

Navajo Perceptions of Asthma and Asthma Medications: Clinical Implications

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ABSTRACT. *Background.* Despite the large number of asthma patients, relatively little is known about the beliefs of asthmatic children and their parent(s), or the extent to which these beliefs influence management of the disease.

Objective. The purpose of this study was to examine how medication-taking and the use of health care services were influenced by perceptions of the disease and beliefs about medications among Navajo families.

Methods. Ethnographic interviews were used to investigate the disease and medication beliefs of 22 Navajo families with 29 asthmatic children.

Results. Most respondents perceived asthma as the transient experience of symptoms in someone who was chronically vulnerable to breathing problems. The majority (97%) of these asthmatics reported using bronchodilators, although only 34% reported current use of antiinflammatory medications. Although controller medications were distinguished from rescue medications, they were thought to have the same effect on the lungs. Many families were concerned about becoming dependent on the medicines and attempted to “wean” the asthmatic from the drugs. A large proportion (80%) of children had assumed responsibility for their own medication taking. Parents often referred to previous attacks requiring treatment in the emergency department when deciding whether to initiate medication or seek medical attention, often resulting in a delay of treatment. Nebulized treatments delivered in the emergency department were perceived to be the strongest therapy available. As a result, visits to the emergency department were common (79%), as were hospital admissions (57%).

Conclusion. This study provides evidence that, among pediatric Navajo asthma patients, perceptions of asthma and beliefs about the activity of asthma medications influence when and how often asthma medicines are taken, as well as the use of health care services. In addition, excessive reliance on emergency treatments and the high rates of hospital admissions suggest that asthma is undertreated in this group of Navajo patients. *Pediatrics* 2001;108(1). URL: <http://www.pediatrics.org/cgi/content/full/108/1/e11>; *asthma, Native Americans, Navajo, perceptions, treatment, medication, health utilization.*

ABBREVIATION. ED, emergency department.

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During the last decade, major advances have been made in the management of asthma. Guidelines for asthma treatment at each age¹ have been developed based on the systematic study of the presentation of asthma symptoms and progression of disease associated with different levels of severity. Treatment regimens increasingly stress the use of antiinflammatory medications, which address the underlying pathology of asthma, rather than reliance on reliever medications such as bronchodilators, which were the main line of defense in the past.

Although it would seem that these advances should prevent or diminish asthma exacerbations, the extent to which they succeed depends in large part on patient behavior. Compliance—or adherence—with medication regimens has been a major concern expressed in the asthma literature,^{2–4} and numerous programs have been developed to foster compliance by educating patients. Unfortunately, these efforts have occurred in the absence of an understanding of patient beliefs about the illness and its management. There is considerable literature showing that patient beliefs about the cause and pathophysiology of their illness, and about how their medications function, constitute critical motivators of medicine-taking behavior.^{5–10} Because few studies have examined the logic of medication use among asthma patients, research into patient perceptions of the disease and its treatment is essential for the advances in asthma management to be realized.

This study reports on the perceptions of asthma and its treatment in a group of Navajo families with 1 or more asthmatic child. These interviews indicate that beliefs, as well as culturally sanctioned behaviors, have important implications for labeling, treatment, and health care utilization for asthma in this population.

METHODS

Ethnographic interviews were conducted between June 1997 and August 1998, with 22 Navajo families with asthmatic children. The families either responded to a letter after being identified by health care providers, or responded to a pediatric clinic flier or a newspaper or radio advertisement requesting interviews with families of asthmatic children. No attempt was made to interview any representative group. Because the families of several of the index cases contained >1 asthmatic member, information was obtained on an additional 7 individuals with asthma, for a total of 29. Interviews were conducted with the parent(s), although the child(ren) often participated in the interview as well.

