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ORIGINAL ARTICLE

STANDARDIZATION OF EPILEPSY EDUCATIONAL MANUALS FOR ETHIOPIAN STUDENTS, MOTHERS AND TEACHERS

Seid Ali Gugssa

ABSTRACT

Introduction: *Epilepsy stigma and treatment gap is enormous in Ethiopia. Epilepsy resolution of the world health assembly calls for coordinated country wide action on the health, social and public knowledge. Effective epilepsy education should target to empower people with epilepsy, create school-based awareness and cascade public education campaign. These emphases the need to develop innovative, collaboratively, linguistically and culturally appropriate community epilepsy education manuals tailored to the needs of the target population.*
Objective: *To develop and standardize epilepsy education manuals for use by mothers and primary students, and to teachers and health extension workers in Ethiopia.*
Methods: *Collaborative framework design and processes, using the principles of Experience- based co-design, was implemented to improve the quality of the draft epilepsy education manuals.*
Results: *The overall feedback from experts and stakeholders was very positive. Students, teachers and parents who had participated in the focused group discussion reported a positive view of the epilepsy education manuals. The feedback from the study participants were used to develop optimized epilepsy educational manuals for "students and mothers" and "teachers and health extension workers".*
Conclusions: *The applied experience-based framework design identified the strengths and weaknesses of the draft epilepsy education manuals. This design allowed experts and stakeholders to identify improvement priorities and to formulate and employ changes on the draft epilepsy education manuals. Follow-up pilot and large-scale implementation trails will clarify the potential of the educational manuals to alleviate epilepsy stigma and treatment gap in Ethiopia.*
Key words*: Standardization, Epilepsy Toolkit. Ethiopia*

INTRODUCTION

Epilepsy is common and considered low priority in many low- and middle-income countries. Epilepsy care in these countries is hindered by limited access to health care facilities, severe shortage of appropriately trained staff, lack of essential antiepileptic drugs, and societal ignorance and misconception.(1,2)

The World Health Organization (WHO) in its WHA68.20 epilepsy resolution emphasized the need to strengthen health system, train non-specialist health care providers, ensure availability of essential antiepileptic drugs and launch public epilepsy awareness campaign to reduced epilepsy treatment gap and societal misconceptions (3).

Community epilepsy education should be appropriate to health literacy of patients, linguistically and culturally appropriate, locally focused, easily accessible, closely linked with epilepsy points of care, innovative and collaborative (4).

Epilepsy in Ethiopia is blanketed by societal misconceptions, as a result majority of people with epilepsy (PWE) never receive medical treatment. Over 90% of the untreated are unaware of the existence of pharmacological epilepsy treatment.(5–11). Instead, spiritual and traditional treatments are the dominant treatment modalities (8).

Sporadic and fragmented epilepsy awareness campaigns are ineffective strategies to avert epilepsy misconception and epilepsy treatment gap in Ethiopia.(12) These emphases the need to develop innovative, collaborative, linguistically and culturally appropriate community epilepsy education material to address the needs of the target population. (4,13-15).

Children and adolescents are most affected by epilepsy in Ethiopia, (16) and considering the need for accelerated public epilepsy awareness creation (14); the investigator identified mothers and children, and teachers and health extension workers (HEW) as target audiences for community epilepsy education.

[1]Neurologist, Department of Neurology, School of Medicine, Addis Ababa University.
*Corresponding Author e-mail address: neuroeth@yahoo.com

The objective of this study is to develop and standardize epilepsy educational manual (EEM) for use by children and mothers, and to teachers and HEW.

PATIENTS ANS METHODS

Design

Intervention

The author drafted the EEM and collaborated with indigenous artist to develop the drawings for children and mothers EEM, and with international artist hired by Wisconsin University to develop EEM for teachers and HEW.

Adapting the intervention

Collaborative framework design and processes, using the principles of Experience- based co-design (EBCD), was implemented to improve the quality of the draft EEM (17).

The processes comprised two repetitive stages of an in-depth interview with expert health care providers and stakeholders; and focused group discussions (FDGs) with upper primary students, teachers, and parents.

The data collected from in depth interview and FGDs was accessible to panel of assessors to assist the author to identify improvement priorities and to formulate and employ changes. The panel of assessors comprised of senior neurologists and psychiatrist from Addis Ababa University; and neuropsychologist from Wisconsin University and child psychiatrist from Johns Hopkins University (Figure 1).

