

# Indigenous Knowledge, Practices, Beliefs and Social Impacts of Porcine Cysticercosis and Epilepsy in Iringa Rural

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## Abstract

Porcine Cysticercosis (PCC) and Human Cysticercosis (HCC)/Neurocysticercosis (NCC) are a burden to the community owing to the reduced value of animals, associated costs of treatment, decreased labour productivity and social discrimination. There is limited knowledge on the management and prevention of PCC and epilepsy in Iringa rural. Therefore, the present study aimed at assessing indigenous knowledge, practices, attitudes and social impacts of PCC and epilepsy in Iringa rural district. A total of 588 people participated in the survey whereby 306 were pig farmers, 223 non-pig farmers and 59 families with epileptic individuals. It was found that 49.8% ( $\chi^2 = 0.003$ , DF = 1,  $p = 0.954$ ) of pig keepers were aware of PCC, whereas the remaining 50.2% were not aware ( $\chi^2 = 25.5$ , DF = 1,  $p < 0.001$ ). The prevalence of late onset epilepsy was significantly higher (62.7%) than that of those who manifested seizures and convulsions in childhood 37.3% ( $\chi^2 = 3.814$ , DF = 1,  $p = 0.51$ ). People in Iringa rural believe epilepsy is caused by evil spirits, witchcraft and/or inheritance. It was concluded that there was limited knowledge on *T. solium* cysticercosis and epilepsy. This ignorance is the cause of poor practices, negative beliefs and attitudes that negatively affect the social life of People with Epilepsy (PWE) in communities. This study recommends that health education to raise awareness on cysticercosis/taeniosis and epilepsy should be one of the intervention measures for elimination of cysticercosis and epilepsy in Iringa rural district.

## Keywords

Neurocysticercosis, Knowledge, Beliefs, Practices, Stigmatization, Segregation

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## 1. Introduction

*Taenia solium* cysticercosis and the associated public health and economic consequences are a growing problem in poor areas of Africa, Asia and Latin America where people eat pork and keep pigs in traditional ways [1]-[3]. The disease is emerging as an important threat to public health and economic well-being of resource-poor smallholder farming communities [4] [5]. The epidemiology of porcine and human cysticercosis is associated with unhygienic habits and free range pig keeping [6] [7]. Effective control of *Taenia solium* therefore, requires knowledge on the life cycle, patterns of infection and the associated risk factors [8] [9].

Consequently, the lack of knowledge on the epidemiology of porcine and human cysticercosis leads to practices that encourage the transmission and persistence of *Taenia solium* [10] [11]. For instance, traditional healers are believed to use a mixture of tapeworm segments and other medicine to treat severe intestinal tapeworm infections [12]. Similarly, it is reported that some women use the contents of tapeworm segments as punishment to their unfaithful husbands or lovers [12] [13]. Elsewhere in developed countries, however, knowledge on *T. solium* cysticercosis is substantial and thus porcine and human cysticercosis is not a big problem as it is in developing countries [14] [15]. Therefore, prevalence of PCC and HCC in Eastern and Southern Africa (ESA) ranks among the highest in the world [16].

Neurocysticercosis (NCC) refers to infection of the brain by the larval form of the pork tapeworm *T. solium*. It is a form of HCC and the main causes of late onset epilepsy. Epilepsy is a devastating clinical problem in communities where there is little education, high rates of poverty, and poor access to health care [17]. Furthermore, the ignorance on the causes of epilepsy and its impacts has resulted into misunderstandings in communities [18]-[20]. The disease is thus emerging as an important social constraint in developing countries particularly in rural communities due to stigmatization and discrimination [21]. People suffering from epilepsy are often misunderstood, ostracised, and limited in their participation in society [17]. It is also considered as contagious, resulting in rejection and even isolation of affected individuals [22]. In some rural communities epileptic seizures are perceived as punishment for sins, a curse and bewitchment or demonic possession [20]. The family members experience shame and may choose to keep the person suffering from epilepsy confined to the home [17]. The segregation and discrimination of epileptic people develop inferiority complex which affects their quality of life [19]. Eradication of epilepsy due to *T. solium* parasite requires the disruption of its life cycle [13]. Likewise, the elimination of discrimination and segregation to people with epilepsy requires proper knowledge on the management which will be able to remove inferiority complex. Therefore, the present study found it necessary to assess the indigenous knowledge, practices and social impacts related to PCC and epilepsy in Iringa rural district.