All interviews were conducted in English, in either the family home or at an office located at Diné College, and averaged an hour in length. Although native Navajo speakers were available to assist with the interview, no families requested them, nor was

their use ever deemed necessary by the research team. Although not Navajo, one of the authors (A.L.W.) has conducted research on the Navajo Reservation intermittently since 1976, on projects involving in-depth interviews about cultural beliefs pertaining to health behaviors. The first author is a doctoral candidate in anthropology at the University of Arizona, and has received extensive training in ethnographic methods and the Native American cultures of the Southwest.

The ethnographic interviews were designed to explore perceptions of asthma, particularly attitudes toward asthma medications (how they are classified, how they work, side effects) and the rationale for their use. Interviews generally followed the respondents' thinking about asthma,¹¹ but efforts were made to cover certain topics in most interviews. Interviews were tape recorded and transcribed verbatim. After review of all interviews, a list of important themes was created. Transcripts from each interview were then coded and analyzed using the ethnographic software package, NUD*IST (Sage Publications Inc, Thousand Oaks, CA). In addition, discrete data from each interview (such as age, gender, whether the child had been hospitalized for asthma, etc) were abstracted to an Excel spreadsheet, to facilitate calculation of percentages. SPSS was used for assessment of statistical significance. Throughout the course of the research project, extensive consultation with native researchers and local experts in Navajo culture informed the focus and technique of interviews, as well as the interpretation and analysis of results.

Permission for the project was obtained from the University of Arizona Human Subjects Committee, and the Navajo Nation Health Research Review Board.

RESULTS

Population Characteristics

The median age of the 29 asthmatics on whom data were obtained was 7 years (range: 3–16 years). Slightly more than half of the sample was male (55.2%).

Table 1 shows the symptoms of asthma reported by asthmatic children and their parents. Families were asked to describe all symptoms associated with asthma in each child. No limit was placed on the number of symptoms, or the kinds of symptoms the family could report. The majority of respondents reported "difficulty breathing" (65.6%) and "wheezing" (65.6%). Breathing during an asthma episode was described as being audible, labored, abnormal, shallow, difficult, or gasping. More than one third

TABLE 1. Reported Symptoms of Asthma for Asthmatic Navajo Children (*n* = 29)

Symptom	Number (%)
Difficulty breathing	19 (65.5%)
Wheeze	19 (65.5%)
Lethargic or tiredness	15 (51.7%)
Shortness of breath	14 (48.3%)
Cough	12 (41.4%)
Nocturnal symptoms	10 (34.5%)
Cyanosis (by color of skin or lips)	8 (27.6%)
Allergy symptoms (itchy eyes, eczema)	7 (24.1%)
Chest pain	5 (17.2%)
Chest tightness	4 (13.8%)
Fever	4 (13.8%)
Irritability or crying	4 (13.8%)
Chest retractions	4 (13.8%)
Loss of appetite	3 (10.3%)
Flushed	3 (10.3%)
Other lung sounds (crackling, rattling, or gurgling)	3 (10.3%)
Seizures	2 (6.9%)
Painful or irritated throat	2 (6.9%)
Other (dry-mouth, lack of mucous or spit; sweating)	2 (6.9%)

(35%) of respondents reported nocturnal symptoms. Other frequently mentioned symptoms included lethargy, shortness of breath, and cough. Observations of cyanosis were reported for 8 asthmatics (27.6%). Symptoms unrelated to asthma, such as fever and loss of appetite, were reported for 19 asthmatics. On average, 4.8 symptoms were reported (range: 1–9).

Families were asked to recall the patient's total number of asthma-related emergency department (ED) visits or hospital admissions. The majority of children (79%) had made at least 1 visit to an ED for an asthma episode, as shown in Table 2. In addition, more than half of those providing information had been hospitalized at least once for asthma. All the individuals who reported multiple hospital admissions (and who had data available on ED use) made multiple visits to the ED as well.

