TEWA CHILDREN WHO HAVE EPILEPSY: A HEALTH CARE DILEMMA

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Abstract: This paper explores the part ethnicity may play in utilization of available western health care methods by Tewa families who have a child with epilepsy. Suggestions are made for appropriate responses by non-Indian health care providers to Tewa patients with epilepsy and their families. Findings indicate that, on the surface, Tewa families behave much like other Americans generally in utilization of western health care services. However, the Tewa are extremely reluctant to discuss with non-Indian health care providers traditional healing practices that may be used simultaneously. Such reluctance is well-documented in literature on the Tewa Pueblos and is substantiated in the present research. Suggestions are made for health care providers who wish to be "culturally aware" about the appropriateness of routinely asking a patient about his or her perception of the traditional etiology of the disease. The roles of the family and the western health care system are challenged. The response of Tewa extended families to children who have epilepsy is complex and not necessarily supportive. Often considered the primary health care provider for Native Americans, the Indian Health Service is based on an acute care model and lacks the ability to serve chronically disabled American Indian children. Finally, the paper argues that epilepsy is varied enough to complicate the development of a single model of chronic illness that is appropriate for those who suffer from the disability.

Much research has been done on the importance of ethnicity in health care response (Adair, Deuschle, & McDermott, 1969; Ahern, 1975; Guilmet & Whited, 1989: Joe, 1980; Leslie, 1976; Rubel, 1960; Saunders, 1954; Spicer, 1977; Vogel, 1970). This is because ethnicity, in part, implies that people who recognize themselves as being part of a particular group share at least some common experiences that influence their basic concepts and attitudes toward health and illness (Harwood, 1982). In a more applied vein, it has been widely accepted that modern health care providers' awareness of non-mainstream therapies and belief systems may help them communicate more effectively with their patients and thus provide the most appropriate interventions (Guilmet & Whited, 1989; Harwood, 1982).

This research is concerned with how Indian parents of the Tewa Pueblos in New Mexico cope with problems of epilepsy among their

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children. The focus of the study was to determine: first, if and how ethnicity plays a part in the response of Tewa families to epileptic children; second, what information medical providers need about Tewa healing practices to enhance the quality of available modern medical care; and third, what behavioral characteristics epileptic patients in a cross-cultural setting share that can contribute to the development of chronic illness models more comprehensive than those that presently exist.

Epilepsy Described

Epilepsy represents a range of seizure disorders. It is not a specific or single chronic disease of the brain, but a symptom and manifestation of abnormal cerebral function that may be due to any one of a large number of causes (Lagos, 1974). These include birth injuries, post-traumatic seizures following a blow to the head, chronic alcohol use (seizures that are not delirium tremens), vascular problems, brain tumors, or inflammatory diseases. In many cases, no cause can be detected.

Epileptic seizures occur more frequently in children than in adults. In approximately 80% of all cases the initial seizure occurs during the first two decades of life. Three age ranges mark the most common occurrence of seizures: the first two years of life, between four and eight years of age, and the years of adolescence. Due to risk of injury at birth, the incidence of seizures is highest among newborns (Lagos, 1974).

Western treatment of epilepsy usually consists of the use of anticonvulsant drugs and, depending on the physician, varying amounts of educational counseling for the patient and family about management of the disorder. The object of drug therapy is to make the epileptic person seizure-free, although this goal is not possible in many cases. Estimates vary, but with drug therapy seizures are controlled in about 50% of the epileptic population, partially controlled in an additional 20 to 25%, and poorly controlled in the remaining 25 to 30%

Levy's research on epilepsy and hysterical seizures among Indian tribes is the most pertinent literature available for this specific population group (Levy, 1979; 1981; Levy, Neutra, & Parker, 1979; 1987; Levy & DeBruyn, 1980). The tribes studied include the Navajo, known for their cultural discernment of seizure syndromes, and three Pueblo groups: the Zuni, Hopi, and Tewa tribes. These studies are epidemiological, and also explore sociocultural components of response to epileptic persons. The prevalence of epilepsy in all four tribes was found to be higher than in the "control" population in Rochester, Minnesota (Hauser & Kurland, 1975). Rochester's rate was 5.7 per 1,000 population as compared to 8.2 among the Navajo, 9.1 among the Zuni, and 7.5 among the Tewa.

