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Illness representations and cultural practices play a role in patient-centered care in childhood asthma: experiences of Mexican mothers

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Abstract

Objective—Patients' cultural health beliefs and behaviors may conflict with biomedical healthcare values and practices potentially leading to non-adherence with asthma treatment regimens. To optimize shared decision-making, healthcare providers should understand and be sensitive to these cultural beliefs and behaviors and negotiate an asthma management plan acceptable to parents. The purpose of this study was to obtain the perspective of Mexican mothers regarding (1) their experiences of living with a child with asthma, (2) their understanding of the nature of asthma, and (3) how their cultural beliefs influence asthma management.

Methods—A qualitative, phenomenological study design was employed to assess mothers' lived experiences with and perceptions of their child's asthma. Individual in-depth interviews were conducted with a purposeful sample of 20 Mexican mothers of children ages 5-17 years with asthma. An inductive, theory-driven, phenomenological analysis approach was used to elicit thematic findings.

Results—Mothers expressed a symptomatic perception of asthma and limited understanding of the disease. Most believe the disease is present only when their child is symptomatic. Many are surprised and puzzled by the unpredictability of their child's asthma attacks, which they report as sometimes "silent". The inconsistency of triggers also leads to frustration and worry, which may reflect their concerns around daily controller medication use and preference for alternative illness management strategies.

Conclusions—Our clinical encounters should be refocused to better understand the context of these families’ lives and the cultural lens through which they view their child’s asthma.

Keywords

asthma; illness representations; Latino; childhood; shared decision-making

Introduction

Illness representations (IRs) and caregivers’ treatment decisions have been identified as factors contributing to inadequate medication adherence and increased asthma morbidity for their children(1, 2). The caregiver’s IR is critical in the decision to seek healthcare and adhere to the prescribed medication regimen which influence children’s asthma health outcomes(1-6). The professional model of asthma management views asthma as a chronic disease that is present even when well-controlled and no symptoms are evident(7). The lay model views asthma as episodic or acute with uncontrollable symptoms, and caregivers view taking controller medications daily negatively. Yoos et al. reported that minority families are less likely to believe that asthma is a chronic disease and to use controller medications. Caregivers with higher education held beliefs congruent with the professional model of asthma and were more likely to have children on an adequate medication regimen(1). Caregiver depressive symptoms have been associated with increased urgent care and ED visits and hospitalizations(8-10) which may be the result of poor asthma control.

Different cultures have health belief systems which describe causes of illness, symptoms, how illness can be treated or cured, and consequences of medical treatment. Some Latino cultures, particularly Mexican, believe asthma to be a ‘cold’ disease based on the notion of humoral balance, and thus many ethnomedical treatments are ‘hot’ (e.g., teas, bundling children in clothing)(11). Following the ‘plumbing model’ of the body, Puerto Ricans use asthma therapies aimed at unclogging air passages and improving air intake (e.g., herbal expectorants, humidifier)(12). These cultural health beliefs and practices “may exist side-by-side with conventional biomedical beliefs and practices”(11). Asthma IRs and ethnocultural practices are frequently overlooked during the asthma visit(2, 13-15) but are critical to medication adherence. Many caregivers are apprehensive about biomedical treatment for asthma due to concerns about side effects, fear of addiction, or beliefs that daily use will result in loss of efficacy (4, 16, 17). Orrell-Valente et al.(16) reported that of the 49% of caregivers who expressed concern about side effects, 3% reported fear of addiction. Additionally, of the 138 caregivers expressing concerns about medications or medication regimen, 8% worried about loss of effectiveness. Chan and DeBruyne(17) reported that 94% of caregivers voiced concerns about side effects and 86% about addiction to inhaled therapy. Some caregivers will use ethnomedical therapies as their first line treatment during an asthma exacerbation and delay the initiation/stepping up of prescribed medications or consciously decide not to administer the medication. This has been labeled as ‘intelligent noncompliance’ or ‘intentional non-adherence’ because non-adherence is the result of a rational decision(3, 18, 19).

As management of chronic illnesses has incorporated more self-management strategies, it is important to understand how the caregiver perceives his/her child's asthma and their beliefs about controller medication and ethnomedical therapy use so that effective communication and shared decision-making regarding treatment expectations and symptom resolution can occur. There is potential to improve adherence to the prescribed medication regimen while remaining sensitive to the caregivers' ethnomedical beliefs.

