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Improving pediatric epilepsy care at the first level of care: A pilot education intervention for clinical officers in Zambia

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Archana A. Patel was the principle investigator for this project, designed the project, obtained funding and ethical approval, helped develop the training the materials for the intervention and deliver the intervention, and development of the manuscript.

Ornella Ciccone is the co-principle investigator and contributed significantly to project design and development, coordinated with local teams in Zambia, development of the training materials and also deliver the intervention, and significantly edited and shaped the manuscript development.

Leah Wibecan is a research assistant who helped in data collection and analysis, as well as development and edits of the manuscript.

Owen Tembo is a research assistant who helped in development of training materials and data collection.

Prisca Kalyelye is a research assistant who helped in project coordination on site.

Manoj Mathew helped with local coordination and partnership development in Zambia, project development, and edits to the manuscript.

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Abstract:

Objective: Epilepsy affects over 70 million people globally, with approximately 80% living in low and middle income countries (LMIC), where access to appropriate care is limited. In these regions, paramedical providers provide the majority of neurologic care due to a shortage of specialists, however they often have limited knowledge about epilepsy management. Training of such providers is, therefore, an essential component to closing the epilepsy treatment gap in these regions.

Setting: In Zambia, the vast majority of healthcare is provided by clinical officers (COs), primary health providers with three years post-secondary general medical education, and is delivered in first level health centers around the country.

Participants: With cooperation from the Ministry of Health, a total of ten COs from 4 surrounding first level health centers around Lusaka participated, with 9 completing the entire course.

Intervention: Recognizing the limitations of pediatric epilepsy knowledge amongst these providers, a structured 3 week course on pediatric seizures and epilepsy, utilizing adapted evidenced based guidelines.

Results: A pre- and post- assessment was conducted to assess the intervention. Following the course, there was improved overall knowledge about epilepsy (69% vs. 81% correct, $p<0.05$), specifically knowledge regarding medication management and recognition of focal seizures ($p<0.05$), improved seizure history taking, and appropriate medication titration ($p<0.05$). However, knowledge regarding provoked seizures, use of diagnostic studies, and general etiologies of epilepsy remained limited.

Conclusions:

This pilot project demonstrated that a focused pediatric epilepsy training program for COs can improve knowledge and confidence in management, and as such is a promising step for improving the large epilepsy treatment gap in children in Zambia. However, the program also demonstrated a need for additional clinical preceptorship and case based training with more repetition of key concepts. Future studies including this, as well as assessments for long term retention are needed.

Strengths and limitations of this study:

- Demonstrates an effective strategy for training first line providers with limited education on effective pediatric epilepsy management
- Provides a model for a feasible training strategy built with partnership within the healthcare system in the country, including the main academic tertiary center and ministry of health, in order to create a sustainable referral system
- As a pilot project, the study was limited in size and scope, and only tested immediate improvement after training with modest effects seen
- Long-term retention was not measured in this project and needs to be assessed in future studies
- Direct impact on patient care practices were not measured

Introduction:

Approximately 70 million people around the world are affected by epilepsy[1], including 0.5-1% of children[2], and out of this population, an estimated 80% are living in the developing world[1 3 4]. While limited epidemiologic data exists from Zambia regarding the prevalence of epilepsy, the available data estimates that the prevalence is as high as 14.6 per 1000 in comparison to 5.8 per 1000 in high income countries (HIC)[5]. Of note, in Africa, epilepsy prevalence studies typically focus on active convulsive epilepsy alone and therefore likely significantly underestimate the true burden. In these same regions, the epilepsy treatment gap- estimated as the percentage of people who are not accessing medical care or on appropriate medication- is estimated to be 70% -80% in most low and middle income countries (LMIC), with estimates in Zambia as high as 90%[6], compared to 10% in HIC[7-9]. Multiple factors contribute to the treatment gap, including geographic barriers to care, misperceptions about treatment and stigma of epilepsy, as well as concern for costs of medications[3 10]. Also contributing is the limited availability of specialist providers and lack of knowledge for epilepsy management amongst the first line nurses, community health workers, and clinical officers who often see these patients[3].

Around the world, and in particular in sub Saharan Africa, the burden of the disorder is enormous. Epilepsy has been estimated to contribute 0.7% to the total global burden of disease[11], and in sub Saharan Africa epilepsy caused 200-250 per 100,000 disability adjusted life years in 2004[12]. Children are more vulnerable, particularly in Africa, with the incidence of epilepsy among children estimated at about 187 per 100,000 per year in this population[13]. In the United States, in children, a delay in treatment of greater than one month was found to lead to a drop in IQ and processing speed[14]. Studies from Zambia have demonstrated that children with epilepsy have fewer educational opportunities, poorer nutrition, and lower socioeconomic status than other children in the country, as well as higher risk of being abused[15 16].

This high impact of the disorder is more disconcerting given that epilepsy is a very treatable condition. With appropriate treatment, up to 70% of individuals with epilepsy have the potential for good seizure control on antiepileptic therapy, including the most common ones available in LMIC, such as phenobarbital, carbamazepine, sodium valproate, and phenytoin[3]. It is economically feasible, as demonstrated by a study out of Zambia in 2012, where it was estimated that the cost of treating epilepsy at the primary provider level was 13.58–18.81USD annually, and that epilepsy training programs would cost an additional 25USD or less per person annually[6].

There is a significant shortage of child neurologists in the world, with increased disparity in LMIC and rural regions. The most recent data from the World Health Organization reports that there are less than 0.4 per 100,000 child neurologists globally, with 0.02 per 100,000 in LMIC and 97% of neurologists located in urban areas globally[17]. In these same regions, up to 91% of neurologic care is provided by paramedical providers who have variable education regarding neurologic disorders[17]. This includes nurses, community

health workers, and clinical officers: primary care providers with three years of post-secondary school general medical education. While this model of task-shifting to paramedical providers is a common one used in lower resource regions and in particular across sub Saharan Africa to deliver health care, there exist significant concerns about these providers' ability to appropriately recognize and manage neurologic conditions due to limited training. A study out of Zambia highlighted this problem, demonstrating that irrespective of the volume of people with epilepsy that primary health care workers had seen in the previous three months, less than 40% correctly identified epilepsy as a brain disorder, and the majority had less than adequate knowledge about seizure management[18].

With so few child neurologists available in LMIC, however, primary health providers are necessary to closing the epilepsy treatment gap. In Zambia, there are currently no Zambian child neurologists and specialist care is provided by either the sole non-Zambian child neurology provider residing in the country or visiting child neurologists traveling annually to the region. Thus, neurologic care for children in this country remains significantly limited in both number and geography, as the care remains isolated to the tertiary care facilities in the country, predominantly based in the capital city of Lusaka. Overall, even with prospect of future training of child neurologists, it is insufficient for providing care amongst this country of approximately 16.5 million people, of which nearly 50% is under the age of 15[19]. Therefore, improving care at the primary care level across the nation is essential.

Shifting specialized care to the level of the primary health provider in regions of limited specialists with specific algorithmic and module based training programs has long been recognized as a necessary and effective strategy in LMIC, given the widescale nature of the problem and limited resources available [4 12 20 21]. Examples of such programs for active convulsive epilepsy have been shown successful in various regions of the world, including Kenya, where a 10% reduction in the epilepsy training gap was seen through a community education program[22], and in Zimbabwe, where a program for education of community health workers significantly improved care seeking and compliance amongst people with epilepsy[23].

Notably, however, such education programs in epilepsy typically focus on a broad approach toward convulsive epilepsy, without any specific focus on children or the significant portion of more subtle epilepsies that can impact a child's development. Therefore, in an effort to address this continued gap of care and unique needs of children with seizures in low resource regions, we developed an educational program aimed at COs in Zambia, focusing specifically on pediatric epilepsy. This pilot project aimed to identify the necessary components for such a program, assess feasibility and interest, and demonstrate effectiveness in improving knowledge and comfort of providers in management of children with seizures and epilepsy.

Methods:

Four first level health centers (Chipata First Level Hospital, Mandevu Primary Health Centre, Matero First Level Hospital, and Chilenje First Level Hospital) were identified for participation in the epilepsy education program by local pediatricians affiliated with the Ministry of Health at the main referral hospital in the region (University Teaching Hospital) and in primary health facilities. First level health centres were identified as feasible implementation sites for this pilot project based upon population of children with epilepsy seen, proximity and ability to refer to the University Teaching Hospital, and capacity to commit to the training. The government supported health care delivery system in Zambia is structured across first, second, and third level health centers which provide the vast majority of care to Zambians due to high cost of private medical centers. First level health centers provide community-level health services and are the most abundant across the nation. They provide the majority of initial care to people as second level centers are rare and tertiary centers are where specialist care is provided with few available and limited access exiting as a result, predominantly due to geographic barriers. Per the 2017 Central Statistics Office of Zambia, the catchment population of the participating health centers ranged from 412,500-451,000, all located approximately 5-7.5 kilometers from the central business district of Lusaka, and all providing care to people with epilepsy, but none having a current dedicated epilepsy or neurology clinic.

Visits to each recommended clinic were made for further assessment of provider interest, availability, and willingness and ability to commit to the training before selecting these locations. COs at each site were then selected by clinic supervisors, based upon interest, likelihood that they would remain at their post within that center for at least one year, and ability to commit to the training. Gender and age did not play a role in selection. Despite concerns we had about the proposed length of training and requirement for the COs to leave their respective clinics for 3 days per week for 3 weeks, there was no difficulty in obtaining approval due to the strong interest of the health centers and ministry of health in our training program[24].

The training was conducted over a 3-week period by two board-certified pediatric neurologists (OC and AAP,) during which time six modules were delivered. Each module was delivered on two separate days, allowing each CO two opportunities to attend the session, in order to maximize completion rates. Out of the ten COs who participated, nine completed the entirety of the training. The objectives of the training were to improve provider knowledge about pediatric epilepsy in order to improve timeliness of management and utilization or health care resources, with the ultimate goal of improving patient outcomes (figure 1).

The teaching materials for this course were drawn from established national and international guidelines and resources, including World Health Organization and International League Against Epilepsy materials, and were adapted for the management of children in Zambia[25 26]. All materials were designed to provide a reasonable knowledge base for the level of a non-specialist provider, with focus on practical application in

the primary level setting. All materials were developed by two child neurologists with additional expertise in epilepsy and experience in Zambia (OC, AAP) and additionally reviewed and edited to be appropriate for the level of a CO education by a trained CO working in our pediatric epilepsy clinic in Zambia (OT).

The 6 educational modules included the following:
Module 1: Basic neuroanatomy, seizure pathophysiology; Epidemiology of seizures/epilepsy in children with epilepsy (CWE) in sub Saharan Africa
Module 2: Basic pediatric neurology history and physical exam
Module 3: Seizure semiology; Other paroxysmal events that can mimic seizures in children
Module 4: Diagnosis and Management of acute/provoked seizures, status epilepticus and first time unprovoked seizures
Module 5: Diagnosis and Management of Epilepsy in children; Basics of childhood epilepsy syndromes
Module 6: Follow up of CWE; Comorbid conditions in CWE, Psychosocial impact of epilepsy

In addition to the formal training modules, open case discussions were held, without any patient identifiers, to encourage practical application of the education. After completion of post-assessments, one of the child neurologists (AAP) visited each clinic where pairs of the COs (6/9) were observed during a patient session to see direct implementation of the training in practice. During these observed sessions, continued guidance and management was provided as each case was reviewed directly. These sessions were not objectively reviewed for assessment of training, but rather utilized for feedback of identifying strengths and weaknesses of the training program for future iterations.

Prior to initiation of training, pre-test knowledge and confidence assessments were provided to each CO. This assessment, based off of the established teaching materials and guidelines, included questions about the medical basis of seizures/epilepsy, identifying different types of seizures common in children, appropriate antiepileptic medication selection for epilepsy, and other common management decisions in caring for children with epilepsy. The assessment also included an evaluation of participants' comfort level with various aspects of treating epilepsy, rated on a 10-point scale. The same knowledge and confidence assessments were performed at the end of the 3 weeks to assess for the impact of the training. This data was analyzed using Stata 14 software, and t-tests were used to compare pre- and post-intervention scores. The methodology for this quality improvement project follow SQUIRE guidelines[27].

