

Psychological and Social Problems of Epileptic Children in Four Southwestern Indian Tribes

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According to traditional Navajo belief, sibling incest causes grand mal seizures. A 10-year study of Navajo epileptics revealed that these patients generally led troubled lives. Epileptic women were raped, gave birth to illegitimate children, and actually committed incest, whereas epileptic men tended to attempt suicide and to drink heavily. In order to test the hypothesis that negative beliefs were the major causes of these social and psychological problems, three Pueblo tribes living in the same region and served by the same health delivery system but without similar beliefs were selected for comparison. The study population consisted of all active cases of epilepsy where seizures started before age 20 and were not complicated by preexisting psychological problems or mental retardation (46 Navajos and 42 Pueblos). As predicted, Navajos were found to have social and emotional problems more often than Pueblos. Navajos exhibited problems prior to age 14 significantly more often, and significantly more Navajo females had severe problems. Navajo parents withdrew from the epileptic child; Pueblo parents treated their epileptic children as normally as possible. Special health education programs are not offered either to families or to schools, and mental health staff are not notified until emotional problems are clearly present. Half of all epileptic Pueblo children and over 70% of epileptic Navajo children do not take their medications regularly. Treatment programs appropriate to each tribe are discussed.

According to traditional Navajo belief, sibling incest causes grand mal seizures. A study of Navajo epileptics, identified in 1964 and followed for 10 years, revealed that these patients generally led troubled lives (Levy, Neutra, & Parker, 1979). Female epileptics were sexually exploited, gave birth to illegitimate children, and were even raped more often than a group of women with hysterical pseudoseizures. Although comparative data from the general population were lacking, we were impressed with the high proportion, some 30%, of female epileptic patients who had pseudoseizures in addition to their epileptic seizures; between 1964 and 1974, 3 patients died from exposure after drinking, suspected foul play, and suicide. Male epileptics tended to drink heavily and were frequently aggressive and violent. Although it was difficult to know whether their drinking was excessive when compared with other Navajos of the same age, a larger than expected number never married and were unable to keep a steady job. In addition, over 30% of the patients in one Health Service Unit had committed incest with a true sibling or with a "clan sibling." In the case of the women, the incest appeared to result from a self-fulfilling prophecy, as the epilepsy had started several years prior to the incestuous act. One male had forcibly and repeatedly committed incest with his younger sister some years after the onset of seizures.

In light of these findings we hypothesized that Navajo beliefs about incest and seizures were a major cause of the social and emotional problems of the epileptic. It

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seemed likely that the family of a child with epilepsy would withdraw emotional support and thus create emotional disturbance soon after the onset of the disease. We hypothesized further that community disapproval would intensify these problems in adolescence and early adulthood, making adjustment to adult life very difficult.

In a society that values children in large part for the economic support they provide, defective offspring might be resented and rejected, regardless of the beliefs surrounding the child's condition. In order to test the hypothesis and to avoid the possible confounding of economic conditions, comparisons with tribes at the same low economic level but without the negative definitions of epilepsy were required (Levy, 1981; Levy & Ghachu, 1979). Three Pueblo tribes living in the same region and served by the same health care delivery system were selected for study. None of these tribes, which share many aspects of culture, gives special attention to seizures.

The *Navajos*, once pastoral seminomads, currently number over 140,000 and live on a reservation the size of the state of West Virginia (some 15 million acres) in Arizona, New Mexico, and southern Utah. The Tuba City Health Service Unit (Indian Health Service) had a population of approximately 10,000 in 1976 (May & Broudy, undated) when it was selected for restudy. This Service Unit is located in the westernmost area of the reservation. It is about the size of the state of Rhode Island (approximately 2.8 million acres) and is thought to be one of the most culturally conservative parts of the reservation. It is also the poorest, is least reliant on wage work, and had the lowest population density. The people live, for the most part, in isolated family groups as far as 30 or 40 miles (mostly by unpaved roads) from the nearest health facility. The Tuba City, USPHS, Indian Health Service hospital, with over 100 beds, serves the entire area. Three Field Health clinics—one permanent, the others held twice monthly—help somewhat to lessen the transportation problem for those living in the communities thus served.

Aboriginally, the Pueblo Indians comprised a common cultural type, despite the diversity of languages represented among them. These tribes were sedentary farmers and continue to live in densely populated villages. Different degrees of contact with Spanish and Anglo-American populations have led to differences among tribes as well as among villages within a given tribe with respect to cultural conservatism, income, and education levels.