The pueblo populations have common features in their belief systems that are different from those of the Navajo. Levy observed that none of the Pueblos have singled out the signs of epileptic seizures for special attention in their own healing systems in the same way the Navajos

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have. Since Navajos believe that signs of grand mal seizures are direct consequences of sibling incest, epilepsy is a major stigma both for the patient and the family. In contrast, Pueblos do not place such negative connotations on the illness, do not see convulsions as the symptom of a single disease process, and do not always believe that their appearance stigmatizes the patient or the family. However, members of the community may suspect, especially if the seizures are chronic and uncontrolled, that something is wrong with the child and his or her family. What that "something" is is vague and undefined, usually implying some emotional disturbance (Levy, 1981).

The Tewa Pueblos

The Native American villages located along the Rio Grande River in New Mexico, 16 in all, comprise the Eastern Pueblos. Six of these represent the population on which this study is based: San Juan, Santa Clara, San Ildefonso, Tesuque, Nambe, and Pojoaque, where the Tewa dialect of the Tanoan linguistic family is spoken. The Tewa Pueblos range in distance between 12 to 25 miles from Santa Fe, New Mexico. In comparison with other American Indian tribes, few details are known about the Eastern Pueblos. This is a result of pueblo history, where traditional ceremonies and beliefs were banned - usually violently - by Spain and later the United States (Ortiz, 1979), and Pueblo peoples became reticent to discuss themselves or allow outside research (Bodine, 1972). Anthropological studies of the 1930s and 1940s among the Eastern Pueblos helped influence this attitude, when Pueblo people were shocked to find their jealously guarded secrets in print (Ortiz, 1979). To be accepted at all, research must have some applied focus that will potentially benefit pueblo residents.

Among the Tewa, breach of tabu was the most frequent explanation for disease, followed by object intrusion and contagious magic. Witchcraft was often used to explain illnesses where it was difficult to determine specific responsibility. Illness and death from natural causes were recognized, but their role was incidental in the overall theory of disease. Breach of tabu encompassed any type of either non-sanctioned or antisocial behavior, or any digression from the ideally conceived way of life, that is, mutual cooperation and sharing with other pueblo members (Ortiz, 1969; 1972). When misfortune, accident, illness or death could not be readily explained in terms of a religious breach of tabu, witchcraft was usually used as the causal explanation. The theory of witchcraft stemmed from a belief in the ability of individuals to acquire supernatural power and control it for their own uses as well as to transfer it to others. Anyone suspected of witchcraft was feared or shunned. Witchcraft served as an indirect social control against aggressive and individualistic actions (Hill, 1972).

Whether or not the Tewa people continue to believe strongly in witchcraft cannot be easily determined, for they do not talk about it to

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outsiders. Any discussion of witchcraft in the presence of a non-Tewa was and is accompanied by obvious uneasiness. Although witchcraft may have been an explanation for epilepsy among the Tewa in the past (Naranjo, 1980), Tewa people today are unwilling to discuss the subject or to say whether the traditional healing system is utilized in regard to seizure disorders.

Methodology

The present research was an outgrowth of the Tewa Epilepsy Project, sponsored by the Indian Children's Program of the United States Public Health Service and Bureau of Indian Affairs. The purpose of the project was to determine the prevalence and causes of epilepsy in the Tewa population and compare these findings with similar data on the Navajo, Hopi, and Zuni Indians. The "control" group from Rochester, Minnesota, comprised an epidemiological sample of the prevalence of epilepsy in a medically sophisticated midwestern community; it also provided comparison of the utilization of western health care facilities and of compliance with the use of prescribed medication across all population samples. During the two years of data collection (September 1979-September 1981), family interviews and ongoing counseling and education were provided about epilepsy by the author to the families in both the Tewa Epilepsy Project and the sample of children chosen for the present research.

