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Innovative approaches reaching underserved and rural communities to improve epilepsy care: A review of the methodology of the Connectors Project

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ABSTRACT

Objective: The Connectors Project, a collaboration between the Epilepsy Foundation and UCB Pharma, was a multiyear project designed to improve epilepsy care in underserved communities. A core objective of the Connectors Project was to pilot new and innovative approaches to epilepsy awareness and education in rural and underserved areas, including standardized curricula for healthcare providers and patients.
Methods: A series of consensus conferences explored opportunities and barriers to epilepsy care throughout the United States including access to local Epilepsy Foundations, neurologists, and epilepsy centers. Data from QuintilesIMS™ were examined for access to newer antiepileptic drugs (AEDs)—a proxy for quality of epilepsy care—in different regions. State factors (e.g., local epilepsy foundation office, access to newer vs. older AEDs, and geographic density and diversity) were used in selecting four states as examples of rural and underserved areas to pilot the awareness and educational programs. For each state, a work team assessed challenges and opportunities, tailored educational curricula, and developed strategies for effective delivery of the educational programs. Interventions were held between June 2016 and June 2017. Interventions consisted of outreach and awareness programs, in-person health education to healthcare providers and patients/families, and digital health education.
Results: Michigan, Nevada, Oklahoma, and West Virginia were identified as pilot states representing geographically diverse areas, ranging from a state with a large high-density population center with several epilepsy centers and a local Epilepsy Foundation office (Michigan) to a state with predominately rural areas and a few small urban cores, two epilepsy centers, and no in-state Epilepsy Foundation office (West Virginia). State work teams tailored interventions and examined options for type, intent, ease of use, and impact. All states implemented outreach and awareness initiatives and in-person health education for patients and healthcare providers; use of digital health education was variable. Measurement of the interventions was agreed to be performed by the use of patient and physician surveys and reevaluation of data from QuintilesIMS for access to newer AEDs.
Conclusion: Local Epilepsy Foundation offices successfully connected healthcare providers in rural and underserved areas to epilepsy education designed to enhance quality care in epilepsy. Educational opportunities for people with epilepsy and their families addressed critical gaps in accessing quality epilepsy care and self-management. Tailored and innovative educational approaches can be used to increase awareness levels and to overcome geographic challenges in reaching underserved populations. Relationship building and repeated, consistent engagement with healthcare providers and patients can assist in improving communication and self-management skills among patients with epilepsy.

Abbreviations: AED, antiepileptic drug; NAEC, National Association of Epilepsy Centers; PAM, patient activation measure; VA, Veterans Health Administration.

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1. Introduction

Epilepsy is a chronic disease that impacts over 3.4 million people in the United States [1]. As with other chronic diseases, health outcomes in people living with epilepsy are influenced by many factors, ranging from socioeconomic status, location, and access to transportation, to other social, behavioral, and environmental dimensions [2]. Health disparities between different populations that contribute to differences in health outcomes, and factors contributing to these disparities, vary between individuals and across population levels. A person living with epilepsy embodies certain behaviors that influence how health information is sought, whereas population-level challenges are related to systems, geographic isolation, and lack of transportation. Access to quality healthcare from knowledgeable healthcare providers affects these health disparities at both individual and population levels. Several studies have investigated health disparities related to the impact of socioeconomic status, education, and transportation on epilepsy care [2–5]. Although social, behavioral, and environmental issues also contribute to health disparities in epilepsy [2], these issues remain among the least understood.

Accordingly, the Connectors Project sought to further characterize some of the social and environmental issues in epilepsy and design state-based initiatives to begin to address these issues. Our committee chose to define and address health disparities in terms of three key issues: (1) factors that impact the delivery of epilepsy care (access to neurologists and use of newer antiepileptic drugs [AEDs]), (2) geographic distribution of clinicians and patients with epilepsy, and (3) behavioral, social, and advocacy factors (e.g., patient activation, stigma, relationships with healthcare providers, and Epilepsy Foundation presence).

1.1. Factors impacting the delivery of care in epilepsy

Quality of care in epilepsy can be influenced by many factors beyond the medical visit, such as care setting, access to specialists, and access to innovation including newer-generation AEDs. Efforts to define quality epilepsy care included a focus on having healthcare providers assess patient educational needs, medication side effects, and providing other sources of support and referral [6]. The collaboration between patient and healthcare provider must be in a supportive environment that optimizes health outcomes. For example, employing nurse practitioner–physician teams versus physician-only care has been associated with improved delivery of epilepsy quality measures such as querying patients regarding AED side effects and providing safety education and behavioral health screenings [7]. In addition, quality of care has been found to be more thorough for patients receiving epilepsy care in both specialist and primary care settings versus either setting alone [8].

Factors pertaining to the delivery of care must also consider referral and/or access to specialist healthcare providers knowledgeable of the latest treatments for epilepsy. However, studies show that 26% of treated and 76% of untreated adults with uncontrolled seizures had not seen a neurologist or epilepsy specialist in the preceding year [9]. In the California Health Interview Survey study, 27% of adults with active epilepsy and 59% of those without current seizures had not visited a neurologist or epilepsy specialist in the preceding year, and 26% with recent seizures were not taking any AED [10]. Access to mental health specialists was also suboptimal, with 43% of patients reporting a need for such services but not obtaining them. Notably, neurologist care is associated with reduced rates of emergency department use for patients with epilepsy, particularly for those with more severe epilepsy (odds ratio, 0.44) [11].

