
Neurological Services for Appalachian Children Provided by a Traveling Team

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THE INADEQUACIES OF MEDICAL SERVICES in rural areas of the United States and the disparity between the quality of care available to rural and urban residents have been of concern since the late 1800s (1). Efforts to correct these inadequacies have been thwarted by the poverty, low population density, geographic isolation, and poor public transportation that are often

characteristic of the rural milieu (2,3). In addition, many physicians are reluctant to reside in rural areas because of professional isolation and inadequate facilities (4).

The complexity of these problems prompted the American Medical Association's Councils on Health Manpower and on Rural Health to suggest "that for



some rural areas solutions completely different from the traditional physician in residence must be sought" (5). We present data that suggest that traveling teams of specialists can help reduce the medical disadvantages of rural living by providing sophisticated services to selected patients.

Background

The major tertiary care centers for the Appalachian counties of eastern Kentucky are 60–175 miles away—in Lexington, Ky., Knoxville, Tenn., and Cincinnati, Ohio. These distances and the lack of public transportation frequently prevent patients needing specialized services from obtaining them.

In 1967, the University of Kentucky Department of Neurology obtained a 3-year grant from the Health Services Project of the U.S. Public Health Service to explore the feasibility of providing services in mountain counties. As a result, a traveling neurology team was formed. Since 1972, a contract from the Growth and Development Branch of the Kentucky Bureau of Health Services has enabled an expanded program that now provides service to 16 Appalachian counties. The contract is supported by maternal and child health funds and requires that services be limited to patients under 21 years old.

The poverty of the Appalachian counties of eastern Kentucky is well known. Statistics for the 16 counties being served by the program indicate that almost one-fifth of their residents receive some form of State monetary or medical assistance, and 30 percent are eligible for food stamps (6). The adults in these counties have an average of 8 years of schooling. In some counties, more than two-thirds of the homes lack some or all of the standard plumbing facilities (7).

The Regional Neurology Clinic Program

Any person under age 21 thought to have a neurological condition is eligible to attend the clinics held by the traveling team in county health departments located in county seats. Patients referred from local sources are screened and scheduled by health department personnel. Patients referred from the Uni-

versity of Kentucky Medical Center are scheduled by the clinic secretary in Lexington.

Many of the 16 counties have as few as 6,000 residents, and it would be difficult to assemble the minimum 15–20 patients needed to hold a clinic in these counties. Therefore, the neurology clinic is scheduled at sites convenient for two to five contiguous counties. The team visits each area a minimum of five times a year and provides regular medical supervision. If required, additional care is available through home visits by the local public health nurses, at clinics in other nearby areas, or at the outpatient clinic in Lexington.

The clinic team is on the road 1½ days every other week, usually leaving Lexington on Wednesday morning, holding a ½-day clinic Wednesday afternoon, staying in a motel overnight, and holding a 1-day clinic in another area on Thursday.

On clinic day the local health department supplies clerks and nurses, and the medical center supplies one staff pediatric neurologist, one neurology resident, and one or two social workers. Two third-year medical students also attend, as may a pediatric resident and a social work student. After each clinic session the clinic staff, students, and local public health nurses review the patients' charts. Emphasis is on explaining diagnostic terms and possible complications of therapy, identifying children who will need nursing services before the next clinic, and coordinating services between different agencies. The charts of children who were scheduled but did not attend the clinic are also reviewed. Those who appear to no longer need the clinic's services are discharged. The others are given a new clinic appointment, and arrangements are made to transmit this information to the parents.

Since the clinic team changes location, the maintenance of communications can be a problem. Parents are told that they can contact the clinic physician or social worker directly and are given the Lexington telephone number or they can contact the public health nurses in their area or their own physician. It is emphasized that the public health nurses and their primary physician will have all the details of the child's history, diagnosis, and treatment.

Many patients who have neither a telephone at home nor ready access to one tend to come to the health department when a problem arises. When the clinic staff wishes to contact these persons, the public health nurse is asked to make a home visit. The following sequence is an example of how this system of communications works. A blood sample for anti-convulsant level determination is drawn by the nurse

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and mailed to the clinic office in Lexington, where the secretary transports it to the toxicology unit. A day or two later the report is returned to the clinic office. The neurologist reviews the report and advises the public health nurse by telephone if changes in regimen are necessary. If indicated, a prescription for a new medication is mailed to the nurse. The nurse then makes a home visit to relay the information to the family and to deliver the prescription.

