*, 2003).

The high (33.3%) prevalence of porcine cysticercosis (Afonso *et al.*, 2001) in the study area and the fact that results show that the community consumed infected pork, including people with epilepsy, could expose them to infection of cysticercosis. Among epileptic people, the result shows that the prevalence is higher in men (70%) than in women (30%) of all ages. This finding indicates consistency with other acceptability studies from Sub-Saharan Africa. For example, a study in Cape Province, South Africa, had found that the prevalence of epilepsy in men was higher than in women (Mafojane *et al.*, 2003). The high prevalence of epilepsy among men in the study area may be related to the fact that most men eat roasted pork in the street, market or in the local roasting centres, where pork may not be well cooked.

Although the result suggests that men seem to be at higher risk of acquiring cysticercosis than women, it is important to mention that all age groups are at risk of acquiring the disease. According to Mafojane *et al.* (2003), cysticercosis is found in all age groups and equally in men and women. This is because, beside pork consumption, people can acquire the disease through faecal-oral contamination with *T. solium* eggs from tapeworm carriers (Garcia *et al.*, 2003).

It also emerges that people's perceptions and knowledge regarding epilepsy is an important means of preventing the disease. Results obtained from the survey show that 91.3% of the respondents perceived epilepsy as sickness. Despite the fact that the majority (98%) of respondents knew or had heard about someone suffering from epilepsy, 93% of respondents did not know the cause of the disease. The same result

was observed among the respondents that had at least someone suffering from epilepsy at the household.

Nevertheless, a small number (7%) of the respondents reported that epilepsy was caused by witchcraft (4%), pork consumption (1%) and malaria (2%). It was among non-pig keepers that epilepsy was associated to pork consumption. This result suggests that the community lacked knowledge on aetiology of the disease and they do not associate it with pork consumption; instead, the disease is associated to other causes.

The perception that epilepsy is associated to witchcraft has been reported in several studies in Africa (Birbeck *et al.*, 2006; Njamnshi *et al.*, 2008) and India (Tran *et al.*, 2007). A study among teachers in Zambia found that the respondents associated the disease to spirit possession, contagion and witchcraft (Birbeck *et al.*, 2006). However, other study conducted in Lao regarding relationship between epilepsy and pork consumption, found that 42% of the respondents viewed epilepsy as having supernatural origin, while 60% associated it with pig consumption (Tran *et al.*, 2007).

Findings also show that respondents had poor knowledge on the transmission of epilepsy. Results from the survey show that 52% said that epilepsy was not contagious and 41.3% respondents were not sure whether the disease was transmitted from one person to the next. This may lead to high risk infection in case of epilepsy related to cysticercosis. According to Carabin *et al.* (2006), tapeworm carrier is an important means of transmission of the disease.

However, the fact that some respondents (6.7%) reported that the disease was contagious and could be passed on through saliva, breathing and contact with epileptic people, may lead to the discrimination of people living with epilepsy. A study in Batibo district, Cameroon, found that about 43% of respondents would object to associating with people with epilepsy and 75.8% would object to their children marrying epileptic people (Njamnshi *et al.*, 2008). In fact, it emerges from this study that some people living with epilepsy were denied schooling opportunities and found it difficult to marry. Some informants suffering from epilepsy reported to have been abandoned by their husbands because of their condition. This result is consistent with Kleinman's statement (1995). According to this author, epilepsy patients are frequently denied schooling, shunned by their peers, find it difficult to marry, and meet active discrimination when they seek employment.

A part from discrimination, people with epilepsy have their productive capacity reduced due to seizures. According to Carpio and Hauser (2002), neurocysticercosis leads to stigmatization, incapacitation and decreased work productivity. Findings of this study show that some informants living with epilepsy find it difficult to perform their normal activities (agriculture, cooking, business) after they suffer from epileptic seizures.

These findings confirmed the assumption that people's knowledge influenced their perceptions of the transmission of white nodules in pigs and epilepsy in humans. However, this farmer's knowledge was common sense, based on their everyday experience with the diseases. People had heard and experienced the disease, but they did not know their aetiology.

7.4 Practices favouring the spread of porcine and human cysticercosis and changing attitudes towards associated risks

One of the assumptions of this study was that local practices related to pig rearing, culinary and hygiene favoured the transmission of neurological disorders in humans and white nodules in pigs. Another assumption was that people could change their attitudes towards neurological disorders and white nodules associated risks if they knew that their practices might expose them and pigs to diseases.

