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Knowledge and attitudes towards epilepsy in Zambia: A questionnaire survey

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ABSTRACT

Misconception and stigma towards epilepsy have a profound impact on this disease in Africa. An unselected sample of Zambian people was interviewed to investigate their knowledge and attitudes towards epilepsy. Proper/improper answers were scored, and a composite score was developed with negative values for unsatisfactory awareness and high stigma levels. The sample comprised 231 people residing in urban (107) or in rural (124) areas. The median and interquartile range of scores for epilepsy awareness and stigma were, respectively, −1 (−3; +1) and +1 (−1; +6). Poor education was the only significant predictor of unsatisfactory awareness ($p = 0.0131$), while education and residency were significantly associated with stigma ($p < 0.0001$ and $p = 0.0004$). Rural people were mostly in the highest stigma level (44.2%) and urban people in the lowest stigma level (60.4%). Misconception and negative attitudes towards epilepsy among Zambian people reflect poor education and rural residency.

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1. Introduction

The care of epilepsy implies not only the correct diagnosis and treatment, but also the management of its main sociocultural consequences (largely, Misconception of the disease and the persistence of stigma) which have a profound impact on patients' quality of life [1–5]. Public knowledge and attitudes towards epilepsy have been repeatedly investigated in developed and developing countries [6–32]. Large gaps have been found in awareness of the causes of the disease, and, even worse, widespread negative attitudes were documented, mainly associated with educational level, age, and sex. Large population surveys in people with epilepsy (PWE) in developing countries involve obvious difficulties; nevertheless, studies have been done even in sub-Saharan Africa [33–43], where socially deprived groups and selected occupational categories could be investigated in particular [44–49]. However, to our knowledge, few studies have compared the opinions and attitudes towards epilepsy of neighboring urban and rural populations. One study that focused on the functional status of PWE in rural versus urban areas found that the burden of the disease was greater in the former [50]. This was explained by hypothesizing a "downward drift" of more impaired PWE towards their families of origin in rural areas, as families in these areas are possibly more willing to care for their disabled members than their counterparts in urban areas. Whether this attitude coexists with a lack of awareness or with stigma towards epilepsy was not clarified. Our specific purpose was, therefore, to determine which factors have a significant impact on the knowledge and attitudes towards epilepsy in rural versus urban areas in a sub-Saharan country.

2. Purpose

The aim of the study was to investigate the knowledge and attitudes towards epilepsy in a sample of Zambian people, some living in two urban aggregates and some in the neighboring rural areas.

3. Materials and methods

3.1. Study population

We contacted an unselected sample of people from two different Roman Catholic parishes in the south of Zambia (districts of Chirundu and Siavonga) in the summer of 2009. They came from urban and rural areas. The education imparted to the local population conforms to a UK model and is divided into two periods, primary school (eight years) and secondary school (four years). The contact was made when people spontaneously attended the official parish meetings and services. On these occasions, participants were asked to complete a simple questionnaire, with no exclusion except those who refused to be

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interviewed. Where needed, local bilingual volunteers helped the interviewees understand the questions. No compensation was offered.

3.2. Instruments

We reviewed previous reports looking for the instruments used for this purpose, particularly studies in similar settings. Some structured questionnaires used in neighboring areas of Zambia, designed to study the prevalence, awareness, and stigma associated with epilepsy, were considered. On this basis, we developed a new English and Chitonga questionnaire to investigate the knowledge and attitudes of Zambian people about seizures, epilepsy, and PWE.

3.3. The questionnaire

The inventory included questions regarding the interviewee's profile (age, sex, marital status, number of children, education, occupation, living in an urban or rural settlement) and his/her knowledge of epilepsy and stigma (see Supplementary material). More specifically, the domains covered by the questions included general knowledge about the disease and its main characteristics (Qs 1–4) and its causes and impact on the individual (Qs 5–9) and society (Qs 10–16). On the basis of questions 5 through 16, we developed a compound score for epilepsy awareness and epilepsy stigma. Each answer was assigned a positive or a negative score. Correct answers were rated with a positive number (+1) and incorrect answers with a negative number (−1). The summary score for "epilepsy awareness" was the sum of the scores for questions 5 through 9. As questions 5–7 permitted multiple answers, the total score ranged between −12 and +6. Based on the summary scores for awareness, two levels were identified: unsatisfactory (≤0) and satisfactory (1–6). The summary score for "epilepsy stigma" was the sum of the scores for questions 10 through 16 (range: −7 to +9). Based on the summary score for stigma, three levels were identified: high (≤0), medium (1–3), and low (4+) according to the distribution in tertiles of the total score.

