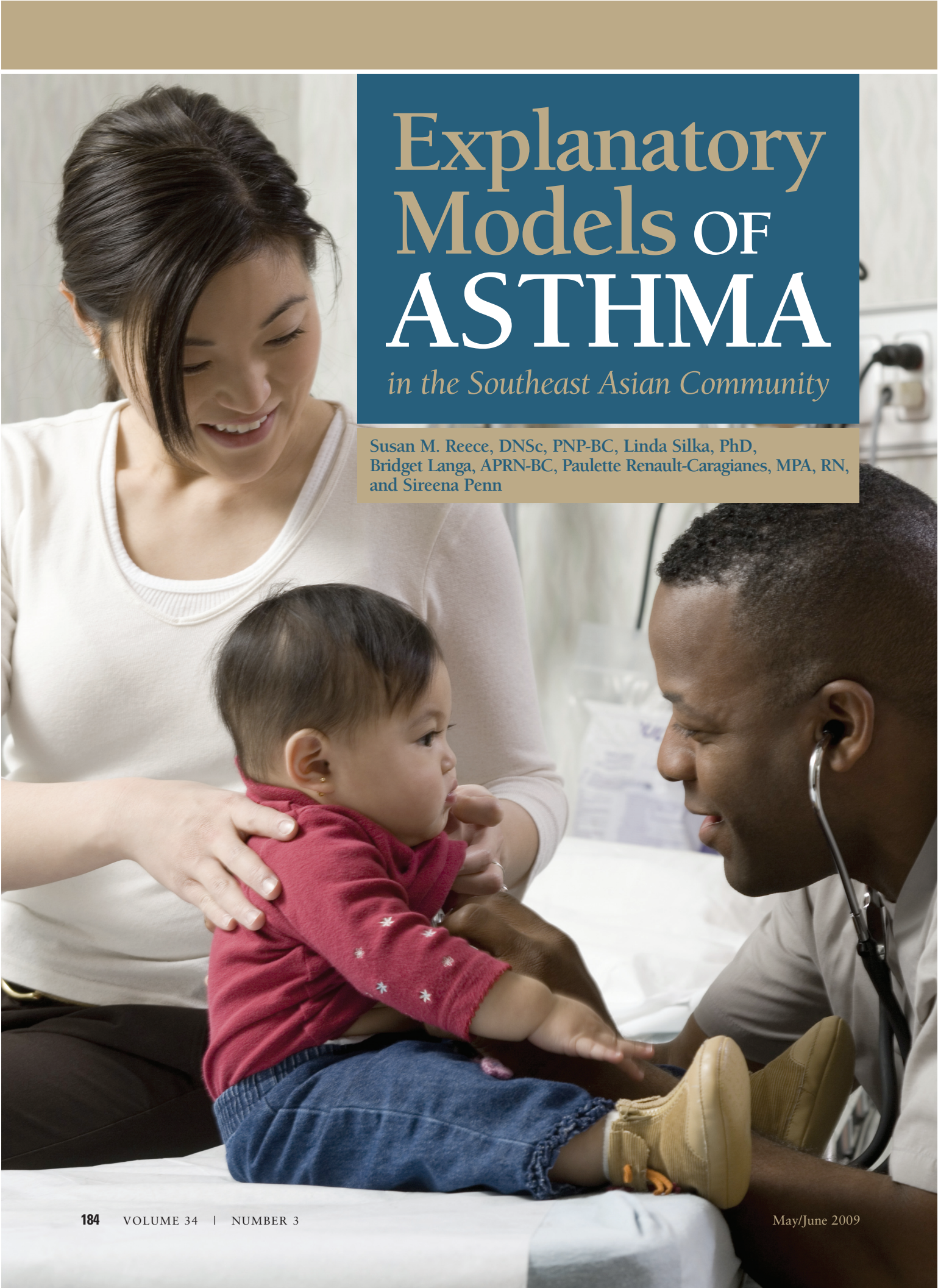


A photograph of a doctor examining a baby held by a mother. The mother is a woman with dark hair, smiling down at the baby. The baby is wearing a red long-sleeved shirt and blue pants. The doctor is a man with dark hair, wearing a white lab coat and a stethoscope, looking at the baby. The background is a clinical setting with a white wall and a power outlet.

