Breathing Easier: Strategizing For Children With Asthma

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Abstract

This paper provides an analysis of the asthma problem affecting the children of our nation. Over the course of the past three decades asthma morbidity and mortality rates have steadily been on the rise, despite new and potent medications and improvements in asthma management practices. Unfortunately, asthma is a very complicated disease. A number of factors serve as barriers to prevention, and help to explain why prevention efforts have not been effective in reducing asthma rates.

This thesis stresses the importance of prevention as the means of controlling and reducing the incidence and severity of the disease, identifies nation wide asthma efforts, and discusses some of the barriers to prevention. A reduction in asthma incidence, hospitalizations, and death rates is possible, but for this to happen there needs to be greater asthma outreach and education for both the affected and unaffected. Several recommendations on how to improve educational efforts and foster behavioral change in asthmatic children and their families are given.

Potential solutions to the asthma problem are discussed in terms of: 1) primary, secondary, and tertiary prevention, 2) educational approaches, 3) behavioral change, and 4) school involvement, with priority give to tertiary prevention.

Recommendations for the use of innovative measures such as story telling, use of puppets, live demonstrations, videos, and computer games are identified as some of the many ways that physicians and health care providers could foster patient behavior change. In addition, suggestions for the provision of asthma equipment, plastic mattress covers, medication, transportation, and environmental exposure assessments by health maintenance organizations are made.

Recommendations for primary and secondary prevention include outreach efforts and research targeted at children who are at risk of developing asthma. Recommendations also are given for the integration of an asthma program and a child treatment plan into schools, and the development of asthma awareness advertising campaign.

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Introduction

When speaking about children in the United States of America the following question arises: How healthy are our children? To gain some insight into this question, the issue of childhood asthma should be explored.

For children, as well as adults, asthma hospitalization and death rates, despite better management of the disease, the development of new and potent medications, and increased educational efforts, have steadily been on the rise. An estimated 14 million people in this country are known to be asthmatic, and yet the average person does not realize the gravity of this issue. There are countless examples which can be used to illustrate the level of seriousness and attention that asthma warrants. The condition of life of those adults and children living in the 10 zip codes of the South Bronx, New York, provides one of the best examples of the severity of asthma in this country, as well as one which may lead to answers to the question raised above.

As pointed out in a recent New York Times article entitled, "Asthma Common and on Rise In the Crowded South Bronx," asthma is a major problem in the South Bronx. In the ten zip codes of the crowded South Bronx, the hospitalization rates are as high as 17.3 per 1,000 people and the death rates as high as 11 per 100,000 people - these numbers are eight times the national average. The incidence rate among children is 8.3% or twice the national average. For those living in the South Bronx, asthma is so common that "the pockets of men on street corners bulge with small breathing pumps the way they might bulge with cigars elsewhere." A large number of men in the South Bronx can't work because of asthma, women worry about their children playing too hard, and many people live in constant fear that they are going to collapse from an asthma attack. Breathing easily is something that most people take for granted, however, for a significant amount of individuals and families living in the South Bronx, it is often a life or death struggle.

Unfortunately, those living in the South Bronx are not alone. Asthma rates nation wide are high, thus making it easier to believe the statistics which reveal a significant increase in asthma prevalence and severity over the past two decades. There are people such as Gale Wienman of the National Heart, Lung, and Blood Institute (NHLBI), who argue that increased awareness among physicians might explain the rise in the number of asthmatics in this country. She says, "physicians may now be recognizing ailments previously diagnosed as a cold or bronchitis as the long-term, chronic illness of asthma." Yet, Gale Wienman also acknowledges that "the increase in asthma cases cannot totally explain the rise in

 $^{^1}$ Nossiter, Adam, New York Times, "Asthma Common and on Rise In the Crowded South Bronx," Page A1 & B2

² Friebele, Elaine, "The Attack of Asthma", <u>Environmental Health Perspectives</u>, Vol. 104, No. 1, January 1996, Pg. 22

its prevalence."³ There are a number of factors, such as environment, economics, access to health care, and lifestyle behavior, that further complicate the asthma issue and help to explain why asthma is on the rise.

Whatever the explanation for increases in observed rates, the asthma paradox remains -- the paradox being that despite improved treatment practices, medication, and education, that asthma is still a major cause of death and hospitalizations. The primary goal of this research effort is to explain why the paradox exists, in hopes that by doing so, recommendations on how to solve the paradox can be made. This thesis will look specifically at education as a preventative measure to asthma, in attempts to determine, as well as, understand the role and importance of education in preventing asthma deaths and hospitalizations. In addition, it will attempt to explain why certain groups, such as African Americans and Hispanics, are at greater risk of dying of asthma than other groups. Suggestions on where future asthma efforts need to be concentrated will also be made.

Lastly, it should be noted that this thesis will draw upon examples of organizations, agencies, and asthma efforts on the local, regional, and national levels. Specific asthma programs carried out by organizations in Rhode Island will be used to illustrate and support various arguments raised throughout this work. However, the recommendations presented should apply to asthma efforts made on the local, regional, and national levels.

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³ Ibid., Pg. 22

Chapter 1: Understanding Asthma

Asthma is a chronic health condition which has become a growing public health problem nationwide. Asthma, is a lung disease best characterized as an irritation of the lungs bronchial airways in the lungs to various stimuli which leads to episodic breathing problems. People with asthma suffer from acute episodes, commonly known as "attacks", when the air passages in their lungs get narrower and breathing becomes more difficult. "Asthma attacks often leave a person gasping for breath as their airways become constricted, the passages inflamed, and clogged with thick sticky secretions." Asthma varies in severity from person to person. "Symptoms can be mild, moderate, severe, or even life threatening, and attacks can come occasionally or frequently." 5

Asthma Triggers

When an asthma episode occurs, difficulties in breathing can arise for a number of different reasons. An oversensitivity of the lungs' airways to certain triggers and environmental changes cause the airways to become "twitchy", (meaning overly responsive), and the result is wheezing, coughing, shortness of breath, chest pain, and restlessness. There are a variety of triggers known to set off an asthma attack, yet it is important to note that each individual's reaction to a trigger or set of triggers differs. Known asthma triggers include allergens, air irritants, respiratory infections, over-exertion, weather, and emotional stress. Of the triggers mentioned, "attacks as a result of exposure to allergens and irritants are the most common."6 Allergens, "are substances to which some people are allergic,"7 and they include pollen, foods, dust, mold, feathers, and animal dander. At least ninety percent of children with asthma and half of all adults with asthma, have allergies that aggravate asthma."8 Allergies that tend to have the greatest effect on asthma are those that are inhaled-pollens, mold, dust, and animal dander. Of these four allergens, "domestic (house-dust) mites are the most common potential indoor allergen and a major cause of asthma."9 Indoor allergens such as domestic mites (most commonly known as dust mites) present major problems for many asthmatics. Many homes are carpeted, heated, cooled, and humidified; and such conditions provide the ideal habitat for these allergens.

⁴American Lung Association, <u>Lung Disease Data 1994</u>, Pg. 1

 $^{^{5}}$ National Institutes of Health, <u>Facts About Asthma</u>, NIH Publication No. 90-2339, October 1990, Pg. 1

⁶ Institute of Medicine, "Indoor Allergens", National Academy Press, Pg. 86

⁷ Ibid., Pg. 1

⁸ Ibid., Pg. 4

⁹ National Institutes of Health & National Heart, Lung, and Blood Institute, <u>Global Initiative For</u> <u>Asthma</u>, Publicatin Number 95-3659, January 1995, Pg. 29

Attacks as a result of exposure to irritants are also very common as mentioned. Irritants in both the indoor and outdoor air include dirt, cigarette smoke, gases, pollution, and odors. Most people spend about 90% of their time indoors, so exposure to potential indoor air pollutants is increased. Nevertheless, the point should be made that both indoor and outdoor irritants exacerbate asthma and maintain chronic airway inflammation in asthma in some susceptible populations.

Colds, flu, sore throats, and bronchitis, can all trigger an asthma attack. "Viral respiratory infections can exacerbate asthma, particularly in children with asthma under the age of ten. Respiratory viral infections may exacerbate asthma by causing epithelial damage and airway symptoms, both of these events may create asthma symptoms." Even too much exertion from over-carrying heavy loads, exercising, and running stairs too fast can trigger asthma. Exercise is the most common trigger of brief episodes of asthma. "It is known to induce airflow limitation in most children and young adults who have asthma."