3.4. Statistical analysis

Descriptive statistics are presented as counts, percentages, and medians and interquartile range (IQR). Univariate analyses were done using the Kruskal–Wallis test or the Spearman correlation, as appropriate, with awareness and stigma scores as dependent variables. The multivariable analysis of covariance (ANCOVA) model included the variables found to be significant in the univariate tests. To account for nonnormal distribution of the data, the ANCOVA model was applied on ranks. The comparison of rural and urban people was assessed with the logistic model. Results are reported as odds ratio (OR) and 95% confidence interval (95% CI); the multivariable logistic model independently tested the effects of age, sex, education, number of children, marital status, stigma, and awareness scores. All tests are two-tailed with significance set at alpha = 0.05. Data were analyzed using the Statistical Analysis System (SAS Institute, Inc., Cary, NC, U.S.A.) package for PC (version 9.2).

4. Results

Overall, 231 unselected Zambian residents answered our survey. Questionnaires were not returned by <5% of those asked to answer. The median age (range) was 32 (13–82) years, and the median (range) number of years of education was 8 (0–20). There was a slight predominance of women (58.6%) and a fairly homogeneous distribution of persons living in urban and rural areas (Table 1). Significant differences were seen for sex (more females from rural areas), number of children (higher in rural areas), years of education (higher in urban areas), and marital status (single prevailing in urban areas). The level of familiarity with fits and seizures differed for rural and urban residents (Table 2), but the percentage of people who claimed they had witnessed seizures was similar. Almost all responders said that they had already heard about "epilepsy", with differences favoring urban residents (p = 0.0309). The median (IQR) scores for epilepsy awareness and stigma were, respectively, −1 (−3; +1) and +1 (−1; +6). Awareness about epilepsy was unsatisfactory in 67.5% of interviewees. Univariate analysis indicated age (p = 0.0097), education (p = 0.0505), and residence (p = 0.0513) as possibly related to epilepsy awareness (Table 3). In the multivariable model, only education (p = 0.0131) retained significance. The level of stigma was high in 29.6% of responders and medium in 33.0%. Sex, education, and residence were significantly associated with epilepsy stigma, but only education and residence were significant in the multivariable model (p < 0.0001 and p = 0.0004). Fig. 1 illustrates the distribution of stigma scores for rural and urban residents. When the summary stigma scores were presented in the three severity levels, rural people were mostly in the first (high stigma: 44.2%) and urban people in the last (low/no stigma: 60.4%).

Table 1
Main characteristics of the sample (231).

		Urban area (107) No. (%)	Rural area (124) No. (%)	p-Value
Age group (years)	<18	14 (13.7)	20 (17.2)	0.4483[a]
	18–29	36 (35.3)	30 (25.9)	
	30–39	28 (27.5)	29 (25.0)	
	>40	24 (23.5)	37 (31.9)	
	Missing	5	8	
Sex	M	57 (54.8)	35 (29.7)	0.0001
	F	47 (45.2)	83 (70.3)	
	Missing	3	6	
Children (No.)	0	36 (35.6)	32 (26.2)	0.0396[a]
	1–2	19 (18.8)	17 (13.9)	
	3–5	25 (24.8)	37 (30.3)	
	>5	21 (20.8)	36 (29.5)	
	Missing	6	2	
Education (years)	0–4	10 (9.4)	31 (26.1)	<0.0001[a]
	5–8	18 (17.0)	56 (47.1)	
	>8	78 (73.6)	32 (26.9)	
	Missing	1	5	
Marital status	Single	47 (45.2)	30 (28.0)	0.0332
	Married	43 (41.4)	60 (56.1)	
	Widow	14 (13.5)	17 (15.9)	
	Missing	3	17	

[a] Cochrane–Armitage test for trend.

5. Discussion and conclusions

This study makes a novel contribution to the existing knowledge by comparing the awareness and attitudes towards epilepsy among urban and rural residents of a region of Southern Zambia.

Age and level of education were the main independent predictors of epilepsy awareness in accordance with most previous reports [11,28,29,32,35,45]. Surprisingly, we found a similarly good knowledge about epilepsy in individuals in urban and rural areas. This might be due to the fairly good level of education in both groups (42% and 57% of interviewees from the rural and urban settings, respectively, attended >7 school years). However, the figures might be misleading because upon more focused questioning about the hallmarks of epilepsy, two-thirds of the interviewees gave unsatisfactory answers.

Interestingly, PWE were subject to greater stigma by rural than urban respondents after correction for age and education; this means that town dwellers seem to tolerate and sympathize with PWE more than rural people. A previous study comparing the disability of PWE among rural Zambians and neighboring urban Zimbabweans [50] found higher rates of disability in the rural cohort, possibly because of a sort of "downward social drift" of more impaired PWE from urban back to rural settings where the family of origin may be more willing to accept severely ill members. These findings are not in contrast with our results: we suggest that disabled patients might be better tolerated

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