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Developing epilepsy training capacity for primary care providers using the project ECHO telementoring model

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Abstract

Background: Primary care providers (PCPs) provide a large proportion of care for people with epilepsy (PWE) and need regular training for updates. However, PCPs treat patients in so many therapeutic areas that epilepsy often becomes a less important concern. We used an established telementoring program, Project ECHO (Extension for Community Healthcare Outcomes), and combined epilepsy education with general neurology topics to generate more interest among PCPs.

Methods: We offered 20 one-hour webinar sessions over a two-year period, each consisting of a panel of neurology experts, with a combination of case presentations, a 20-minute didactic presentation, and live, interactive question and answer. Attendees logged in from their own computers or phones, and all presentations were archived online for future viewing. Interviews with PCPs indicated a combination of epilepsy and general neurology topics would be better received, so epilepsy topics alternated monthly with general neurology topics (e.g., headache, stroke, and dementia). Session evaluation included participants' comfort in treating patients with neurological disorders and confidence in knowledge of the topic area.

Results: After the second session, mean attendance was 27.5 participants (range 15–38), with a total of 164 unique individual participants. Attendees were a mix of mostly regional, some out of state, and a few international learners, including practicing PCPs, trainees, and nurse practitioners. Archived presentations on our website were viewed 212 times; seizure topics were the most viewed. Mean evaluation scores for relevance, value, and increased knowledge were all in the “agree to strongly agree” range. Over 97% of respondents reported greater interest in improving care of patients with epilepsy or neurological disorders, and over 98% reported greater comfort and self-efficacy when treating patients with these conditions. Only eight cases were submitted for review prior to the sessions.

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Conflict of interest

The authors declare no conflict of interest to report.

Conclusions: We successfully piloted a telementoring program using Project ECHO methodology, which was effective in educating PCPs about epilepsy treatment. Combining epilepsy and other neurology topics was an effective strategy in garnering interest among PCPs, but additional methods are needed to encourage participants to present their own cases.

Keywords

Epilepsy; Telehealth; Project ECHO; Epilepsy education

1. Introduction

Long-term care of people with epilepsy (PWE) may be provided by specialists in epilepsy, neurologists with less advanced epilepsy training, or primary care providers (PCPs). Specialists in epilepsy typically work at comprehensive epilepsy centers that offer advanced diagnostic and treatment options, such as resective epilepsy surgery, implantable devices for epilepsy, new antiseizure medications (ASM), and clinical trials of new treatments. The National Association of Epilepsy Centers recommends that PWE who fail two appropriately chosen ASM should be evaluated at an epilepsy center [1]. However, most PWE are not evaluated at an epilepsy center, and even if they have been, may continue follow-up care with a neurologist not affiliated with an epilepsy center or with a PCP [2]. A national report found that in 2017, among all adults with active epilepsy, 53% saw both a PCP and a neurologist or a specialist in epilepsy in the 12 months preceding the survey; 27% saw only a PCP; 9% saw only a neurologist or a specialist in epilepsy; and 11% saw neither [3]. Another population study reported that 55% of non-medication adherent adults with seizures were seen only by a general doctor in the year preceding the survey [4].

Project ECHO (Extension for Community Healthcare Outcomes) is an evidence-based method for building primary care capacity to meet critical community health needs for patients requiring complex care [5]. It uses videoconferencing technology to connect PCPs with specialty providers. A key strength of Project ECHO is being a “force multiplier,” by providing front-line clinicians with the knowledge and support needed to manage their patients with similar specialized or complex conditions, thereby “multiplying” the depth and breadth of care through their practice. In addition to being mentored by specialists, the case-based presentations facilitate PCPs’ interactions with peers regarding the selected topic, which creates a community of engaged learners interested in advancing practice in the same area. By empowering PCPs in selected areas of specialized care, the Project ECHO model has demonstrated similar outcomes to specialist management and may also improve patient outcomes in some cases, because the local provider can provide treatment within the context of the local community [6]. This becomes particularly relevant in the case of a chronic disease like epilepsy, where treatment in the context of the local community could improve adherence, which is a major factor in seizure control. With support from the U.S. Maternal and Child Health Bureau, the American Academy of Pediatrics (AAP) has implemented several pediatric epilepsy ECHOs to improve access to quality health care for children and youth with epilepsy (CYE). A recent evaluation of an April–December 2018 AAP Epilepsy and Comorbidities ECHO, which was implemented among seven pediatric practices across five states, reported significant improvements in quality measures regarding

ASM side effects, safety education, screening for behavioral health, and documentation of a transition plan for CYE [7]. The U.S. Department of Veterans Affairs has also implemented an epilepsy ECHO pilot with results forthcoming [8].

