The Craniofacial Team and the Navajo Patient

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The craniofacial team at the University of New Mexico Medical Center in Albuquerque, New Mexico has treated a large population of Navajo Indians. Team awareness of the Navajo concept of health as man In balance with his environment has resulted in more expedient treatment of the Navajo children. An understanding of Navajo concerns with ghosts, skinwalkers, and rules for orderly living has allowed team members to integrate the family and the Navajo medicine man In caring for the children with craniofacial disease.

Special concerns for Informed surgical consent and genetic counseling of the Navajo are reviewed. Respect for the traditional Navajo healing ceremonies and special handling of disposed body parts in surgery are required of the health professionals caring for these people.

KEY WORDS: *Navajo health and religion, Navajo craniofacial disease, Navajo cleft lip and palate.*

Craniofacial and cleft palate teams must deal frequently with distinct cultural, ethnic, and traditional attitudes to achieve timely and effective treatment of patients. At the University of New Mexico Hospital, Albuquerque, New Mexico, a large proportion of the patients are Navajo Indians. An estimated 160,000 Navajos live on a reservation that covers 24,700 square miles, including areas in Arizona, New Mexico, Utah, and Colorado. This group makes up 23% of the total American Indian and Alaska Native Indian populations (Milligan, 1984). Thus, many Navajo children born with craniofacial anomalies and cleft lip and palate are treated at the University Medical Center. The proper care of these children entails a basic understanding of the attitudes and multifactorial cultural elements of this unique society and serves as the basis of this report.

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The Navajo concept of health is quite different from that of the Caucasian population. Physicians and nurses must respect Navajo beliefs in order to expedite care of the children with craniofacial deformities. Permissive treatment has been more effective than an authoritarian attitude with the families.

We have undertaken this paper as an effort to provide health care professionals with a fundamental background for more effective interaction with the Navajo patient. This report is divided into two sections. The first section outlines the traditional Navajo beliefs about health and disease. It also includes observations about the traditional Navajo lifestyle. The second section is a description of specific concerns and recommendations in the clinical management of the Navajo patients and families.

In traditional Navajo culture, health is regarded as the correct relationship between man and his environment. Good health is associated with blessings, beauty, and positive values in life, whera s illness is an indication that one has fallen from balance. Disease may be linked to a transgression of rules that guide Navajo behavior. Disease may also be the demonstrable result of contact with ghosts of the dead or even misdeeds of a Navajo who has resorted to witchcraft (Lynch, 1969).

Despite the level of education and economic position of Navajo men or women, many adhere to some of their basic, traditional Navajo teachings. Harmony with nature and guidelines for good living are part of Navajo beliefs and arc explained in ceremonial rituals. The Navajo population borrows from other cultures. Nevertheless, even individuals who have converted to a given Western religion often tend to adhere to some Navajo beliefs relating to the rules for orderly living (Lynch, 1969).

THE NAVAJO CONCEPT OF DISEASE

Traditional Navajos do not distinguish *between* religion and medicine as seen in Western culture. These are perceived as aspects of a unified whole. Navajo beliefs arc oriented toward helping the individual maintain or restore a harmonious balance with the environment. It is estimated that as many as one third of the waking hours of Navajo elders are devoted to healing ceremonies to drive evil from the body. Navajo religion stresses maintenance of life over the regularity of death or a concern for afterlife. Harmony and cooperation are highly valued and emphasized (Kluckhohn and Leighton, 1960; Brady, 1984).

In the Western world, religion is often considered a separate and defined aspect of life. The traditional Navajo, however, perceives his life as a whole with each daily act colored by the influences of supernatural forces. Many Navajos attribute illness to certain transgressions, such as having violated a taboo or having said harmful things to people, or as a result of witchcraft (Kluckhohn and Leighton, 1960; Lynch, 1969; Milligan, 1984). For the Navajo, the universe is said to contain two classes of forces. These are the earth's surface people, both living and dead, who are ordinary human beings, and the holy people, who are believed to possess great powers to aid or to harm the earth's surface people. Navajos are also fearful of the harm that may come to them from the ghosts of the earth's surface people. The dead may return as a potential danger to avenge some neglect or offense, including improper burial or disturbance of a grave (Kluckhohn and Leighton, 1960).