Extreme emotional stress and weather are also risk factors that cause asthma exacerbations. Emotional stress or expression such as excessive laughing, crying, anger, or fear can lead to hyperventilation, and thus cause the lungs airways to narrow. Nevertheless, it is important to notice that while emotional factors can bring on an asthma attack, they are not the cause of an asthma attack. Adverse weather conditions including freezing temperatures, high humidity, or sudden changes in weather patterns can trigger an asthma episode but do not cause asthma.

Avoidance

The key to preventing and controlling asthma is to reduce (and eventually) eliminate exposure to the agents that cause the attack. By taking certain steps to eliminate exposure to allergens such as pollen, and pollutants such as cigarette smoke, the severity of an individual's asthma can decrease significantly. In addition to avoiding contact with triggers, individuals with asthma should take medications, to help prevent and reduce the severity of asthma attacks.

Medications

Asthma, can not be cured, in addition it is a very difficult disease to diagnose "since it can resemble other respiratory problems such as emphysema, bronchitis, and lower respiratory infections." Nevertheless, asthma episodes and severity can be minimized and controlled with proper treatment and medication. Prescription medication to prevent or control asthma symptoms such as wheezing, can help individuals manage their episodes, yet it is important

¹⁰ Ibid., Pg. 35

¹¹ Ibid., Pg. 35

 $^{^{12}}$ National Institutes of Health, <u>Facts About Asthma</u>, NIH Publicatioono NO. 90-2339, October 1990, Pg.1

to note that drug treatment varies depending on the frequency, severity, and the triggers of the episodes. For instance, some individuals may only take medication when they feel symptoms arising or before they are exposed to certain triggers, while others may take medication on a daily basis. There is a great variety of medications available on the market, and they are used and intended to relieve symptoms and make breathing easier. Amongst those medicines most commonly used to avoid or lessen episodes are corticosteroids, anti-allergy drugs, and bronchodilators - all these medicines are anti-inflammatory agents.

Anti-inflammatory medications are those taken by asthmatic persons to reduce the inflammatory response of the lungs airways that occurs at the onset of an episode. Those anti-inflammatory agents most commonly used to reduce symptoms are corticosteroids, anti-allergy drugs, and bronchodilators. Of these three types of medicine, Corticosteroids have proven "to be increasingly important anti-asthma drugs since they directly reduce the inflammatory response of the lung." Corticosteroids, come in both pill and aerosol form, however, because of "the serious side effects associated with taking oral steroids, prolonged use is usually reserved for severe asthmatics." The side effects associated with inhaled corticosteroids tend to be less serious, and because they are thought to be safer and effective in reducing symptoms, they are more commonly used.

Anti-allergy drugs are another effective way of treating asthma symptoms and reducing the severity of attacks. Amongst the most known anti-allergy drugs are cromolyn sodium, nedocromil, and ketotifen. Anti-allergy drugs are used to prevent episodes and are most often taken by individuals with mild to moderate asthma. The limitation of anti-allergy medication is that once an episode has begun, they are not effective.

Bronchodilators are medicines used to relax the lung's muscles and they help to open up the lung's air passages - they provide temporary relief of symptoms. Bronchodilators come in liquid, capsule, and tablet form, with the most commonly used types being theophylline, adrenergic (beta agonists), and atropine, which is an anti-cholinergic agent. Of the three, atropine, the oldest form, is used the least, since other medicines have proven to be more effective in reducing symptoms.

Bronchodilators, such as Adrenergic bronchodilators, come in both aerosol and tablet form, with the tablet form working more slowly and having more side effects. The aerosol form is breathed into the lungs through the use of an inhaler or nebulizer.

Theophylline also comes in all three forms (liquid, tablet, and capsule), and it has proven "to be very effective for individuals who suffer from night

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¹³ Ibid., Pg. 5

¹⁴ Ibid., Pg. 5

attacks of asthma - because its effectiveness tends to last long."¹⁵ Nevertheless, theophylline is not as strong as adrenergic bronchodilators, and it tends to have more side effects such as vomiting, heart abnormalities, and nausea.

Immunotherapy, is another form of drug treatment used to help prevent and reduce asthma episodes. Immunotherapy treatment is usually given in the event that asthma symptoms can't be controlled with other medication or changes in environment. In such cases, allergy shots are given to help control symptoms that may result from allergic reactions to cats, dust mites, or pollen. **Treatment**

In addition to avoiding likely asthma triggers and taking medications to help prevent and control asthma symptoms, monitoring one's condition is extremely important. One of the most commonly used devices to help individuals monitor their asthma conditions and lessen episodes is the peak flow meter. This small portable device is used specifically to monitor lung function. Before an asthma attack occurs the function of the lung decreases, yet changes in peak flow precede lung function deterioration. In other words, the peak flow meter acts as an "early warning" signal of an attack. If used properly it can be very instrumental in preventing severe attacks, and even "enhance a physician's ability to give a clinical assessment by telephone of an asthma exacerbation and the patient's response to treatment." By using the peak flow meter to measure breathing and learn of an episode before it has started, a person can prevent attacks from becoming serious problems.

Who Does Asthma Affect?

Despite the fact that all these potent medications and treatments are available, and when taken help to minimize asthma symptoms and prevent asthma episodes, asthma is still a growing national concern. In this country alone, 14 million people suffer from the illness. It is ranked the 7th most common condition, and it leads to 500,000 hospitalizations annually. Incidence of asthma is steadily on the rise, especially in crowded cities like the South Bronx, where the hospitalization and death rates are 8 times higher than the national average and where mothers of young children constantly worry that their children are playing too hard.

Asthma affects both the young and old, killing approximately 5,000 Americans a year, "more than 100 of them are children who don't live long enough to enter high school." Each year \$6.2 billion is spent in health care costs fighting asthma, and yet for unknown reasons it is on the rise. National trends in asthma mortality and hospitalizations amongst children and adults (specifically

¹⁵ Ibid., Pg. 5

¹⁶ Moffitt, John & Gearhart, Judith, "Management of Asthma in Children", <u>American Family</u> Physician, Vol. 50, No. 5, October 1994, Pg. 1044-1045

 $^{^{17}}$ American Lung Association, <u>Children With Asthma: Helping Them Breath Like Everyone Else</u>, Pg. 1

those under age 25) have been on the rise since 1980. The Center for Disease Control reported "during 1980-1993 asthma accounted for 3,850 deaths for persons aged 0-24 years, with the annual age specific death rates increasing by 118% (from 1.7 to 3.7 per million population)." During the 1980-1993 time period, the highest increase in death rates was noted for African Americans, specifically those between the ages of 15 and 24. "However, asthma death rates also increased amongst children ages 0-4 (from 1.8 to 1.9 per million), and amongst children 5-14 years of age. For children in the 5-14 age bracket, asthma death rates doubled, climbing from 2.5 to 5.2 per million." 19

As mentioned, increases in asthma hospitalization rates were also noted during 1980-1993. "For individuals aged 0-24, hospitalization rates from 1980-1993 increased by 28% annually, with the highest rates amongst children under the age of 1 year (increasing from 35.6 to 64.7 per 10,000 population)."²⁰ And specifically for children aged 1-4 years, "hospitalization rates during the 1980-1992 period, increased from 38.3 to 60.1 per 10,000 population."²¹

There are many in the field of health who attribute the rise in asthma rates to increased awareness among physicians. The Center for Disease Control, supports this belief, and goes on to argue that "the increase in hospitalizations among young children may be related to changes in coding and reimbursement, increases in morbidity, or changes in diagnostic practices."²² There are other authorities in the field of health who also attribute the increase in asthma severity to changes in physician's diagnosis, arguing that "it is possible that less severe forms of the disease, or clinical entities not previously called asthma, are now being labeled as such."²³ On the contrary, there are those that argue that the rise in morbidity as well as mortality rates, can be attributed to decreases in access to care and overreliance on home administered drugs, such as betaagonists, which then result in delays in seeking medical help. "Suboptimal patient education and failure to use medications (anti-inflammatory agents) in a timely fashion, especially in minorities and the poor, are identified as other factors contributing to the rise in asthma morbidity and mortality rates."²⁴

¹⁸ Center for Disease Control, "Asthma Mortality and Hospitalizations Among Children and Young Adults-- United States, 1980-1993", <u>Morbidity and Mortality Weekly Report</u>, May 3, 1996, Pg. 350

