Luchando por el Aire: The Burden of Asthma on Hispanics



Preface

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Asthma is a widespread and serious health threat – particularly for children - that requires regular and consistent health care to control. For some, this can be a daunting challenge. As a Pediatric Pulmonologist in Newark, NJ, I have often worked with Latino families who may face limitations such as language barriers and difficult socioeconomic conditions. Some families may use the emergency room as the primary way of treating their child's asthma, and therefore have inconsistent health care providers. We have found that many of these families lack the knowledge necessary to manage their children's asthma conditions and some are using ineffective folk remedies to treat symptoms and/or are using prescribed asthma medications incorrectly.

Asthma affects people of all ages, races, genders, and socioeconomic status. However, it occurs at disproportionately higher rates among some ethnic and racial populations. African-Americans have some of the highest rates of illness when compared to Caucasians and Hispanics as a whole. However, when you take a closer look within the Latino population, Puerto Ricans have higher rates of disease than any other group. Despite progress in asthma treatment and management, there are still many additional opportunities to collaborate and to reduce the burden of asthma among some of our most vulnerable populations.

The American Lung Association has selected to highlight the burden of asthma on Hispanics, the fastest growing population in the country. This is a population with great diversity and a complex array of social and economic stresses, making it a challenging population in which to work. Clinicians, researchers, community based organizations, advocates, the business community and all levels of government need to collaborate to address the needs of this growing community, particularly as it relates to chronic illnesses, like asthma.

We can all take a part in reducing the burden of asthma on Hispanics. Join the American Lung Association in our fight to eliminate lung health disparities and save lives.

The numbers say a lot in this report, but asthma affects individual people and their friends and families:

Dina's Story

Dina was diagnosed with asthma two years ago. She has many family members that also have asthma, including an aunt who died from the disease.

Originally from Guatemala, she has been living in the U.S. since 1991. She has healthcare coverage through a state-sponsored health plan that serves low-income Los Angeles County residents. She goes to the clinic regularly, but often gets sick between visits.

Despite the number of medications she takes, her asthma has prevented her from living her life as she once did. Her asthma is poorly controlled and she suffers from the disease on a daily basis. She struggles with depression, but is grateful for her family and community support system.

Lydia's Story

Lydia was born in the United States and speaks fluent English. Asthma has always played a role in her life. She has been an asthma patient since birth and her husband and two of her children also have asthma.

Lydia does not have health insurance, but her children do. The family owns their own home, and they have been able to make changes to remove asthma triggers.

Lydia's daughter Stephanie was 15 when she died from an asthma attack while at school. Lydia fell into a state of depression that increased the severity of her own asthma. Now five years after the accident, she hopes to inspire others to realize the seriousness and importance of managing this chronic condition.

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Introduction

Asthma is a serious chronic lung disease that, when not well controlled, can rob people of health, quality of life, and the security of knowing they will be able to easily draw their next breath. Nearly 25 million people in the U.S. have asthma, including 3 million Hispanics. For reasons that are not clear, the proportion of people who get asthma varies widely among Hispanics based on their country of origin. Puerto Ricans are especially hard hit by the disease, being more likely to have a diagnosis of asthma than any other population group. Mexican-Americans, by contrast, have some of the lowest rates of asthma, although there is evidence to suggest that they are significantly under-diagnosed.

If little is understood about who gets asthma and why, a great deal is known about how to keep people with asthma healthy and prevent asthma attacks, lost productivity, hospitalization and even death. Unfortunately, the social and economic disadvantages that Hispanics in the U.S. face every day leave them less able than other groups to manage the disease. Low levels of education and English-language proficiency, especially among recent immigrants, limit employment opportunities. Low-paying jobs in agriculture, construction and service provide no health benefits, while at the same time often exposing workers to serious respiratory hazards. The housing available to low-

income families is often sub-standard, and located near roadways and other sources of pollution that can worsen asthma.

Many Hispanics, especially recent immigrants, have limited access to and knowledge of the nation's complex and intimidating health care system. Hispanics with asthma are less likely than non-Hispanic whites to be in the care of a regular doctor or clinic and to get preventive care. They are also less likely to be prescribed appropriate medicines to prevent asthma symptoms and to have access to asthma specialists when needed. As a result, when they get sick they are much more likely to end up being treated in the emergency department or hospitalized. This causes expense and trauma for families and is a significant, costly burden on the health care system that could be largely prevented by addressing some key inequities.

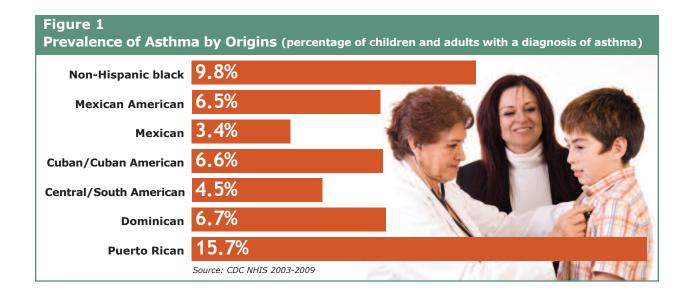
As the Hispanic population continues to grow and disperse throughout the country, the urgency of addressing their burden of asthma grows with it. The American Lung Association calls on government agencies, the health care system, businesses, patient advocates, community leaders and families to take steps to eliminate these disparities so that all Americans can breathe easier.