The living may bring harm to their Navajo neighbors. It is believed that by employing witchcraft, evil men and women can obtain property and cause illness or the death of those whom they hate. To the Navajo, witches are those who intend to do evil to others. They arc characterized as independent, aggressive, competitive, and acquisitive. lithe Navajo becomes wealthy and does not share his goods, he or she may be suspected of witchcraft. Witches can inflict psychologic ailments upon others by using ointments or by shooting magical agents through the air. They are grave robbers who use old jewelry and body parts in their ceremonies,

Skinwalkers are human witches who wear coyote skins and travel at night. In Navajo myth, the coyote is characterized in sinister terms and there exist specific restrictions in the eating and killing of these animals. As a primal culture hero, the coyote embodies attributes of both the positive and negative sides of life.

Skinwalkers are the most pervasive of all Navajo witches. According to traditional beliefs, they may climb on top of a hogan while a family sleeps to drop pollen made from the bones of human infants into the smoke hole. Contact with this substance brings a sleeping person ill health, social problems, and sometimes death. Anyone, man or woman, may become a witch, Witchery is learned from a relative. Skinwalkers constantly threaten the highly valued order and balance in Navajo society. They defy the culturally dictated categories of men and animals and exist somewhere between man and animal, between order and chaos. The Navajo skinwalkers constantly move between the worlds of humans and animals, throwing the two differing domains together (Brady, 1984)

Mental or physical disease may be perceived as emanating from a supernatural origin. The idea of locating the cause of the disease as a physiologic process is foreign to traditional Navajo thought. Treatment addresses causative factors, not the specific illness or injury. It is the duty of the Navajo stargazer or handtrembler, consulted as a diagnostician, to discover the cause of the present illness. Such causes may include contact with lightning-struck objects or the breaking of a proscription. In other instances, the patient presumably may have been affected in utero because his mother looked at a forbidden object during pregnancy. When illness is persistent or mysterious from the Navajo point of view, witchcraft may be assigned as the cause (Milligan, 1984).

Whenever an individual believes he or she has been witched by a skinwalker, a ceremony must be held to counteract the effects of the witchcraft. Other perceived causes of illness may also be treated with a "sing"; the diagnostician would suggest a "sing" to be performed. The family would then contact the singer, who knows the required ceremony and arrange a payment. All sings carry a charge, and it is believed that a payment is essential to ensure efficacy of treatment (Lynch, 1969; Milligan, 1984).

Modern Navajo patients do not hesitate to

seek Western medical care, but when the illness is chronic or not responding to medical treatment by physicians, patients may turn to medicine men or other healers. If a Navajo cannot afford a specific ceremony, he may get some form of first aid treatment consisting of herbs or other temporary therapy until he can afford the complete ceremony. The medicine man may suggest a referral to a Western doctor but always cautions the patient to return and finish the ceremony that has been interrupted or again risk illness. Although the Navajos believe that the white doctor can rid the body of pain and drive out germs, an understanding that only the singer can restore the harmony of the patient with his environment predominates.

In 1972, public health service clinic patients in Shiprock, New Mexico, indicated that 60% of them had visited a Navajo medicine man to be cured for an illness. While only 4% indicated the medicine man to be the first choice to consult for sickness, 22% indicated the medicine man was a second choice after seeing a Western trained physician (Bozof, 1972).

NAVAJO PREGNANCIES AND CHILDBIRTH

When a traditional Navajo woman finds that she is pregnant, she shares this information with her husband. The expectant mother is said to relive the creation story as she prepares to bring forth into the world an earth boy or girl. The couple must observe proscriptions governing their thoughts, speech, and actions. It is their belief that anything they think, say, or do will be heard by and affect the unborn child. The lessing Way Ceremony is performed for a Navajo woman in pregnancy and after delivery. This is done to promote a peaceful growth of the fetus and an uncomplicated delivery as well as for newborn protection and newborn survival (Wilson, 1978; Milligan, 1984).

In 1977, the Native American Indian Health Service reported that 99% of Indian children were delivered in hospitals the preceding year. Unfortunately, many of these mothers had received no prenatal care. Childbirth is considered to be a normal, natural part of life. Thus, problems with pregnancy are not anticipated and not necessarily interpreted as symptoms. Going to a clinic or hospital to obtain prenatal care is a foreign concept to the most traditional Navajo view of life. It is considered natural to endure the hardships and discomforts of pregnancy. It is generally accepted that a Navajo woman should continue her normal work throughout the course of her pregnancy (Lynch, 1969; Wilson, 1978; Milligan, 1984).

