




BMJ Open What is the community's knowledge and understanding regarding epilepsy? Epilepsy knowledge and its determinants among residents of Dehub Bench District, Bench Sheko Zone, Southwest Ethiopia, 2019: a cross-sectional study

Elsabeth Legesse ¹, Tadesse Nigussie ¹, Yohannes Kebede ², Mamusha Aman,² Mulugeta Chaka,² Dejene Tilahun²

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¹Public Health, Salale University, Fiche, Ethiopia

²Health, Behavior and Society, Jimma University, Jimma, Ethiopia

Correspondence to

Elsabeth Legesse;
elsabethlegesse@gmail.com

ABSTRACT

Objective Epilepsy is a neurological condition marked by recurring seizures. People with epilepsy, particularly in low-income and middle-income countries, are stigmatised due to a lack of understanding and a negative attitude towards the disease. Increased public awareness of epilepsy will aid in the search for therapy and the quality of life of the patients. The study aimed to assess knowledge about epilepsy and the associated factors among residents of Dehub Bench District, Bench Sheko Zone, Southwest Ethiopia in 2020.

Setting This community-based, cross-sectional study triangulated with qualitative method was conducted from 25 April 2020 to 20 May 2020. Multistage sampling technique was used to select 601 participants. A structured and interviewer-administered questionnaire was used to collect data. Data were entered in EpiData Manager V.4.0.2.101 and exported to SPSS V.23 for analyses. Multivariable logistic regression was carried out to identify the factors associated with knowledge of epilepsy. A p value of <0.05 was taken to indicate statistical significance.

Results A total of 601 respondents participated, of whom 340 (56.6%) were male. The mean age of the respondents was 34.84±11.42 years. The proportion with good knowledge of epilepsy was 55.1%. Factors associated with good knowledge of epilepsy were attending primary education (adjusted OR (AOR)=2.06, 95% CI 1.27 to 3.34), secondary education (AOR=5.01, 95% CI 2.62 to 9.58), above secondary education (AOR=5.67, 95% CI 2.35 to 13.69), being in high wealth index (AOR=1.74, 95% CI 1.09 to 2.78), being a government employee (AOR=3.69, 95% CI 1.39 to 9.83), being a merchant (AOR=3.16, 95% CI 1.80 to 5.54) and being an urban resident (AOR=2.15, 95% CI 1.36 to 3.42).

Conclusion Only 55% of the residents have sufficient knowledge about epilepsy. Factors associated with knowledge of epilepsy were educational status, wealth index, occupation and residence.

Strengths and limitations of this study

- The study was conducted on an issue that needs behavioural change to improve patient safety.
- The study attempted to assess community knowledge using both quantitative and qualitative methods.
- The study included both urban and rural populations and attempted to explore the differences between them.
- The cross-sectional design of the study does not show causal relationship.
- People with epilepsy were excluded from the study with the assumption that they have better knowledge than relatively healthy people.

BACKGROUND

Epilepsy is defined as a neurological illness marked by recurring seizures.¹ It is a chronic medical condition with many social aspects, documentations of which have existed since the earliest historical times.² There are three main groups of seizures: generalised, focal and unknown. 'Unknown' refers to a situation where the onset is unknown but other manifestations are known.³

Epilepsy has numerous detrimental health repercussions in people's lives. Depression is the most common of these consequences and can have a wide range of effects on the lives of people with epilepsy (PWE). According to a study conducted among PWE in the Menit community, more than half of the patients on treatment were depressed.⁴

Globally, in 2016, there were 45.9 million patients with all-active epilepsy.⁵ More than

85% of PWE live in the developing world.⁶ Epilepsy is prevalent in Africa, with rates ranging from 2.2 to 58 per 1000 people. For example, a recent population study in five African nations, namely Kenya, Tanzania, Uganda, Ghana and South Africa, found that the prevalence of epilepsy was higher in these countries, ranging between 7 and 15 per 1000 persons.⁷

Of patients with epilepsy in developing nations, 80%–90% do not obtain adequate treatment.⁸ Poor community understanding about epilepsy, the stigma associated with epilepsy and the prevalent misconceptions about epilepsy, such as that it is contagious or has supernatural origins, are all issues that have been recognised as contributing to treatment gap.^{9 10}

The Global Campaign Against Epilepsy (GCAE), the International League Against Epilepsy and the International Bureau for Epilepsy were founded with the goal of improving epilepsy acceptability, treatment, services and prevention in the world. Perhaps appropriately, the GCAE has focused its efforts mostly in underdeveloped countries, where stigma towards epilepsy and lack of information are most severe. There have been some advancements for PWE in certain parts of the world.¹¹

Knowledge about epilepsy is crucial for healthy social support. Poor social support is connected to ineffective treatment seeking.¹² Patients with social support are more likely to seek treatment in a health institution than from a traditional healer, according to a study done among patients with epilepsy at the University of Gondar Hospital's outpatient department.¹³ In addition, lack of awareness and misconceptions concerning epilepsy in the general public have been cited as major impediments to epileptic treatment.¹⁴ People who were less educated, had lower socioeconomic standing and had never been exposed to PWE had more misconceptions and lack of awareness regarding epilepsy.¹⁵

The most significant issues that PWE have in daily life are frequently related not only to the severity of the disease, but also to the societal perceptions about epilepsy.¹⁶ Understanding the knowledge of the community is critical to improving the health-seeking behaviour, social engagement and overall quality of life of patients with epilepsy. The goal of this study was to evaluate the knowledge of epilepsy and its determinants among the residents of Debus Bench District, Bench Sheko Zone, Southwest Ethiopia.

METHODS AND MATERIALS

Study area and period

The study was conducted in Debus Bench District from 25 April 2020 to 20 May 2020. Bench Sheko Zone has seven districts, one of which is Debus Bench District. It lies 28 km south of Mizan Aman Town (which is in the Bench Sheko Zone) and 589 km south of Addis Ababa (the capital city of Ethiopia). The overall population and households, according to a report acquired from the Debus Bench District Health Office, were 148 285 and

29 464, respectively. The urban population was 25 717, while the rural population was 122 568. There are 29 kebeles (the smallest administrative unit in Ethiopia) in the district, with 2 urban and 27 rural kebeles. There are 6 health centres, 29 health posts and 20 private clinics in the area.¹⁷

Study design

A community-based, cross-sectional study was done, which was triangulated with qualitative methods.

Population

Source population

Adults (aged ≥ 18 years) who had been residents of Debus Bench District were the source population.

Study population

The study population consisted of randomly selected adult residents of the Debus Bench District. Adult community members who did not engage in the quantitative part of the study were invited to participate in a focus group discussion (FGD) for the qualitative part of the study.