The Burden Of Asthma

Asthma is a serious chronic lung disease that affects almost 25 million people in the United States, including over 7 million children. For reasons that are not fully understood, that number has been rising steadily for the last 30 years. In 1980, only 3.5 percent of the population had a diagnosis of asthma, but by 2009 that percentage had more than doubled to over eight percent.1 Asthma affects people of all ages, races, genders and segments of society. But the burden is not equally shared across racial and ethnic groups. It is most often a disease of the young and of the poor. Children and people living below the poverty level are among the groups most likely to have asthma and most likely to suffer from severe asthma attacks, hospitalization and even death.2

Hispanics, as one of the nation's youngest and poorest populations, are impacted by asthma in complex ways. Taken as a whole, they are less likely to be diagnosed with asthma than other racial and ethnic groups. But there is much variation among Hispanic subgroups, depending on where they originate from. Puerto Ricans are hit especially hard by asthma, being more then twice as likely as non-Hispanic whites to be diagnosed with the disease (15.7 vs. 7.5 percent). Recent Mexican immigrants, by contrast, have some of the lowest rates of diagnosed asthma.3 The reasons for this variation are unclear, and some of the possible contributing factors are discussed in this report. But regardless of their origins, far too many of the nearly 3 million Hispanics in the U.S. with asthma live every day with significant disadvantages that impact their health and well-being. Compared to non-Hispanic whites, they are more likely to live and work in environments that may make them sick and are less likely to have access to appropriate health care.



ABOUT ASTHMA

Asthma is a chronic lung disease that makes breathing difficult for millions of Americans, both young and old. The airways in people with asthma are always slightly inflamed, and abnormally sensitive to irritation. Contact with a trigger, such as cigarette smoke, air pollution or animal dander, can cause an asthma episode or attack. The muscles around the airways tighten, narrowing the breathing tubes. At the same time, the cells that line the insides of the airways swell and produce excess mucus, further limiting air flow. Symptoms of an asthma episode include coughing, wheezing and shortness of breath. Without proper treatment, asthma can become life threatening.

Causes and Triggers

What causes asthma to develop in an individual is not yet fully understood, but it appears to be a combination of genetics and environment. Asthma tends to run in families and susceptibility to the disease may be inherited. People with a genetic tendency for allergies are at higher risk for asthma. Premature birth, early childhood viral

infections, *in utero* exposure to maternal smoking and certain indoor and outdoor air pollutants have all been linked to the development of asthma, and researchers continue to discover new connections.⁴

For people who have asthma, the triggers that cause asthma symptoms vary depending upon the sensitivities of the individual.
Respiratory infections, allergens, chemicals, odors, physical activity, emotions, seasonal changes and smoking can all irritate the airways, causing asthma symptoms.

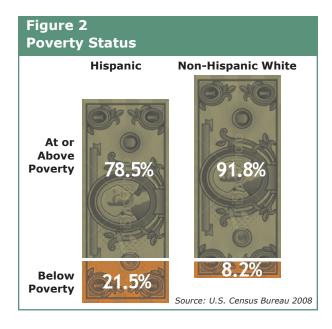
Treatment and Control

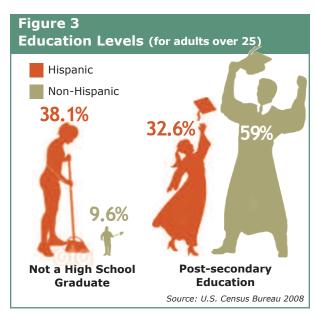
There is no cure for asthma, but it can be managed and treated so that people with asthma can live a normal, healthy life. As with other chronic illnesses like heart disease and diabetes, optimal management of asthma requires good medical care, patient involvement in decision-making and community support for a healthy environment.

For people with persistent asthma, the medical management of the dis-

ease includes scheduled visits with a usual health-care provider; "control" medicine, usually inhaled corticosteroids, that reduces the chronic inflammation of the airways; and quick-relief medicine that relaxes the constriction of the airway muscles at the onset of a flare-up of asthma symptoms. Clinicians should also provide their patients with education and an asthma action plan, a written, individualized worksheet that shows the steps to take to prevent asthma from getting worse.

People with asthma and their families assume responsibility for following their asthma action plans, taking medication as prescribed and minimizing their exposure to asthma triggers. Because asthma is a complex, costly and episodic disease, with symptoms that come and go, many people find it difficult to adhere to treatment over time. Community support, including school and employer-based asthma education and environmental control, helps reinforce asthma management, keeping people healthy and active.





Asthma costs the nation \$50 billion in direct health-care expenses and another \$6 billion in indirect costs, such as lost productivity, for a staggering total of \$56 billion every year.⁵ Some of this cost is for the normal, preventive management of the disease, such as regular doctor visits and prescription medicines. Much of the overall health and economic burden of asthma is borne by those whose asthma is not well managed, who stay home from work and school or are treated in emergency departments or hospitals for asthma emergencies. Urgent care accounts for one-third of the total costs associated with asthma.⁶ If this preventable burden is to be brought under control, it is imperative to understand and address the health and health care disparities experienced by Hispanics with asthma.

Hispanics in the U.S.