BIRTH DEFECTS AND INFANT HEALTH

Part of the Navajo belief system involves the avoidance of taboos in order to achieve an orderly and harmonious life. Most taboos are well thought out and told in Navajo legends or ceremonies. Some examples are presented by Kosick (1986), Director of Nursing Continuing Education at Navajo Community College:

> Don't sew a saddle while your wife is pregnant; it will ruin the baby's mouth. Don't look at a dead person while pregnant and don't view dead animals; this will cause bad luck for the baby; it will be a sickly baby. Don't put on your yei mask while your wife is pregnant; the baby will have a big head and look strange. Don't let a baby's head stay to one side in the cradleboard, it will have a wide head. Don't watch or look at an accident while your wife is pregnant; it will affect the baby.

Reluctance to discuss birth deformities may be explained by some relation to the origin legend of the Navajos. Certain abnormal practices of the women during the period of separation of the sexes resulted in the birth of monsters. Whereas contact with ghosts is considered dangerous during pregnancy, there is otherwise limited information on the subject of unusual births in the literature (Bailey, 1950).

The three major causes of Navajo neonatal death during 1981 were (1) congenital anomalies incompatible with life, (2) prematurity, and (3) pneumonia. Mortality statistics among Navajo babies indicate that the greatest number of deaths are in post-neonatal infants. These deaths were attributed to congenital anomalies, metabolic disease, sudden infant death syndrome, diarrhea, pneumonia, meningitis, and trauma.

The leading diagnoses for ambulatory care visits by infants were respiratory problems, otitis media, parasitic infections, and gastroenteritis with diarrhea. Although the prevalence of congenital anomalies in the Navajos is not known, the most frequently observed conditions are congenital hip dislocation, cleft lip with or without cleft palate, Down syndrome, cardiac abnormalities, and central nervous system deformities (Milligan, 1984).

CHILDREARING

Anthropologists have viewed Navajo social life as a tripartite structure consisting of (1) the household or the nuclear family; (2) the resident group, camp, or extended family; and (3) the outfit. The Navajo system of social relations is based on a network of kin ties that were traditionally matrilocal. Navajos feel very strongly

that it is important to help one's family. They live under a diffuse moral obligation to give aid, either when it is requested or when it appears to be needed, especially by relatives. Sharing and cooperation are given freely and without any expectation of reciprocity.

From infancy, Navajo children of traditional homes are taught that they are safer with relatives. They are instructed about the dangers of the social world around them and the precautions they must take with strangers and nonrelatives. This social apprehension among strangers is instilled in young Navajo boys and girls in a variety of ways, mostly by verbal warnings in specific situations. Traditional Navajos will on occasion become tense, anxious, and suspicious when these emotions may seem quite unwarranted to an observer. Because one never really knows the exact nature of another individual, all others must be viewed with suspicion. The fear and anxiety potentially associated with involvement with strangers and nonrelatives becomes a part of the lives of Navajos at an early age (Brady, 1984).

Those who are accused of being witches are usually characterized as selfish, acquisitive, and lacking concern for family members. A skinwalker presents a reverse picture of a good Navajo, since he negates the most highly valued qualities of Navajo life. Small children in the Navajo household hear about witches who are competitive, aggressive, and acquisitive. The children learn subliminally that to be a success in the Western world, they need to act very much like witches. As they approach puberty, dating, and adult concerns, this discrepancy often gives rise to intense internal conflict demonstrable by suicide, alcoholism, and delinquency (Brady, 1984).

Care of the Navajo infant is substantively different than that occurring in Western Caucasian families. Typically, the infant sleeps with the mother until the age of 1 year. The timing of everyday events is extremely flexible. The child eats meals when hungry, and the infant is nursed upon demand. There are no set bedtimes. In the Navajo camp or home, the social interactions are family-centered and most events are unscheduled. The children are indulged. There is often a psychologic boundary 100 feet beyond the camp. Infants in very traditional homes might not see strangers until they are 3 to 5 years of age. For this reason, Navajo children in the second year of life may have a greater fear of strangers than non-Navajo children as the result of limited social exposure.