Although newer AEDs have similar efficacy as older AEDs, they have fewer drug interactions and improved pharmacokinetics, leading to potential safety and tolerability advantages [12]. Despite these potential benefits, a study of state prescriptions for AEDs reported that older-generation AEDs are prescribed for 25.7% of patients with newly diagnosed epilepsy [13]. Furthermore, a study of elderly patients (>65 years of age) treated through the Veterans Health Administration (VA) found an increasing, although fairly low (20%), use of newer AEDs [14]. This finding is troublesome because the elderly are characterized by age-related changes in metabolism, weight, multiple comorbidities, and comedications that may render this population particularly susceptible to adverse events and other safety concerns [15,16]. Additionally, one large database study found that only 52.2% of newly diagnosed epilepsy patients received at least one AED treatment within 1 year after the index date, indicating a need for improved education and epilepsy management [17].

Socioeconomic factors and insurance coverage also impact AED access. Analysis of National Health Interview Surveys showed that of adults with active epilepsy and seizures, nearly half had household incomes of <$25,000, and 13.2% did not take any AED [3]. Compared with adults without epilepsy, those with active epilepsy have a 2.4-fold increased risk of not being able to afford medications [18]. Furthermore, patients without insurance are more likely to access healthcare via an emergency department visit versus those with insurance [19] therefore increasing the overall cost of treatment of epilepsy in emergency departments. Inappropriate use of emergency departments for epilepsy care highlights one of the challenges in managing treatment for underserved patients with epilepsy. Receiving appropriate and optimized AED therapy, as well as ensuring adherence, is critical to prevent breakthrough seizures. However, even when patients adhere with AED treatment, the population with uncontrolled epilepsy incur significantly more hospitalizations and emergency room visits, and 2.3 and 8.1 times higher overall cost and epilepsy-related costs, when compared with patients who have effective seizure control [20].

1.2. Geographic distribution of clinicians and people with epilepsy

Many people living with epilepsy reside in geographically isolated and rural areas where access to healthcare providers knowledgeable in epilepsy care and management may be challenging. Nationwide, 19% of Americans <65 years of age live in rural areas, and 15 states are considered to be 50–100% rural [21]. Healthcare delivery in rural and underserved settings is affected by factors such as lack of employment, lower household income, lack of transportation, limited insurance coverage, lower density of healthcare providers and specialists, and long commute distances to healthcare providers [21]. These factors can lead to delays in care and access to newer AEDs, and lack of adequate support and education, all of which may result in preventable hospitalizations.

Access to neurologists is challenging because of a low supply nationwide, with rural areas especially affected [22]. Compounding this shortage is the limited availability of epilepsy care specialists in rural areas. Indeed, Comprehensive Epilepsy Centers are mostly concentrated in urban areas, and there are a limited number of centers in many states and no centers in some states (Alaska, Montana, North Dakota, South Dakota) [23]. Closure of rural hospitals further hinders healthcare access for patients living in these communities [24].

These limitations have a direct impact on people with epilepsy. A global study reported that people with epilepsy in rural areas had a two-fold increased risk of remaining untreated than those in urban areas [25]. A follow-up study reported that epilepsy treatment was more likely in areas where there was a higher density of physicians [26]. People with active epilepsy were greater than five times more likely the general population to lack transportation to healthcare services [18]. Medical programs that incorporate elements of electronic delivery (e.g., telemedicine) have shown promise in providing services to people with epilepsy in rural communities [27], and efforts are underway to improve epilepsy care for underserved and rural children with epilepsy [28].

1.3. Behavioral, social, and advocacy factors

Health outcomes are influenced by a range of environmental, behavioral, social, and advocacy factors. The environment in which people live, play, learn, and work affects health outcomes as well as quality of life [29]. In the California Health Interview Survey, 75% of adults with recent seizures reported only fair-to-poor health and nearly 28% reported extreme limitations to their activities because of epilepsy or its treatment [30]. Compared with people without epilepsy, those with epilepsy reported three times as many physically and mentally unhealthy days per month, and 2.5 times as many limited activity days per month [30].

The impact of epilepsy on a person's health status and their ability to manage their health are critical components of epilepsy self-management. Self-management behaviors are implemented for a number of chronic diseases and may include taking medicines regularly, seeking proper healthcare, and preventing and managing comorbidities [31]. For people with epilepsy, self-management also includes employing proper seizure first aid and using appropriate safety plans [32,33]. Surveys of people with epilepsy reveal that they want to be more informed and involved in their epilepsy treatment [34,35]. The impact of an online community to assist patients with epilepsy management showed improvements in both disease management and treatment efficacy among VA patients with epilepsy [36]. Self-management strategies may take on particular importance for patients residing in rural communities, and several telephone- or internet-based initiatives are available [37,38]. Such approaches may also help individuals avoid any identified seizure triggers, as well as circumvent stigma-related barriers to care. Among rural parents of children with psychosocial needs, stigma associated with assessing mental health services was associated with decreased treatment-seeking behavior [39]. Finally, although the Epilepsy Foundation provides a critical source of information, advocacy, and support services, their reach is hampered in some regions lacking an in-state Epilepsy Foundation office [40].

1.4. Overarching approach to address disparities

To improve healthcare in people with epilepsy in rural and underserved communities, multiple and effective strategies to reach both patients and healthcare providers must be employed for achieving optimal health outcomes [41]. Although rural and underserved areas may have similar challenges, unique characteristics of these communities must be considered in designing interventions, with strategies tailored to each community's unique strengths and gaps. The capacity for effective epilepsy management and quality of epilepsy care varies by state [42]. Even in states with high density urban centers and numerous epilepsy centers, some underserved communities and populations within these urban centers may not access healthcare appropriately (because of stigma, cultural beliefs, and socioeconomic disadvantages [43,44]), or may delay care until an emergency department encounter [45].

Treatment by a neurologist has been associated with improved epilepsy outcomes (i.e., decreased hospital [46] and emergency department [11] encounters). This suggests that access to a neurology specialist may improve care and lower overall costs. One example is the VA network of Epilepsy Centers of Excellence [47], which resulted in increased coordination of care between neurologists and other healthcare providers [48]. Yet, a survey of the utilization of the National Centers of Epilepsy Excellence estimated that only 22% of Americans with refractory or uncontrolled epilepsy are seen at an epilepsy center in any given year [49]. These findings led the Epilepsy Foundation and UCB Pharma to initiate the Connectors Project to identify needs and to support tailored and specific efforts by states, with an aim of enhancing access to AEDs and physicians and improving education and patient connectivity across a variety of settings to improve the quality of care and patient outcomes.