Fundamental to any provider training program is determining how to fit programming into the busy schedules of PCPs. Other common Project ECHO teleconference topics include chronic pain, headache, and hypertension, which represent a greater percentage of a PCP's practice. For example, a local study estimated a chronic pain prevalence of approximately 26% in primary care practices in the area [9]. Given the relatively low prevalence of epilepsy, PCPs may find it difficult to justify taking much time to learn about epilepsy care. However, there is a similar need for PCP education in other neurological disorders due to a relative shortage of neurologists in multiple regions of the US, including several states neighboring Ohio that have been labeled "neurology deserts," and expected shortages of specialists in epilepsy [2,10]. To increase provider education about epilepsy and close treatment gaps, and with support from the U.S. Centers for Disease Control and Prevention (CDC) and the Epilepsy Foundation (EF), this program leveraged existing Project ECHO capacity at the University of Cincinnati to institute a telementoring program that was focused on epilepsy, but also included broader neurology topics for PCPs who treat adults.

2. Methods

The project was approved by the University of Cincinnati Institutional Review Board (IRB#2018-5297).

2.1. Justification and design of the intervention

Because our study intervention was based at the University of Cincinnati in Ohio, we initially considered regional burden and potential reach of the program. For example, applying the latest U.S. national data on epilepsy burden to 2017 U.S. Census data for Ohio, we estimated that among adult Ohioans with active epilepsy (~108,000), about 57,000 are being followed up by both a PCP and a neurologist, and about 29,000 are being followed up by a PCP only [11,12]. Applied to the Greater Cincinnati Metropolitan Statistical Area (MSA) with an estimated 1.6 million adults in 2017, we estimate that among adults with active epilepsy (~19,600), about 10,300 are being followed up by both a PCP and a neurologist or a specialist in epilepsy, and 5200 are being followed up by a PCP only [13]. The U.S. Health Resources and Services Administration identifies 8886 PCPs in 2017 in Ohio, and 1792 PCPs in 2017 in the Greater Cincinnati MSA [14]. Thus, on average a PCP in Ohio is following up approximately ten PWE, and this includes about nine PWE per PCP in the Greater Cincinnati MSA. Therefore, there is a need for PCP education on optimal epilepsy treatment and indications for referrals to an epilepsy center.

Initial planning included core team participation in the Project ECHO training led by the University of New Mexico [15]. Another key step included obtaining local provider input from several regional leaders in primary care (e.g., primary care network medical director, family medicine residency program directors) and several Project ECHO experts (e.g., AAP ECHO project managers) to assess perceived feasibility for an Epilepsy Project ECHO program serving adult PCPs in Ohio and the surrounding region. These stakeholders

suggested that a broader focus on neurological disorders and epilepsy comorbidities would likely appeal to more PCPs. Therefore, to best meet the needs of PCPs, we proposed a combined Epilepsy/Neurology Project ECHO program.

PCPs who treat PWE include providers in the fields of Family Medicine, Internal Medicine, and Internal Medicine/Pediatrics, all of whom would benefit from updated information and methods to improve efficiency in caring for PWE (Fig. 1). In addition, many women rely on their obstetrician/gynecologist for primary care, and issues related to contraception, teratogenesis, and pregnancy in women with epilepsy are critical educational targets for these providers.

We originally targeted providers in Ohio and then expanded to the surrounding states of Indiana, Kentucky, and West Virginia. Recruitment strategies included communication with multiple regional primary care and rural health practitioners and leaders, as well as in-person presentations to a primary care clinic in Dayton and a large primary care group in Cincinnati. Program coordinators included advertisements in newsletters of medical societies and utilized marketing strategies through the EF website (www.epilepsy.com), social media, and partner websites. Marketing efforts also included outreach to the following audiences: Federally Qualified Health Centers in Ohio, the Academy of Medicine Cincinnati chapter, the neighboring state departments of health and medical associations, primary care networks, family and internal medicine residency practices and training programs, EEG technologists, neurology residents, neurology nurses and nurse practitioners (both hospital-based and outpatient-based), and Ohio rural health associations. We recruited specialists from the University of Cincinnati College of Medicine Department of Neurology to serve as session presenters and compensated their time to prepare for the teleconference and participate in the live session. To increase provider participation, EF used their network of social media to raise national awareness of the availability of the program among providers outside of the Ohio region.