Explanatory Models OF ASTHMA

in the Southeast Asian Community

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ABSTRACT

Purpose: To examine how two groups (parents and healthcare providers) perceive asthma in Southeast (SE) Asian children in the United States, and to address issues of access to asthma care.

Study Design and Methods: Using Kleinman's Explanatory Models (EM) approach, semistructured interviews were used with 12 families and 26 providers. Families were interviewed in a clinic setting. Providers read a case example of a SE Asian child with asthma and were asked to anticipate the case family's EM of asthma. Data were analyzed using template analytic technique in which segments were clustered into etiology, causation, treatments, asthma impact, and access to asthma care.

Results: Families predominately followed current asthma practice guidelines, whereas providers believed that SE Asian families primarily followed cultural practices. Families described the severity and impact of asthma as more intense than the providers described the same items. While families identified barriers to care as difficulty getting appointments and unavailable providers, providers viewed family barriers to be predominately culturally based. Both groups noted the need for education and frequent healthcare visits as facilitators to care.

Clinical Implications: This study suggests that important differences may exist between the way providers and SE Asian families perceive childhood asthma. Nurses are encouraged to ask the families in their care how they explain their children's asthma, thus facilitating more culturally competent care and increased ability to meet the family's needs. Implications for policy change relative to improving access to care to immigrant groups are also suggested.

Key Words: Childhood asthma; Cultural competence; Explanatory models; Southeast Asian culture.

Asthma ranks first as a chronic illness among children under 15 and is the third leading cause of hospitalization; in 2005, the prevalence of childhood asthma in the United States was 8.9% (Akinbami, 2006; Akinbami, Rhodes, & Lara, 2005; American Lung Association, 2006; World Health Organization, 2008). The highest asthma prevalence and attack rates occur in children 5 to 17 years of age, among poor and non-white children, and among children born of immigrant parents (American Lung Association; Brugge, Lee, Woodin, & Rioux, 2007). Family management of asthma is rigorous and involves symptom recognition, trigger avoidance, medications one to four or more times per day, and timely help seeking from healthcare providers (American Academy of Pediatrics, 2004; Yoos & McMullen, 1999). Since young children with asthma often require frequent monitoring for signs of exacerbation and since the symptoms can be frightening, parents frequently describe fear, difficulty, and stress, as well as a need for more information on the disease (Kieckhefer & Ratcliffe, 2000).

For providers, there are many challenges in caring for children with asthma, including ineffective treatment, less than optimal adherence to medication regimens, and lack of education (American Lung Association, 2006; Skoner, 2001). One of the barriers discussed in the literature about poor adherence to asthma regimens has been miscommunication about the disease between providers and

families who may have cultural beliefs about the disease that differ from western medical practices (Poureslami, Rootman, Balka, Devarakonda, Hatch, & Fitzgerald, 2007). This can be an issue because partnerships between the family and healthcare provider are important for mutual understanding of the illness and its treatments (Warman, Johnson Silver, McCourt, & Stein, 1999). The effectiveness of partnerships becomes more complex when cross-cultural issues exist, and therefore the provider who wants to provide culturally competent care for children of varied ethnic groups with asthma should work toward a better understanding of which family cultural beliefs might interfere with prescribed treatments.

The Asian population in the United States is growing. According to the most recent census, Asians make up 4.2% of the U.S. population, and this number is projected to triple by 2050 (www.USCensus.gov). According to the U.S. Census (2002), the term "Asian" refers to "people having origins in any of the original peoples of the Far East, Southeast (SE) Asia, or the Indian subcontinent (Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, Philippine Islands, Thailand, and Vietnam)." Because nurses are caring for Asian groups across the country, it is important that the cultural values of Asian populations be considered in the nursing literature. Cultural views of asthma have received little such attention, especially for the different Asian groups.

Liu's (1994) research on different Cambodians found asthma or, */jum'ng hurtl/*, translated as a sense of shortness of breath, fatigue, or exhaustion, especially after vigorous activity. "Wheeze" was not a familiar word, although an SE Asian med-

ical dictionary used */kraet'kraut/*, to describe the sound of "tight breathing" (Liu, p. 2). Remedies were primarily herbal teas, traditional healers, and herbalists for adults (Liu).