The sample of children for the present study was selected both through the use of the computerized data retrieval system of the Albuquerque Area Indian Health Service (IHS) from entries covering July 1, 1971 through June 30, 1978, and by referrals from health workers and community residents. A computer search was made for all Tewa children with diagnostic codes for seizures of any type, including febrile seizures, syncope (fainting spells), headaches, and medication that is usually given for epilepsy. Medical records of individuals seen during the period who had seizures at some time in their lives were abstracted and all families of children were interviewed, where possible. Up to three separate interviews were conducted per family.

Nine persons in the Tewa Epilepsy Project were included in the present study because they were less than 19 years of age during the time period. Twenty-two additional children were included in the present research, making a total of 31 children and 28 households (since there are three sets of siblings) in the research sample.

Direct inquiries about traditional beliefs and practices regarding epilepsy or other health matters were not made. The present study was acceptable to Pueblo officials largely because of the promise that questions about traditional medicine and religious beliefs would not be asked.

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The Children and Their Families

Of the 31 children, 13 suffered only from some form of epilepsy, six had epilepsy along with other handicaps, and 12 had experienced febrile seizures. The seizures of the majority of children were controlled by anticonvulsant medication. Twenty children had some history of seizures in the immediate or extended family: in six cases there was a family history of epilepsy, in nine cases there was a family history of febrile seizures, and in five cases both epilepsy and febrile seizures were represented in the family. The remaining 11 children had no family history of either epilepsy or febrile seizures. Two children are deceased, one eight years prior to 1979 when the research began; the other died in an accident during the two-year period in which the research was conducted.

Of the 28 households, 22 included nuclear families; two had extended relatives, either grandparents or parents' siblings; and four households were headed by single parents. Adults living in the same household as the child were usually the most important caretakers, both emotionally and economically. Some non-resident grandmothers cared for the child during the day and some children were placed in day care facilities.

The majority of children had one non-Tewa parent. In only 10 families were both parents full-blood Tewa, although not necessarily from the same Tewa pueblo. It must be noted, however, that children living in the pueblos followed the dictates of the Tewa village, and the non-Tewa parent's ethnicity was most often not emphasized by the family and community when referring to the child. Most of the children (26) lived in pueblo communities; five older children had moved away.

Tewa Response to Epilepsy in Children

When the first seizure occurred, Tewa parents commonly reacted with fear for the child's life. This was followed by denial of the child's epilepsy, self-blame for the development of the disorder, and social isolation of the mother. Long-term family reactions varied depending on the child's behavior, visibility of the disorder, and whether or not development was otherwise normal. If a child had poorly controlled seizures, over-protection was a common reaction.

Mothers and fathers differed in their willingness to talk about a child's disorder. Mothers would attend a parent support group started during the course of the research to discuss their concerns about their children with epilepsy; although invited, fathers did not attend. It was explained by the mothers that men had more difficulty discussing these issues, and that the women were the primarily caretakers for their children.

Relatives appeared to be less willing to help care for the child if one parent - especially the mother - was not a member of the pueblo. Relatives were particularly unwilling to take responsibility for care in the case of an epileptic child with poorly controlled seizures. Many children therefore

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suffered some social isolation, especially since schoolmates increased their teasing as children with poorly controlled seizures grew older.

Familial response to a child's first severe seizure, usually grand mal, included dismay and fear. In every case, the child was rushed to the emergency room at the nearest hospital. Families also responded with great concern at the first awareness of petit mal seizures, taking the child to a nearby hospital or clinic as soon as they recognized that the seizures were something other than daydreaming or inattention. Parents with professional medical training or previous experience with epilepsy were as frightened as those who knew nothing about the disorder. They differed only in that parents who had no information about epilepsy thought the child was dying.