Inclusion and exclusion criteria

Inclusion criteria

Adult individuals who have lived for at least 6 months in the district before the study period were included in the study.

Exclusion criteria

Adults who were unable to hear, severely ill during the time of data collection and were PWE were excluded.

Patient and public involvement

Patients and/or the public were not involved in this study.

Sample size determination and sampling technique

Sample size determination

The sample was determined using a single population proportion formula: $(n = [(Z_{\alpha/2})^2 p (1-p)] / d^2)$, where n is the sample size; $Z_{\alpha/2}$ is the standard score at the 95% confidence level (1.96); p is the proportion of good knowledge, 14%;¹⁸ and $d = 3.35\%$, the margin of error since the prevalence in a previous study was less than 30% for knowledge and attitude and 5% for stigma towards patients with epilepsy. The sample size for knowledge about epilepsy was derived using the following formula: $n = [(1.96)^2 \times 0.14 (1 - 0.14)] / (0.035)^2 = 378$. By taking a design effect of 1.5% and 10% non-response, the total sample size has to be 624.

For the qualitative part of the study, four FGDs were planned and were conducted as per the plan. There were 8–10 participants per group.

Sampling technique

The method employed was a multistage sampling technique. Debus Bench District was chosen due to the investigator's professional experience in the district. The district is divided into rural and urban kebeles. There are 27 rural kebeles and 2 urban kebeles in the area.

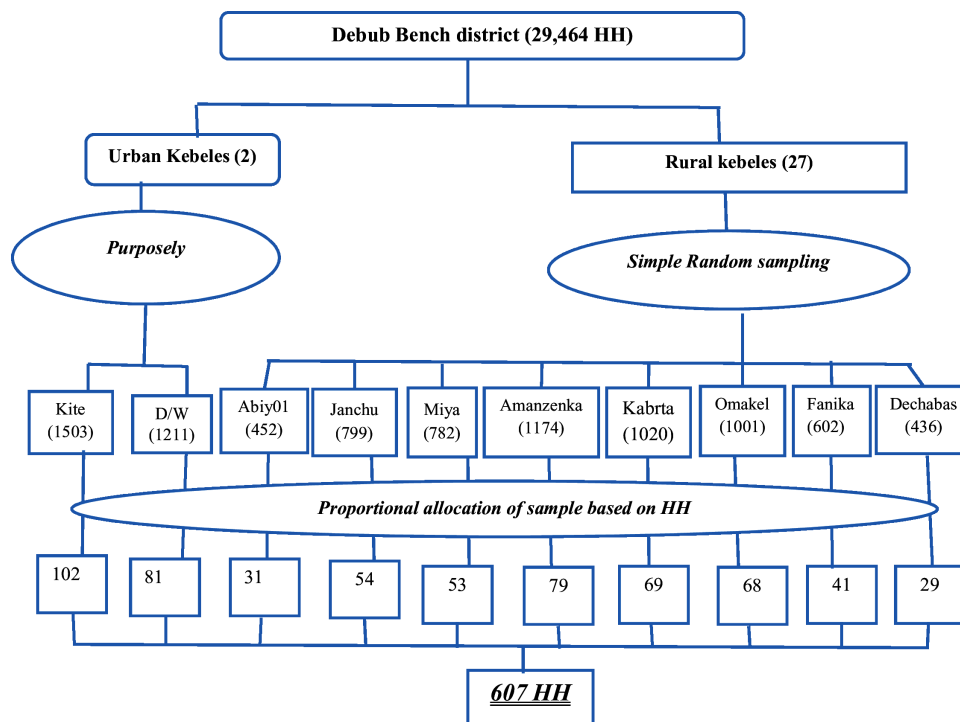


Figure 1 Diagrammatic presentation of sampling procedure for the study on knowledge of epilepsy and its determinants among residents of Debus Bench District, Bench Sheko Zone, Southwest Ethiopia. D/W, Debrework; HH, household.

Out of 29 kebeles, 30% were randomly chosen from 2 urban kebeles and 8 rural kebeles. Kite and Debrework from urban kebeles and Abiy 01, Janchu, Mihya, Amanze Nika, Kabarta, Omakel, Fanika and Dechabas from rural kebeles were picked at random based on the criteria. The kebeles chosen have a total of 8980 households. Systematic random sampling was then performed to choose households. The total number of homes in selected kebeles was divided by the sample size to arrive at the value of k , which was 14 (figure 1). Individual lottery selection was employed in households with more than one adult. With the assumption of getting relevant data to supplement the research aims, a purposeful sampling approach was used with maximum variability in mind. The goal was to look at the specifics of epilepsy and common societal misconceptions.

Data collection tool and personnel

Data were collected using a standardised, interviewer-administered questionnaire. It was adapted from a variety of sources^{18–20} and has six parts, namely sociodemographics, experiences related to epilepsy, knowledge about epilepsy, attitude towards PWE, stigma towards PWE and household wealth index (added as online supplemental material 1). To ensure uniformity, the English questionnaire was translated to Amharic and then back to English. In Semen Bench District, the questionnaire was pretested on 5% of the sample size. Some changes were made to the sequences and how the interview was conducted based on the results of the pretest. Experts evaluated whether the data collection instrument measured what it claimed to measure and was thorough enough to collect all of the

data needed to meet the study's goal. Cronbach's coefficient was used to determine the tool's internal consistency. For items used to test knowledge, the Cronbach's coefficient was 0.78. After studying related literatures, tools for qualitative data collection were designed.^{21–24}

Data collection personnel and technique

Trained data collectors gathered the information. For data collection, five diploma nurses who are proficient in Amharic and Bench language were chosen. Two supervisors with a bachelor's degree in public health were hired to help with data collection. The data collectors and supervisors were chosen based on their previous data collection experience. Data collectors and supervisors received a 2-day training on the study's goal, interview methodology and informed consent. They were also given instructions on how to keep themselves and research participants safe from COVID-19 infection.

One Master of public health (MPH) in public health expert and the primary investigator performed the focus groups. The debate was moderated by the primary investigator, while a public health professional with a master's degree took notes throughout. Health extension workers assisted in the selection of FGD participants. Before a participant could join the group, they had to give their informed consent. The participants' pen names were chosen to maintain anonymity. A ground rule was established and authorisation for voice recording was obtained orally. The primary investigator concluded the discussion by summarising it for the participants and asking for clarification if any misconceptions were identified, before thanking them.

Study variables

- ▶ Dependent variable: knowledge of epilepsy.
- ▶ Independent variables: sociodemographic factors: age, sex, religion, marital status, educational status, occupation, wealth index, residence, distance from health facility and ethnicity.
- ▶ Exposure to PWE: having a family member with epilepsy, having a friend with epilepsy and have witnessed a seizure.