The *Hopis*, numbering about 6,200 on the reservation in 1976, live in 12 villages on a reservation completely surrounded by that of the Navajos in the state of Arizona.¹ The westernmost villages tend to use the Tuba City Hospital, whereas the easternmost use the Keams Canyon Indian Health Service Hospital, which has 84 beds. Field clinics are held weekly in several centrally located villages. Patients live no more than 30 miles by paved road from the nearest hospital.

The *Zunis* had a reservation population of about 6,300 in 1976 (Levy & Ghachu, 1979). They live almost entirely in one large village about 35 miles south of Gallup, New Mexico and receive health care from the large Indian Health Service referral hospital there, as well as from the 85-bed Indian Health Service hospital located some 5 miles from the village.

¹This figure was arrived at by using the Indian Health Service estimate of the Hopi reservation population, including the village of Moenkopi, for January 1975 (6,054) and adding an estimated 2.4% annual growth from that time to prevalence day, December 31, 1976.

The *Tewas*, with an on-reservation population of about 2,500 in 1976 (Indian Health Service estimate), live in five politically independent villages from 20 to 30 miles north of Santa Fe, New Mexico. Health care is provided by the Santa Fe Indian Health Service hospital with over 100 beds. Field clinics are held weekly in the three larger villages, which are also close to two private hospitals. All of the villages are connected by paved roads with the hospitals.

In contrast to the Navajo, none of the Pueblo groups believes that seizures represent a distinct illness, although all of them make a distinction between seizures which start in childhood and those which start later in life. The Zunis most often attribute childhood epilepsy to the killing of a game animal by a parent who did not perform the proper hunt ritual, the *Tewas* most often suspect the effects of an evil wind, whereas the Hopis do not single out any one cause. Childhood epilepsy generally indicates to these groups the presence of a parental problem, while adult epilepsy suggests that unless the diagnosis of witchcraft has been made, the patient is somehow responsible. Witchcraft is always considered to be a possible cause, and adults also are often said to suffer seizures resulting from a sudden fright. This phenomenon is most frequently due to the appearance of a recently deceased spouse or other beloved kinsman who is trying to take the patient back with him or her to the Underworld.

Method

All patient contacts, whether in an Indian Health Service or in a contract facility, are recorded in a computerized data retrieval system. Because of the expense of a neurological work-up, Indian patients seen in private hospitals are referred back to the federal system, either as patients or through the practice of billing the Indian Health Service. Because of the need to replenish medications, virtually all on-reservation residents are seen at some time, even if only on an outpatient basis.

The medical charts of all individuals from the four tribes who were seen for seizure disorders of any type in the two-state region served by the Albuquerque, Phoenix, and Navajo Health Areas between 1971 and 1978 were reviewed. Using Indian Health Service criteria, each was judged for adequacy of diagnosis. Only patients with active epilepsy as of December 31, 1976, and who had been reservation residents for 3 or more of the 5 years prior to that date were included in the study. Field Health family folders also were reviewed to obtain data about other family members and when these records were deemed insufficient, the patient or patient's family were interviewed. A total of 84 Navajos and 111 Pueblos (Hopi, Zuni, and Tewa) were identified as active epileptics by this procedure.

The sample of interest here consists of all patients whose epilepsy started before age 20, whose convulsions were not the direct consequence of a preexisting emotional problem (i.e., excessive drinking leading to head trauma), and who were not also retarded. The latter exclusion was made because most moderately and severely retarded children are institutionalized and because their emotional problems might be more closely associated with their retardation than with their seizures. From the population of identified epileptics, a study group of 46 Navajos and 42 Pueblos was obtained.

Results

Prevalence of Problems

As predicted, Navajos were found to have social and emotional problems more

often ($p < .05$) than did Pueblos. (See Table 1.) The difference is due to ethnicity and not to any difference in the distribution of the problem by sex.

Table 1
Prevalence of Emotional and Social Problems among Epileptics with Age at Onset Less than 20 Years

Problems	Navajo	Pueblo	Total
Present	28	16	44
Absent	<u>18</u>	<u>26</u>	<u>44</u>
Total	46	42	88

$$\chi^2 = 4.55; df = 1; p < .05.$$

Age at Onset of Problems

For this and subsequent comparisons, all individuals aged 0–5 years were excluded from consideration. There were 3 Pueblo children under 6 years of age who were said by their mothers to cry easily or to be quick to anger. These minimal complaints may persist, but as so few Navajo preschoolers have good contact with the medical system, our data on them are lacking, and we felt that noting problems at this age would bias the findings. Again, Navajos were found to exhibit problems prior to age 14 significantly more often ($p < .05$) than the Pueblos. (See Table 2.)