2.2. Implementation of the Project ECHO program

Ten one-hour sessions were offered at noon on the first Thursday of the month, starting in September 2018 and concluding in June 2019 (Year One; Y1), with an additional ten sessions offered between October 2019 and July 2020 (Year Two; Y2). Each session featured a panel of two or three neurology specialists in a live webinar format, and attendees could view and interact from their own computers or call in via phone. Sessions were broadcast from a conference room using a laptop and inexpensive web camera. All sessions were archived on the University of Cincinnati Project ECHO website (www.cincinnatiecho.com) and could be accessed at any time after the live broadcast. Epilepsy topics alternated monthly with nonepilepsy neurology topics (Table 1). All presentations focused on improving knowledge on epilepsy or other neurology topics for PCPs. The program used the standard Project ECHO format, starting with a case presentation, followed by a 20-minute didactic presentation, with active question and answer throughout the webinar. Depending on the time left in the session, a second case presentation or an open question and answer discussion on any related topic was included. The neurology specialists' panel provided the didactic presentations, patient case reviews,

and answered questions from the participants. Participants received 1 AMA PRA Category 1 Credit™ for their participation and provided online evaluations after each of the attended sessions.

2.3. Evaluation methods

Each session was evaluated using a standardized approach with a series of questions (see Section 3.2 Evaluation) that assessed PCP comfort in treating patients with neurological disorders and confidence in knowledge of the topic area (e.g., new-onset seizures, mood disorders in epilepsy, referral to the epilepsy center). Direct data on patient outcomes could not be obtained within the funding period. The session evaluation was distributed using REDCap, a HIPAA-compliant data collection platform [16]. Providers completed the evaluation at the end of each session. We examined scores at the item-level and in aggregate for the outcomes assessed.

3. Results

3.1. Attendance

Attendance for the first two sessions of Y1 was below 12, but from the third session on through the end of Y2, mean attendance was 27.5 and ranged from 15 to 38 participants (Fig. 2), with a total of 164 unique individual participants, and 48 attendees who attended more than one session. 59% of attendees were local or regional (e.g., Ohio, Kentucky, Indiana), 22% were from outside of the tristate area (e.g., Illinois, Michigan, Pennsylvania, North Carolina, Maryland, Florida, Arizona, California, Utah, Minnesota, New York, Texas, Colorado), and 6% were from international locations (e.g., Germany, Canada, United Kingdom, France), who learned about the program from press releases on the EF website. 79% of attendees were practicing PCPs, family medicine trainees, nurses, and nurse practitioners.

Twenty-eight percent of respondents reported seeing zero adult patients with epilepsy each week, 42% reported seeing 1–5 PWE, 12% reported seeing 6–15 PWE, and 19% of respondents reported seeing 16 or more adult PWE each week. 27% reported seeing zero adult patients with other neurological disorders and 38% reported seeing 1–5 adult patients with other neurological disorders each week. These findings were generally consistent with our preliminary estimates.

Didactic presentations archived on the University of Cincinnati website (www.cincinnati.cho.com) have been viewed over 212 times, with seizure topics as the most viewed (Fig. 3).

3.2. Evaluation

Among 514 session attendees, of whom 164 were unique participants, we received 95 responses to the after-session survey (evaluation response rate 18.48%). On a scale of 1–5 (1 = strongly disagree, 2 = disagree, 3 = neutral, 4 = agree, 5 = strongly agree), participants rated the following items: pertinent and relevant to my practice (Mean = 4.29, Median = 4, IQR = 1, Range = 3–5); increased my confidence in managing this type of patient (Mean =

4.26, Median = 4, IQR = 1, Range = 3–5); case provided valuable information to my practice needs (Mean = 4.38, Median = 4, IQR = 1, Range = 3–5); knowledge on topic increased (Mean = 4.40, Median = 4, IQR = 1, Range = 3–5); and video coaching was an effective means to provide education (Mean = 4.40, Median = 4, IQR = 1, Range = 3–5).