Free roaming pig practice is considered as one of the risk factor for porcine cysticercosis (Lekule and Kyvsgaard, 2003). Results from the survey show that 92% of the pig keepers allowed their pigs to roam freely from one to ten months. Pigs were allowed to roam freely during harvesting and fallowing periods and they were enclosed during planting and growing period. However, some pig keepers allowed their pigs to roam freely during growing period. This is similar to findings of other studies in the study area. For example, a community based survey in the same district (Gule, 2008) found that pigs were only housed when there were crops in the field, but after harvest, were allowed to roam freely.

Several other studies (Mafojane *et al.*, 2003; Boa *et al.*, 2001; Ngowi *et al.*, 2004) have associated free range practice with spread of cysticercosis. A study done in Eastern Cape Province, South Africa, reported the highest prevalence of cysticercosis due to the common practice of free-range pig farming (Mafojane *et al.*, 2003).

The reasons for allowing pigs to roam freely in the study area were related to lack of capital to buy pigs feed and the belief that pigs grow quickly and become fat when they are allowed to roam freely. Other reasons were associated to the time taken to manage the pigs and normal practice of allowing pigs to roam freely in a certain period of the year. Pigs were also allowed to roam freely when there were no crops in the field. Apart from these reasons, poor construction of pig pens seemed to favour free roaming.

Hygiene, such as lack of latrines in the community has also been considered as one of the risk factor for porcine cysticercosis. This is because, pigs get infected by the disease when they eat infected human faeces (Vilhena *et al.*, 1999; Ngowi *et al.*, 2004; Margono *et al.*, 2006). A study conducted in Mbulu district found that porcine cysticercosis prevalence was high in households with no latrines and in free ranging pigs (Ngowi *et al.*, 2004). The results of this study show that 95.3% of respondents had latrines at home and the majority (91%) of respondents reported that they always used them. This suggests that the problem is not only related to the lack of latrines, but also to its proper utilization.

Other risk factors that could favour the transmission of cysticercosis in the study area were lack of veterinary field officers and meat inspection facilities. This finding is similar to other studies carried out in the same district. A community-based survey in the same study area (Gule, 2008) found that there was a lack of and proper pork inspection. For example, the same study found that some inspected carcass were positive of porcine cysticercosis.

These risk factors (free roaming pig practice and lack of and proper pork inspection) could also favour the transmission of cysticercosis in humans. The findings of the study show that farmers slaughtered pigs at the household, but the pork was not inspected. Farmers also traded in and consumed pork from infected pigs. However, pork was not properly cooked, especially in pork roasting centres. These practices could put people at risk of infection of *T. solium*.

Other risk factors that could favour the spread of *T. solium* were lack of treatment of drinking water and poor knowledge on the aetiology of the disease. For example, more than half (54.7%) of respondents used a well to fetch water, but only 26% boiled drinking water. The remaining respondents reported that they would boil water if they knew that this would protect them against diseases. These findings suggest that cultural

and environmental factors play important roles in spreading the *T. solium* among pigs and humans.

Regarding changing attitudes towards cysticercosis associated risks, the findings reveal that farmers would accept their pork to be inspected by meat inspector; they would cook pork for a longer time if they knew that there was a problem with it and they would start boiling drinking water if they knew that this would protect them against disease.

Basing on these findings, the assumption that local practices related to pig rearing, culinary and hygiene favoured the transmission of white nodules in pigs and neurological disorder in pigs is confirmed. On the other hand, the findings confirmed the assumption that people would change their attitudes towards neurological disorders and white nodules associated risks if they knew that their practices might expose them and pigs to diseases. However, the confirmation of this assumption has to be interpreted prudently. This is because the findings were based on farmer's discourse and not practices. Sometimes, what people do in their everyday practices may not necessarily meet their discourse.

7.5 Health seeking behaviour in relation to white nodules and epilepsy

The discussion in this section concerns actions taken to treat white nodules in pigs and health seeking behaviour in relation to epilepsy. One of the assumptions of the study was that the way people understood the causes of neurological disorders in humans and white nodules in pigs would determine the means that they would employ to cope with the disease.