Cause, Course, and Pathophysiology of Asthma

Parents were asked to identify and describe possible causes of asthma in their child(ren). No limit was placed on the number of potential causes. Beliefs about cause of asthma among the 22 families included heredity, reported by 59% of families, as well as environmental pollution and local geographical conditions (Table 3). Others blamed the development of asthma on physical changes in the lungs that might occur as a result of either chronic respiratory infections or acute attacks of severe lung disease, such as pneumonia, during childhood. Individual behaviors, such as having an unhealthy diet, not taking care of oneself, and not getting enough exercise, were also cited as potential causes. Only 4 families suggested traditional causes of asthma, such as exposure to lightning. Although 1 family identified only environmental causes of asthma, 6 families identified only individual causes of asthma. The remainder identified some combination of environmental and individual, and in some cases, traditional causes.

Respondents were asked how asthma "worked in the body," and to describe what they imagined would happen with the disease in the future. Although all 22 families acknowledged that asthma might present a long-term problem, most viewed the disease process as a series of distinct, transient episodes of symptoms resulting from exposures to relevant triggers during times of increased individual

TABLE 2. Utilization of Health Care Services for Asthma Among Navajo Children

	Number (%)
Number of ED visits (<i>n</i> = 24)*	
None	5 (20.8%)
One	3 (12.5%)
Multiple	16 (66.7%)
Hospitalizations for asthma (<i>n</i> = 21)**	
None	9 (42.8%)
One	5 (23.8%)
Multiple	7 (33.3%)

No information was obtained on *5 and **8 children with asthma, respectively. Percentages calculated on the number of asthmatics for whom information was available.

TABLE 3. Number (Percentage) of Families Reporting Cause of Asthma (*n* = 22)

Cause	Number (%)
Environment	
Air pollution	9 (40.9%)
Weather or climate	6 (27.3%)
Local environment	6 (27.3%)
Uranium exposure	5 (22.7%)
Wood smoke	4 (18.2%)
Other (water pollution, chemicals, contagion)	3 (13.6%)
Individual	
Heredity or genetics	13 (59%)
Past lung infection or insult	7 (31.8%)
Premature birth or birth defect	5 (22.7%)
Diet	4 (18.2%)
Individual constitution	4 (18.2%)
Lack of physical activity	4 (18.2%)
Allergy or immune system	3 (13.6%)
Personality or psychology	2 (9.1%)
Medications	2 (9.1%)
Being overweight	2 (9.1%)
Not taking care of self	1 (4.5%)
Traditional	
Traditional violation	3 (13.6%)
Loss of traditional lifestyle	1 (4.5%)

* Mean number of causes reported per family: 3.8, range: 1–7.

vulnerability. What was believed to be chronic was the potential to respond to these triggers with asthma symptoms, rather than any underlying process of inflammation or ongoing pathophysiology. Periods of vulnerability ranged in duration from a few days, to a season, or even to particularly sickly years of a child’s life, depending on what was perceived to trigger the attacks. This view of asthma as a temporary susceptibility to symptoms led the majority of parents (80%) to suggest that their children would outgrow the disease.

Explanations of the pathophysiology of asthma centered on the transient events of a particular episode. Asthma symptoms were commonly described as being a struggle for air resulting from air passages that were closed or constricted, obstructed, inflamed, or swollen. As one respondent described it: “It seems like there’s a narrow opening—a narrow opening like if you took a paper towel roll . . . and twisted it and made that crimp in it. That’s how I would feel.

That’s what’s happening in my lungs . . .” Another common explanation for obstruction centered on mucous, which may “back up in the lungs,” or “stop up the air ducts.” One mother said she monitored her son’s breathing for “the sound of the mucus inside . . . the messy sound that’s inside his lungs.” In addition, others noted that a loss of respiratory rhythm, usually induced by exercise, becoming emotional, or persistent coughing, might cause an attack to occur.