The authors provide care in a large city in the northeast United States, which is the home to the second largest population of Cambodians in the United States (25,000 Cambodians in 2000) (Lowell Community Health Center, 2006). We therefore wanted to gain a better understanding of how these SE Asian immigrants in the United States viewed asthma in their children, and also how well the providers of care to this population understood the families. Given the challenge to provide culturally competent asthma care, this qualitative study was undertaken to explore how SE Asian families and healthcare providers/key informants view childhood asthma.

Study Design and Methods

This was a cross-sectional qualitative study.

Theoretical/Conceptual Framework. The Explanatory Model (EM) framework proposed by Kleinman provided the theoretical underpinnings for this exploratory study. Kleinman (1980, 1988) believes that meanings relevant to illness include (a) the disease (biomedical approach); (b) the patient or family experience of living with the illness; and (c) the sickness, or societal interpretations. EMs are influenced by ethnicity, the social environment, and interpretations of past experiences. Within this framework, illness beliefs can be explained by etiology/pathophysiology, course, and treatment (Kleinman, 1978, 1980). Health professionals most likely have scientifically based EMs for many illnesses, but for the parent of a young child with asthma, EMs are the meanings the family attributes to the diagnosis, its symptoms, and its treatments. Families may hesitate to volunteer their EMs out of fear of ridicule or intimidation. Ideally, a provider listens to and understands the family's EMs and what they desire from the care provided (Kleinman, 1980, 1988).

Parents perceived that barriers to care were (1) the availability of providers and (2) getting same day appointments; providers perceived barriers for patients as (1) lack of compliance with asthma regimens and (2) family adherence to cultural practices and beliefs.

Gulzar's (1999) conceptual analysis of access to care provided a context for understanding the presence of barriers and facilitators to asthma care. Barriers and facilitators are defined by "system" and "user" characteristics. System characteristics are

features such as cost, organization, quality, resources, type of services offered, insurance, and personnel. User characteristics are family/individual attitudes and behaviors, type of illness, and sociopsychological factors (Gulzar, p. 5).

Sample. Two convenience samples were used:

1. Twelve parents of children with asthma recruited by posted notices throughout the community (average time in US = 17.5 years; range = 4–26 years). Ten families spoke Khmer or both Khmer and English at home, one spoke Laotian and English, and one spoke English. Inclusion criteria were that the parent be from the SE Asian community and have a child age 2–10 years with a diagnosis of asthma, plus the answer of "yes" to at least four symptoms consistent with an asthma diagnosis (National Asthma Education and Prevention Program, 1997);
2. Twenty-one healthcare providers recruited from clinics and visiting nurse association, and five key informants working in the same community (key informants were combined for analysis into the "provider" group). Within the provider group, nine were born outside the United States including five who were born in Cambodia. Average number of years living in the United States for these nine participants was 19.1 (range = 4–26 years). Table 1 describes additional characteristics of the sample. All participants signed the informed consent approved by the Institutional Review Board of the university and by each participating agency. Consent forms were available in both English and Khmer.

Instruments. A semistructured exploratory interview was based on Kleinman's (1980) work to elicit family and provider EMs. Examples of questions were: "What do you think has caused your child's problem?" "What does the illness do?" "How severe to you think it is?" "What kind of treatment do you think he/she should receive?" "What are the chief problems the illness has caused for you?" "What do you believe would help your child get

Table 1. Demographic Characteristics of Families, Providers, and Key Informant Participants (*N* = 37)

	Families (<i>n</i> = 12)	Providers (<i>n</i> = 21)	Key Informants (<i>n</i> = 5)
Relationship/position	12 Mothers with a child between 2 and 10 years and having asthma	4 MD 2 NP 6 RN Clinic 3 LPN 6 RN VNA	1 Medical interpreter 1 Outreach worker 1 Daycare provider 1 Financial counselor 1 Phlebotomist
Mean age (range)	Parent 31 (20–39)	Provider 38 (21–63)	Informant 45 (31–50)
Mean child age (range)	5.8 (2–10)		
Ethnicity	8 Cambodian 2 Thai 1 Laotian 1 Filipino	13 Caucasian 3 Cambodian 4 Other Asian 1 Hispanic	2 Caucasian 2 Cambodian 1 Other
Education	5 less than HS 1 HS 3 Some college 2 College graduates	5 Some college 9 College graduates 3 Graduate school 4 Medical school	2 HS 2 Some college 1 College graduate

better?” and “What do you feel stands in the way of your child getting better?” Demographic data were also collected. Providers/key informants were asked about their current job.

