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Educating People Participating in the Pig Industry to Reduce Epilepsy due to *Taenia Solium*

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1. Introduction

In the developing countries of Africa, Asia and Latin America, neurocysticercosis is the major cause of adult-onset epilepsy (Garcia et al., 2004; Roman et al., 2000; Garcia et al., 2005; Sarti et al., 1994; Sciutto et al., 2000; Mahajan RC, 1982). In 1992, this form of epilepsy, and the *Taenia solium* tapeworm was declared a potentially eradicable disease by the International Task Force for Disease Eradication (Aarata et al., 1992; Shantz et al., 1993). However, there are several barriers to eradication such as lack of knowledge, lack of resources, poor hygiene and the fundamental implications of the management of pigs as a source of banking and income generation for the poorest of the poor. This chapter will discuss promising results of an educational program, the fact that the education should include the various actors in the swine industry, and illustrate the need for a broader geographic focus to promote the eradication of epilepsy due to neurocysticercosis.

2. Life cycle of the *Taenia solium* parasite

T. solium, called the pork tapeworm, has people as its definitive host. The adult tapeworm grows in the intestine of the infected person, shedding proglotids which are mature segments of the worm. These proglotids, that contain approximately 50,000 eggs, are shed each day in the stool of the infected person. Pigs, as the intermediate host, are infected by *Cysticercus cellulosae*. When a pig ingests the eggs that have been shed in the stool of the human, the egg crosses the intestinal wall. Next, the egg enters the blood stream and migrates to the muscle tissue. There the egg develops into a larval cyst. The tapeworm is transmitted to another person when this second person eats infected, undercooked pork. However, people can also act as an intermediate host. If a person ingests a tapeworm egg, it crosses from the intestine to the blood stream and preferentially migrates to nervous tissue. There it develops into a larval cyst. Epilepsy is caused by the space occupying lesions of the cysts in the brain of the infected person. This form of the disease is called neurocysticercosis (Serpa et al., 2007).

Epilepsy is a devastating clinical problem in rural areas where there is little education, high rates of poverty, and poor access to health care. People suffering from epilepsy are often misunderstood, ostracised, and limited in their participation in society. The family members

experience shame and may choose to keep the person suffering from epilepsy confined to the home. Often the affected person will not receive a proper diagnosis or appropriate medication. Epilepsy left unmedicated may advance significantly to increase the frequency and severity of seizures and may result in secondary trauma such as severe lacerations or burns. The eradication of the epilepsy due to this parasite requires the disruption of its life cycle (Mafojane et al., 2003; Phiri et al., 2003).

3. Situation in Sub Saharan East Africa

Pig rearing in Sub Saharan East Africa has been increasing by 10% per year over the past decade and in Uganda pork production increased by ten times between 1985 and 2005. Many people living in rural areas of East Africa depend for their livelihood on smallholder pig farming. The advantage of keeping pigs over cattle or sheep are that pigs grow faster and have more offspring in a short time period, eat leftover food, and are very easy to sell (Lekule & Kyvsgaard 2003; Mutua *et al.* 2010). Smallholder farmers typically live in extended family compounds on an average of one to two acres of land (Kagira *et al.* 2010; Mutua *et al.* 2010). Some family members may not use a latrine because of cultural norms or they may not have a functional latrine in the family compound (Githigia et al., 2005; Mutua et al., 2007). When one or more family members does not use the latrine, the life cycle of *T. solium* is enhanced because pigs gain access to human stool. Smallholder farmers who live in poverty grow their own food and therefore have insufficient land for other livestock. Therefore, *T. solium* tends to be a problem of the poorest of the poor. If there is a competition between the food resources between people and pigs, the pigs are kept in the traditional manner in a mixture of free range and tethered management style, largely because the inputs are much lower than under intensive management (Kagira *et al.* 2010; Lekule & Kyvsgaard 2003). Pigs are purchased when the family has some extra money to buy a weaned piglet. Then the pigs are kept to bank small amounts of money, for income generation, and to source money in a hurry when there is a family emergency such as medical needs, school fees, or for food between harvest seasons (Kagira *et al.* 2010; Lekule & Kyvsgaard 2003; Mutua *et al.* 2010).

