

11. Annexes

Annex I. Primary Caregiver's Information sheet and Consent Form

Consent to participate in the study entitled: "Seizure Impact on the School Attendance in Children with Epilepsy: Prospective Study in the Pediatrics Neurology Clinic at Tikur Anbessa Specialized Hospital between April-July 2018."

Purpose of the study:

This study was conducted to the School Attendance in Children with Epilepsy: Prospective Study in the Pediatrics Neurology Clinic at Tikur Anbessa Specialized Hospital between April-July 2018. The purpose of the study is to know the magnitude absenteeism and associated factors in school aged children with seizure disorder. The study was helpful for planning and providing appropriate interventions for children and adolescents who need them.

What participation involves:

Those consented to participate in this study, was interviewed for information regarding the child's or adolescent's socio- demographic situation and health related information. They were asked to fill out school information's in the past 6 months.

Risks associated with participation:

There was no potential harm to you and child participating in this study.

Confidentiality:

The child's name was not recorded in the questionnaire. The information provided about the child will be kept confidential.

Right not to participate or withdraw participation:

You have a full right not to participate in this research, and you can withdraw your consent of participation at any point during the study. The child will continue to receive all medical services regardless of participation.

Benefits of participation:

If you consent to participate in this research, the information you provide about the child will be utilized for other children to improve the health care given for children.

A Primary caretaker consent form

I have read and understood the information provided above. My questions have been answered. I, hereby, consent that the child's data can be used for the research. I confirm my agreement to let my child participate in the study with my signature below.

Name _____

Signature _____

Date _____

Contact information of the Primary Investigator:

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Annex II. Study Questionnaire

Title of the Research –“Seizure Impact on the School Attendance In Children With Epilepsy: Prospective Study In The Pediatrics Neurology Clinic At Tikur Anbessa Specialized Hospital Between April-July 2018.”

Instructions – Please take your time to carefully complete the information below.

Code number _____

Date ____/____/____

Part I – Socio-demographic Data of child or adolescent

1. Date of birth ____/____/____ Age in years |__|_|

2. Sex:

A. Male B. Female

3. Birth order

A. First B. Second C. Third D. Greater than 3

4. Family size |__|_|

5. Address (region)

A. AA B. Oromia C. Amhara D. SSNPR E. Others (specify) _____

6. Religion:

A. Orthodox Christian B. Muslim C. Protestant D. Catholic E. Other (specify)_____

7. Child’s level of education

A. Nursery B. Primary school (grades 1-8)

C. Secondary school (grades 9-12)

8. Did a child repeat a grade?

A. Never repeated a grade B. Repeated a grade

Part II–Family and Primary caregivers’ information

1. Who is/are the primary caregiver?

- A. Mother
- B. Father
- C. Both parents
- D. Adult relative
- E. Non relative adult
- F. Orphanage
- G. Other (specify) _____

2. If in the above question, the parents are the caregivers, what is the marital status of parents?

- A. Single parent
 - B. Married
 - C. Divorced
 - D. Widowed (specify the deceased)
- _____

3. Primary caregiver's highest level of education

- A. <High school
- B. High school
- C >High school

4. Primary caregiver's occupation _____ and Monthly income(Birr)_____

5. Monthly income (as perceived by primary care giver to support the family):

- A. Partially Adequate income
- B. Inadequate income

Part III – seizure related information of the child or adolescent

1. Age at onset of seizure diagnosis (in years) _____

2. Total duration of seizure (in years) _____

3. seizure type: (more than one answer is possible)

A. Focal onset

- 1.1- Focal Clonic
- 1.2- Focal Tonic
- 1.3- Focal Myoclonic
- 1.4- Focal With Impaired Awareness (Complex Partial Seizure)
- 1.5- Focal To Bilateral Tonic Clonic
- 1.6- Other(Specify)

B. Generalized onset

2.1- Tonic Clonic

2.2- Tonic

2.3- Clonic

2.4- Myoclonic

2.5- Atonic

2.6- Typical Absence

2.7- Atypical Absence

2.8- Other (Specify)

C. Unknown onset (specify)

D. Unclassified

4. Seizure frequency(average in the past 6 months)

A. ≤ 1 /month

B. >1 /month

5. Type of therapy:

A. Monotherapy

B. Monotherapy with side effects,

C. Polytherapy

D. Polytherapy with side effects

6. Any known psychiatric disorders or history of other diseases or medications on medical cards _____

7. Was the seizure symptomatic?, specify _____

A. Yes

B. No

8. Seizure control

A. Complete seizure control B. Partial seizure control C. Poor seizure control D. Not documented

Part IV –The information concerning school

- 1- Did the patient ever miss a school day because of the seizures? A.
Yes (number of days missed school in past 6 months) _____ B. No
- 2- If the above answer is yes, why? (More than one reason is possible)
- A. Had a seizure before going to school
 - B. Had a seizure at school and needed to go home.
 - C. Had a medical appointment.
 - D. Had a test (EEG, blood work, MRI) scheduled?
 - E. Other(specify)
3. Did he/she ever have a seizure at school? A. Yes B. No
4. If yes to Q3, did he/she go home before the end of classes? A. Yes B. No
5. Do you think that if the child has a brief seizure at school he/she should go home immediately, or he/she can go back to his/her activities after recovering from the post-ictal period?
- A. Should go home immediately.
 - B. Can stay at school if he/she is feeling well.
- 6- Did any teacher show apprehension regarding the diagnosis of epilepsy to guardians?
A. Yes B. No
- 7- If yes, what type of apprehension?
- A. Fear of not being able to assist the child if he/she had a seizure.
 - B. Fear of decline in school performance.
 - C. Fear that the patient could disturb the other children during the classes.
 - D. Other.
- 8- Did any teacher suggest that the child should be kept at home because of seizures?
A. Yes B. No
- 9- Did you ever allow your child to miss a day of school even if he/she is not sick?
A. Yes B. No
- 10- If yes, why?
- A. Fear that he/she might have a seizure at school.

B. No particular reason, after all he/she is been through, he/she deserves to stay at home once in a while.

C. Other.

11- If you have another son/daughter, did he/she ever have to miss a school day due to his/her brother/ sister's seizures?

A. Yes

B. No

Part V –Did guardians disclose epilepsy status of a child to teacher or peer?

1. Teacher A. Yes B. No

2. Peer A. Yes B. No

Data collector information

Name: _____

Signature: _____

Date: _____