Hispanics are the fastest growing population in the country. In 2010, there were 50.5 million Hispanics in the U.S., up from 35.3 million in 2000. That represents a 43 percent growth rate, more than four times that of the total population.⁷ This growth occurred in every region in the country, with some of the fastest change in

the Southeast. The U.S. Census Bureau projects that by the year 2050, the Hispanic population will grow to 103 million people, accounting for 25 percent of U.S. residents. Because of high birth rates in Hispanic women and ongoing immigration by young adults, the Hispanic population is considerably younger than average. About 40 percent of the Hispanic population is under the age of 20, with an average age of 27 years, compared to the U.S. average of 36 years.⁸

Nearly two-thirds of Hispanics living in the U.S. are of Mexican heritage, a total of 31.7 million people. The next largest subgroup is Puerto Ricans at nine percent, which includes 4.4 million people on the mainland and another four million in Puerto Rico. People of Cuban, Salvadoran, and Dominican origin each represent around 3 percent of the overall Hispanic population, although their presence in concentrated communities can be much larger. The rest are from all over Central and South America.⁹

Hispanics share a common language, but are quite diverse in terms of genetic make-up, heritage and culture. Each Latin American region and country has a different legacy of settlement and mixing of indigenous, European and African ancestors. Puerto Ricans and Mexicans for exam-

ple have on average very different origins: Puerto Ricans have 66 percent European, 16 percent African and 18 percent Native American ancestry while Mexicans have 45 percent European, 3 percent African and 52 percent Native American ancestry. This variation appears to be significant when looking at the differences in people's genetic susceptibility to asthma and other chronic diseases. ¹⁰

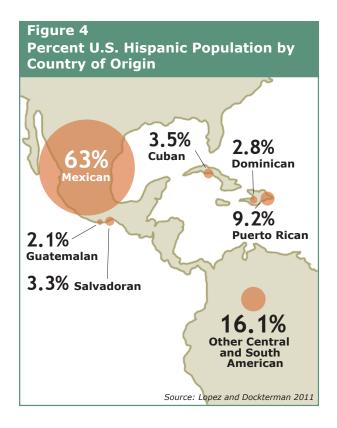
Like other populations of color and immigrant groups, Hispanics as a whole struggle economically. Although their rates of employment are comparable to other groups, Hispanics are more likely to work in low-wage jobs in service, manufacturing and construction and maintenance. Twenty-one percent of Hispanics live below the poverty level, compared to a U.S. population average of 12.5 percent. Nearly a quarter of Hispanics in the U.S. older than 25 have less than a ninth grade education, and only about 12 percent have completed a bachelor's degree or higher, compared to U.S. averages of fewer than 7 and more than 26 percent respectively.¹¹

Behind The Burden

To address the burden of asthma among Hispanics, it is important to understand the factors that may cause or worsen the disease and impact how well individuals and communities manage it. Among these factors are a number of key contributors to asthma disparities, including:

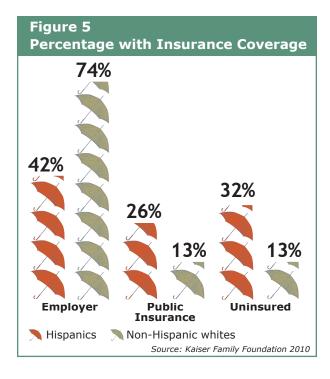
- Access to and quality of health care;
- Environmental exposures at home, work and in the community;
- Poverty and social stress; and
- Biological susceptibility.

Dina went to the emergency department 7 or 8 times for her asthma last year. "I know the ER is expensive, but I can't breathe and I don't know what to do."



Too Much of the Wrong Care

Getting appropriate, affordable care is critical to the treatment of asthma as a manageable disease rather than a crisis. Asthma treatment specialists and researchers have been working together for more than 20 years to develop and disseminate guidelines on what constitutes the best asthma care, and the advancement of knowledge and treatment options has dramatically improved asthma management for the majority of the population. Unfortunately, Hispanics with asthma face a number of barriers to getting the recommended level of preventive care and treatment. Compared to other groups, they are as a whole less likely to be insured, less able to navigate the complexities of the U.S. healthcare system, and less able to communicate with and understand their health-care provider. As a result, Hispanics with asthma have fewer regular preventive visits, delay seeking a doctor's care when they get sick and are more likely to end up being treated in the emergency department or hospitalized than non-Hispanic whites. 12,13,14



Dina was told by a patient advocate that she should see a specialist because her asthma is so poorly controlled. She said, "I had to fight with my doctor to give me a referral." She waited months for a referral, and now there is a hold up with her insurance.

No access, no prevention

Although Hispanics make up only about 16 percent of the U.S. population, they account for nearly one-third of those who are not protected by health insurance. Hispanics are less likely than non-Hispanic whites to receive health insurance as a benefit from an employer, which is the most common source of coverage for workingage adults and their children in the U.S. Many Hispanics work in low-wage jobs, or in labor and service occupations that do not provide health

insurance to their employees. Those who are eligible for Medicaid or other forms of public or private insurance have poor rates of enrollment, possibly because of language barriers, confusion about complex eligibility rules or fears related to legal status.¹⁶

The "safety net" of public health insurance programs, such as Medicaid and the Children's Health Insurance Program (CHIP), provides coverage for many low-income Hispanics. But states differ in their eligibility rules, and some of the states with the largest population of Hispanics, including Arizona, Florida and Texas, have some of the most restrictive provisions for coverage of immigrants. A number of states bar recent immigrants from receiving benefits in their first five years of residency, and almost all exclude undocumented immigrants. Lacking health insurance makes the costs of health-care services prohibitive and is the most important barrier to adequate preventive health care. 17,18

Having a usual source of care is another key to accessing coordinated, consistent health services. A usual source of care is a provider or health center that people can to go to when they are sick or need advice about their health. For people with asthma, having a regular health-care provider increases the likelihood that they will get preventive visits, appropriate medication, an asthma management plan and referral to specialists as needed. Unfortunately, more than a quarter of all Hispanics lack a usual source of care, including 49 percent of recent immigrants.¹⁹

Studies of Hispanic children with asthma have shown that they are less likely than non-Hispanic white children to have a usual source of care. Children from immigrant families and Spanish-speaking households have the lowest rates of usual source of care of any group. Some of the external factors that determine whether or not a family uses a regular source of care include the ability to afford co-pays, the proximity to providers and/or transportation, and the ability be seen without taking time off from work.