Response to the diagnosis of epilepsy was usually denial, most frequently by the father. Both parents blamed themselves for the child's disorder. A mother frequently began to isolate herself from others. Parental anxieties were not easily dispelled either by health workers or other members of the family.

The extent of self-blame was unexpected. Women reported that their husbands shared the sense of blame but would not talk about it. How much parents suffered became apparent during informal gatherings on a one-to-one basis or in group situations where mothers talked together. During the talks, women often wept. They said again and again that a bad thought or action during pregnancy or early in the child's life may have caused the illness. This reference to self-blame that may be related to traditional Tewa beliefs was unsolicited. However, self-blame by parents for the illness or death of a child is a nearly universal phenomenon and should not be relegated necessarily to a single cultural belief system. Furthermore, many of the mothers at group sessions expressing these feelings were non-Tewa and non-Indian.

Mothers would ask, "Was it a bad thought I had when I was carrying my child? I can't help but think it was something I thought or did that caused my child's seizures." Sometimes women asked, "Why me?" but then returned to asking what they had done to cause the epilepsy. Mothers also said they wished they could take the child's disorder upon themselves: "I often think, if only I could take on my child's problems. He's just a baby and I am so much stronger. If only it were me instead of my baby who had the seizures."

Variation of Family Response with Control Over Seizures

When seizures can be controlled, epilepsy can accurately be described as an "invisible handicap" (Freeman 1979). Tewa families who had children with medically controlled seizures usually treated them "normally," encouraging them to play with their siblings and other children, and to participate in the general life of the society. Only a few families with such children tried to overprotect them - sometimes even when the child

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had not had convulsions for years and was no longer on medication - saying, for example, "Don't upset her, she might have a seizure."

It is easier to deny the existence of epilepsy when seizures are controlled. Periodic seizures are a constant reminder of the disability. Interview data from 17 mothers with children whose seizures were controlled show that they both treated their children normally and denied the presence of the disorder. Health care workers encouraged them to treat the children normally, but the parents also wanted to forget about the disorder altogether. Consequently, they were unlikely to talk to the child about his or her epilepsy, and the children knew little or nothing about their disability. Their siblings knew only that a brother or sister "has to take pills all the time." Those children who were aware that they had epilepsy did not want their peers at school to know. They also were growing up with little understanding of their disability, and were not aware that the environment outside the family was likely to be less nurturing and less oblivious than the family setting.

Six children in the sample had poorly controlled seizures. They and their families faced constant frustrations, continual adjustment of medication, curtailed social activities, and family disruption. Parents lived in fear that the child would have a seizure when away from them. They were strongly tempted to be overprotective even if they were opposed to over-protecting the child. While children with controlled seizures participated in the normal run of social activities, seizure-prone children were restricted.

Parents of seizure-prone children also tended to direct much of their attention toward the disability, neglecting other children. They did not have the extra emotional strength needed to meet the demands of their "normal" children. Siblings close in age to the epileptic child displayed many attention-getting behaviors, especially when young, but such attempts usually met with little response from overburdened parents. Mothers said they could not help but be more concerned about the child who was developing differently, even if additional caretakers were available.

Six children suffered from other disabilities in addition to epilepsy. Families preferred to keep multiply handicapped children at home. In two instances, however, the burden became too great and the children were institutionalized. In another case, one mother told of her child who had had epilepsy and an additional handicap, whom the father had institutionalized. Although the child died eight years before this study began, his mother still regretted having sent him away, stating he died of loneliness. Despite the strain on the family, Tewa parents usually preferred to keep their disabled children at home. The two who had placed their children in institutions visited them frequently and brought them home for weeks at a time, especially for holidays.

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Employment and Caretaking

Employed women were likely to give up their jobs when they had to care for an epileptic child, especially if the child had uncontrolled seizures or multiple handicaps. Five of the 18 women who were consistently or sporadically employed between 1979 and 1981 faced serious crises with their epileptic children. All five either quit work, changed to half-time work, or took time off.