1.5. Overview of Connectors Project

The Connectors Project was a pilot collaboration to improve care in adults with epilepsy in underserved areas within the United States. The primary objectives of this pilot were as follows: (1) to improve the diagnosis and management of epilepsy in underserved geographic areas, which lack sufficient epilepsy centers or epilepsy healthcare specialists; (2) to improve patient and caregiver knowledge of epilepsy and partial onset seizures and increase epilepsy self-management; (3) to improve communication skills between undertrained healthcare providers, patients, and caregivers for better health outcomes; and (4) to use project outcomes to design or improve communication tools aimed at improving healthcare provider knowledge about epilepsy and supporting patient involvement in managing their epilepsy.

A major strategy of the collaboration is to provide epilepsy education to both rural and urban healthcare providers who currently care for people with epilepsy, but whose training in epilepsy diagnosis and care is insufficient to lead to optimal patient outcomes, using published quality measures in epilepsy [6]. A secondary audience for this collaboration is the epilepsy community — specifically people living with epilepsy, their caregivers, and families. The Connectors Project steering committee employed new and tailored approaches at the community level to assess the best public health education practices. This article describes the overall methodology and implementation of the Connectors Project in pilot states.

2. Methods

Methodology was separated into two phases: phase 1 to choose pilot states, and phase 2 to plan and implement tailored interventions to each region and agree on the methods to evaluate the impact of those interventions.

2.1. Phase 1

A project steering committee consisted of epileptologists, nurses, national Epilepsy Foundation staff with expertise in education and public health, local Epilepsy Foundation staff and health educators with knowledge of the local landscape, other healthcare professionals and stakeholders invested in epilepsy and rural health, and people with epilepsy. The assessment portion of phase 1 was outlined in a recent paper [13].

Results from the assessment allowed the Connectors steering committee to explore the underserved epilepsy population by state and to assess areas with the greatest educational needs. Selection criteria were established to identify states with the following: (1) high differences regarding access to newer versus older AEDs, (2) an association with an Epilepsy Foundation local office, (3) support from the local office to employ a partnership for epilepsy education for healthcare providers and people living with epilepsy, (4) participation in digital education, services and support from www.epilepsy.com, the public use website of the Epilepsy Foundation, and (5) geographical diversity (e.g., rural or urban areas with variance in access to medical care). Qualitatively, state scorecards from the Epilepsy Foundation were used to assess access to AEDs and epilepsy care [42]. These scorecards provided information about the utilization of newer AEDs, as well as the availability of neurologist care, for each state compared with other states. Estimates for the number of active epilepsy cases were extracted from state-specific data reported for 2015 [1].

Access to AEDs was evaluated by examining a large national database, QuintilesIMS™, which provides longitudinal retail prescription data and office medical claims data. These data helped to determine the initial state of epilepsy care by tracking prescription drug use for patients with newly diagnosed epilepsy as a proxy for quality epilepsy care. State AED-specific data from 2013 to 2015 were evaluated, and patients with a prescription for phenytoin, other older AEDs, or newer AEDs were identified [13].

Data on the number and location of comprehensive epilepsy centers were derived from the National Association of Epilepsy Centers, and the number of epileptologists and neurologists was assessed with data from the American Board of Psychiatry and Neurology.

Access to local Epilepsy Foundations was assessed by mapping the aforementioned data to states with a local Epilepsy Foundation office.

Participation in digital education and resources was assessed using heat maps that demonstrated the use of www.epilepsy.com within each state. This allowed the steering committee to examine opportunities and gaps for use of digital education in select areas.

Geographic diversity was based on the analyses by the Connectors steering committee. Four states chosen for the Connectors Project pilot had various resources for epilepsy care. Collectively, they represented gaps in access to care for people with epilepsy in underserved and rural communities across the United States. A description of the pilot states includes the following:

1. Michigan: State with a large high density population center and smaller cities at a distance with numerous epilepsy centers and a local Epilepsy Foundation office.
2. Nevada: State with a large geographic area with two high density population centers, large rural underserved regions, two epilepsy centers, and a local Epilepsy Foundation office.
3. Oklahoma: State with a moderate size population center, large rural underserved areas, one epilepsy center, and a local Epilepsy Foundation office.
4. West Virginia: State with predominant rural areas with a few small urban cores, two epilepsy centers, and no in-state Epilepsy Foundation office.

2.2. Phase 2

Work teams were established for each pilot state that included the Epilepsy Foundation's national and local office staff and a healthcare provider familiar with epilepsy care in the state. The state teams further analyzed and evaluated epilepsy care within their states for factors affecting the delivery of epilepsy care, geographic distribution of clinicians and patients, and behavior, social, and advocacy factors (Fig. 1). The state teams reviewed federal, state, and private datasets to inform their evaluation of epilepsy care, and to identify potential barriers that may impede access to care. The work teams considered the availability of primary care providers, neurologists, epilepsy centers, and population data. Additionally, the state teams considered access to healthcare providers and a variety of adult learning strategies to best reach providers and people living with epilepsy for the pilot activities.

2.2.1. Educational curricula and initiatives

A standardized educational curriculum was developed for healthcare providers and patients that focused on new-onset seizures in adults and incorporated the 2014 quality indicators for epilepsy from the American Academy of Neurology [6], information from other epilepsy guidelines and best practices [50,51], the importance of patient-centered care (using the Epilepsy Care Model [2]), patient-provider communications, and self-management education and behaviors.