No diagnosis, no care

Evidence suggests that the low rates of asthma reported for some subgroups of Hispanics, particularly Mexican-Americans, may be due, at

THE "HEALTHY IMMIGRANT" EFFECT

Public health workers have long recognized that immigrants arrive in the U.S. with relatively low rates of chronic disease, but over the course of several generations they take on the same rate of disease as the rest of the nation.²² Hispanic immigrants tend to be healthier when they arrive than might be expected, considering their lower average socioeconomic status, but as a group their health deteriorates over time spent here.²³

This so-called *healthy immigrant* effect has been shown to occur with asthma. Mexican-Americans born in the United States are two to three times more likely to have asthma than Mexican-Americans born in Mexico.²⁴ Explanations for why Hispanics born in the U.S. have more asthma than the foreign-born have included the possibilities that only the healthiest people migrate, and that immigrants who get sick are more likely to return to their home country. Immigrants undoubtedly experience a lot of stress when leaving home and family and resettling in a new, not always welcoming, culture. And over time many immigrants adopt unhealthy behaviors that are more common in the U.S., and are linked to asthma, including increased smoking, less breastfeeding, higher rates of childhood inactivity and obesity, and more antibiotics use in early childhood.^{25,26}

least in part to under-diagnosis. One study among adolescents in North Carolina found that Mexican-Americans students were more likely than non-Hispanic whites to report having undiagnosed frequent wheezing. The undiagnosed wheezers in this study were much less likely to have received health-care services or medications than the children with similar symptoms who had an asthma diagnosis.²⁷ Another study of recent immigrants to Colorado found that fewer than half of the children in the study with active symptoms had been diagnosed with asthma.²⁸ In a large study of school children in Chicago, 12.0 percent of Hispanic children had received diagnoses of asthma, but another 12.7 percent were found to have asthma symptoms but no diagnoses.²⁹

There is no simple, surefire test for asthma.

Asthma diagnosis often depends on a patient's or parent's perception of symptoms, their trust in and access to the health-care system, and the clinician's beliefs and practices.³⁰ Physician assumptions can influence whether a person with breathing problems gets a diagnosis of asthma. Several studies have found that physicians are more likely to diagnose asthma in some racial and ethnic groups than in others, even when presented with the same symptoms.^{31, 32}

Education levels, cultural beliefs and experiences with asthma can also determine whether a patient or parent seeks out a diagnosis. This appears to be especially true for recent immigrants. When questioned about their children's health, Hispanic parents in one study used vague terms to describe breathing problems and expressed little recognition of the possibility of asthma as a treatable, chronic disease.³³ The word "wheeze" does not have a direct equivalent in Spanish, which can be a serious problem in bilingual communication about asthma symptoms.³⁴

Lydia's mother said that Lydia would turn purple and they would get so scared. She went to the family doctor. "He would treat my asthma like it was the common cold." At age 22, Lydia ended up in the emergency department because she could not breathe.

Poor quality, or poor communication?

When compared to non-Hispanic whites, Hispanics with asthma are less likely to be prescribed appropriate asthma medications and less likely to have access to asthma specialists. Those who have an asthma emergency that sends them to the emergency department or the hospital are less likely to receive follow-up care or an asthma action plan. 35,36,37,38 This is true

About the day that her daughter Stephanie died, Lydia said, "When she left for school she was fine. So you just don't know. I thought I was doing everything I could to control her asthma."

even among children in the Military Health System, which provides comprehensive health insurance to all its members, indicating these differences are not just a matter of access.³⁹

There is little evidence that clinicians actively discriminate or intentionally deprive patients of good care. When surveyed, however, some Hispanic patients say they believe they would be treated better if they were from a different background. This is especially true for those who prefer to use Spanish. 40 Communication and trust between patients and clinicians is a critical component of quality care. Asthma is a complicated disease that requires collaboration and engagement by both parties. Patients must feel comfortable discussing their concerns about med-

ications, environmental controls and possible workplace issues if they are to be successful in managing their illness.

Part of good patient-provider communication is the ability to empathize and work with the culture and beliefs of his or her patients. Cultural practices and family beliefs about health and health care can have a strong impact on the ability of the clinician to connect with the patient, as well as the willingness of the patient to cooperate with care management plans. Research has shown that patients who see clinicians who have received training in cultural competence have better results in managing their asthma.⁴¹

The other inescapable factor in communication between providers and Hispanic patients is the potential language barrier. According to the U.S. Census, half of Hispanics report speaking English less than "very well".⁴² Hispanics of all subgroups experienced less confusion and frustration, and better overall ratings of health-care quality, when a health-care provider is able to use the patient's preferred language.⁴³ When asked, most Hispanics express a preference to be treated by other Hispanics. Unfortunately, compared to the size of the Hispanic population, the number of Hispanic clinicians overall is very low. Only 6.3

CULTURAL CONSIDERATIONS FOR ASTHMA CARE

Among Hispanics, cultural practices naturally vary, depending on country of origin, level of acculturation, asthma knowledge and individual preference. There are, however, some widely shared values and beliefs that need to be taken into consideration when delivering culturally competent asthma care.

