Urban American Indian Family Caregivers’ Perceptions of Barriers to Management of Childhood Asthma

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American Indian family caregivers of children with asthma face numerous barriers to effective management of the illness. The purpose of this qualitative, community-based study is to identify those barriers as perceived by family caregivers in a large Midwestern city. An ecological perspective and principles of family-centered care provided the theoretical orientation for the study. Interviews were conducted with 16 urban Ojibwe family caregivers of children with asthma. Five categories of barriers characterize the families’ experiences: provider (individual and system), condition-related, family caregiver, socioeconomic, and environmental. Examination of these findings suggests directions for improving care to American Indian children with asthma and their families.

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Asthma is an important health problem among American Indian children, and there exists a gap in the literature regarding barriers that their families experience in managing the condition. The purpose of this article is to identify barriers to effective management of childhood asthma as perceived by urban American Indian family caregivers. Principles of family-centered care (Hutchins & McPherson, 1991) and Bronfenbrenner’s ecological model (1979) provide a framework for viewing barriers from a systems perspective. Examination of the identified barriers provides implications for improving health care for American Indian children with asthma, with a goal of reducing health disparities for this population.

LITERATURE REVIEW

Childhood Asthma

Asthma is widely recognized as the most prevalent chronic illness and cause of disability among US children (Miller, 2000; Newacheck & Halfon, 2000). In a nationally representative sample of 3-year-olds, Miller (2000) found an asthma prevalence of 10.6% among poor children and 5.6% among children in middle- or higher-income families. Poor children with asthma had higher rates of emergency department use than their nonpoor counterparts. Risk factors for asthma were maternal cigarette smoking, having 3 or more siblings, low birth weight, and urban residence.

In their national survey, Newacheck and Halfon (2000) focused on childhood disability (long-term reduction in ability to participate in usual activities) due to asthma and found that disabling asthma increased by 232% from 1969 to 1995, resulting in restricted activity and lost school days at almost twice the rate of disability due to other childhood chronic conditions. Of children with disabling asthma, 40% could not engage fully in school activities. Adolescents, black children, male children, and children from low-income and single-parent families experienced higher rates of disability. Disabling asthma was also associated with high use of physician and hospital services.
Asthma in American Indian Children

Although ethnic and racial groups have been identified as being disproportionately affected by asthma, few studies have reported asthma rates among American Indian children (Liu et al., 2000; Stout, Sullivan, Liu, & Grossman, 1999). American Indians and Alaskan natives (AI/AN) are often not included in asthma surveys in sufficient numbers, because they are such a small proportion of the population (Stout et al., 1999). Only 0.9% of respondents identified themselves as AI/AN in the 2000 census (US Census Bureau, 2001). Stout et al. (1999) analyzed national data from 1987 and concluded that although the prevalence of parent-reported asthma was similar for AI/AN children (7.06%) and all US children (8.40%), the AI/AN sample was too small to provide stable estimates. Because the 1987 study surveyed the population living on or near reservations who were eligible for care from the Indian Health Service (IHS), urban AI/AN families were less likely to be represented. According to Joe (1997), over 50% of the American Indian population reside off reservation, and many do not use IHS facilities. Considering the increasing prevalence of asthma and the number of AI/AN families living in urban areas, the findings of Stout et al. (1999) are not likely to represent current asthma prevalence rates in the AI/AN population. On the basis of IHS data documenting an increase in asthma-related ambulatory care visits and hospitalizations, Brenneman (1997) asserts that asthma is “an important emerging chronic health problem among Indian children” (p. 269).

Liu et al. (2000) compared rates of hospitalization for asthma and bronchiolitis in AI/AN children and all children in the state of Washington, using data for 1987 through 1996. Under 1 year of age, AI/AN children had hospitalization rates 2 to 3 times higher than the rates for all children. Hospitalization rates increased by 50% for all children and nearly doubled for AI/AN children under 1 year of age. The disparities in rates also increased over time. The authors concluded that AI/AN infants have disproportionately high rates of asthma and bronchiolitis, although the reasons for these high rates are unclear. They recommended that AI/AN infants be targeted in public health measures to improve asthma management (Liu et al., 2000).