Table 2
Age at Onset of Problems, Individuals over 5 Years of Age

Age at onset	Navajo	Pueblo	Total
0–13 years	11	—	11
14–19 years	<u>17</u>	<u>13</u>	<u>30</u>
Total	28	13	41

Fisher's Exact Test: $p < .05$.

Severity of Problems

Most of the individuals identified as having psychological problems had at least one such problem, either over time or at a given time. For the purposes of this study, all psychotic disorders were classed as severe, as were pseudoseizures, hyperventilation, and hysterical reactions (if there was a history of many episodes over a period of a year or more for these three neurotic disorders), suicide attempts, murder, attempted murder, and death by murder (when other problems were also present), and chronic alcoholism. Classed as mild were single episodes of hyperventilation, "hysterical overlay," withdrawn behavior, neurotic depression, manipulative behavior, suicidal ideation, aggression, drinking bouts, and any single episode of drug overdose in the company of friends. (See Appendix.)

Although males in the two groups did not differ, significantly more Navajo females had severe problems than did Pueblo females ($p < .05$). (See Table 3.)

Table 3
Severity of Problems, Individuals over 5 Years of Age

Males			
Problems	Navajo	Pueblo	Total
Severe	6	3	9
Mild	<u>9</u>	<u>4</u>	<u>13</u>
Total	15	7	22

χ^2 (corrected for continuity) = .351; $df = 1$; $p < .5$.

Females			
Problems	Navajo	Pueblo	Total
Severe	10	1	11
Mild	<u>3</u>	<u>5</u>	<u>8</u>
Total	13	6	19

χ^2 (corrected for continuity) = 3.893, $df = 1$; $p < .05$.

Only Navajos (2 males and 1 female) were diagnosed as psychotic. Only Navajos were involved in homicide or homicide attempts: 2 females were murdered, 1 male murdered his brother, and another was seriously stabbed by his brother. Only Navajos (2 males and 1 female) made serious suicide attempts.

Seven Navajo women were diagnosed as having persistent hysterical reactions and another had a few isolated episodes. One Pueblo male also had a few episodes. The difference between groups was not significant, but the impression that Navajos tended to have more flamboyant pseudoseizures whereas Pueblos tended to go rigid or to hyperventilate needs more careful examination.

Attitudes

Interviews with parents revealed different ways of reacting to and dealing with the epileptic child. There were overprotective parents in both groups, though the overprotective Navajo parent tried to keep the child in isolation, an impossibility for the village-dwelling Pueblos. The characteristic style of Navajo parents was withdrawal and hostility. One boy told us that his parents would leave home for hours whenever he had a convulsion. In consequence, preschool-age Navajo children tended to be brought to hospital for treatment of seizures less frequently than Pueblo children. School-age children were most often monitored and given medication by school nurses and counselors who maintained contact with the hospital.

By contrast, Pueblo parents tried to treat the epileptic child as normally as possible. They took special pains to talk with their own and their neighbors' children so the children would react calmly when witnessing a convulsion and would not tease. Pueblo children, in consequence, developed normally until they were old enough to realize that their seizures made them different from other children. This usually occurred in junior high school, a time at which numerous problems came to the surface. The outward placidity of Pueblo parents masked a tendency to deny the serious and chronic nature

of the disease. The child was brought to hospital when seizures occurred, but the parents were resistant to the idea that the epilepsy might be a chronic condition which the child would ultimately have to cope with on his own. By treating the child as normal, Pueblo parents avoided dealing with the medical and social problems posed by the disease. By not speaking about the disorder with their epileptic child and not answering his questions, Pueblo parents provided the child with few means of coping as he became more independent in the adolescent period. After the age of 14, Pueblo epileptics began to experience emotional problems with as much frequency as did the Navajos. Neither group was well maintained on medications, and seizures tended to recur frequently as a result. *In effect*, Pueblos were not "better" patients than Navajos, despite the more placid atmosphere that surrounded them.

Discussion

We have found that Navajo epileptics have more social and emotional problems than do Pueblo epileptics and that these problems tend to start earlier in life. Moreover, the Navajo females have more serious problems than do Pueblo women. It is tempting to argue that the original hypothesis has been confirmed, i.e., that Navajo beliefs about epilepsy, perhaps buttressed by their need for productive offspring and their inability to care for handicapped children, do indeed have a debilitating effect upon the epileptic child. During the course of the research, however, several factors came to light which, taken together, make the null hypothesis at least a possibility. It is to a consideration of these factors that our attention must be directed, although in balance we do not feel that further investigation will negate the present findings.