Pig keepers used various methods to treat white nodules in pigs. They mixed pig's feed with salt, charcoal or ashes to cope with the disease. Although the methods did not bear positive results, none of the respondents reported to visit a traditional healer or extension field officer for treatment of white nodules infection in pigs.

In terms of health seeking behaviour in relation to epilepsy, almost all the respondents who reported having people with epilepsy at the household went through a process of multiple and varied health seeking patterns. Respondents (44%) tried two different options to treat the disease. The traditional sector (Kleinman, 1980) was the first option utilized by 53% of respondents before seeking help from hospital. This is similar to

findings in epilepsy studies in Zambia (Atadzhanov *et al.*, 2006; Baskind and Birbeck, 2005).

Findings of this study show that people consulted their families or relatives and neighbours who also had people suffering from epilepsy before choosing the health care option. This suggests that social networks play important role in health seeking behaviour. According to Kleinman (1995), people develop interpersonal networks which help them to identify and take decisions about their conditions. *These social networks are organized in the popular sector, where lay people decide when and whom to consult, whether or not to comply, when to switch between treatment alternatives, whether care is effective or whether they are satisfied with its quality (Kleinman, 1980).* For example, some informants reported that they sought treatment in traditional sector because they were advised by other people who had similar problems and, other respondents did not take any action to treat the disease because they were told that it was not treatable.

Folk and professional sectors were consulted for the treatment of epilepsy. According to the respondents, people who were suffering from epilepsy sought treatment both from hospitals and traditional healers. Responses of those surveyed and the informants show that people switched from one sector to another. Some respondents went to the hospital after they had failed to get treatment from the traditional sector. On the other hand, those who could not get treatment in the hospital resorted to traditional healers. However, those who did not get better after consulting both hospital and traditional healer, decided to go back home and treat the disease in the popular sector. As Kleinman (1980) argues, there is interaction among health care sectors and the patients use popular sector to choose the health care sector. The boundary between sectors functions as point of entrance and exit for patients who follow the trajectories of their illness through the intricacies of the health care system.

These findings confirmed the assumption that the way people understand the cause of white nodules and epilepsy determine the means that they employ to cope with the disease. However, the understanding of the disease was influenced by social network and lack of knowledge on the aetiology of the diseases. For, example, some respondents consulted traditional healers because they were told that their relatives were bewitched.

The findings of this study can be summarized as follows:

(i) People in Angónia rural district are familiar with white nodules and epilepsy, but they have poor knowledge of the aetiology of the diseases. There is no significant difference between pig keepers and non-pig keepers in terms of knowledge regarding cysticercosis. However, a small percentage of non-pig keepers associate epilepsy to pork consumption.

(ii) Pig keepers allow their pigs to roam freely which is associated to lack of capital to buy pig feeds, beliefs and lack of time for proper management of pigs when they are in pens. Free range practices, lack of proper use of latrines and shortage of veterinary field officers were identified as risk factors that could favour the spread of porcine cysticercosis, while risk practices that could favour the transmission of human cysticercosis were: home pig slaughtering, lack of meat inspection, consumption of infected pork, lack of health facilities and specialized personnel, pork preparation methods and lack of treatment of drinking water.

(iii) In terms of changing attitudes regarding cysticercosis associated risks, findings suggest that people would change their attitudes if they knew that their practices might put them and their pigs at risk of infection.

(iv) People use various methods to cope with white nodules in pigs and epilepsy. Pig keepers mixed salt with maize bran, charcoal with maize bran and ashes with pig feed to treat the disease in pigs. On the other hand, patients suffering from epilepsy consulted both folk and professional sectors for the treatment of the disease. The choice of health care sector is influenced by social networks and beliefs institutionalized in the popular sector.

7.6 Conclusion

Cysticercosis is an agricultural and public health problem. As evidenced in this study, cysticercosis affects the livelihood of small scale farmers and their health status. Farmers perceived white nodules as pig disease and epilepsy as sickness, but they did not know their causes and the manner in which they were transmitted. It also emerges that respondents lacked knowledge on the *T. solium* cycle and they did not associate white nodules in pigs and epilepsy in humans. These findings suggest that poor

knowledge on the aetiology of the diseases influenced practices that could lead to risk factors for the transmission of white nodules in pigs and *T. solium* in humans.