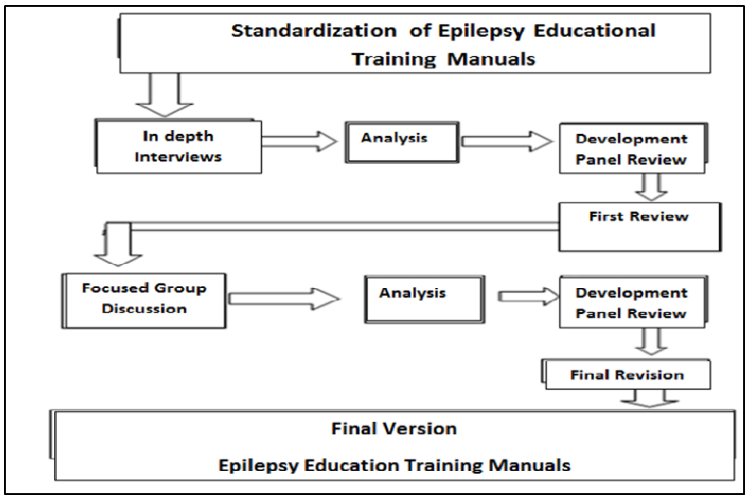

Figure 1: The standardization process of the draft epilepsy training manuals
Addis Ababa, Ethiopia 2018.

Procedure

Sage 1

Qualitative interview with health professionals and stakeholders

Purpose.

To verify the information in the draft EEM were correct and complete; to guarantee the draft EEM were appropriate to train children and mothers, and teachers and HEW.

Recruitment

Study participants were purposively selected from relevant departments of College of Health Sciences (CHS) & faculty of law of Addis Ababa University (AAU), Ministry of Health (MoH), Ministry of Education (MoE), CareEpilepsy Ethiopia (epilepsy patients' society), former president of Ethiopian Medical Association (EMA) and the media.

Process

Process Justification: Study participants reviewed the draft EEM to determine whether: the information was accurate, simple and understandable; culturally and linguistically appropriate; and EEM meet the standards of epilepsy training manuals.

Process Task: After study participants had reviewed the draft EEM for two weeks, data was collected via semi-structured audio recorded face to face interview.

Process Outcome: The interviewees gave feedback on i) accuracy and adequacy of information ii) potential to bring change in knowledge, iii) ways of maximizing benefit, v) the best implementation strategies and vi) weakness and strengths of the draft EEM.

Analysis
The audio-recorded interviews were transcribed word for word and imported to qualitative data analysis software (ATLAS Ti.7). The data was organized into different data types and sources to code and cross-reference the data within and across individuals. The codes were then grouped into themes.

Sage 2
FGDs with parents, teachers and upper primary students
A total of eight FGDs were held: three with parents, two with teachers and three with upper primary students. Each FGD lasted for 60 to 90 minutes.

Purpose
To verify the amended EEM addressed what users had been calling for, and to ensure the amended EEM were acceptable to the norms and values of the target population.

Recruitment
The FGDs were clustered in three purposively selected primary schools: two governmental primary schools (Bethel and March 8 located in Kolfe-Keranio and Bole sub-cities of Addis Ababa respectively); and one private primary school (Daliyah Youth Academy located in Kolfe-Keranio sub-city of Addis Ababa.) The school principals in each school identified and invited FGD participant students, teachers and parents.

Process
Process Task: FDGs were held after the views and comments of experts and stakeholders were incorporated and the EEM amended. A comparative and international education doctoral fellow delivered the course using case vignettes, illustrative diagrams, and PowerPoint slides. The course was categorized into different lessons, and the principal investigator monitored FDG participants' engagement with the course materials, group members and facilitator. Finally, the participants gave feedback on the course content and implantation strategies.

***Process outcome*:** FDG participants gave feedback on i) relevance and cultural appropriateness of stories and arts ii) clarity, flow and content of the story iii) best means of implementations, and iv) weakness and strengths of the amended EEM.

***Analysis*:** The audio-recorded interviews were transcribed word for word and imported to ATLAS Ti.7. The data was organized into different data types and sources to code and cross-reference the data within and across individuals. The codes were then grouped into themes.

Ethical consideration and data safety: The Institutional Review Board of the CHS of AAU approved the study (study protocol #049/17/Neuro). Data was collected from the study participants who consented to participate in the study from May to June 2018. The data was assigned a code, kept in a secured file, and entered in a password protected electronic database.