A lack of caretaking on the part of extended kin was surprising given the general belief that the Tewa extended family provides a strong support system for its members. Parents of children with multiple handicaps or poorly controlled seizures had a difficult time in obtaining and keeping caretakers. In most cases it was the mother who bore the brunt of the caretaking tasks. Relatives who would have helped care for normal children usually needed special instruction in dealing with an epileptic child. If a child had a seizure, a caretaker was often reluctant to continue caring for the child. Visible seizure activity was frightening and much more difficult to cope with than making certain that a child had its medication at appropriate times. A few caretakers who had learned what to do if a seizure occurred were willing to continue to help, but in most cases, extended kin helped only sporadically. This added to the mother's sense of isolation, and made it almost impossible for a woman with such a child to continue to work at a regular job.

Societal Behavior Toward the Children

Older children whose seizures were poorly controlled faced constant teasing by peers. Teasing was clearly evident for one child approaching adolescence whose seizures had begun to shift from petit mal to psychomotor and grand mal epilepsy. The child was labelled in school as a "monster" and considered "contagious" by classmates.

Five children in the sample were reported by their mothers and health personnel to have emotional problems. All were between ages 10 and 19. Two had controlled seizures, and three had seizures that were uncontrolled. Studies of epilepsy among the Zuni, Hopi, and Tewa people indicate that emotional problems begin just prior to or during adolescence (Levy, 1981), probably due to the parents' denial of the disorder.

Pueblo parents who try to treat an epileptic child as normally as possible fail to answer the child's questions or to address what the child is about to face both socially and emotionally. The child then has "few means to adjust to the illness when he becomes more independent during adolescence" (Levy, 1981, p. 48).

It is probable that as they mature, Tewa children who have epilepsy will face continuing problems. The experience of adults included in the Tewa Epilepsy Project sample indicates that epileptics face a high degree of social isolation. It is not possible to determine cause-effect relationships

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between seizures and other emotional problems, but all those Tewa who had suffered from epilepsy for a long time also experienced alcoholism and other emotional and somatic problems. Seven adults included in the project sample had experienced seizures since childhood. Two had severe alcohol problems at the time of the study, while two more had a history of chronic alcoholism and may still have been abusing alcohol. Two had serious emotional problems, and one refused any medical or psychological treatment. One, whose brother also suffered from epilepsy, had suffered from severe gastroenteritis for years, a common complaint in his family.

These data lend credence to the hypothesis that even epileptic children whose seizures are controlled eventually have problems in part because of their parents' refusal to face the implications of the disorder, i.e., they become adults who do not know how to cope either with their epilepsy or their social environment. However, family attitudes may not be the crucial variable. Regardless of family treatment of epileptic children (e.g., nurturing among the Tewa and alienating among the Navajo), adults with seizures face serious social problems. It has been suggested that Navajos who have epilepsy are more likely to develop severe alcohol problems and suffer violent deaths, while Tewa people who have epilepsy temper social isolation with alcoholism. Nevertheless, Tewa people with epilepsy also may come to violent ends; in recent years, two Tewa adults with epilepsy died violently and three were reported as having died violent deaths in earlier years.

The Search for Treatment

Unlike more isolated American Indian groups, the Tewa have access to a wide variety of health care services, including the United States Public Health Service (IHS), state programs that focus on disabled children, physicians in private practice, local hospitals in addition to the Santa Fe Indian Hospital, home remedies, traditional curers, acupuncturists, and herbalists. In fact, the whole Santa Fe, New Mexico, area is noted for its variety and interest in different healing traditions from all parts of the world.