Patient and Public Involvement:
No patients were directly involved in this study.
Ethical approval was obtained through the Boston Children's Hospital Institutional Review Board and University of Zambia Biomedical Research Ethics Committee.

Results:
A total of 9 COs completed the training intervention, including pre- and post- knowledge and comfort assessments. The participating COs ranged on average in age from early 20s-early 30s, with one participant in their later 30s. There were 6 female and 4 males initially enrolled with one male not completing the program.

Knowledge assessment results are depicted in Table 1. All participants were familiar with the neurological basis of epilepsy and were able to define epilepsy as having at least two unprovoked seizures. Participants were reliably able to identify generalized tonic-clonic, myoclonic, and absence seizures as representing seizures both prior to and following training. Overall, there was a significant difference in knowledge scores between the pre- and post-intervention assessments, with participants answering 68.8% of multiple-choice questions correctly prior to training, compared to 80.6% correct following training ($p < 0.001$).

While only five (50%) participants were able to identify a focal seizure with altered awareness prior to training, 100% were able to identify these symptoms as representing a focal onset seizure following training ($p = 0.015$). Prior to training, 60% of participants correctly indicated that they would increase the dose of anti-seizure medication in order to reach therapeutic effect; following training 100% of participants answered correctly ($p = 0.037$).

In addition, although not statistically significant in the small sample size, there was a notable trend of improvement in selecting an appropriate antiepileptic based upon seizure description, with a correct response rate improvement from 40% to 80% for using carbamazepine as first choice for focal seizures and 50% - 70% for using sodium valproate first for generalized seizures (presented in clinical scenarios in which these were best first-line options). In addition, most (90%) participants were unfamiliar with the treatment of infantile spasms with prednisolone (first-line treatment in Zambia), with a 20% improvement after training.

Both prior to and following training, about half of participants could not correctly identify that neither imaging nor medication is necessary for a simple febrile seizure. In addition , we did find that 80% of participants correctly recommended to obtain imaging after a febrile seizure with focality prior to training, yet following training, just 20% responded correctly ($p = 0.005$), despite clear review of guidelines in the course.

In both the pre- and post-training assessments, almost all participants responded that they believed epilepsy is not contagious and recognized it as a medical condition, and reported that individuals with epilepsy can attend school, work, and have children.

In the confidence assessments (Table 2), there were significant increases in participant comfort with most aspects of management, particularly in taking a history to identify characteristics of seizures (p=0.0145), knowing when to prescribe medication (p=0.0024), selecting which medication to use (p=0.000), changing medications (p = 0.0009), treating status epilepticus (p=0.0013), providing guidance about side effects (p=0.0003), answering caregivers' questions (p=0.0114), and providing safety guidance (p=0.0018). Comfort with the identification of causes of seizures was reported as still limited, and participants reported that they desired more knowledge about epilepsy, both theoretical as well as practical application, continuing to express the lack of neurologic education exposure that they received in general. ***Data collected during this study is represented in the two tables presented here; no additional data is available.***

Discussion:

The epilepsy treatment gap in LMIC is estimated at 75%, compared to 10% in HIC[9], yet there is a dearth of specialists available in these regions to help address the need. The lack of neurology providers means there is a lack of neurology education throughout the medical system and within communities, compounding misinformation, misperceptions of the disorder being untreatable, and other associated stigma, all which is further expanding the gap instead of closing it. Education of first line providers has been shown as an effective method of not only improving care, but also health seeking behaviors and awareness in communities, as well as reduction of stigma[4 7 8 28]. In Zambia, where the epilepsy treatment gap remains as high as 90% in some rural regions[6], and the accessibility of specialists is extremely limited, this is an important strategy to consider as an option for expanding care.

Our pilot education program for pediatric epilepsy in Zambia demonstrated feasibility of this approach in our setting. Using proven strategies from efforts in low resource regions of medical conditions traditionally managed by specialist to be shifted to the care of primary care providers, including introducing focused education and algorithmic approached[4 22 29], we demonstrated that similar methods could be utilized over more in depth and focused training in efforts to address the specific needs related to pediatric epilepsy.

Through our program, providers gained significant confidence in management of epilepsy in children, recognition of the specific impact that seizures can have on a child's development, improvement in how to optimize medications available, and learned how to conduct a proper pediatric neurology history and physical exam, in particular gaining awareness of the utility of such an assessment in identifying focality of a child's condition clinically. Furthermore, a significant interest in improving pediatric epilepsy care has

been raised throughout the participating COs, as well as their health centers and the Ministry of Health by our efforts, and strong encouragement and cooperation for future trainings has been assured.

Through both this pilot project, as well as follow-up feedback sessions from clinical officers throughout the region, certain limitations have become apparent. First, the content of the sessions were ultimately felt to be too in depth to be practical at times when tested across COs of varying levels of experience and knowledge for our purposes, despite our initial efforts in refining materials based upon existing materials for community health workers and reviewed by a clinical officer with experience in epilepsy, and frankly initial concerns of being too simplistic. We found interestingly that some COs could be trained to recognize specific seizure types and epilepsy syndromes, yet they did not gain ability to apply knowledge of more simple concepts that were crucial to care, such as recognizing provoked versus unprovoked seizures and utility of diagnostic testing based upon focal versus generalized semiology. This leads us to believe this initial training should be a focused course for base knowledge, utilizing a model of preceptored clinics, cased-based discussion, with brief lectures and focused reviews each day, so to be effective across all levels of knowledge and experience and maintain engagement and interest of all participants.

Similarly, in focusing on the pediatric history and physical exam, we found that utilizing a clear assessment tool that was simplified and captured basic exam techniques that were relevant to our purposes was more effective. We have also found that the COs struggled to implement their acquired knowledge if trained in isolation as the knowledge gap on management of seizures and epilepsy in children is a problem across providers, and inclusion of nurses and medical officers as part of an epilepsy team within the participating health centers is essential for effective implementation.

Interestingly, in assessing for any incorrect misconceptions and personal bias against those with epilepsy, objectively on our assessments we found no evidence of this even before the training. However, during open case discussions, there were clear elements of societal beliefs which persisted, including that of a diagnosis of epilepsy meaning one could no longer contribute to the family, often would not go to school, and would continue to struggle in the community. Providers were more open about sharing these concerns, even expressing that they personally held them in certain instances, when it was done in a more informal setting, leading us to believe that this data would be better ascertained from a focus group mechanism in the future.

Our pilot project had additional limitations, including the lack of objective measurement of the impact of the intervention. Due to logistical challenges, a pre- and post- chart audit was not feasible during this pilot project, however it is planned for future expansion. Chart audits in our setting are very difficult due to patients carrying their own files in many circumstances, poor documentation in general, and frequently

lost files. However, we have plans for attempting assessments of documentation of important epilepsy management indicators pre- and post- intervention during our planned expansion, as more objective measures of the impact of an education initiative is ultimately desired. In addition, assessment of retention of knowledge was not possible due to the pilot nature of this project, which was done to assess feasibility of this strategy. In future trainings, a plan for follow-up knowledge assessments and an online platform for continued education and formation of a community of epilepsy providers across the country is being developed.

An additional limitation was the fairly centralized location of the participating health centers. Due to the necessary logistics for this as a pilot project, the targeted health centers were located in the surrounding regions of Lusaka, the capital city of Zambia. These are still fairly urban regions, and despite the large need in this region, the rural areas across the nation are enormous, and expanding training across provinces with a direct link to the tertiary care center in each region will be optimal.

Finally, despite the trends of improvement that were observed, the sample size is necessarily small for an effective education strategy. Thus, only with larger scale implementation will we be able to fully assess if such a strategy can have long-standing impact. However, overall, the training was demonstrated as feasible and well received in our setting, and with incorporation of planned adjustments as noted above, can be expanded in different regions in the country.

To the best of our knowledge, ours is the first in depth training of this kind in Zambia which focuses specifically on seizures and epilepsy in children, taking in account the special needs of this population. This is unique from the majority of epilepsy education programs that primarily combine adult and pediatric populations and focus on active convulsive epilepsy alone. We argue this is an important distinction as focus on active convulsive epilepsy alone may miss a significant period of time for intervention in many children in a region where the seizures are often focal and can be subtle at onset[13], and these delays in treatment can cause significant impairments in development which may have been reducible if not preventable by appropriate early epilepsy management[14].

The Pediatric Epilepsy Training courses that have been developed by the British Paediatric Neurology Association is one exception of a training program with similar goals, and are an excellent option for short, one day courses for medical providers to improve knowledge broadly in the management of pediatric epilepsy. However, these courses are both dependent upon availability as well as are better suited for the level of medical doctors. The three levels of training are designed for providers ranging from pediatricians, pediatric nurses, and pediatric neurologists[30]. Given our experience, we feel they are potentially too advanced for the COs in our setting without any other training, as they require a base level of knowledge that we have found the COs in Zambia do not usually have. In addition, these courses are

offered in limited areas and have yet to be offered in Zambia. However, for general medical providers and in particular pediatricians in the country, they are a potential excellent option for the future.

We recognize that the training of providers in first line health centers is only one step of improving pediatric care across the country, as training at multiple levels will be required- that of paramedical providers, general medical officers, pediatricians, and ultimately training of pediatric neurologists- for a sustainable system of timely management and appropriate referrals. At the time of this manuscript, an initiative for the first training program for neurologists had just been launched in Lusaka, with two trainees enrolled for child neurology, providing new hope for the landscape of neurologic care in this country. However, efforts in training specialists will be limited in reaching the large population in need, thus targeting care improvement at all levels is required, beginning with the first line providers as we have elected to do so in this initiative.

Conclusions:

Overall, this study demonstrated that directive education on pediatric epilepsy can be effectively delivered to primary care providers in Zambia, with improved knowledge outcomes as well as greater confidence among providers in caring for epilepsy. Given the lack of specialists in the region, this type of education-based intervention targeting primary health providers may significantly improve neurologic outcomes, as these providers are involved in the earliest aspects of management of children with epilepsy. Further expansion of the training with incorporation of methods to objectively measure practice change as well as knowledge retention will be required to better assess the long-term impact of these measures and their potential effect on the epilepsy treatment gap.

KEY POINTS	
What is already known?	Training of non-specialist providers on disease-specific management is an effective method for improving care in resource limited regions and has been demonstrated in trainings for active convulsive epilepsy in this manner.
What are the new findings?	Training on pediatric epilepsy, including identification of varying seizure semiologies and impact on development, can be delivered in a similar mechanism, utilizing a more in depth approach to education.
What do the new findings imply?	Improving the management of pediatric seizures and epilepsy at the level of first level providers across Zambia could

	improve neurologic outcomes in children and reduce the epilepsy treatment gap in this country.