Medication Use

Information on medication use was obtained for all 29 asthmatics (Table 4). All but 1 of the children (96.5%) currently used at least 1 kind of bronchodilator. Approximately one third of respondents (34%) reported current use of inhaled steroids or other inhaled antiinflammatory medicines. None of the children was currently taking oral steroids, although many (34.5%) had used these drugs in the past. Families also used a number of over-the-counter medicines to control or prevent symptoms, including antihistamines and other allergy pills (45.4%), vitamins (13.7%), cough syrups (9%), and acetaminophen (4.5%).

Interviews revealed that 60% of the asthmatic children for whom information was available (*N* = 25) had complete responsibility for taking their own medications. An additional 20% were partially or occasionally responsible. The level of responsibility for medication taking was age-dependent (*P* < .001). All children in the sample age 7 and above had assumed a significant level of responsibility for their medications (Fig 1). The parents of these children explained that their child was in the best position to tell when they needed medication, that they knew how to take the medicines properly, and that they would let the parents know if something was seriously wrong. For example, one mother described the day she turned over responsibility for management to her daughter: “I told her, ‘You’re the one that knows your body. You need to know how to deal with that asthma. So, if you think that you need to use your inhaler, use it.’”

Fig 1. Reported level of responsibility by age of child.

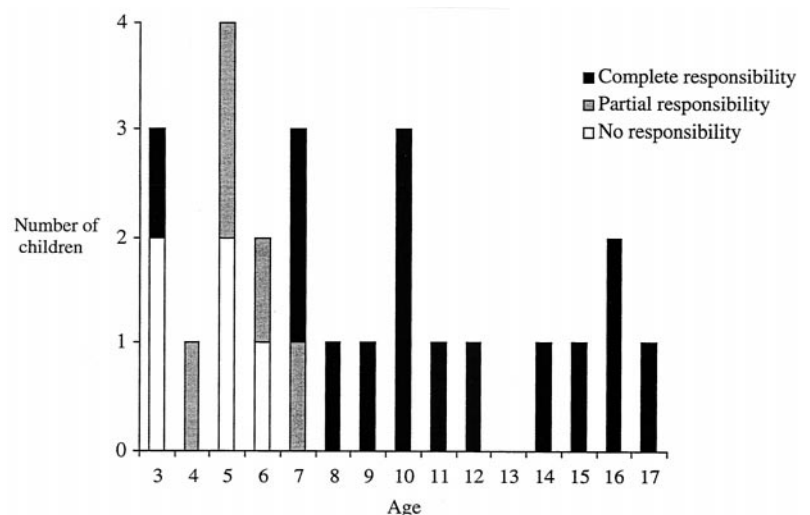


TABLE 4. Number (Percentage) of Asthmatics Reporting Current Use of Prescription Asthma Medications ($n = 29$)

Medication	Number (%)
Bronchodilators	28 (96.5%)
Inhaled steroids	6 (20.7%)
Other antiinflammatories	4 (13.8%)
Nasal steroids	1 (2%)

Despite the presence of alternative healing traditions on the Reservation, the majority of families in our sample did not attempt to address asthma with traditional medicine. Just over one fifth (21%) of the families on whom accurate information was available ($N = 19$) had participated in ceremonies for asthma.

Activity of Medications

Respondents were asked to explain how they thought their medications worked. Bronchodilators, such as albuterol, were usually perceived as “expanding” the lungs, or “relaxing” the airways to allow the air to flow back in. Alternatively, they might help clear or “loosen” the mucous so that it may be coughed up or thinned, to “allow oxygen to get through.” Controller medications, such as cromolyn sodium and triamcinolone acetonide, which were typically distinguished from bronchodilators by those who were prescribed both classes of drugs, were believed to protect the individual from future attacks during periods of vulnerability. Both preventative and rescue medications were perceived to work in the same manner, by opening the airways or clearing obstruction. Some parents stated that the controller medications helped the asthmatic “get through the night” or other periods when they might not be able to take rescue medications. Most observed that medications such as cromolyn sodium would not help relieve symptoms or end a particular episode, yet some reported administering such medications to try to control an episode after symptoms had begun. Because physical response to bronchodilators was usually immediate and dramatic, most parents believed that these medications were the most effective means to control asthma, despite the short duration of their effects. However, all parents who reported regular use of preventive medications reported that their children’s asthma was improving, and often credited the improvement to the regular medication.