7.7 Recommendations

From the findings of this study, it is recommended that campaigns are needed to increase awareness of cysticercosis transmission and implementation of measures for its prevention. Health education should focus on better methods of rearing pigs and the existence of epilepsy related to *T. solium*, as well as control measures to prevent the disease. In addition, community should be sensitized on proper the use of latrines, proper hygiene in handling and preparing food and treatment of drinking water.

Free roaming pig practice appears to be a risk factor for porcine cysticercosis. For this reason, pigs should be housed. However, to ensure that pigs are properly enclosed, it requires that community be trained on how to construct better pig pens.

Inspection facilities should be put in place, and there should be veterinary field officers in order to diagnose and treat pig diseases in the community. This would enable the community to consume proper inspected pork, and therefore, prevent them from acquiring cysticercosis.

Control measures for cysticercosis should be put in place in both animal disease and humans (acquired epilepsy). The community should be involved in planning and implementation of strategies to control the disease. The programs for cysticercosis prevention should target all members of the community (pig keepers and non-pig keepers, adults, elders, youth and children) and local institutions (schools, hospitals).

Government should construct more health facilities and allocate specialized personnel to deal with both epilepsy and cysticercosis, as well as promote the construction and use of safe sources of water (boreholes) to the community.

To better understand the relationship between cysticercosis and epilepsy, further studies are needed to investigate the association between the high epilepsy prevalence and the high cysticercosis prevalence in the study area.

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APPENDICES

Appendix I: Questionnaire for pig keepers and non-pig keepers

I am Carlos Eduardo Cuinhane, a student of Anthropology at the Institute of Anthropology, Gender and African Studies in Nairobi University, Kenya. I come here to study perceptions and practices of the transmission of white nodules in pigs and neurological disorders in humans. This study is conducted in this district because of increase of pig production. Your contribution is very important and will help Government and Non Government organizations to come up with policy to address the problems you face regarding pig diseases and neurological disorders in humans (epilepsy). All information that you will give me will be confidential and will be used only for the purpose of this study. If you wish your name will not be mentioned. I ask your permission to begin the interview. If you agree, please sign your name:

Name: _____ . Signature: _____ . Date ____/____/____

0 General information

Date of interview: _____/_____/_____ (date/month/year)

Starting time: _____

Finishing time: _____

Questionnaire number _____

District _____

Village _____

Name of interviewer _____

I. Socio-demographic information

1. Name of interviewee(optional): _____

2. Age _____ (years)

3. Sex:

a. Female _____

b. Male _____

4. What is the highest schooling grade you have completed?

- 1) None
- 2) Primary school (years completed)
- 3) Middle school (years completed)
- 4) Other (specify) _____

5. What is your main occupation?

- 1) Farmer
- 2) Teacher
- 3) Tailor
- 4) Other (specify) _____

II. Information on pig production (for non pig producers skip to Q. 33)

6. Do you keep pigs at your homestead?

- 1) Yes
- 2) No

7. Why do you keep pigs? (Multiple answers)

- 1) To help my family (sell and get money)
- 2) To access meat
- 3) To access manure
- 4) Other (specify) _____

8. How long have you been keeping pigs? _____

9. What type of pigs do you keep?

- 1) Natives (locals)
- 2) Foreign (from other country)
- 3) Other (specify) _____

10. Where did you get your pigs from?

- 1) From local district (neighbour)
- 2) From another district/province (specify)
- 3) From another country (specify)
- 4) Other (specify) _____

11. How many pigs do you have? _____

12. What do you intend to do with your pigs? (Multiply answers)

- 1) Selling
- 2) Consumption
- 3) Reproduction
- 4) Other (specify) _____
- 5) Not yet decided

13. Do you ever leave your pigs roaming freely?

- 1) Yes
- 2) No

14. Where do you keep your pigs during the following seasons:

Seasons	In pens	Free range	Tethering	Other (specify)
Planting				
Growing				
Harvesting				
Fallowing				

15. For how long do you leave the piglets roaming freely? _____

16. Why do you leave the piglets roam freely?

- 1) I have no food to feed them
- 2) To grow big (to get fat)
- 3) Because there are no cultures in the field
- 4) I have no time to manage them while in pens
- 5) Because it is an habit
- 6) Other (specify) _____

17. If it was not the reason you evoke, would you confine your pigs during whole year?

- 1) yes
- 2) No

18. Who manage the pigs when they are in pens?

- 1) Woman
- 2) Man
- 3) Both woman and man
- 4) Children
- 5) All
- 6) Other (specify) _____