Navajo homes may have no electricity. The diet is often lacking in proper nutrients, thereby causing fatigue and illness in the children. For a long time, Navajo concerns have focused on meeting only daily needs. Their prevalent philosophy has been and often continues to be "not to worry about tomorrow." If your family is hungry—you worry about that today (Henry, 1986).

IMPLICATIONS FOR THE CRANIOFACIAL TEAM

The traditional health beliefs have been outlined to assist the Western health care professional in understanding the general differences in the Navajo family approach to health care, The modem Navajo family may not necessarily follow the traditional Navajo teachings. For example, the parents may be unconcerned with the taboos or proscriptions for orderly living associated with conception and birth. The physician however, needs to be aware of the cultural background that may influence the Navajo parents of a child with a craniofacial deformity. To successfully transmit new ideas, techniques, and beliefs to the more conservative members of the Navajo population seeking health care, it may be very beneficial to use acculturated Navajo patients who can interpret for the family and physician (Adam, 1970).

In 1981, a study of 479 expectant Navajo women reviewed traditional Navajo beliefs in pregnancy and child care (Milligan, 1984). Eighty percent of the respondents were under 30 years of age and had completed 12 or more years of formal education. Ninety-two percent spoke Navajo, but only 31% spoke primarily Navajo in the home. When asked about their religious affiliations, most respondents followed the Navajo way (70%). Respondents did note, however, that more than half had some other church affiliation in a Christian denomination. They did reveal that the traditional cultural beliefs and practices were still supported by most of the young, expectant Navajo women. Seventy-five percent of the surveyed women believed in witchcraft, and 59% would have a ceremony for the infant to rid harmful influences to which ***he*** or she may have been exposed while hospitalized. The perception of the hospital as a house of death, an old Navajo belief, was declining, and most women were willing to be delivered in a hospital facility (Lynch, 1968; Milligan, 1984).

In order to work successfully with the Navajo family in treating the children with craniofacial deformities, it is important not to require or expect them to give up their traditional beliefs. They must understand, however, that Western medicine can be a positive reinforcement to

their healing ceremonies. If the physician understands the patient's idea of the cause of his or her condition, the patient and the physician can work closely together. The patient's family support system can also positively influence therapy. It is important to realign the patient with his or her usual group of family and peers as well as with the new social institutional groups of the medical system (Morgan. 1981).

Physicians who work in the public health system frequently encourage the participation of the medicine man in the care of an ill patient. Some feel that the patients come to the hospital in a better frame of mind and are better prepared for surgery. They have noted that these patients feel much better on the first postoperative day than somebody who does not have this faith in the Navajo way (Williams, 1984).

The Navajo medicine man's attitude toward his professional work may be similar to that of the psychotherapist. He relies on knowledge rather than trances or magic. He is restrained and dignified in his demeanor. He must undergo a long period of training and apprenticeship. In some cases, he will participate as the patient in the chosen chants several times. In the position of a surrogate parent or grandfather, he may offer the patient good advice. Most medicine men do not treat their own relatives. Although they charge a considerable fee, it may be scaled down to the patient's means (Sandner, 1979).

Ashen skin streaks and body paints are visible signs of a healing ceremony in progress for a patient. Herbs are another indicator of a ceremony in progress and may be detected by sight and smell. They are often tied in the hair, and a braided strand of yucca is worn as an amulet. For the healing process to have its full effect, the signs must not be disturbed. Generally, they are left in place for 4 days and provide protection for the patient from external evil spirits, thus reestablishing harmony.

Navajos with simple illnesses do not usually undergo a ceremonial chant prior to visits to the clinic or prior to hospitalization. When the illness is chronic, unsolved, or mysterious, it is more likely that a patient will participate in a ceremony prior to hospitalization if the family believes in traditional Navajo healing. Our conversations with the Navajo patients and families from the clinics offer little support that the common cleft lip or cleft palate deformity would require elaborate Navajo ceremonies prior to surgical repair.

Patients who have unusual craniofacial deformities, such as aneneephaly or holoprosencephaly, have been considered more of a problem for the families. Our team had experience with a median cleft lip deformity in a child with holopmsencephaly. The family required the services of a medicine man upon completion of our evaluation of the newborn. This child was judged to have been affected because his mother saw an animal struck by lightning during the pregnancy. Another anencephalic baby was thought to be the result of witchcraft, and a medicine man was consulted. A ceremony for the child was required before the parents and grandparents would allow continued hospitalization. even though surgery was later denied for this patient.