Within the range of medical services, the most important factor in choice of agency was the complexity of the child's disorder. When children could be maintained on anticonvulsant medication and otherwise needed only periodic check-ups, families used the IHS exclusively. In contrast, families of children with poorly controlled seizures and/or multiple handicaps most often sought help outside the IHS system. Fourteen of the 31 children in the sample used IHS primarily while 11 most often used non-IHS help. Data were not available for six of the children. Of the 14 users of IHS, 13 had controlled seizures. Of the 11 taken to non-IHS practitioners, seven had poorly controlled seizures and/or multiple handicaps.

Although some families utilized non-IHS facilities because they thought they could receive more consistent care, most children with poorly

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controlled seizures or multiple handicaps were in need of on-going therapeutic services such as occupational, speech, or physical therapy that the IHS could not provide. Moreover, multiply handicapped children faced a variety of tests and screenings wherever they were taken. Due to poor coordination among service agencies, the children often had the same work-up several times. The situation improved, however, during the course of the research. When the research began in 1979, the problem was to find services that would provide follow-up and on-going care. However, in 1981, through outreach efforts on the part of the IHS and the New Mexico Department of Disabilities, new state programs specializing in the care of handicapped children became aware that Indian children needed more consistent services than the IHS could provide. As a result, there was greater coordination between IHS and these state programs, at least during the remaining course of the research period.

Lack of On-going Treatment by the IHS

For reasons that are outlined here, the IHS could not consistently provide the necessary services for chronically ill or disabled children. This was especially noticeable in the treatment of the more severely handicapped epileptic children in the sample, those most in need of continuity of care.

There are various factors that affect the ability of the IHS to serve the Tewa people. First of all, the Tewa population is mobile. Some families in the sample left the area for a time during the two years of they study, taking their children with them (at least four families moved out of the community and back within the research period). The children then received treatment outside the area, creating a gap in their medical records. When they returned, it took time and effort to send for records, and this sometimes was never done.

The high turnover of professional staff, particularly doctors, within the IHS also affected continuity of care. During 1979-1981, many physicians left after only two or three years of service, moving on to private practice or to another Public Health Service position. Physicians commented to me that they left not because of the people they served, but in reaction to the government restrictions on treatment and the heavy burden of paperwork that kept them from "doing real medicine." Often, the physicians had repaid the two-year service period they owed from accepting government loans during their schooling and were anxious to move into private practice. Since consistent care is best obtained from a physician familiar with a child's history and family situation, the practice of rotating IHS physicians caused some Tewa families to turn to private physicians. They used the IHS only for medication refills and periodic check-ups. The more severe the child's handicaps, the more likely Tewa families were to use a private physician.

Lack of funding also affects continuity. The IHS has been plagued by insufficient funding since it was established in 1955 and, with the cuts of

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the early 1980s, auxiliary services became even more limited. Like the rest of the medical system in the United States, the IHS developed with an emphasis on acute care. Even though in the early days widespread sanitary efforts were made to improve reservation environments, the acute care focus has prevailed. It has become even more prevalent in response to budget cuts.

The severely disabled children in the sample needed many resources not provided by the IHS. Private health insurance, Medicare and Medicaid, or Social Security Income met the cost of some of the treatment for some of the children, but not for all. Frequently IHS doctors, community health nurses, social workers, and mental health personnel found themselves desperately searching for appropriate treatment facilities outside the IHS system. They did so at some personal risk. IHS physicians were reprimanded on occasion for referring a child to a non-IHS facility when funding was not specifically contracted for such care.

Willingness of Parents to Use Medical Services

The evident willingness of Tewa families to discuss their children with medical personnel and to seek their help is a relatively new phenomenon. This may be related to families' knowledge that medication regimens developed since 1938 (Freedman et al., 1975), which became more consistently available to Native Americans after the Public Health Service takeover of Indian health services in 1955, are likely to be effective in controlling the disorder.