¹⁹ Ibid., Pg. 351

²⁰ Ibid., Pg. 351

²¹ Ibid., Pg. 352

²² Ibid., Pg. 352

²³ Weitzman, Michael & Gortmaker, Steven, "Recent Trends in the Prevalence and Severity of Childhood Asthma, " <u>Journal of the American Medical Association</u>, Vol. 268, No. 19, November 18, 1992, Pg. 2676

²⁴ Shuttari, Mir F., "Asthma: Diagnosis and Management", <u>American Family Physician</u>, December 1995, Pg. 2225

In is true that increases in asthma cases and asthma severity have been occurring in all age, race, and sex groups. Yet, the point should be made that a disproportionate rise in asthma incidence and mortality has been felt by the urban poor and ethnic minorities. For instance, for African-Americans asthma has proven itself a major problem. "The prevalence of asthma in 1993 for African-Americans under 45 years of age was about 23% higher than for Whites. And in 1992 the hospitalization rate for African-Americans was more than 400% higher than the rate for Whites."25 And in terms of asthma deaths, the death rate for African-Americans is almost three times the rates of Whites. "These statistics are shocking especially when one takes into account that African-Americans only make up 12% of the population, but over 20% of asthma deaths."26 Similar disequities are found in arguments for Hispanic populations, particularly in the subgroup, Puerto Ricans. Like African Americans, Puerto Ricans, have high rates of asthma and asthma mortality, higher than that of other Hispanic populations. "During 1982-1984, prevalence of asthma in Puerto Rican children living in New York City was 11.2%, while in comparison the prevalence rate for Mexican American children was 2.7%."²⁷ "And in terms of asthma mortality rates, in 1979-1981, the rate for Puerto Ricans was much higher (4 per 100,000), than rates for non-Hispanic whites (0.8 per 100,000) and Mexican Americans (0.5 per 100,000)."28

Although asthma impact on adults is significant, its impact on children is far greater. For children, especially for those living in poverty, asthma presents a major problem. "Children (those under 18 years of age) have a 41 percent higher prevalence of asthma then the general population." Asthma's impact on children is five times greater than its impact on adults, with asthma rates among children climbing 58% between 1982 and 1992. For children, asthma is the top ranking chronic illness. Each year, more than 1 million school-aged children suffer from asthma, making it the number one reason for morbidity, disability, and school absenteeism in children in the United States. Children with asthma miss an average of one week each year because of this illness which accounts for 10 million lost school days --twice the amount for children without asthma. Asthma affects children of all races and ethnicities, many of whom live in urban

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 $^{^{25}}$ <u>Asthma Management in Minority Children</u>, "Introduction," Published by: National Institutes of Health & the National Heart, Lung, and Blood Institute,

Pg. 1

²⁶ American Lung Association, <u>Lung Disease Data 1994</u>, Pg. 1

²⁷ <u>Asthma Management in Minority Children</u>, "Introduction," Published by: National Institutes of Health & the National Heart, Lung, and Blood Institute,

Pg. 1

²⁸ Ibid., Pg. 1

²⁹ Ibid., Pg. 1

³⁰ American Lung Association, <u>Children With Asthma: Helping Them Breath Like Everyone</u> <u>Else</u>, Pg. 1

environments; specifically the inner city, "where prevalence and mortality rates for children are highest." Nevertheless, when examining childhood asthma prevalence it becomes clear that there are significant racial disparities (just as in the case of overall asthma prevalence). Among all who are affected, asthma poses the greatest risk to African American children, particularly those who are poor and reside in urban areas. "African American children have a 24% higher prevalence of asthma than White children and more limitation of their activity due to asthma." Asthma hospitalization rates have an even more dramatic disparity. "Hospitalization rates for Black children with asthma are 150% higher than for White children."

What is it about Black children that causes them to suffer from higher incidents of asthma? And what, if anything, are Black children being more exposed to that may contribute to asthma that other children are not? These are the kinds of questions that must be answered, before strategies can be developed to reduce these disparities. There are some in the health field who believe that "lack of continuity of medical care, lack of adherence to treatment regimens, low education and literacy levels, and environmental factors are to blame for the inability to decrease and control asthma among Black children" and children of other racial/ethnic groups. Research has shown that proper medical treatment and education about how to control asthma can make a significant difference in the lives of asthmatic children; by reducing symptoms, attacks, and emergency room visits, and thus make them healthier and more active.

For these reasons, those involved in the struggle to decrease asthma incidence and prevalence (i.e. health care providers, agencies, and organizations) have stressed the importance of prevention.

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³¹ Call, Robert & Smith, Thomas, "Risk Factors for asthma in inner city children," Journal of Pediatrics, December 1992, Vol. 121, No. 6, Pg. 862

^{32 &}lt;u>Asthma Management in Minority Children</u>, "Introduction," Published by: National Institutes of Health & the National, Heart, Lung, and Blood Institute,

³³ Willies-Jacobo, Linda, "Socioeconomic status and allergy in children with asthma," <u>Journal of Allergy and Clinical Immunology</u>, Vol. 92, No. 94, Pg. 631

³⁴ Fizpatrick, Sherahe Brown, MD & Coughlin, Steven S., Ph.D, " Novel Asthma Camp Intervention For Childhood Asthma Among Urban Blacks," <u>Journal of the National Medical</u> Assocation, Vol. 84 No. 3, Pg. 233

Chapter 2: The Importance of Prevention

Asthma, is extremely burdensome and costly to individuals, families, and society as a whole, and it is for these reasons that prevention needs to be stressed as a solution. "The risk of many diseases can be reduced through health promotion, early identification, and effective delivery of prevention." When speaking specifically of asthma, emphasis on prevention is crucial if a decrease in morbidity and mortality rates are to be evidenced. As mentioned, "\$6.2 billion is spent in health care costs treating asthma," yet by stressing prevention, a reduction in treatment costs and an overall improvement in health outcomes can be attained.

Asthma cannot be cured, but appropriate management can lead to control of the illness. Prevention is seen as the means through which: 1) health can best be promoted, 2) reductions in asthma hospitalizations can occur, and 3) recent trends in asthma hospitalizations and deaths can be reduced. And most involved in combating the illness consider educational intervention to be a powerful, crucial tool, since it has proven to improve self management, help parents adjust to the demands the illness can have on a family, improve a child's attendance at school, and help children with the illness be healthier and more active. Yet, even more importantly, as proven by "several randomized control studies, patient education programs effectively reduced the number of asthma episodes, emergency visits, and hospitalizations, especially of previously hospitalized children."³⁷

Prevention of asthma through intensive education has been the focus of most asthma efforts. Health care providers along with agencies and organizations in both the public and private sectors, argue that attitudes and lifestyle play a vital role in determining the health of an asthmatic child. In order to control and manage asthma, parents and children must be equipped with certain skills and information that enable them to take control of symptoms and of the child's health.

"The aim of education is to increase understanding, skills, confidence, satisfaction, compliance, and management of asthma." By educating asthmatic children and their families, they can successfully achieve control of the illness and maintain a good quality of life. "Education includes education about primary, secondary, and tertiary prevention, and it is an essential part of the

³⁵ Silbergeld, Ellen, <u>New Solutions</u>, "Investing In Prevention: Opportunities to Reduce Health Care Costs Through Identifying and Reducing Environmental Contributions to Preventable Disease," Fall 1993, Pg. 37

³⁶ Ibid., Pg. 44

³⁷ National Heart, Lung, and Blood Institute, Office of Prevention, Education, and Control, National Asthma Education and Prevention Program, "Program Description and Background Information", November 1994, Pg. 3

³⁸ National Institutes of Health & National Heart, Lung, and Blood Institute, <u>Global Initiative For Asthma</u>, Publication Number 95-3659, January 1995, Pg. 147

overall management of asthma."³⁹ Still, education also involves an alteration in behavior, and this is especially important when talking about asthma, because present behavioral issues indicate a need for asthma education - education on: 1) chronicity of asthma, 2) asthma's potential to be fatal, 3) importance of environmental control measures 4) how to recognize asthma severity and prevent an episode, 5) how to take medication correctly, and 6) proper management of asthma episodes.

As mentioned, prevention of asthma through education has been the focus of most education efforts, with the goal of prevention being to reduce the intensity and frequency of the illness. "Prevention of asthma involves both the prevention of the initial development of asthma and the prevention of exacerbations in those who already have the condition." And it is stressed on three levels: primary, secondary, and tertiary.