Because of the need for home visits, elective changes in regimen for patients without telephones are often postponed until the next clinic visit. Appointments for laboratory tests or consultation at the medical center are arranged at the time of the clinic visit. The social worker explains the reasons for these appointments to the families before they leave the health department.

Generally, mail communications are used only when no telephone is available and a home visit is impractical or for transmitting simple and straightforward information. Families too poor or too remote to have a telephone often find written directions confusing.

The clinic team informs and coordinates services with other physicians and agencies. A copy of each patient's medical record for each clinic visit is mailed to the patient's primary physician, to the health department, and to each agency currently active in the patient's management. The record for a new patient (usually two typewritten pages) consists of the traditional categories—history of present illness, general history, physical examination, and so on. The record for a return visit takes about three-quarters of a page. The examiner dictates the medical notes into a portable recorder. If a patient has an urgent problem (an unusual circumstance), the examiner telephones the patient's physician.

When the team returns to Lexington, the secretary transcribes the tapes and mails carbon copies to the physician and the pertinent agencies within 2 weeks of a clinic meeting. These procedures required three-quarters of a secretary's time for 745 patient visits in 1976.

A logsheet inside the cover of each chart indicates the diagnosis, drugs prescribed, tests and referrals agreed upon, and date of next visit. To enhance the value of these records, a child's current medicines, dose, and frequency of administration are included in the history, and a summary of all current medicines—preexisting ones and those newly prescribed—is the first item in the disposition. An outline of tests or referrals is also included and, for children with difficult therapeutic or diagnostic problems,

future strategies are discussed.

Social service notes appear on a separate page. Because of the personal information in these notes, they are not transmitted routinely. When indicated, a social worker summarizes the pertinent information and sends it with her recommendations. At each clinic visit, the patient or parent is asked to sign a release for the transfer of information. At that time also, the identification page on the chart is reviewed and updated for accuracy concerning the family's current primary practitioner, active agencies, and telephone or lack of one.

The clinic does not charge a fee, but, when possible, third-party payers are billed for clinic visits. The Kentucky Bureau for Health Services uses maternal and child health funds to pay for medications, laboratory tests, hospitalizations, and other medical services when in the opinion of the social workers a family lacks adequate funds and has no third-party payer.

The clinic provides both diagnostic evaluations and continuing neurological care for children who need but might not receive these services because of geographic isolation, poverty, or other factors. Other goals include providing an educational experience for medical students and residents, encouraging research into neurological disorders prevalent in this population, and improving services available to neurologically disabled Appalachian children.

Patient Population and Costs, 1976

Because pediatric neurologists and neurology clinics have been traditionally associated with urban medical centers (8,9), a major question has been whether such specialized service is needed in rural areas. In fiscal year 1976 the clinic staff saw 275 new and 470 return patients for a total of 745 visits, an ample patient population. As shown in the following table, the majority of the 275 new patients had classic neurological disorders, and most of the remainder had the types of complaints that are usually evaluated by neurologists.

<i>Primary diagnoses</i>	<i>Number</i>	<i>Percent</i>
Classic neurological disease (includes seizure disorders, cerebral palsy, and neurocutaneous syndromes)	189	69
Loss of consciousness (includes syncope and hyperventilation, excludes seizures)	17	6
Disorders of higher cerebral function (includes mental retardation without apparent etiology and learning disorders)	30	11
Other (includes children seen for developmental assessment and thought to be normal and children with school problems believed to have a psychiatric basis)	39	14

These diagnoses indicate that the patient population is certainly similar to that of an urban neurology clinic for children (8).

Physicians can easily determine which patients need a specialist's services. However, because of the shortage of rural physicians, less than one-half of our 275 patients were referred directly by physicians. The referral sources for all 275 patients were as follows:

<i>Referral sources</i>	<i>Number</i>	<i>Percent</i>
Health departments	116	42
Private physicians	93	34
University of Kentucky Medical Center ...	39	14
Regional mental health centers	12	4
Schools	7	3
Other	8	3

The local public health nurses have helped to solve the problem of physician shortage by taking the responsibility for deciding which patients should attend the neurology clinic and which ones require referral to other services. The appropriateness of the clinic population, shown earlier, reflects the nurses' skills. Not only have they learned which patients can be helped by a neurologist, but their knowledge of local resources—which vary among counties—and of local families, as well as their contacts with referring agencies, enable them to make the kinds of decisions that would be difficult for an employee in Lexington to make.