Measurement and operational definition

Knowledge of epilepsy

Knowledge was measured by 17 yes or no questions. A correct answer was coded as 1 and incorrect as 0. The sum score and mean score were computed. The sum score ranges between 0 and 17. Higher scores indicate higher knowledge level about epilepsy and lower scores indicate lower knowledge level. Knowledge was also categorised as good and poor, that is, residents whose score was above the mean score were considered to have good knowledge or poor otherwise.^{25 26}

Wealth index

The wealth index is a composite assessment of a household's overall living standard and is based on a household's possession of certain assets, such as agricultural land, coffee plantations, cattle, radios, bicycles, motorcycles, building materials and a bank account. Using principal component analysis, the wealth index places individual families on a continuous scale of relative wealth. Data on each household asset were collected and a weight or factor score was calculated using principal component analysis. After combining these factors, an index was created and used to determine the wealth tertile breakpoints, which are as follows: lowest wealth tertile, middle wealth tertile and highest wealth tertile.

Data analysis procedure

Quantitative data processing and analysis

Data were manually checked for correctness before being entered, cleaned and checked by EpiData Manager V.4.0.2.101 and then exported to SPSS V.23 for analysis. Different variables were subjected to descriptive analysis and were reported in the form of frequencies, percentages and text. Logistic regression was used to analyse parameters linked to epilepsy knowledge. In binary logistic regression, variables with a p value of less than 0.25 were selected for multivariable logistic regression analysis. Variables with a p value less than 0.05 in the multivariable logistic regression were considered factors linked to community knowledge about epilepsy. OR was used to explain the magnitude of the association.

Qualitative data analysis

The field notes and audio recordings were transcribed to English. ATLAS was used to import the transcripts. The ATLAS.ti V.7.1 program was used for analysis. Coding and categorisation were used to create the primary categories, which were done both inductively and based on

the study's established concepts/objectives. In addition, verbatim quotes from participants' expressions exemplifying key themes were employed in the analysis and interpretation.

Data quality management

Data collectors and supervisors received a 2-day training on data collection techniques. With the data collectors, we addressed data collection methods, tools and how to tackle ethical issues. Data were collected by translating the questionnaire to the respondent's preferred language. The supervisor and principal investigator monitored the data collection process on a regular basis to ensure that all required data were obtained correctly. During the data collection process, filled questionnaires were double-checked for accuracy and consistency on a daily basis. To prevent errors during data entry, EpiData Manager V.4.0.2.101 was used. SPSS V.23 was used for analysis.

An interview guide was created in accordance with the study's goal for qualitative data. The principal investigator and a professional data collector conducted the interviews. For each data source, the impressions of the facilitators and note takers were recorded. Furthermore, members were checked by summarising the interview at the end of each FGD. Debriefing discussions with peers were held to ensure that the interpretation of the findings made sense. Before preparing the final paper, the investigator checked the analysis and interpretation against the audio-taped data and notes.

Letter of support was obtained and study participants were informed about the objectives and purposes of the study. Written informed consent was required from all respondents before the start of each interview. After informed consent was obtained from each study participant, their rights to refuse participation at any point were explained.

RESULTS

Sociodemographics

A total of 601 respondents were interviewed, resulting in a response rate of 96.3%. The mean age of the respondents was 34.84±11.42 years. From the total respondents, 340 (56.6%) were male. Of the respondents, 381 (63.4%) were married and 232 (38.6) had attended primary education. With regard to place of residence, 417 (69.4%) were from rural areas. About half (300, 49.9%) were from the Bench ethnic group. Of the respondents, 231 (38.4%) were farmers in occupation. About two-thirds (413, 68.7%) of the respondents travel more than 30 min to get to a health facility (hospital or health centre) (table 1).

Exposure to PWE

All study participants have heard about epilepsy and 281 (46.8%) of them have heard of epilepsy from family members (figure 2).

Knowledge of epilepsy

The mean score for knowledge of epilepsy was 8.62, with an SD of 3.62. The maximum score was 16 while the

Table 1 Sociodemographic characteristics of adult residents of Debub Bench District, SNNPR, August 2020

Variables	Categories	Frequency	Per cent
Age group	18–19	16	2.7
	20–29	211	35.1
	30–39	184	30.6
	40–49	128	21.3
	50–59	33	5.5
	≥60	29	4.8
Sex	Male	340	56.6
	Female	261	43.4
Marital status	Single	147	24.5
	Married	381	63.4
	Divorced	42	7.0
	Widowed	31	5.2
Religion	Protestant	335	55.7
	Orthodox	205	34.1
	Muslim	44	7.3
	Catholic	17	2.8
Educational status	No education	155	25.8
	Primary	232	38.6
	Secondary	131	21.8
	Above secondary	83	13.8
Ethnic background	Bench	300	49.9
	Amhara	119	19.8
	Kafa	116	19.3
	Sheko	24	4.0
	Oromo	25	4.2
	Others*	17	2.8
Occupation	Farmers	231	38.4
	Merchant	115	19.1
	Housewife	88	14.6
	Student	87	14.5
	Government employee	67	11.1
	Others†	13	2.2
Area of residence	Rural	417	69.4
	Urban	184	30.6
Wealth index	Lower	200	33.3
	Middle	200	33.3
	Higher	201	33.4
Time it takes to reach health facility	≤30 min	188	31.3
	>30 min	413	68.7

*Silte, Sheka, Wolayita and Tigre.

†Daily labourer and driver.

SNNPR, Southern Nations, Nationalities, and People's Region.

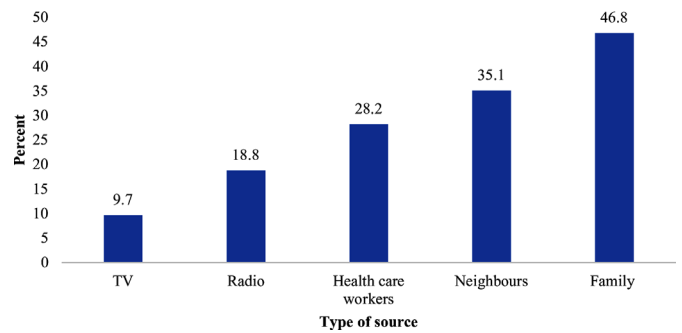


Figure 2 Sources of information about epilepsy among adult residents of Debub Bench District, Bench Sheko Zone, SNNPR, August 2020. SNNPR, Southern Nations, Nationalities, and People's Region; TV, television.

minimum was 0 out of 17 knowledge questions. Based on the mean score, about 331 (55.1%) participants had good knowledge of epilepsy.