The Three Levels of Prevention

"Preventing the development of conditions is a more attractive option then treating an established condition."41 This is the intent of primary prevention. Primary prevention means preventing the disease from occurring in healthy individuals by removing risk factors, a most difficult task, since the causes of asthma are not fully known. The focus of primary prevention is on controlling exposures suspected of causing asthma. Primary prevention interventions include vacuuming the home regularly and using plastic covers on pillows and bedding to reduce exposure to indoor allergens, such as dust mites. In addition, it consists of making sure that the home is clean in order to prevent cockroaches. (It is important to note that many of these same measures are carried out on the tertiary level after the illness has occurred). "Primary prevention strategies are often carried out by families with a history of asthma, since there is some belief that susceptibility of asthma is genetically determined."42 If a child is born to one or two parents with asthma or to a family with a history of asthma, it is thought that there is a good chance that the child will be at risk of developing asthma.

Secondary prevention involves the screening of children (and adults) who have been diagnosed with respiratory problems or asthma-like symptoms. At this level physicians are screening children for subclinical illness, in other words, attempting to identify potential allergies and irritants that can trigger asthma. Through secondary prevention efforts "a successful diagnosis could lead to early effective intervention and perhaps to improved prognosis."⁴³

³⁹ Ibid., Pg. 140

⁴⁰ Ibid., Pg. 64

⁴¹ Ibid., Pg. 64

⁴² Ibid., Pg. 64

⁴³ Ibid., Pg. 64

Secondary prevention efforts include lab tests, peak flow monitoring, chest x-rays, bronchio challenge tests, as well as blood and allergy tests. Lung function measurement tests, such as peak flow monitoring and bronchio challenge tests, are often carried out. "They are thought to be very helpful for the diagnosis of asthma since they provide direct assessment of airflow limitation and indirect assessment of airway hyperresponsiveness."

Tertiary prevention, is the last level of intervention, and it is on this level that most asthma efforts are concentrated. At the primary and secondary levels, much less is known about risk factors for the development of asthma. However, much more is known about factors that aggravate existing conditions. At the tertiary level, a child has already developed asthma, and the factors that aggravate existing asthma are being identified, thus the intent is now to reduce the intensity and frequency of the illness. At the tertiary level there are two main goals. The first goal is to identify all the causes of the disease, and the second, to prevent asthma from worsening, avoid deterioration in lung function, and prevent death from the condition in those who have the illness.

Prevention of asthma on the tertiary level is carried out through intensive education, screening efforts, and initiation of medical treatment, environmental, and housing interventions. In regard to environment and housing, efforts are directed towards identifying, reducing, and preventing further exposure to potential sources, such as dust, that may trigger asthma. These include encasing pillows and mattresses in plastic covers, vacuuming, having an environmental exposure assessment of the home completed (to determine the level of exposure to potential allergens and irritants that may trigger asthma), as well as controlling indoor air pollutants such as tobacco smoke, carbon monoxide, and nitrogen dioxide. In terms of medical treatment, tertiary prevention includes immunotherapy, using breathing machines, inhalers, nebulizers, anti-inflammatories, and other such medications to control and decrease the severity of an asthma attack. At this level, medications are to be taken daily or regularly on a long-term basis in order to control the illness.

⁴⁴ Ibid., Pg. 64

Chapter 3: Who Is Involved In The Fight For Asthma Prevention

As stressed in the previous chapter, education is a key component of asthma prevention. It is an obvious and realistic response to asthma, and many agencies, organizations, and health care providers have determined that by educating children, doctors, and parents about asthma, asthma incidence, hospitalizations, and deaths can be decreased. Presently, there are hundreds of organizations and agencies working, locally, regionally, and nationally working to develop educational information and programs targeted specifically for high risk groups, schools, health care providers, physicians, and parents. To get a clearer idea of some of the asthma prevention initiatives being implemented on the local, regional, and national level, information on the efforts of a number of organizations and agencies will be revealed.

Amongst the many organizations and agencies working to combat asthma and improve the quality of life for children with asthma are: the National Heart, Lung, and Blood Institute (NHLBI), Environmental Protection Agency (EPA), American Lung Association (ALA), the Visiting Nurses Association of Rhode Island (VNA), and Zeta Phi Beta Sorority, Incorporated. These organizations range from the community based/grassroots level to the national level, and they are amongst those who are making a commitment to preventing asthma through educational interventions.

Environmental Protection Agency

The Environmental Protection Agency (EPA) is a government agency in strongly supports of asthma education and prevention, and the agency is promoting asthma prevention "as part of its general commitment to environmental and health protection, and its specific commitment to environmental justice." The EPA is presently working to reduce pollution levels both indoors and outdoors that can cause problems for people with asthma.

In terms of asthma education, the EPA is helping to fund workshops and provide material to promote the importance of asthma prevention. The EPA sees its role as one which will "help people understand how air pollution can affect asthma and how avoidance of potential triggers is an effective way to control and manage asthma." ⁴⁶ Thus far the EPA has developed and distributed literature on pollution prevention, biological, and indoor air pollutants. The EPA is working closely with the National Heart, Lung, and Blood Institute and the American Lung Association to promote asthma awareness.

National Heart, Lung, and Blood Institute

"The mission of the National Heart, Lung, and Blood Institute (NHLBI), is to provide leadership for a national program in diseases of the heart, blood

 $^{^{45}}$ Environmental Protection Agency, "Asthma, Air Quality, and Environmental Justice: EPA's Role in Asthma Education and Prevention", EPA-402-F-95-001, July 1995, (fact sheet), Pg. 1 46 Ibid., Pg. 1

vessels, lungs, and blood."47 The NHBLI, a federal agency, has also committed to reaching those populations most affected by asthma. The NHLBI claims that "behavioral issues indicate a need for asthma education," 48 and thus they have made education the focus of their asthma programs. The NHLBI provides people with information and training that empowers them to take control of their asthma, and with this principle in mind, they have developed specific education programs, mass media campaigns, and educational material that target physicians, the public, schools, families, and high risk groups, such as Black and Hispanic children. Through the development of their National Asthma Education and Prevention Program (NAEPP), "they have attempted to: 1) raise awareness of patients, health professional, and the public that asthma is a serious chronic disease, 2) ensure the recognition of the symptoms of asthma by patients, families, and the public and the appropriate diagnosis by health professionals, and 3) ensure effective control of asthma by encouraging partnerships among patients, physicians, and other health care professionals through modern treatment and education programs."49 The NHLBI is confident that by accomplishing these goals, they will succeed in their mission of decreasing asthma morbidity and mortality rates. Their confidence is based on the success of several randomized, controlled studies, which concluded that "patient education" programs effectively reduced the number of asthma episodes, emergency department visits, and hospitalizations, particularly in previously hospitalized children."50 These same studies found that as a result of these education programs school absences decreased, grades improved, and significant cuts in health care cost for high-risk populations were observed.

For the NHLBI, educational intervention is the key to increasing knowledge about asthma and changing behavior. In addition to individual efforts, the NHLBI has worked in close partnership with agencies such as the American Lung Association (ALA), and the Environmental Protection Agency (EPA), providing them with asthma publications for ongoing programs.

American Lung Association (ALA)

The ALA with help from the EPA and NHLBI (in terms of resources and material), has also attempted to help children and their families prevent asthma through education efforts. The ALA's primary asthma initiative is the Open-

⁴⁷ National Heart, Lung, and Blood Institute, Office of Prevention, Education, and Control, National Asthma Education and Prevention Program, "Program Description and Background Information," November 1994, Pg. 1

⁴⁸ Ibid., Pg. 3

⁴⁹ Ibid., Pg. 2

⁵⁰ Ibid., Pg. 3

Airways for Schools program, an asthma education curriculum for elementary schools, which emphasizes the importance of asthma management and prevention. However, unlike many asthma programs, this one targets children instead of parents. The ALA has concentrated its efforts on educating 3rd, 4th, and 5th graders through the elementary school system, since the ALA believes that it is at this age that children can begin to take control of their health. The ALA argues that by providing children with the necessary skills and information to combat asthma, they are empowering them to take control of their illness.