In areas where *T. solium* is endemic, eradication is only possible by eliminating the reservoirs of the parasite. However, it is difficult to find live infected pigs because the test that is used, an examination of tongue for evidence of cysts, has a very low sensitivity of approximately 50%. Therefore, the only method of keeping infected pigs from the food chain is to ensure that all pigs are inspected by a government official after slaughter. In many developing countries the inspection system is poor and often people in the villages use home slaughter after which they sell meat from the family's farm (Roman et al., 2000).

4. Education

One study indicates that community behavioural and environmental practices must be modified to prevent continued transmission of cysticercosis and taeniasis (Sarti et al., 1992). This is perhaps best accomplished through education. Researchers have found that education in conjunction with community involvement reduces opportunities for transmission of *T. solium* in the human-pig cycle Sarti et al., 1997. A successful long-term change will only occur if the intervention program is associated with community participation and health education programs (Sarti et al., 1997; Cao et al., 1997; Sanchez et al., 1999; Carrique-Mas et al., 2001).

Education of farmers, butchers and government extension workers is likely the best method to prevent the lifecycle of *T. solium*. The government workers should include public health, adult education, veterinary and livestock specialist and social workers who are responsible for facilitating farmer groups. Ideally the education will also include key community leaders such as teachers, village elders and village chiefs (or the equivalent depending on the societal structure) whose opinion will be valued. It is important that the education includes the pig butchers as well because they are often responsible for slaughtering the pigs and selling raw and cooked pork. The farmers are in the most opportune position to interrupt the life cycle of the parasite by keeping the pig tied and away from human stool and the pig butchers and government veterinary inspectors can identify infected pigs to reduce the number of positive pigs in the food chain.

5. Education model

Although there are many education models that are likely successful, one such model that was used in Western Kenya will be described in this chapter (Wohlgemut et al., 2010). Regardless of the education model used, the long-term success of the program must be evaluated.

5.1 Farmer education

This four-part study included baseline data collection using individual farmer interviews followed by a workshop. Approximately half of any group of farmers is expected to attend one-day workshops. The farmers included in the data collection were randomly chosen within each selected village whereas the workshops were open to all pig farmers, village elders and village chiefs who wished to attend. Two subsequent farm visits followed the workshop, each 5 months apart. During these farm visits, a questionnaire was completed followed by one-on-one training. Farmers were asked if they attended the workshop and if not, they were given the education about the lifecycle of *T. solium* and prevention of the disease in people and in pigs. All farmers were encouraged to ask questions about *T. solium*, pig management or disease. The farmer was not limited in the number of questions they could ask or the time the researchers spent answering questions. During each visit, the farmer was interviewed in their native tongue by a local person who was hired by the research team and trained to conduct the interview. These research assistants translated for the English speaking researchers who were experts in pig production and disease. Phase 3 of the program was to provide a 2nd set of workshops for the farmers two years after the first farm visit. The workshop was based on the research results obtained during the longitudinal project and provided an opportunity to discuss *T. solium*. The final phase was to return to the community four years after the start of the study, which was two years after the phase 3. During this phase the researchers conducted one-on-one interviews to determine what behaviours the farmers adopted in response to the education (Wohlgemut et al., 2010).

5.2 Government staff education

A Training of the Trainers model was used in this project. The advantage of this model is that the government staff are taught the material that the researchers hope to spread to the entire community. The education program is longer term and more widespread because the staff can continue to disseminate the information for years after the project has ended. It is also important that the staff are given the same information that the farmers receive. Finally, the staff are able to converse with the farmers in their own local language. The researchers

provided three, one-day workshops for government staff and local community leaders including teachers and village chiefs. The workshops occurred at the start of the project and then two and four years later. At each workshop, the staff were given 20 to 30 page booklets that summarized the information taught and gave the background scientific information to justify the content. Staff who attended the workshops included veterinary, livestock, public health, and adult education specialists, veterinarians and social workers. The workshops included sections of the lifecycle of *T. solium*, the cause of neurocysticercosis and pig management, housing, breeding, feeding, diseases, and care. Each participant was required to participate in at least 3 workshops for the farmers in the local villages. At the end of the government workshop, the researchers assisted the staff in the preparation and planning for the farmer workshops (Wohlgemut et al., 2010).