Following the sessions, over 97% of respondents reported increased interest in improving care of patients with neurological disorders, including epilepsy. Over 98% of respondents reported increased comfort and self-efficacy when treating patients with neurological disorders, including epilepsy, and improved knowledge and utilization of varied resources for treating these patients. Over 98% of respondents reported that the presentations were balanced and evidence-based.

Participants were asked what changes they will make to their practice as a result of attending the session, and the general response themes were improved diagnosis and treatment of epilepsy and other neurological disorders, appropriate use of medications, and improved understanding of when to refer to an epilepsy center for further assessment. For instance, one participant commented, “this lecture and case presentation helped with my ability to make a diagnosis of migraine headache,” and another “appreciated the case studies provided as real-life examples comparable to individuals I’ve worked with regarding coping and adapting to changes in their strategies to manage their seizures.” Regarding the session on psychogenic seizures, one participant commented, “I really am able to take information back to my setting where I have multiple people with this problem,” and another remarked that they “practice in a very rural area--takes 5 months to get referral to neurologist and months for referral to psychiatry for patients with or without insurance. It is a huge issue so appreciate all insights related to what primary care can do when [patients] can’t see neuro, psych, or whoever for a period of time. Even our Columbus [Ohio] neurologists are booked out for months.” One participant commented that they “will attempt to refer refractory patients earlier,” and another that, “some of [their] patients are not well controlled for a variety of reasons--will discuss referral with them to the epilepsy center.” Further, one commented that they now “understand when to refer patients suspected of PNES [psychogenic nonepileptic seizures],” and another “will be better equipped to answer questions about psychogenic seizures.” Survey respondents also reported that they planned to share the knowledge learned with colleagues and residents. There were very few negative comments from respondents. The constructive comments included wanting more information on a topic or study and more time to hear more about the case discussions. Two early survey respondents reported issues with audio quality/connection affecting their participation in the session.

Participants were also asked if they had any suggestions for future teleconferences and we received 24 suggestions. The most common requests included ASM ($N=5$), headache/migraine ($N=5$), and dementia ($N=3$). Headache/migraine and dementia were covered in both years one and two and a review of ASM was incorporated into the year two curriculum.

All faculty who were asked to present didactic presentations agreed to do so; additionally, each one gave positive feedback on the sessions, and all volunteered for future sessions. One specialist remarked that he “felt able to discuss [his] topic in detail to a wider audience in

a dynamic format.” Another was “grateful to take part in education and open dialogue with our peers in primary care, as epilepsy care depends on such collaboration.”

4. Discussion

The goal of successfully piloting the first Epilepsy/Neurology Project ECHO targeting PCPs who care for adults with epilepsy in Ohio and the surrounding region was achieved. Feasibility outcomes indicated that use of the Project ECHO model was successful in that it was rated favorably by providers and showed increasing attendance over time. In addition, we had enthusiastic participation from epilepsy and neurology faculty presenters. The overwhelming majority of participants reported greater interest in caring for, as well as greater comfort in treating, patients with neurological disorders. Primary care providers can improve confidence in managing issues that do not necessarily require a neurologist or epileptologist, and at the same time identify those patients who do need a referral to a specialist. The program also instructed participants on the most expeditious way to make those referrals to a neurologist or epilepsy center.

Attendance rates were similar to comparable Project ECHO programs, as mean attendance for other neurology-based ECHO sessions were 24 and 14 [17,7]. Compared to a recently published Project ECHO program on epilepsy education for pediatricians and provided details about attendance rates, our attendance numbers were substantially higher per session and we had 212 views of the recorded and archived didactic presentations on our website. The focus of the Joshi et al. study was to collect specific quality improvement data and the requirement of participants to attend every session and perform chart reviews may have limited their participation [7]. Our higher participation rates may have also been due to the marketing efforts completed in partnership with EF or the combination of alternating epilepsy and other neurology topics. For instance, a PCP seeing a large number of patients with headache may log on to the teleconference on headaches and migraine, and finding value in the virtual educational format, may be more likely to log on to a future epilepsy session.