Barriers to Management of Childhood Asthma

To identify barriers to asthma management among urban minority children from parents’ perspectives, Mansour, Lanphear, and DeWitt (2000) conducted focus groups with African American parents of school-aged children with asthma. Predominant barrier themes included (a) parental beliefs about medications, which affected adherence; (b) concern about the effect of physical activity restriction on their children; (c) parental quality-of-life issues; and (d) school issues. Other themes included the need for education about asthma, relationships with health care providers, continuity and availability of providers, financial barriers, and environmental factors such as control of asthma triggers. Peterson, Sterling, and Weekes (1999) found that African American families’ explanatory models for their children’s asthma hindered illness management and participation in health care. Walsh, Kelly, and Morrow (1999) identified access barriers (transportation problems, physician access, and financial or insurance problems) among parents of Head Start children with asthma.

Other studies, not specific to asthma, have identified barriers to health care from the perspective of consumers (Higgs, Bayne, & Murphy, 2001; Johnson, 2001). Minority and low- to middle-income consumer participants in focus groups in the Higgs et al. (2001) study identified health care access and availability, providers’ lack of understanding of low-income families’ needs, and lack of information about community resources as major barriers. Johnson (2001) also used focus groups to identify perceived barriers to health care for a vulnerable population of women and children in a medically underserved area. Lack of health care insurance was the most important barrier to obtaining appropriate and timely health care. Other barriers included disrespectful treatment by providers and staff, competing family issues, provider gender, long waiting times, difficulty scheduling appointments, and lack of knowledge of health care provider roles. Although advanced practice nurses served the area, participants had limited knowledge of their role in primary care for women and children.

Newacheck, McManus, Fox, Hung, and Halfon (2000) also found health insurance to be a major determinant of access to health care. Uninsured children with special health care needs were more likely than insured children to be without a usual source of care and to have unmet health needs. Publicly insured children were more likely than privately insured children to be without a usual source of care, and their families were more likely to be dissatisfied with their care. Newacheck et al. (2000) also suggested that language and cultural
barriers may have a significant impact on health care access. Numerous barriers to pediatric emergency medical care have also been identified (American Academy of Pediatrics, Committee on Pediatric Emergency Medicine, 2000); many of these can affect urban American Indian children with asthma.

Barriers influence families’ ability to access care and to follow management plans. The barriers to asthma care in urban American Indian children, as perceived by their family caregivers, have not been described. It is important that these barriers be identified so that strategies to address them can be implemented.

**CONCEPTUAL FRAMEWORK**

Integration of principles of family-centered care (Hutchins & McPherson, 1991) and Bronfenbrenner’s ecological model (1979) forms the conceptual framework for this study. Both models honor diversity, are consistent with the high value that American Indians place on immediate and extended family, and invite health care providers to embrace a holistic view of the family in society.

**Family-Centered Care**

The family-centered care framework focuses on the following principles: (a) recognizing that the family is the constant in the child’s life; (b) facilitating collaborative partnerships with families; (c) honoring the ethnic, cultural, and socioeconomic diversity of families; (d) recognizing family strengths; (e) keeping families informed; (f) facilitating family-to-family support; (g) implementing policies and programs that meet the needs of families; and (h) designing accessible health care systems that are flexible, culturally competent, and responsive to family-identified needs (Hutchins & McPherson, 1991). Professionals who practice family-centered care promote a family’s confidence and competence in caring for their child and in working with the health care system (Vessey & Mebane, 2000). The principles of family-centered care are consistent with traditional American Indian family values, such as high regard for children, family responsibility, tolerance of differences, interpersonal relationships, and kinship communities (Red Horse, 1997).

