

Medical Management of Asthma and Folk Medicine in a Hispanic Community

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Objective: To describe beliefs about asthma and asthma treatment in a Hispanic (Dominican-American) community to determine how alternative belief systems affect compliance with medical regimens.

Method: Twenty-five mothers of children with asthma were interviewed in their homes, in their primary language, Spanish. Mothers were questioned about their beliefs regarding asthma etiology, treatment, prevention of acute episodes, and use of prescribed medications.

Results: Most mothers (72%) said that they did not use prescribed medicines for the prevention of asthma; instead, they substituted folk remedies called “zumos.” The home remedies were derived from their folk beliefs about health and illness. Most mothers (60%) thought that their child did not have asthma in the absence of an acute episode. Eighty-eight percent said that medications are overused in this country and that physicians hide therapeutic information from them.

Conclusions: Mothers' reliance on home remedies for asthma prevention leads to a high rate of noncompliance with prescribed regimens. Yet they perceive themselves as compliant with an effective regimen that differs from standard medical practice. Further studies should explore ways of promoting physician/patient communication in order to find ways of coordinating medical and folk beliefs to enhance compliance with medically prescribed regimens.

Key words: *asthma; alternative belief systems; compliance.*

A critical component of the medical management of children with severe, chronic asthma is the development and maintenance of an effective and trusting relationship between parent and physician. A recent study of problems in parent-physician relationships among parents of children with severe asthma and their pediatricians found that both pediatricians and parents were dissatisfied. Pediatricians

complained that parents' ways of thinking about asthma management differed from those that they were trying to communicate and that this typically resulted in nonadherence with their recommendations. Parents, on the other hand, reported problems and negative relationships with their pediatricians, even though pediatricians perceived no problems with how they believed parents felt about them (Cohen & Wamboldt, 2000). Another study found that poor patient-clinician communication was a primary factor associated with adherence problems with inhaled steroid therapy among adult asthmatics, particularly those who were poorly edu-

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cated and had lower socioeconomic status (SES) (Apter, Resine, Barrows, & ZuWallack, 1998).

Asthma is the most common chronic disease of childhood and adolescence. It affects 4.8 million Americans under 18 years of age and accounts for 2.2 million annual visits to pediatricians (Adams & Marano, 1995). It is the most frequent cause of school absenteeism and pediatric hospitalization (Eggleston, 1994). The prevalence of asthma is steadily increasing (75% from 1980 to 1994 [Manino et al., 1998]). Among urban children from low-income families, the prevalence is as high as 14.3% (Crain et al., 1994) compared to a 6% overall prevalence rate for U.S. children (Taggart & Fulwood, 1993). The reason for this disparity in rates has not been readily discernable but is associated with increased mortality despite improved guidelines issued by the National Heart, Lung, and Blood Institute (National Asthma Education and Prevention Program, 1997) for managing asthma as well as improved medications, particularly inhaled anti-inflammatory agents.

Studies of low-income minority pediatric patients with asthma found disproportionate underutilization of medical facilities and inadequate day-to-day management of asthma. They further found that asthma care was episodic and in response to acute asthma crises rather than ongoing, that self-treatment involving over-the-counter medications and folk remedies was the norm, a general disregard for preventive self-management, and that delays in seeking treatment were common (Strunk, 1987; Zimmerman, Bonner, Evans, & Mellins, 1999). Regimens for asthma are complicated by the following factors: (1) asthmatic attacks are intermittent on a periodic basis; (2) the attacks vary in severity from mild episodes consisting of slight wheezing to asthmatic crises that are intense and continuous; (3) they are reversible in that the airways often revert to normal either spontaneously or after treatment; (4) symptoms of asthma are variable and include, for example, trouble breathing, chest pain, neck-throat tightness, and coughing (Chai, 1975); and (5) a wide range of factors may trigger an attack including pollen, dust and dust mites, cockroaches, feathers, tobacco smoke, rodents, mold and mildew, cold weather, and exercise.