5.3 Butcher education

The workshops for the pig butchers were facilitated directly by the researchers (Levy et al., 2009). The workshops focused on a study of the fixed and variable costs of a pig butcher business, income and profit calculation. The workshop also included a section on enhancing pork safety that included the life cycle of *T. solium*, the recognition of larval cysts in pig muscle, the importance of having every carcass inspected, and personal and butchershop hygiene. Finally, each butcher determined the cost of slaughtering the pig at a slaughter slab and government inspection based on the required kilogram of pork sales per pig to cover the cost. Many butchers were not able to leave their work to attend the workshops. One-on-one training was given to these butchermen. This format was not likely as valuable because during the workshops, the butchers discussed many of the issues presented and shared information with one another.

6. Knowledge acquisition

The educational opportunities enabled the farmers to learn about the life cycle of *T. solium*. However, the life cycle is complicated and the one-on-one training was more effective than the workshops in the longterm retention of the knowledge. One-on-one training enabled the farmer to ask the researcher questions as she explained the lifecycle of *T. solium*. Further, the farmer was able to hold a picture of the life cycle during the training rather than relying on following a poster at the front of the classroom. One-on-one training was also associated with having heard of the tapeworm in people and having seen the proglotids in a person's stool. This may have been because the researcher showed a picture of the proglotids during the training. Although one-on-one training is expensive, it is worth the cost if it results in long-term behaviour changes in a community that then reduce the incidence of *T. solium* due to epilepsy. That too has a high societal cost (Wohlgemut et al., 2010).

All farmers who had some education were more likely to correctly describe how pigs and people became infected and how people developed epilepsy from *T. solium* than before the study began (Wohlgemut et al., 2010). However, farmers who had been taught one-on-one were more able to correctly describe how people and pigs became infected than farmers who had only attended the workshop. Farmers who had completed primary school were also more likely to retain this information than farmers with less formal education. Leonard (1977) found that the level of education and prior knowledge of Swahili impacted the Kenyan farmers' capacity to understand complex messages. This puts an extra responsibility on the educators who must first be well educated to understand, and subsequently convey clear and accurate

messages (Flisser & Lightowlers, 2001). The connection between former education and knowledge acquisition illustrates the potential advantage of introducing this information into the late primary school education curriculum. If people who are used to learn in a classroom are more likely to understand and retain this material, a large number of families can be accessed through the educational system. This may be the most appropriate educational model in countries with a high uptake of primary school education among the poor.

Understanding the lifecycle of the tapeworm enables the farmer to determine how to interrupt the transmission through regular use of a pit latrine, improved personal hygiene and confining the pig. It is important that farmers understand the connection between the tapeworm and epilepsy so that they have a reason to make management changes to the pig rearing operation. Pigs that are tethered or housed must be fed on a daily basis. This takes time and money. Farmers who are not used to feeding their pig must also be taught about the locally available foods that can be used in combination to provide a complete ration for the pigs (Mutua et al., 2011). By using waste food stuff such as fruits that are spoiled, weeds, kitchen waste, and inexpensive sources of protein, farmers are able to reduce the costs of feeding the pig. All farmers, from the beginning of the study knew that they should seek medical treatment if they saw worms in their stool. The educators should encourage whole families to use anti-parasitides if one family member has proglotids in their stool.

7. Extension of knowledge to the community

The information about the life cycle of *T. solium* was rarely conveyed from one family member who attended the workshop to another family member who was interviewed five months later. This fact was frustrating for the researchers. One report from the United States Agency for International Development noted that it is of special importance to ensure access of education and training to women, as they are key contributors to the agricultural workforce, and could further contribute if recognized as a priority audience.²³ However, when looking at the long-term behaviour changes from the educational program, four years after the project began, farm families had adopted preventative management changes. Regardless of whether it was a man or woman who attended the training, four years after the start of the study, women were boiling the pork for 20 minutes prior to frying. Also, all the pigs were either in barns or tethered. A few farmers also mentioned either repairing or building pit latrines for the family to use. One study found that the prevalence of porcine cysticercosis was higher in pigs reared in households lacking latrines than pigs raised in households that had latrines (Ngowi et al., 2004). Similarly, the decline in *T. solium* infections in parts of Europe over the past century was due to improved public sanitation, rather than any specifically targeted control measures (Mahajan, 1982). Approximately 18% of families that did not participate in the educational project adopted behaviour changes because their neighbours had shared the information.

