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Topical Review

Pediatric Teleneurology: A Model of Epilepsy Care for Rural Populations

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ABSTRACT

BACKGROUND: Approximately 2.7 million individuals in the United States are affected by epilepsy. It is the fourth most common neurological disorder and affects people of all ages, races, and economic backgrounds. In many rural states, the few pediatric neurologists commonly practice in the metropolitan areas. The inadequate resources present challenges for families residing in rural areas or with limited transportation resources. One remedy for this situation is to deliver pediatric neurology services to rural areas through videoconferencing. **METHODS:** The University of Kansas Center for Telemedicine and Telehealth has been providing telemedicine consultations in various clinical specialties for 25 years, including mental health and teleneurology. On the basis of the telemedicine models provided at the University of Kansas Center for Telemedicine and Telehealth and other programs, we explain how to provide teleneurology services to rural communities while maintaining high quality care, including direction for assessing need, technology, privacy, administrative and clinical support, credentialing and legality, and sustainability. **CONCLUSIONS:** We provide a protocol for teleneurology development, outlining examples of needed staff, and measures to ensure a smooth implementation and execution, ending with an example of the current teleneurology clinic provided at the University of Kansas Center for Telemedicine and Telehealth.

Keywords: pediatric epilepsy, pediatric neurology, telemedicine, teleneurology, rural, videoconferencing

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Introduction

Approximately 2.7 million individuals in the United States are affected by epilepsy. It is the fourth most common neurological disorder and affects people of all ages, races, and economic backgrounds.[1-3] For people in rural areas and those of lower socioeconomic status, finding adequate resources for diagnoses and care can be a challenge, especially for younger patients. Children with epilepsy often require the specialized services of a pediatric neurologist, and early diagnosis can be critical for the treatment or prevention of associated cognitive or behavioral issues.[4] In many rural states, the few pediatric neurologists tend to practice in metropolitan communities, presenting challenges for families residing in rural areas.

One remedy for this situation is to deliver pediatric neurology services to rural areas through videoconferencing. Videoconferencing services for neurological care, also known as teleneurology, are becoming a more common and viable alternative to care. In this article we discuss how the needs of epilepsy services of rural communities are being met with videoconferencing-focused clinics at the University of Kansas Center for Telemedicine and Telehealth (KUCTT). The shortage of resources in rural areas, evidence-supported videoconferencing services, and a model for delivering care via videoconferencing will be explored.

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Literature review

Barriers to care

Because of the prevalence and complicated nature of epilepsy, there is a high need for provider identification and treatment of conditions. However, the number of providers in neurology is limited, whereas prevalence of conditions seems to be on the rise.[5] A pediatric neurology workforce study conducted by Bale et al.[6] documented a shortage of providers through a survey of pediatricians. Sixty-seven percent of the survey responders indicated that they make fewer referrals because of a lack of available neurologists in their area, which might hinder proper diagnoses and treatment. Conversely, pediatric neurologists encounter a limited number of pediatricians in rural areas with knowledge of epilepsy diagnosis and treatment. In 2007, Hawley et al.[7] published a study focused on epilepsy and the need for neurologists in the Midwest, which found that neurologists across the Midwest perceive that their patients have challenges in finding primary care providers knowledgeable about epilepsy (Kansas, Nebraska, Oklahoma, and Western Missouri). High turnover of primary care providers in rural areas has continued to intensify the challenges of serving children with epilepsy in rural areas.

Beyond access to pediatric neurologists and primary care physicians knowledgeable about epilepsy in children, other factors keep children in rural areas from receiving adequate care.[8] Hawley et al.[7] also found that neurologists believed low income was the primary barrier preventing patients from seeking treatment (55%), followed closely by lack of insurance (48%), which could be interrelated. In addition, travel was reported as another significant barrier in epilepsy treatment for rural families. Travel challenges include finding childcare services for siblings, paying the cost of travel for long distances, taking time off from work and school, and finding appropriate lodging if needed. A diagnosis of epilepsy is often accompanied with significant costs, which may keep or deter families from seeking help. Furthermore, long distances spent in the vehicle for children with comorbidities can be challenging because of decreased comfort, short attention spans, and fears or phobias associated with travel. Even when travel is successful, it is often difficult to navigate medical centers or hospitals because of unfamiliarity with the area or facilities and limited parking opportunities.

Disorders that present with seizures are sometimes associated with a stigma in the community, which further isolates families and inhibits access to necessary care and resources.[3] Patients may show reluctance to visit a physician in their community regarding their disorder for fear of being seen or having to discuss personal information with a fellow community member. Sander[9] reported that almost a quarter of epilepsy patients feared social stigma related to the disorder. Hawley et al.[7] reported that 81% of surveyed neurologists believed that the public is not well educated on epilepsy and it is hereditary or a mental illness, and 46% believed that these stigmas affected the willingness of patients to seek help or adhere to treatment plans. One way to alleviate the burdens on rural residents who have limited access to care is to deliver services through videoconferencing, also known as telemedicine.

Evidence-supported services

The KUCTT has been providing telemedicine consultations in various clinical specialties for 25 years. The KUCTT program has a long history of delivering services to children across sites, including the first school-based telemedicine program in the country. With videoconferencing, the provider is able to converse with a patient, as well as examine and observe nonverbal behavior in real time, which approximates the relationship developed in an on-site clinic. In addition, videoconferencing allows for other providers, teachers, and caregivers to participate in appointments enhancing care. The most common and active telemedicine specialties have been mental health and stroke programs, which present good models for providing care for pediatric epilepsy.

Mental health

Mental health services through telemedicine have been widely practiced and studied for many years, making it a useful model for starting other telemedicine clinics, and emphasizing that telemedicine is a practical and appropriate way to deliver health care. Mental health services delivered *via* videoconferencing have been known by names including telemental health, telepsychiatry, and telepsychology[10] Psychiatry has been using technology to serve patients for decades, focusing mainly on medication management, whereas psychology, for both adults and children, has been used by clinicians for counseling, behavior assessment, and management of various mental health conditions.[11-14] Assessment *via* telemedicine has shown to be achievable, reliable, and acceptable for disorders such as depression, substance abuse, and cognitive impairment.[15-19]

Telestroke

Videoconferencing stroke services—telestroke—have developed for more than almost two decades, with the major impact of care on rural areas.[1] Stroke patients in rural areas are often unable to access hospitals with appropriate stroke providers within the recommended three-hour treatment window, and videoconferencing fills this gap of limited availability of stroke providers and stroke services in rural areas, meeting the need for rapid assessment and treatment.[20-22]

Meyer et al.[23] found that the accuracy of diagnosis of telestroke patients over videoconferencing was 98%, compared with 82% with telephone consultations. Similarly, Rubin[24] reported that National Institutes of Health Stroke Scale scores between on-site and telemedicine methods are strongly correlated, and long-term outcomes were similar. A review of 18 telestroke networks indicated that most studies were reported as positive, with three indicating high levels of satisfaction by patients and health care providers.[25]

Pediatric neurology

Limited literature exists on the use of telemedicine for pediatric neurology. Rasmusson and Hartshorn compared an epilepsy telemedicine clinic with an on-site clinic to determine if the videoconferencing clinic approximated the same service as on-site models.[8] They found that there was no significant difference between the clinics, and that the