With regard to the cause of epilepsy, more than half (352, 58.6%) of the respondents reported that epilepsy is caused by a supernatural power (God). According to qualitative study participants from Debub Bench District, the people call epilepsy as ‘Gino’ in Bench language and ‘Azurit or yemitil beshita’ in Amharic. They believe that the disease hates water and fire. This is why PWE fall down in water and fire. The community believes that the cause of epilepsy varies, such as staying in garbage areas, smoking tobacco, curse from God and evil spirit. For instance, a 41-year-old male FGD participant explained: “I do not know the cause of this disease. May be curse from the God. I don’t know, God knows about this.”

On the symptoms of epilepsy, 360 (59.9%) mentioned a brief loss of consciousness. There are different thoughts in the study area with regard to the symptoms of epilepsy. Most FGD participants explained that PWE can be identified from people without epilepsy when they saw an occurrence of seizures. They also mentioned symptoms such as getting calm, sweating, falling down, and convulsion (for 10 min) and drooling.

Of the total respondents, 357 (59.4%) believed that epilepsy is communicable. Most FGD participants believed that epilepsy can be transmitted from PWE to healthy individuals. Among the methods of transmission, contact with saliva during seizure was the most frequently mentioned. Because of this, people fear to touch an individual’s saliva, perceiving that it is transmitted through saliva. For example, a 43-year-old male FGD participant said: “During the occurrence of seizure, no need of touching them since it is transmitted through the contact of saliva....”. The community also believes that epilepsy can be transmitted by sharing household materials such as drinking cup. One 46-year-old male FGD participant explained his idea regarding epilepsy transmission:

The disease is transmittable. It is transmitted through contact. For instance, by sharing cup of drinking water. I have some history on this issue. He was my friend (co-worker). Once upon the time I went to my home



with him. After eating lunch, in between, I went to toilet. During the moment the individual add his drinking water to my cup. Just intentionally to transmit the disease to me. Previously, I did not know him as he is epileptic. When I return back from the toilet, I went to the toilet by his turn. One individual informed me that your friend is a known epileptic and not to drink that water. Then after, we cut our friendship. This is to mean that the disease is transmittable.

The community also believes that epilepsy is a genetic disease inherited from the family. They think PWE cannot conceive healthy babies. Also, some FGD participants believe epilepsy can be spread to family members if they have long-term exposure to PWE. For example, a 38-year-old female participant said: "...I have seen such like individuals. E.g. from brother to brother...sometimes it can be transmitted also genetically." They also contemplate that epilepsy can be transmitted from PWE to relatively healthy individuals through flatus. A 41-year-old male participant said: "...people also belief that it is transmitted through flatus from the one who had epilepsy to the normal person." It was mentioned that epilepsy can also transmit through the body odour of PWE to relatively healthy individuals. A 36-year-old female participant said: "It can occur due to body odor of epileptic patient, sleeping together with epileptic patient...". There is also a belief that healthy people can get the disease while PWE die. For example, a 34-year-old female participant said: "...And also during dying process (when the soul of patient is separated from the flesh) the relative who is around him/her and if shocked it can be transmitted. For instance, in my neighbor the brother of the epileptic patient acquired the disease since he was only the one who cares the patient when he was died."

On treatment of epilepsy, 494 (82.2%) respondents said that it is treatable with modern medicine. Of the respondents, 340 (56.6%) said there is no need to continue taking antiepileptic drugs once seizures have stopped (table 2). Most of the participants of the qualitative part of the study correctly mentioned the appropriate treatment option for epilepsy, that is, modern medication. As well, some study participants mentioned traditional and spiritual options. A 53-year-old male participant said:

Just the solution is that the drugs for this disease which is found at Hospital. Therefore, the epileptic individual should have to take this medication continuously without interruption. We heard that it is possible to control this disease by taking the medication from health facilities.

Factors associated with knowledge of epilepsy

To assess the factors associated with knowledge of epilepsy, variables such as sex, age group, educational status, marital status, wealth index, occupation, residence, presence of radio, distance from health facility and presence of a family member with epilepsy with a p

value less than 0.25 were included in the binary logistic regression. To control for possible confounding, multi-variable logistic regression was conducted. Hosmer and Lemeshow test was performed to test for model fitness and showed a p value of 0.14. In the multivariable logistic regression, educational status, occupation, area of residence and wealth index were associated with knowledge of epilepsy. Participants who attended primary education were 2.06 times more likely to have good knowledge of epilepsy when compared with no education (adjusted OR (AOR)=2.06, 95% CI 1.27 to 3.34). Respondents who also attended secondary school were 5.01 times more likely to have good knowledge of epilepsy than those with no education (AOR=5.01, 95% CI 2.62 to 9.58). Similarly, respondents who attended above secondary school were 5.67 times more likely to have good knowledge of epilepsy when compared with those with no education (AOR=5.67, 95% CI 2.35 to 13.69). Respondents who were in the high wealth index category were 1.74 times more likely to have good knowledge of epilepsy when compared with those in the lower category (AOR=1.74, 95% CI 1.09 to 2.78). In terms of occupational status of the respondents, government employees were 3.69 times more likely to have good knowledge of epilepsy when compared with farmers (AOR=3.69, 95% CI 1.39 to 9.83). Similarly, merchants were 3.16 times more likely to have good knowledge of epilepsy when compared with farmers (AOR=3.16, 95% CI 1.80 to 5.54). Lastly, area of residence was associated with knowledge of residents, that is, respondents from urban areas were 2.15 times more likely to have good knowledge of epilepsy when compared with participants from rural areas (AOR=2.15, 95% CI 1.36 to 3.42) (table 3).

DISCUSSION

The study aimed to assess community knowledge regarding epilepsy and demonstrated a magnitude of good knowledge of 55.1%. This indicates that more than half of the participants have sufficient knowledge regarding the cause, symptoms and treatment options for epilepsy. This finding is similar to the study conducted in Debre Berhan, North Shoa, Amhara Region, which showed that 55.4% of participants have good knowledge of epilepsy.²⁷ This finding is also similar to the study conducted in East Gojjam in Northern Ethiopia, which revealed that 52.5% of the community have adequate knowledge about epilepsy.²⁵ The magnitude of good knowledge in this study is higher than the study conducted in Ile-Ife, Nigeria, which showed only 15.3% of respondents had good knowledge about the disease.²⁸ The magnitude of good knowledge in this study was also higher than the study conducted in Southwest Ethiopia among the Menit community, which revealed that only 14.4% of respondents have good knowledge of epilepsy.¹⁸ The discrepancy might be that majority of the Meinit community are pastoralists and they lack information regarding the disease.