Personalismo

Translated as "formal friendliness," personalismo represents the expectation that the patient-provider relationship be warm and personal. Gestures such as shaking hands, in-

quiring about work and family, and minimizing physical distance during personal interactions increase patient satisfaction and improve adherence to treatment.⁴⁴

Familismo

A strong cultural loyalty to the extended family, *familismo*, impacts the way Hispanics make health decisions. Family obligations may take priority over individual needs, especially when resources are scarce. Patients may want to involve other family members in office visits and health-related problem solving.

Use of alternative therapies

According to a survey conducted in 2008, 87 percent of Hispanics believe that sick people should receive care only from medical professionals. But one in ten report that someone in their household gets care from a folk healer or uses some folk medicine. ⁴⁵ Clinicians are advised to learn about a patient's use of alternative therapies, and accommodate those that are safe into a patient's management plan. Harmful practices can be replaced with harmless ones that are consistent with the patient's beliefs. ⁴⁶



"My friend tells me I should move away from here... Maybe I should move, but where would I go?" Dina

percent of physicians, 8.8 percent of nurses and 10.8 percent of respiratory therapists identify themselves as Hispanic.⁴⁷ Using an interpreter has been shown to increase patient satisfaction but cannot replicate the quality of good interpersonal interaction between patient and provider.⁴⁸

Language proficiency doesn't just affect patient satisfaction, however. It also affects patients' health. In one study, Hispanics with limited English proficiency had significantly poorer asthma control than their English-speaking counterparts from all racial and ethnic groups, and they were more likely to have asthma episodes that required emergency care. When questioned about their beliefs about asthma, they were more likely to report concerns about potential side effects or the possibility of becoming addicted to the controller medication and less likely to understand the chronic, lifelong nature of the disease. Not surprisingly, this group reported having an overall poorer health-related quality of life.⁴⁹

No Room to Breathe

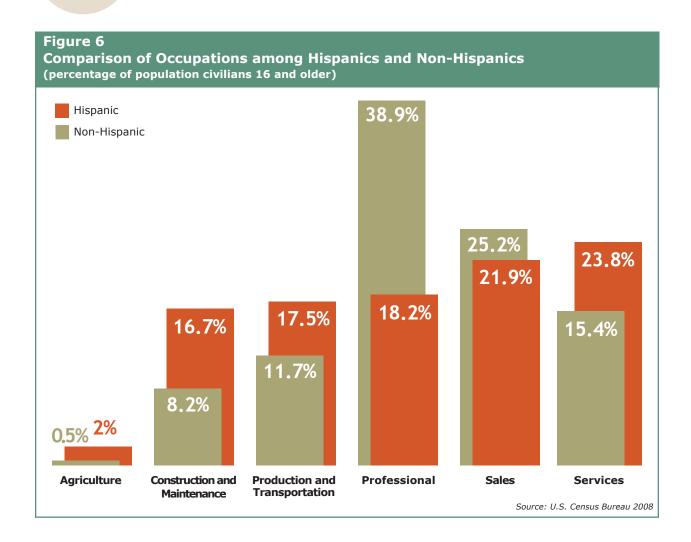
The relationship between health and place is undeniable. Disease is determined not just by who you are, but also where you are. Asthma is in part an environmental disease. Exposure to pollutants and other environmental conditions has in a few cases been shown to cause the onset of the disease and is clearly implicated in triggering asthma symptoms and illness. 50 Because Hispanics are more likely to live and work where pollution is higher, those who have asthma are at disproportionate risk of aggravating their disease.

Particulate matter and ozone are two widespread air pollutants that have been proven to worsen asthma and even cause premature death among those living with chronic disease. Because the Hispanic population is largely concentrated in the urban areas of the Southwest and the Northeast, 51 they are among the groups most heavily impacted by these air pollutants. Hispanics are 165 percent more likely to live in counties with unhealthy levels of particulate matter pollution, and 51 percent more likely to live in counties with unhealthy levels of ozone than are non-Hispanic whites. 52

Environmental conditions vary from neighborhood to neighborhood within a larger community, and Hispanics, like other primarily low income populations, tend to live in neighborhoods that have the highest proportion of local sources of air pollution, crowded conditions and deteriorated housing stock, all of which have an impact on asthma.53 Living in close proximity to heavy traffic has been linked to the onset of asthma in children, as well as increased symptoms and disease severity in children and adults.⁵⁴ One study of Hispanic children with asthma in Los Angeles County found that children living within two miles of a freeway were twice as likely to have uncontrolled asthma than children living farther away.55 Poor housing quality has been linked to a variety of poor health outcomes, including asthma attacks and hospitalization. 56,57 School children in New York City living in public housing have higher rates of asthma than children living in all types of private housing. The higher frequency of water leaks, rats, cockroaches and secondhand smoke in those public housing units have all been found to affect the children's asthma.58

Personal tobacco use and exposure to secondhand smoke are all associated with asthma at every stage of life. The extent to which Hispanics with asthma are at risk from tobacco use and secondhand smoke varies by country of origin. Smoking rates tend to be lower among Hispanics overall, at 14.5 percent compared to non-Hispanic whites at 22.2 percent. Hispanic men smoke much more than women, except in Puerto Ricans and Cubans, where the difference between genders is not as large.⁵⁹ Puerto Ricans and Cubans of both genders are more likely to be heavy smokers than Mexican-Americans.⁶⁰ Maternal smoking during pregnancy has been linked to the development of asthma in children. Hispanics as a whole are less likely to smoke during pregnancy than other groups, but over nine percent of Puerto Ricans reported smoking while pregnant compared to less

Lydia owns her own home and has worked hard, with help from an asthma educator, to reduce the asthma triggers inside.