## 2. Materials and Methods

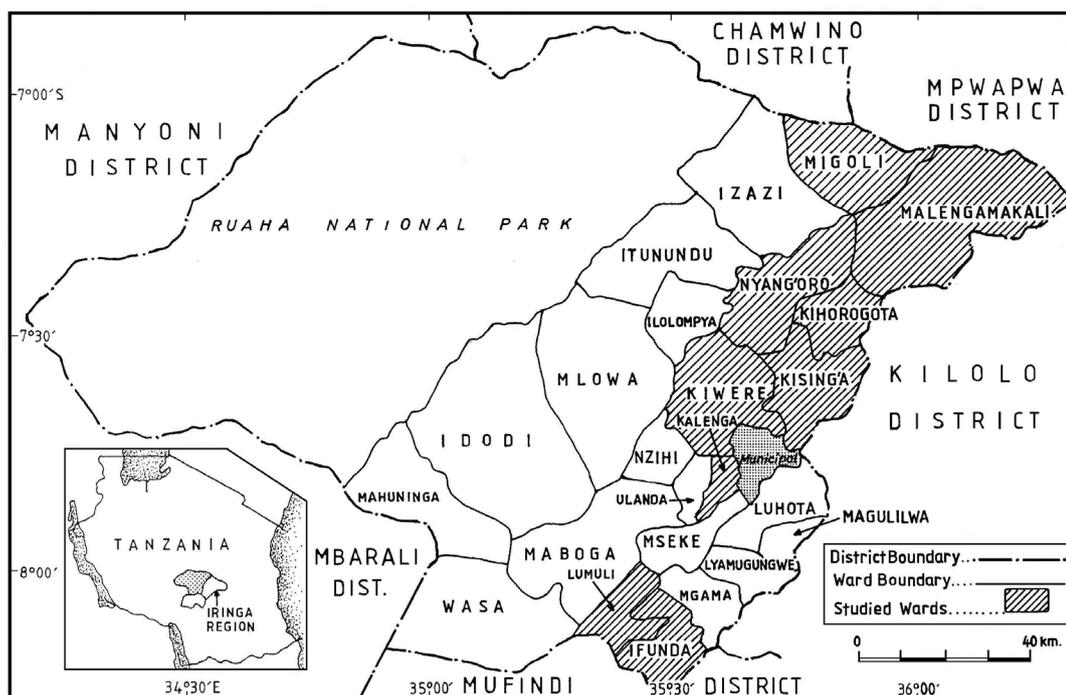
### 2.1. Study Site

The study was carried out in the following villages: Kising'a, Igingilanyi, Ihominyi, Mikongw'i, Matembo, Ilambilole, Kihorogota, Igula, Ngano, Kiwere, Mfyome, Kipera, Nyamihuu, Nyang'oro, Chamdindi, Holo, Ikengeze, Mangawe, Malengamakali, Nyakavangala, Mkulula, Usolanga, Iguluba, Makadupa, Kibena, Muwimbi, Ifunda, Mibikimitali, Mfukulembe, Udumuka, Migoli and Mtera. These villages were selected from nine wards of Iringa rural district, Tanzania as per illustration in **Figure 1**. The district lies at 1600 - 2700 m above sea level, with an area of 20,576 sq. kms, and an estimated population of 245,625 people. Average temperatures are normally below 15°C with rainfall ranging between 1000 mm to 1600 mm per annum falling in a single season from November to May. The dry and cold season occurs after the rain season and lasts from June to September.