Although little information is available about the beliefs concerning unusual births and, specifically, cleft lip and cleft palate, it appears that the families recognize that common cleft lip and palate deformities respond well to surgical management. In the more unusual defects or those without good surgical solutions, an underlying Navajo cause is sought for treatment in addition to surgery.

The lifestyle and child-rearing issues have implications in clinical situations. Many patients with facial deformities are tolerated and lovingly cajoled about their deformities in the family setting. Therefore, there is less tendency to ostracize or to point out as different the Navajo child who has a defect. For this reason, the Navajos seem to accept less than ideal results for repair of the cleft lip and associated nasal deformities. It may be difficult to convince parents to bring the children back at preschool age for additional touch-up surgery. Adolescents who are active in the social environment of school have a sensitive body image and are more willing to return for additional surgery.

Because the Navajo may be slow to develop a sense of trust in the health care provider, it is important to minimize turnover of surgical staff in cleft Paialeclinics. In many cases when children might benefit from surgery, surgery was delayed up to a year, requiring several return visits of the parents before trust in the physician was established and hospitalization could proceed.

There may be difficulties in getting the patients to the hospital in a timely fashion. We have had to set limits so that the patients do not arrive during the middle of the night for admission prior to surgery. This is usually solved by explaining to the parents that the physicians will not be available to see the patients if they do not arrive in the afternoon on the time schedule assigned. We have had to insist that the Navajo families observe a Western time schedule.

Considering general health problems in the

Navajo infant, it has been important to have the mothers check with local pediatricians prior to arriving at the University Hospital if they are to travel great distances. Often the children arrive with respiratory infections or infected ears, forcing cancellation of surgery and return to the reservation by airplane the following day. If the children have had repeated upper respiratory infections or pneumonia, in some cases we have hospitalized these children several weeks in advance of surgery to clear up their infections so that surgery could be completed in a timely fashion. Despite the current trend of decreasing postoperative hospitalization time following cleft lip and palate repair, we have continued to keep these patients in the hospital for 5 days following surgery. During this time the nurses provide wound care while the parents are taught proper postoperative cart, especially the importance of elbow splinting and avoidance of utensils to prevent wound disruption. With the patient in the hospital on the fifth day, suture removal is accomplished prior to discharge, since we cannot depend on parents to return with the child for timely suture removal.

Because young, inexperienced Navajo mothers are expected, in their culture, to know how to provide and care for the children, they generally do not ask questions. According to the public health field nurses, young mothers often feel that seeking such information would show their lack of ability or an incompetence in childbearing. Our posture has been to provide this needed information on a frequent and repetitive basis, thereby teaching mothers how to care for the baby with cleft lip, cleft palate, or craniofacial deformity. We have tried to provide an abundance of information that is then reinforced by the nurse during home visits.

Provision of genetic information and counseling to Navajo families in a culturally appropriate and sensitive manner may present a dilemma for the physicians and counselors who are not familiar with Navajo customs and beliefs. The task of the genetic counselor is to determine the family's belief system and understanding of genetic concepts. In counseling the families prior to surgery or for genetic planning, the physician must be patient in obtaining histories. Many irrelevant details may be 'provided by the family. These points may seem very significant to those recounting the history of birth defects in the family and in explaining their ideas about the origin of the defects. It is unwise to try to direct or limit this discussion once the family begins to provide information and show confidence in talking with the physician (Cope, 1987).

Typically, on the first clinic visit, the family may avoid direct eye contact with the physician until a sense of trust develops. Verbal communication may be minimal. The Navajo who lowers his eyes and head does so in an expression of respect and should not be interpreted as avoiding or misunderstanding the health care worker. When a family genetic history is to be established, it is helpful to invite members of the family to sit around the table, although this may be very time-consuming and marked by long periods of silence. It should be explained to the family that questioning is necessary to determine whether an illness occurred in previous generations. Privacy and avoidance of gossip are important. Navajo families have been known to go to medical centers in another community where they are not known by the staff. Discretion must be used when asking personal questions in the presence of Navajo medical staff (Cope, 1987).