Twelve families (54%) suggested that the disease had a personal history, and as a result, that its processes, course, and optimal treatment varied among individuals. Consequently, each type of inhaler—including different packaging of the same basic drug—was thought to offer a unique formulation that might be more or less compatible with any particular individual’s constitution. The effort to understand and control asthma was thus a circuitous course through medications, in an attempt to find the one that “works best” for each child’s unique combination of physiology and disease process. Commonly, the immediate efficacy of albuterol was taken to signify that the medication “agreed” with the child

and was appropriate for their individual disease. In contrast, antiinflammatory medications, the effects of which were subtle and long-term, were less likely to be seen as personally effective, and were therefore less likely to be taken as directed.

Medication Side Effects and Dependence

Concerns about potential side effects of medications led many parents to deviate from prescribed treatment regimens. In fact, most parents were at least as interested in and knowledgeable about the side effects of their medications as they were in their effects (Table 5). In particular, many expressed significant concern over the short- and long-term side effects of oral steroids. Prescriptions for oral steroids or the need to have “breathing treatments” created additional concern among parents by signifying an increase in asthma severity.

More than two thirds of (68%) parents expressed hesitations about asthma medications. On average, they expressed 1.8 concerns (range: 0–4). Almost half (45%) of parents specifically feared that their child would become dependent on asthma medications, in part because it was thought that asthma would disappear on its own if the body was allowed to heal itself. Others were concerned that long-term use of asthma medications might “cause other things to go wrong.” As a result, more than one third (36%) of the families reported attempts to get through episodes without using bronchodilators, to “teach” the asthmatic child’s body how to handle the symptoms, or to avoid dependence on the medication. As one teenage girl explained, “I tried to, I guess, wean myself from the inhaler, but it didn’t really help. I would still get that chest pain and end up taking it anyway.” When asked why she would want to wean herself from the medication, she replied, “I was always afraid of getting too dependent on it. To the point to where, you know, I was taking it almost every day . . . I didn’t want that to happen.” Concern about dependency was most commonly expressed about oral steroids, followed by albuterol inhalers, and daily preventive medications. In addition, some respondents withheld long-term antiinflammatory medication(s) from their children to determine if the asthma had been cured. A minority of respondents

TABLE 5. Reported Side Effects of Asthma Medications in Children ($n = 23$)

Side Effect	Number (%)
Drowsy or groggy	6 (26.1%)
Nervous or jittery	6 (26.1%)
Bad taste	4 (17.4%)
Weakness	3 (13%)
Increased appetite	3 (13%)
Nausea	3 (13%)
Weight gain	2 (8.7%)
Swelling	1 (4.3%)
Calcium deposits	1 (4.3%)
Dizzy or lightheaded	1 (4.3%)
Headache	1 (4.3%)
Irritable	1 (4.3%)
None	3 (13%)

Percentages calculated on the number of asthmatics for whom information was available.

suggested that preventive medications might help the disease to “go away” or increase the chance that their child will “grow out of it.” Although most respondents expressed a generalized distrust of medications, the parents of 2 asthmatics expressed concern about under treatment of their children’s asthma.