### 2.2. Methods

#### 2.2.1. Study Design and Population Surveyed

The survey was carried out in the selected wards from July 2012 to August 2012. The households with pigs were randomly selected to participate in the study. The infection in pigs was inspected by lingual palpation and confirmed through postmortem examination. The questionnaire and interviews were used to collect data on risk factors for taeniosis, which was verified via direct observation.



**Figure 1.** Iringa rural district, study sites.

### 2.2.2. Sample Size Estimation

The sample size estimation was calculated using the formula:  $n = Z^2 PQ/L^2$  [23] where:  $n$  is the number of pigs,  $Z$  is the score for a given confidence interval,  $P$  is a known estimated prevalence whereby for the present study was 8.4% the prevalence reported by Boa *et al.* [24],  $Q = (1 - P)$  and  $L$  is the permissible error of estimation. In this study the desired confidence interval was 95% with the permissible error of an estimation of 0.05%. Therefore, based on the formula the sample size was calculated as  $n = 1.96^2 \times 0.084 \times 0.916/0.05^2 = 118$ . In order to maximize the number of respondents, the sample size 118 was then multiplied by 1.5 or  $150/100 \times 118 = 177$ . Using simple random sampling a total of 588 participants were involved whereby 306 were pig farmers, 223 non-pig farmers and 59 families with epileptic individuals.

### 2.2.3. Data Collection

#### 1) Questionnaire administered to pig keepers.

The structured questionnaire had a range of questions including: time since started to raise pigs, ways of keeping pigs, awareness of PCC, transmission of *T. solium* cysticercosis to pigs, ways of prevention, the fate of affected pigs, clandestine (non-official) market, preference of eating pork, pork preparation methods, place of finding pork, hygienic and sanitary practices, how human acquire tapeworms.

#### 2) Questionnaire administered to families with epileptic individuals and non-pig keepers.

The structured questionnaire comprised of a range of questions including; the age of epileptic individual; time since the epileptic signs manifested; symptoms; place of treatment, reasons for selecting type of treatment, awareness on the causes of epilepsy, means of transmission, means of prevention, knowing somebody with epilepsy, effects of epilepsy, segregation and discrimination to individuals and family members in marriage and reasons for segregation.

### 2.2.4. Data Analysis

Data on indigenous knowledge, practices and beliefs were analyzed by the statistical package for social sciences version 19.0 for windows (SPSS Inc., Chicago, IL, USA). The significance of parametric data was tested using t-test and non-parametric data were tested by using Chi-square analysis. P-value less or equal to 0.05 was considered to be significant. The 95% confidence interval was used in the present study (CI = 95%) for various factors at individual level.

### 3. Results

#### 3.1. Community Knowledge and Practices on Porcine Cysticercosis

A total of 306 pig keepers were surveyed during the study for the assessment of knowledge and practices on *T. solium* cysticercosis. About 49.8% ( $\chi^2 = 0.003$ , DF = 1,  $p = 0.954$ ) of the pig farmers were aware of PCC, but among these only 33.7% knew that human faeces were the source of *T. solium* cysticercosis infection to pigs. About 50.2% ( $n = 306$ ) believed that cysticercosis in pigs was caused by jiggers and mice. Thirty five percent (35%) of non-pig keepers were aware of pork tapeworms and 21.7% believed pork and vegetables or unwashed fruits as the source of taeniasis in humans. About 44.8% of the respondents mentioned “under the tongue” as the predilection site for cysts in pigs, 8.5% mentioned “under the skin and legs” and 46.8% did not know. Only 31.8% of pig keepers were able to detect (identify) cysts in live pigs. The general community’s awareness on the pork tapeworm was high (59.1%) but knowledge on transmission was low (35.0%) ( $\chi^2 = 25.5$ , DF = 1,  $p < 0.001$ ). About 22.7% slaughtered pigs at home and sold uninspected pork. The majority of the surveyed population 89.8% ( $\chi^2 = 185.287$ , DF = 1,  $p < 0.001$ ) eat pork; while 10.2% do not eat pork due to various reasons including allergy and religious beliefs (Table 1).