Figures and Tables:
Figure 1. Conceptual framework for improving quality of care and patient outcomes for children with epilepsy
Table 1: Knowledge Assessment Results
Table 2: Comfort Assessment Results

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Figure 1. Conceptual framework for improving quality of care and patient outcomes for children with epilepsy

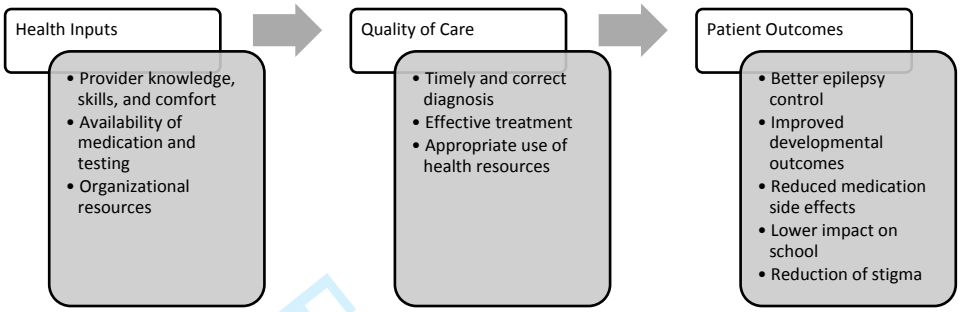

Table 1: Knowledge Assessment Results

Question	Pre-test correct	Post-test correct	p-value*
Seizures are caused by abnormal electrical activity	100%	100%	--
Epilepsy is defined as > 2 unprovoked seizures	100%	100%	--
Identifying developmental delay	90%	90%	--
Seizure first aid	70%	100%	0.0811
Identifying absence seizures	100%	100%	--
Identifying myoclonic seizures	90%	100%	0.3434
Identifying GTCs	100%	100%	--
Identifying syncope	70%	70%	--
Identifying focal seizures	50%	100%	**0.0150**
Treat focal seizures with carbamazepine	40%	80%	0.1679
Treat generalized seizures with sodium valproate	50%	70%	0.2244
Treat infantile spasms with prednisolone	10%	30%	0.3434
Increase the dose of an AED to reach therapeutic effect	60%	100%	**0.0368**
Add a second AED when a single AED is at max dose	40%	60%	0.5086
No imaging or medication for a simple febrile seizure	40%	50%	0.5911
Obtain imaging for a complex febrile seizure	80%	20%	**0.0051**
Give diazepam for status epilepticus	90%	100%	0.3434
Epilepsy is not contagious	100%	100%	--
Epilepsy cannot be caused by witchcraft	90%	100%	--
A child with epilepsy can go to school	100%	100%	--
An adult with epilepsy can go to work	100%	100%	--
Should not drive if has had a seizure recently	70%	90%	0.3434
People with epilepsy can get married and have kids	100%	100%	--

Traditional remedies can have negative effects	90%	90%	--

*Bolded values are significant to the level of $p < 0.05$

Table 2: Comfort Assessment Results

Comfort and confidence measures	Pre-test average	Post-test average	p-value*
Comfort treating children with epilepsy	5.7	7.8	0.1769
Differentiating seizures and other events	6.8	8.8	**0.0273**
Asking questions about characteristics of seizures	7.4	9.1	**0.0145**
Focal versus generalized seizures	6.2	9.3	**0.0073**
Deciding when to obtain images or tests	6.5	8.9	**0.0368**
Identifying the cause of seizures	6.2	8.3	0.1156
Knowing when to prescribe medication	6.5	9.0	**0.0024**
Selecting which medication to use	5.7	9.0	**0.0000**
Changing medication dose or adding medication	4.4	8.7	**0.0009**
Treating status epilepticus	6.4	9.3	**0.0013**
Providing guidance about side effects	5.9	8.7	**0.0003**
Answering families' questions	6.7	9.1	**0.0114**
Providing safety guidance to patients	6.8	9.8	**0.0018**

*Bolded values are significant to the level of $p < 0.05$

Revised Standards for Quality Improvement Reporting Excellence (SQUIRE 2.0)
September 15, 2015

Text Section and Item Name	Section or Item Description
Notes to authors	• The SQUIRE guidelines provide a framework for reporting new knowledge about how to improve healthcare • The SQUIRE guidelines are intended for reports that describe system level work to improve the quality, safety, and value of healthcare, and used methods to establish that observed outcomes were due to the intervention(s). • A range of approaches exists for improving healthcare. SQUIRE may be adapted for reporting any of these. • Authors should consider every SQUIRE item, but it may be inappropriate or unnecessary to include every SQUIRE element in a particular manuscript. • The SQUIRE Glossary contains definitions of many of the key words in SQUIRE. • The Explanation and Elaboration document provides specific examples of well-written SQUIRE items, and an in-depth explanation of each item. • Please cite SQUIRE when it is used to write a manuscript.
Title and Abstract	
1. Title pg 1	Indicate that the manuscript concerns an initiative to improve healthcare (broadly defined to include the quality, safety, effectiveness, patient-centeredness, timeliness, cost, efficiency, and equity of healthcare)
2. Abstract pg 3	a. Provide adequate information to aid in searching and indexing b. Summarize all key information from various sections of the text using the abstract format of the intended publication or a structured summary such as: background, local problem, methods, interventions, results, conclusions
Introduction	*Why did you start?*
3. Problem Description	Nature and significance of the local problem pg5
4. Available knowledge	Summary of what is currently known about the problem, including relevant previous studies pg 6

5. Rationale	Informal or formal frameworks, models, concepts, and/or theories used to explain the problem, any reasons or assumptions that were used to develop the intervention(s), and reasons why the intervention(s) was expected to work pg 5-6
6. Specific aims	Purpose of the project and of this report pg 6
Methods	*What did you do?*
7. Context	Contextual elements considered important at the outset of introducing the intervention(s) pg 7
8. Intervention(s)	a. Description of the intervention(s) in sufficient detail that others could reproduce it b. Specifics of the team involved in the work pg 7
9. Study of the Intervention(s)	a. Approach chosen for assessing the impact of the intervention(s) b. Approach used to establish whether the observed outcomes were due to the intervention(s) pg 9
10. Measures	a. Measures chosen for studying processes and outcomes of the intervention(s), including rationale for choosing them, their operational definitions, and their validity and reliability pg 9 b. Description of the approach to the ongoing assessment of contextual elements that contributed to the success, failure, efficiency, and cost c. Methods employed for assessing completeness and accuracy of data
11. Analysis	a. Qualitative and quantitative methods used to draw inferences from the data b. Methods for understanding variation within the data, including the effects of time as a variable
12. Ethical Considerations	Ethical aspects of implementing and studying the intervention(s) and how they were addressed, including, but not limited to, formal ethics review and potential conflict(s) of interest pg9
Results	*What did you find?*
13. Results	a. Initial steps of the intervention(s) and their evolution over time (*e.g.*, time-line diagram, flow chart, or table), including modifications made to the intervention during the project pg 9 b. Details of the process measures and outcome c. Contextual elements that interacted with the intervention(s) d. Observed associations between outcomes, interventions, and relevant contextual elements pg 9-10 e. Unintended consequences such as unexpected benefits, problems, failures, or costs associated with the intervention(s). f. Details about missing data N/A
Discussion	*What does it mean?*
14. Summary	a. Key findings, including relevance to the rationale and specific aims b. Particular strengths of the project pg 12-13

15. Interpretation	a. Nature of the association between the intervention(s) and the outcomes pg 13 b. Comparison of results with findings from other publications c. Impact of the project on people and systems pg 12, 14 d. Reasons for any differences between observed and anticipated outcomes, including the influence of context e. Costs and strategic trade-offs, including opportunity costs
16. Limitations	a. Limits to the generalizability of the work b. Factors that might have limited internal validity such as confounding, bias, or imprecision in the design, methods, measurement, or analysis c. Efforts made to minimize and adjust for limitations pg 12-13
17. Conclusions	a. Usefulness of the work pg 14-15 b. Sustainability c. Potential for spread to other contexts d. Implications for practice and for further study in the field e. Suggested next steps
Other information	
18. Funding pg 2	Sources of funding that supported this work. Role, if any, of the funding organization in the design, implementation, interpretation, and reporting

Table 2. Glossary of key terms used in SQUIRE 2.0. This Glossary provides the intended meaning of selected words and phrases as they are used in the SQUIRE 2.0 Guidelines. They may, and often do, have different meanings in other disciplines, situations, and settings.

Assumptions
Reasons for choosing the activities and tools used to bring about changes in healthcare services at the system level.

Context
Physical and sociocultural makeup of the local environment (for example, external environmental factors, organizational dynamics, collaboration, resources, leadership, and the like), and the interpretation of these factors ("sense-making") by the healthcare delivery professionals, patients, and caregivers that can affect the effectiveness and generalizability of intervention(s).

Ethical aspects
The value of system-level initiatives relative to their potential for harm, burden, and cost to the stakeholders. Potential harms particularly associated with efforts to improve the quality, safety, and value of healthcare services include opportunity costs, invasion of privacy, and staff distress resulting from disclosure of poor performance.

Generalizability
The likelihood that the intervention(s) in a particular report would produce similar results in other settings, situations, or environments (also referred to as external validity).

Healthcare improvement
Any systematic effort intended to raise the quality, safety, and value of healthcare services, usually done at the system level. We encourage the use of this phrase rather than "quality improvement," which often refers to more narrowly defined approaches.

Inferences
The meaning of findings or data, as interpreted by the stakeholders in healthcare services – improvers, healthcare delivery professionals, and/or patients and families

Initiative
A broad term that can refer to organization-wide programs, narrowly focused projects, or the details of specific interventions (for example, planning, execution, and assessment)

Internal validity
Demonstrable, credible evidence for efficacy (meaningful impact or change) resulting from introduction of a specific intervention into a particular healthcare system.

Intervention(s)
The specific activities and tools introduced into a healthcare system with the aim of changing its performance for the better. Complete description of an intervention includes its inputs, internal activities, and outputs (in the form of a logic model, for example), and the mechanism(s) by which these components are expected to produce changes in a system's performance.

Opportunity costs

Loss of the ability to perform other tasks or meet other responsibilities resulting from the diversion of resources needed to introduce, test, or sustain a particular improvement initiative

Problem
Meaningful disruption, failure, inadequacy, distress, confusion or other dysfunction in a healthcare service delivery system that adversely affects patients, staff, or the system as a whole, or that prevents care from reaching its full potential

Process
The routines and other activities through which healthcare services are delivered

Rationale
Explanation of why particular intervention(s) were chosen and why it was expected to work, be sustainable, and be replicable elsewhere.

Systems
The interrelated structures, people, processes, and activities that together create healthcare services for and with individual patients and populations. For example, systems exist from the personal self-care system of a patient, to the individual provider-patient dyad system, to the microsystem, to the macrosystem, and all the way to the market/social/insurance system. These levels are nested within each other.

Theory or theories
Any "reason-giving" account that asserts causal relationships between variables (causal theory) or that makes sense of an otherwise obscure process or situation (explanatory theory). Theories come in many forms, and serve different purposes in the phases of improvement work. It is important to be explicit and well-founded about any informal and formal theory (or theories) that are used.

BMJ Open

Improving pediatric epilepsy care at the first level of care: A pilot education intervention for clinical officers in Zambia

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Improving pediatric epilepsy care at the first level of care: A pilot education intervention for clinical officers in Zambia

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Contributorship statement:

Archana A. Patel was the principal investigator for this project, designed the project, obtained funding and ethical approval, helped develop the training the materials for the intervention and deliver the intervention, and development of the manuscript.

Ornella Ciccone is the co-principal investigator and contributed significantly to project design and development, coordinated with local teams in Zambia, development of the training materials and also deliver the intervention, and significantly edited and shaped the manuscript development.

Leah Wibecan is a research assistant who helped in data collection and analysis, as well as development and edits of the manuscript.

Owen Tembo is a research assistant who helped in development of training materials and data collection.

Prisca Kalyelye is a research assistant who helped in project coordination on site.

Manoj Mathew helped with local coordination and partnership development in Zambia, project development, and edits to the manuscript.

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Abstract:

Objective: Epilepsy affects almost 50 million people globally, with approximately 80% living in low and middle income countries (LMIC), where access to specialist care is limited. In LMIC, primary health workers provide the majority of epilepsy care, despite limited training in this field. Recognizing this knowledge gap amongst these providers is an essential component to closing the epilepsy treatment gap in these regions.

Setting: In Zambia, the vast majority of healthcare is provided by clinical officers (COs), primary health providers with three years post-secondary general medical education, who predominantly work in first level health centers around the country.

Participants: With cooperation from the Ministry of Health, a total of ten COs from 4 surrounding first level health centers around the capital city of Lusaka participated, with 9 completing the entire course.

Intervention: COs were trained by a structured 3 week course on pediatric seizures and epilepsy, based on adapted evidenced based guidelines.

Results: A pre- and post- assessment was conducted to assess the intervention. Following the course, there was improved overall knowledge about epilepsy (69% vs. 81% correct, $p<0.05$), specifically knowledge regarding medication management and recognition of focal seizures ($p<0.05$), improved seizure history taking, and appropriate medication titration ($p<0.05$). However, knowledge regarding provoked seizures, use of diagnostic studies, and general etiologies of epilepsy remained limited.

Conclusions: This pilot project demonstrated that a focused pediatric epilepsy training program for COs can improve knowledge and confidence in management, and as such is a promising step for improving the large epilepsy treatment gap in children in Zambia. With feasibility demonstrated, future projects are needed to expand to more rural regions for more diverse and larger sample of primary health provider participants, and encompass more case-based training and repetition of key concepts, as well as methods to improve and assess long term knowledge retention.

