

# Prevalence Of Epilepsy And General Knowledge About Neurocysticercosis At Ngangelizwe Location, South Africa

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## Citation

H Foyaca-Sibat, A Del Rio-Romero, L Ibanez-Valdes. *Prevalence Of Epilepsy And General Knowledge About Neurocysticercosis At Ngangelizwe Location, South Africa*. The Internet Journal of Neurology. 2004 Volume 4 Number 1.

## Abstract

Fifteen medical students from the University of Transkei divided into 5 groups were sent to make a community diagnosis of the Ngangelizwe community. The main goal was to evaluate the socio-economic status of the community, to identify major risk factors in the community, to find out the prevalence of epilepsy, and investigate the level of knowledge about neurocysticercosis and HIV/AIDS in the community.

Setting: The Ngangelizwe community, is located at 6 km away from Mthatha (Capital of the former Transkei) being the closer to others locations investigated previously such as: Sidwadweni, Nkalukeni, Ngqwala, Kwandugwane and Makaula locations

Design: A two-stage design study was used. The first stage involved screening of the general population on door-to-door basis by interviewing peoples living in 100 households selected by block-randomisation procedure, and using an internationally validated questionnaire for detecting epilepsy and knowledge about other associated diseases. The second stage consisted of a neurological assessment of the peoples who screened positive. The questionnaire covered four main areas: Demographics and Socio-economics; Main Risk Factors; Health Services, Traditional Medicine; and Knowledge about neurocysticercosis and epilepsy.

Results: A total of 2341 adults were screened. The prevalence of active epilepsy in these adults was 13.8/1000. Only 14.7% of epileptic patients were under regular anti-epileptic treatment, 100% of the total population had not idea about NCC, and 28% did not know the cause of AIDS. Our findings revealed that Ngangeliswe village was a low socio-economic area. Level of unemployment was high, incomes were low, education level was mostly to high school, and housing was mostly of poor quality and crowded. There was a problem with the supply of water in the area. Few people actually boiled their water. There was much indoor pollution from cooking. Toilets were unhygienic and there were no flush toilets. Food storage was a risk for diseases as there was no electricity. Many people still prefer traditional healers rather than medical doctors and one of the reasons that we found surveying this community was language barrier because all doctor working at the clinic are not from the former Transkei therefore they do not speak the native language (isiXhosa) and many patients do not speak English, although good support for translation is getting from the native nurses the necessary privacy for affording some health problems like epilepsy is absent.

Conclusions: The prevalence of epilepsy is high compared with a similar location but a poor utilization of anti-epileptic treatment is cause for concern. Poor communication and the stigma of epilepsy make it a more difficult problem to treat. NCC and HIV/AIDS awareness campaign at the rural locations in the former Transkei should be made as soon as possible while permanent solutions are implemented.

## INTRODUCTION

Neurocysticercosis (NCC) is an infection of central nervous system (CNS) caused by the larval stage (*Cysticercus cellulosae*) of the pig tapeworm *Taenia solium*. This is the most common helminthes to produce CNS infection in human being. The occurrence of acquired epilepsy or the syndrome of raised intracranial pressure in a person living in or visiting a region where taeniasis is endemic or even in one

living in close contact with people who have taeniasis should suggest a diagnosis of cysticercosis; patients with NCC may remain asymptomatic for months to years, and commonly a diagnosis is made incidentally when neuroimaging is performed, many symptomatic forms can predominate. Symptoms and signs are related both to the parasite, which can show a different biological behavior from one place to another, and different inflammatory-immunological

responses on different hosts. NCC is the most common cause of acquired epilepsy worldwide and most of the patients taking phenytoin or carbamazepine for a proper control of their seizures, respond very well.<sup>1,2,3,4,5</sup> Other aspects related to NCC from our region are also available on line,<sup>6,7</sup> this study was designed for Nkalukeni location which is situated at the former Transkei. Transkei was one of the three administrative authorities of the so-called independent homelands (Ciskei, Transkei and the Cape Provincial Administration under different apartheid governments) it is currently region D and E of Eastern Cape Province of South Africa; Umtata is the capital for the former Transkei which is one of the poorest region countrywide, and serves as a labor reservoir for other wealthier provinces, with men leaving behind women and children whilst they seek and find employment elsewhere.<sup>8</sup>