#### 3.2. Community Knowledge, Practice, Belief and Social Impacts on Epilepsy

A total of 282 participants responded to the questionnaire on the assessment of knowledge, practices and beliefs on epilepsy. About 54.7% ( $n = 276$ ) of respondents knew somebody with epilepsy, but the majority were ignorant on the prevention measures for the epileptic condition 65.6%, ( $\chi^2 = 41.362$ , DF = 1,  $p < 0.05$ ). In Iringa rural 62.7% of the epileptic individuals had late onset (adulthood) epilepsy, whereas 37.3% developed seizure since childhood. When an individual showed epileptic symptoms, the hospital was the preferred place for treatment (56.9%), (30.4%) used traditional healer and 12.7% used both hospitals and traditional healing. The choice of treatment was mostly determined by family decision (80.8%) ( $\chi^2 = 88.615$ , DF = 1,  $p = 0.001$ ) and the beliefs of the sufferer were slightly considered (19.2%).

Based on the responses of the surveyed population in Iringa rural, epilepsy is caused by different agents. About (38.2%) sited evil spirits and/or witchcraft as causes of epilepsy, 24% sited pork and other raw/undercooked foods, 18% sited personal hygiene and 20.1% said it was inherited from parents. Over half (56.6%) of respondents believed epilepsy was transmitted from one person to another by sleeping with an epileptic individual, and 8.5% mentioned sex and contact with the saliva of epileptic patients during convulsions.

Epilepsy was reported by respondents to have various consequences on the health of the sufferers; physical discomfort was the most (67.5%) pronounced effect; other effects included falling (16.8%) and failure to work (15.7%). About 69.5% of epileptic people experienced headaches. In school children poor performance was the most sited (44.7%) effect, and being forced to drop from school was the least sited (15.4%) effect. About 73.7% of respondents considered epileptic individuals as disabled who needed close attention, while 65.3% reported that epileptic individuals were not allowed in community gatherings because of unpredictable attacks manifested by seizures, convulsions and personal discomfort. About 67.4% ( $n = 261$ ) responded that family members did not segregate epileptic individuals but the segregation and discrimination arises during social functions. Both people with epilepsy (51.5%) and 48.5% of the other members of the family experience difficulties in getting married. In marriage, epilepsy was the source of quarrels (58.7%), and at sometimes caused divorce (12.2%) (Table 2).

### 4. Discussion

Indigenous knowledge (IK) is a set of perceptions, information and behaviours that guide members of particular community towards a certain way of living or behaving. It can be used in various sectors for instance in veterinary medicine with the intimate understanding of their environments [25]. In the present study jiggers and mice were mentioned as the causes of Porcine Cysticercosis (PCC). The incrimination of jiggers as the causative agents for PCC might be due to their similarity in morphology to *T. solium* cysts. Furthermore, the mention of “legs” and “under the skin” as the predilection of *T. solium* cysticercosis in pigs was due to morphological misconception between jiggers and *T. solium* cysts.

Some pig farmers know that indiscriminate disposal of human faeces is central to the transmission of *T. solium* infection. Most of such farmers live along the main roads and were frequently visited by paravets. On the

**Table 1.** Community knowledge and practices on porcine cysticercosis.

Factors	Responses (%)
<b>Knowledge on <i>T. solium</i> cysticercus (n = 299)</b>	49.8
Yes	50.2
No	
<b>Possibility to see cysticercus in live pigs (n = 277)</b>	
Yes	31.8
No	68.2
<b>Predilection sites for cysts in live pigs (n = 201)</b>	
Under skin	8.5
Under the tongue	44.8
Don't know	46.8
<b>How human can get tapeworm (n = 198)</b>	
Through pork	59.1
Without washing hands	5.6
Contaminated food and water	16.2
Don't know	9.2
<b>Do you know anything about tapeworm (n = 283)</b>	
Yes	35
No	65
<b>How pigs can be infected by <i>T. solium</i> cysticercosis (n = 288)</b>	
Human feaces	33.7
Pigs feaces	4.9
From pigs with larva	12.8
Don't know	48.7
<b>What do you do when your pig is infected with cysticercus (n = 260)</b>	
Selling pigs	3.8
Giving the local medicine	12.3
Destroying the larva	8.1
Don't know	47.3
Other means	28.5
<b>Which methods are used to prevent cysticercosis infection in pigs (n = 280)</b>	
Using pigpen	36.4
Local medicine	3.6
Cleaning the environment	30.4
Don't know	29.6
<b>Have you ever diagnosed cysts in your pigs (n = 285)</b>	
Yes	20.7
No	79.3
<b>Did you manage to sell your infected pigs (n = 59)</b>	
Yes	35.1
No	64.9
<b>Do you prefer to slaughter pigs at your home (n = 295)</b>	
Yes	22.7
No	77.3