The curriculum for patients and their families/caregivers, *Seizures and Epilepsy in Adults: Quality Care Takes Teamwork*, consisted of modules that could be provided in three sections or otherwise tailored to meet the needs of the target audience(s). The curriculum included an overview of seizures and epilepsy, the initial diagnosis, treatment options, concerns for women with epilepsy, and self-management strategies.

The curriculum for healthcare providers, *Diagnosing and Treating Seizures and Epilepsy for Providers*, provided an overview of epilepsy and seizures, the initial diagnosis, treating epilepsy in adults, and enhancing access, communication, and quality care. The provider curriculum was designed to be delivered as a 60- to 75-min in-person presentation or shorter modules for online learning. The target audience was healthcare providers who lacked an extensive background in epilepsy (e.g., internal medicine practitioners, physicians' assistants, family practitioners, nurses, and emergency room physicians) who provided care to people with epilepsy.

Educational interventions were adapted and tailored by state work teams to address the local needs of each site, and included a variety of outreach and awareness and in-person and digital health education (Table 1). Work teams identified stakeholders, work plans, and interventions that could be tailored to state needs and gaps. All states

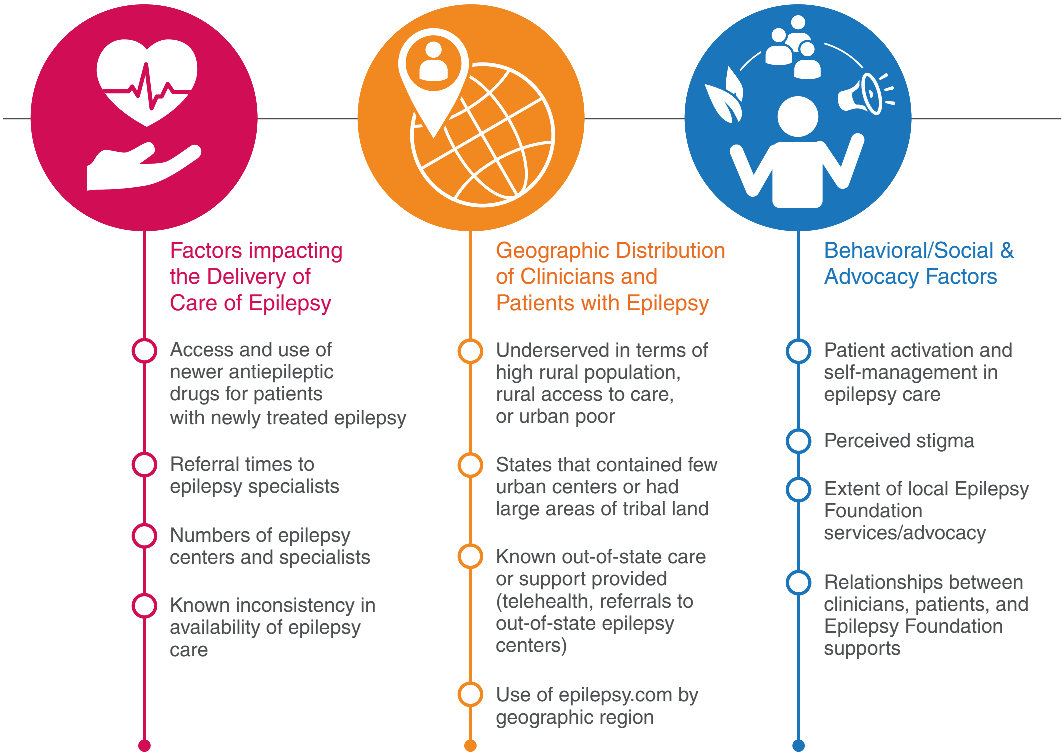

Fig. 1. Factors affecting the quality of care in epilepsy.

Table 1
Types of interventions.

	Outreach and awareness	In-person health education	Digital health education
Clinicians	Advisory group meetings Individual outreach to clinicians and centers Physician panels Regional and national exhibits Relationship building with clinicians and healthcare organizations	Small group meetings Grand rounds Local or regional conferences Visits to practice settings	Conference calls Referral to epilepsy.com for additional learning and resources Webinars
People with epilepsy	Direct mail Organized walks Support groups Regional and national exhibits	Small group meetings Patient support groups Local or regional conferences	Conference calls Referral to epilepsy.com for additional learning and resources Webinars

included outreach and awareness strategies to different degrees. For example, a state with poor public awareness of epilepsy or lack of communication among stakeholders might focus on engagement strategies first. Multiple interventions were held between June 2016 and June 2017, and quantitative data were collected using pre- and postintervention surveys.

2.2.2. Methods of evaluation

The impact of the Connectors Project in the four pilot states was evaluated in terms of changes in participant performance, competence, knowledge acquisition, and patient activation. The following measures were employed:

1. Performance: (a) Quintiles IMS database to measure AED use in adults with newly diagnosed epilepsy as a proxy for quality care, (b) self-reported frequency of provider communication with patients/families about epilepsy quality indicators, (c) patient/family reported changes in referral to epilepsy centers, and (d) digital analytics and heat maps to capture the number of educational sessions on epilepsy.com.
2. Competence: (a) provider confidence in communicating with patients/families about epilepsy quality indicators, and (b) patient/family satisfaction with information provided and comfort communicating with their healthcare team.
3. Knowledge acquisition and patient activation: (a) patient/family survey to assess knowledge about epilepsy-related topics, and (b) completion of the patient activation measure (PAM).

With the exceptions of AED use and website activity, all other measures were captured with self-report surveys completed before the intervention and at 3 and 6 months after the intervention period. Healthcare provider surveys included questions regarding practice setting, learning preferences, confidence in and communication with patients and families about critical care issues. These care issues included topics from the 2014 quality measure set in epilepsy and other areas deemed important by the Connectors steering committee (e.g., seizure frequency, referral to specialist). Patient surveys captured demographic and epilepsy-related information, as well as their satisfaction with information and comfort discussing topics with their providers, basic epilepsy knowledge, and measures of patient activation.