Strengths and limitations of this study:

- Demonstrates an effective strategy for training first line providers with limited education on effective pediatric epilepsy management
- Provides a model for a feasible training strategy built with partnership within the healthcare system in the country, including the main academic tertiary center and ministry of health, in order to create a sustainable referral system
- As a pilot project, the study was limited in sample size and geographic scope, and only tested immediate improvement after training with modest effects seen
- Long-term retention was not measured in this project and needs to be assessed in future studies
- Direct impact on patient care practices were not measured

Introduction:

Approximately 50 million people around the world are affected by epilepsy[1], which includes 0.5-1% of children globally[2]. Out of those affected, an estimated 80% are living in the developing world[3-5]. In Zambia, the prevalence of epilepsy is estimated to be as high as 14.6 per 1000[6]. The burden is not only high in low and middle income countries (LMIC), but also compounded by a persistently high treatment gap- the percentage of people who are not accessing medical care or on appropriate medication. The epilepsy treatment gap remains above 70-80% across most of LMIC[7]. This is despite epilepsy being a very treatable condition, with an estimated 70% of people achieving good seizure control on appropriate and cost effective therapy, including the most common ones available in LMIC[4]. Children are a particularly vulnerable population. In Zambia, children with epilepsy have been shown to have fewer educational opportunities, poorer nutrition, and lower socioeconomic status than other children[8].

One of the largest contributing factors to the pediatric epilepsy treatment gap is the significant shortage of child neurologists in the world, with increased disparity in LMIC and rural regions. The most recent data from the World Health Organization reports that there are less than 0.4 per 100,000 child neurologists globally, with 0.02 per 100,000 in LMIC[9]. As a result, up to 91% of neurologic care is provided by paramedical providers who have variable education regarding neurologic disorders[9]. This includes nurses, community health workers, and clinical officers (primary care providers with three years of post-secondary school general medical education). While this model of care delivery is essential to cover the health care needs in these regions, it creates significant concerns about this level of non-specialist providers' ability to appropriately recognize and manage neurologic conditions due to limited training. Demonstrating this, a study out of Zambia showed that irrespective of the volume of people with epilepsy that primary health care workers had seen in the previous three months, the majority had less than adequate knowledge about seizure management[10].

Programs utilizing algorithmic and module based training for specialized care provided by the primary health worker have been shown effective to not only improve care, but also improve health seeking behaviors and awareness in communities[5, 11-13]. Examples of such programs for active convulsive epilepsy have been shown successful in various regions of the world, including Kenya, where a 10% reduction in the epilepsy training gap was seen through a community education program[14], and in Zimbabwe, where a program for education of community health workers significantly improved care seeking and compliance amongst people with epilepsy[15]. In Zambia, where the epilepsy treatment gap remains as high as 90% in some rural regions[7], and the accessibility of specialists is extremely limited, this is an important strategy to consider as an option for expanding care. Notably, however, such education programs for epilepsy typically focus on a broad approach toward convulsive epilepsy, without any specific focus on children or the significant portion of more subtle epilepsies that can impact a child's development.

Recognizing the unique management needs of children with seizures, we developed an educational program aimed at COs in Zambia, focusing specifically on pediatric epilepsy. This pilot project aimed to identify the necessary components for such a program, assess feasibility and interest, and demonstrate effectiveness in improving knowledge and comfort of providers in management of children with seizures and epilepsy.

Methods:

Four periurban first level health centers surrounding the capital city Lusaka were identified for participation in the epilepsy education program based upon population of children with epilepsy seen, ability to refer to the University Teaching Hospital, and capacity to commit to the training. In 2017, the catchment population of the participating health centers ranged from 412,500- 451,000[16]. At the time of the training, none of the participating centers had a dedicated epilepsy or neurology clinic.

COs at each site were selected by clinic supervisors, based upon interest, likelihood that they would remain at their post within that center for at least one year, and ability to commit to the training. Gender and age did not play a role in selection. Due to the strong interest of the health centers and ministry of health in our training program, there was strong commitment and availability for COs to attend for the required period.

The training was conducted over a 3-week period by two board-certified pediatric neurologists (OC and AAP) during which time six modules were delivered. Each module was delivered on two separate days, allowing each CO two opportunities to attend the session, in order to maximize completion rates. Out of the ten COs who participated, nine completed the entirety of the training. The objectives of the training were to improve provider knowledge about pediatric epilepsy in order to improve timeliness of management and utilization or health care resources, with the ultimate goal of improving patient outcomes (figure 1).

The teaching materials for this course were drawn from established national and international guidelines and resources, including World Health Organization and International League Against Epilepsy materials, and were adapted for the management of children in Zambia[17-18]. All materials were designed to provide a reasonable knowledge base for the level of a non-specialist provider, with focus on practical application in the primary level setting. All materials were developed by two child neurologists with additional expertise in epilepsy and experience in Zambia (OC, AAP) and additionally reviewed and edited to be appropriate for the level of clinical officer education by a trained CO working in our pediatric epilepsy clinic in Zambia (OT).

The 6 educational modules included the following:
Module 1: Basic neuroanatomy, seizure pathophysiology; Epidemiology of seizures/epilepsy in children with epilepsy (CWE) in sub Saharan Africa
Module 2: Basic pediatric neurology history and physical exam
Module 3: Seizure semiology (video based); Other paroxysmal events that can mimic seizures in children
Module 4: Diagnosis and management of acute/provoked seizures, Status epilepticus and first unprovoked seizures
Module 5: Diagnosis and management of epilepsy in children; Basics of childhood epilepsy syndromes
Module 6: Follow up of CWE; comorbid conditions in CWE, Psychosocial impact of epilepsy

In addition to the formal training modules, open case discussions were held, without any patient identifiers, to encourage practical application of the education. After completion of post-assessments, one of the child neurologists (AAP) visited each clinic where pairs of the COs (6/9) were observed during a patient session to see direct implementation of the training in practice. During these observed sessions, continued guidance and management was provided as each case was reviewed directly. These sessions were not objectively reviewed for assessment of training, but rather utilized for feedback of identifying strengths and weaknesses of the training program for future iterations.

The intervention effectiveness was assessed by a 24 item knowledge assessment and 10 item confidence survey, given both before module delivery and at the completion of the training program. The knowledge assessment contained 17 multiple choice questions based off established teaching materials and guidelines, and were directed toward common management decisions in caring for children with epilepsy, including identification of seizure types common in children based on case description, appropriate antiepileptic medication selection for seizure type, and diagnostic and referral decision points. It also included 7 true and false questions assessing beliefs regarding epilepsy (such as ability of children with epilepsy to go to school, seizures being caused by spirits and other common societal beliefs). The 10-item confidence assessment rated using a 10 point scale evaluated the general comfort in items such as treating seizures, prescribing medications, managing status epilepticus, and providing seizure safety guidance. Pre- and post-assessment group scores were compared. Data was analyzed using Stata 14 software using paired t-test analysis. The methodology for this quality improvement project follow SQUIRE guidelines[19].

Patient and Public Involvement:
No patients were directly involved in this study.
Ethical approval was obtained through the Boston Children's Hospital Institutional Review Board and University of Zambia Biomedical Research Ethics Committee.

Results:

A total of 9 COs successfully completed the entire training course. There were 6 female and 4 males initially enrolled with one male not completing the program.

Knowledge assessment results are depicted in Table 1. Overall, there was a significant improvement in knowledge scores between the pre- and post-intervention assessments, with participants answering 68.8% of multiple-choice questions correctly prior to training, compared to 80.6% correct following training ($p < 0.001$). The most notable improvements were seen in the improvement in ability to identify a focal seizure with altered awareness (by case description), improving from 50% of participants in the pre-test to 100% in the post-test ($p = 0.015$). In addition, prior to training, only 60% of participants correctly indicated that they would increase the dose of anti-seizure medication in order to reach therapeutic effect; following training 100% of participants answered correctly ($p = 0.037$).

Furthermore, although not statistically significant in the small sample size, there was a notable trend of improvement in selecting an appropriate antiepileptic based upon seizure description, with a correct response rate improvement from 40% to 80% for using carbamazepine as first choice for focal seizures and 50% - 70% for using sodium valproate first for generalized seizures (presented in clinical scenarios in which these were best first-line options). Also notable was that 90% of participants were unfamiliar with the treatment of infantile spasms with steroids (prednisolone available in Zambia) prior to training, with a 20% improvement after completion.

Improvement of febrile seizure management was not seen during this course, despite content review on the topic. Both prior to and following training, about half of participants could not correctly identify that neither imaging nor medication is necessary for a simple febrile seizure. Notably, we also found that prior to training, 80% of participants responded correctly to obtain neuroimaging in clinical scenario depicting a child with focal seizures in the setting of fever, but after training, only 20% did.

In both the pre- and post-training assessments, almost all participants responded that they believed epilepsy is not contagious and recognized it as a medical condition, and reported that individuals with epilepsy can attend school, work, and have children.

Table 1: Knowledge Assessment Results

Question	**Pre-test** (% of participants answered correct)	**Post-test** (% of participants answered correct)	**p-value***
Seizures are caused by abnormal electrical activity	100%	100%	--
Epilepsy is defined as > 2 unprovoked seizures	100%	100%	--

Identifying developmental delay	90%	90%	--
Seizure first aid	70%	100%	0.081
Identifying absence seizures	100%	100%	--
Identifying myoclonic seizures	90%	100%	0.343
Identifying GTCs	100%	100%	--
Identifying syncope	70%	70%	--
Identifying focal seizures	50%	100%	**0.015**
Treat focal seizures with carbamazepine	40%	80%	0.168
Treat generalized seizures with sodium valproate	50%	70%	0.224
Treat infantile spasms with prednisolone	10%	30%	0.343
Increase the dose of an AED to reach therapeutic effect	60%	100%	**0.037**
Add a second AED when a single AED is at max dose	40%	60%	0.509
No imaging or medication for a simple febrile seizure	40%	50%	0.591
Obtain imaging for a complex febrile seizure	80%	20%	**0.005**
Give diazepam for status epilepticus	90%	100%	0.343
Epilepsy is not contagious	100%	100%	--
Epilepsy cannot be caused by witchcraft	90%	100%	--
A child with epilepsy can go to school	100%	100%	--
An adult with epilepsy can go to work	100%	100%	--
Should not drive if has had a seizure recently	70%	90%	0.343
People with epilepsy can get married and have kids	100%	100%	--
Traditional remedies can have negative effects	90%	90%	--

In the confidence assessments (Table 2), there were significant improvements in participant comfort with most aspects of management, particularly in taking a history to identify characteristics of seizures (p=0.015), knowing when to prescribe medication (p=0.002), selecting which medication to use (p=0.000), changing medications (p = 0.001), treating status epilepticus (p=0.001), providing guidance about side effects (p=0.000), answering caregivers' questions (p=0.011), and providing safety guidance (p=0.002). Comfort with the identification of causes of seizures was reported as still limited, and participants reported that they desired more knowledge about epilepsy, both theoretical as well as practical application, continuing to express the lack of neurologic education exposure that they received in general.

Table 2: Comfort Assessment Results

Comfort and confidence measures	Pre-test average	Post-test average	p-value*
Comfort treating children with epilepsy	5.7	7.8	0.177
Differentiating seizures and other events	6.8	8.8	**0.027**
Asking questions about characteristics of seizures	7.4	9.1	**0.015**

Focal versus generalized seizures	6.2	9.3	**0.007**
Deciding when to obtain images or tests	6.5	8.9	**0.037**
Identifying the cause of seizures	6.2	8.3	0.116
Knowing when to prescribe medication	6.5	9.0	**0.002**
Selecting which medication to use	5.7	9.0	**0.000**
Changing medication dose or adding medication	4.4	8.7	**0.001**
Treating status epilepticus	6.4	9.3	**0.001**
Providing guidance about side effects	5.9	8.7	**0.000**
Answering families' questions	6.7	9.1	**0.011**
Providing safety guidance to patients	6.8	9.8	**0.007**

Discussion:

Our pilot education program for pediatric epilepsy in Zambia demonstrated the feasibility of this type of structured educational intervention for primary health providers in our setting. Using proven strategies of shifting care of a condition traditionally managed by a specialist to primary health providers in limited resource regions via a focused education and algorithmic approach[5, 14, 20], we demonstrated that similar methods could be effective for pediatric epilepsy through a focused program for basic level providers.