19. Can your wife sell the pigs without your permission?

- 1) yes
- 2) No

20. Who decide the selling of pigs and application of the money?

- 1) Man
- 2) Woman
- 3) Both man and woman

21. What problems do you encounter when you keep your pigs in pens?

- 1) No problem
- 2) Food to feed them
- 3) Time to manage them
- 4) They do not grow big
- 5) Disease (African swine fever)
- 6) Paralyze of pig's feet due to mud
- 7) Other (specify) _____

22. What do you feed your pigs on? (Multiply answers)

- 1) Commercial feed (maize brain)
- 2) Sweet potatoes leaf
- 3) Banana's leaf
- 4) Pumpkin's leaf

- 5) Mangoes
 - 6) Kitchen's leftover
 - 7) Cabbage
 - 8) Local herbs (specify) _____
 - 9) Other (specify) _____
-

23. Do you or anyone in your household slaughter any of your pigs?

- 1) yes
- 2) No

24. How often are pigs slaughtered at your home?

- 1) At least once a year
- 2) 2 times per year
- 3) Between 2 or 3 times a year
- 4) Never

25. Have you ever have your meat inspected by a meat inspector?

- 1) Yes
- 2) No

26. Why your meat is not inspected?

- 1) because there is no meat inspector in the community
- 2) Because I have no money to pay for inspection
- 3) Other (specify) _____

27. How often is your meat inspected?

- 1) Never
- 2) Each time I slaughter a pig to sell in the market

28. When do slaughter or sell your pigs?

- 1) When they are one year
- 2) Between 2 and 3 years
- 3) 3 years and more

29. How do you sell your pigs?

- 1) Slaughtered
- 2) Live pig
- 3) Both slaughtered and live pig
- 4) Not yet sold

30. What is the value of a pig when it is ready to be slaughtered? _____

31. What is the age of the pig?

- 1) 1 year and half
- 2) 2 years
- 3) 2 to 3 years
- 4) 4 or more years

32. To whom do you sell your pigs?

- 1) Neighbours (in the district)
 - 2) Local wholesalers
 - 3) People from Malawi
 - 4) Other (specify) _____
 - 5) I do not remember
-

33. Why did you sell your pigs?

- 1) Because they were big
- 2) Because I wanted money to solve family problems
- 3) Because they had disease (African swine fever)
- 4) Because they were many
- 5) Other (specify) _____

III. Information on porcine cysticercosis (knowledge, beliefs, perceptions, cause, transmission and management)

34. What disease do your pigs suffer from? _____

35. Why don't you keep pigs?

- 1) I have no money to buy them
- 2) They die frequently from diseases
- 3) They are difficult to keep
- 4) Other (specify) _____

36. Have you ever heard about white nodules in pigs?

- 1) Yes
- 2) No

37. From whom did you hear about white nodules in pigs?

- 1) Neighbours (in the district)
- 2) People who come to buy pigs
- 3) My family (parents, uncles, cousins)
- 4) People who sell pigs/pork
- 5) People who keep pigs

38. Have you ever seen a case of white nodules in pigs?

- 1) Yes
- 2) No

39. What are the local names for these white nodules? _____

40. How do you view these white nodules?

- 1) Normal condition of pigs
- 2) Between normal and pig's disease
- 3) Pig disease
- 4) Pig and human disease

41. Do you know where you can find white nodules in pigs?

- 1) it is not possible to find them in a live pig
- 2) Under the skin
- 3) Under the pig's tongue
- 4) Mouth
- 5) Whole pig's body
- 6) I do not know

42. Do you know how do pigs get these white nodules?

- 1) from another infected pig
- 2) When they are free and eat dirty
- 3) By eating human faeces
- 4) I do not know

43. What seasons do white nodules appear?

- 1) Whole year
- 2) Harvesting period
- 3) Dry season
- 4) Rain season
- 5) Fallowing period
- 6) I do not know

44. Have your pigs been infected by white nodules?

- 1) Yes
- 2) No

45. How do you detect white nodules in pigs?

- 1) Through pig's tongue
- 2) Only when it is slaughtered
- 3) Whole pig's body
- 4) Through pig's mouth
- 5) I do not know