Table 2 Frequency table showing the knowledge score regarding epilepsy among adult residents of Debub Bench District of Bench Sheko Zone, SNNPR, August 2020

Variables	Categories	Frequency	Per cent
Epilepsy is caused by a supernatural power (God).	Yes	352	58.6
	No	249	41.4
Epilepsy is caused by a brain defect.	Yes	344	57.2
	No	257	42.8
Epilepsy is a hereditary disease.	Yes	330	54.9
	No	271	45.1
Epilepsy results from an unknown origin.	Yes	368	61.2
	No	233	38.8
Epilepsy is an infectious disease.	Yes	357	59.4
	No	244	40.6
Stress causes some seizures.	Yes	356	59.2
	No	245	40.8
Epilepsy is a type of mental retardation.	Yes	358	59.6
	No	243	40.4
All people with epilepsy have similar symptoms.	Yes	361	60.1
	No	240	39.9
Epilepsy manifests as a brief loss of consciousness.	Yes	360	59.9
	No	241	40.1
Patients with epilepsy show only muscle twitching as a symptom of seizure.	Yes	302	50.2
	No	299	49.8
All people with epilepsy lose consciousness during epileptic seizures.	Yes	519	86.4
	No	82	13.6
Epilepsy is treatable with modern medicine.	Yes	494	82.2
	No	107	17.8
Patients with epilepsy take drug lifelong.	Yes	268	44.6
	No	333	55.4
Drugs to be successful must be taken regularly.	Yes	427	71.0
	No	174	29.0
Seizures are well controlled soon after starting regular.	Yes	418	69.6
	No	183	30.4
Seizures stop with antiepileptic drug and epilepsy is cured.	Yes	345	57.4
	No	256	42.6
No need to continue taking antiepileptic drugs if seizures have stopped.	Yes	340	56.6
	No	261	43.4

SNNPR, Southern Nations, Nationalities, and People's Region.

According to this study, having strong knowledge is linked to where people reside. When compared with rural residents, urban residents were more likely to have good knowledge. This could indicate that fewer efforts are being made to combat epilepsy among rural individuals. A study from Uganda's Mukono District also found that rural populations have less knowledge than city dwellers.²⁶ Another study in Oromia Region's Sululta District found that city dwellers were more knowledgeable than rural dwellers.¹⁹ This could be because rural individuals face

different barriers to information compared with urban residents, who have access to a variety of information sources such as television, radio and written materials.

Knowledge of epilepsy was similarly influenced by educational status. When compared with those with no education, those with primary, secondary or postsecondary education were more likely to have good knowledge. This finding matches that of a study conducted in Ile-Ife, Nigeria,²⁸ among the Menit community, Southwest Ethiopia,¹⁸ and in Goncha Siso Enese Woreda, East

Table 3 Factors associated with knowledge of epilepsy among adult residents of Debub Bench District of Bench Sheko Zone, SNNPR, August 2020

Variables	Categories	Knowledge status		COR	AOR
		Good	Poor		
Sex	Male	175 (51.5)	165 (48.5)	1	1
	Female	156 (59.8)	105 (40.2)	1.40 (1.01 to 1.94)	1.19 (0.75 to 1.88)
Age group	18–19	9 (56.3)	7 (43.7)	2.86 (0.81 to 10.10)	1.28 (0.29 to 5.60)
	20–29	133 (63.1)	78 (36.9)	3.79 (1.64 to 8.73)	1.37 (0.49 to 3.79)
	30–39	118 (64.1)	66 (35.9)	3.97 (1.71 to 9.23)	2.61 (0.97 to 6.99)
	40–49	48 (37.5)	80 (62.5)	1.33 (0.56 to 3.16)	1.29 (0.47 to 3.57)
	50–59	14 (42.4)	19 (57.6)	1.64 (0.58 to 4.66)	2.07 (0.63 to 6.77)
	≥60	9 (31.0)	20 (69.0)	1	1
Educational status	No education	44 (28.3)	111 (71.7)	1	1
	Primary	123 (53.0)	109 (47.0)	2.85 (1.84 to 4.39)	2.06 (1.27 to 3.34)*
	Secondary	95 (72.5)	36 (27.5)	6.66 (3.96 to 11.18)	5.01 (2.62 to 9.58)*
	Above secondary	69 (83.1)	14 (16.9)	12.43 (6.35 to 24.35)	5.67 (2.35 to 13.69)*
Marital status	Single	92 (62.5)	55 (37.5)	1	1
	Married	214 (56.2)	167 (43.8)	0.77 (0.52 to 1.13)	1.58 (0.90 to 2.75)
	Divorced	16 (38.1)	26 (61.9)	0.37 (0.18 to 0.75)	0.69 (0.29 to 1.64)
	Widowed	9 (29.0)	22 (71.0)	0.245 (0.11 to 0.57)	0.77 (0.27 to 2.19)
Wealth index	Lower	91 (45.5)	109 (54.5)	1	1
	Middle	108 (54)	92(46)	1.41 (0.95 to 2.08)	1.31 (0.83 to 2.07)
	High	132 (65.7)	69 (34.3)	2.29 (1.53 to 3.43)	1.74 (1.09 to 2.78)*
Occupation	Farmer	85 (36.8)	146 (63.2)	1	1
	Government employee	59 (85.1)	8 (14.9)	12.67 (5.78 to 27.78)	3.69 (1.39 to 9.83)*
	Merchant	81 (70.4)	34 (29.6)	4.09 (2.53 to 6.62)	3.16 (1.80 to 5.54)*
	Housewife	48 (54.5)	40 (45.5)	2.06 (1.25 to 3.39)	1.66 (0.95 to 2.89)
	Student	53 (60.9)	34 (39.1)	2.67 (1.61 to 4.44)	1.46 (0.69 to 3.12)
	Others	5 (38.5)	8 (61.5)	1.07 (0.34 to 3.39)	0.74 (0.20 to 2.67)
Residence	Rural	195 (46.8)	222 (53.2)	1	1
	Urban	136 (73.9)	48 (26.1)	3.22 (2.20 to 4.72)	2.15 (1.36 to 3.42)*
Presence of radio	Yes	69 (61.1)	44 (38.9)	1.35 (0.89 to 2.04)	
	No	262 (53.8)	225 (46.2)	1	1
Distance from health facility	≤30 min	129 (68.6)	59 (31.4)	2.28 (1.59 to 3.29)	1.25 (0.77 to 2.03)
	>30 min	202 (48.9)	211 (51.1)	1	1
Presence of family member with epilepsy	Yes	42 (62.7)	25 (37.3)	1.42 (0.84 to 2.40)	1.55 (0.88 to 2.81)
	No	289 (54.1)	245 (45.9)	1	1

*Associated variables.

AOR, adjusted OR; COR, crude OR; SNNPR, Southern Nations, Nationalities, and People's Region.