The use of epilepsy.com as a source of information, education, and self-management resources was encouraged by the pilot sites, with educational curricula tailored to direct participants to complementary pages on epilepsy.com. Baseline data for the year before interventions, from June 2015 to June 2016, were obtained for each state and compared with the state's population as well as the number of people with active epilepsy during that time period. The activity was compared with the overall state population because the type of user (i.e., person with epilepsy, family member, healthcare professional, or other) was unknown. Results from the four pilot states were also compared with nationwide use of epilepsy.com during the same time period.

3. Results and insights

States selected for implementation of the Connectors Project possessed unique structural and social system challenges that contribute to health disparities as defined by the committee (i.e., geography, social, and environmental issues) (Fig. 2). Selected environmental and system challenges are highlighted below for each state and in Table 2. Across the contiguous United States, the majority of patients newly diagnosed with epilepsy were prescribed newer AEDs (eslicarbazepine, lacosamide, lamotrigine, levetiracetam, oxcarbazepine, perampanel, topiramate) versus older AEDs (carbamazepine, phenytoin, valproate) compared with the overall population with epilepsy [13]. Despite this trend, a notable proportion of patients still received older AEDs (Table 2).

3.1. Phase 1 — pilot states

3.1.1. Michigan

Michigan is a large state with a large urban core. The major concern of the Michigan state work team was related to problems referring patients to epilepsy centers as well as the initial treatment selected by emergency room clinicians. Referral issues often resulted in decreased access and quality care for people with epilepsy, while emergency room treatment may focus on acute management with less emphasis on the long-term treatment implications resulting from the initial AED selected (e.g., considerations related to switching from intravenous to oral dosing).

Despite the availability of 49 epileptologists in Michigan, many people with epilepsy are evaluated and seen by general neurologists for several years. They are typically referred to an epileptologist only when they have failed all or most of the available AEDs, therefore impacting the chance of successful seizure controlled in the future. Studies show that delayed control of epilepsy impacts the probability of success of new treatments [52]. Fear of permanently losing a patient to an epileptologist may be a barrier to referral for some general neurologists, highlighting the need to educate clinicians on the benefits related to referral (e.g., the role they play in follow-up after the epileptologist visit to ensure optimal patient care). Lack of knowledge among emergency care physicians and clinicians was a problem for people with epilepsy in urban settings, adding to delays in referral to specialty care (personal communications, M. Spanaki, R. Derry, June 2016). Despite the abundance of epilepsy specialty care in Michigan, delays in the recognition of refractory epilepsy in the community and referral to comprehensive epilepsy centers remain a significant problem. After a referral, waiting times at a Comprehensive Epilepsy Center can add months to the years of delays that patients have already endured, highlighting the need for a better patient journey in Michigan.

There are eight Level 4 Comprehensive Epilepsy Centers in the state of Michigan, including two adult/pediatric centers, three adult centers, and three pediatric centers [23]. In 2012, adherence to epilepsy quality measures by neurologists in Michigan was assessed [53]. The results of this assessment revealed adherence was related to the number of

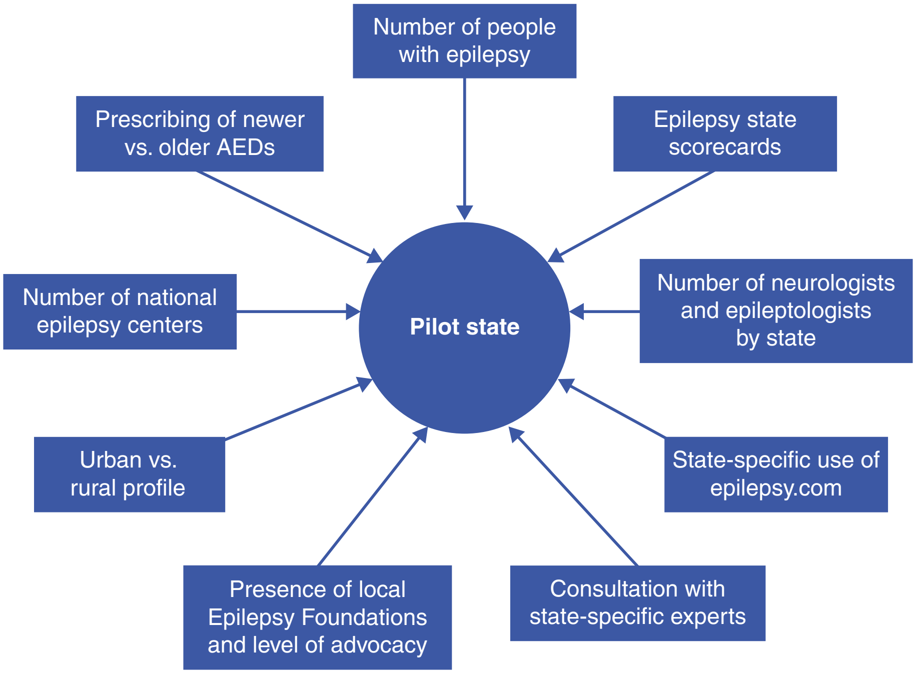

Fig. 2. State-specific factors impacting selection of pilot states for the Connectors Project.

years in practice, volume of patients with epilepsy, and fellowship training in epilepsy. Findings suggest a need for increased awareness and educational efforts in order to improve the quality of care of patients with epilepsy.