Epilepsy is the most common chronic disorder of the central nervous system (CNS) manifested by recurrent unprovoked seizures that affect approximately 1% of the U.S. population, During 1986-1990; approximately 1.1 million persons in United States annually reported having epilepsy and the overall prevalence of epilepsy was 4.7. The point prevalence of epilepsy is estimated at about 0.4 % to 0.8 % in some European countries,<sup>10,11</sup> the prevalence of epilepsy is said to be about 3 to 9 per 1,000 population. As countries in Asia, the prevalence rates from published reports are: China (4.6),<sup>12</sup> Parsi (4.7), Kashmir (2.47) rural Bengal also in India (3.05),<sup>13</sup> Pakistan (9.0), Guam (4.9), Singapore (3.5), rural Thailand (7.2),<sup>14</sup> and the Philippines League Against Epilepsy (2.3). The lower prevalence rate reported in the last study was most likely related to differences in the communities surveyed, because the Philippine study was conducted in a mixed urban and rural community.<sup>15</sup> Central and South American countries exhibit high prevalence rate of epilepsy compare with North America. In Andean region of Ecuador lifetime point-prevalence rates between 12.2/1000 and 19.5/1000 were recorded,<sup>16</sup> rural Bolivia (12.3) confirming that epilepsy is a major health problem in rural areas of developing countries,<sup>17</sup> African countries show different prevalence rates from Gambia (4.6),<sup>18</sup> to Benin (15.9).<sup>19</sup> However, that prevalence in Gambia may be an underestimate as some studies from other developing countries (such as Colombia, Liberia, Togo, Bangladesh, Cameroon, Mali, Madagascar, West Uganda, Nigeria, Panama, United Republic of Tanzania and Venezuela) suggest a prevalence of more than 10 per 1,000. In 2000 a two-phase design study for to determine the prevalence of

epilepsy in rural South Africa children aged 2-9 years was done showing a prevalence rate of 7.3/1 000.<sup>20</sup> A similar study done in Sidwadweni, Nkalukeni, Ngqwala, Kwandugwane and Makaula locations showed a prevalence between 13.7/1 000 and 18.3/1000.<sup>21,22,23</sup>

The main objective of this study is to determine the prevalence of epilepsy, and the knowledge about NCC and HIV/AIDS as conditions frequently associated with recurrent epileptic seizures apart from other epidemiological aspect.

## **MATERIAL AND METHODS**

This descriptive study is based in a questionnaire applied on 100 households from Ngangeliswe. The study was outlined in two stages, and the investigation was door-to-door for those houses selected by block-randomization procedure. Ngangeliswe Health Center offers primary health care services to this community and two medical practitioner and 5 registered nurses staffed it at the prevalence day. A team of 15 senior medical students from University of Transkei in South Africa trained in the diagnosis of epilepsy and NCC implemented the questionnaire. The training consisted of a series of seminars, graphics, bibliographic material and PBL (Problem Basic Learning) tutorials about these topics. They administered a standard screening instrument for epilepsy, NCC, HIV/AIDS, and socioeconomic living conditions among other issues. After to be introduced to the CHESP coordinator for the community and obtained permission for this survey from the Community Leaders, the group was divided into smaller group of two member each, where at least one was fluent in their native language (isiXhosa). The survey was conducted between 12 and 16 hrs when most of the men would be out working therefore most of interviewed were women.

Since its foundation Ngangeliswe community was interviewed for the second time along this study first survey was applied in 2001. First phase consisted in preparation, coordination through community's leaders, training and data collection, and the second one for reassessment of identified candidates and processing of findings.

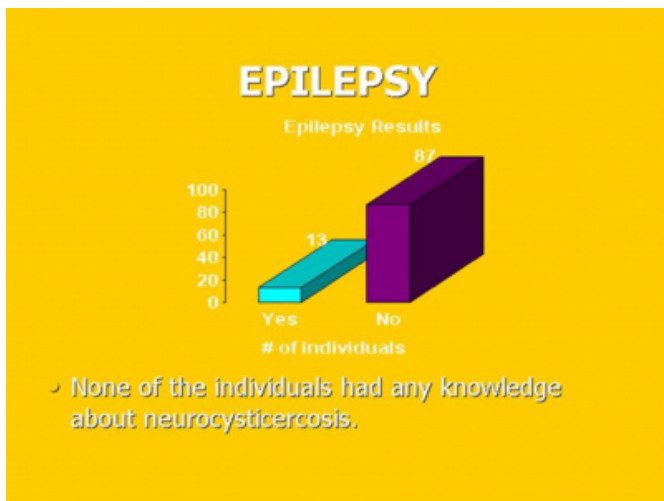
## **RESULTS**

On screening, the positive subjects were re-assessed by one of us. On the basis of the definition proposed by the International League Against Epilepsy, we detected a prevalence of 13.8 1000 (Figure 1), 72.3% of patients had active epilepsy on the prevalence day (October 14th, 2003). The mean age at onset was 22.3 years for motor partial