Through our program, participating COs gained significant confidence in management of epilepsy in children, had improved recognition of the specific impact that seizures can have on a child's development, improvement in how to optimize medications available, and learned how to conduct a proper and efficient pediatric neurology history and physical exam for a general provider's level to guide management and referral when indicated. Furthermore, a significant interest in improving pediatric epilepsy care has been raised throughout the participating COs, as well as their health centers and the Ministry of Health as a result of this program, with cooperation for future trainings assured.

Although the overall concept was successful in execution, there were notable limitations. Due to the fact that this was a test of feasibility for this specific education module, our sample size was necessarily small and limited to the Lusaka region, the most urban area in the country. The small sample size, as well as the short time frame of outcome assessments is limited in fully assessing the true impact on provider practice change. In addition, utilizing centers that were all within the Lusaka region also is limiting as the challenges of care- including more limited knowledge in even basic pediatrics and neurology and access to medication and diagnostics, is significantly more challenging in the more rural regions.

Therefore, although the content of the education program was assessed to the best of our ability as appropriate for this setting, further informal review amongst COs across the country of varying levels of experience and knowledge has revealed that more repetition and hands on training is required for truly effective training. Elements of these issues were echoed in our results of this study, where we

interestingly found some COs could be trained to recognize specific seizure types and epilepsy syndromes, yet they did not gain ability to apply knowledge of more simple concepts that were crucial to care, such as recognizing provoked versus unprovoked seizures and utility of diagnostic testing based upon focal versus generalized semiology. Of note, the specific weakness in worsening of provoked seizure management seen after our training was not felt to be a result of our training, but rather further demonstration of lack of knowledge on recognizing and managing provoked seizures in general, and difficulty in understanding this concept despite the training. Feedback from participants has revealed this to be one of the most challenging concepts for them to grasp. This further serves to demonstrate the need for increased repetition and case-based learning for effective education.

We also found that when focusing on the pediatric history and physical exam, utilizing a clear assessment tool that was simplified and captured basic exam techniques relevant to our purposes was the most effective. Finally, we have found that the COs struggled to implement their acquired knowledge if trained in isolation as the knowledge gap on management of seizures and epilepsy in children is a problem across providers, and inclusion of nurses and general medical officers (to whom the COs must report to if they want to refer a child) as part of an epilepsy team within the participating health centers will be essential for effective implementation of these trainings in the future.

Our pilot project had additional limitations, including the lack of objective measurement of the impact of the intervention, due to logistical challenges. Use of a written exam to assess provider's improvement in epilepsy management is not fully effective to judge change in care practices and further monitoring and evaluation methods to overcome these for future education interventions is essential to fully assess the impact of this type of program.

Interestingly, in assessing for any incorrect misconceptions and personal bias against those with epilepsy, objectively on our assessments we found no evidence of this even before the training. However, during open case discussions, there were clear elements of societal beliefs which persisted, including that of a diagnosis of epilepsy meaning one could no longer contribute to the family, often would not go to school, and would continue to struggle in the community. Providers were more open about sharing these concerns, even expressing that they personally held them in certain instances, when it was done in a more informal setting, leading us to believe that this data would be better ascertained from a focus group mechanism in the future.

To the best of our knowledge, ours is the first in depth training of this kind in Zambia which focuses specifically on seizures and epilepsy in children, taking in account the special needs of this population. Overall, our results have identified that our model of training can be successful. However, improvements focused on increased hands on clinical training, increased repetition of core concepts, and inclusion of

participants in multiple roles in the first level health system across both urban and rural settings is necessary. For future trainings, a plan for follow-up knowledge assessments and an online platform for continued education and formation of a community of epilepsy providers across the country is also being developed.

This model is unique from the majority of epilepsy education programs that primarily combine adult and pediatric populations and focus on active convulsive epilepsy alone. We argue this is an important distinction as focus on active convulsive epilepsy alone may miss a significant period of time for intervention in many children in a region where the seizures are often focal and can be subtle at onset[21], and these delays in treatment can cause significant impairments in development which may have been reducible if not preventable by appropriate early epilepsy management[22].

We recognize that the training of providers in first line health centers is only one step of improving pediatric care across the country, as training at multiple levels will be required- that of paramedical providers, general medical doctors, pediatricians, and ultimately training of pediatric neurologists- for a sustainable system of timely management and appropriate referrals. The Pediatric Epilepsy Training courses developed by the British Paediatric Neurology Association are one of the few existing pediatric epilepsy training programs for non-specialist providers, and are an excellent option for one day courses to improve knowledge broadly in the management of pediatric epilepsy for pediatricians and general medical doctors[23]. Programs like this cannot sufficiently target the primary level provider our program aims to do, but it can help expand the referral system, strengthening knowledge of providers in every level of the health system for consistent care quality. Furthermore, at the time of this manuscript, an initiative for the first specialty training program for neurologists had just been launched in Lusaka, with two trainees enrolled for child neurology. While this provides new hope for access to specialist care in Zambia, the large burden of epilepsy will continue to require care improvement at all levels, beginning with the first line providers as we have elected to do so in this initiative.

Conclusions:

Overall, this study demonstrated that education on pediatric epilepsy can be effectively delivered to primary care providers in Zambia, with improved knowledge outcomes as well as greater confidence in epilepsy knowledge. Given the lack of specialists in the region, this type of education-based intervention targeting primary health providers may significantly improve neurologic outcomes, as these providers are involved in the earliest points of care for children with epilepsy. Further expansion of the training across different first level health center providers and rural and urban regions, with incorporation of methods to objectively measure practice change as well as knowledge retention will be required to better assess the long-term impact of these measures on the epilepsy treatment gap.

Figures:
Figure 1. Conceptual framework for improving quality of care and patient outcomes for children with epilepsy

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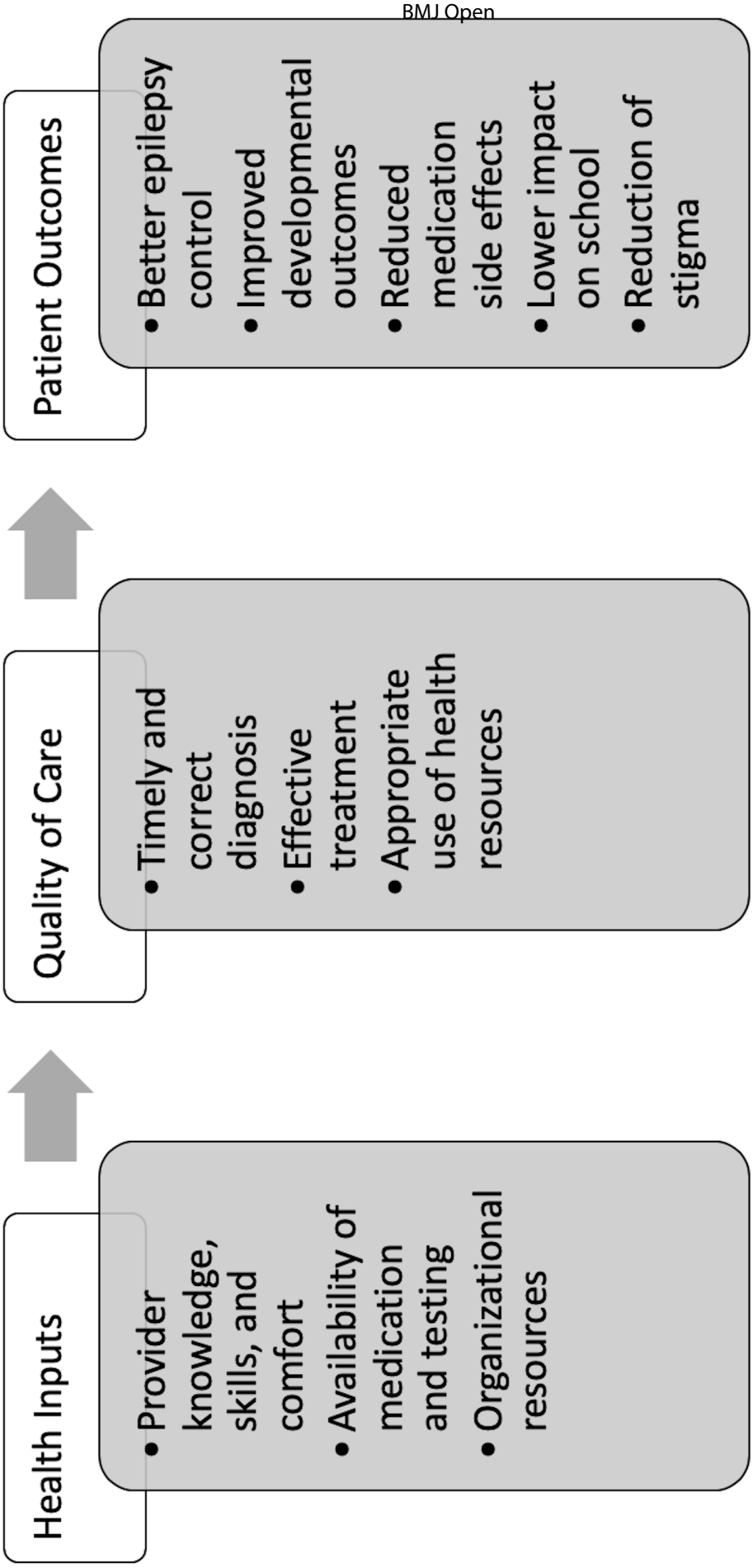

Figure 1. Conceptual framework for improving quality of care and patient outcomes for children with epilepsy

Revised Standards for Quality Improvement Reporting Excellence (SQUIRE 2.0)
September 15, 2015

Text Section and Item Name	Section or Item Description
Notes to authors	• The SQUIRE guidelines provide a framework for reporting new knowledge about how to improve healthcare • The SQUIRE guidelines are intended for reports that describe system level work to improve the quality, safety, and value of healthcare, and used methods to establish that observed outcomes were due to the intervention(s). • A range of approaches exists for improving healthcare. SQUIRE may be adapted for reporting any of these. • Authors should consider every SQUIRE item, but it may be inappropriate or unnecessary to include every SQUIRE element in a particular manuscript. • The SQUIRE Glossary contains definitions of many of the key words in SQUIRE. • The Explanation and Elaboration document provides specific examples of well-written SQUIRE items, and an in-depth explanation of each item. • Please cite SQUIRE when it is used to write a manuscript.
Title and Abstract	
1. Title pg 1	Indicate that the manuscript concerns an initiative to improve healthcare (broadly defined to include the quality, safety, effectiveness, patient-centeredness, timeliness, cost, efficiency, and equity of healthcare)
2. Abstract pg 3	a. Provide adequate information to aid in searching and indexing b. Summarize all key information from various sections of the text using the abstract format of the intended publication or a structured summary such as: background, local problem, methods, interventions, results, conclusions
Introduction	*Why did you start?*
3. Problem Description	Nature and significance of the local problem pg5
4. Available knowledge	Summary of what is currently known about the problem, including relevant previous studies pg 6

5. Rationale	Informal or formal frameworks, models, concepts, and/or theories used to explain the problem, any reasons or assumptions that were used to develop the intervention(s), and reasons why the intervention(s) was expected to work pg 5-6
6. Specific aims	Purpose of the project and of this report pg 6
Methods	*What did you do?*
7. Context	Contextual elements considered important at the outset of introducing the intervention(s) pg 7
8. Intervention(s)	a. Description of the intervention(s) in sufficient detail that others could reproduce it b. Specifics of the team involved in the work pg 7
9. Study of the Intervention(s)	a. Approach chosen for assessing the impact of the intervention(s) b. Approach used to establish whether the observed outcomes were due to the intervention(s) pg 9
10. Measures	a. Measures chosen for studying processes and outcomes of the intervention(s), including rationale for choosing them, their operational definitions, and their validity and reliability pg 9 b. Description of the approach to the ongoing assessment of contextual elements that contributed to the success, failure, efficiency, and cost c. Methods employed for assessing completeness and accuracy of data
11. Analysis	a. Qualitative and quantitative methods used to draw inferences from the data b. Methods for understanding variation within the data, including the effects of time as a variable
12. Ethical Considerations	Ethical aspects of implementing and studying the intervention(s) and how they were addressed, including, but not limited to, formal ethics review and potential conflict(s) of interest pg9
Results	*What did you find?*
13. Results	a. Initial steps of the intervention(s) and their evolution over time (*e.g.*, time-line diagram, flow chart, or table), including modifications made to the intervention during the project pg 9 b. Details of the process measures and outcome c. Contextual elements that interacted with the intervention(s) d. Observed associations between outcomes, interventions, and relevant contextual elements pg 9-10 e. Unintended consequences such as unexpected benefits, problems, failures, or costs associated with the intervention(s). f. Details about missing data N/A
Discussion	*What does it mean?*
14. Summary	a. Key findings, including relevance to the rationale and specific aims b. Particular strengths of the project pg 12-13