The Open-Airways for Schools curriculum is presently being implemented in schools nationwide, with the hope that by 1996 the asthma curriculum will be integrated into the curriculum of 1100 schools (unfortunately, this goal has not yet been attained). Amy Schiaffino, of the Boston ALA, argues that much of the asthma problem can be attributed to the fact that physicians are not educating children and parents, in addition to the fact that many of the children with asthma- are living in inner city environments where poor housing is widespread. For these reasons she says the success of the Open-Airways for Schools program will depend largely on the efforts may by school nurses to identify children with asthma and place them in the program. In the Open-Airways for Schools program, school nurses select children with asthma to participate in the program. Children enrolled in the program receive six forty minute group asthma lessons which teach them how to: 1) prevent episodes of asthma, 2) recognize symptoms, 3) carry out asthma management, 4) discuss and solve asthma problems, and 5) demonstrate confidence when dealing with asthma. Throughout these six lessons there are basic health messages that the school nurse tries to get across. The messages are: asthma is treatable, episodes do not have to be a crisis, medication should be taken when symptoms first arise, solutions to asthma problems can be found, and a normal life is possible for an asthmatic child. The hope is that upon completion of the lessons, the children enrolled will have gained the communication and asthma management skills that they need to stay healthy and live an active, normal life, and more importantly, that they will feel empowered.

Zeta Phi Beta Sorority, Incorporated

Zeta Phi Beta Sorority, Incorporated ($Z\Phi B$), is a Black sorority 70,000 members strong, which, like the EPA and NHLBI, is working very closely with the ALA to prevent asthma (as well as to advance the effectiveness of asthma outreach efforts). According to Jylla Moore Foster, the president of Zeta Phi Beta, asthma is having a critical impact. She further states, "It was very shocking to me to learn about the mounting toll of asthma suffering and deaths in the African American community. I don't believe that asthma has received enough publicity

or been treated with the seriousness it deserves."⁵¹ For these reasons, the sorority has committed itself to working as volunteers, to address the devastating effects that asthma has had on the African American community. The Zeta's are working to mobilize inner city communities with high asthma rates and asthma education has been made the cornerstone of the sorority's National Health Campaign. All chapters within the sorority have been mandated to get involved in addressing the chronic illness, as well as other health issues which disproportionately affect African Americans.

The Zeta's hope is that as volunteers they can become agents of change within their local communities, helping to empower disadvantaged and minority children with asthma.

Visiting Nurses Association

The Visiting Nurses Association of Rhode Island (VNA), is a community home health care provider that serves 9,000 people of Rhode Island. The VNA provides home care services of all kinds, including IV therapy, mental health services, diabetic management and HIV/AIDS management services to adults and children with asthma.

The VNA receives asthmatic clients by referrals from hospital emergency rooms and physicians offices, and works in partnership with parents of children with asthma, pediatricians, hospital staff, nurses, and Health Maintenance Organizations (HMOs). According to Nancy Bowering of the Providence VNA, they visit a large number of children who live in areas such as South Providence, Rhode Island, where the number of asthma cases seems to be rising, The VNA provides health education and medication equipment, such as nebulizers and breathing machines to asthmatics, and they perform environmental exposure assessments of the home during their first home visits, in order to identify asthma triggers. Nancy Bowering claims that the focus of the VNA in terms of asthma is tertiary prevention, and that their hope is that by educating families about medication, asthma management, and asthma triggers that they can help reduce asthma severity.

Health Maintenance Organizations

The ALA, EPA, and NHLBI, have an outreach focus concentrated mainly on the national level. The activities of Health Maintenance Organizations (HMOs) in contrast have a local. HMOs were researched for three reasons: 1) to determine what level of emphasis is placed on asthma prevention, 2) to determine whether the most disadvantaged populations are being served, since they are likely to be at greatest risk of developing asthma, and 3) to test the hypothesis that HMO's have the greatest incentive of all organizations to stress

⁵¹ American Lung Association, <u>Children With Asthma: Helping Them Breathe Like Everyone Else</u>, Pg. 3

asthma prevention, since their purpose is to promote health. This hypothesis is based upon the fact that HMO's provide health care at the least amount of dollars for the largest number of people, and thus it would be to their advantage to attempt to prevent diseases in order to significantly reduce health care costs.

Health maintenance organizations in the state of Rhode Island, were specifically researched, since the five HMOs in the state provide services to those AFDC and Medical Assistance families enrolled in the state's RIte Care Program. RIte Care is a Rhode Island program which provides health insurance coverage specifically for families on AFDC and Medical Assistance through a managed health care system. The program is administered by the Department of Human Services' Office of Managed Care and it was developed to ensure available health care, increase access to primary care, improve the quality of care provided, and to help control the rate of growth in Medical Assistance program expenditures. "Before the advent of the RIte Care program, those families receiving AFDC and Medical Assistance who were eligible for care had great difficulty finding a doctor to serve them, thus the result was over-reliance on hospital emergency rooms for routine care by families, or the delay of needed care which would have resulted in preventable hospitalizations." 52

The majority of those individuals and families who receive AFDC and Medical Assistance in the state of Rhode Island will join the RIte Care program. "In addition to offering services to these beneficiaries of the program, Rhode Island has expanded eligibility to uninsured pregnant women and children up to age six up to 250% of the Federal poverty level." "The State also offers buy-in provisions for pregnant women up to 350% of the Federal poverty level; uninsured siblings of eligible children, and uninsured children up to age six who are above 250% of the Federal level." Nevertheless, by extending coverage to all these groups the RIte Care program hopes to improve health care for pregnant women and young children, as well as, make primary and preventive care more accessible. The RIte Care program is the state's attempt to provide universal health access to all of its residents.

RIte Care participants enroll in one of the five following health plans: 1) Harvard Community Health Plan of New England, 2) HMO Rhode Island, 3) Neighborhood Health Plan of Rhode Island, 4) Pilgrim Health Plan, and 5) United Health Plans of New England. Once enrolled in a health plan, participants choose a primary care physician. Through their primary care physician they receive benefits such as physicians visits, hospitalization, drugs, lab tests, mental health and substance abuse treatment, emergency room care, ambulance services, and nursing and home health care. "Additional services

 $^{^{52}}$ Office of Managed Care, Rhode Island Department of Human Services, "RIte Care Program", (Program Informational Packet), Pg. 1

⁵³ Ibid., Pg. 2

include childbirth education programs, parenting classes, free unlimited bus passes, and taxi and van rides when necessary."⁵⁴

HMO Asthma Programs

Of the five health maintenance organizations mentioned above which offer services to RIte Care beneficiaries, three offer asthma education programs that promote asthma prevention. Of the five HMOs, Harvard Community Health Plan of New England, Pilgrim Health Plan, and United Health Plans of New England, provide specific services to meet the needs of their asthmatic clientele. In order to get a better understanding of the asthma efforts these HMOs have engaged in, their programs will be discussed in detail.

Harvard Community Health Plan offers its asthma clientele, a program which emphasizes the importance of asthma education and asthma management. According to Jeanie G'Agostino, a respiratory therapist, who helps run the program, "emphasis is placed on teaching patients how to take control of their condition." The asthma program at Harvard Community Health Plan offers lessons to both adults and children, and enrollment in the program can range from one visit to months of involvement. Asthma program participants are identified once they've been hospitalized or admitted to the emergency room for a visit. They are then referred by their primary care physician to Harvard Community Health Plan's asthma program. Once enrolled in the program participants are taught: 1) how to properly use their medication properly, 2) the importance of strict adherence to medication, 3) how to identify potential triggers, 4) the importance of making behavioral and environmental changes and 5) asthma management skills.

The primary goal of the program is for each individual enrolled to develop a written control plan. In other words, each individual is to identify his or her personal best peak flow level. By doing so, participants can learn how to: effectively monitor their own asthma, keep their asthma severity to a minimum, and take control of their condition. Jeanie G'Agostino argues that identification of one's peak flow level is particularly important for those adults and children with moderate to severe asthma. "What we are trying to do is help ensure for our patients normal activity on the least amount of medication." ¹⁵⁶

For this particular program, emphasis on prevention is placed largely on the tertiary prevention level. However, secondary prevention efforts are offered to those persons who have asthma-like symptoms. Bronchio challenge tests are given to those adults and children who have been identified as potential asthmatics by their physicians. When asked why bronchio challenge tests are offered over blood and skin tests, Jeanie G'Agostino responded, "bronchio

⁵⁴ Ibid., Pg. 5

⁵⁵ Telephone interview with Jeanie G'Agostino of Harvard Community health Plan

⁵⁶ Telephone conversation with Jeanie G'Agostino of Harvard Community Health Plan

challenge tests are more effective because they allow you to determine the level of hyperreactivity within the lung, whereas blood and allergy tests don't diagnose asthma. Allergy and blood tests just identify that a child or adult is allergic to something. A person can have allergies but not asthma."⁵⁷

In addition to offering educational services to program participants and their families, an educational program is offered to Harvard Community Health Plan doctors and nurses. This four hour lesson consists of information on: 1) what asthma guidelines to follow, 2) how to treat asthma, and 3) classification of severity.