One set of parents said that as recently as the 1960s, families were secretive about such matters. Tribal leaders and community members repeatedly spoke of a change in village attitudes during the 10 to 15 years prior to 1980. They said that in the past such children were "never seen outside the home," and that people needed "to know about these problems." When asked why pueblo parents were unwilling to talk about their disabled children in the past, staff members responded: "Relatives do not give constructive advice about disabled children. They give pity, which parents do not need. Professionals (trained in the developmental disabilities area) are more helpful." In other words, with more services available since the mid-1960s, parents are bringing their disabled children "out of the closet."

Although most Tewa are now prepared to consult medical staff about their children, this does not mean that they are prepared to talk about all aspects of the child's treatment. As in many ethnomedical systems, traditional Tewa beliefs about causation and healing are contained within the religious and spiritual sphere. Any discussion of Tewa religion with non-Tewa in specific terms is considered tabu. To be asked directly about those beliefs by a non-Tewa person is considered rude and discourteous. Contacts during the during the research period (1980-1983) and continued contact through 1991 made it evident that many Tewa respect different kinds of healing knowledge - both modern medicine and their own - and will

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utilize them according to proved effectiveness. However, Tewa have no problem in keeping these medical paradigms separate from each other. Medical personnel, particularly physicians and nurses, are highly thought of because of their knowledge about how to stop seizures. The Tewa appreciate the sensitivity shown by those physicians and nurses who do not thoughtlessly ask questions about traditional healing practices that Tewa are not supposed to discuss with outsiders.

Discussion Of Research Findings

On the surface, the health care-seeking behavior of the Tewa regarding their children who have epilepsy could be descriptive of any population in the United States that has access to modern western medical care and appreciates its efficacy. As expected, however, indicators of ethnicity were present, in both medical and non-medical interactions with non-Tewa persons. First, traditional healing practices are kept distinctly separate from modern western medicine. And second, the Tewa are extremely reluctant to discuss traditional healing and religious practices with outsiders. The fact that Tewa families utilize the western health care system with such efficiency does not alter their sense of being Tewa. They utilize an easily available form of modern medical intervention that often demonstrates positive results. It is very likely that they are also responding differently at another level, utilizing their own medicine. This the outsider does not see.

One example of numerous conversations regarding this issue is noted here. A tribal elder, asked what western health providers needed to know to counsel and work with Tewa families, said they need to know nothing: "You have your area of expertise and our pueblo medicine people have theirs. Our families know the difference and can choose according to what each of you has to offer."

Implications For Health Care Policy

What do the research findings mean with respect to health care policy for the Tewa and, by extension, for patients from other traditional societies with indigenous medical systems? Probably most important is the fact that Tewa people do not talk about traditional healing practices with non-Tewa outsiders. One of Harwood's main points in his discussion on guidelines for culturally appropriate health care is that clinicians should take care to elicit the patient's concept of his or her problem and its cause (1982).

This concept is far too simplistic for use with people across different ethnic groups. Rather, if health professionals wish to be culturally sensitive to their Tewa patients, they need to do their homework. First, they must read about Tewa history and culture, and learn why the pueblos have needed to keep cultural information secret (Scheper-Hughes, 1987). Second, physicians and other service providers need to "learn how to ask"

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(Briggs, 1986). Listening to patients and letting their cues guide questions can make all the difference as to how that patient interacts with the service provider. If a physician or service provider is not willing to take the time to learn Tewa culture history and find appropriate ways of asking delicate questions (and asking those questions only when the answers are necessary for appropriate treatment), it seems clear that the professional should not ask about traditional Tewa beliefs. The Tewa are usually well versed in modern medical symptomatology and can answer questions about cause and problems of illness without reference to tabu topics. Specifically, Tewa parents with children who have epilepsy easily give information on family history of the condition and possible environmental determinants of seizures without having to reference their traditional paradigm of disease etiology and cure.

Like other non-western groups (Foster & Anderson, 1978), Tewa parents gladly use modern medicine when they can see that it helps their children. Hence, where non- IHS care is available and the IHS itself cannot provide sufficiently for children who have epilepsy, every effort must be made to assure coordination among agencies that can provide the needed care.