Theoretical Framework

The Common Sense Model of Self-Regulation is an integrated model that takes into account environmental, social, and cultural factors and patients' beliefs about health and illness (20, 21). The three principles of this model are the caregiver is an active problem solver; the IR is the central cognitive construct that drives the caregivers' treatment decision and appraisal of the child's health outcomes; and IRs are individualized and may not agree with medical facts(21-23) The model describes a cognitive processing system comprised of situational stimuli (perception of the child's symptoms), objective representation of the health threat (illness representation) with its treatment decisions (CAM and controller medication use) and appraisal of outcomes (asthma control) for the success/failure of those treatment decisions. The model contains a feedback loop with IRs potentially changing over time as the caregiver gains experience with managing their child's asthma. The processes of IR, treatment decision, and appraisal of outcomes are shaped by the caregiver's prior history managing their child's asthma, personality traits, and social and cultural contexts. The cultural context in which an individual lives plays an important role in IRs. Culture provides labels for symptoms defining a particular illness, affords a culturally common view of the illness, and offers social and personal contacts that the individual uses in constructing the IR and developing the action plan (23). There are five distinct attributes of IRs(24):

- *identity* – disease label and somatic symptoms associated with the disease
- *cause* – ideas about what causes the disease
- *consequences* – perceived short and long term effects and the physical, social, emotional, and economic consequences of the disease
- *timeline* – expectations about disease duration: acute, chronic, or episodic/cyclical
- *controllability* – ideas about cure or recovery

It is necessary to gain a thorough understanding of how culture and lived experiences shape the asthma IRs formed by ethnic minority caregivers and influence the treatment decisions they make for their children. Integrating this knowledge into the clinical encounter will enhance the partnership between the healthcare provider (HCP) and caregiver, yielding a shared-decision model which stands a greater likelihood of successful implementation. The research questions in this study were: 'What are the experiences of Mexican mothers with a child with asthma?' and 'How do these experiences and her culture influence their representations of asthma?'

Methods

Design

This study employed a phenomenological analysis design with qualitative interviews. Individual semi-structured interviews were used with a sample of Mexican mothers to “find the essence or common themes in their experiences”(25).

Sample & Setting

A purposeful random sample of 23 Mexican-heritage mothers of children with asthma was recruited from two school-based health clinics which provide integrated primary care services in Phoenix, AZ for over 7,000 families. Three of these mothers participated in piloting the interview questions and the remaining 20 mothers completed the main study. These FQHC clinics serve as a medical home for these families and at the time of the study, were staffed by a physician and clinic nurse who split their time between these clinics. Children with asthma are seen every three months per the National Asthma Education and Prevention Program guidelines(7)and caregivers were required to attend each visit. The sample was enrolled from April through August, 2010. Eligibility criteria were adult primary caregiver of a child 5-17 years old diagnosed with asthma (obtained from the child's medical record) responsible for the day-to-day management of the child's asthma and self-identified Mexican ethnicity.

The clinic nurse generated a list of eligible families from the electronic health record. The sample was numbered and a random number generator in SAS ordered the list. Prospective participants were called in order by the clinic nurse. After verbal assent to participate was obtained, a bilingual research assistant (RA) contacted the caregiver and made an appointment to complete the informed consent and interview. Recruitment and interview materials were available in English and Spanish. An incentive of \$30.00 was offered for participation. The Institutional Review Boards of Arizona State University and Scottsdale Healthcare approved this research.

Procedures

Data were collected using individual, in-depth semi-structured interviews conducted in the setting and language of the mothers' choice. A bilingual RA trained in qualitative interviewing conducted the interviews. An interview guide of 14 open-ended questions (Figure 1) was informed by our theoretical model. Probing techniques were used to elaborate participants' responses. The interview guide was piloted with three Mexican mothers of children with asthma and revised accordingly. Notes were taken during interviews to aid in probing and assess data quality. The interviews lasted 60-90 minutes and were digitally recorded with the participants' consent. A short exit questionnaire was also administered to obtain demographic characteristics, mothers' depressive symptoms (CES-D) (26), and perceptions of the quality of her relationship with the child's HCP(6, 27). All interview recordings were transcribed verbatim. Spanish transcriptions were translated into English by a certified translator and reviewed by the bilingual RA to ensure comparability of the content to the original version. Qualitative data were entered into NVIVO 9™ and quantitative data entered into SAS 9.3.

Data Analysis

Data were analyzed following a theory-driven phenomenological analysis approach. Although phenomenological analysis does not require data coding, data were coded to increase analytic rigor. A codebook with definitions was developed inductively and iteratively to guide and provide consistency to the coding. Four analysts – the two investigators and two RAs trained in interpretive qualitative analysis – independently coded the first four transcripts and met to develop the codebook through consensus. Several *a priori* codes were derived from the Common Sense Model literature, which served as the analytic lens. The RAs independently coded the next six transcripts, and the principal investigator conducted consensus coding and inter-rater reliability (IRR). IRR was $>.90$ across the six interviews, thus the remaining interviews were single coded. Each analytic team member independently reviewed coding reports searching for patterns in the informants' asthma IRs, management practices, and interactions with the HCP before meeting to develop themes, by consensus, representing the main findings. Themes were developed by combining interrelated coding categories. To enhance the rigor of the research and trustworthiness of findings, the researchers performed reflexivity, kept an audit trail, and conducted negative case analysis. These involved reflecting on researcher biases, keeping detailed records of procedures throughout the study, and reviewing raw data for evidence that contradicted findings(25), which were then reconciled.