epileptic seizures and 21,6 years for generalized seizures. Only 14.7 % of patients had received anti-epileptic medication for more than three month and nobody had knowledge about NCC. Socioeconomic status was characterized by unemployment or very low salaries (Figure 2), Compared with 2001 the level of employment became worst, because of this situation the average of income diminished leading to more poverty (figure 3) We also found limited access to primary health care and health education, limited access to toilet facilities, and no proper refusal disposal however a percentage of peoples with access to safe and clean water at acceptable distance were higher compared with other locations (Figure 4) Unfortunately lack of education in most peoples did not impede access of pigs to human feces and free-range pig farming was commonly seen. In spite of the high qualifications of the interviewers whom had not communication problems due to language-barrier, a number epileptic patients were probably not reported because of poor recognition of some non-convulsive epileptic attacks, traditional beliefs, cultural traditions, and stigmas associated with epilepsy. Twenty eight percent of the peoples interviewed did not know the cause of AIDS (Figure 5)

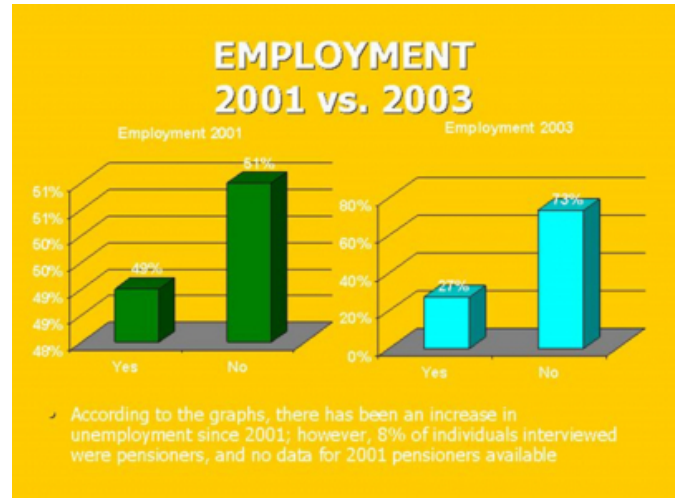
**Figure 1**

Figure 1: Prevalence of epilepsy on October 14th, 2003 (13,8/1000). Higher prevalence compared with similar locations as Ngqwala (13.7/1000) and Sidwadweni (13.2/1000) at the same prevalence day.



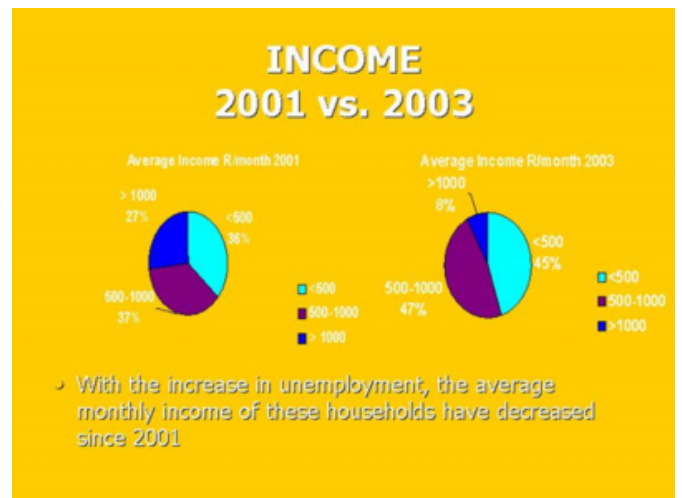
**Figure 2**

Figure 2: Socio-economic status. Currency on October 2003: 1USD = 7.28 Rands and 69 % had a monthly income of 500-1000 Rands for a family of 5 or more peoples. Level of unemployment increased compared with 2001.



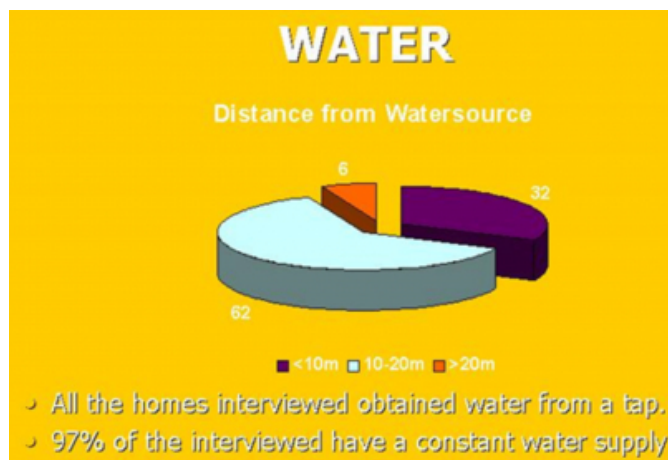
**Figure 3**

Figure 3: Average of income in 2003 decreased compared with 2001.