15. Interpretation	a. Nature of the association between the intervention(s) and the outcomes pg 13 b. Comparison of results with findings from other publications c. Impact of the project on people and systems pg 12, 14 d. Reasons for any differences between observed and anticipated outcomes, including the influence of context e. Costs and strategic trade-offs, including opportunity costs
16. Limitations	a. Limits to the generalizability of the work b. Factors that might have limited internal validity such as confounding, bias, or imprecision in the design, methods, measurement, or analysis c. Efforts made to minimize and adjust for limitations pg 12-13
17. Conclusions	a. Usefulness of the work pg 14-15 b. Sustainability c. Potential for spread to other contexts d. Implications for practice and for further study in the field e. Suggested next steps
Other information	
18. Funding pg 2	Sources of funding that supported this work. Role, if any, of the funding organization in the design, implementation, interpretation, and reporting

Table 2. Glossary of key terms used in SQUIRE 2.0. This Glossary provides the intended meaning of selected words and phrases as they are used in the SQUIRE 2.0 Guidelines. They may, and often do, have different meanings in other disciplines, situations, and settings.

Assumptions
Reasons for choosing the activities and tools used to bring about changes in healthcare services at the system level.

Context
Physical and sociocultural makeup of the local environment (for example, external environmental factors, organizational dynamics, collaboration, resources, leadership, and the like), and the interpretation of these factors ("sense-making") by the healthcare delivery professionals, patients, and caregivers that can affect the effectiveness and generalizability of intervention(s).

Ethical aspects
The value of system-level initiatives relative to their potential for harm, burden, and cost to the stakeholders. Potential harms particularly associated with efforts to improve the quality, safety, and value of healthcare services include opportunity costs, invasion of privacy, and staff distress resulting from disclosure of poor performance.

Generalizability
The likelihood that the intervention(s) in a particular report would produce similar results in other settings, situations, or environments (also referred to as external validity).

Healthcare improvement
Any systematic effort intended to raise the quality, safety, and value of healthcare services, usually done at the system level. We encourage the use of this phrase rather than "quality improvement," which often refers to more narrowly defined approaches.

Inferences
The meaning of findings or data, as interpreted by the stakeholders in healthcare services – improvers, healthcare delivery professionals, and/or patients and families

Initiative
A broad term that can refer to organization-wide programs, narrowly focused projects, or the details of specific interventions (for example, planning, execution, and assessment)

Internal validity
Demonstrable, credible evidence for efficacy (meaningful impact or change) resulting from introduction of a specific intervention into a particular healthcare system.

Intervention(s)
The specific activities and tools introduced into a healthcare system with the aim of changing its performance for the better. Complete description of an intervention includes its inputs, internal activities, and outputs (in the form of a logic model, for example), and the mechanism(s) by which these components are expected to produce changes in a system's performance.

Opportunity costs

Loss of the ability to perform other tasks or meet other responsibilities resulting from the diversion of resources needed to introduce, test, or sustain a particular improvement initiative

Problem
Meaningful disruption, failure, inadequacy, distress, confusion or other dysfunction in a healthcare service delivery system that adversely affects patients, staff, or the system as a whole, or that prevents care from reaching its full potential

Process
The routines and other activities through which healthcare services are delivered

Rationale
Explanation of why particular intervention(s) were chosen and why it was expected to work, be sustainable, and be replicable elsewhere.

Systems
The interrelated structures, people, processes, and activities that together create healthcare services for and with individual patients and populations. For example, systems exist from the personal self-care system of a patient, to the individual provider-patient dyad system, to the microsystem, to the macrosystem, and all the way to the market/social/insurance system. These levels are nested within each other.

Theory or theories
Any "reason-giving" account that asserts causal relationships between variables (causal theory) or that makes sense of an otherwise obscure process or situation (explanatory theory). Theories come in many forms, and serve different purposes in the phases of improvement work. It is important to be explicit and well-founded about any informal and formal theory (or theories) that are used.

BMJ Open

Improving pediatric epilepsy management at the first level of care: A pilot education intervention for clinical officers in Zambia

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Improving pediatric epilepsy management at the first level of care: A pilot education intervention for clinical officers in Zambia

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Contributorship statement:

Archana A. Patel was the principal investigator for this project, designed the project, obtained funding and ethical approval, helped develop the training the materials for the intervention and deliver the intervention, and development of the manuscript.

Ornella Ciccone is the co-principal investigator and contributed significantly to project design and development, coordinated with local teams in Zambia, development of the training materials and also deliver the intervention, and significantly edited and shaped the manuscript development.

Leah Wibecan is a research assistant who helped in data collection and analysis, as well as development and edits of the manuscript.

Owen Tembo is a research assistant who helped in development of training materials and data collection.

Prisca Kalyelye is a research assistant who helped in project coordination on site.

Manoj Mathew helped with local coordination and partnership development in Zambia, project development, and edits to the manuscript.

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Abstract:

Objective: Epilepsy affects almost 50 million people globally, with approximately 80% living in low and middle income countries (LMIC), where access to specialist care is limited. In LMIC, primary health workers provide the majority of epilepsy care, despite limited training in this field. Recognizing this knowledge gap amongst these providers is an essential component to closing the epilepsy treatment gap in these regions.

Setting: In Zambia, the vast majority of healthcare is provided by clinical officers (COs), primary health providers with three years post-secondary general medical education, who predominantly work in first level health centers around the country.

Participants: With cooperation from the Ministry of Health, a total of ten COs from 4 surrounding first level health centers around the capital city of Lusaka participated, with 9 completing the entire course.

Intervention: COs were trained in a 3 week structured course on pediatric seizures and epilepsy, based on adapted evidenced based guidelines.

Results: A pre- and post- assessment was conducted to assess the intervention. Following the course, there was improved overall knowledge about epilepsy (69% vs. 81%, $p<0.05$), specifically knowledge regarding medication management and recognition of focal seizures ($p<0.05$), improved seizure history taking, and appropriate medication titration ($p<0.05$). However, knowledge regarding provoked seizures, use of diagnostic studies, and general etiologies of epilepsy remained limited.

Conclusions: This pilot project demonstrated that a focused pediatric epilepsy training program for COs can improve knowledge and confidence in management, and as such is a promising step for improving the large epilepsy treatment gap in children in Zambia. With feasibility demonstrated, future projects are needed to expand to more rural regions for more diverse and larger sample of primary health provider participants and encompass more case-based training and repetition of key concepts, as well as methods to improve and assess long term knowledge retention.

Strengths and limitations of this study:

- Demonstrates an effective strategy for training first line providers with limited education on effective pediatric epilepsy management
- Provides a model for a feasible training strategy built with partnership within the healthcare system in the country, including the main academic tertiary center and ministry of health, in order to create a sustainable referral system
- As a pilot project, the study was limited in sample size and geographic scope, and only tested immediate improvement after training with modest effects seen
- Long-term retention was not measured in this project and needs to be assessed in future studies
- Direct impact on patient care practices were not measured

Introduction:

Approximately 50 million people around the world are affected by epilepsy[1], which includes 0.5-1% of children globally[2]. Out of those affected, an estimated 80% are living in the developing world[3-5]. In Zambia, the prevalence of epilepsy is estimated to be as high as 14.6 per 1000[6]. The burden is not only high in low and middle income countries (LMIC), but also compounded by a persistently high treatment gap- the percentage of people who are not accessing medical care or on appropriate medication. The epilepsy treatment gap remains above 70-80% across most of LMIC[7]. This is despite epilepsy being a very treatable condition, with an estimated 70% of people achieving good seizure control on appropriate and cost effective therapy, including the most common ones available in LMIC[4]. Children are a particularly vulnerable population. In Zambia, children with epilepsy have been shown to have fewer educational opportunities, poorer nutrition, and lower socioeconomic status than other children[8].

One of the largest contributing factors to the pediatric epilepsy treatment gap is the significant shortage of child neurologists in the world, with increased disparity in LMIC and rural regions. The most recent data from the World Health Organization reports that there are less than 0.4 per 100,000 child neurologists globally, with 0.02 per 100,000 in LMIC[9]. As a result, up to 91% of neurologic care is provided by paramedical providers who have variable education regarding neurologic disorders[9]. This includes nurses, community health workers, and clinical officers (COs) (primary care providers with three years of post-secondary school general medical education). While this model of care delivery is essential to cover the health care needs in these regions, it creates significant concerns about this level of non-specialist providers' ability to appropriately recognize and manage neurologic conditions due to limited training. Demonstrating this, a Zambian study showed that irrespective of the volume of people with epilepsy that primary health care workers had seen in the previous three months, the majority had less than adequate knowledge about seizure management[10].

Programs utilizing algorithmic and module-based training for specialized care provided by the primary health worker have been shown effective to not only improve care, but also improve health seeking behaviors and awareness in communities[5, 11-13]. Examples of such programs for active convulsive epilepsy have been shown successful in various regions of the world, including Kenya, where a 10% reduction in the epilepsy training gap was seen through a community education program[14], and in Zimbabwe, where a program for education of community health workers significantly improved health seeking and compliance amongst people with epilepsy[15]. In Zambia, where the epilepsy treatment gap remains as high as 90% in some rural regions[7], and the accessibility of specialists is extremely limited, this is an important strategy to consider as an option for expanding care. Notably, however, such education programs for epilepsy typically focus on a broad approach toward convulsive epilepsy, without any specific focus on children or the significant portion of more subtle epilepsies that can impact a child's development.

Recognizing the unique management needs of children with seizures, we developed an educational program aimed at COs in Zambia, focusing specifically on pediatric epilepsy. This pilot project aimed to identify the necessary components for such a program, assess feasibility and interest, and demonstrate effectiveness in improving knowledge and comfort of providers in management of children with seizures and epilepsy.

Methods:

Four periurban first level health centers surrounding the capital city Lusaka were identified for participation in the epilepsy education program based upon population of children with epilepsy seen, ability to refer to the University Teaching Hospital, and capacity to commit to the training. In 2017, the catchment population of the participating health centers ranged from 412,500- 451,000[16]. At the time of the training, none of the participating centers had a dedicated epilepsy or neurology clinic.

COs at each site were selected by clinic supervisors, based upon interest, the likelihood that they would remain at their post within that center for at least one year, and ability to commit to the training. Gender and age did not play a role in selection. Due to the strong interest of the health centers and ministry of health in our training program, there was strong commitment and availability of COs to attend the required period of training.

Ethical approval was obtained through the Boston Children's Hospital Institutional Review Board and University of Zambia Biomedical Research Ethics Committee.

The training was conducted over a 3-week period by two board-certified pediatric neurologists (OC and AAP) during which time six modules were delivered. Each module was delivered on two separate days, allowing each CO two opportunities to attend the session, in order to maximize completion rates. Out of the ten COs who participated, nine completed the entirety of the training. The objectives of the training were to improve provider knowledge about pediatric epilepsy in order to improve timeliness of management and utilization or health care resources, with the ultimate goal of improving patient outcomes (figure 1).

The teaching materials for this course were drawn from established national and international guidelines and resources, including World Health Organization and International League Against Epilepsy materials, and were adapted for the management of children in Zambia[17-18]. All materials were designed to provide a reasonable knowledge base for the level of a non-specialist provider, with focus on practical application in the primary level setting. All materials were developed by two child neurologists with additional expertise

in epilepsy and experience in Zambia (OC, AAP) and additionally reviewed and edited to be appropriate for the level of clinical officer education by a trained CO working in our pediatric epilepsy clinic in Zambia (OT).