46. Do you usually separate infected pigs from non-infected pigs?

- 1) Yes
- 2) No

47. What do you do to treat white nodules in pigs? _____

48. When your pigs have white nodules, are able to sell them?

- 1) Yes
- 2) No

49. To whom do you sell pigs with white nodules?

- 1) Wholesalers
- 2) People from Malawi
- 3) I do not remember

50. Do you sell them with the same price of other pigs without white nodules?

- 1) Yes
- 2) No

a) What is the value of a pig with white nodules? _____

b) If you do not sell pigs with white nodules, what do you do with them? _____

51. If you knew that eating pigs with white nodules you can acquire disease, would you continue selling it?

- 1) Yes
- 2) No

52. Do you use pig's faeces as manure?

- 1) Yes _____ . How often? _____
- 2) No _____ . Why _____

IV. Information on Epilepsy (knowledge, beliefs, perceptions, cause, transmission and management)

53. Do you know or hear of people suffering from epilepsy?

- 1) Yes _____ (fill the table)
- 2) No

Number of people suffering from epilepsy	Sex	Age	Time from which the disease started

54. Do you know how people get epilepsy?

- 1) By eating infected pork
- 2) Witchcraft
- 3) Malaria
- 4) Other
- 5) I do not know

55. How do you view epilepsy?

- 1) Normal condition of people
- 2) Between normal and sickness
- 3) Sickness

56. Do you think epilepsy is transmissible?

- 1) Yes
- 2) No

57. How can you acquire epilepsy? _____

58. What do you do to treat epilepsy?

- 1) I go to hospital
- 2) I go to witchdoctor
- 3) I go to hospital and witchdoctor
- 4) I use herbs _____ (specify _____)
- 5) It is untreated _____ . why _____

59. What was your first option to treat epilepsy (only respondents living with people suffering from epilepsy)? Why did use the option you are referring to?

60. What do you think it should be done if a person suffers from epilepsy?

- 1) Go to hospital
- 2) Go to witchdoctor
- 3) Go to hospital and witchdoctor
- 4) I do not know

V. Information on sanitary conditions

61. From where do you usually get your drinking water?

- 1) River
- 2) Well
- 3) Borehole
- 4) Other (specify) _____

62. Do you usually boil your drink water?

- 1) Yes
- 2) No

63. How often do you drink your drink water?

- 1) Always
- 2) Sometimes
- 3) Never

64. If you never boil or you sometime boil it, would you always boil it, if you know that drinking non-boiled water can bring disease?

- 1) Yes
- 2) No _____. Why?

65. Do you eat pork?

- 1) Yes
- 2) No _____. Why?

a) How often do you eat pork?

- 1) Always
- 2) Sometimes
- 3) Never

66. How do you prepare your pork?

- 1) Boiled
- 2) Fried
- 3) Roasted
- 4) Other _____

67. How long do you usually cook your pork?

- 1) Less than 30 minutes
- 2) Between 30 and 1 hour
- 3) More than one hour
- 4) Other (specify) _____

68. If you cook less than 30 minutes, would you cook more than 30 minutes?

- 1) Yes
- 2) No _____. Why? _____

69. Do you have a latrine at home?

- 1) Yes
- 2) No _____. Why? _____

70. How often do you use a latrine?

- 1) Always
- 2) Sometimes

3) Never. Why?

71. Who mostly use the latrine?

- 1) Adults only. Men _____ . Women _____
- 2) Children _____
- 3) All (adult and children) _____

73. Is there any problem with disposal of human faeces in this community?

- 1) Yes _____ . Why? _____
- 2) No _____

74. How do you view human faeces disposal in the community?

- 1) Normal
- 2) Very bad
- 3) Dirty

75. If you never use or use it sometimes, would you always use it, if you know that defecating outside can bring disease?

- 1) Yes
- 2) No _____ . Why?

Our interview ends here. I would like to thank you once more for your cooperation, and remind you that no one else will access the information you gave me and it will not be used for other purposes different from the objectives of this study.