Results

Table 1 presents the sample characteristics. The mean age of mothers was 37 years and their children were 10 years. Mothers had an average of 11.7 years of education, the majority (12/20) was married, over half (11/20) rated their standard of living as 'just getting by' or 'poor', and 5% reported depressive symptomatology in the clinical range. Over half (11/20) of the mothers reported their child's asthma was well-controlled; 7 mothers were unsure. Quality of the caregiver-HCP relationship was fairly low ($M=2.07$, $SD=.40$ on a 5-point scale). A total of 43 coding categories were identified which yielded eight overarching themes: (1) symptomatic representations of illness; (2) unpredictable and episodic nature of asthma; (3) asthma knowledge and information sources; (4) beliefs about illness onset and knowledge of triggers; (5) perceptions of illness severity; (6) beliefs about medication use; (7) hope for the passing of illness or a cure; and (8) caregiver and family worries and concerns. Each theme reflects one of the five attributes of the theoretical model (Table 2). A narrative of thematic findings is presented with representative examples.

Symptomatic representations of illness (Identity)

The primary symptoms mothers reported were shortness of breath, choking, coughing, chest tightness, wheezing, sneezing, restlessness, fatigue and/or fainting. When asked what they think asthma is one mother stated, "asthma causes them to be unable to breathe. They feel like they are choking...That is what I think asthma is...the chest closes up tightly...he feels like fainting..." Other mothers compared it to the 'flu', a 'cold' or 'allergy' reporting, "it's like getting the flu, but it turns into asthma"; "asthma is like having a cold all the time"; and "asthma is a problem of allergies more than anything else." Only a few mothers described asthma in clinical terms; as an inflammatory condition of the respiratory system. One

mother stated that “asthma is a physical problem that has to do with the respiratory airways,” and another said that “it is an obstruction of the ducts.”

Unpredictable and episodic nature of illness (Timeline)

Many mothers viewed asthma as acute and episodic, and believe the disease is present only when their child is symptomatic. Mothers described their child’s asthma as an illness that is unpredictable, dangerous, deceiving, and potentially life-threatening. Its unpredictability was deemed particularly troubling, as one mother explained, “...it’s a frightening illness because he can be literally fine in the morning and severely ill by the evening. It comes very quickly...” Another mother noted, “he had this episode where the asthma kind of manifested itself very silently...that scared me and was very frustrating.” Mothers also perceived the episodic nature of asthma based on seasons. One mother noted “...they can be fine from January through August and when August ends I know that it will come....” Another said “when it’s cold there is a little cry in the throat...when it’s hot I don’t really feel it.”

Asthma knowledge and information sources (Identity)

Many participants had little knowledge about asthma, knowledge was primarily derived from lay sources, and few knew anything about asthma prior to their child’s diagnosis. According to one mother, “to tell you the truth I didn’t know what asthma was, and in Mexico they don’t speak much about asthma.” Lay sources of asthma knowledge included: personal experience, relatives and friends, and the media. As one mother noted, “...other people who have children with asthma tell me, and sometimes I ask for information.” Some mothers learned about asthma from internet sources: “If I know a bit more it’s because I look it up in the internet or other resources, not because [doctors] have given me the information.” Lay knowledge also changed with caregiving over time. As one mother noted, “...knowledge about asthma changes as you live the experiences of asthma with your children.” Few mothers described asthma from a medical perspective as a chronic respiratory illness of the airways that can be controlled but not cured. Knowledge derived from HCPs about asthma was limited for many mothers. One mother stated, “before [daughter] developed asthma I wasn’t well informed about [it]...Now that I’ve been going to the clinic I still don’t know that much...” Another one described, “...I’ve also done some research, spoken to different doctors, nurses, providers...The frustrating part is that, depending on who you speak to you get a different answer. There’s no consensus ...[for] best treatments for asthma...” The reported lack of accurate, consistent information is reflected in the low ratings mothers reported for the quality of their relationship with the HCP. A few mothers did report receiving the information they needed, as evidenced by this mother:

I ask the doctor[s], ‘why does this happen?’...and they’ve informed me there are stages, and how it is, and her case, like how to calm her down...it helps, the information...it has been very important, he’s answered a lot of questions.

Beliefs about illness onset and knowledge of triggers (Causes)

When mothers were asked what they believed caused their child’s asthma, their responses reflected heritability, environmental exposures, or physical activity. Because the Spanish

term ‘cause’ can also mean ‘to provoke’, mothers also reported triggers of exacerbations as ‘causes’ of asthma. Thus, interviewers probed separately for beliefs about factors that led to illness development and factors that led to symptoms. Hereditary explanations provided justification for mothers who had relatives with asthma but puzzled others who did not. One mother expressed, “because my mom had it, and I do too, and now my kids, I think that it is a hereditary problem.” Another mother reported, “I don’t know if it is also genetic...because in my son’s case nobody in my family suffers from asthma...” One mother thought that one of her children had ‘infected’ a younger sibling with asthma, but the doctor told her that “... maybe it’s hereditary, but not contagious.” Some mothers believed that asthma can be caused by exposures during pregnancy. One mother felt that her child’s asthma was due to her use of antibiotics during pregnancy: “...when I was eight months pregnant I got a cough...[it] was getting more intense... The doctor said I was going to need an inhaler...it was provoking bronchitis...” Another mother blamed her exposure to chemicals: “...I was pregnant...died my hair a lot...the chemicals to dye hair have a very strong smell...[the chemicals] affected them because they have very low defenses, they are so little, what the mother breathes, smells, feels the baby feels.” Other mothers believed that environmental exposures caused their child’s asthma. One mother observed, “when we lived in apartments with carpet that would make him have more frequent attacks.... when we step on it the dust comes up and that causes my kids to generate more asthma.” Another mother reported:

City children get sick with asthma more even though country children are in closer contact with animals. They have stronger immune systems. However, in the city there is more pollution. The doctor said my child did not have a [strong] immune system. He needs to play with dirt. He got better [when] in contact with dirt.

Several examples of environmental exposures support the humoral balance theory of disease. One mother stated, “He gets asthma more when the weather gets cold. He does not get it when the weather is hot.” Another one reported, “...when it gets cold, in the winter well I have them covered up...I cover them because I don’t want them to get asthma.” Cold foods or liquids were also identified as asthma triggers: “When he constantly eats...ice cream or very cold drinks, sometimes that brings on the cough...and that starts triggering the asthma.” Physical activity was also cited as a cause/trigger. As one mother stated, “she gets home and at night is tired because she danced so much and starts panting, and I tell her you see?” Another mother recounted, “When he runs a lot he can’t breathe well and...feels pain in his chest and has to use his inhaler fast... It’s not constant, only when he runs.” Interestingly, notably absent from their narratives of causation was spiritual influences and life stressors (common cultural beliefs of illness among Latinos), cockroaches and dust mites. One mother nicely summed up the challenges they all face when trying to identify causes of their child’s asthma, “...there’s so many factors that we can’t agree on what triggers or what causes asthma, it varies from child to child.”

Perceptions of illness severity (Consequences)

Illness severity included impact on health and quality of life. Almost all mothers reported that asthma is a dangerous disease because the child could die if not treated quickly. One mother noted, “when you mention the word asthma people don’t think of it as a severe illness but it can turn into something fatal or pretty tragic if it’s not addressed quickly.”

Severity was also classified by the extent of their child's activity limitations. One mother explained, "...it's a horrible illness for them...to have all of these things prohibited so it doesn't cause them asthma..." Mothers also perceived illness severity by their child's symptoms, frequency and duration of symptoms, type of treatment required, and type of health care they seek during an exacerbation. Choking, chest tightness, and wheezing were associated with more severe asthma. As one mother said, "if after the third time he's getting worse...meaning the shortness of breath or wheezing gets worse, that's when I'm supposed to take him to the hospital immediately." A second mother stated "That [whistle] indicates that it is a crisis, and that I should be alarmed and not waste time...because he could lose his life..." How well the child's asthma is controlled also influenced their perception of severity. One mother stated "...there are times that at the first dose the whistling goes away, but there are times I have to use 2-3 doses a day so the whistling would go away...there's very aggressive [asthma]." Use of the 'spray' (Albuterol) was viewed as routine, while having to use the 'machine' (nebulizer) was indicative of more severe illness. One mother described, "...the doctor decided to not give it to her in the machine...she had a strong reaction...and with the inhaler she had no reaction...it's asthma but not a strong asthma." Severity was also determined by whether they could adequately treat their child at home or if they needed to go to the doctor or emergency room. One mother stated "[my child] doesn't have advanced asthma and is not bad because I've only taken her to the hospital 3-4 times in four years."

Beliefs about medication use (Controllability)

Mothers did not feel their children were prescribed the wrong medicine but did express concerns about their child taking too much medication, side effects and long-term effects of the medications, medication addiction, or that loss of efficacy would occur if used too often. Some mothers were apprehensive about the number of their child's medications:

If he's going to use 'Singulair' then why give him 'Zyrtec' at the same time? And why use 'Albuterol' and then 'Advair' too and the shots for the allergies, for a kid that's 10 years old? I understand it's for his health but it's a lot for a 10 year old child...like an old man, he takes three types of inhalers, three types of pills, and shots for his allergies...

Another mother decried, "the more frustrating part is...not wanting to always medicate the child, [but] you're very limited...because that's usually the only option, more medication, stronger medication..." Those who did not give their child controller medications as prescribed explained they only used it when the child had symptoms as demonstrated by this mother:

He uses the spray medication only when he gets asthma, not if he doesn't have it... if he uses it daily it will not work when his asthma is very bad...[doctor] recommends using it daily even if he has no symptoms because later he could get worse...