Additional services that neither the clinic team nor local facilities could provide were required for 118 of the patients, and they were referred to the University of Kentucky Medical Center. Of 22 patients referred for admission, 19 were admitted to University Hospital; of 96 referred for outpatient tests, 73 obtained the tests. Thus, 92 of the 118 patients referred were actually seen at the medical center.

On the other hand, the neurology clinic is not intended to be a screening program for detecting children with exotic diseases who can be referred to University Hospital. This is evidenced by the 470, or 63 percent, return visits among the 745 patient visits in 1976; these return visits indicate continuing supervision of neurological conditions. Moreover, 75 percent of the patients were managed locally.

It is often difficult to determine how effectively a clinic is reaching its target population. A valuable outgrowth of a prevalence study of epilepsy in Clay County, Ky., were data describing the proportion of the school-age epileptic population served by the traveling clinic team in that county (10). The study

focused on children with active epilepsy, which was defined as follows: "active"—either having had a seizure or having been on anticonvulsant medication during the 5 years preceding September 1, 1973, and "epilepsy"—two or more seizures of which at least one was not associated with an acute toxic or neurological illness or with fever. Of 40 children discovered to have active epilepsy, 18, or 45 percent, had been seen by the clinic staff in the preceding year. As a group, children who had been seen at the clinic had more frequent seizures, and more of these children were recognized as having focal seizures than the children not seen at the clinic.

All of the clinic's patients were receiving anticonvulsant medicine, whereas only three-quarters of the other children had ever received such medicine. (All basic information was obtained from the mothers of both groups of children.) In the judgment of the neurologist conducting the study, 4 or 22 percent of the clinic children had not received optimal drug therapy (primarily because of noncompliance) in contrast to 10 or 45 percent of the other group. Since this neurologist also conducts the clinics, this judgment may not have been entirely objective. However, an effort was made to avoid judging clinic children differently from the rest of the study population. Children who attended the clinic also were less likely to be from a well-educated, middle-income family, but the parents of a majority of the children in both groups had less than an eighth grade education and were receiving some type of government monetary assistance.

The direct operating cost of the regional neurology clinic program for fiscal year 1976 was \$57,760; \$50,000 was for salaries, and the remainder was for travel and office expenses. If this figure is divided by 745 patient visits, the cost per patient visit is \$78. To calculate the cost of a visit another way, the salaries of the clinic social workers can be deducted, and the cost per patient can be determined by the type of medical services received. This method produces the costs of \$90 for each new patient visit and \$17 for each return visit; these figures are almost identical to the current charges for such services at University Hospital. For many rural patients, the cost is considerably less than that for a visit and transportation to Lexington.

Startup costs were similar to the operating cost because no major capital investment was required. Of course, the smaller initial load produced higher per-patient costs in the first year. The costs cited indicate that a traveling clinic team can be an economically viable means for delivery of services, which

was especially evidenced by the willingness of the neurologists and other physicians to travel from Lexington to rural towns on a regular basis.

Discussion

Traveling clinic teams have long served underpopulated areas, but the literature is scant on the extent to which they are used or how their clinics have been adapted to different populations and service demands. The only broadly based figures are from the 1930s. Itinerant clinics were envisioned as a major means of implementing Title V of the Social Security Act of 1935 which provided funds "for the purpose of enabling each state to extend . . . (especially in rural areas . . .) . . . services and care . . . for children who are crippled or who are suffering from conditions which lead to crippling" (11). In 1938, 456 such clinics were scheduled. Subsequently, traveling clinics have not been separately identified and reported (1976 personal communication from the Office for Maternal and Child Health, Department of Health, Education, and Welfare).

The limited recent literature includes a report of a traveling neurologist in New Jersey (12) and mention of traveling clinic teams for epileptic children in Maryland (13), Mississippi (14), and Virginia (15). A mobile health clinic for preschool children (16) and a child psychiatry clinic (17) have been reported. Additionally, we know of traveling pediatric and cardiology clinic teams who serve rural Kentucky, and we assume that other programs exist elsewhere.