Use of the ED and Nebulized Medicines

Although severity of an attack was a principal consideration in seeking treatment in the ED, other factors were also relevant. First, the only source of medical care available during nonclinic hours is that provided by the ED. Secondly, many families perceived the “breathing treatments” (nebulized medicines) given in the ED to be the strongest and most effective medicine, and the only way to conclusively end an episode. “Only the respiratory treatment will really help,” explained one mother. “I guess that is as far as they will go with the asthma is the respiratory treatment and then the Prednisone. I guess that is as far as they can go.” Another mother, who blames the chronicity of the disease in her son on the fact that he receives nebulized medication only during periods of significant exacerbation, has tried unsuccessfully to purchase a nebulizer for home use; only 3 households had a home nebulizer. Parents also reported that because treatment is given in a clinic setting by health care providers, it relieves the considerable anxiety brought about by asthma attacks.

Because parents believed that an episode could only be conclusively treated in the ED, trying to control the symptoms at home with prescription medication was sometimes perceived to only “prolong the suffering” of the child. Some families expressed a reluctance to give their child regular medications, when a strong therapy like breathing treatments was available. “If I don’t get them treated, they’ll just get worse. So, I take them in right away and they get their breathing treatments.” For other respondents, ED nebulizer treatments became first line therapy. One mother explained: “Once she starts wheezing, [the ED] is her next step. If this one [albuterol] doesn’t work, she starts wheezing and then that is when she gets the respiratory treatment.” Some mothers believed that taking their child to the ED indicated good mothering: “That’s when we know that we did our—we did our part as a parent, you know, by bringing them in and getting them checked before it had gotten any worse.” Nighttime attacks were particularly likely to result in a trip to the ED for a breathing treatment. One woman explained: “Well, it’s hard for me to hear him—when he’s sleeping, to hear that wheezing sound. So when he’s treated, when we get home, he sleeps a lot better, and it seems to help him get over his cold right away.”

Serious attacks that required treatment in the ED changed perceptions and future management of the disease for many individuals. During these pivotal episodes¹² the asthmatic and their family members learned about the progression of symptoms and the activity of medication, and identified personal markers of severity that could provide reference points for

subsequent episodes. These pivotal episodes became the standard for decision-making during later acute attacks, and were used to decide when to use medications, how much of the drug(s) to take or administer, and when to seek medical attention. Use of this worst case scenario often resulted in the delay of use of medicines because the symptoms had not yet approached the remembered severity. More objective indicators of asthma status, such as peak flow meters, were used by only 3 families, and then only to gauge severity of the attack, rather than to anticipate exacerbations, or inform timing and dosage of medications. Pivotal episodes also seemed to contribute to a normalization of symptoms: a number of parents expressed the idea that symptoms were something “one gets used to,” and did not recognize or expect that treatment would create an asymptomatic state.

DISCUSSION

This study provides evidence that, among pediatric Navajo asthma patients, perceptions of the disease and beliefs about the activity of medications influence how they take their medicines. The Navajo families we interviewed are hesitant to use long-term controller medications, particularly in the absence of symptoms, because they consider asthma to be a series of acute episodes rather than a chronic disease. In addition, many parents were concerned that their child would become dependent on the medications, diminishing the body’s ability to “grow out” of the disease, and thus tried to “wean” the asthmatic from the medicines over time. Similar concerns about dependence have been observed among other populations as well.^{4,13} Because bronchodilators were perceived as being immediately effective, these drugs were used by most of the respondents. These perceptions and behaviors seem to contribute to the low level of use of controller medications: only one third of participants (34%) reported use of inhaled steroids or other antiinflammatories for their asthma.

Although we made no attempt to classify the severity of asthma according to the NAEPP Guidelines,¹ the excessive reliance on emergency treatments and the high rates of hospital admissions in these Navajo patients suggests that asthma is under treated.¹⁴ Nevertheless, the proportion who reported using antiinflammatory therapy in this sample is comparable to that reported for children with moderate to severe asthma in other populations. One study found that only 23.5% of inner-city children who had presented at an ED for their asthma were using antiinflammatory medications.¹³ A school-based study of medication use among inner-city asthmatics reported that only 11% took some form of daily antiinflammatory medication.¹⁵ Even in a managed care population, bronchodilators dominated asthma treatment, and less than one third of asthma patients received any antiinflammatory medications.¹⁶ Finally, although the use of antiinflammatory medications has increased since the 1980s, this accounts for only a small fraction of the overall increase in use of asthma medications.² Clearly, prescribing practices, as well as patient beliefs, contribute to the

suboptimal level of use of controller medications for asthma in many populations.