It is helpful to ask the family in advance why they believe such a deformity may have occurred. This will provide an insight into the traditional beliefs of the family. They must be assured that by providing this information, it is not the intention of the physician to dispute their beliefs. It can be stressed, however, to the family that medicine is a science that has been proven to be true. Nevertheless, caution must be used in predicting future birth defects because this may be interpreted as the equivalent of wishing problems for the family (Antic, 1987; Cope, 1987).

This same concern carries over in requesting informed consent from the families. If the surgeon describes to the family the entire spectrum of potential risks and complications, he or she may find that the family does not sign the consent form and decides to leave the hospital that same night. Discussion of surgical risks and complications may be interpreted by the family as the equivalent of wishing or predicting complications for the child who is to undergo surgery. It is best to explain to the family that other children who have had this surgery have had problems of this sort and things can go wrong during any surgery. On one occasion, a mother. after reading the form and noting that the possibility of death was mentioned, left with her child who had cleft lip. This was despite many reassurances of very low probability of such an occurrence.

In dealing with the patients who will undergo surgery, recognition of the family's beliefs within the continuum of traditional Navajo beliefs is essential. The very traditional Navajo would be concerned with the handling of body

parts to be disposed of, such as hair shaved from the head of the child. Were these body parts to fall into the hands of Navajo witches, harm to the patient might then be arranged by the witch. The families may request that the body parts be returned to them. In some cases, they will accept assurances that the parts will be disposed of properly. These concerns need to be discussed in advance of any surgical procedure (Wilson, 1978).

To better understand the beliefs and background of the Navajo patients, we have interviewed mothers of the patient's with cleft lip palate seen by our team. Also, we have interviewed older Navajo children treated in the hospital on the plastic and reconstructive surgery service. An interview was conducted with a field nurse from the public health service who worked with the Navajo families in the home. Two Caucasian nurses who worked in an outreach hospital also provided input about their observations of the role of the medicine man in the hospitals.

Unfortunately, direct input from Navajo health care workers has been offered with less cooperation than we had requested. The Navajo nurses who were contacted provided limited information about some of the Navajo beliefs and taboos relating to birth defects. Of the five nurses contacted, only two offered information. The medical director of a public health Indian hospital in New Mexico was asked to collaborate in the production of this paper. He is a Navajo who is a physician in the Western system of medicine. He declined to participate and said he was not familiar with Navajo beliefs related to birth defects. Likewise, he felt he did not have the resources to research the subject. The Director of the New Mexico State Public Health Service who coordinates the cleft palate team clinics is a well-educated Navajo woman. She offered some insights into the cultural background of the Navajo patient but did not wish to collaborate in the production of this paper. Attempts to meet with Navajo medicine men, even with offers of payment, were declined.

Many Navajo people and Navajo health care professionals are secretive about beliefs. Navajo parents whom we interviewed would not discuss their beliefs about ghosts and witchcraft. Only the children would offer some information about beliefs in witchcraft and skinwalkers. Our experience in understanding current Navajo beliefs is similar to that of Brady (1984). She interviewed Navajo children for information about the folklore that would assist in understanding the current culture.

Admittedly, only four of our 13 references in the preparation of this paper are Navajo authors. A group of Navajo graduate students who reviewed the first draft of this paper were critical and stated that perhaps the traditional beliefs had been overemphasized. They accused the authors of presenting Navajo religion as unsophisticated. They strongly suggested that the paper would benefit from the input of Navajo health professionals. We agree with their suggestion; however, attempts to obtain this important input were mutely rebuffed.

Therefore, this paper is a compilation of available literature resources, interviews of patients, and the combined experience and observations of a craniofacial team in working with Navajo patients. The authors do not claim that this report is the authoritative reference on current Navajo beliefs. It is intended to describe a number of traditional attitudes and beliefs that appear to apply in varying degrees, even to the modern Navajo. It is important for Western health care workers to determine where, along the spectrum of traditional beliefs, the patient and family are located. The Health care workers must avoid insulting the modern Navajo and therefore must understand the cultural differences that may exist regarding the diagnosis and treatment of disease. With this background of information, the health care worker may more readily develop the basic trust of the patient and family and, where appropriate, encourage the integration of traditional Navajo medicine, such as the medicine man, in providing the best care for the patient.

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