RESULTS

Participants
Expert Health Professionals and Epilepsy Stakeholders
A total of 12 expert health care providers and stakeholders were recruited for in depth interview. Seven were expert health care providers: 4 neurologists, 1 psychiatrist, 1 public health specialist in anthropology and epidemiology, and 1 former president of Ethiopian Medical Association. Five were stakeholder participants: 1 mental health officer at MoH, 1 curriculum adviser to MoE, founder of CareEpilepsy Ethiopia, 1 Journalist & Activist who works for Duestch-Welle Radio Amharic Services and Weyet Magazine, and 1 human right doctoral fellow at AAU.

Service users
A total of 50 FGD participants were recruited from 3 purposively selected primary schools in Addis Ababa: 22 upper primary students in grades 5-6 and 7-8 (9 M/ 13 F), 17 parents (5 M/12 F), and 11 teachers (6 M/ 5 F.)

Feedback
Expert Health Professionals and Epilepsy Stakeholders
Experts and stakeholders' comments were categorized into three areas: initial impression, identified major areas of change, and course delivery and implementation.

Initial Impression
Overall, the interview participants rated the children and mothers EEM very useful and important initial step. They appreciated the novelty of approach, simplistic story presentation and illustrative diagrams (Tables 1).

Table 1: Initial impression themes and illustrative quotes: views from expert health professionals and stakeholders, Addis Ababa, Ethiopia 2018.

Area	Theme	Illustrative quotes
Initial impression	Misconception	"QU 9:12 Actually the material has addressed the most important issues. Especially the traditional healer story has addressed the major misconception."
	Innovative	"QU: 3:41 What makes this intervention special is that it is a school-based intervention. The material is prepared for school children. This is what I like most. It is very creative..."
	Impact	"QU: 22:1 I absolutely agree that it is problem-solving. I appreciate the initiative. Epilepsy prevails in every school. Addressing school children is brilliant." "QU: 19:12 When I read this material, I was shocked that I let him ride a bike. This training material can change a lot of attitudes like this…"
	Adequacy of the information	"QU: 6:9 I like the material. It includes lots of facts: epilepsy definition, misconceptions, wrong practices, symptoms, treatment issues, first aid measures… It gives the full picture. The way it is presented is suspense and attractive. I finished reading it in few minutes (smiles…)"

Identified major areas of change

***Sexism*:** Reviewers reprimanded the case vignettes and illustrative drawings as portraits of female prejudice and promoters of male chauvinism. *"Qu: 19:9 … I want to comment about sexism. When we create awareness, we should not introduce a problem."*

***Isolationism and protectionism*:** The society encourages passive health communication. Parents follow similar suite and entertain absolute power over their sick child that favours religious and traditional treatment over medical treatment.

***Bullying*:** The reviewers depict peer victimization, harassment, and mistreatment as common practice. They urged including peer discrimination and stigma in the EEM.

Level of the materials: The reviewers commented to lower the level and omit some contents. *"QU: 9:27 the discussion under non-epileptic spells is confusing even for health professionals. I would remove that section to avoid misguiding the learners."*

***Format and structure*:** Many were confused about the purpose of teachers and health extension workers EEM. *"QU: 4:25 what is this material for? Is it job aid, supportive document or is it a training manual? I don't understand the intention of this material* (Table 2)*."*

Course delivery and implementation

R*eviewers u*niversally agreed to implement the EEM at primary school and to translate it into local languages. *"QU: 22:3 ….translation of the training material to a local language is mandatory. I am a true believer of mother tongue education..."*

Almost all reviewers suggested that the EEM should be owned by governmental institutions to ensure accessibility. The best middle ground suggestion was, "*QU: 22:3 the education and health sector intersect in this intervention ….both Ministries should cooperatively lead the intervention…"*

Role-play dramas, cartoon film, group discussion and storytelling were the suggested implementation strategies. *"QU: 22:5 … but for Ethiopia, it is important to know how much the curriculum is loaded and the required resources to incorporate the EEM into the curriculum. It is wise to start as a co-curricular activity …"*

Service users

Comment accommodation

Experts and stakeholders' comments were accommodated in the EEM scripts, case vignettes and illustrative drawings.

Table 2: Needed change themes and illustrative quotes: views from expert health professionals and stakeholders, Addis Ababa, Ethiopia 2018.