While a 50% overall rate of medication non-compliance continues to plague treatment plans and recovery rates for all illnesses among adults as well as children (Haynes, Taylor, & Sackett, 1979; Lemanek, 1999) medications typically are the foun-

dation of asthma management, and medication noncompliance has been shown to be the leading factor in poor asthma control (Alessandro, Vincenzo, Marco, Marcello, & Enrica, 1994; Lemanek, 1999; Sackett & Hayner, 1976). The following issues have been found to affect compliance: socioeconomic status (SES) and affordability, general life stress/distress, family structure, social support, frequency of follow-up health care visits, complexity of regimes, use of cueing techniques to remind patients of schedules, and coordination of services among community resources (e.g., home and school) (Bender, Milgrom, Wamboldt, & Rand, 2000). In addition, we often assume that if patients clearly understand the rationale of the medical management plan, the nature of the disease, and the function of the medications, they generally will adhere to treatment guidelines. However, knowledge and understanding are rarely associated with compliance (Bearison, 1998). Studies of urban children and their adult caregivers have found that knowledge of asthma triggers and medical management did not predict appropriate asthma care (Rich, Lamola, Amory, & Schneider, 2000; Wade et al., 1997). For example, in a national study of inner-city children with asthma, the children's caretakers averaged 84% correct responses on an asthma information test; however, they were found to manage their children's asthma in ways that were "potentially dangerous or maladaptive" (Wade et al., 1997). Although interventions aimed specifically at educating patients about appropriate medication use have shown increased knowledge, they showed little improvement in asthma morbidity (Hilton, Sibbald, Anderson, & Freeling, 1986; Howland, Bauchner, & Adair, 1988; Tettertsel, 1992). Shope (1981), in an extensive review of studies of medication compliance in pediatrics, concluded that "knowledge about the disease being treated has rarely had any relationship to compliance behavior" (p. 19), and Beck et al. (1980), reviewing intervention programs designed to increase patients' medication knowledge, found that "there was no association between compliance and the patient's initial, final, or improvement in medication knowledge" (p. 1096).

It is our hypothesis that parents' and patients' nonadherence to medical regimens for asthma arise from their community-based cultural beliefs and attributions about the cause and treatment of asthma. Consequently, instead of following critical and long-term aspects of standard therapies for asthma,

they often resort to folk remedies that are logically consistent with their culturally supported beliefs about asthma, in particular, and illness, in general. The purpose of this study was to explore how mothers' beliefs about the etiology and treatment of asthma create barriers to adherence with their children's prescribed medical regimens. Although this report focuses on a community of Dominican-American immigrants living in an urban environment in the United States, the impact of their attitudes about home remedies, folk beliefs, and alternative therapies is of considerable importance to other communities as well. Recent reports from Australia (Andrews et al., 1998) and the United Kingdom (Ernst, 1998) found that a substantial percentage (55% and 41%, respectively) of children with asthma were treated with alternative therapies either in addition to or in place of standard therapies.

Method

Participants were mothers of 25 Dominican children 7 to 12 years old (12 girls, 13 boys) who were diagnosed with moderate to severe asthma and did not have any other illness. Children with asthma were selected with the assistance of teachers, school nurses, and guidance counselors at two inner-city elementary schools in a predominantly Dominican community having strong cultural ties to the Dominican Republic (Duany, 1994). Mothers were informed of the study on the phone, and those who gave informed consent (82%) were individually interviewed (by the second author) in Spanish in their homes. All of the mothers had been born in the Dominican Republic, and all but one had been living in the United States for more than 1 year; approximately half of the mothers had lived in the United States for more than 10 years. Eighty percent of the mothers had at least a high school education, and approximately half lived with one of the fathers of their children. Approximately half of the sample had incomes below the federally designated poverty level, and three-fourths resided in households with four to five people in a one-room apartment.

Mothers were asked to talk openly about their children's asthma in a semi-structured interview that focused on three topics: (1) the nature of asthma including its etiology, diagnosis, prognosis, and factors contributing to the occurrence of

Table I. Mothers' Beliefs about Asthma: Cause, Symptoms, and Triggers

| Belief | % expressing belief |
|--|---------------------|
| Asthma causes | |
| Asthma is caused by phlegm in the lungs | 92 |
| Asthma is curable | 72 |
| Asthma is wheezing | 48 |
| Child has asthma only during an attack, at other times doesn't have asthma | 40 |
| Asthma is an environmental problem | 32 |
| Asthma is a hereditary problem | 12 |
| Asthma symptoms | |
| Coughing | 100 |
| Slow/tired breathing | 48 |
| Wheezing (i.e., "pitico") | 32 |
| Lethargy | 24 |
| Retractions | 16 |
| Pale or purple face | 16 |
| Asthma triggers | |
| Being cold | 72 |
| Exercise | 72 |
| Changes in temperature | 48 |
| Foods | 48 |
| Changes in emotions | 36 |
| Odors (e.g., perfumes and cleaning products) | 32 |
| Dust | 24 |
| Animals | 24 |
| Plants, pollen | 20 |
| Other illnesses (e.g., colds) | 8 |
| Carpets | 8 |

asthma attacks in their children; (2) the treatment for asthma, particularly the use and function of medically prescribed asthma medications; and (3) what can be done to prevent or limit their children's asthma attacks.