Gojjam, Ethiopia,²⁵ which showed having higher education was associated with good knowledge of epilepsy. Furthermore, a Chinese study found that respondents' educational status has a favourable impact on community knowledge of epilepsy.²⁹ This could be because along with increase in educational level, people's ability to acquire information from various sources, such as written

materials, increases as well. Schools may also provide information on epilepsy to educated people.

Higher socioeconomic position was also linked to better knowledge of epilepsy. This could be because people with higher income have more access to health information from various sources. This finding is consistent with a study conducted in Australia, which found a

link between poor economic status and a lack of understanding regarding epilepsy.³⁰

Occupation was likewise linked to respondents' knowledge status. Compared with farmers, government employees and merchants were more likely to have strong expertise. This could be because government employees and merchants interact with a variety of people, allowing them to share disease-related knowledge.

There are some limitations to this study. As a cross-sectional study, it is not possible to show and determine a causal relationship between the dependent and independent variables. PWE were also excluded from the study with the assumption that they have gained a better understanding of their condition through dialogues with health professionals during follow-ups. It would have been better if we had compared the knowledge of PWE and people without epilepsy.

CONCLUSION

Only 55% of the residents have sufficient knowledge about epilepsy. When planning to increase awareness of epilepsy in the community, educational status, wealth index, occupation and residence have to be considered. Attention has to be given on creating awareness regarding epilepsy in the community, especially in rural communities.

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ORCID iDs

Elsabeth Legesse <http://orcid.org/0000-0002-4914-8423>
Tadesse Nigusie <http://orcid.org/0000-0003-3123-5809>
Yohannes Kebede <http://orcid.org/0000-0003-3142-5266>

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English version Questionnaire

Instruction: Ask the following questions and read the response options for the respondents. Then, encircle to the respondent's response. For the responses not find in the response options write on the space provided based on the response obtained.

Sr.No	Question	Answer	Remark
	Part I: Socio-demographic		
101	Age in full years	_____ years	
102	Sex	1. Male 2. Female	
103	Religion	1. Orthodox 2. Muslim 3. Protestant 4. Catholic 5. Other (specify) _____	
104	Marital status	1. Single 2. Married 3. Divorced 4. Widowed	
105	Educational status	1. No education 2. Primary education 3. Secondary education 4. Above secondary	
106	Residence	1. Rural 2. Urban	
107	What is your role in a family?	1. Head of house hold 2. Husband 3. Wife 4. Child 5. Worker 6. Other (specify) _____	
108	Ethnicity	1. Bench 2. Amhara 3. Kaffa 4. Sheko 5. Other (specify) _____	
109	Occupation of respondents	1. Occupation 2. Merchant 3. Government employee 4. Farmer 5. Housewife	

		6. Cattle rearing 7. Other (specify) _____	
110	Is health facility available in your area?	1. Yes 2. No	
111	Distance from health facility	_____	
	Part II: exposure to epilepsy communication		
201	Do you know epilepsy?	1. Yes 2. No	
202	Have you heard about it?	1. Yes 2. No	
203	If yes for 202 from where?	1. Magazines 2. TV 3. Radios 4. Family members 5. Health care provider 6. Other (specify) _____	
204	What have heard about epilepsy? [Don't read options)	1. Main causes 2. Treatment 3. Care 4. Other (specify) _____	
205	Have a family member with epilepsy?	1. Yes 2. No	Skip
206	If yes what is the relation with you	1. Father 2. Mother 3. Sister 4. Brother 5. Son 6. Daughter 7. Servant	
207	Have epileptic friend?	1. Yes 2. No	
208	Have epileptic neighbors?	1. Yes 2. No	
209	Have you ever seen a seizing epileptic patient on the road?	1. Yes 2. No	
210	What do you do if you see convulsing epileptic patients?	1. Nothing 2. Runaway 3. Smoking match stick 4. Supporting head 5. Other specify _____	
	Part III: Knowledge of epilepsy		
301	Is epilepsy caused by supernatural power?	1. Yes 2. No	
302	Is epilepsy caused by brain defect?	1. Yes 2. No	
303	Is epilepsy hereditary disease?	1. Yes 2. No	
304	Can epilepsy result from unknown origin?	1. Yes 2. No	

305	Is epilepsy infectious disease?	1. Yes	2. No	
306	Can stress cause some seizures?	1. Yes	2. No	
307	Is epilepsy a symptom of mental illness?	1. Yes	2. No	Symptom of epilepsy
308	Do all people with epilepsy have similar symptoms?	1. Yes	2. No	
309	Can epilepsy manifest as brief loss of consciousness?	1. Yes	2. No	
310	Can epileptic patients show only muscle twitching as symptom of seizure?	1. Yes	2. No	
311	Do all people with epilepsy lose consciousness during epileptic seizures?	1. Yes	2. No	
312	Is epilepsy treatable with modern medicine?	1. Yes	2. No	Treatment of epilepsy
313	Are all epileptic patients those start drugs for their epilepsy have to take them for life?	1. Yes	2. No	
314	In order for anti-epileptic drugs to be successful, they must be taken regularly	1. Yes	2. No	
315	Most peoples' seizures are well controlled soon after starting regular drug treatment	1. Yes	2. No	
316	If seizures stop with anti-epileptic drugs, this means that your epilepsy is cured	1. Yes	2. No	
317	There is no need to continue taking your anti-epileptic drugs if seizures stop	1. Yes	2. No	
Part 4: Wealth index				Remark
401	What is the main source of water for members of your household?	1. Piped water 2. Protected well 3. Unprotected well 4. Protected spring 5. Unprotected spring 6. Surface water (river) 7. Other specify_____		Multiple answer is Possible
402	What kind of toilet facility do members of your household usually use?	1. Ventilated improved pit latrine (VIP) 2. Pit latrine with slab 3. Pit latrine without slab/ open pit 4. No facility/bush/field 5. Other specify _____		

403	Does your household have:	<ol style="list-style-type: none"> 1. Bed 2. Bicycle 3. Motorcycle 4. Car 5. Table 6. Chair 7. Watch 8. Radio 9. Mobile telephone 10. Electricity 11. Solar 	multiple answer is possible
404	Do you have separate room that is used as kitchen?	<ol style="list-style-type: none"> 1. Yes 2. No 	
405	Main material of the floor	<ol style="list-style-type: none"> 1. Earth/mud 2. Wooden 3. Cement 4. Other specify_____ 	Record Observation
406	Main material of the roof	<ol style="list-style-type: none"> 1. Grass 2. corrugated iron sheet 3. cement 4. other specify_____ 	Record Observation
407	Main material of the walls	<ol style="list-style-type: none"> 1. wooden and mud 2. wood/sticks and Cement 3. Bricks (shekila) 4. Other (specify)_____ 	Record Observation
408	How many household members are sleeping in one room?	_____	
409	Does any member of this household own land that can be used for agriculture?	<ol style="list-style-type: none"> 1. Yes 2. No 	If 2 skips to No 612
410	How many hectares?	_____	
411	How many crops in kuntal do you get from the total agricultural land you have?	<ol style="list-style-type: none"> 1. Maize_____ 2. Teff_____ 3. Sorghum_____ 4. (Others)_____ 	
412	Does any member of this household own land that can be used for Coffee?	<ol style="list-style-type: none"> 1. Yes 1. No 	If 2 skip to No 614
413	How many kuntal annually do you get?	_____	
414	Does this household own any livestock, herds, or farm animals?	<ol style="list-style-type: none"> 1. Yes 	If 2 skip to No. 716