Direct observation: Interviewer must observe the following at the household:

1. Presence of latrine at home
 - 1) Present
 - 2) Absent
2. Material used to build a latrine
 - 1) Wood
 - 2) Stones
 - 3) Other (specify)
 1. Presence of a door in the latrine
 - 1) Present
 - 2) Absent
2. Pig rearing practice
 - 1) Roaring
 - 2) Confined
3. Pig's feed
 - 1) Maize bran
 - 2) Herbs (specify)
 - 3) Kitchen left over
 - 4) Others
4. Presence of pig pen
 - 1) Present
 - 2) Absent

5. Presence of door in the pig pen
 - 1) Yes
 - 2) No

6. Material used to construct the pig pen
 - 1) Wood
 - 2) Stones
 - 3) Other

7. Distance between pig pen and latrine
 - 1) Far
 - 2) Near
 - 3) Other

8. If the latrine is near the pig pen: why is your latrine near the pig pen?

9. Material used to build the house
 - 1) Stones
 - 2) Wood
 - 3) Grass
 - 4) Other

10. Home environ
 - 1) Clean (describe)
 - 2) Dirty (describe)

Appendix II: Interview guide for key informants (traditional healers and health workers)

I. Perceptions, causes and transmissions of neurological disorders (for Folk healers and Doctors/nurses)

1. How long have you been practicing humans and animal diseases management?
2. Where did you learn to manage humans and animal diseases?
3. What are the causes of neurological disorders (epilepsy)?
4. Are neurological disorders transmissible from person to person? How?
5. What practices do you think increase the predisposition of infection and transmission of neurological disorders in humans?
6. How do you prevent the transmission of neurological disorders?
7. How often do people that suffer from neurological disorder consult you?
8. What does community think of a person with neurological disorders?
9. What community beliefs are related with neurological disorders?
10. What do you do to manage neurological disorders in humans?

II. Perceptions, causes and transmissions of neurological disorders (for folk healers).

11. What are the causes of white nodules in pigs?
12. Are white nodules transmissible to other pigs or humans? How?
13. What practices do you think increase the predisposition of infection and transmission of white nodules in pigs and humans?
14. How do you prevent the transmission of white nodules in pigs and humans?
15. What is the major constrain regarding prevention of white nodules in pigs?
16. What do you do to manage white nodules in pigs?

Appendix III: Focus group discussion guide

I. Pig production (Pig system management and perceptions)

1. How pigs are raised in this district?
2. What do you think about the type of system used to raise pigs?
3. What challenges pig producers face in this district?
4. Would you change current pig system management (allowing pigs to roam) if you have other alternative (for group discussion with pig keepers)?

II. Pig disease (practices, causes, infection/transmission and management)

1. What are the common pig diseases in this district?
2. How do you call white nodules?
3. What is the cause of white nodules in pigs?
4. Can these white nodules be observed in live pigs? Where?
5. Are these white nodules transmissible to other pigs and humans? How? If not, why?
6. What practices contribute to infection and transmission of white nodules in pigs?
7. How do you prevent the transmission of white nodules?
8. What usually do you do when you find a pig with white nodules?
9. What happens to pork with white nodules?
10. Do veterinarians visit you to check the animals? How often? If not, why?

III. Neurological disorders (practices, causes, infection/transmission and management)

11. How do you view a person with neurological disorder (epilepsy)?
12. What causes this disease?
13. Is this disease transmissible from one person to another? How? If not, why?
14. What practices contribute to infection/transmission of this disease?
15. How can you prevent the transmission of this disease?
16. Is this disease curable? How? If not, why?
17. How the disposal of human faeces is viewed in this area? Is there any problem with it? Why?

Appendix IV: Screening questions for people suffering from epilepsy

1. Have you ever had sudden loss of consciousness and episodes of incontinence or foaming of the mouth or tongue biting?
2. How often have you had these symptoms?
3. How old were you when the first symptom occurred?
4. Have you ever had seizures or fits?
5. When did seizure episodes occurred?
6. How often does a seizure episode happen
7. Were you ever told that you had an epileptic seizure?
8. Have you ever had head injury that made you loose consciences?
9. Have you ever had a brief period of absence or loss of control with the surrounding?
10. Have you ever had uncontrollable twitching or jerking or abnormal movimentof one or more limb (s) (convulsions) that start surddenly and lasts for a period of a few minutes?

Appendix V: Narrative guide

1. Timing of the disease (the first time he or she experienced the problem. How was it like?)
2. Causes (what is the perceptions regarding causes of epilepsy?)
3. Diagnosis (how community identify the disease)
4. Methods used to treat epilepsy (popular, professional or folk sector)
5. Challenges of the people living with epilepsy

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