3.1.2. Nevada

Nevada is a large rural state with 15 counties. Nearly 88% of the state's population lives in two counties, Clark and Washoe [54], which are approximately 9 h apart by automobile. There are only two major population centers, Las Vegas and Reno. Las Vegas, the larger of the two cities, and its surrounding area of Clark County have over 72% of the state's population [55]. In 2016, 13.1% of nonelderly Nevada residents did not have health insurance [56], and one-third of residents were enrolled in Medicaid and/or Medicare [57]. Although the University of Las Vegas is the largest academic institution in the state, there is no major medical center or a school of medicine at this university. Rather, the major medical center is located in Reno.

There are 6299 allopathic physicians (medical doctors) in Nevada, and over 90% of the physicians practice in two counties [54]. Therefore, most remote and geographically isolated populations in Nevada do not have access to a physician. Just under 5% of the physicians practice in 14 rural and frontier counties [54]. The American Board of Psychiatry and Neurology further indicates that there are only 76 neurologists, two of whom are epileptologists practicing in Las Vegas [58].

According to the National Association of Epilepsy Centers (NAEC), there are two Level 3 Epilepsy Centers in Nevada; one in Las Vegas and the other in Reno [23]. According to the local Epilepsy Foundation office in Las Vegas, there is a strong relationship between the local epilepsy center and general physicians, but not with many neurologists. In practice, neurologists may refer patients to out-of-state epilepsy

Table 2
Characteristics of pilot states.

	Michigan	Nevada	Oklahoma	West Virginia
Population				
State [60], n	9,928,300	2,940,058	3,923,561	1,831,102
People with epilepsy [1], n	108,900	31,600	41,100	21,500
Population/mile^2 [56,59,63,64], n	174.8	24.6	54.7	77.1
Population density rank [65]	19	44	37	31
Rural population [56,59,63,64], %	25.4	5.8	33.4	50.9
Population in poverty [56,59,63,64], %	15.0	13.8	16.3	17.9
Physicians, n				
Primary care [61]	17,525	2941	4660	2751
Neurologists [58]	492	75	106	67
Epileptologists [58]	49	6	3	5
National Epilepsy Centers [23], n	8	2	1	2
Presence of EF in state	Yes	Yes	Yes	No
Use of phenytoin, other older AEDS, and newer AEDs [13], %				
Total patients, %	15.0, 24.5, 60.6	16.3, 22.0, 61.7	17.2, 21.8, 61.0	16.2, 23.9, 59.8
Newly treated patients, %	11.1, 16.7, 72.2	9.4, 14.0, 76.6	13.4, 13.2, 73.4	10.9, 13.0, 76.1
Scorecard rank[a] [42]				
Utilization of newer AEDs	B	C	C	C
Access to neurologists	B	F	D	C
Use of www.epilepsy.com				
Sessions in baseline period (June 2015 to June 2016), n	230,125	53,362	52,717	29,056
Sessions per population in the baseline period, %	2.32	1.81	1.34	1.59

[a] Reflects state rank, where A = 1–6, B = 7–16, C = 17–34, D = 35–44, F = 45–50.

centers, which limits access to specialty care for many patients. The Nevada work team found that communication among healthcare providers and patients/families was not ideal, and that awareness of epilepsy and of the local Epilepsy Foundation chapter was low.

3.1.3. Oklahoma

Oklahoma is also a large rural state with two major population centers, Oklahoma City and Tulsa. The state has a population of 3,923,561 [59]. Demographically, 66% of Oklahomans are non-Hispanic whites [59]. Native Americans, non-Hispanic blacks, and Hispanics each represent 8–10% of the state's population. According to the US Census Bureau, Oklahoma has high unemployment and 16% of the population lives below the US poverty line.

Oklahoma has less than 110 neurologists and epileptologists, which limits access to specialty care. Because the waiting time for an appointment at the epilepsy center can take up to 18 months, many patients receive epilepsy care from their primary care physician. Some patients with epilepsy seek care in neighboring states because of the lengthy delays for care in Oklahoma.

Oklahoma has only one NAEC-certified epilepsy center [23]. This Level 4 Epilepsy Center is part of the Oklahoma University Medical Center and is located in Oklahoma City, the largest city in the state. This center offers adult and pediatric epilepsy programs. Although not NAEC-certified, St. Anthony Hospital in Oklahoma City has an epilepsy monitoring unit for adults.

3.1.4. West Virginia

West Virginia is a mountainous rural state with many small geographically isolated communities. West Virginia ranks among the poorest states in the United States. With a population of just over 1,830,000 [60], West Virginia is noted for its depressed economy partly because of the state's declining coal industry. Because of its vast rural geography and lack of public transportation, many communities throughout the state are challenged with accessing primary healthcare. Additionally, physicians deal with much more than just seizure care as they work through insurance problems, lack of resources, frequent missed appointments, nonepileptic seizures, and much more.

West Virginia has two NAEC-certified epilepsy centers, Huntington (Level 4) and Morgantown (Level 3) [23]. The Level 4 epilepsy center is located within West Virginia University Hospital Center. For those patients with epilepsy able to overcome access and isolation barriers, there are strong connections to the epilepsy centers. There is no permanent in-state Epilepsy Foundation office, though services have been provided intermittently through the Ohio office of the Epilepsy Foundation of Greater Cincinnati and Columbus. According to the Epilepsy Foundation's local office, nearly 50% of people with epilepsy in West Virginia are connected to an epilepsy center while the rest seek treatment from general neurologists. Advance practice providers and school nurses are also a major source of care for people with epilepsy.

3.2. Phase 2 — types of interventions

Each state team selected a combination of awareness, outreach, and health education strategies to address healthcare providers, patients, and families. Implementation of these strategies was tailored to the state's opportunities and gaps. Fig. 3 lists the tailored interventions that each state selected.

3.2.1. Michigan

The Michigan team sought to improve education regarding early access to epilepsy care, particularly for people previously treated in emergency rooms. Provider education focused on grand rounds to emergency medicine and internal medicine physicians to help strengthen the referral network and to provide best practices about care of seizure emergencies. Patient/family education focused on access to care and self-management strategies for epilepsy and quality care. Printed information on access to care and quality indicators, in-person conferences, and conference call education and support sessions were used. Effectiveness of educational programs was assessed by the number of participants and pre/post surveys.