Dina used to clean houses, but can no longer work because the chemicals bother her too much. She has developed sensitivity to all kinds of environmental exposures. "I always have a little wheeze in my chest."

than two percent of Mexican-Americans.⁶¹ Hispanics are also less protected from secondhand smoke in the workplace than any group except for American Indian/Alaska Natives. They report that only 69.1 percent of their workplaces are smokefree, compared to the 76.3 percent reported by non-Hispanic whites.⁶²

Hispanics, especially the foreign-born who have the lowest levels of education and English proficiency, are more likely to work in dirty, dangerous jobs than any other large population group. Almost 70 percent of Mexican-born workers labor in the lowest paid jobs in the U.S.⁶³ Many of these occupations are associated with higher risks for asthma or asthma triggers, including agriculture, food services, cleaning and maintenance, construction, food production, and transportation and material movement.^{64,65,66}

Agriculture in particular exposes workers to a complex mixture of asthma triggers, including organic and mineral dust, animals and plants, toxic gases, mold and diesel exhaust. One study that looked at the health of elderly Hispanics in west Texas found that those who had worked on farms were most likely to have asthma, followed by those who reported service-related occupations.⁶⁷ Children on farms are also at increased risk from asthma, either because they are doing work themselves or because contaminants are brought into the home by their parents.^{68,69}

Poverty and Social Stress

Asthma is a disease that in effect discriminates against the poor. It is unclear, however, whether poverty itself actually causes elevated rates of illness or is more of a surrogate for other problems experienced by low-income people, like exposure to environmental pollutants and inadequate health care. Researchers have differed in their opinions over time, but at least one major review concluded that poverty itself is probably not the primary driver of asthma disparities. It does not, for example, explain the differences among Hispanic subgroups, since Puerto Ricans and Dominicans, who have higher rates of asthma, experience similar economic conditions as Mexican-Americans, who have lower rates of asthma.70

However, there is emerging evidence that social stress creates a lasting biological response in the body that is damaging to health. When subjected to adverse social conditions over a long period of time, a person's biological emergencyresponse mechanisms get overloaded and eventually stay "on" all the time. The result causes wear and tear on all body systems, which has been linked to the development of a number of chronic diseases. 71,72 In patients with asthma, exposure to long-term or extreme stress, including living in poverty, changes the cellular activity that regulates the body's immune response. The result is increased inflammation and airway obstruction.⁷³ Children from lower socioeconomic backgrounds have shown greater expression of the genes regulating inflammation and more asthma symptoms, compared to children from more privileged backgrounds. According to one researcher, the larger social environment literally "gets under the skin" and results in physical changes at the molecular and cellular level.74

THE ONGOING ASTHMA CRISIS AMONG PUERTO RICANS

Duerto Ricans, both in Puerto Rico and in the continental U.S., have higher rates of asthma than any other population group. Puerto Rican children with asthma have more frequent asthma episodes, more missed school days and greater functional impairment than African American, white or other Hispanic children.75 Island Puerto Ricans are especially frequent users of emergency health care, with very high rates of emergency department visits and hospitalization.76 Researchers have been searching for an explanation for this disproportionate burden for years, but to date the causes are not fully understood. Studies have examined a number of known risk factors for asthma, including poverty, environmental exposures, household

smoking, and obesity, and none of them fully explain the differences in health outcomes between Puerto Ricans and other Hispanics.^{77,78}

Genetic studies have determined that Puerto Ricans with asthma may have a predisposition to more severe asthma when compared to other Hispanics. They have higher levels of chronic airway inflammation, so their baseline breathing ability is worse. Then, when they are given a dose of the quick-relief medicine albuterol, they have a weaker response. Because albuterol is the most commonly prescribed treatment for asthma worldwide, subgroups that do not respond well to this therapy may be at significant risk of poorer health outcomes.⁷⁹

Recent research of the impact of stress on health may provide additional insight. In many ways, Puerto Ricans experience similar social and environmental stressors as other Hispanics, but they have some unique asthma-related points of stress that have been identified. Puerto Ricans are less likely than other racial and ethnic groups to have a family plan in place for responding to an asthma episode or attack.80 Children report taking on self-management responsibilities at a very early age, and teens have expressed the desire for more help from their parents. Puerto Ricans also express high levels of fear of the disease, which compounds an already stressful situation for these families.81

"I cry because I don't feel like a normal person." Dina

This is an area where Puerto Ricans seem to be more vulnerable than other groups. In a variety of health and mental health studies, Puerto Ricans report more pain and other physical symptoms, and suffer more emotional distress in response to trauma than do other Hispanics or non-Hispanic whites.82,83 Similarly, they appear to be what researchers term "over-perceivers" of asthma symptoms, meaning that they report feeling more severe breathing problems than would be expected from breathing tests results. Some researchers have speculated that this overperception of respiratory distress is part of a cycle: in Puerto Rican communities where rates of severe asthma are high, children and their families are more likely to have had negative experience with near-death or fatal asthma episodes, are more fearful and are more likely to overreact to symptoms. The overreaction results in overuse of

medication and excessive use of emergency health care, which perpetuates the problem.⁸⁴

Somewhat surprisingly, few of the studies of asthma in Hispanics address the issue of legal status and citizenship, although it clearly plays a role in the economic status and stress level of many Hispanics. Puerto Ricans, whether they live in Puerto Rico or on the mainland, are all U.S. citizens. That is not the case for Hispanics from other places who were born outside the United States. Undocumented status for many Hispanic immigrants is a source of chronic stress that appears to affect physical and emotional health. This is made worse by the fear of seeking medical and social services.85 Immigrants who obtain legal status are more likely to seek health care — 75 percent of Mexican-born individuals with U.S. citizenship have a usual source of health care, compared to 50 percent of those without U.S. citizenship.86

Dina feels like she can't go outside "because of the weather." Her doctor wants her to lose a little weight, so she started walking every day, but she gets so breathless she has to stop and rest.