Outmigration is considerably higher from the Pueblo villages than it is from the Navajo reservation, and it has been shown that Hopis and Tewas tend to eject deviants from the village. In a study of Hopi social pathologies (Levy, Kunitz, & Henderson, in press) it was discovered that the genesis of drinking was about the same in all the villages but that the conservative villages expelled their drinkers before they became too disruptive. Although these social controls currently appear to be changing, several severely disturbed epileptic Hopi adolescents were found living away from the reservation; they were the children of drinking parents or, in some instances, of parents who had made disapproved marriages. It is possible, then, that some of the more troubled Hopi and Tewa epileptics are living away from the reservation.

Another factor that may elevate the reporting of problems among Navajo epileptics—especially among those under 14 years of age—is the different structuring of the contact between epileptic patients and the Indian Health Service in the three Health Service Units. Due to the scattered settlement patterns of the Navajos, their distance from the hospital, the lack of paved roads, the lack of field clinics, and perhaps, also, the persistence of language differences, the Indian Health Service maintains contact with the younger Navajo epileptics through school personnel. These teachers, counselors, and nurses are less emotionally involved than parents and thus may tend to report behavioral and emotional problems more readily than would parents in either group.

A larger proportion of Navajo children attend federal schools because of the isolation of the western portion of the reservation. We have already seen that federal school personnel have direct contact with the Indian Health Service and that, in boarding schools, it is proper for the school to stand *in loco parentis* so that the reporting of problems might be more than would be expected if the responsibility were solely that of the parents. The situation is different in public schools, however, where the children

live at home and are considered to be the responsibility of their parents. Navajo children in the Tuba City Service Unit attend public school if they live in or near Tuba City or the town of Page, located at the northern boundary of the Service Unit. Hopi children living near Tuba City go to public school there, and almost all Hopi children of high school age are bused to an off-reservation public school. Virtually all the Zuni and Tewa children in New Mexico attend local public schools. There are, however, considerable differences between the school systems in the two states. Arizona is a wealthier state than New Mexico and allocates more money for special programs. It is possible that school personnel in Arizona "overdiagnose" behavioral and learning problems so that special education classes may be filled and the regular classroom teachers can work with minimum distraction. Without the same level of funding, Zuni and Tewa children are kept in regular classrooms and school personnel do not make referrals to medical services unless a child is markedly retarded. The possibility exists, then, that there is some bias toward underreporting in New Mexico.

Finally, some comment on culturally patterned styles of presenting symptoms when seeking medical help is in order. Among the Navajo, threats of violence and irrational behavior are used to signal the need for individual attention. For over a year, Levy gave a screening interview to every patient admitted to the Tuba City hospital for mental problems. Of approximately 15 patients diagnosed as schizophrenic, 3 paranoid schizophrenics brought to the hospital actually became violent. Family members of the other patients reported violent and bizarre behavior but under close questioning they revealed that no violence or even threats of violence had been made. Rather, the families and sometimes the patients themselves felt that if medical attention was not obtained immediately, violence *would* ultimately be the outcome. At admission, schizophrenic patients appeared somewhat paranoid because the withdrawal and flat affect were rarely mentioned. After admission, however, these signs were most common. Depressed patients were described by their families as having "spells," a term that in Navajo implies either convulsions or extreme erratic behavior thought to threaten violence. Hysterical patients described miniscule tremors with the same terms used for epileptic convulsions. Ultimately, of course, an accurate or tentative diagnosis would be made, but descriptive passages in the Navajo medical charts are rather flamboyant when compared with those of Pueblo patients.

Generally, the Pueblos present a more restrained demeanor. Neither patients nor their families elaborate much on their symptoms. Virtually all Pueblo patients speak English adequately so that it is not easy to tell whether they are expressing important Pueblo concepts or have adopted common English expressions from the surrounding Anglo-American populations. Symptoms may be masked or played down because of cultural preference or they may actually be fewer and less flamboyant than English words would suggest. One must ask how these contrasting styles have affected the research results and even whether they influence the diagnostic process itself.