The 6 educational modules included the following:
Module 1: Basic neuroanatomy, seizure pathophysiology; Epidemiology of seizures/epilepsy in children with epilepsy (CWE) in sub Saharan Africa
Module 2: Basic pediatric neurology history and physical exam
Module 3: Seizure semiology (video based); Other paroxysmal events that can mimic seizures in children
Module 4: Diagnosis and management of acute/provoked seizures, Status epilepticus and first unprovoked seizures
Module 5: Diagnosis and management of epilepsy in children; Basics of childhood epilepsy syndromes
Module 6: Follow up of CWE; comorbid conditions in CWE, Psychosocial impact of epilepsy

In addition to the formal training modules, open case discussions were held, without any patient identifiers, to encourage practical application of the education. After completion of post-assessments, one of the child neurologists (AAP) visited each clinic where pairs of the COs (6/9) were observed during a patient session to see direct implementation of the training in practice. During these observed sessions, continued guidance and management was provided as each case was reviewed directly. These sessions were not objectively reviewed for assessment of training, but rather utilized for feedback of identifying strengths and weaknesses of the training program for future iterations.

The intervention effectiveness was assessed by a 24 item knowledge assessment and 10 item confidence survey, given both before module delivery and at the completion of the training program. The knowledge assessment contained 17 multiple choice questions based on the established teaching materials and guidelines, and were directed toward common management decisions in caring for children with epilepsy, including identification of seizure types common in children based on case description, appropriate antiepileptic medication selection for seizure type, and diagnostic and referral decision points. It also included 7 true and false questions assessing beliefs regarding epilepsy (such as ability of children with epilepsy to go to school, seizures being caused by spirits and other common societal beliefs). The 10-item confidence assessment rated using a 10 point scale evaluated the general comfort in items such as treating seizures, prescribing medications, managing status epilepticus, and providing seizure safety guidance. Pre- and post-assessment group scores were compared. Data was analyzed using Stata 14 software using paired t-test analysis. The methodology for this quality improvement project follow SQUIRE guidelines[19].

Patient and Public Involvement:

No patients were directly involved in this study.

Results:

A total of 9 COs successfully completed the entire training course. There were 6 female and 4 males initially enrolled with one male not completing the program.

Knowledge assessment results are depicted in Table 1. Overall, there was a significant improvement in knowledge scores between the pre- and post-intervention assessments, with participants answering 68.8% of multiple-choice questions correctly prior to training, compared to 80.6% correct following training ($p < 0.001$). The most notable improvements were seen in the improvement in ability to identify a focal seizure with altered awareness (by case description), improving from 50% of participants in the pre-test to 100% in the post-test ($p = 0.015$). In addition, prior to training, only 60% of participants correctly indicated that they would increase the dose of anti-seizure medication in order to reach therapeutic effect; following training 100% of participants answered correctly ($p = 0.037$).

Although not statistically significant due to the small sample size, there was a notable trend of improvement in selecting an appropriate antiepileptic based upon seizure description, with a correct response rate improvement from 40% to 80% for using carbamazepine as first choice for focal seizures and 50% - 70% for using sodium valproate first for generalized seizures (presented in clinical scenarios in which these were best first-line options). Also notable was that 90% of participants were unfamiliar with the treatment of infantile spasms with steroids (prednisolone available in Zambia) prior to training, with a 20% improvement after completion.

Improvement of febrile seizure management was not seen during this course, despite content review on the topic. Both prior to and following training, about half of participants could not correctly identify that neither imaging nor medication is necessary for a simple febrile seizure. Notably, we also found that prior to training, 80% of participants responded correctly to obtain neuroimaging in clinical scenario depicting a child with focal seizures in the setting of fever, but after training, only 20% did.

In both the pre- and post-training assessments, almost all participants responded that they believed epilepsy is not contagious and recognized it as a medical condition, and reported that individuals with epilepsy can attend school, work, and have children.

Table 1: Knowledge Assessment Results

Question	**Pre-test** (% of participants answered correct)	**Post-test** (% of participants answered correct)	**p-value***

Seizures are caused by abnormal electrical activity	100%	100%	--
Epilepsy is defined as > 2 unprovoked seizures	100%	100%	--
Identifying developmental delay	90%	90%	--
Seizure first aid	70%	100%	0.081
Identifying absence seizures	100%	100%	--
Identifying myoclonic seizures	90%	100%	0.343
Identifying GTCs	100%	100%	--
Identifying syncope	70%	70%	--
Identifying focal seizures	50%	100%	**0.015**
Treat focal seizures with carbamazepine	40%	80%	0.168
Treat generalized seizures with sodium valproate	50%	70%	0.224
Treat infantile spasms with prednisolone	10%	30%	0.343
Increase the dose of an AED to reach therapeutic effect	60%	100%	**0.037**
Add a second AED when a single AED is at max dose	40%	60%	0.509
No imaging or medication for a simple febrile seizure	40%	50%	0.591
Obtain imaging for a complex febrile seizure	80%	20%	**0.005**
Give diazepam for status epilepticus	90%	100%	0.343
Epilepsy is not contagious	100%	100%	--
Epilepsy cannot be caused by witchcraft	90%	100%	--
A child with epilepsy can go to school	100%	100%	--
An adult with epilepsy can go to work	100%	100%	--
Should not drive if has had a seizure recently	70%	90%	0.343
People with epilepsy can get married and have kids	100%	100%	--
Traditional remedies can have negative effects	90%	90%	--

In the confidence assessments (Table 2), there were significant improvements in participant comfort with most aspects of management, particularly in taking a history to identify characteristics of seizures (p=0.015), knowing when to prescribe medication (p=0.002), selecting which medication to use (p=0.000), changing medications (p = 0.001), treating status epilepticus (p=0.001), providing guidance about side effects (p=0.000), answering caregivers' questions (p=0.011), and providing safety guidance (p=0.002). Comfort with the identification of causes of seizures was reported as still limited, and participants reported that they desired more knowledge about epilepsy, both theoretical as well as practical application, continuing to express the lack of neurologic education exposure that they received in general.

Table 2: Comfort Assessment Results

Comfort and confidence measures	Pre-test average	Post-test average	p-value*
Comfort treating children with epilepsy	5.7	7.8	0.177

Differentiating seizures and other events	6.8	8.8	**0.027**
Asking questions about characteristics of seizures	7.4	9.1	**0.015**
Focal versus generalized seizures	6.2	9.3	**0.007**
Deciding when to obtain images or tests	6.5	8.9	**0.037**
Identifying the cause of seizures	6.2	8.3	0.116
Knowing when to prescribe medication	6.5	9.0	**0.002**
Selecting which medication to use	5.7	9.0	**0.000**
Changing medication dose or adding medication	4.4	8.7	**0.001**
Treating status epilepticus	6.4	9.3	**0.001**
Providing guidance about side effects	5.9	8.7	**0.000**
Answering families' questions	6.7	9.1	**0.011**
Providing safety guidance to patients	6.8	9.8	**0.007**

Discussion:

Our pilot education program for pediatric epilepsy in Zambia demonstrated the feasibility of this type of structured educational intervention for primary health providers in our setting. Using proven strategies of shifting care of a condition traditionally managed by a specialist to primary health providers in limited resource regions via a focused education and algorithmic approach[5, 14, 20], we demonstrated that similar methods could be effective for pediatric epilepsy through a focused program for basic level providers.

Through our program, participating COs gained significant confidence in management of epilepsy in children, had improved recognition of the specific impact that seizures can have on a child's development, improvement in how to optimize medications available, and learned how to conduct a proper and efficient pediatric neurology history and physical exam for a general provider's level to guide management and referral when indicated. Furthermore, a significant interest in improving pediatric epilepsy care has been raised throughout the participating COs, as well as their health centers and the Ministry of Health as a result of this program, with cooperation for future trainings assured.

The overall concept was successful in execution, yet there were notable limitations. Due to the fact that this was a test of feasibility for this specific education module, our sample size was necessarily small and limited to the urban area of the Lusaka region. The small sample size and the short time frame of outcome assessments limited full assessment of the true impact on provider practice change. In addition, utilizing centers that were all within the Lusaka region is also a limitation as the challenges of care- including more limited knowledge of basic pediatrics and neurology and access to medication and diagnostics- is significantly more challenging in the more rural regions.

Our pilot project had additional limitations, including the lack of objective measurement of the impact of the intervention, due to logistical challenges. The knowledge assessment used, which consisted primarily

of case based questions, is continuing to be utilized in future expansions of this study, therefore has not been included in this paper. However, we acknowledge that use of a written exam to assess provider's improvement in epilepsy management is not fully effective to judge change in care practices and further monitoring and evaluation methods to overcome these for future education interventions is essential to fully assess the impact of this type of program.

Therefore, although the content of the education program was assessed to the best of our ability as appropriate for this setting, further informal review amongst COs across the country of varying levels of experience and knowledge has revealed that more repetition and hands on training is required for truly effective training. Elements of these issues were reflected in our results of this study, where we interestingly found some COs could be trained to recognize specific seizure types and epilepsy syndromes, yet they did not gain ability to apply knowledge of more simple concepts that were crucial to care, such as recognizing provoked versus unprovoked seizures and utility of diagnostic testing based upon focal versus generalized semiology. Of note, the specific weakness in worsening of provoked seizure management seen after our training was not felt to be a result of our training, but rather further demonstration of lack of knowledge on recognizing and managing provoked seizures in general, and difficulty in understanding this concept despite the training. Feedback from participants has revealed this to be one of the most challenging concepts for them to grasp. This further serves to demonstrate the need for increased repetition and case-based learning for effective education.

We also found that when focusing on the pediatric history and physical exam, utilizing a clear assessment tool that was simplified and captured basic exam techniques relevant to our purposes was the most effective. Finally, we have found that the COs struggled to implement their acquired knowledge if trained in isolation as the knowledge gap on management of seizures and epilepsy in children is a problem across providers, and inclusion of nurses and general medical officers (to whom the COs must report to if they want to refer a child) as part of an epilepsy team within the participating health centers will be essential for effective implementation of these trainings in the future.

Interestingly, in assessing for any incorrect misconceptions and personal bias against those with epilepsy, objectively on our assessments we found no evidence of this even before the training. However, during open case discussions, there were clear elements of societal beliefs which persisted, including that of a diagnosis of epilepsy meaning one could no longer contribute to the family, often would not go to school, and would continue to struggle in the community. Providers were more open about sharing these concerns, even expressing that they personally held them in certain instances, when it was done in a more informal setting, leading us to believe that this data would be better ascertained from a focus group mechanism in the future.

To the best of our knowledge, our study is the first in depth training of this kind in Zambia which focuses specifically on seizures and epilepsy in children, taking to account the special needs of this population. Overall, our results have identified that our model of training can be successful. However, improvements focused on increased hands on clinical training, increased repetition of core concepts, and inclusion of participants in multiple roles in the first level health system across both urban and rural settings is necessary. For future trainings, a plan for follow-up knowledge assessments and an online platform for continued education and formation of a community of epilepsy providers across the country is also being developed.

This model is unique from the majority of epilepsy education programs that primarily combine adult and pediatric populations and focus on active convulsive epilepsy alone. We argue this is an important distinction as focus on active convulsive epilepsy alone may miss a significant period of time for intervention in many children in a region where the seizures are often focal and can be subtle at onset[21], and these delays in treatment can cause significant impairments in development which may have been reducible if not preventable by appropriate early epilepsy management[22].

We recognize that the training of providers at multiple levels will be required- that of paramedical providers, general medical doctors, pediatricians, and ultimately training of pediatric neurologists- for a sustainable system of timely management and appropriate referrals. The Pediatric Epilepsy Training courses developed by the British Paediatric Neurology Association are one of the few existing pediatric epilepsy training programs for non-specialist providers, and are an excellent option for one day courses to improve knowledge broadly in the management of pediatric epilepsy for pediatricians and general medical doctors with a good basic knowledge base[23]. Programs like this cannot sufficiently target the primary level provider who require more extensive training as our program aims to do, but it can help expand the referral system, strengthening knowledge of providers in every level of the health system for consistent care quality. Furthermore, at the time of this manuscript, an initiative for the first specialty training program for neurologists had just been launched in Lusaka, with two trainees enrolled for child neurology. While this provides new hope for access to specialist care in Zambia, the large burden of epilepsy will continue to require care improvement at all levels, beginning with the first line providers as we have elected to do so in this initiative.