**Continued**

<b>Do you prefer eating pork (n = 293)</b>	
Yes	89.8
No	10.2
<b>What type of preparation do you prefer most (n = 284)</b>	
Fried	76.4
Boiled	13.7
Roasted	9.9
<b>Where do you get pork (n = 274)</b>	
From known butcher	54
From local clubs	43.8
From people house	2.2

**Table 2.** Community knowledge, practice, belief and social impacts of epilepsy.

Factors	Responses (%)
<b>When did you start to suffer (n = 59)</b>	
Childhood	37.3
Late onset	62.7
<b>Sudden falling (n = 173)</b>	
Yes	91.3
No	8.7
<b>Health consequences of epilepsy (n = 203)</b>	
Falling and convulsion	16.8
Physical discomfort	67.5
Functional impairment	15.7
<b>Do you experience headache (n = 59)</b>	
Yes	69.5
No	30.5
<b>The place epileptic patients seek treatment (n = 220)</b>	
Hospitals	56.9
Traditional healer	30.4
Both	12.7
<b>The reasons for the choice of a place for treatment (n = 277)</b>	
Family affordability of treatment cost	80.8
Belief of the sick person	19.2
<b>Knowledge on causes of epilepsy (n = 267)</b>	
Evil spirits	38.2
Food related	24
Personal hygiene	18
Inheritance from parents	20.1
<b>Knowledge on ways to prevent epilepsy (n = 294)</b>	
Yes	29.4
No	70.6

**Continued**

<b>Do you know any other person with the disease (n = 276)</b>	
Yes	54.7
No	45.3
<b>Effects of epilepsy to education (n = 228)</b>	
Forced to stop studies	15.4
Refused to be admitted in schools	17.5
Absentees	22.4
Poor performance	44.7
<b>Is the epileptic person cause burden to others (n = 259)</b>	
Yes	73.7
No	26.3
<b>Why epileptic condition cause burden to others (n = 282)</b>	
Cost for health care	54.5
Lowers family income	45.5
<b>The effects of epilepsy in marriage (n = 282)</b>	
Quarrels to the partner	58.7
Separation	29.1
Divorce	12.2
<b>Do you stay far from social functions (n = 240)</b>	
Yes	52.9
No	47.1
<b>Effects on getting marriage (n = 260)</b>	
Other member of the family	48.5
Epileptic individual	51.5
<b>Ways of epilepsy transmission (n = 106)</b>	
Sleeping with epileptic person	56.6
Eating with epileptic person	25.5
Shaking hands	9.4
Sex and touching saliva	8.5
<b>How can you prevent (n = 305)</b>	
Prayers	15.5
By treatment	19
Don't know	65.6

other hand, non-pig producers had little understanding of the pork tapeworm (*T. solium*) and how it is transmitted, because such knowledge was provided by paravets through livestock seminars. The lingual muscle was the best site for ante-mortem diagnosis of cysticerci infection in pigs and was understood by most pig farmers in Iringa rural. Unfortunately, the method requires physical force and technique, this is probably the reason most pig farmers failed to diagnose the infection in pigs.