Procedure. Parents were interviewed individually in a clinic room by a certified medical interpreter fluent in the participant’s preferred language (Khmer or English). Interviews took approximately 30 minutes and were audiotaped and transcribed.

Providers read a fictitious case exemplar of a “typical” 3-year-old SE Asian child, “Sen Kem,” who comes to the clinic wheezing, is diagnosed with asthma and sent home with medications and a treatment plan. The case included the age of his parents (20’s), time in the United States (15 years), household composition (living with parents, grandparents, and older sister), having a smoker in the house, and parental employment. After reading the case, providers were interviewed with the same exploratory interview questions. Questions were worded to ask what they thought the Kem family’s EMs to be; for example, “What do you believe the Kem family thinks caused their child’s asthma?”

Data Analysis. Template analytic technique (Miller & Crabtree, 1992) was used to analyze the data. Researchers immersed themselves in the transcriptions searching for meaningful segments representing EMs of asthma (etiology/causation, treatments, severity, and the problems that asthma has caused [impact]), and access to asthma care. The team collaborated in investigating the meanings of words and in reducing segments into units representing Kleinman’s (1980) and Gulzar’s (1999) frameworks. Results were clustered under these categories for group comparison and contrast.

Results

Etiology/Causation. Family EMs for causality were primarily tied to environmental exposure such as, “cold weather or air (which) freezes lungs,” “dry air,” “winter,” exposure to cigarette smoke,” “mold,” “stuff in the environment,” and foods in general such as dyes, coloring, and dairy products. Genetics were also mentioned: “It comes from the family,” and “My husband had it.” Other causes listed were infections or “sicknesses and viruses”; activity “too much physical activity, running, hyperactivity”; and “vac-

Table 2. Family and Provider/Key Informant Explanatory Models for Asthma Treatments

	Cultural Orientation	Participant Statements
Family EMs		
Treatments their child should receive	Eastern	None mentioned
	Western	"Nebulizer, Inhaler, Nothing but the nebulizer, Flovent, Allergy medications, Prescriptions, Specialist care."
Results they should have		"Breathe better, Improvement, Stop coughing, Stay healthy and keep asthma controlled. I hope it remains managed well and she does not have to be hospitalized again. Clear his breathing."
Home treatments	Eastern	"Coining"
	Western	"Nebulizer," "Cold medication ("doesn't help much"), "Tylenol, Humidifier," "Keep house clean with little dust"; "change linens every week." "Vitamins and drinks to keep healthy."
	Other	"Vaporizer with eucalyptus oil or peppermint oil boiled on the stove to get in the air." "Vicks VapoRub rubbed on chest and back," "Carrot juice—helps build up lining of lungs."
Provider Beliefs of Family EMs		
Treatments family thinks will work	Eastern	"Cupping, Coining to draw out evil spirits," "Hot soup," "Burning incense," "Keeping extremely warm" child should receive "Boiled ginger root drink," "Herbs, Elixirs."
	Western	"Nebulizer," "Meds," "Over the counter medications," "Asthma medications," "Antibiotics."
What results should they have?		"Stop symptoms," "Eradicate asthma," "Cure asthma," "Stop coughing," "Feel better," "Improved breathing."
Home treatments	Eastern	"Cupping, Coining, Herbs, Elixirs, Ointments, Paste, Tiger balm on chest, Roots/medicines in steam baths," "Meditation," "Coining over forehead, head, chest," "Medicine from trees to make vapor," "A combination of Eastern & Western treatments," "Boiled ginger root."
	Western	"Nebulizer & Albuterol," "They don't use anything."

cines." What asthma does was described as "tightening up airways," "mucus build up," "swelling," cutting circulation," and "breaking down breathing."