Several mothers worried about their child becoming addicted. One mother stated, "...sometimes they become addicted [to medication] and they have to give them stronger medication...I'm afraid to give them medication because later on they would have no effect because they become addicted." Concerns about side effects were also discussed. One

mother stated, “I was happier with the treatment he had in Mexico... called Ketotifeno, I trusted it more, it didn’t agitate [him]. Now that I give him Albuterol he says that his heart jumps a lot.” Long-term effects of asthma medication use were also a concern, as evidenced by one mother, “...secondary effects...you don’t know what’s going to happen...giving them too much medication...it might give her cancer...or stomach ulcers...” Only three mothers reported using the controller medications daily as prescribed by their HCP. One of them reported, “Until now he hasn’t had an attack...because I give him the medication that the doctor recommended daily...I give it to him daily and I don’t skip a day.”

Hope for the passing of illness or a cure (Controllability)

Most mothers believed there is no cure for asthma. “It’s an illness that doesn’t go away completely...it gets better but never goes away. You have to learn to live with it,” described one mother. “Asthma isn’t something you can fix. There is no medication that the doctor can give to cure it,” noted one mother. Some mothers believed their child could eventually outgrow their asthma. One mother said, “[the doctor] told us that when he turned seven years old it could go away...that if by [then] it didn’t go away he would have it for the rest of his life...” Still, another mother believed her son’s asthma will abate when “...his immune system can take it...until he’s strong enough to get rid of it...I don’t see this as a chronic illness anymore.” Mothers who spoke of a cure referred to natural remedies that are commonly used in Mexico. One mother observed, “...the star flower is good...he said you can be cured of asthma forever...” Another mother stated, “...in Mexico... the asthmatic person there gets cured with remedies. My mom said when my daughter was sick that many people that have asthma get cured with Chihuahua dogs.” A few others who expressed hope for a cure also referred to spiritual intervention as reported by this mother: “I tell him that God will cure him...we need to ask God to take care of you and to cure you, and he does it, I teach him to pray.”

Caregiver and family worries and concerns (Consequences)

Another important theme that emerged for caregivers and family members was the fear, worry, and even desperation they experienced in caring for a child with asthma. Several of these concerns overlapped with other themes presented above, particularly around medication use and unpredictability of asthma symptoms. Because of its unpredictability, most mothers reported the need of always having the ‘spray’ (Albuterol) or ‘machine’ (nebulizer) close by in case of an attack and shared a major concern of not being present or having the medication close by when an attack occurs. One mother stated fearfully, “...that he will get an asthma attack when I’m not around to help him, because many of his teachers don’t believe him when he tells them he’s sick.” Another mother remarked, “It worries me that someday I’m not there...when he has a sleep-over at a friend’s house...he gets an asthma attack...and the family doesn’t know what to do in that moment.”

Mothers and family members were also very worried that their child could die from an asthma attack, as this mother reported: “My child’s having a severe episode and...it’s severe enough where I’m racing against time to get him to the hospital...that would be any parent’s severe fear...where it’s kind of a life-death situation...” Another mother stated, “The girls get scared because they feel that he would suffocate.” Some mothers also expressed feelings

of desperation or hopelessness as described by one mother: “Desperate...I felt impotent of not knowing what to do, to not know how to control it...I wanted for her to not feel anything and...to be well.” Another mother relayed this about her husband: “He feels desperate that he can’t do anything for him... he only sees him like that and he cries and cries.”

Limitations on the child’s activities and family lifestyle were frequently reported as a major concern, particularly if the illness interfered with ordinary child activities. According to one mother, “It is hard to take because there are things he cannot do...there are a lot of things we cannot do with him, he cannot go to some places...because he could get asthma there.”

Also, other relatives of the child, including father, siblings and extended family, shared many of these worries. One mother reported not telling her daughter or her siblings about the daughter’s asthma diagnosis because she did not want to worry them. As she noted, “I don’t know if it’s bad that I haven’t told her what she has exactly, since she hasn’t had it that strong I try to not worry her.” Siblings, in particular, felt scared about the child’s asthma attacks. In one case, a mother described, “He got very sick on three occasions and was in such terrible condition... my girl was small and would scream...’mami, I don’t want anything to happen to [him]’. ‘No, no it won’t happen.’ We were traumatized...”

Several families have adapted to caring for and living with a child with asthma and shared few concerns. This experience is nicely illustrated by one mother: “...at first I was worried, then while time went by we’ve learned how to control it so that it’s normal...we’re making it part of our lives so it’s not traumatic and we have options...”