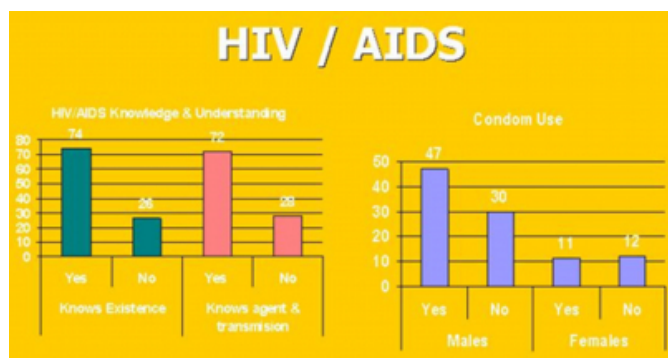
**Figure 4**

Figure 4: Percentage of peoples with propels access to safe and clean water at acceptable distances was higher compared with other locations.



**Figure 5**

Figure 5: Ngangeliswe community reflects an acceptable understanding of HIV/AIDS compared with Ngqwala, Nkalukeni, and Sidwadweni



**COMMENTS**

We found that only 14,4 % of epileptic patients was under regular anti-epileptic treatment for the past three consecutive months. Traditional healers provide treatment to an important number of epileptic patients because proper communication in their native language is possible and because epilepsy is thought to be related to a visitation by the devil, to witchcraft or to spirits, and those families belief that they have been visited by their ancestors, whom arriving at night while they are sleeping, they also consider that the first place for visiting is the toilet being it another powerful reason why they do not use the toilet more often in spite of its availability. In other places epilepsy is thought as a disease where the heart gets blocked by foam, restricting circulation and resulting in seizure. One generalized belief is that Xhosa-sangomas shaking some bones and helped by

their ancestors while is Imphepho burned can find out the cause of the problems and treat it succesfully. Conventional medical care was not available for peoples living in most of those region during apartheid era therefore almost all traditional medicines and cures were made from available material, such as leaves, roots, spider webs, axle grease, and water among other products. Some studies have shown that there are still many misconceptions existing within many cultural communities, where only tonic-clonic seizures are recognized as epilepsy and non-epileptic seizures are labelled as nervous disturbances, emotional stress or insanity, and for most of people epilepsy is still considered an infectious disease or an invasion by supernatural unknown spirit or ancestors. Poverty, poor food hygiene and sanitation, lower cultural level, myths and superstitions attached with epilepsy on those region impede to move forward in the early detection of the disease, identification of their causes, and an adequate management. Because that misinformation about epilepsy the exact number of untreated epileptic patients will remind unknown for a long time until a sustained campaign to build up public awareness on this matter, and a better health education plus alleviation of poverty among other factors will take effect. Same statement should be applied to NCC/HIV/AIDS awareness campaign in order to reduce the increasing number of epileptic patients due to NCC/HIV/AIDS.

**CONCLUSIONS**

The prevalence of epilepsy is high and a poor utilization of anti-epileptic treatment is cause for concern. Poor communication and the stigma of epilepsy make it a more difficult problem to manage. NCC and HIV/AIDS awareness campaign in the rural locations at the former Transkei should be made as soon as possible while permanent solutions like better primary health care system and health education, proper sanitation, better food hygiene, access to safe and clean water, and alleviation of poverty as a best way for solving this problem will be implemented.

**ACKNOWLEDGEMENTS**

To all peoples who made possible to make this report with special recognition to those medical students allocated at Ngangelizwe Health Centre for Community Medicine Clerkship.

**References**

1. Foyaca SH, Ibanez V.LdeF, Awotedu A, Fernandez MC. Neurocysticercosis in critical stage. Third International Congress of critical care medicine on Internet.