Results

Table I lists the percentage of participants who expressed different beliefs about the nature of asthma, its cause, and what triggers an asthma attack. Most mothers (92%) described asthma as having phlegm in the lungs that clogs the lungs and, hence, impairs a child's ability to breathe. Airway inflammation is known to be an important element in the pathophysiology of asthma; therefore, this view among mothers was consistent with standard medical knowledge. All mothers stated that cough was a symptom of asthma, and this also is consistent with

Table II. Mothers' Beliefs About Medications

| Belief | % expressing belief |
|--|---------------------|
| People in the the United States take too many medicines | 88 |
| Physicians hide therapeutic information from us | 88 |
| Prefer folk remedies (i.e., zumos) to standard therapies | 84 |
| Administer folk remedies (i.e., zumos) as preventive treatment | 72 |
| Administer prescribed medication only in symptom specific crises | 72 |

standard knowledge about asthma. Less than half of the mothers acknowledged other asthma symptoms, such as wheezing, lethargy, and retractions. This may explain their difficulty in recognizing the onset of an acute exacerbation. Exposure to cold and exercise were cited as asthma triggers by 72% of the mothers; these are known asthma triggers. However, in contrast to how physicians understand asthma, only 32% and 12% of the mothers acknowledged asthma as either an environmental or hereditary problem, respectively. Also, most mothers explained that asthma triggers were associated with hot and cold bodily humors (being cold, exercise, changes in temperature, foods, and changes in emotions). As will be shown, mothers' beliefs about the function of bodily humors in triggering their children's asthma were associated with generally held and culturally derived folk beliefs about illness and treatment. Accordingly, other asthma triggers commonly known by physicians (e.g., dust, animals, pollen, carpets) were less likely to be recognized as such among mothers.

The most notable finding was that mothers reported treating their children's asthma differently depending on whether it was for preventive purposes or in response to an asthma attack (Table II). Mothers were much more likely to accept medically prescribed therapies in response to their children's asthma attack. Although 96% of mothers spoke of the need for longer-term preventive therapies, 40% stated that asthma was episodic and the children did not have asthma in between acute exacerbations (Table I). Their ideas about adequate preventive treatments were based primarily on folk ideologies having to do with an imbalance in body humors or temperature. Most mothers (72%) said that they used what they referred to as *natural medicines*, *home remedies*, or *zumos* to prevent asthma but

relied on medically prescribed therapies when their children had an asthma attack (Table II). An illustration of how mothers differentiated between symptomatic and preventive therapies is the following statement: "When she had an attack, I would first give her the medicine, then I would take her to the hospital, give her albuterol for two or three times a day, then I would throw it away and give her the home remedies." The prescription, however, called for the albuterol to be administered every 4 to 6 hours for 2 weeks. Another mother who readily acknowledged that the prescription label called for her to administer albuterol every 4 hours said that she does not because "it is bad to take so many medicines. I would only give it to her in extreme situations or when the nurse was here."

Many mothers (72%) had strong reservations about using prescribed medications as directed for other than acute exacerbations of asthma. Table II lists the percentage of mothers expressing different beliefs about asthma medications. It documents their general mistrust of medically prescribed preventive therapies for their children. Greater than 80% of the mothers said that they preferred folk remedies, believed that physicians do not disclose to them all relevant information, and that "people in this country take too many medicines." The mothers' reluctance to use prescribed asthma medications was based on two factors: (1) fear of dependency on the medications and (2) suspicion of physicians' failure to disclose medication side effects. One mother, for example, although aware that the prescribed dosage for cromolyn was every 6 hours, said that she administers it to her daughter only twice a day because "it makes the kids very nervous. It's like a drug. It behaves like a drug. [What do you mean when you say it is like a drug?] It causes addiction. I notice that she becomes desperate if she doesn't put it on. . . . I know prednisone, for example, destroys her bones. [How do you know that?] Many people have told me. [The doctor that gave it to her?] No, they never tell you these things about the medicine." Another mother said about prednisone, "I hardly ever give it to her, only when she is in the hospital." Another mother said, "They don't tell you what the consequences might be . . . so parents won't stop using the medicine because, if one knows, then one would stop using them." The addictive quality of prescribed medications was a common theme in how mothers talked about them: "I don't give him medicine [when he is well] so that the body can build its own immune

system. If one takes too many medicines, the body starts to rely on them and becomes lazy." Another mother said, "This is for the machine [showing albuterol]. They also give it to her in liquid but I give it away, I don't use it."