Biological susceptibility — genetics, allergic sensitization and obesity

Asthma often runs in families, and it has been assumed for decades that genetics plays an important role in the disease. The extent to which the innate biological characteristics of individuals and population groups impact their susceptibility to asthma is a topic of intense study, especially in the area of genetics.

More than 118 genes have been linked to asthma so far, and the findings from genetic research are enhancing the understanding of how the disease develops and how best to treat it. Unfortunately, very few studies have included racial and ethnic minorities. When they have been included, the small sample sizes and the diversity across Hispanic subgroups have made it difficult to interpret results. No gene studied in multiple racial and ethnic groups has been found to affect asthma in every group, and genes that affect susceptibility to asthma can "behave" differently in different subgroups.87 For example, a team of researchers working with Hispanics carefully identified by country of origin found different responses to the same genetic mutations among different subgroups. Puerto Ricans with the genetic mutation have reduced responsiveness to bronchodilator medication, meaning that their breathing ability does not improve as expected. Mexican-Americans who have the same mutation do not react the same way.88 Presumably, this variation is due to gene interactions with some currently unknown factors that are unique to specific populations.

People who are sensitized to indoor allergens such as dust mites, cat dander and cockroaches are more likely to have asthma than those without allergies. Interestingly, although known asthma rates are low among Mexican-Americans as a group, a large study of Mexican-American children found that their rates of atopy, or the

tendency to develop a reaction to allergens, which is measured with a simple blood test, were higher than among non-Hispanic whites. ⁸⁹ Puerto Ricans are also more likely than whites to be sensitized to both indoor and outdoor allergens. ⁹⁰

Obesity has recently been positively identified as a major risk factor for the development of asthma. Obesity-related asthma tends to be more severe, and does not respond as well to treatment. Obesity is a significant health problem among Hispanics, across subgroups. Nearly 37 percent of Mexican-Americans are obese, as compared to 30 percent of non-Hispanic whites. A large study of Mexican-American adults found a near twofold increase in asthma rates among the participants who were obese. Similar results have been found among Puerto Ricans.





Promising Practices

In the 20 years or so since soaring asthma rates galvanized the public health community to action, a great deal of progress has been made in understanding and combating this disease. The steep rate of increase in asthma rates has moderated somewhat, and the number of deaths from asthma each year is mercifully dropping. Unfortunately, the overall disparities gaps remain stubbornly unchanged.94 Disparities experts say this is not unusual, that improvements in treatments and practices tend to benefit the more privileged first. However, some researchers, health systems and innovative community programs have successfully reduced the burden of Asthma on Hispanics. It is imperative that this work be continued and expanded in ways that will make the most difference for those at highest risk. The following are a few of the strategies that have been proven successful, as well as some promising opportunities.

Strengthening the Public Health Infrastructure

Since its inception in 1999, the Centers for Disease Control and Prevention's National Asthma Control Program has worked to integrate and coordinate the public health response to asthma control. The National Asthma Control Program has strengthened national and state-specific data collection, which allows officials to track and better understand asthma trends – ultimately allowing decision makers to focus resources on populations that are most in need. The CDC has also provided much-needed funding support for states, cities and school programs to help them improve tracking of asthma, train health professionals, educate individuals with asthma and their families, and explain asthma to the public.

For a number of the state programs, identifying and reducing asthma disparities has been a priority. In Texas, the state asthma control program partnered with a local university to bring public health services to the heavily Hispanic Lower Rio Grande Valley, where asthma-related hospitalization rates were among the highest in the state. They organized the McAllen Asthma Coalition, which provided respiratory therapy and nursing students to conduct outreach in local elementary schools, identify children with asthma and provide asthma management education for school staff, the children and their families. With funding from the state's Asthma Control Program, the coalition has also trained Spanish-speaking community health workers, known as promotores, to help families reduce asthma triggers in the home.95

"To fully understand and meet the needs of our communities, we must first thoroughly understand who we are serving."

Garth Graham, M.D., HHS Director of the Office of Minority Health "The biggest single step we've taken to address health disparities is last year's health care law, the Affordable Care Act. This is not just the most important law for improving Latino health of the last two years. It's the most important law for improving Latino health since the creation of the Medicare and Medicaid law 45 years ago."