Providers' descriptions of the Kems' beliefs about causation were primarily culturally attributed. Examples were, "Spirits," "Ying and Yang," "Evil spirits," "Hot and cold," "They think they did something wrong," "Punishment," "Night air," "Cat or dog," and "Going out without a shirt." Genetics and viruses, ear infections, smoking, bronchitis were also mentioned. Several said that the Kems "didn't know" the cause. Often they explained the Kems' beliefs symptomatically such as "causing difficulty breath-

ing," "congestion," "a decrease in activity," "fatigue," and "suffocation."

Treatment. EMs for treatments are shown in Table 2. All the families described treatment in terms of western medicine, including home treatments that reflected knowledge about standard asthma guidelines. Additional home treatments included Vicks VapoRub, which predominated as a home treatment either by inhalation or rubbed on the body. Eucalyptus or peppermint oil in the air was also mentioned. One participant mentioned coining, which is a common SE Asian healing practice for "wind illness" that consists of rubbing warm coins on the chest and arms

(Graham & Chitnarong, 1997), and one mother stated, “No coining.”

In contrast, providers gave elaborate lists of Eastern plus a few Western treatments that they believed the Kem family would use (Table 2). Most of the cultural attributions were provided by U.S. born Caucasian providers. Only one SE Asian provider mentioned cultural treatments that would be used at home.

Severity. All but two of the parents portrayed their child’s illness as very severe: “*Really bad that she might have to be hospitalized again,*” “*Really, really bad breathing*”; and “*One time it was so bad that we ended up bringing him to the emergency room, because he was not breathing at all for a few minutes.*”

Most providers said that the parents in the fictitious case study viewed the illness as temporary and not that severe; “*an acute type of thing that will go away*”; “*They take it very lightly*”; or “*Not as important as I see it. They think it will go away*”; and “*Most SE Asian families do not take it seriously.*”

Impact. Families expressed the impact of asthma in several different ways. They demonstrated chronic worrying when they said: “*I am always worried, always stressed*”; “*I worry about her stopping breathing*”; “*about her suffering.*” They also described their constant vigilance about monitoring symptoms: “*I am always calling to see if he is ok*”; “*I have to pay close attention to his breathing, a sign he needs medication*”; “*I bring him into our room at night, use the baby monitor*”; “*If he runs, I have to monitor his breathing.*” The families were also exhausted: “*The main problem is lack of sleep for me and my husband*”; “*You get up every couple of hours to give medication while they are sick*”; and “*We had bad nights for a long time,*” and were also plagued by the labor intensiveness of dealing with asthma: “*Besides the attack, you put him down for 10 to 20 minutes on the nebulizer*”; “*I need to keep the house clean, change the linens weekly*”; “*I cook everything from scratch*”; “*I try to keep her healthy as possible because if she gets viruses, it contributes to her asthma.*”

Providers said that the impact of asthma had to do with anxiety and fear “*frightening, unpredictable, dangerous*”; “*causes worry, scares the family*”; “*uncontrollable cough*”; and inconvenience “*disruption in routine*”; “*missing work*”; “*taking time to care for him*”; “*time for inhala-*

tion”; “*becomes a chore in an already stressful life*”; and “*transportation difficulties.*” Providers also cited family financial costs: “*money for meds,*” and “*expensive meds and equipment.*” Financial issues were not mentioned by families in their responses.

Access to Care, Barriers and Facilitators. There were differences in perceptions of access to care between the two groups, described in Table 3. Providers did not perceive any healthcare system barriers, but rather described a multitude

Table 3. Barriers and Facilitators to Asthma Care as Described by Families and Providers

Family Descriptions	Provider/Informant Descriptions
Barriers	
System	
Medical insurance, cost of insurance	None listed
Difficulty getting to PCP	
PCP not available	
Getting same day appointments	
Family	
Money	Religion, cultural beliefs and remedies
Resources	Don’t understand Western beliefs
	Language
	Grandparents don’t believe in medication
	Lack of family support or support group
	Taking meds chronically is “bad” for you
	Don’t believe in prevention
	Lack of compliance
	Lack of knowledge about asthma, triggers hygiene, environmental controls
	I don’t think they know
	Transportation
	Time off from work, shift work
	Don’t wait for MD, so go to ED
	Smoking at home

(continued on next page)