Program leadership also influenced attendance, as well as the type of practitioner who attended. Participants from primary care training programs were expected in even greater numbers; however, because schedules of trainees are tightly controlled by leadership, the selected Thursday noon timeframe did not fit with the schedules of several of the regional primary care trainees. By the end of Y2, working more closely with the leadership from regional residency training programs in regard to scheduling allowed for more attendees, thus indicating that fitting in a Project ECHO program for these participants could take more than a year of advanced planning. Although unexpected, a few providers from outside the United States, who learned of the program and requested to participate, were allowed to do so as their participation did not limit U.S. attendees in any way—demonstrating the appeal and reach of the program.

Additionally, lack of understanding of the Project ECHO program model by leaders of regional large PCP groups may have influenced attendance. Although these leaders wrote letters of support for the initial Project ECHO funding proposal, there was limited

participation among these groups. Based on discussions between the PI and some regional healthcare leaders, we speculate that there may have been an underlying suspicion that the Project ECHO program was intended to divert specialty patients (i.e., those with epilepsy) away from their current system of care. On the contrary, the goal of the program is the opposite; Project ECHO seeks to empower PCPs to provide care to complex patients without having to send the patients to experts many miles away or in other health systems. The Project ECHO goals were clearly communicated in all outreach activities, marketing materials, and in direct discussions with leaders. Nevertheless, we believe increasing competition for patients among regional healthcare systems created a reluctance to participate in the Project ECHO program. Undoubtedly, this is not unique to epilepsy and there may be lessons learned from application of Project ECHO to other conditions that can inform future implementation efforts. Additionally, applying strategies to engage regional leaders collectively to address and overcome territory concerns, as is commonly done when implementing public health community-based interventions, may be helpful in clarifying goals and minimizing turf battles [18].

In delivering the program, case solicitation proved to be a challenge. Eight patient cases were submitted to the Project ECHO team for review and consultation, but faculty presenters provided most of the real patient cases to illustrate the topics presented. This Project ECHO program was instrumental in addressing issues for high-risk subgroups of PWE. For example, special considerations for women with epilepsy, especially related to pregnancy, is an important topic for PCPs and Obstetrics/Gynecology providers that was covered in the program curriculum. Many publications and guidelines were summarized for participants, including newer information on the multiple risks of valproate during pregnancy. It is important for PCPs to have this knowledge because although the number of unintended pregnancies in the US has dropped (from 51% in 2008 to 45% as of 2011), the large number of unplanned pregnancies is a major concern, and many women with well-controlled seizures may not be in regular follow-up with a neurologist [19]. Thus, many women at risk for adverse pregnancy outcomes due to ASM will rely on PCPs or Obstetrics/Gynecology providers for pre-pregnancy counseling. Another subgroup of PWE targeted included those with comorbid mental illness. Primary care providers gained knowledge on how to identify depression and anxiety in PWE using validated, time-efficient tools in the clinic and the safety of using a variety of antidepressants and anti-anxiety medications. Participants also learned about the readily available self-management tools developed by the CDC Managing Epilepsy Well (MEW) network and how to refer patients to the Epilepsy Foundation, where counseling services and enhanced access to the CDC/MEW programs are available. Finally, it should be noted that Project ECHO provided an opportunity to meet regional provider needs regarding the use of medical marijuana in epilepsy care, which demonstrated a promising approach to address timely medical education needs.

Critical to epilepsy care, the Project ECHO program raised awareness among PCPs about the indications and urgent need to refer patients with medication-resistant epilepsy to an epilepsy center when they have exhausted treatment options. Engel described the problem succinctly: “While diagnosis and treatment at a full-service ([National Association of Epilepsy Centers] levels 3 and 4) epilepsy center are demonstrated to improve seizure control, fewer than 1% of people with DRE [drug-resistant epilepsy] are referred, and

those who are, are referred an average of over 20 years after onset of habitual seizures. A possible reason for this is the misconception that all these epilepsy centers offer is surgery” [2]. Project ECHO programs in multiple therapeutic areas have demonstrated that the referral process improves when guidelines for referral are distributed with standard referral forms and when the consulting clinicians are involved in teaching about referring. Simply distributing guidelines and providing healthcare professionals with feedback about how they are referring may not improve the process [20]. The many versions of protocols and guidelines for timely referrals to epilepsy centers have not been effective in getting the majority of PWE who need advanced diagnosis and treatment to an epilepsy center. Through the Project ECHO program, PCPs learn basics of new-onset seizures and seizure-like episodes, and when to refer to the epilepsy center for video or EEG monitoring for advanced diagnostics, as well as advanced nonsurgical treatments.