Conclusions:

Overall, this study demonstrated that education on pediatric epilepsy can be effectively delivered to primary care providers in Zambia, with improved knowledge outcomes as well as greater confidence in epilepsy knowledge. Given the lack of specialists in the region, this type of education-based intervention targeting primary health providers may significantly improve neurologic outcomes, as these providers are

involved in the earliest points of care for children with epilepsy. Further expansion of the training across different first level health centers, with incorporation of methods to objectively measure practice change and knowledge retention, will be required to better assess the long-term impact of these measures on the epilepsy treatment gap.

Figures:
Figure 1. Conceptual framework for improving quality of care and patient outcomes for children with epilepsy

Data availability statement: All data relevant to the study are included in the article in the presented analyses.
Data sharing statement: Deidentified individual participant data will be available beginning 9 months and for up to 36 months after publication of this article to individuals whose proposed use of data has been approved by review committees at both Boston Children's Hospital and the University of Zambia, under whom the ethical permission for this study was conducted.

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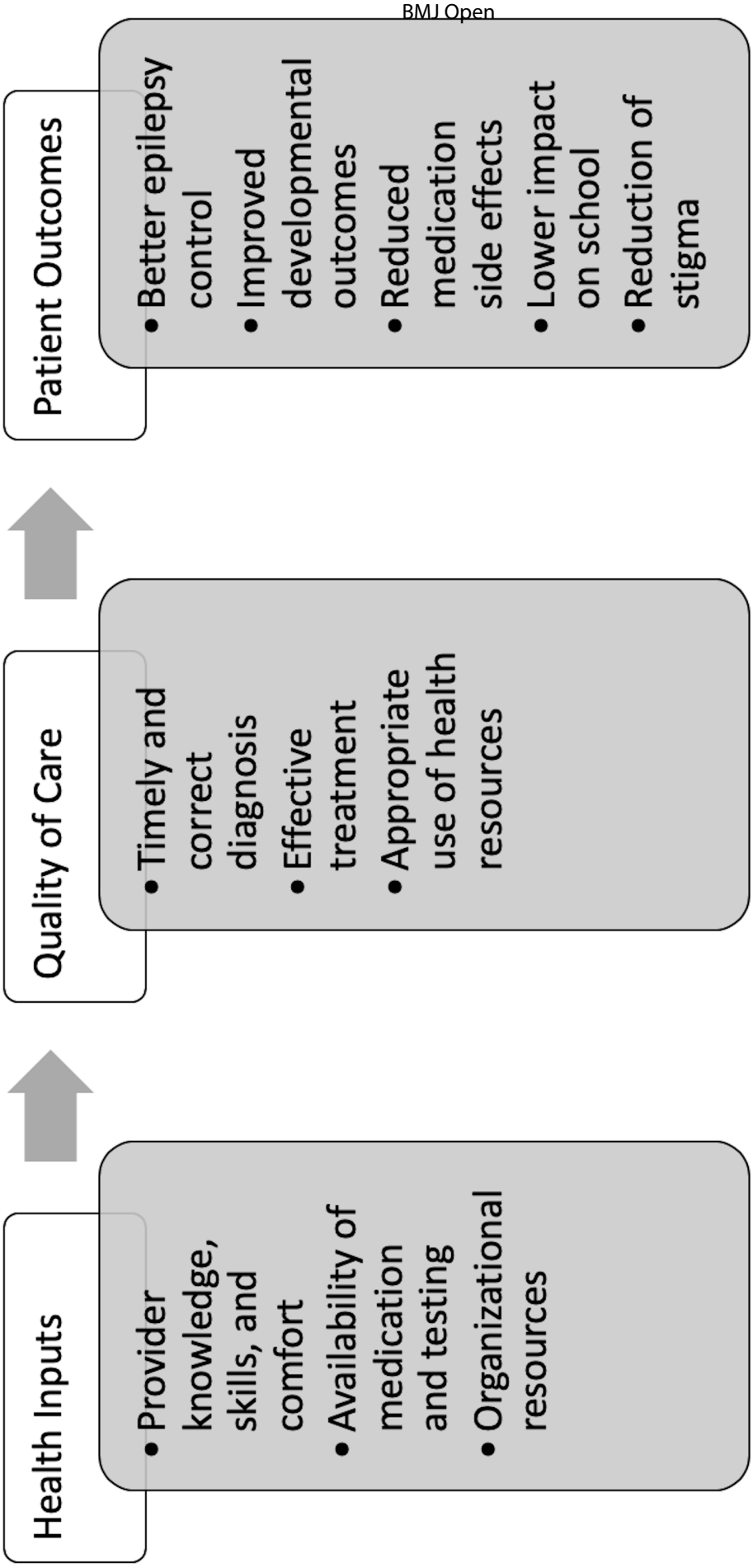

Figure 1. Conceptual framework for improving quality of care and patient outcomes for children with epilepsy

Revised Standards for Quality Improvement Reporting Excellence (SQUIRE 2.0)
September 15, 2015

Text Section and Item Name	Section or Item Description
Notes to authors	• The SQUIRE guidelines provide a framework for reporting new knowledge about how to improve healthcare • The SQUIRE guidelines are intended for reports that describe system level work to improve the quality, safety, and value of healthcare, and used methods to establish that observed outcomes were due to the intervention(s). • A range of approaches exists for improving healthcare. SQUIRE may be adapted for reporting any of these. • Authors should consider every SQUIRE item, but it may be inappropriate or unnecessary to include every SQUIRE element in a particular manuscript. • The SQUIRE Glossary contains definitions of many of the key words in SQUIRE. • The Explanation and Elaboration document provides specific examples of well-written SQUIRE items, and an in-depth explanation of each item. • Please cite SQUIRE when it is used to write a manuscript.
Title and Abstract	
1. Title pg 1	Indicate that the manuscript concerns an initiative to improve healthcare (broadly defined to include the quality, safety, effectiveness, patient-centeredness, timeliness, cost, efficiency, and equity of healthcare)
2. Abstract pg 3	a. Provide adequate information to aid in searching and indexing b. Summarize all key information from various sections of the text using the abstract format of the intended publication or a structured summary such as: background, local problem, methods, interventions, results, conclusions
Introduction	*Why did you start?*
3. Problem Description	Nature and significance of the local problem pg5
4. Available knowledge	Summary of what is currently known about the problem, including relevant previous studies pg 6

5. Rationale	Informal or formal frameworks, models, concepts, and/or theories used to explain the problem, any reasons or assumptions that were used to develop the intervention(s), and reasons why the intervention(s) was expected to work pg 5-6
6. Specific aims	Purpose of the project and of this report pg 6
Methods	*What did you do?*
7. Context	Contextual elements considered important at the outset of introducing the intervention(s) pg 7
8. Intervention(s)	a. Description of the intervention(s) in sufficient detail that others could reproduce it b. Specifics of the team involved in the work pg 7
9. Study of the Intervention(s)	a. Approach chosen for assessing the impact of the intervention(s) b. Approach used to establish whether the observed outcomes were due to the intervention(s) pg 9
10. Measures	a. Measures chosen for studying processes and outcomes of the intervention(s), including rationale for choosing them, their operational definitions, and their validity and reliability pg 9 b. Description of the approach to the ongoing assessment of contextual elements that contributed to the success, failure, efficiency, and cost c. Methods employed for assessing completeness and accuracy of data
11. Analysis	a. Qualitative and quantitative methods used to draw inferences from the data b. Methods for understanding variation within the data, including the effects of time as a variable
12. Ethical Considerations	Ethical aspects of implementing and studying the intervention(s) and how they were addressed, including, but not limited to, formal ethics review and potential conflict(s) of interest pg9
Results	*What did you find?*
13. Results	a. Initial steps of the intervention(s) and their evolution over time (*e.g.*, time-line diagram, flow chart, or table), including modifications made to the intervention during the project pg 9 b. Details of the process measures and outcome c. Contextual elements that interacted with the intervention(s) d. Observed associations between outcomes, interventions, and relevant contextual elements pg 9-10 e. Unintended consequences such as unexpected benefits, problems, failures, or costs associated with the intervention(s). f. Details about missing data N/A
Discussion	*What does it mean?*
14. Summary	a. Key findings, including relevance to the rationale and specific aims b. Particular strengths of the project pg 12-13

15. Interpretation	a. Nature of the association between the intervention(s) and the outcomes pg 13 b. Comparison of results with findings from other publications c. Impact of the project on people and systems pg 12, 14 d. Reasons for any differences between observed and anticipated outcomes, including the influence of context e. Costs and strategic trade-offs, including opportunity costs
16. Limitations	a. Limits to the generalizability of the work b. Factors that might have limited internal validity such as confounding, bias, or imprecision in the design, methods, measurement, or analysis c. Efforts made to minimize and adjust for limitations pg 12-13
17. Conclusions	a. Usefulness of the work pg 14-15 b. Sustainability c. Potential for spread to other contexts d. Implications for practice and for further study in the field e. Suggested next steps
Other information	
18. Funding pg 2	Sources of funding that supported this work. Role, if any, of the funding organization in the design, implementation, interpretation, and reporting

Table 2. Glossary of key terms used in SQUIRE 2.0. This Glossary provides the intended meaning of selected words and phrases as they are used in the SQUIRE 2.0 Guidelines. They may, and often do, have different meanings in other disciplines, situations, and settings.

Assumptions
Reasons for choosing the activities and tools used to bring about changes in healthcare services at the system level.

Context
Physical and sociocultural makeup of the local environment (for example, external environmental factors, organizational dynamics, collaboration, resources, leadership, and the like), and the interpretation of these factors ("sense-making") by the healthcare delivery professionals, patients, and caregivers that can affect the effectiveness and generalizability of intervention(s).

Ethical aspects
The value of system-level initiatives relative to their potential for harm, burden, and cost to the stakeholders. Potential harms particularly associated with efforts to improve the quality, safety, and value of healthcare services include opportunity costs, invasion of privacy, and staff distress resulting from disclosure of poor performance.

Generalizability
The likelihood that the intervention(s) in a particular report would produce similar results in other settings, situations, or environments (also referred to as external validity).

Healthcare improvement
Any systematic effort intended to raise the quality, safety, and value of healthcare services, usually done at the system level. We encourage the use of this phrase rather than "quality improvement," which often refers to more narrowly defined approaches.

Inferences
The meaning of findings or data, as interpreted by the stakeholders in healthcare services – improvers, healthcare delivery professionals, and/or patients and families

Initiative
A broad term that can refer to organization-wide programs, narrowly focused projects, or the details of specific interventions (for example, planning, execution, and assessment)

Internal validity
Demonstrable, credible evidence for efficacy (meaningful impact or change) resulting from introduction of a specific intervention into a particular healthcare system.

Intervention(s)
The specific activities and tools introduced into a healthcare system with the aim of changing its performance for the better. Complete description of an intervention includes its inputs, internal activities, and outputs (in the form of a logic model, for example), and the mechanism(s) by which these components are expected to produce changes in a system's performance.

Opportunity costs

Loss of the ability to perform other tasks or meet other responsibilities resulting from the diversion of resources needed to introduce, test, or sustain a particular improvement initiative

Problem
Meaningful disruption, failure, inadequacy, distress, confusion or other dysfunction in a healthcare service delivery system that adversely affects patients, staff, or the system as a whole, or that prevents care from reaching its full potential

Process
The routines and other activities through which healthcare services are delivered

Rationale
Explanation of why particular intervention(s) were chosen and why it was expected to work, be sustainable, and be replicable elsewhere.

Systems
The interrelated structures, people, processes, and activities that together create healthcare services for and with individual patients and populations. For example, systems exist from the personal self-care system of a patient, to the individual provider-patient dyad system, to the microsystem, to the macrosystem, and all the way to the market/social/insurance system. These levels are nested within each other.

Theory or theories
Any "reason-giving" account that asserts causal relationships between variables (causal theory) or that makes sense of an otherwise obscure process or situation (explanatory theory). Theories come in many forms, and serve different purposes in the phases of improvement work. It is important to be explicit and well-founded about any informal and formal theory (or theories) that are used.