		1. No	
415	How many of the following animals do this household own?	1. Milk cows _____ 2. Oxen or bulls _____ 3. Horses _____ 4. Donkeys _____ 5. Mules _____ 6. Goats _____ 7. Sheep _____ 8. Chickens _____ 9. Others _____	
416	Do you have bank account?	1. Yes 2. No	
417	How many ETB do you have on the account?	2. _____ Ethiopia birr	

Thank you for your participation!!!

FGD GUIDE

1. What have you heard about epilepsy? **Probe:** From where and from whom? Is there other name can your community use to describe epilepsy? What do people in your community (friends, family, self) know about epilepsy? **Probe:** How does someone get epilepsy? What are the causes of epilepsy? What are the signs and symptoms of epilepsy? Management/treatment of epilepsy (traditionally, Health facility (modern medicine), spiritually, etc.)? What do people do when epileptic patient seizing (at home, on the road, school, other places)?
2. Do you think epilepsy is transmitted/passed from one person to another? **Probe:** How/through what? Is it transmitted from parent to children (hereditary)?
3. Who do you think can be affected by epilepsy? **Probe:** Age? Sex? Religion? etc. How?
4. How are epileptics being treated in the community? I.e. what do you think about the communities feeling and perceptions towards the epileptics? **Probe:** in the household/ community (like Marriage, Acceptance, Participation (Ikub, Idir, ceremonies, etc.), and sharing position)? In public places (like schools, church/mosque, market, etc.)? What are some of the reasons that make people feel this way? Can they marry and lead healthy life?
5. How common is stigma and/or discrimination about epilepsy among your communities? **Probe:** in any context, work, social life, etc.? Would you give me examples without mentioning his/her name? Do you have any other comment or opinion regarding stigma and discrimination of epilepsy?
6. What would be the complication and/or the negative impacts of epilepsy? **Probe:** on the individual suffering of the problem, families, communities, and the society in general?
7. What are your recommendations to decrease stigma related to epilepsy towards epileptic patients? Families, communities, health care providers, government, etc.?
8. We have now reached the end of our discussion; do you have any questions we should address before ending?

If yes address questions/concerns. If no Summarize the discussion and END

Amharic Version Questionnaire

መመሪያ: የምክተሉትን ጥያቄዎች ከጠየክ/ሽ በኋላ የመልሱን ምርጫ አክብ/ቢበት

ተ.ቁ	ጥያቄ	መልስ	ማሳሰቢያ
ክፍል I: አጠቃላይ የማህበራዊ መረጃ			
101	ዕድሜ	_____ ዓመት	
102	ፆታ	1. ወንድ 2. ሴት	
103	ሀይማኖት	1. ኦርቶዶክስ 2. ሙስሊም 3. ፕሮቴስታንት 4. ካቶሊክ 5. ሌላ (ግለጽ _____)	
104	የጋብቻሁኔታ	1. ያላገባ/ች 2. ያገባ/ች 3. የተፈታ/ች 4. በሞትየተለዩ	
105	የትምህርት ደረጃ	1. ያልተማረ/ች 2. አንደኛ ደረጃ 3. ሁለተኛ ደረጃ 4. ከሁለተኛ ደረጃ በላይ	
106	መኖሪያ ቦታ	1. ገጠር 2. ከተማ	
107	በቤተ ሰብ ውስጥ ድርሻህ/ሽ ምንድነው?	1. የቤተሰብ አስተዳዳሪ 2. ባል 3. ምስት 4. ልጅ 5. ሠራተኛ 6. ሌላ (ግለጽ _____)	
108	ብሄር	1. ቤንቸ 2. አማራ 3. ካፋ 4. ሸኮ 5. ሌላ (ግለጽ _____)	
109	የስራ ሁኔታ	1. ገበሬ 2. የመንግስት ሠራተኛ 3. ነጋዴ 4. የቤት ዕመቤት	

		5. ተማሪ 6. ሌላ (ግለጽ _____)	
110	በአከባቢያቸው በቅርብ የሌላ ተቋም አለ?	1. አዎ 2. የለም	
111	የሌላ ተቋም ርቀት ከቤታቸው ምን ህል ነው?	----- ደቂቃ (በእግር) ----- ደቂቃ (በመኪና)	
ክፍል 2: የሚጥል በሽታ ጋር ተያይዞ ያለው ልማዶች			
201	የምጥል በሽታ ያወቃሉ?	1. አዎ 2. አይደለም	
202	ስለምጥል በሽታ ሰምተው ያወቃሉ?	1. አዎ 2. አይደለም	
203	201 አዎ ከሆነ ከዜጎች ስሙ?	1. ቲቪ 2. ራድዮ 3. ከቤተሰብ አባል 4. ከሌላ ግለሰብ 5. ሌላ (ግለጽ _____)	
204	202 አዎ ከሆነ ምን አይነት መረጃ አገኙ?	1. ስለ መንስዔው 2. ስለ ህክምና 3. ስለ እንክብካቤው 4. ሌላ (ይግለጹ) _____	
205	የሚጥል በሽታ ያለበት ከቤተሰባቸው አባል ውስጥ አለ?	1. አዎ 2. የለም	
206	205 አዎ ከሆነ ታማሚው ማነው?	1. አባት 2. እናት 3. እህት 4. ወንዳም 5. ወንድ ልጅ 6. ሴት ልጅ 7. ሰራተኛ	
207	የሚጥል በሽታ ያለበት ጓደኛ አለዎት?	1. አዎ 2. የለም	
208	የሚጥል በሽታ ያለበት ጎረቤት አለዎት?	1. አዎ 2. የለም	
209	በመንገድ ላይ የሚጥል በሽታ ያለበት ሰው ወድቆ አይተው ያወቃሉ?	1. አዎ 2. የለም	
210	በመንገድ ላይ የሚጥል በሽታ ሰው ወድቆ ብያዩ ምን ያደርገሉ?	1. ምንም 2. እሮጣለሁ 3. ክብረት አጨስለታለሁ 4. ጭንቅለቱን እንዳይጎደግ ደግፋለሁ 5. ሌላ (ይግለጹ) _____	
ክፍል 3: ስለሚጥል በሽታ ዕውቀት			
301	የሚጥል በሽታ በፈጣሪ ትዛዝ ይመጣል?	1. አዎ	