Implications Of Research For Chronic Illness Models

Research findings point to a number of factors to be considered when developing models of chronic illness behavior in any group. One of the most widely criticized models of illness behavior is Parsons' (1951), in which the sick person is neither expected to carry out normal role responsibilities nor is blamed for the illness. However, the sick person is expected to get well and must seek technically competent help in order to do so (Parsons, 1951).

Most researchers have criticized the Parsonian model as addressing only acute illness. They call for models that account for the effects of chronic illness on the behavior of patients and physicians (Stewart & Sullivan, 1982). They ask for a definition of sociocultural determinants of behavior during illness (Stewart & Sullivan, 1982; Hopper, 1981), and for discussion of the social and psychological problems faced by the chronically ill (Kassebaum & Baumann, 1965; Strauss, 1975).

In contrast to Parsons, Strauss (1975) outlines a framework for thinking systematically about the experiences of those suffering from chronic illness, noting that any given chronic disease potentially causes multiple problems in daily living both for patient and family. These include the prevention of medical crises and their management once they occur, control of symptoms, carrying out prescribed regimens, prevention of or living with the social isolation caused by lessened contact with others, adjustment to changes in the course of the disease, attempts at normalizing both interactions with others and style of life, and finding the necessary financial resources to pay for treatments. Strauss also recognizes that the

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importance of medical personnel is secondary to a patient's day to day "carrying on" in the face of the disease.

Strauss' generalizations about chronic illness help elucidate the first factor that must be considered in developing models of chronic illness, i.e., how patients and families adapt to everyday life in response to the disease. For epileptic persons, the control of symptoms is particularly important because of the range of visibility of seizure disorders. As was demonstrated in the Tewa family response data, when epilepsy is not apparent to the outside world, patient and family can function with relative normalcy, denying the reality of the affliction to self and others. However, when evidence of the disorder is visible because of seizure activity, the patient assumes the overt behavior attributed to the classic Parsonian patient role. During an epileptic crisis, the patient role fits Parsons' model. It is in the daily role of the person who has epilepsy - especially among those whose next seizure is imminent but unpredictable - that the classic patient role breaks down. Rather, the patient must become "committed to the meaning and implications of the disability" (Gussow, 1964), facing multiple problems of day-to-day life as posed by Strauss. The disability, in fact, becomes part of the patient's self-identity. The patient, then, falls in and out of the classic sick role, and adapts to the inevitability of recurrent seizures. Consequently, there is a continuum between the non-visibility and visibility of epilepsy that gives rise to different behavioral responses at different times.

Conclusions

The research findings about how Tewa families respond to epilepsy in children question broad generalizations about the response of non-western peoples to modern medicine and the definition of illness behavior. That physicians should learn how to ask questions and not assume the appropriateness of asking about traditional medicine behavior among the Tewa challenge Harwood's simplistic statement that clinicians should always elicit the patient's concept of the problem and its cause. Further, ethnic identity as a Tewa person is strong. Overt health-seeking behavior can overshadow nuances that well-meaning health professionals may overlook, thereby making for communication difficulties.

The research also demonstrates that epilepsy is varied enough in character as a chronic illness to complicate the development of a single chronic illness model appropriate to its victims. The fact that response to epilepsy varies depending on its degree of visibility underlines the importance of considering each patient's situation individually as well as in cultural context before predicting what his or her behavior will be.

Finally, the research shows that Tewa families who have a child with epilepsy face a large number of problems. They are plagued by social isolation and the lack of adequate care. They are faced with the consequences of their denial of the disorder as it affects the children, and

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in the cases of children whose seizures are poorly controlled, a future that drains emotional and financial resources. Nor is the world outside the Tewa community very supportive. The Age of Enlightenment is an idle dream for the person who has epilepsy. Other than the usefulness of modern medicine when it can control seizure activity, the western world has little compassion or comfort to offer when it comes to understanding the effects of a very complex chronic illness.

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Notes

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