Secretary Kathleen Sebelius, U.S. Department of Health and Human Services, addressing the League of United Latin American Citizens, June 2011

Expanding Access to Care

The Affordable Care Act that was passed by Congress in March 2010 has tremendous potential to reduce health disparities. The law extends health coverage to many millions of Americans who would otherwise remain uninsured, and includes other programs related to disparities. Some of the key provisions that will address issues affecting Hispanics with asthma that have been discussed in this report are the following:

- Medicaid expansion: The new law increases the income cut-off for individuals and families who are eligible for state Medicaid coverage to 133 percent of the Federal Poverty Level, which in 2009 was \$10,830 for an individual and \$22,050 for a family of four. This expansion could provide coverage to up to 16 million people in need.⁹⁶
- Health exchange: Uninsured individuals who are not eligible for Medicaid will be able to purchase coverage through newly created plans called health exchanges. To ensure that the insurance is affordable, credits toward premium payments will be available for those with low to moderate income levels.
- Employer coverage: The new law does not require employers to provide health insurance, but it does use penalties to encourage larger employers to provide coverage. If an employee of a company without coverage has to get coverage through a health exchange, then that company can be penalized. Although the penalty applies only to companies with 50 or more employees, this should encourage more employers to offer benefits.
- Increased community health services: Federal funding will increase the number of community health centers serving low-income people. This funding will also increase the number of primary care providers in medically underserved communities.

Reducing Environmental Exposures in the Community

As part of its robust, long-term effort to reduce asthma disparities in the San Francisco Bay Area, Regional Asthma Management and Prevention (RAMP) has been working to reduce pollution from diesel exhaust in its communities. Because diesel pollution is highest along roadways and in industrial areas like ports, rail yards and cargo-handling distribution centers, it is a particular problem for low-income communities of color that are disproportionately affected by asthma, including Hispanics. In 2003, RAMP decided to take a two-pronged approach to the diesel problem in the Bay area. RAMP first worked with partners to develop a grassroots regional diesel collaborative, in which the more traditional asthma stakeholders joined forces with





existing environmental justice advocates. This group conducted a community-based education and outreach campaign and was able to promote enforcement of a state anti-idling law for diesel trucks, among other activities. The second approach was to pursue state-level advocacy efforts to reduce the amount of allowable diesel emissions from a wide range of sources, including trucks, construction equipment and mowers. Organizations such as the Latino Issues Forum were instrumental in getting the attention of policy-makers. Both of these successful initiatives involved the formation of new partnerships and an appeal to those interested not just in asthma, but in healthier communities.

Reaching People Where They Are

Asthma patients and caregivers need to be able to follow complicated medication regimens, make changes to their home environment, monitor and record their symptoms and coordinate care between different providers. All this does not come easily. Education is a key component of asthma management, and has been repeatedly shown to make the difference in patients' ability to maintain good control.97 Because Hispanics are less likely to access health care, it is important to proactively reach them where they are. A number of successful programs have used promotores to conduct home visits to help reduce home asthma triggers. They are from the target community; they speak the same language, and are a trusted source for information. Also, their home visits allow them to provide comfortable, tailored service to the entire family, which is well suited to the Hispanic values of personalismo and familismo.98

Health-care systems and providers that have made an effort to improve their cultural competence have reported improved asthma outcomes in their patients. One review of clinician practices found that instituting cultural competence policies resulted in better patient management of control medications and higher patient satisfaction. The policy changes included recruiting ethnically diverse and bilingual staff, providing multi-lingual patient education materials, and providing training on cultural diversity and communication. 99 Another research team working with Medicaid providers developed a successful asthma-education program for providers that improved their communication skills and increased their confidence in interacting with patients and families. Interestingly, the study also found that the improvements are not permanent, and that cultural competence education needs frequent reinforcement. 100

Lydia is grateful for the help she has gotten from the American Lung Association in California and other groups. Her goal is to become a certified asthma educator. She wants to tell her story to other parents and to school personnel to protect other children. "No one should die from this disease."

"This disease has changed my life. I can't go camping with my family or do the things I want to do. I ask God to help me, I suffer a lot." Dina

Taking Action

The problem of asthma disparities in Hispanics is as complex as the disease itself, and aspects of it are as deeply engrained in the culture as poverty and language. As the Hispanic population continues to grow and disperse throughout the country, the imperative to address these issues becomes more urgent, and more relevant to all communities. It is a big job. But there has been progress, and there are some concrete, manageable opportunities to make a difference. The American Lung Association calls on government agencies, the health-care system, patient advocates, community leaders and families to take the following actions to narrow the gap so that all Americans can breathe easier:

- > The Centers for Disease Control and Prevention and all state Departments of Health should collect standardized, detailed ethnicity data as part of public health surveillance surveys.
- > Federal agencies should continue to aggressively implement the Affordable Care Act, extending health care coverage to many millions of Americans who would otherwise remain uninsured.
- The Centers for Disease Control and Prevention must continue to fund the National Asthma Control Program, including state programs, at levels totaling at least \$31 million.
- > The Environmental Protection Agency must act to reduce asthma triggers in the environment by adopting the proposed Mercury and Air Toxins Rule, and strengthen the limits on ozone and particulate matter.
- Congress should help protect Hispanics from workplace and community exposures to diesel exhaust, a major asthma trigger in construction, agriculture and transportation, by continuing to fund the cleanup of the existing fleet of dirty diesel vehicles and heavy equipment.

- Public and private funders should increase investment in disparities-related research, including genetic studies of subpopulations, and community-based participatory research on asthma policy and environmental and systems change approaches.
- > Health-care systems and providers should assess and track patient language and communication needs, and provide access to and reimbursement of interpreter services as needed.
- Health-care systems and providers should collect information about their patients' occupation and workplace in medical records to better identify potential workrelated asthma.
- > Insurers, health systems and advocacy organizations should provide access through Community Health Workers/ Promotores de Salud to home-based asthma education and environmental trigger reduction for high-risk patients and hard-to-reach patients.
- Hispanic community leaders and advocacy organizations should raise awareness of the expanding health coverage available through the Affordable Care Act, and facilitate enrollment of eligible community members.

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