Use of health care services was also influenced by the beliefs of these Navajo families. Because earlier severe attacks were used as a standard against which current symptoms were evaluated, the necessity and urgency of medicine use was often underestimated. For example, medications were often avoided or their use delayed during acute episodes, because it was hoped the body would "heal" itself. In addition, 3 parents considered cyanosis to be an indication to begin use of medications. Finally, nebulized medicines available only in the ED were considered the only conclusive way to end an episode. As a result, two thirds (66%) of the asthmatics in our sample reported multiple ED visits. Navajos on the Reservation are served by a number of regional medical facilities, administered by the US Public Health Service, where health care is free for tribal members who do not have private insurance. Although the absence of direct economic barriers to health care may have increased the likelihood of visiting the ED, other significant barriers to medical care in this population, such as long distances to the Indian Health Service clinic and transportation difficulties, likely compensate for the financial accessibility in the use of services. In addition, asthmatics may be reluctant to seek emergency care during exacerbations to avoid being stigmatized for letting their disease get out of control, despite the fact that one of the major risks for dying from asthma is delay of treatment.¹²

Relatively few studies have investigated the perceptions of asthma in pediatric populations among whom hospitalization for asthma is common,¹⁷ or among Native Americans, among whom the incidence of asthma is increasing.¹⁸ In fact, to the best of our knowledge, the results of this study represent the first qualitative information of asthma among a pediatric Native American population. Ethnographic studies of adult asthmatics in Wales described 2 main orientations toward the disease.⁵ The deniers, who rejected the label of asthma, de-emphasized their symptoms, and never used the antiinflammatory medications they had been prescribed, in part because of fear of addiction. The acceptors assimilated the identity of asthmatic, and stressed their desire to control the disease through use of preventive medication. In contrast, Navajo asthmatics or their parents personalized management of their illness by trying different medicines in different combinations to find a regimen that "agreed" with the particular individual. In addition, all Navajo children age 7 and older had assumed at least partial responsibility for their own medications. Similar figures have been reported among inner-city asthmatic children age 12 and under.¹⁵ Although we did not examine factors contributing to the high rate of self-medication among children in our sample, this transfer of responsibility to the child is consistent with the value placed on individual autonomy in Navajo culture.¹⁹ This finding underscores the importance of identifying who is responsible for supervising medication use within the family, so that educational messages about the medications can be targeted to

the appropriate persons, in many cases the child as well as the parent.

One limitation of this study is its reliance on the recall of parents and asthmatic children. We were unable to validate reported ED visits, hospital admissions, and prescribed medications by medical record review. Second, because the study was conducted in the Shiprock area, located on the periphery of the Reservation, it is possible that the perceptions and practices of these families do not accurately represent those of Navajo families who live in interior areas of the Reservation. In short, we cannot speculate about the extent to which the findings reported here can be generalized to other populations, including other Native Americans. However, anecdotally, clinicians have responded to our findings by noting that the beliefs and behaviors we report are very similar to those held by other Navajo, as well as non-Navajo, patients.

CONCLUSION

Knowledge of the beliefs and behaviors of patients with asthma is clinically useful in determining perceptual barriers to treatment, as well as patterns of use of health care services. Ethnographic research, such as that reported here, provides valuable information about how drugs are actually used, as well as the logic of medicine taking. Understanding the perceptions that discourage use of inhaled antiinflammatory medication in these Navajo asthmatics should lead to the development of appropriate educational materials, improved management, and a substantial reduction in costs of care.

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David Van Sickle and Anne L. Wright

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