Theme	Illustrative Quotations
Sexism	"QU: 16:10 Hmm, Ha-Ha-Ha.., I don't know if it is me or if it is consensus… The examples and stories are a bit sexist. You know it is up to us to teach the society. Instead of saying the boy likes to play football and the girl likes to help her mom, I would rather say, 'They like to play and help their parents. Hmm… I don't know if it is me… Hmm"
Omission of cast lists	"QU: 19:15 The public education must include the issue of peer discrimination and stigma. For example the classmates of my nephew will call him by name and then jerk and shake mimicking his fits … Bullying is a big deal among school children. So this has to be addressed. They have to be supportive." "QU: 23:1 …… Ethiopian patients are not involved in health communication, especially when she/he is a child. No one asks them about their illness instead parents respond for them. This same thing has happened in this story. It revolves around parents than the epileptic children. I guess, 'I know this because I am an epileptic.' "
Omission of major malpractices	"QU: 19:12 the problem related to traditional healers or religious institutions doesn't necessarily have to be about physical injuries. Most parents keep their epileptic child at home 'to protect him/her from harm.' They don't take them to clinics instead they take them to church or holly water treatment."
Level of the material	"QU: 3:19 I have concern on the level of the material for teachers/HEW. Even after translated to a local language, I believe the facts mentioned thereof are very difficult to understand. There is a saying, 'When you plan a community awareness creation, plan to meet the level of a grade 6 student.' "
Format and Structure	"Q: 22:2 I read two materials… I am not sure about the purpose of each material. I mean, what are the competencies at the end of the training? This is not clear. If these are training manuals, the purposes and expected outcomes should be clearly stated." "QU: 6:21 the training manual preparation protocol has to be followed…. Content outline, objective and justification… timetable, trainee selection criteria, teaching methods, stakeholders responsibilities, and expectations and outcomes are not clearly stated… That's my observation."

Parents

Before training

Parents identified tonsillitis, epistaxis, flue, stomachaches and fainting illnesses as school health problems. *"QU: 15:8 … She faints frequently and awakens after sometime. Students with heart cases have tiredness, fast heartbeat, sweating, and unconsciousness."* Parents associated fainting with evil spirit, diabetes, hunger and heart disease. Commonly cited interventions were prayer, Holy water, soft drinks and smelling match smoke. *"QU: 15:17 … It is evil spirit because prayer and holy water makes them better…"*

After Training

Parents had extremely positive impression about the EEM. The training had brought change in their knowledge, attitude and practice. *"QU: 12: 33 Earlier I said, 'Epilepsy is evil spirit.' Now, I know it is a medical condition…"* They ranked the EEM excellent and suggested making it available to rural community, teachers, health professionals, traditional healers and mothers. *"QU: 15:32 … The pictorial presentation is attention-grabbing…translate it into different languages..."*

Teachers

Before training

Teachers identified fainting disease as the most difficult to handle. *"QU: 18:20 fainting is common at schools. "Arefa" or bubbles of saliva come out of their mouth."* Teachers think fainting to be caused by evil spirit, diabetes, hunger and heart disease. Commonly cited intervention were prayer, Holy water, soft drinks and smelling match smoke. *"QU: 18 23 …when she collapses, she always talks to someone invisible... to evil spirit. That is why we let them go to holy water."*

After Training

Teachers had extremely positive impression about the EEM. The training brought change to their knowledge, attitude and practice. *"QU17: 24 epileptic children can cope up with normal school environment. I used to believe it was necessary to send them to special school…"*

They ranked the training as good and suggested making it available to rural community, teachers, health professionals and mothers. *"QU: 18:40 it should be prepared in local languages and distributed to different schools ..."*

Students

Before training

Students were aware of 'fainting disease' before training. *"QU: 14:35 I saw a man fainting… shaking and saliva coming out of his mouth … They said, 'this is diabetes.' … He was then taken to a hospital and the doctor said, 'He is epileptic.' "* The students associated fainting to evil spirit, Diabetes, and hunger. Commonly cited interventions were prayer, Holy water, soft drinks and smelling match smoke. *"QU: 14:40 … When we recite the Quran on them, they get better… so it is spirit."*

After Training

Students had extremely positive impression about the EEM. *"QU14: 50 … one person can make a difference. … We can change our families and classmates... Earlier I said, 'Smelling match smoke could be the solution for epilepsy.' … But now, I have changed my mind ..."*

Students suggested the EEM to reach to teachers, rural community dwellers and traditional healers. *"QU: 13:52 … teachers mostly use water, sugar or soft drinks as first aid. …that is because they don't know about epilepsy."*

DISCUSSION

The applied experience-based framework design identified the strengths and weaknesses of the draft EEM. This design allowed experts and stakeholders to identify improvement priorities and to formulate and employ changes on the EEM. The FGDs reaffirmed the potentials of the EEM to bring the intended behavioural change among target audiences. The EEM were applauded for their cultural appropriateness, simplicity, novelty and problem-solving potential.