**The Ecological Model**

In the ecological model (Bronfenbrenner, 1979), all spheres of the child’s environment (i.e., home, school, and community) and their relationships with the child and with one another influence the child’s health and development (Zigler & Hall, 2000). The ecological perspective focuses on factors in the natural and constructed physical environment, as well as on biological, social, and intrapersonal factors, as determinants of health behaviors. This perspective is particularly applicable to health-promotion research with children and families because it recognizes, at several levels, the contexts in which health behaviors exist. It goes beyond the child’s proximal environment, such as the family unit, to include more distal contextual influences, such as health care provider systems. The emphasis, then, is on family and community factors as they influence the child’s health (Hayman, 1998). These factors may be personal competencies, environmental resources, or social, political, economic, and cultural influences. Thus the ecological perspective for both research and practice requires knowledge from several domains and promotes bridging of professional disciplines (Pridham, 1998).

**METHOD**

The following research question guided the study: What are the barriers to effective management of childhood asthma as perceived by urban American Indian family caregivers? Barriers were defined as factors that hindered management of childhood asthma by the child and family, extended family, school, community, and health care system.

Data for this article were drawn from a subset of 16 Ojibwe families with children with asthma who were enrolled in the Indian Family Stories Project (Garwick & Auger, 2000), which was approved by the Institutional Review Board at the University of Minnesota, Minneapolis, MN. This study was developed in collaboration with families, community leaders, and health care providers with the use of a participatory action research (PAR) approach (Travers, 1997). PAR is based in the community, emphasizes empowerment, involves community members in the research process, and gives high priority to actions of potential benefit to the community that are based on issues defined by its members. To implement this PAR approach, leaders from community organizations that serve American Indian children and families were actively involved in the design, recruitment, and implementation of the Indian Family Stories Project. In keeping with the PAR framework, participants were the first to learn about the preliminary findings at a feast held in the community. After honoring participants for their contributions, we
worked together to prioritize needs and develop an action plan. This article is in response to one component of the action plan, which was to decrease barriers to care by sharing families’ experiences and recommendations for improving care with health care providers.

Primary family caregivers were selected as key informants regarding the management of childhood chronic conditions in their families. Participants were recruited, by a snowball sampling technique (in which participants were nominated by community leaders or referred by other participants), from Minneapolis, MN, which is the city with the largest American Indian population in the state (Urban Coalition, 1994). Community leaders identified families and invited them to participate. Information was also provided in flyers in community agencies and in community newspapers. Potential participants contacted the project coordinator, who informed them about the project in more detail and conducted a screening interview to ensure that they met the following inclusion criteria: an American Indian adult family caregiver (over age 16 years) who had the primary responsibility for managing the care of a child (aged 3-12 years) with a chronic illness or disability of at least 1 year in duration and who was living at home at the time of the interview. All of the eligible participants who contacted the project coordinator agreed to participate in the study. Informed written consent was obtained from the family caregivers before their participation in the interview. Each participant received a $25 honorarium.

The primary caregivers who had children with asthma included 14 mothers, 1 aunt, and 1 grandmother who ranged in age from 21 to 44 years (mean, 29.4 years). Their educational level ranged from junior high school to vocational or technical college education. The majority of children (n = 12) lived in a single-parent or aunt- or grandparent-headed household; 4 lived in a two-parent household. The family household size ranged between 2 and 7 members (mean, 4; mode, 6); and the family income ranged from less than $10,000 to $29,999 per year. Nine of the children were male, and seven were female. Their ages ranged from 3 to 12 years (mean age, 6 years). Their age at diagnosis ranged from 6 months to 9 years; all had lived with their asthma for at least 1 year.

Family caregivers were interviewed in their homes by the project coordinator, a social worker who is Abenaki Indian in background. The semi-structured, in-depth interviews, conducted in English, focused on the participants’ cultural background and their experiences caring for their children with asthma. The interviews, which lasted approximately 90 minutes, were tape-recorded and transcribed verbatim.

**ANALYSIS**

The primary goal of analysis was to identify the range and types of barriers to asthma management described by family caregivers during interviews. From an ecological perspective, factors that hindered management of the illness by the child and family, extended family, school, community, and health care system were identified as barriers in the analysis.