This study has several limitations. We relied on participants’ self-report on comfort in treating patients with neurological disorders, knowledge of the topic areas, and relevance to their practice, but did not do chart reviews to discern whether the learnings were put into practice. We have not determined if participants have increased referrals to an epilepsy center, although with the relatively small number of epilepsy cases per PCP, this analysis would likely take several years. Other Project ECHO programs have offered maintenance of certification (MOC) credit along with continuing education credits (CME), whereas we offered only CME. MOC requirements are more rigorous, and require tracking quality improvement efforts over time, through participants’ consistent attendance and mandatory patient case submissions for review. Thus, offering MOC may draw in more consistent participants, as seen in the Joshi et al. study, but the flexibility of offering CME per session may have increased our overall numbers [7].

Primary care providers provide a large proportion of care for many adults with epilepsy, including at least one-half of those with uncontrolled seizures, so they need regular training for updates. However, PCPs treat patients in so many therapeutic areas that epilepsy often becomes a less important concern. The University of Cincinnati Epilepsy/Neurology Project ECHO program took advantage of the convenience of telehealth and combined epilepsy education with general neurology topics to generate interest among providers. This approach was successful based on evaluations and attendance. Improved knowledge and confidence among PCPs is expected to lead to improved care for PWE, through improved management of ASM, better monitoring for comorbidities, optimizing ASM use during pregnancy, and timely referral to epilepsy centers. Our initial findings add to the growing evidence for use of the Project ECHO model for both adult and pediatric providers to improve provider knowledge about, and confidence in, appropriate epilepsy treatment and care for the estimated 810,000 U.S. adults with epilepsy followed up primarily by their PCP [10]. Additional research is needed to explore impact on patient outcomes.

5. CDC Disclaimer

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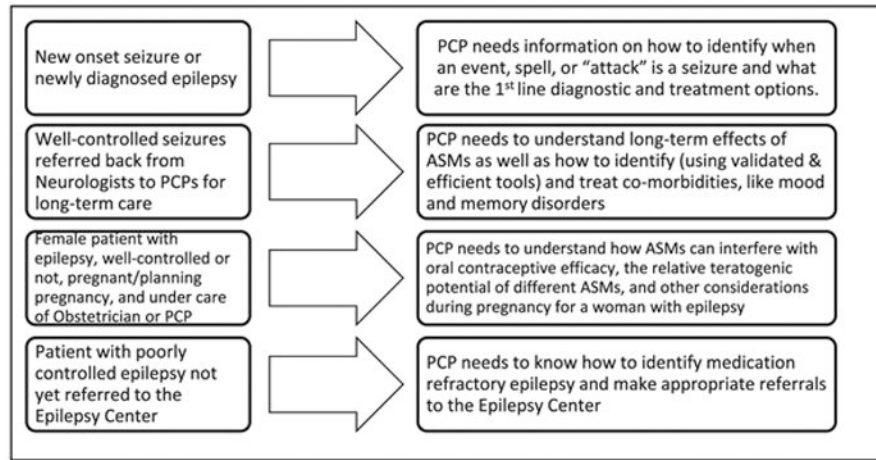


Fig. 1. Common epilepsy-related scenarios faced by primary care providers (PCP).