3.2.2. Nevada

In Nevada, interventions first focused on outreach and awareness in order to address the lack of epilepsy awareness and communication problems that affect access to care. Interventions were used to engage healthcare providers, patients, and families, with a focus on in-person health education activities for both providers and patients/families.

3.2.3. Oklahoma

Because transportation is a major barrier to receiving healthcare services in this rural state, digital strategies were used most often. The standardized curricula for patients and families were adapted for use in webinars and also used at local conferences in person. Local epilepsy specialists were used as faculty to help bridge gaps between patients and epilepsy centers. Interventions for healthcare providers focused on outreach and awareness to engage healthcare providers in epilepsy care and resources of the local services.

3.2.4. West Virginia

Because of the lack of consistent in-state Epilepsy Foundation services, the initial focus in West Virginia was on outreach and awareness between the Epilepsy Foundation of Greater Cincinnati and Columbus with local healthcare providers and the epilepsy centers. This engagement led to delivery of educational programs to nonepilepsy and epilepsy healthcare professionals. Given transportation barriers, educational webinars with local epilepsy specialists as faculty, combined with support groups, were preferred interventions for patients and families. An illustration of the implementation of these educational initiatives is presented in Fig. 3.

4. Discussion

Many factors contribute to health outcomes in underserved and rural communities, as well as communities that may present with other challenges, such as suboptimal patient care journeys. Geographic location and access to physicians and other healthcare providers can influence health outcomes regardless of the settings. However, compared with urban areas, people living in rural and underserved communities have greater challenges in accessing physicians and the healthcare system [2]. When people in these communities gain successful entry into the healthcare system, they commonly encounter a primary care provider rather than a specialist. Of the 951,061 US physicians who spend most of their time in direct patient care, slightly under one-half are specialists in primary care [61]. Although nearly 20% of Americans live in rural areas [62], a fraction of the physicians practice in these communities. Based on specific barriers and challenges to epilepsy care unique for each state, the Connectors Project employed innovative strategies in rural and underserved areas to address delays and gaps in diagnosis and treatment of epilepsy in adults. Additionally, the project emphasized patient activation and self-management strategies to enhance self-confidence and communication affecting management of their epilepsy.

Although there are some common factors — such as geography, behavioral and cultural aspects, access to transportation, stigma, and specialty care access — that present barriers to epilepsy care, all rural and underserved communities are not the same and experience these factors differently. The Connectors Project explored common factors that impede access to epilepsy care. Using prescribing patterns as a proxy for AED access, the Connectors Project demonstrated disparities in care across the country [13]. Access to healthcare providers knowledgeable of newer AEDs and the ability to access these AEDs has the potential

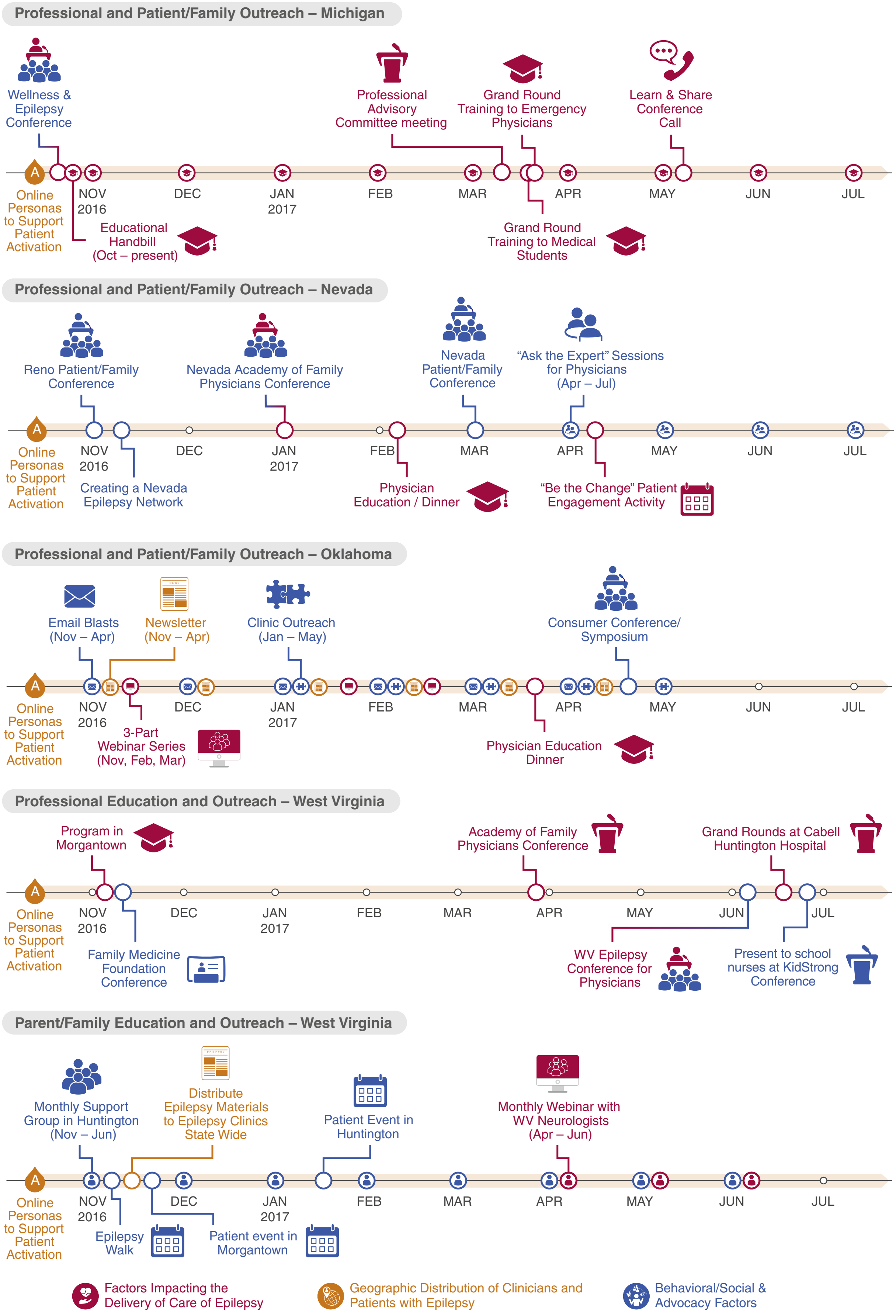

Fig. 3. Implementation of selected interventions in each pilot state.