Currently, epileptic patients are handled almost exclusively by hospital services. Special health education programs are not being offered either to families or to schools, and mental health staff are not notified until emotional problems are clearly present. That half of all epileptic Pueblo children and over 70% of epileptic Navajo children do not take their medications regularly, if at all, speaks poorly of the prevalent treatment methods. Because Pueblo parents are the contact between hospital and patient, it appears most helpful to provide education and mental health consultation directly to Pueblo patients and families prior to the emergence of emotional problems during

adolescence. This consultation should be accomplished in the village itself through referral of the case to field health staffs, indigenous Community Health Representatives (CHRs), and Mental Health Technicians (MHTs). The desire of Pueblo parents to treat their epileptic children as normally as possible makes them receptive to a consistent, family-oriented approach.

The Navajo situation is a more difficult one. Logistically, it is almost impossible to maintain good contact with families for any extended period of time, given the isolated and dispersed settlement pattern. Nor would intensified efforts in this area necessarily achieve the desired results, given the negative attitudes of so many Navajo parents. Rather, the contact must be made directly with the child. Therapy groups can be formed by bringing school-age epileptics together in Tuba City each month. This would break the children's sense of isolation by providing contact with fellow sufferers. With the realization that this problem is manageable and that he or she is not the only one who has epilepsy, the child can begin to lay the groundwork for healthy adjustment.

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Appendix

Clinical Descriptions of Individuals with Psychological and Emotional Problems Arranged by Tribe, Sex, Age at Prevalence Day, and Severity of Problem

A. Navajo Males ($n = 12$)

6-13 years

- Severe • Childhood psychosis, crying jags, hits head on wall, kids throw stones at him
- Mild • Shy, lonely, does poorly in school, in special education
- Anxious and depressed, in special education
 - Depressed, lonely, misses father he has never seen
 - Very hyperactive, bizarre behavior at age 13, confused states, stress at school

14-19 years

- Severe • Attacks mother, hits showers, starts heavy drinking at age 18
- Problems with family start at age 14, binge drinking, suicide attempt at age 18, murdered his brother at age 20
 - Suicide attempt with gun at age 20
 - Rebellious between ages 14 and 19, problems with family, possible hysterical overlay after age 20, stabbed by brother
 - Lives with grandparents between ages 14 and 19, severe alcoholism after age 20
- Mild • Hyperactive, hostile, aggressive, starts fights at school, seizures and behavior problems stop at age 14
- Dislikes school and wants to stay home

Appendix (continued)

B. Pueblo Males ($n = 6$)

14-19 years

- Mild
- Excessive drinking
 - Hostile and aggressive
 - Anxiety reactions, possible hysterical seizures

20+ years

- Severe
- Alcoholism
 - Chronic alcoholism
 - Severe alcoholism

C. Navajo females ($n = 13$)

6-13 years

- Severe
- Manipulative, fears loss of love, nightmares, somatic complaints, hysterical seizures at age 13, sent on LDS (Mormon Church) placement at age 14
 - Severe emotional problems, maintained on Thorazine

14-19 years

- Severe
- Severe psychological problems, hysterical episodes between ages 6 and 13, hyperventilation after age 14
 - Isolated by overprotective family until age 13, then aggressive at home and school, siblings leave home to avoid her, becomes promiscuous, has illegitimate child, raped and murdered at age 19
 - Between 14 and 19 years of age possible hysterical overlay, killed, murder suspected

- Mild
- Isolated, lonely girl kept out of school by mother
 - Before age 13 withdrawn and depressed, after age 14 problems with family.
 - Easily angered, does poorly in school, in special education, seeing psychologist

20+ years

- Severe
- Between age 14 and 19 suicide attempt, complex hysterical disorder, hysterical overlay after age 20
 - Hysterical seizures between ages 14 and 19, acute alcoholism after age 20
 - Between age 14 and 19 taken out of 6th grade by mother, promiscuous, has illegitimate child, multiple social problems after age 20, unspecified psychiatric disorder
 - Pseudoseizures before age 19, then hysteria, multiple pseudoseizures and somatic complaints, on Thorazine
 - Unhappy and maladjusted before age 20, then hysterical neurosis, psychotic depression, anxiety states, somatization, and hallucinations

D. Pueblo Females ($n = 6$)

14-19 years

- Mild
- Drug overdose in company of friends, does not take medications
 - Manipulative behavior, poor compliance, illegitimate pregnancy

20+ years

- Severe
- Albino, exogenous depression, 20-year history of pseudoseizures, hyperventilation, hysterical reactions, and anxiety states

- Mild
- Anxiety reactions, hyperventilates after arguments
 - Suicidal ideation, neurotic depression, problems at home
 - Drinks, fights with father, arrested for driving while intoxicated.