Content analysis strategies (Kvale, 1996; Weber, 1985) were used to identify and categorize barriers from the verbatim transcripts. Transcripts were first read in their entirety to gain an understanding of the context of the interviews. Each transcript was then read on a line-by-line basis, and caregiver statements describing barriers to effective management of the child’s asthma were identified. A summary list of 29 barriers was developed, and each barrier was assigned a code. The barriers were then organized into 5 categories that emerged during the analysis: provider (individual and system), condition-related, family caregiver, socioeconomic, and environmental barriers. To establish trustworthiness (Lincoln & Guba, 1985), the research team met weekly for in-depth discussions of the analysis. An independent rater with a background in qualitative methods analyzed 4 randomly selected transcripts using the established coding scheme and decision rules to validate the coding scheme. Interrater agreement was 93%. An audit trail consisting of raw data, data analysis notes, development and revision of codes and categories, personal notes, and communications was kept as additional evidence of trustworthiness. Results were also validated in interviews conducted in a follow-up project by the first author with 3 American Indian women leaders in the same metropolitan community. Those interviews focused on the experience of American Indian families of children with asthma.

**RESULTS**

Five categories of barriers were identified: provider (individual and system), condition-related, family caregiver, socioeconomic, and environmental. The types of barriers are listed in Table 1, and the results are reported by category.
Table 1. Barriers to Management of Childhood Asthma Identified by Family Caregivers

<table>
<thead>
<tr>
<th>Provider</th>
<th>Individual</th>
<th>System</th>
<th>Condition-related</th>
<th>Family caregiver</th>
<th>Socioeconomic</th>
<th>Environmental</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Amount and quality of information</td>
<td>• Ineffective school response</td>
<td>• Seasonal changes</td>
<td>• Fear</td>
<td>• Transportation problems</td>
<td>• Winter weather</td>
</tr>
<tr>
<td></td>
<td>• Not listening to caregivers or talking them seriously</td>
<td>• Traditional care providers not being available</td>
<td>• Flare-ups at night</td>
<td>• Lack of understanding about asthma</td>
<td>• Difficulty paying for child care, transportation, or medications</td>
<td>• Night-time episodes</td>
</tr>
<tr>
<td></td>
<td>• Perceived prejudice</td>
<td>• Busy clinic</td>
<td>• Unexpected flare-ups</td>
<td>• Role strain</td>
<td>• Insurance constraints</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Not understanding cultural factors</td>
<td>• Uncomfortable clinic atmosphere</td>
<td>• Critical nature of episodes</td>
<td>• Feeling inadequate, inferior, or reluctant to ask questions</td>
<td>• Not having a telephone</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Over-reliance on drugs to treat condition</td>
<td></td>
<td>• Flare-ups with other illnesses</td>
<td>• Worry about steroids</td>
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<tr>
<td></td>
<td>• Limited time and lack of continuity</td>
<td></td>
<td></td>
<td>• Feeling alone</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>• Minimizing seriousness of asthma</td>
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Barriers are listed in descending rank order, by category and within categories.

Provider Barriers (Individual and System)

The most frequently mentioned provider barriers identified by family caregivers were related to the amount and quality of information that they received about asthma. Over half of the families said that their health care providers gave them inadequate or unclear information about asthma. Families described having limited time and lack of continuity with providers in a busy clinic, making it difficult to understand what was wrong with their child or what was expected of them as caregivers. A few family members thought that their physicians minimized the seriousness of asthma. An aunt of a child with asthma thought that the child’s mother was disregarded and given insufficient information:

Just because somebody’s a young mother doesn’t mean they’re stupid. If you give them the information and you treat them like you treat anybody else, with respect, they understand what you’re talking about. My niece, she may have been young when her baby was born, but she had good mothering instincts. Another thing, the probabilities can kill a kid. I mean, they need to diagnose and if they’re not sure if somebody has asthma, like they should have told us, “He has upper respiratory infection; however, he may have asthma. Here’s the information about asthma. If any of these signs come, come in immediately.” They didn’t do that for us. It was more or less we were left on our own, and they had the information. They could have provided it to us and they didn’t, and it was like they weren’t very helpful.