to influence health outcomes and the quality of life for people with epilepsy in rural and urban settings.

Using state demographic and social data to further characterize the problems related to access to newer AEDs was the first in a series of steps that the state work teams used to develop an approach for implementing the projects in their states. The work teams developed customized approaches for outreach and education activities to their target audiences.

4.1. Provider education

In this project, state work teams including local epilepsy stakeholders informed the strategies to best reach the target audiences in each state. Michigan represented a state with a large high-density population center and smaller cities at a distance with numerous epilepsy centers and a local Epilepsy Foundation office. One of the strategies Michigan epilepsy stakeholders used for the project was to train emergency medicine physicians. Although access to a neurologist has demonstrated less emergency department use for people with epilepsy [11], most patients in rural and underserved areas may not have this luxury. Therefore, access to emergency medicine physicians knowledgeable in epilepsy care may mitigate future emergency department use for people with epilepsy and improve appropriate referrals and access to an epilepsy specialist. This improved care process would be expected to reduce overall epilepsy-related healthcare costs beyond the direct costs of AEDs.

4.2. Provider relationships

Provider location and interplay between specialists and subspecialists can influence access to epilepsy care. States with large geographic areas and high-density population centers, like Nevada, do not have adequate numbers of physicians knowledgeable in epilepsy care to support the adult population of people living with epilepsy. Although there was a good working relationship between primary care providers and the epilepsy center in the most populous county of Nevada, the same relationship was not noted among epileptologists and neurologists. As a result, often neurologists referred patients with epilepsy for out-of-state care. These actions impact access to epilepsy care, particularly in a state where many residents have economic challenges. During the waiting period to see a specialist, patients are likely to suffer from a failure among healthcare professionals to provide quality epilepsy care [53]. This pilot used a local Epilepsy Foundation office to enhance relations within and throughout the healthcare and delivery systems.

4.3. Cultural considerations

Oklahoma represented a state that has a large rural underserved population with a moderate size urban center. Nearly 30% of Oklahoma's minority population is evenly divided among African Americans, Native Americans, and Hispanics. In addition to rural challenges associated with access to epilepsy specialists in this state, cultural barriers and challenges must be considered in developing effective epilepsy programs. Beyond assuring healthcare providers are knowledgeable in epilepsy care, understanding cultural barriers and differences in health-seeking behaviors must be incorporated into approaches intended to reach vulnerable populations. Long referral times only compound the problems in epilepsy care and access to healthcare providers. Therefore, educating and empowering patients and their families about self-management care and how to access quality epilepsy care may mitigate the challenges of living with epilepsy and help them advocate for appropriate epilepsy care.

4.4. Partnerships and collaborations

In sparsely populated rural states with very small urban cores, like West Virginia, partnerships and collaborations are necessary and important strategies to reach healthcare providers and people with epilepsy. West Virginia represented an additional challenge of not having a local Epilepsy Foundation office dedicated to serving people living with epilepsy. Therefore, strong partnership and collaborations with local Epilepsy Foundation offices in a neighboring state proved to be an effective strategy to provide epilepsy educational training for clinicians and raise awareness for people impacted by epilepsy. In areas where resources were severely limited, partnerships with similar healthcare stakeholders (e.g., nurses) and collaborations with planned community events fostered in-person awareness opportunities that employed digital strategies. The use of community partnership and regional and local collaborations supported epilepsy education in rural communities.

4.5. Conclusion

Access to clinicians and other healthcare providers knowledgeable of AED treatments, and the ability to access newer AEDs, has the potential to influence health outcomes and the quality of life for people with epilepsy. Improving patients' knowledge, confidence, and communication about epilepsy treatment can serve as a method to empower people about epilepsy. Engaged and activated patients tend to have better outcomes in epilepsy care. Healthcare providers working in concert with patients with epilepsy to access treatments with fewer side effects and better manage their epilepsy can improve the quality of life and health outcomes for patients. Lessons learned from the Connectors Project highlight the role of the integrated local stakeholders and provide the groundwork to better serve people with epilepsy who live in rural and underserved communities.

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Author contributions

Drs Sirven and Owens and Patty Shafer developed the first draft of the manuscript; all authors reviewed all drafts of the manuscript and approved the content of the final version.

Conflicts of interest

Steve Owens is an employee of the Epilepsy Foundation. Joseph I. Sirven has served as a consultant for UCB Pharma, Acorda Therapeutics, and Upsher-Smith. Patricia O. Shafer has served as a consultant to Upsher-Smith and Acorda Therapeutics, and is an employee of the Epilepsy Foundation. Jesse Fishman and Imane Wild were employees of UCB Pharma at the time that this analysis was conducted. Mark Findley is an employee of the Epilepsy Foundation of Greater Cincinnati. Russell Derry is an employee of the Epilepsy Foundation of Michigan. Jenniafer

Walters is an employee of the Epilepsy Foundation of Oklahoma. Vicki Kopplin is an employee of the Epilepsy Foundation of Minnesota. Jody Kakacek is an employee of the Epilepsy Foundation.

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