Folk Medicine. For many Latinos, and particularly this sample of Dominican mothers, their general ideas about the nature of illness, its etiology, and therapeutics is based on a hot-cold system derived from Hippocratic theories of disease transplanted to the western hemisphere by the Spanish and Portuguese in the sixteenth and seventeenth centuries. According to the Hippocratic theory, the bodily humors (blood, phlegm, black bile, and yellow bile) vary in temperature and moistness. Illness, according to this system, is caused by an imbalance that induces the body to become excessively dry, cold, hot, wet, or a combination of these states. Therapies, accordingly, are based upon the ingestion of plants or other kinds of medications that also are classified as being wet or dry, hot or cold, and that, therefore, are able to restore the body to its natural balance. Thus, for example, a cold disease, such as arthritis, is treated by ingesting hot plants or medications. For reasons that are not clear, the wet-dry dichotomy became insignificant in transplanting the system to Latin American folk practices and the hot-cold dimension came to dominate the system of balance/imbalance as determinants of health and illness (Harwood, 1971; Martinez & Martin, 1966).

The kinds of preventive therapies expressed by mothers in this sample were inferred from the above ideas about the restoration of balance between hot and cold humors. For example, 76% of mothers said that, in order to prevent their children from having an asthma attack, it is important to dress them warmly, and 76% also attributed the cause of their children's asthma attacks at school to teachers who permitted them to go outside in cold weather. The kinds of zumos used by 84% of mothers who said that they preferred them in place of standard therapies for preventing asthma are listed in Table III. Because asthma is thought to be a cold disease in Latino folk medicine, the appropriate zumos are believed to have hot qualities, and hence, are able to restore the humoral balance. Although the list of zumos might constitute kinds of treatments that physicians would consider benign and unlikely to cause harm (but provide no benefit), problems arise in medical management when they are used in place of standard therapies.

Table III. Common Ingredients That Mothers Used in Zumos

| Ingredients | % using it |
|-------------------|------------|
| Whale oil | 68 |
| Cod liver oil | 60 |
| Honey/royal jelly | 52 |
| Onion/garlic | 40 |
| Almond oil | 36 |
| Castor oil | 36 |
| Oregano | 28 |
| Lemon | 28 |
| Aloe vera juice | 28 |

While mothers seemingly felt free to disclose to us their distrust of standard asthma therapies along with their practice of often discarding prescribed medications and relying instead on zumos, they said that they did not discuss their beliefs about folk remedies and their distrust of standard medication with their pediatricians: "I give her natural medicines as any mother would do before using the medicines that the doctors recommend." Another mother said of her home remedies, "I know it can't hurt them because it is all natural. Bianca had the worse cold and they kept on changing her from antibiotics. I stopped giving them to her and she got well. It's incredible; home remedies really work!" However, this mother refused to tell her pediatrician that she employed zumos in place of prescribed therapy for preventing her daughter's asthma attacks. An important factor in mothers' reluctance to discuss their health beliefs with pediatricians was their sense that pediatricians typically do not explain their rationale for medical management with them. Hence, pediatricians maintain a set of beliefs about preventing asthma attacks that, in several compelling ways, seriously contradicts a set of beliefs ascribed to by mothers. Both sets are logically consistent with broader, more encompassing belief systems about the nature of illness and treatment in general; however, they rarely are ever talked about and compared, each to the other, in the physician-patient relationship. Mothers spoke about this in the following ways: "The doctors don't take the time to explain things to me.; When he was four, they told me that he had asthma, but I don't know because doctors never tell the truth [Why not?] So one will not get worried. . . . They don't tell you what the consequences might be so parents won't stop using the medicines because if one knows then one would stop using them. They

have a lot of patients so I know I can't ask many questions because they are busy."