Family caregivers also described experiences in which they felt mistreated or misunderstood by providers. One third of the participants described what they perceived as prejudice, in which they felt that providers were insulting or talking down to them, as well as not listening to them. One mother talked about this feeling:

Sometimes I feel that the doctors, when I go to the emergency room, are very arrogant, and I don’t like to ask them questions, because I feel that I’m less of a parent because I don’t know all this stuff about my child’s needs. So, I just feel that they need to be more sensitive, and sometimes they act like you’re really stupid. I mean, they read stuff slow to you or they look at you strange and it’s just not very helpful. It’s like, because you’re Indian, or whatever you might be, that you don’t know anything.

Some participants thought that providers did not recognize their knowledge and expertise regarding their own children. Being told to wait while their child was in respiratory distress was particularly stressful.

I took her down to the emergency room, and when I got there the administrative desk was like, “OK . . . have a seat.” And, I’m like an assertive person and I said, “No. My daughter needs to be seen as soon as possible. She can’t breathe.” And they are like, “Ma’am, I told you to take a seat!” And I said, “NO, I would like to see the doctor as soon as possible. If you don’t let me see him I will walk in there by myself, right now.” So . . . they admitted her right away. They put her on the nebulizer machine and gave her some oxygen because, at that time she was just . . . very short of breath.

Some thought there was a lack of cultural understanding of American Indian families when, for example, providers did not understand the importance of the extended family/kinship network.

And usually the security guards will walk up and say, “You know what, you guys can’t all be here.” They don’t realize just because that isn’t our child, it’s a member of our family and we feel deeply, and I mean we’re very close. I mean you can see that I have a very small house, but come Christmas time every family member that I have will be in the house, including extended family members.
And we’re all very close, and that’s something that a lot of hospitals don’t understand, and then it’s like they stick their security guards on you.

Family members also had concerns about providers’ approaches to diagnosis and treatment of their child’s asthma. Some described delayed diagnosis that resulted in a period of inadequate or ineffective treatment; others felt that physicians over-relied on drugs to treat their children and were not willing to explore alternative treatments. Some participants expressed regret that they did not have access to native healers or traditional care providers.

I believe in Indian way, the traditional way. But, being able to go to a traditional healer is harder than going to a regular clinic because . . . we don’t have that with anybody we know . . . the healers I know, they’re on the reservation and it’s a long travel, a long journey and we don’t always have the money to get there, or transportation to get there.

Family caregivers were also concerned about management of their child’s asthma at school. There was a lack of coordination between hospital or clinic health care providers and the school. A third of the families described situations in which school personnel were uninformed or did not respond appropriately to their child’s asthma attacks. For example, one mother talked about her lack of confidence in her daughter’s school:

It’s really hard, and the school nurse is never there when my daughter needs her, or when I go to drop off a new medication at the school that the doctor’s giving us, the personnel at the school don’t want to listen, because it’s not their job. When really you know, a child is their concern. It should be their job if they’re working in a school. So the nurse is there like every other day in the afternoon. I mean, my daughter could have an asthma attack anytime and nobody really understands what to do.

Condition-Related Barriers

The majority of family caregivers described the unique features of asthma that also were barriers to effective management of the illness. Flare-ups at night, seasonal changes, unexpected episodes, and the critical nature of the episodes are examples of condition-related barriers presented by asthma that typically created lack of predictability and an urgent need for care, as expressed by one mother:

He gets sick just immediately. It’s not like he gets a cold and it progresses into illness. He just, one minute he’s fine and an hour later he’s really, really ill with this reactive airway disease and with the fluid building up in his lungs, and it usually ends up that he makes a visit to the emergency room . . . it comes on so fast that it’s scary. It’s scary for me to deal with it.

Family Caregiver Barriers

Almost all of the family members described personal barriers to effective management of their child’s asthma. Two described feeling inadequate or inferior in the presence of health care providers. Although half of the participants expressed having a lack of understanding about asthma, a few were reluctant to ask questions or felt afraid to ask questions without other family members present.

It is hard for Indian people to ask for the services they need, because it is our way that you should have your family members there to help you. If we don’t ask a question, it’s not that we know it all, but it’s just that we might be afraid to ask the question because of feeling inferior.