Pilgrim Health Plan is another health maintenance organization that offers educational and asthma management services to its asthmatic clientele. Pilgrim Health Plan has two programs that pertain specifically to asthma: the Childhood Asthma Management Program (CAMP) and the Central Pediatric Asthma Program, educational lessons on asthma triggers, proper use of medication, and the importance of environmental control are given. The Childhood Asthma Management Program, in conjunction with the NHLBI, is conducting a study on asthma medication. Eight of Pilgrim Health Care's twelve health centers are conducting the study in order to determine what the best treatment is for children with mild to moderate asthma. This study, which is to be completed in July of 1999, is open to children between the ages of 5 and 12 years. One requirement is that those who participate remain in the study for five years.

The study is a case-control study based on double-blind randomization, with each child being required to take study medication twice a day. Participants are given one of three medicines: a placebo, nedrocromin (a non-steroidal medicine), or budesonide (a steroid inhaler). Those involved in the study are taught the importance of environmental control and recognition of asthma symptoms is taught. Participants are also provided with plastic encasements for pillows and bedding to reduce dust mite exposure, and dust samples are collected.

Three times a year for 2 to 2 1/2 hours the children visit one of the participating study clinics, during which time they will be asked such questions as: Were you awakened during the course of the night? What were your symptoms? And, did you contact your doctor when your symptoms developed? The hope is that the answers gained from the questions and visits will help answers about what treatment is best for children with mild to moderate asthma.

United Health Plans of New England is the third health maintenance organization of Rhode Island that offers an asthma program for its clientele. United Health Plans of New England runs the Pediatric Asthma Care and

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⁵⁷ Telephone converstation with Jeanie G'Agostino of Harvard Community Health Plan

Education Program (PACE). The overall goal of PACE is to "reduce the incidence" of adverse events such as hospitalizations and emergency room visits by 1%"58 This program targets children up to 18 years of age, and it is an in home program. As in the case of the other health plans, individuals who have been hospitalized for asthma or admitted to the emergency room are referred by their physician to participate in PACE. Once parents have given their child permission to enroll in the program, an assessment of the home is completed by a respiratory therapist of the health plan, in order to identify the possible triggers of the child's asthma. Next, suggested asthma lessons are implemented by the respiratory therapist. The six lessons offered include: 1) general information about asthma (feelings about asthma are discussed), 2) identifying signs and controlling asthma symptoms, 3) learning how to stay strong in body and mind, 4) learning peak flow use, 5) devising individual school plans (learning how to let teachers and nurses know about child's condition), and 5) proper use of equipment (i.e. inhalers, nebulizers, peak flow meters). The number of lessons covered depend upon the child's level of asthma awareness. The goal of the lessons is to help the children understand and better manage their disease, as well as reduce their panic level during an asthma attack. The children enrolled in the program are also provided with peak flow meters free of charge.

Duration of enrollment in the program ranges from 4 to 8 weeks, and in addition there are 30 days and 6 months follow ups. The follow up sessions occur over the phone, with the intent of determining how useful the lessons were, whether children and their families are still making use of the information, and to see if the child has used the hospital since their enrollment in the program.

This program does not focus on primary or secondary prevention; the focus is on children with asthma or a history of hospitalization. Still, Diane Brandlee, co-director of the program, argues that asthma education and early intervention are the key to asthma prevention. Her claim is based on the results gained from program data collected that compared the number of children with asthma in pediatric practices to the level of emergency room hospitalizations for these children. "What we found was that in some cases the number of hospitalizations was very low, even though asthma rates in these pediatric practices were high. When we spoke to doctors what we found was that they educated their patients in the office and sent them home immediately with asthma equipment. Early intervention is the key." 59

In addition to the Pediatric Asthma Care and Education program, United Health Plans, runs the Asthma and COPD (chronic obstructive pulmonary disease) Education program, better known as ACE. This program was developed as a result of working with families of asthmatic children. United Health Plans recognized that there is a need for education for individuals who are older than

⁵⁸ Telephone conversation with Diane Brandlee of United Health Plans of New England

⁵⁹ Telephone conversation with Diane Brandlee of United Health Plans of New England

age 18, specifically the elderly, who were ending up in hospital emergency rooms because of non-compliance. ACE's goal is to prevent chronic respiratory illnesses such as asthma and emphysema, and program efforts are concentrated on educating adults on the use of respiratory equipment, good nutrition, and how to breathe normally.

This chapter presents a picture of some of the organizations and agencies on the local, regional, and national levels involved in the struggle to promote asthma education and asthma prevention. Despite the efforts of organizations such as these, asthma is still on the rise. For these reasons, chapter four will identify some of the barriers to asthma prevention in order to explain why the asthma paradox exists. It will also attempt to reveal how complex the asthma issue is and explain why certain groups are at greater risk of suffering from asthma.

Chapter 4: Barriers to Asthma Prevention

There are some health professionals who attribute our inability to decrease and control asthma among children, especially children of color, to lack of continuity of medical care, lack of adherence to treatment regimens, low education, and environmental factors. Research has even shown that proper medical treatment, management, and education about how to control asthma can significantly impact the lives of asthmatic children. Despite this fact, "under-utilization of medical care and day to day management of asthma exists." 60

If parents and children are to gain control of asthma, they must be equipped with certain skills and information, which will enable them to take care of their child's health, recognize the importance of medication and management, and, most importantly take control of asthma. Yet, as Dr. Peter Gergen of the U.S. Public Health Services states, they must also be made aware that asthma is a multifaceted condition, since there are a number of factors, some known and some unknown, that contribute to asthma prevalence and serve as barriers to asthma prevention. For instance, when trying to understand how complicated the issue of asthma is, and why the asthma paradox exists, it is important to realize that lack of basic care coupled with economic barriers, living environment, lifestyle/behavioral factors, and psychological factors, help to explain why asthma is a major problem for African American children, children of other racial and ethnic backgrounds, and those agencies and organizations involved in the fight to prevent asthma.

A family's economic situation and social class position "can increase a child's risk of developing asthma, or in the case of a child with asthma, increase the severity of their illness." Many studies note the strength of the association between asthma morbidity and mortality and socioeconomic status. For African Americans and others of low social class position, demands of a child with an illness such as asthma may be a big financial burden. This has proven to be the case for some poor families in Chicago "who on average were spending more than 60% of their total income on rent each month, and in some cases 80% of their income on rent." Asthma is an illness that requires continuous medical care to manage it, however, if a family also has to worry about paying for food, household expenses, and transportation expenses, management may seem impossible. Furthermore, a family's social class position often determines the environment in which they live. "Children of lower social class position are likely to sleep on older mattresses, have older carpets, and live in older deteriorated

⁶⁰ Fisher, Edwin B., Jr. Ph.d, "Targeting High Risk Groups," <u>Ches</u>t, Vol. 106 (4), October 1994, Supplement, Pg. 248S

⁶¹ Weiss, Kevin, "Inner-City Asthma: The Epidemiology of an Emerging US Public Health Concern," <u>Chest</u>, Vol. 101 No. 6, June 1992, Supplement Pg.364S

⁶² Ibid., Pg. 364S

housing."63 Older mattresses increase the likelihood of dust mites and older carpets can breed mold. Sleeping on older mattresses, having older carpets, living in deteriorating housing, and other such living conditions can pose major environmental risks, especially since "leaky and dysfunctional appliances such as boilers and kerosene heaters can increase exposure to poor indoor air pollution which in turn can trigger asthma."64

Social class position can also result in differences in exposure to air pollutants. For instance, families and persons of low income levels are less likely to have air conditioners in their homes, and thus more likely to keep windows open during the summer months when ozone levels are highest. There is some belief that "certain levels of ozone exposure may increase bronchial responsiveness to allergens among persons with asthma." Without air conditioning indoor concentrations of ozone can approach 80% of outdoor concentrations."