Discussion

Our findings are of concern not only because they demonstrate that many of these mothers' beliefs about the nature, cause, and particularly preventive management of asthma are at variance with and contradict medical standards but also because Dominican mothers of children with asthma maintain their folk beliefs and practices without ever discussing them or confirming their validity with their pediatricians. Thus, there is no basis to negotiate some reconciliation between their own ways of managing their children's asthma and medically prescribed regimens. Their aversion to seeking medical advice for maintenance care is based on mistrust of the physician's practices because standard medical practice is at variance with their traditions and cultural beliefs about illness in general and asthma in particular. Because their cultural belief systems about health and illness are logically consistent and coherent to these mothers, they do not see themselves as being noncompliant or failing to provide adequate care. However, by our standards, based on our beliefs and confirmed by our empirical findings, the care that they offer their children is neither adequate nor in the best interests of their children. Hence, it becomes our responsibility to acknowledge their folk beliefs about asthma and the home remedies they use in order to break the taboo about discussing differing belief systems about illness management. By so doing, we can begin to find ways to reconcile critical differences. Efforts to simply educate and enhance patients' knowledge of asthma are not sufficient. From these findings, it is apparent that we need to go deeper and question parents and patients about their beliefs about the etiology as well as the treatment of asthma.

Further research should examine the effects of acknowledging and discussing parents' folk beliefs about asthma etiology and treatment on their adherence to Western standards of medical care. By so doing, we can recognize that patients' beliefs about illness and treatment typically extend beyond biological/medical boundaries to broader social and cultural contexts that derive meanings from and are sustained by the local communities in which they live and work (Frankenberg, 1986; Young, 1982). It then becomes important for us to recognize how

their ideas about treatment management match or mismatch those of the patient's community and how we might help them to reconcile contradictory practices (Bearison, 1996). Our findings confirm those of Mellins, Evans, Zimmerman, and Clark (1992), who, in a cogent editorial about pediatric asthma management, concluded that "patients made decisions for themselves based on their own perceptions of what works" (p. 1377).

This kind of negotiated approach to compliance constitutes a major shift from earlier perspectives about treatment regimens that considered patients' failure to comply as somehow being deviant, irrational, irresponsible, self-destructive, or simply due to their ignorance (Trostle, 1988). Instead, we propose a patient-focused perspective that recognizes that their behavior, while noncompliant according to physicians' perspectives, is logically consistent with their own belief systems and ways of understanding and making sense of serious and chronic illness. Their behavior becomes understandable, rational, and even compliant within the context of their personal belief systems about how drugs work in the body, how their efficacy can be evaluated, and how quickly benefits should be evident if the medication is useful (Siegel, Schrimshaw, & Dean, 1999).

Patients often report taking medication in response to the appearance of symptoms and then ceasing to use them when the symptoms abate (Chubon, 1989). Physicians see this as noncompliance. Our evidence suggests, however, that patients are compliant, but with a regimen based on folk beliefs rather than standard medical practices. Pediatricians, social workers, pediatric psychologists, and other health professionals, therefore, need to find ways to speak to parents about prevention in asthma management so that medical recommendations may be reconciled and coordinated with their folk beliefs. Inasmuch as many of the mothers in our sample expressed beliefs concerning asthma etiologies (e.g., cold, exercise, certain foods) that are generally accepted by pediatricians, there is common ground on which to begin a collaborative dialogue. The impact of folk beliefs on adherence to preventive or maintenance regimens should be taken seriously. Once these issues are clearly put forth as topics of common concern between mothers and pediatricians seeking the best means of managing their children's asthma, we need to do more to encourage parents to enter a mutually reciprocal process of negotiating ways of managing

and monitoring asthma care that reflects potentially competing approaches. Following a biopsychosocial model, we can better appreciate and understand the complementary and adjunctive qualities of common folk remedies (i.e., zumos) and how they might be incorporated, without harm, as part of a viable standard of care. Obviously, this will require us to understand and collaborate with patients—from asking and telling to listening and negotiating treatment regimens with them.

Although this study focused on a small community with a specific folk ideology about using alternative or complementary therapies, the lessons

learned from them about the impact of cultural beliefs and patient-physician relationships on compliance may extend to families from other cultures and other pediatric conditions. Further research in this area therefore is warranted. The use of alternative medication should be considered within the broader context of conditions associated with generally low SES and accompanying issues of life stress.

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