		2. አይደለም 3. አላውቀዉም	
302	የሚጥል በሽታ የሚፈጠር በአንጎል ውስጥ ችግር ነዉ?	1. አዎ 2. አይደለም 3. አላውቀዉም	
303	የሚጥል በሽታ የስነ አእምሮ በሽታ ነዉ?	1. አዎ 2. አይደለም 3. አላውቀዉም	
304	የሚጥል በሽታ ከቤተሰብ የሚወረስ ነዉ?	1. አዎ 2. አይደለም	
305	የሚጥል በሽታ በማይታወቅ መንስኤ ሊመጣ ይችላል?	1. አዎ 2. አይደለም	
306	የሚጥል በሽታ ከሰው ወደ ሰው ይተላለፋል?	1. አዎ 2. አይደለም	
307	ጭንቀት የሰውነት መንቀጥቀጥ ሊያመጣ ይችላል?	1. አዎ 2. አይደለም	
308	የሚጥል በሽታ ያለባቸዉ ሰዎች ሁሉ አንድ አይነት ምልክት አላቸዉ?	1. አዎ 2. አይደለም	
309	የሚጥል በሽታ በቅፅበታዊ አእምሮ ንቃት ማጣት ሊገለፀ ይችላል?	1. አዎ 2. አይደለም	
310	የሚጥል በሽታ ያለባቸዉ ሰዎች የጡንቻ መንቀጥቀጥ ብቻ እንደ ምልክተ ሊያሳይ ይችላሉ?	1. አዎ 2. አይደለም	
311	የሚጥል በሽታ ያለባቸዉ ሰዎች ሁሉም ስያንቀጠቅጣቸዉ ራሳቸዉን ይስታሉ?	1. አዎ 2. አይደለም	
312	የሚጥል በሽታን ሀክምቶ በመድሃኒት ማከም ይችላሉ?	2. አዎ 2. አይደለም	ስለሚጥል በሽታ ህክምና
313	ለሚጥል በሽታ መድሃኒት የጀመሩ ሰዎች ዕድሜ ልካቸዉን ይወስዳሉ ?	1. አዎ 2. አይደለም	
314	የሚጥል በሽታ በደንብ ለመቆጣጠር መድሃኒቱ በተከታታይ መወሰድ አለበት	1. አዎ 2. አይደለም	
315	ከሚጥል በሽታ ጋር የሚኖሩ ብዙ ሰዎች መደበኛ ህክምና ከጀመሩ በኋላ በሽታዉ ይቆጣጠራል	1. አዎ 2. አይደለም	
316	የሚጥል በሽታ ምልክቱ ከጠፋ በሽታዉ ጠፋ ማለት ነዉ	1. አዎ 2. አይደለም	
317	የሚጥል በሽታ ምልክቱ ከጠፋ መድሃኒቱ መቆም አለበት	1. አዎ 2. አይደለም	
ክፍል 4: ስል ሀብት ብዛት			
401	ለቤተሰቡ የመጠጥ ምንጭ ከዬት ነዉ	1. ከበዋንባ 2. የተጠበቀ ጉድገዋድ	

		<ol style="list-style-type: none"> 3. ያልተጠበቀ ጉድገዋድ 4. የተጠበቀ ምንጭ 5. ያልተጠበቀ ምንጭ 6. ምንጭ 7. ሌላ: _____ 	
402	ምን አይነት ሽንት ቤት ነው ያላቸው?	<ol style="list-style-type: none"> 1. VIP 2. ትንሽ ጉድገድ ጣርያ ያለው 3. ትንሽ ጉድገድ ጣርያ የለለው 4. ጭካ 5. ሌላ: _____ 	
403	ቤተሰቡ የሚከተሉ መሳሪያዎች አለዎት?	<ol style="list-style-type: none"> 1. አልጋ 2. ሳይክል 3. ሞተር ሳይክል 4. መኪና 5. ጠረጴሳ 6. ወንበር 7. የእጅ ሰዓት 8. ሬድዮ 9. ሞባይል 10. ኤሌክትሮኒክ 11. ሰላር 	
404	ኩሽና ሌላ ክፍል የተለያየ ነው?	<ol style="list-style-type: none"> 1. አዎ 2. አይደለም 	
405	የቤቱ ወለል ከምንድነው የተሰራ?	<ol style="list-style-type: none"> 1. አፈር/መሬት 2. እንጨት 3. ሲሚንት 4. ሌላ: _____ 	
406	የቤቱ ጣርያ ከምንድነው የተሰራ?	<ol style="list-style-type: none"> 1. ሳር 2. ቆርቆሮ 3. ሲሚንት 4. ሌላ: _____ 	
407	የቤቱ ግርግዳ ከምንድነው የተሰራ?	<ol style="list-style-type: none"> 1. እንጨትና ጭቃ 2. እንጨትና ሲሚንት 3. ሸክላ 4. ሌላ: _____ 	
408	አንድ ክፍል ውስጥ ስንት ሰው ነው የሚተኛ?	_____	
409	ቤተሰቡ ለእርሻ የሚሆን መሬት አለው?	<ol style="list-style-type: none"> 1. አዎ 2. አይደለም 	
410	ስንት ሄክታር	_____	
411	በዝህ ዓመት ስንት ኩንታ እህል አመረታችሁ	<ol style="list-style-type: none"> 1. በቆሎ: _____ 2. ጤፍ: _____ 3. ሌላ: _____ 	
412	ቤተሰቡ ለቡና የሚሆን መሬት አለው?	<ol style="list-style-type: none"> 1. አዎ 2. አይደለም 	
413	በዝህ ዓመት ስንት ኩንታ እህል አመረታችሁ	4. _____	

414	ቤተሰቡ የቤት እንሰሳት አለዉ?	1. 1. አዎ 2. አየደለም	
415	ቤተሰቡ ስንት የቤት እንሰሳት አለዉ?	1. ላም : _____ 2. በሬ: _____ 3. ፈረስ: _____ 4. አህያ: _____ 5. በቅሎ: _____ 6. ፍየል: _____ 7. በግ: _____ 8. ዶሮ: _____ 9. ሌላ: _____	
416	ቤተሰቡ የባንክ ደብተር አለዉ?	1. አዎ 2. አየደለም	
417	ቤተሰቡ ከባንክ ደብተር ስንት ብር አለዉ?	_____	

ስለ ተሳትፎዎ እናመሰግናለን!!!