Half of the participants described how frightening it was for them when their children were so sick, as expressed by one mother: “Our children are sick, and sometimes we’re afraid they’re going to die.”

Another participant felt that a parent’s fear could be misunderstood by care providers:

They need to know that number one, Indian people are very, very edgy about their children, especially when they’re sick, and I think doctors at hospitals mistake that for parents being, some parents are really quiet because they’re so worried. They mistake that for parents not caring or parents trying to act all tough and that’s not what it is. Most Indian people that I know, when their kids get sick are just scared to death.

Some participants also experienced role strain when they had one child in the hospital and other children at home or when more than one child was sick with asthma. One mother of 4 children with asthma described having 3 of them hospitalized at one time, in separate rooms. Another mother talked about having a child in the hospital and others at home:

It was hard, being he was the baby, but yet I had a 2-year-old and a 3-year-old at home, so it was always hard to find someone to come in and take care of my children when I was at the hospital. There was times Dad, when we were still together, he would take days off from work because we couldn’t find someone to stay with the kids, and then we would take turns. He would stay a night at the hospital for a day, and then I would come take care of things at home, then I would go back, so . . . I would be just stressed out, tired cause I couldn’t get any sleep. I was always taking care of him and Dad was missing work.

Some family members expressed their concerns about long-term use of medications, especially steroids, to treat their child’s asthma.
I’ve seen a lot of quick fix, here’s a prescription, get this filled. They don’t talk about the possibility of these drugs being habit-forming. They don’t talk about him being on steroids for his asthma at least 7 times in his life, and he’s 4-years-old. They never once told me how dangerous steroids could be for him or what some of the possible side effects are. I asked a pharmacist about it and then went to my doctor and said, “Isn’t this true, that this could have problems with his growth, that it could possibly shorten his life span?” And the doctor just dismissed it by saying, “Well, yes it could have side effects but look at the long range help that it’s going to do for his asthma.” And I asked him about alternatives to this and he was just insulted that I would ask about that and more or less said, “Well, who’s the doctor here, you or me?”

A few family members described feeling alone, either as the only American Indian person in the health care setting or in not knowing anyone else in their community with a child with asthma.

**Socioeconomic Barriers**

Eleven of the sixteen family caregivers described socioeconomic barriers. Finding and paying for transportation to the hospital emergency room or the primary care clinic were a major concern. Some families did not have a telephone; others found it difficult to pay for medications. For some, their insurance provider limited who could provide care for their child, which caused more difficulty in accessing care. Transportation was a major problem for families who did not have a car:

Especially in the middle of the night, you know, and you don’t have any family members around, you don’t have transportation, and if your current medical supplier doesn’t supply a cab for you, how are you going to get down there? You don’t want to call 911 because that ambulance ride is going to cost you $300, you know.

A family member described what a young mother did when her son had an asthma attack at night: “Well, his mother, the first time he had one in the middle of the night, his mother dressed him and walked to Children’s with him. (Now) I make sure that she knows not to walk to the hospital with him, that if his lips start turning blue or something that she should call 911.”

**Environmental Barriers**

Accessing care for the child was also made difficult by winter weather. A mother described needing to anticipate those times: “It seemed like when he would have the asthma attacks it would be mainly in the winter time, the coldest months, when they’d come on and so I always made sure I had money put away for cab fare, especially in the winter time.”

The child with asthma often experienced episodes during cold weather and at night. Nighttime visits to the emergency department during winter months were even more difficult when families needed to find care for their other children or else take them along.

Sometimes we have to get up in the middle of the night, if her medicine isn’t helping her, and we have to take her to the emergency room a lot of times during the winter months. It’s hard, it is hard. And it’s really stressful to have to get up some times at 3, 4 o’clock in the morning, get the other kids up or try to get someone to come sit with them or haul them to the neighbors at 3 o’clock in the morning to take her to the ER [emergency room].

**Experiencing Multiple Barriers**

Many of the family caregivers told stories that wove together threads from all 5 categories of barriers. For many, it was a struggle to come to understand the disease and to be understood, to feel comfortable as an American Indian dealing with health care providers, to feel respected and confident, to access care with limited means under harsh conditions, to fit asthma into their family life, and to manage frightening symptoms of an illness that presented unique challenges.