The objectives of EEM align with Article 4 of the United Nations Committee on the Rights of Persons with Disabilities (CRPD) that states people with disability are entitled to the full realization of human rights and fundamental freedoms without any kind of discrimination; and with Article 8 that urges governments to take speedy, real and suitable measures to educate the public in order to alleviate stigma and related practices to persons with disability(18)

Successful public epilepsy education awareness program should engage all stakeholders. (19) The Experience- based co-design processes engaged stakeholders from AAU, MoH, *CareEpilepsy Ethiopia* (epilepsy patients' society of Ethiopia),MoE, human rights expert and EMA and the media. *"RQU:22:18 study conducted by the African Child Policy Forum in Ethiopia revealed ….where there was disabled people's organizations support, community leaders reported positive attitudinal changes throughout their communities."* (20).

The principles of experience- based co-design identified strengths and weaknesses of the EEM and allowed experts and stakeholders to identify improvement priorities and to formulate and employ changes. The experts correctly identified major areas of needed changes to the EEM: sexism, omissions of cast lists and omission of major malpractices that are commonplace in Ethiopia. *"RQU: 22:9: … Surveys conducted in Cameroon, Ethiopia, Senegal, Uganda and Zambia disclosed that 38% of respondent caregivers of children with disabilities reported hiding them away, or forbidding them to take part in social activities owing to stigma or in order to protect them from perceptions of stigmas. ... For example, fear and ignorance about the causes of epilepsy can result in exclusion from school for children with seizure disorders."* (20).

The EEM shares the values recommended in the fight against epilepsy stigma: empowering PWE, sensitizing and educating the public, designing school based interventions, undertaking law and policy reforms, active reporting of human rights violation against PWE, and making integrated epilepsy treatment affordable and accessible(3,12-15,21).

Challenges for scaling-up neuropsychiatric care in Ethiopia include lack of proper documentation, lack of properly trained health professionals, shortages of essential drugs and low level public literacy (22). The optimized EEM is hoped to cascade public epilepsy education program in two arms: to health extension workers, community health practitioners, and mothers; and to teachers and primary school students (Figure 2). Follow-up pilot and large-scale implementation trails as proposed will help clarify the potential of the EEM to alleviate epilepsy misconception and treatment gap in Ethiopia.

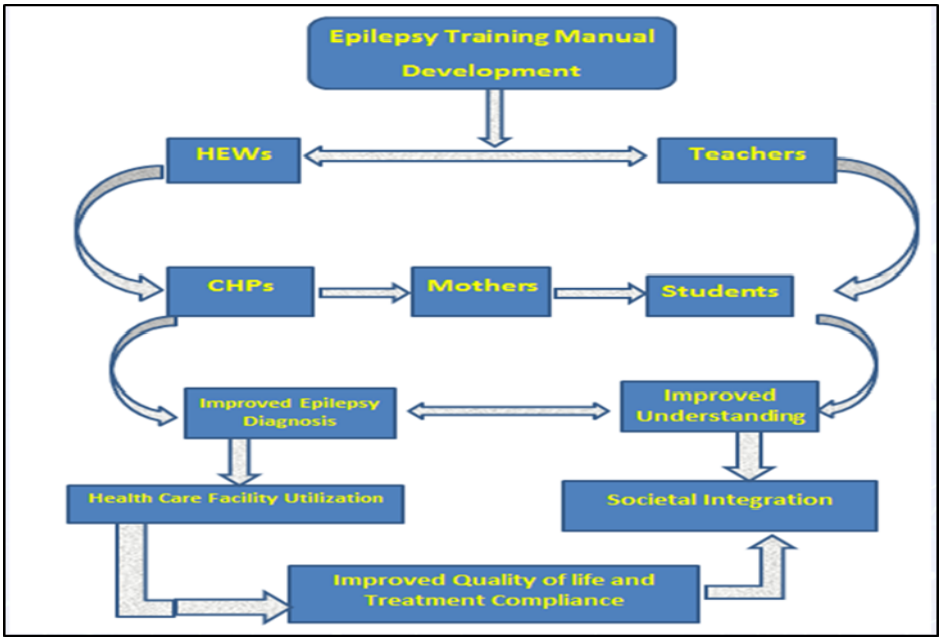

Figure 2: Conceptual model depicting how health education will cascade in the community and impact epilepsy treatment gap and stigma, 2018.

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Competing Interest

The author declare that this manuscript was approved in its current form and that no competing interest exists.

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