Despite that paravets provided knowledge on PCC and other animal diseases through livestock seminars, they only focused on livestock problems and did not link with human health. Additionally, while paravets insisted on indoor pig keeping, they did not include packages on the elimination of diseases. This might explain the fact that neither pig farmers nor non-pig farmers had knowledge on the prevention of cysticercosis infection in pigs and humans in the study area. Likewise, the health workers in dispensaries and health centers provided education on environmental sanitation, personal hygiene and related matters. Unfortunately, only the sick and expectant mothers attend such seminars while the large population remained unformed. It is, therefore, justifiable to rec-

commend the scaling up of the efforts to educate people on the causes, transmission and prevention of the *T. solium* parasite in Iringa rural communities.

About 62.7% of epileptic people involved in the present study developed seizures from the age of 21 years onwards. Secka *et al.* [26] reported similar observations in Gambia, they noted that people aged between 21 - 40 were the most affected compared to other age categories but was not caused by cysticercosis. It could be surmised that most epileptic cases reported in the present study could be due to NCC (neurocysticercosis), though confirmation was beyond the scope of the present study. It was believed, in the studied areas that the late appearance of epileptic symptoms (particularly seizures) was associated with evil spirits and witchcraft, which promoted fears and negative perceptions towards epilepsy; childhood epilepsy was passed down from parents (inherited). In addition, evil spirits, witchcraft and food allergy were mentioned as causes of epilepsy, which corroborates the findings by Joseph *et al.* [27]. The association of evil spirits as the cause of epilepsy might be due to the reason that epilepsy is incurable; this leads people to believe that epilepsy could be cured through prayers and traditional healing.

Furthermore, the social discrimination of people with epilepsy was increased by the belief that epilepsy could be transmitted through contact (e.g. touching saliva, sleeping together and shaking hands). The sudden falling accompanied with convulsions created fear among families and friends not to allow epileptic individuals into large gatherings. The segregation and discrimination experienced by epileptic people induced in them an inferiority complex that was the cause of their failure to live with their partners in marriage. Likewise, the belief that epilepsy could be transmitted through sex and that it can be inherited leads to discrimination of epileptic people and the members of their families in marriage [28]. Therefore, it is necessary that knowledge on epilepsy is provided to communities for the elimination of the negative perceptions and attitudes for the betterment of the welfare of epileptic people.

Since, sudden falling and convulsions often lead into injury to epileptic individuals, care is therefore, needed to protect them as when it happens it renders them helpless. In school children, epilepsy often interrupts attendance and effective schooling, resulting into truancy, poor performances and sometimes withdrawal from school. Sanya *et al.* [19] reported that when children are recognized to be suffering from epilepsy they could be denied admission into some schools. Discrimination has serious psychological consequences to epileptic individuals; they often develop a sense of not being wanted, an inferiority complex that degrades the quality of their life. Generally the community does not understand the causes, transmission, prevention and how to manage epilepsy, particularly late onset epilepsy. The lack of knowledge on causes and prevention of epilepsy lead people proposing close care and providing balanced diet as the means of preventing epileptic person from acquiring other diseases. Therefore, it is necessary to educate people about late onset epilepsy so as to reduce the impacts that result from social segregation and discrimination.

## 5. Conclusion

There was little knowledge on the causes, transmission and prevention of *T. solium* cysticercosis and epilepsy in Iringa rural areas. The continued persistence of PCC in the study area is contributed by absence of meat inspection and hygiene, slaughter slabs and consumption of uninspected pork. The proportion of condemned pigs due to *T. solium* cysticercosis was negligible because the affected pigs were slaughtered at home and pork was sold in street bars and in the community. There were more cases of late onset epilepsy than those of childhood epilepsy. People have limited knowledge on the causes and transmission of epilepsy; this has led to social segregation and discrimination of epileptic individuals. Since both pig keepers and non-pig keepers have little knowledge on *T. solium* infection in humans, it is imperative to provide education on the life cycle of *T. solium* as part of the control efforts of the disease in Iringa rural areas.

## Limitations/Weakness

- Financial: Consistency coverage of the proposed study areas could not be achieved due to financial constraints.
- Community consent: A few people simply refused to participate in the project and thus some good information was not disclosed.
- Information on socio-demographic characteristics of the participants was not documented and hence forms one of the weaknesses to this study.

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