**DISCUSSION**

The results of this study should be interpreted with consideration of the small sample size and specific geographic location, as well as within the community and cultural context. The goal was to identify the range of perceived barriers that can serve as a basis for developing strategies to improve care within this community of American Indian families. There are more than 500 American Indian tribes and Alaskan native villages recognized by the US government, with diverse values and traditions (Indian Health Service, 2000). Cultural data collected within one tribe or community may not be applicable to another (Hodge, Weismann, & Roubideaux, 2000). Further research is needed to determine whether the same barriers exist in other urban American Indian communities. Meanwhile, the categories of barriers alert providers to the range of barriers to consider when planning interventions for American Indian families who have children with asthma.

The families in this study experienced a wide range of barriers to effective management of childhood asthma, and many of these were cultural barriers. Tripp-Reimer, Choi, Kelley, and Enslein (2001) point out that health care providers often perceive that the patient’s culture is a barrier to
care. The authors suggest a different perspective—that barriers arise from the culture of biomedicine. Adopting such a view will provide direction for strategies to remove barriers, improve health care for diverse populations, and reduce health disparities affecting minority populations. Health care providers need to recognize the interactions of poverty, ethnicity, and policy and how those interactions affect access to care, as well as racism and lack of cultural competence among providers. Health systems need to address issues of service availability, accessibility, acceptability, and continuity, with an emphasis on issues of trust and respect (Tripp-Reimer et al., 2001).

The family caregivers in this study perceived a lack of respect in the way they were treated by health care providers. Their experiences are strikingly similar to those of First Nations women in their encounters with mainstream health care services in northwestern Canada, described by Browne and Fiske (2001). The First Nations women described invalidating and affirming encounters. Invalidating encounters included dismissal by health care providers, needing to transform oneself to gain credibility, being negatively stereotyped and treated accordingly, feeling marginalized from the mainstream, feeling an extreme sense of vulnerability, and disregard for personal socioeconomic circumstances. In contrast, affirming encounters conveyed respect and trust and involved active participation of the women in health care decisions, receiving exceptional care, affirmation of personal and cultural identity, and development of positive long-term relationships with health care providers. Browne and Fiske (2001) interpreted the affirming encounters as representing “exceptions to everyday, taken-for-granted experiences of discrimination that continue to disadvantage and marginalize First Nations women” (p. 143).

Affirming encounters between health care providers and families can reduce or eliminate many barriers in health services to American Indian families and counter many of the barriers identified by family caregivers in this study, particularly provider and family caregiver barriers. Although the other categories of barriers (condition-related, socioeconomic, and environmental) cannot be reduced or eliminated by affirming encounters, their effects might be mitigated through acknowledgment and understanding of their influence on families’ use of health services and compliance with therapeutic plans. Browne and Fiske (2001) suggest that some health disparities may not be the result of high-risk status or cultural beliefs but of “avoidance of a health system that is not culturally safe and that does little to acknowledge or counter patterns of individual or institutional discrimination” (p. 129).

Family caregivers expressed concerns about delays in diagnosing and treating their children’s asthma. One explanation may be that health care providers are not listening to family members’ concerns about their children’s breathing difficulties; another might be lack of continuity in care or not having a consistent relationship with a health care provider. Health care providers also face barriers in diagnosing asthma in children (Werk, Steinbach, Adams, & Bauchner, 2000) and in using asthma practice guidelines (Cabana et al., 2000). Werk et al. (2000) confirm that delayed diagnosis is a problem that may be troubling to families and result in inadequate treatment, persistent symptoms, and chronic pulmonary changes. American Indian families may be particularly vulnerable to these provider barriers, because of complex factors involving provider-family communication patterns, cultural competence issues, and families’ powerlessness in relation to provider systems.