Discussion

The five attributes of IRs addressed by the Common Sense Model of Self-Regulation – identity, timeline, cause, consequences, and controllability – were all reflected inductively in the findings and parallel findings by Pachter et al.(11). In terms of ‘identity’, mothers labeled and understood asthma mostly based on a phenomenological symptomatology, given its contextual manifestation and their personal experience and limited biomedical knowledge. A study of lay definitions of asthma in a Puerto Rican community supports this IR, particularly among the uneducated poor(28). In terms of ‘timeline’, most mothers viewed asthma as an acute and episodic illness and believed it present only when their child is symptomatic. This notion of ‘no symptoms, no asthma’ is consistent with lay models of asthma and has been frequently reported in other studies.(1, 2, 28-31) Regarding ‘causes’ and ‘consequences’, whereas heredity made sense to mothers who had relatives with asthma, it was puzzling to those who did not and thus, other cultural and popular justifications were contemplated, particularly involving specific environmental exposures. Mothers reported that they are caught by surprise by their child’s asthma attacks, which are sometimes ‘silent’ and the inconsistency of triggers leads to frustration and worry – all of which could be indicators of poor control. This may be a direct reflection regarding ‘controllability’ where most mothers expressed concern about daily use of controller medications validating the notion of ‘intelligent non-compliance’ or ‘intentional non-adherence’(3, 18, 19). The influence of other factors, such as caregivers’ concerns about over-medicating their child and potential side effects or long-term consequences of asthma treatment and beliefs about nurturing the child’s own immune system defenses should not be discounted. Mothers

perceived illness severity (consequence) by the types of symptoms the child is exhibiting, frequency and duration of symptoms, type of treatment their child is on, and type of health care they seek during an exacerbation.

The mothers in our study reported that fathers, siblings, and extended family members experienced feelings of fear, worry and helplessness in living with a child with asthma. These emotional responses are rarely discussed in clinical encounters with families but are important to consider because they could interfere with proper illness management. It is important to consider how other family members offer support or increase burdens in caring for a child with asthma. In the Mexican culture “familismo” (high importance placed on the immediate and extended family members in decision-making and as support in dealing with life’s challenges), plays a large role in caregiving(32). We found that extended family members, particularly the grandparents, provided a great deal of advice on alternative treatments based on their heritage. Mothers described ethnomedical treatments to manage and even cure asthma, as reported in other asthma studies with Latinos(11, 12), that extended family members had recommended.

Knowledge derived from HCPs about asthma was limited for many mothers. Overwhelmingly, these mothers felt the asthma information they received was not comprehensive enough or tailored for their child and inconsistent from provider to provider. Our survey findings indicating low ratings of quality of the mother-HCP relationship support these qualitative findings. Previous research has demonstrated that a poor relationship with the HCP is associated with poor asthma control(1, 2), thus increased efforts to provide comprehensive, culturally-relevant, tailored asthma information are warranted.

There were several limitations to our study. Only 50% of the mothers were high school graduates and 25% reported depressive symptoms in the clinical range. As stated above, lower education and higher depressive symptomatology have been shown to be related to caregivers’ IRs aligned with the lay model, poor asthma control, and increased healthcare utilization. The results of this study may not be reflective of mothers with fewer depressive symptoms or higher educational attainment. The sample was recruited from two school-based health care centers located in the Southwest. The experiences reported by these mothers may differ from those who seek care at primary care or pediatric asthma clinics. Objective measures of children’s asthma health outcomes were not collected and thus, not considered in relation to the mother’s IRs. Lastly, we did not capture the HCPs’ experiences with this sample.

Conclusions

Different cultures have health belief systems describing causes of illness, symptoms, illness treatment or curability, and consequences of treatment. Understanding these systems is essential in development of treatment plans that patients can accept and adhere to. Asthma IRs and ethnocultural practices are frequently overlooked during the healthcare visit, yet are critical in optimizing shared decision-making for the child’s asthma management. Asthma action plans that do not consider and integrate the caregiver’s asthma IRs are more likely not to be followed as recommended(33) and our study provided evidence supporting this. HCPs

need to reconsider the content of their clinical encounters with children with asthma and their caregivers in order to understand the context of the families' lives and the cultural lens through which they view their child's asthma. If HCPs engage families in these discussions, they can address beliefs and practices that may be incongruent with the medical model for asthma management in a respectful, culturally-appropriate manner. HCPs who are familiar with and sensitive to IRs and care needs of diverse groups can play a decisive role in improving health outcomes of patients with asthma by heightened awareness of and respect for cultural differences among the children and families they interact with.