- <http://www.uninet.edu/cimc2001/comunicaciones/foyaca/index.html>
2. Foyaca SH, Ibanez V, LdeF. Clinical trial of praziquantel and prednisone in rural patients with neurocysticercosis presenting recurrent epileptic attacks. *The Internet Journal of Neurology* 2002;1(2). <http://www.ispub.com>
  3. Foyaca SH, Ibanez V, LdeF, Awotedu A, Fernandez MC. Neurocysticercosis in the former Transkei. 7th Internet World Congress for Biomedical Sciences INABIS 2002. [http://www.inabis2002.org/poster\\_congress/area\\_01/010111/010117.pdf](http://www.inabis2002.org/poster_congress/area_01/010111/010117.pdf)
  4. Foyaca SH. Tapeworm and the brain. *Science in Africa*. June 2002;XVIII:3. <http://www.scienceinAfrica.co.za/2002/june/worm.htm>
  5. Foyaca SH, Ibanez V, LdeF. Intraventricular neurocysticercosis. II Virtual Congress of Neurosurgery. <http://www.neuroc.sld.cu/papers/tl-neurocys.htm>
  6. Foyaca S.H, Ibanez V. LdeF. Vascular dementia type Binswanger's disease in patients with active neurocysticercosis. *Elect J Biomed* 2002;1(1):1-12 Available online at: <http://www.uninet.edu/biomed/rebio/reb/2002/n1/foyaca.htm>
  7. Foyaca S.H, Ibanez V, LdeF. Enfermedad de Binswanger en pacientes con neurocysticercosis activa. IV Internet Congreso de Psiquiatria Interpsiquis2003. Available online at: <http://www.psiquiatria.com/interpsiquis2003/9638>
  8. Mahlalela X, Rohde J, Meidany F, Hitchinson P, Bennett J. Primary Health Care in the Eastern Cape province. 1997-2000 EQUITY PROJECT. South Africa Department of Health.
  9. Hauser WA, Headorferr DC. *Epilepsy: frequency, causes and consequences*. New York: Epilepsy Foundation of America, 1990.
  10. Hauser WA. Incidence and Prevalence, *Epilepsy: A comprehensive Textbook*, Engel J, Pedley TA and Jr (eds): Lippincott-Raven, 1997:47-57.
  11. Forsgren L. Prevalence of Epilepsy in Adults in Northern Sweden. *Epilepsia* 1992;33(3):450-458.
  12. <http://www.epilepsyfoundation.org/epilepsyusa/developing.cfm>
  13. Das Sk, Sanyal K. Neuroepidemiology of major neurological disorder in rural Bengal. *Neurol India* 1996;44(2):47-58.
  14. Asawavichienjinda T, Sitthi-Amoru C, Tanyanont W. Prevalence of epilepsy in rural Thailand: a population-based study. *J Med Assoc Thai* 2002;85(10):73.
  15. <http://www.plae.org/web/epilepsy-information4.php>
  16. Placencia M, Shorvon SD, Paredes V, Bimos C, Sander JW, Suarez J, Cascante SM. Epileptic seizures in an Aedeon region of Ecuador. Incidence and prevalence and regional variation. *Brain* 1992;115(30):771-782.
  17. Nicoletti A, Regio A, Bartoloni A, Failla G et al. Prevalence of epilepsy in rural Bolivia; a door-to-door survey. *Neurology* 1999;53(9):2064-2069.
  18. *Bulletin of the World Health Organization* 2002;80(5):378-383.
  19. Debrock C, Preux P-M, Houinato D, Druet-Cabnac M, Kassa F et al. Estimation of prevalence of epilepsy in the Benin region of Zinvie using the capture-recapture method. *Int J Epidemiol* 2000;29:330-335.
  20. Chritianson AL, Zwane ME, Manga P, Rosen E, Venter A, Kromberg JG. Epilepsy in rural South African children: prevalence, associated disability and management. *S Afr Med J*. 2000;90(3):262-266.
  21. Foyaca-Sibat H, Del Rio AI, Ibanez-Valdes LdeF, Vega E. Neuro-epidemiological survey for epilepsy and knowledge about neurocysticercosis at Ngqwala location, South Africa. *The Internet Journal of Neurology*. 2004;1(1) Available online from: <http://www.ispub.com>
  22. Foyaca-Sibat H, Del Rio-Romero AI, Ibanez-Valdes LdeF, Vega-Novoa EdelC. Neuroepidemiological survey for epilepsy and knowledge about neurocysticercosis at Sidwadweni location, South Africa. *Electron J Biomed* 2004;2(1):40-48 Available Online from: <http://www.uninet.edu/2004/n1/foyaca.html>
  23. Del Rio AI, Foyaca-Sibat H, Ibanez-Valdes LdeF, Vega EdelC. Neuroepidemiological survey for epilepsy and knowledge about neurocysticercosis at Nkalukeni Location, South Africa. *The Internet Journal of Neurology*. Available online from: <http://www.ispub.com>

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