Kieckhefer and Ratcliffe (2000) found that parents of children with asthma had concerns about long-term use of medications, especially steroids. Family caregivers in our study also expressed these concerns. Parents’ perceptions may affect management of the illness. In an ethnographic study of perceptions of asthma and asthma medications in Navajo families of children with asthma, Van Sickle and Wright (2001) found the perception that asthma is a temporary, episodic experience of symptoms in someone who is vulnerable to breathing problems, rather than an underlying, ongoing process of inflammation, or a chronic condition. Consequently, most parents preferred bronchodilators or rescue medications, because of their immediate and dramatic, albeit short-term, effects. Because of their more subtle and long-term effects, controller or preventive medications, such as anti-inflammatory drugs or oral steroids, were less likely to be considered effective and therefore, less likely to be taken regularly. Parents in their study were also very concerned about side effects and dependence with asthma medications, sometimes attempting to get through episodes without the use of bronchodilators or to wean children from their use. It is important for health care providers to explore American Indian perceptions of the nature of asthma, the difference between bronchodilator and controller medications, and the importance of
early treatment and preventive therapy. The reports of family caregivers in our study regarding the amount and quality of information about asthma given to them by health care providers suggest that families have inaccurate perceptions because clear and adequate information is not being provided. Mastering complex information is the central task for families after their child is diagnosed with asthma (Horner, 1998), and their concerns and fears change over time (Kieckhefer & Ratcliffe, 2000).

Children with asthma and their families frequently rely on hospital emergency departments for treatment of acute episodes. Family caregivers in our study described many negative experiences in emergency settings. Health care providers in emergency departments need to examine their approaches to American Indian families and implement principles of family-centered care. Eckle and MacLean (2001) provide a self-assessment inventory for use in evaluating family-centered care practices for pediatric patients in emergency departments, as well as strategies for developing and implementing a model of family-centered care.

Family caregivers in our study thought that school responses to their children’s asthma episodes were ineffective, which is consistent with the lack of preparedness among school health personnel, teachers, and ancillary staff described by Sapien and Allen (2000) and Palmer (2001). Health care providers can work with school personnel to develop emergency plans for acute episodes for each child with asthma. School-based health centers (SBHCs) are becoming increasingly important sources of health care to medically underserved children and can provide children with acute episodic care, as well as assist families with long-term asthma management (Lurie, Bauer, & Brady, 2001; Spencer, Atav, Johnston, & Harrigan, 2000; Vel sor-Friedrich & Foley, 2001). SBHCs can be particularly helpful to urban minority children who may not have continuity with health care providers in other settings. Lurie et al. (2001) found that an inner-city SBHC in Minneapolis, MN, improved asthma outcomes for children, including fewer hospitalizations, improved preventive care, and less disruption of sleep and family plans.

Community-based asthma management programs (Slutsy & Bryant-Stephens, 2001; Yoo et al., 1997) have been successful in reducing barriers. Community-based programs are particularly well suited to minority families in urban inner-city communities where resources may be limited, because they strive to be accessible, culturally competent, and committed to partnerships among families, health care providers, and the community. Monsen (2000) calls for the creation of more such linkages to reduce asthma disability through coalitions involving families, health care providers, and neighborhoods. On the basis of the types of barriers identified in our study and the principles of family-centered care (Hutchins & McPherson, 1991), we also recommend community-based asthma management programs.

The range and types of barriers reported by American Indian family caregivers illustrate the complexity of managing childhood asthma. The findings from this study illustrate the importance of identifying barriers to managing asthma from an ecological perspective. To reduce health disparities, health care providers need to be aware of the barriers that children and families experience at home, at school, in health care settings, and in the community. Furthermore, providers and agencies need to provide culturally appropriate care in order to prevent cultural barriers from interfering with the management of childhood asthma.

In conclusion, health care providers can improve care for urban American Indian families who have children with asthma by (a) educating children and their families about asthma management, with the use of culturally appropriate strategies; (b) supporting families by recognizing their strengths and fears, the burden and disruption caused by the illness, and barriers to effective management; (c) linking families to one another and to relevant resources; and (d) partnering with families and other providers to create school- and community-based asthma management programs. Most importantly, health care providers should make affirming encounters the core of their practice in working with American Indian families of children with asthma.

REFERENCES