References

1. Yoos HL, Kitzman H, Henderson C, McMullen A, Sidora-Arcoleo K, Halterman JS, et al. The impact of the parental illness representation on disease management in childhood asthma. *Nursing Research*. 2007; 56(3):167–74. [PubMed: 17495572]
2. Sidora-Arcoleo K, Feldman J, Serebrisky D, Spray A. A multi-factorial model for examining racial and ethnic disparities in acute asthma visits by children. *Annals of Behavioral Medicine*. 2012; 43(1)
3. Callery P, Milnes L, Verduyn C, Couriel J. Qualitative study of young people's and parents' beliefs about childhood asthma. *British Journal of General Practice*. 2003; 53:185–90. [PubMed: 14694693]
4. Horne, R. Representations of medications and treatment: Advances in theory and measurement. In: Petrie, KJ.; Weinman, JA., editors. *Perceptions of health and illness*. Harwood Academic Publishers; Netherlands: 1997. p. 155–88.
5. Yoos HL, Kitzman H, McMullen A. Barriers to anti-inflammatory medication use in childhood asthma. *Ambul Pediatr*. Jul-Aug;2003 3(4):181–90. [PubMed: 12882595]
6. Sidora-Arcoleo K, Feldman J, Serebrisky D, Spray A. Validation of the asthma illness representation scale (AIRS©). *Journal of Asthma*. 2010; 47:33–40. [PubMed: 20100018]
7. U.S. Department of Health & Human Services: National Asthma Education Program. Expert panel 3 report: Guidelines for the diagnosis and management of asthma. U.S. Department of Health & Human Services; Bethesda, MD: 2007.
8. Brown ES, Gan V, Jeffress J, Mullen-Gingrich K, Khan DA, Wood BL, Miller BD, Gruchalla R, Rush AJ. Psychiatric symptomatology and disorders in caregivers of children with asthma. *Pediatrics*. 2006; 118(6):1715–20.
9. Bartlett SJ, Kolodner K, Butz AM, Eggleston P, Malveaux FJ, Rand CS. Maternal depressive symptoms and emergency department use among inner-city children with asthma. *Archives of Pediatrics and Adolescent Medicine*. 2001; 155:347–53. [PubMed: 11231800]
10. Weil CM, Wade SL, Bauman LJ, Lynn H, Mitchell H, Lavigne J. The relationship between psychosocial factors and asthma morbidity in inner-city children with asthma. *Pediatrics*. 1999; 104(6):1274–80. [PubMed: 10585977]
11. Pachter LM, Weller SC, Baer RD, de Alba Garcia JE, Trotter RT 2nd, Glazer M, et al. Variation in asthma beliefs and practices among mainland puerto ricans, mexican-americans, mexicans, and guatemalans. *J Asthma*. Apr; 2002 39(2):119–34. [PubMed: 11995676]
12. Zayas LE, Wisniewski AM, Cadzow RB, Tumiel-Berhalter LM. Knowledge and use of ethnomedical treatments for asthma among puerto ricans in an urban community. *Annals of Family Medicine*. 2011; 9(1):50–6. [PubMed: 21242561]
13. Sidora-Arcoleo K, Yoos HL, McMullen A, Kitzman H. Complementary and alternative medicine use in children with asthma: Prevalence and sociodemographic profile of users. *Journal of Asthma*. 2007; 44:169–75. [PubMed: 17454333]
14. Sidora-Arcoleo K, Yoos HL, Kitzman H, McMullen A, Anson E. Parental nondisclosure of complementary and alternative medicine and over-the-counter medication use in Children's asthma management. *J Pediatric Healthcare [childhood asthma, nondisclosure,]*. 2008; 22(4):222, 223–229.

15. Yoos HL, Kitzman H, McMullen A, Sidora-Arcoleo K, Anson E. The language of breathlessness: Do families and health care providers speak the same language when describing asthma symptoms? *J Pediatr Health Care*. Jul-Aug;2005 19(4):197–205. [PubMed: 16010258]
16. Orrell-Valente J, Jarlsberg LG, Rait MA, Thyne SM, Rubash T, Cabana MD. Parents' specific concerns about daily asthma medications for children. *J Asthma*. Jun; 2007 44(5):385–90. [PubMed: 17613635]
17. Chan PW, DeBruyne JA. Parental concern towards the use of inhaled therapy in children with chronic asthma. *Pediatr Int*. Oct; 2000 42(5):547–51. [PubMed: 11059547]
18. Weintraub M. Compliance in the elderly. *Clin Geriatr Med*. May; 1990 6(2):445–52. [PubMed: 2331663]
19. Horne R. Compliance, adherence, and concordance: Implications for asthma treatment. *Chest*. Jul 01; 2006 130(1 suppl):65S, 65S–72S, 72S. [PubMed: 16840369]
20. Cameron, LD.; Leventhal, H., editors. *The self-regulation of health and illness behavior*. Taylor & Francis; London, UK: 2003.
21. Leventhal, H.; Benyamini, Y.; Brownlee, S.; Diefenbach, M.; Leventhal, EA.; Patrick-Miller, L., et al. Illness representations: Theoretical foundations. In: Petrie, KJ.; Weinman, JA., editors. *Perceptions of health and illness*. Harwood Academic Publishers; Netherlands: 1997. p. 19-45.
22. Diefenbach M, Leventhal H. The common-sense model of illness representations: Theoretical and practical considerations. *Journal of Social Distress and the Homeless*. 1996; 5(1):11–38.
23. Leventhal H, Leventhal EA, Contrada RJ. Self-regulation, health, and behavior: A perceptual-cognitive approach. *Psychology and Health*. 1998; 13:717–33.
24. Leventhal, H.; Diefenbach, MA. The active side of illness cognition. In: Skelton, JA.; Croyle, RT., editors. *Mental representation in health and illness*. Springer Verlag; New York: 1991. p. 247-72.
25. Padgett, DK. *Qualitative methods in social work research*. Sage Publications; Thousand Oaks, CA: 2008.
26. Radloff LS. The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*. 1977; 1:385–401.
27. Sidora-Arcoleo KJ, Feldman J, Serebrisky D, Spray A. Validation of the asthma illness representation scale-spanish (AIRS-S©). *Journal of Asthma*. 2010; 47(4):417–21. [PubMed: 20528596]
28. Zayas LE, Jaen CR, Kane MP. Exploring lay definitions of asthma and interpersonal barriers to care in a predominantly puerto rican inner-city community. *Journal of Asthma [asthma, barriers, Puerto Rican]*. 1999; 36:527, 528–537.
29. Halm EA, Mora P, Leventhal H. No symptoms, no asthma: The acute episodic disease belief is associated with poor self-management among inner-city adults with persistent asthma. *Chest*. Mar; 2006 129(3):573–80. [PubMed: 16537854]
30. Ponienman D, Wisnivesky JP, Leventhal H, Musumeci-Szabo TJ, Halm EA. Impact of positive and negative beliefs about inhaled corticosteroids on adherence in inner-city asthmatic patients. *Ann Allergy Asthma Immunol*. Jul; 2009 103(1):38–42. [PubMed: 19663125]
31. Tumiel-Berhalter L, Zayas LE. Lay experiences and concerns with asthma in an urban hispanic community. *J Natl Med Assoc*. Jun; 2006 98(6):875–80. [PubMed: 16775908]
32. Smith-Morris C, Morales-Campos D, Alvarez EAC, Turner M. An anthropology of familismo: On narratives and description of Mexican/Immigrants. *Hispanic Journal of Behavioral Sciences*. Sep 20.2012
33. Ring N, Jepson R, Hoskins G, Wilson C, Pinnock H, Sheikh A, et al. Understanding what helps or hinders asthma action plan use: A systematic review and synthesis of the qualitative literature. *Patient Education and Counseling*. 2011; 85(2):e131–43. [PubMed: 21396793]