Table 3. Barriers and Facilitators to Asthma Care as Described by Families and Providers (*Continued*)

Family Descriptions	Provider/Informant Descriptions
Facilitators	
System	
Follow up with MD	Education on asthma, triggers, smoking
Available and able MDs	Home visitor, someone from culture to help
Education	Interpreters
Asthma resources	Asthma Action Plan
	Learn about their beliefs
	Incorporate Eastern and Western approaches
	Frequent MD visits
Family	
Getting away from smokers	Compliance
Continue with follow up with MD	Use of nebs
Education, more information	Signs of early “trouble”
Having the necessary equipment	
Money	

Note: Bold type indicates concordance between the two groups.

of family barriers to care. Conversely, for families, numerous system barriers were mentioned.

Clinical Implications

We anticipated that SE Asian families would view asthma through the lens of Eastern cultural beliefs, but this study did not support that. These parents were relatively well-educated about their children’s asthma and appeared to be following current asthma guidelines (National Heart, Lung and Blood Institute [NHLBI], 2007). The providers, however, felt that the families would be viewing asthma through their cultural belief system. There were also differences in how the families versus providers felt that asthma impacted on the family’s life. For families, a sense of the “*long haul*” of dealing with their child’s illness, as described by Rolland (1994, p. 48), permeated their descriptions. This long haul involves coping with asthma through both flexibility and ongoing management of day-to-day regimens, plus preparedness to deal with acute crises or flare-ups (Rolland). Their words communicated weariness with the stress of the experience of living with asthma. These families also revealed a sense of loss that

was similar to that in another study in which 76% of the mothers worried about their children dying from asthma (Handelman, Rich, Bridgemohan, & Schneider, 2004). In contrast, when providers read the fictitious case study, they suggested that the impact of asthma was acute and episodic, and not nearly as severe as perceived by the families.

The lack of concordance between the two groups’ beliefs about barriers to care was concerning. The major system barrier expressed by families was the lack of an available MD, yet providers did not see this barrier for the patients. System barriers were not mentioned by any providers in this study. Providers felt that barriers to care for SE Asian families were primarily culturally attributed and tied to their cultural beliefs. In their study on provider satisfaction in working with ethnic immigrant groups (some of whom were Cambodian) Kamath, O’Fallon, Offord, Yawn, and Bowen (2003) found that some providers felt that their immigrant patients did not understand disease prevention and management of chronic conditions; such patient-provider encounters yield-

ed lower satisfaction in providing care than with control patients. They concluded that further education and research on cultural variations and stereotyping were necessary.

Concordance between the two groups did exist about facilitators to care (asthma education and provider availability). Asthma education was a high priority for both groups, a finding that was similar to that of another qualitative study of parents of asthmatic children (Peterson-Sweeney, McMullen, Yoos, & Kitzman, 2003).

This research has relevant practice, education, and policy implications. It suggests that regardless of a patient’s cultural background and the nurse’s knowledge of cultural practices of a particular group, using an EM approach can facilitate mutual understanding and the individualization of patient care. Cultural competence education including an introduction to Kleinman’s framework (along with how to ask questions about EMs) and how to listen to patients is suggested. Finally, policy implications of this study relative to access to care suggest that there is a need for institutionally based policy change to address system barriers and promote facilitators through

SUGGESTED CLINICAL IMPLICATIONS

Nurses working with SE Asian families of children with asthma should:

- Ask questions about parental beliefs about their child's illness in order to promote the provision of culturally competent nursing care.
- Use the EM framework to better understand what parents are experiencing.
- Find out the user and system barriers as well as facilitators that parents are experiencing.
- Address system barriers to access and promote facilitators through patient education, scheduling changes, family support and creative change to improve patient access and provider availability.
- Work with parents understanding that the day-to-day experiences of living with a child with a chronic condition such as asthma have life-altering impacts.

patient education, scheduling changes, support and creative change to improve provider availability. ✚

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ONLINE



Centers for Disease Control and Prevention:

www.cdc.gov/nchs/data/ad/ad381.pdf

Cambodian health statistics:

www.cch2010.info/Health2010audios.htm

Guidelines for the management of asthma:

www.nhlbi.nih.gov/guidelines/asthma/asthgdln.htm