Epilepsy is a major neurological disease of childhood. Epidemiologic data indicate that the Clay County Regional Clinic serves a substantial percentage of the school-age children with epilepsy in that locale. Moreover, the clinic patients as a group appear to have more severe disease (as measured by seizure frequency) and to be from a more disadvantaged background than the nonclinic patients. These findings suggest that the clinic is reaching the patients for whom it is intended—those needing the services of a specialist and unable to use physically distant facilities. Although three-quarters of the clinic's patients receive optimal drug therapy, which suggests a high quality of medical care, the discovery of untreated children with epilepsy in a county with a pediatric neurology clinic and clinic patients who have not received optimal therapy is disconcerting. Both findings may be related to factors beyond the clinic's control (such as the stigma associated with having epilepsy and fatalistic parental attitudes), but they also indicate areas of weakness in the program. The presence of untreated children points out a need

for more aggressive casefinding, which has not been feasible because of manpower limitations. The question of optimal therapy for clinic patients has been addressed in two ways. Since the survey was undertaken, the clinic has hired a second social worker to increase the amount of counseling available to families. Also, blood anticonvulsant levels are being obtained more frequently to detect noncompliance with the drug regimen. Although no new data are available, the clinic staff believes that both measures have improved the level of care.

The literature contains few references to special problems associated with conducting clinics by traveling teams, particularly establishing and maintaining a relationship with local agencies. We have overcome this difficulty by working through local health departments. The advantages have been (a) access to patients who have difficulty traveling out of the area for services and who are also traditional users of the health department and (b) access to the services of public health nurses. In addition, health departments usually have clinic space available and agree with the regional clinic's policy of free services. Such space is seldom available in physicians' offices or rural hospitals; moreover, both of these are on a fee-for-service basis.

It is unfortunate that rural public health departments often are not in the mainstream of medical care delivery, and this circumstance can adversely affect the clinic operation. To help overcome this isolation, members of the clinic staff have met with officers of county medical societies and some local hospital administrators and have given talks at meetings of hospital staffs and medical societies. Also, the health departments notify local physicians of clinic dates and activities, and the clinic staff informs physicians about their patients.

Also helpful in promoting community acceptance is the regional clinic's policy of using local services when possible. Thus, most psychometric testing is performed by psychologists in local mental health units, and physical therapy and speech and hearing tests often are arranged through local hospitals. These services also cost less than they would if the patients had to travel to Lexington to obtain them. The university-based team's interchange of patient information with local staffs and their use of local services, rather than obtaining them in Lexington, help to strengthen the local facilities' position in their communities.

Training is another positive outcome of the neurology clinics, which have provided excellent clinical experience for medical students and house officers.

The clinics demonstrate how an effective team uses members of different disciplines (neurologist, public health nurse, and social worker), geographically distant facilities, and different levels of care. Through regular post-clinic, patient-oriented discussions and various ad hoc conferences, training has also been provided for public health nurses, school personnel, local mental health workers, and other professionals. Although educational efforts directed toward local practitioners have been limited to traditional lectures at meetings of medical societies, the neurology clinics could be a medium for mini-residences and other educational activities.

The clinics have also generated research in neurological problems endemic to eastern Kentucky (10). We hope that the ample numbers of patients seen at the clinics have encouraged medical students interested in specialty practice to consider serving a rural population. Finally, by providing consultation services, the clinics have helped to diminish the isolation of some rural practitioners and to strengthen local services for neurologically impaired children.

We have discussed many positive aspects of the neurology clinics. However, we would be remiss if we did not mention two problems not yet overcome. First, despite our considerable communications efforts, we still discover some patients who are bewildered about whom to contact for services; quite likely, there are other such patients who do not come to our attention. Second, most staff members find the amount of travel necessary to conduct the clinics is not only tiring, but it also infringes on the time they would otherwise spend with their families; these factors limit the time a team can be on the road without incurring a high rate of staff turnover.

Conclusions

The renewed interest in rural medical care has stimulated efforts to increase medical services in rural areas. The emphasis has been on primary care, with attempts to attract new primary care practitioners and to enhance the effectiveness of those already practicing in such areas. In light of persisting shortages of primary practitioners, it is not surprising that little attention has been given to the need for specialists. However, our data demonstrate a need for neurologists, and certainly there must be a need for other specialists.

Traveling clinic teams enable specialists to live in urban areas, and they provide a way to deliver services that bypasses some of the social and economic problems that hinder recruitment of practitioners. The clinics held by these teams are economically

viable; local public health nurses and other personnel are used where a shortage of physicians would otherwise interfere with screening and referral of patients. While solutions to the overall problems of rural medical care are still being sought, traveling practitioners can provide needed services to rural patients.

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