1. What do you think asthma is?
2. What do you think causes asthma?
3. How do you think your Mexican beliefs and values influence the way you view your child's asthma?
4. How has your knowledge of asthma changed over the years (or since you moved to the U.S.)?
 - a. What made you change?
5. What worries you most about your child having asthma?
6. How do you treat your child's asthma?
 - a. How does the medication work?
 - b. How often does your child use his/her medications?
 - c. How do you know when your child needs his/her medications?
 - d. What worries, if any, do you have about your child's asthma medications?
7. Are there any other things you do to treat your child's asthma?
8. How do you think your Mexican beliefs and values influence the way you treat your child's asthma?
9. How has your treatment of your child's asthma changed over the years (or since you moved to the U.S.)?
 - a. What made you change?
10. How do you think your child feels about having asthma?
11. What is it like for your family to have a child with asthma?
12. What kind of help or support, if any, do you or your child get from family, friends or other people you know in taking care of his/her asthma?
13. What things do relatives or friends do (or don't do) that make it difficult for you or your child to take care of his/her asthma?
14. What resources are in your community that have helped or could help you take care of your child's asthma?

What else have we not discussed that would be important to know?

Figure 1.
Interview Guide by Question

Table 1

Sample Characteristics ($N=20$)

Variable	N (%)
Marital Status	
Married	12 (60)
Single but have a partner	4 (20)
Divorced	3 (15)
Separated	1 (5)
Standard of living	
Living comfortably	1 (5)
Living reasonably comfortably	8 (40)
Just getting along	8 (40)
Nearly poor	2 (10)
Poor	1 (5)
Child's asthma is under good control	
Agree	11 (55)
Unsure	7 (35)
Disagree	1 (5)
Depressed (CESD>16)	5 (25)
	Mean (<i>SD</i>); Range
Mother's age (years)	36.5 (4.7); 29-50
Child's age (years)	10.3 (3.2); 6-17
Years of education completed – mother	11.7 (3.6); 6-20
Quality of parent-healthcare provider relationship	2.7 (0.4); 1.9-3.5
Maternal depression	9.8 (7.4); 0-24

Table 2

Summary of themes by illness representation (IR) construct with illustrative codes.

#	Thematic Finding	IR Construct
1.	Symptomatic representations of illness (e.g., shortness of breath, tight chest, weakness, choking)	Identity
2.	Unpredictable and episodic nature of asthma (e.g., sudden, silent onset of symptoms, nighttime onset of symptoms, inconsistency of symptoms)	Timeline
3.	Asthma knowledge and information sources (e.g., problems with the bronchial tubes, chronic illness, doctors, others with asthma)	Identity
4.	Beliefs about illness onset and knowledge of triggers (e.g., heritability, environmental exposures, physical activity)	Causes
5.	Perceptions of illness severity (e.g., use of “spray” vs. nebulizer, risk of death)	Consequences
6.	Beliefs about medication use (e.g., only use when there are symptoms, need to have the “spray” nearby, using it every day make lead to it not working when needed)	Controllability
7.	Hope for the passing of illness or a cure (e.g., there is no cure, can possibly outgrow, cured with Chihuahua dogs)	Controllability
8.	Caregiver and family worries and concerns (e.g., child might die, not being present when child has an attack, siblings get scared)	Consequences