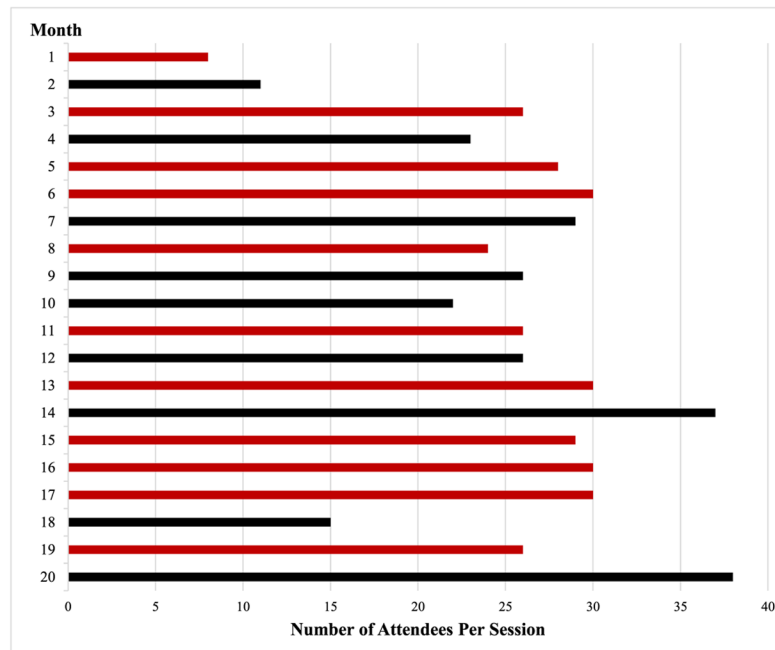


Fig. 2. Project ECHO Epilepsy/Neurology Program Number of Attendees by monthly session. The color red indicates the session focused on an epilepsy topic (e.g., ASMs, referrals to Epilepsy Centers). The color black indicates the session focused on a non-epilepsy neurology topic (e.g., traumatic brain injury, migraines).

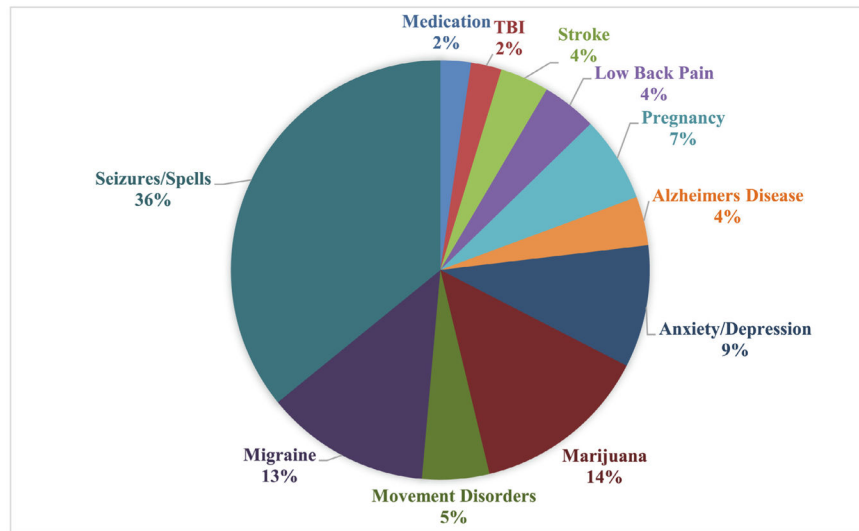


Fig. 3. Project ECHO Epilepsy/Neurology Program Archived Video Views by Topic on Website (% of total views).

Table 1

Project ECHO Epilepsy/Neurology Program Didactic Presentation Topics.

Y1 + 2	Primary Care Approach to Seizures, Syncope, and Other Spells
Y1 + 2	Primary Care Approach to Treatment of Migraine & Severe Headache
Y1 + 2	Primary Care Approach to Seizure Diagnosis & Treatment & Role of Epilepsy Center
Y1 + 2	Marijuana for Epilepsy & Other Neurological Indications
Y1 + 2	Primary Care Approach to Treatment of Alzheimer’s Disease & Dementias
Y1 + 2	Women & Epilepsy: Considerations for Pregnancy
Y1 Only	Mood Disorders & Anxiety in Epilepsy, Including Self-Management
Y1 Only	Primary Care Approach to Recognizing Parkinson’s and Other Movement Disorders
Y1 Only	Primary Care Approach to Treatment of Acute & Chronic Low Back Pain
Y1 Only	Primary Care Approach to Stroke Diagnosis & Treatment
Y2 Only	Traumatic Brain Injury, Concussions and Seizures
Y2 Only	Primary Care Review of Antiseizure Medications and Integrative Treatments
Y2 Only	Risks and Comorbidities Associated with Epilepsy
Y2 Only	Psychogenic neurologic disorders including psychogenic seizures & movement disorders

(Year 1 = Y1; Year 2 = Y2).