One third of African-Americans live in poverty, and over one half live in central cities, which are often plagued by poverty and high pollution levels. Yet, aside from African-Americans, there are also a disproportionate number of other people of color and people from low income households, living in such conditions. According to the Environmental Protection Agency (EPA), "these exposures coupled with inadequate health care may explain why many African Americans die from asthma." 67

Just as in the case of economics and social class position, environmental risk factors are also linked to asthma morbidity and mortality, since some areas, particularly urban environments, often have higher levels of outdoor pollution. This is best noted in the cases of African Americans and other minority children who live close to highways and factories where there are high levels of pollution, and thus possible increased risks of asthma. However, the effect of environment can also result in less concern about asthma rates for those living in the inner city. "In minority communities especially, attention is directed, by necessity, on day to day survival, and thus little emphasis is placed on efforts for "staying" healthy." For many children and adults living in the city, violence, peer pressure, family concerns, crime, and job loss, as well as other related risks, are

⁶³ Willies-Jacabo, Linda, "Socioeconomic status and allergy in children with asthma," <u>Journal of Allergy and Clinical Immunology</u>, Vol.92, No. 94, Pg.631

⁶⁴ Weiss, Kevin, "Inner-City Asthma: The Epidemiology of an Emerging US Public Health Concern," <u>Chest</u>, Vol. 101 No. 6, June 1992, Supplement Pg. 365S

⁶⁵ Environmental Research Pg. 66

⁶⁶ Ibid., Pg. 57

⁶⁷ United States Environmental Protection Agency, (fact sheet), "Asthma, Air Quality, and Environmental Justice: EPA's Role in Asthma Education and Prevention," July 1995

⁶⁸ Jones, Edith Irby, MD, "Preventing Disease and Promoting Health In The Minority Community", <u>Journal of The National Medical Association</u>, Vol. 78, No. 1, 1986

often more salient and substantial, and thus attention to problems like asthma may be low priority.

Another risk factor for asthma is lack of access to health care. The problem of access to quality health care is two sided, with both patients and physicians being to blame for inadequate health care. As voiced by a number of physicians and health care providers at an asthma conference in Roxbury, Massachusetts, families may have real life barriers that prohibit them from taking advantage of the health care system. Families often have more immediate concerns such as employment loss, rent, transportation expenses, travel time, day care for other children poverty and crime, to contend with, and it is these factors which may prevent them from providing adequate health care for an asthmatic child. "Access to health care is related to purchasing power, and thus lower income groups have limited potential for acquiring the assistance they both need and desire."69 In addition, many families may feel intimidated and confused about how to take advantage of a health care system that they consider to be impenetrable and impossible to understand. These feelings of intimidation are often combined with feelings of powerlessness, and it is this sense of powerlessness which combines "an attitude of self blame, a sense of generalized distrust, a feeling of alienation from resources of social influence, disenfranchisement and economic vulnerability, and a sense of hopelessness,"70 that keep many families from utilizing health care facilities.

In addition to the issues of intimidation and finances, utilization of health care facilities is affected by one's belief system. For instance, beliefs about illness, accessibility, and stigmas associated with seeking help from an organized health system, prevent many families and individuals from taking advantage of our health care system. This argument proves to be especially true within Mexican American, Asian American, and African American communities, where traditional healing practices, family consultations, and self-care practices are common. For instance, "a great deal of health care, within the African American community, occurs outside the formalized health-care delivery systems."

Nevertheless, as mentioned, the problem of access to quality health care is two sided, and thus as pointed out by health providers at the Roxbury conference, physicians must share the blame for inadequate health care and under utilization. Physicians often have problems maintaining contact with

⁶⁹ Nugent, Katherine, "A Model for Providing Health Maintenance and Promotion to Children from Low-Income, Ethnically Diverse Backgrounds", <u>Journal of Pediatric Health Care</u>, Vol. 2, No.4, July-August 1988, Pg. 176

⁷⁰ Braithwaite, Ronald, PhD. & Lythcott, Ngina, DrPh, "Community Enpowerment as a Strategy for Health Promotion for Black and Other Minority Populations", <u>Journal of the American</u> Medical Association, Vol. 261 (2), January 13, 1989, Pg. 283

⁷¹ Thomas, Veronica, PhD., "Explaining Health Disparities Between African American and White Populations: Where Do We Go From Here?", Journal of the <u>National Medical Association</u>, Vol. 84, No. 10, Pg. 839

asthmatic patients who visit their offices, and often fail to have their staff followup on a patient to make certain that appointments are being kept. One primary care provider from a community health center in Boston, mentioned that 24% of scheduled health visits at her clinic were not kept. There are also communication problems to contend with. Physicians sometimes examine up to 50 patients in a day, giving them limited time to interact with each individual patient. And often when physicians communicate with patients, patients have problems interpreting what the physician has instructed them to do. One health care administrator at the conference mentioned that after conducting a survey, he found that only 14% of the patients interviewed could summarize the information they received from their provider. Another example which further illustrates the problem of communication is raised in an article pertaining to health maintenance and promotion for low income, ethnically diverse children. The argument raised in the article is that creative methods of collecting healthrelated information are often needed, in order to contend with communication problems. Asian Americans are used to effectively illustrate the author's point. "Asian Americans tend to be stoic and uncomplaining. They also tend to be polite, respectful, and reserved with strangers... Out of feelings of respect, they may nod their heads and say "yes" even though they may completely disagree or may not understand what is being said."72

Lifestyle and behavioral factors are additional factors that complicate the asthma issue, and they often present major barriers to asthma prevention. Lifestyle and behavioral changes are thought to be key to decreasing asthma rates, and there are a number of recommended behavioral changes that are known to help reduce exposure to allergens and irritants for asthmatic children and adults. Positive behavior and lifestyle changes include purchasing plastic covers to encase pillows and bedding, not smoking in the presence of an asthmatic child, removing old carpeting, purchasing and using a vacuum cleaner regularly, keeping the home pet-free, and taking one's medication on a regular basis. The implementation of these behavioral practices have proven to result in reduced exposure to asthma triggers and reduced severity of asthma attacks. Nevertheless, as mentioned, there are barriers to implementing behavioral and lifestyle changes such as these. For low income, inner city families, implementation of environmental control measures may be impossible if they don't have the means to make lifestyle changes. Families may not be able to purchase plastic mattress and pillow covers for their asthmatic child, or they also may not be able to purchase a vacuum or dehumidifier (all devices which help to reduce dust mite exposure). "And in the case of poor families who rent apartments, they may not be allowed to pull up carpeting that collects dust mites

⁷² Nugent, Katherine, "A Model for Providing Health Maintenance and Promotion to Children from Low-Income, Ethnically Diverse Backgrounds", <u>Journal of Pediatric Health Care</u>, Vol. 2, No.4, July-August 1988, Pg. 180

and animal dander."⁷³ There is also the point that families living in the inner city who have pets may refuse to part with a pet, such as a dog, since the animal is often considered a means of security. These various examples are used to illustrate the point that for many families living in the inner city, environmental changes such as these are not only expensive but impractical.

Behavioral and lifestyle factors can also be risk factors for asthmatic children, when parents refuse to make behavioral changes such as not smoking in the presence of their asthmatic child. Tobacco smoke is a known irritant to asthmatic children, and some parents, despite being educated about the ill effects that smoking may pose for their child, refuse to refrain from smoking when in the company of their child.

And finally, in terms of behavioral factors, asthmatic children and adults often refuse to take their medication. As raised by Dr. John Zwetchkenbaum, who runs an Allergy, Asthma, and Immunology clinic, on the East Side of Providence, Rhode Island, not only do patients voice their concerns about the side effects of medication, but more importantly that they only want to visit the doctor's office and/or take their medication when they are sick. As Dr. Zwetchkenbaum states, "No one wants to take medication when they feel well. And no one wants to see a doctor unless they are sick. And when they do visit the doctor they want immediate improvement."⁷⁴

The final risk factor to asthma to be discussed in this chapter is the psychosocial factor. Psychosocial risk factors seem to pose the greatest problem for those children and families living in the inner city. For parents and children alike, "stresses of inner-city living are likely to increase psychosocial risk factors for asthma."⁷⁵ Families living in inner city neighborhoods often are living in areas where crime, violence, and drug-dealing is rampant. And these factors in combination with other poverty- related stresses are often difficult to contend with. "Many parents find it difficult to cope with these stresses... and pressures of daily living may leave them with little time or inclination to see that children comply with medical treatment."⁷⁶ Even for single parents and parents who don't live in inner city areas, the stress of raising children, providing for their family, dealing with work related problems, and taking care of a sick child can be mentally and emotionally draining.