8. Confining pigs

After the initial farmer training workshop, the number of farmers that tethered their pigs increased from 32% to 51%. This rate increased to 62% after the one-on-one training. Four years after the study began, 100% of the farmers who had either participated in the research program or attended one of the workshops were either housing or tethering their pigs. This illustrates the long-term behaviour changes that results from these educational opportunities.

9. Safe pork

Four years after the study began, farmers and butchers were boiling the pork for 20 minutes before they fried the meat. The larval cyst will be killed if it is cooked at a boiling temperature for 10 minutes. Farmers said they purchased pork from butchers rather than from backyard operations because they wanted to buy meat that was inspected. Butchers regularly took the pigs to the slaughter slab to have them inspected prior to sale. The business education was important to the butchers because they kept track of their expenses and were sure to save enough money from each pig to pay for the inspection of the next pig. In a World Bank project in Kenya found that over 80% of farmers who are taught recommended practices choose to adopt them (Gautam 2000). This education had both a positive short- and long-term impact (Gautam 2000).

10. Conclusions

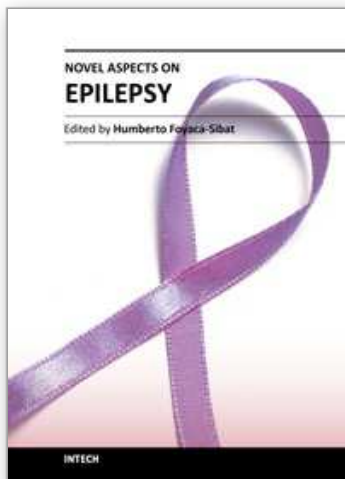
Reducing the prevalence of epilepsy due to neurocysticercosis requires people working in the pig industry to make substantial behaviour changes. To interrupt the lifecycle of the *T. solium* parasite, pigs must be confined so that they cannot gain access to human stool; pork must be inspected to keep infected carcasses out of the human food chain; pork must be well cooked to ensure that cysts not observed by inspectors are killed; people who carry the tapeworm must be treated; and people must be encouraged to improve personal hygiene by using a pit latrine and washing their hands after defecating. Knowledge is power. People will be motivated to make behaviour changes when they understand the link between the pork tapeworm, pigs, pork, hygiene and epilepsy. There are financial implications to preventing epilepsy due to *T. solium* and interrupting the lifecycle. Farmers who keep their pigs confined must source feed for the pig. There is a cost to purchase some of the food and other food, such as weeds, will require the farmer to spend time collecting. The butchers must spend additional money to transport the pig to and from the slaughter slab, to use the slab and to have the government staff person inspect the carcass. If the carcass is condemned due to cysts, the butcher assumes the entire purchase price of the pig.

Workshops using a Training of the Trainers model by teaching the government staff and local community leaders who then teach the farmers are an effective way to increase knowledge and elicit long-term behaviour changes by the farmers. One-on-one training of the farmers increases the level of knowledge, in particular, for difficult concepts such as the lifecycle of the tapeworm. It is important that workshops are followed up by individual training sessions between farmers and researchers so that the material is presented more than once, in more than one training method and those farmers have an opportunity to ask questions in a safe and private environment. Workshops for the pork butchers in which the education is linked to business practice were particularly important. The butchers acquired useful information about how to track and understand the costs, income, and profits of their business. They learned about their role in preventing epilepsy due to neurocysticercosis and felt responsible for ensuring the safety of the pork they sell. The butchers did change their behaviour by having a higher proportion or all of the pork carcasses inspected prior to sale. Both farmers and butchers changed how they cooked the pork by boiling it for 20 minutes prior to consumption or sale. Together, the systematic changes across the entire pig industry are expected to reduce the prevalence of epilepsy in these communities. This model needs to be repeated around the world, wherever pigs are kept in a free range manner and neurocysticercosis occurs.

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Novel Aspects on Epilepsy

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This book covers novel aspects of epilepsy without ignoring its foundation and therefore, apart from the classic issues that cannot be missing in any book about epilepsy, we introduced novel aspects related with epilepsy and neurocysticercosis as a leading cause of epilepsy in developing countries. We are looking forward with confidence and pride in the vital role that this book has to play for a new vision and mission. Therefore, we introduce novel aspects of epilepsy related to its impact on reproductive functions, oral health and epilepsy secondary to tuberous sclerosis, mitochondrial disorders and lisosomal storage disorders.

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