The stress that results from inner city living can both trigger and increase the severity of their asthma attacks in children. Feelings of alienation as a result of their illness and pressure from their peers to fit in can be huge. For these and

⁷³ Block, Stanley Hoyt, Inner-City Asthma: An Allergist's Perspective, Rhode Island Medicine, Vol. 76, April 1993, Pg. 192

⁷⁴ Interview with Dr. John Zwetchkenbaum at his Asthma Clinic

 $^{^{75}}$ Evans, Richard III, MD, "Asthma Among Minority Children: A Growing Problem," <u>Chest, Vol. 101</u> (6), June 1992, Supplement, Pg. 369S

⁷⁶ Ibid., Pg. 369S

other such reasons, many children suffer from the symptoms of anxiety, depression, anger, rejection, or protectiveness. "At least one study found that aggression, anxiety, and depression are risk-factors for asthma mortality."

⁷⁷ Ibid., Pg. 369S-370S

Chapter 5: Analyzing The Asthma Problem

Throughout the course of this work efforts have been made to reveal the complexity of this multifaceted disease. In chapter one, disease causality and treatment were discussed, in chapters two and three, the importance of asthma prevention and educational interventions were stressed, and in chapter four, barriers to asthma prevention were discussed in order to explain why asthma prevention efforts have not been completely effective. Identifying and understanding the risk factors for asthma is crucial and should be viewed as the first step towards developing effective strategies for the prevention of the disease. Developing innovative prevention and educational interventions is the second step, and if successful, they can help to reduce asthma severity and prevalence. Health care providers as well as the organizations and agencies involved in the fight to prevent asthma, have successfully identified the causes of asthma, identified the ingredients necessary to prevent asthma (i.e. treatment, management, and education), and continue to develop and implement measures to reduce asthma prevalence and incidence. Nevertheless, despite good treatment, adequate medication, and major educational and prevention efforts, the asthma paradox remains. Asthma hospitalization and death rates continue to rise.

The rise in morbidity and mortality rates is both disheartening and frustrating, yet there is hope. Research efforts, carried out over the course of the past two semesters, have revealed a number of findings which if addressed could help to eliminate the asthma paradox.

In this chapter, four major findings will be discussed. The findings are: 1) emphasis on primary and secondary prevention is insufficient 2) the approach taken to educate asthmatic children and their families matters, 3) behavioral changes are affected by four major factors, and 4) environmental, social, and structural factors greatly influence health behaviors. From the analysis of these findings will come recommendations for change. The hope is that if the recommendations are accepted and further addressed, a significant number of the children who suffer and die from asthma each year may be saved.

The first finding to be discussed pertains to primary prevention. Over the course of the past two semesters, I discovered that the amount of emphasis placed on primary prevention is minimal. The majority of the asthma prevention efforts carried out by those organizations and agencies involved with asthma are focused on the tertiary level. Tertiary prevention is the focus of asthma efforts, primarily because it is at this level that the onset of the disease has occurred. Tertiary prevention is also promoted over primary prevention because much less is known about the risk factors for the development of asthma than about the factors that aggravate existing asthma. Also, emphasis is not placed on primary prevention because it is costly, time consuming, and not guaranteed to reduce asthma incidence. In other words, primary prevention is just too risky. This very argument is made by Darryl Zeldin, who is presently conducting a primary

prevention asthma research trial at the National Institutes of Health. "Primary prevention is very costly. Primary prevention trials such as the one that I'm conducting range in cost from \$20 to \$30 million. They require a large study population and take a long time to conduct- often more than 6 to 7 years to complete. And of course there's the point that it is not certain whether the tested intervention will be effective."⁷⁸

In the field of health, there are many such as Martha Tata of the Childhood Asthma Management Program at Harvard Pilgrim Health Care, who argue against the promotion of primary prevention. Ms. Tata's argument is, "primary prevention is illogical, it doesn't make sense to educate people who don't have asthma, especially if they haven't been diagnosed." In contrast, there are others who argue that "disease prevention is an essential component of any plan to improve the health status of Americans," and thus prevention of a disease on all levels is crucial.

Even in the cases of the health maintenance organizations involved in the RIte Care program, primary and even secondary prevention is rarely stressed, if stressed at all. Initially this was somewhat surprising to me since the primary purpose of HMO's is to promote disease prevention. Nevertheless, after some thought, it is not difficult to understand why the focus of those health maintenance organizations with asthma programs is on tertiary prevention. One of the reasons for emphasizing tertiary prevention, as mentioned by Jeanie G'Agostino of Harvard Community Health Plan and Samuel Booker of United Health Plans of New England, is that program participants are identified by emergency room visits and hospitalizations for asthma, and from doctors referrals. Both G'Agostino and Booker argue that their asthma programs are intended to help asthmatic persons effectively manage asthma, reduce asthma hospitalizations, and prevent sickness. And as Samuel Booker adds, "outreach efforts especially in terms of primary prevention are both time consuming and costly, and thus not as worthwhile. By focusing primarily on educating asthmatic patients and providing them with quality primary care, we anticipate that reductions in emergency room visits, length of hospital stays, and overall hospitalizations will result."81

Regardless, the point remains that there is a need for measures which advocate prevention prior to the onset of the disease. Tertiary prevention (as well as secondary prevention) can only reduce asthma hospital and death rates, but not asthma incidence. Primary prevention might reduce the risk of asthma in

⁷⁸ Telephone interview with Darryl Zeldin of the National Institutes of Health

⁷⁹ Telephone interview with Martha Tata who runs the Childhood Asthma Management Program at Harvard Pilgrim Health Care

⁸⁰ Johnson, Charles, "Status of Health Care Among Black Americans," <u>Journal of the National Medical Association</u>, Pg. 125

 $^{^{81}}$ Telephone interview with Samuel Booker of United Health Plans of New England

healthy sensitive individuals; thus there is some incentive to invest in it. As stated by Darryl Zeldin, "if primary prevention works the payoff is big. Asthma costs the public about \$6 billion dollars a year in emergency room visits, doctors visits, missed work days, hospital stays,... if prevalence could be decreased by 2 to 3%, an enormous amount of money would be saved. There is enormous incentive for primary prevention ."82

Lastly, in terms of primary prevention there is the point that "the public is largely uninformed about asthma, even though the extent of ignorance and apathy is unknown." This is coupled with the fact that the majority of healthy individuals are not interested in asthma prevention efforts since they do not have to contend with the disease. For these reasons alone, primary and even secondary prevention must be stressed. If asthma incidence is to be decreased, then those who in the future could be at risk, those presently at risk, and those who are under diagnosed must be targeted for prevention.

Nevertheless, if asthma prevalence is to decrease, the behavior of asthmatic children and their families must change. Despite major educational efforts by organizations and agencies, such as the NHLBI and the ALA, rates are not decreasing. The goal of education is to raise awareness and ensure effective control of asthma, but this goal has not been met. The NHLBI argues that behavioral changes are key to reducing asthma severity and this is the reason why the NHLBI has made education the focus of its asthma programs. The NHLBI claims that "behavioral issues indicate a need for asthma education." In order to change behavior, organizations, agencies, health care provider, and policy makers, must understand some of the factors which influence behavior.

Firstly, they must realize that "health behaviors are influenced by many factors such as lifestyle, information, cultural beliefs, previous health habits, and available resources." In other words, those involved in the fight against asthma must realize that health is but one component of an individual's life. In addition, they must come to realize that competing survival needs often make health promotion and the implementation of behavioral changes a low priority, particularly for poor families. Poor families often face a number of barriers which prevent them from effectively using outpatient asthma services. "These include financial barriers that may prevent asthmatics from purchasing medications or

⁸² Telephone Interview with Darryl Zeldin of the National Institutes of Health

⁸³ Bailey, "Asthma Prevention", Chest, Vol. 102 (3), September 1992, Supplement, Pg. 227S

⁸⁴ National Heart, Lung, and Blood Institute, Office of Prevention, Education, and Control, National Asthma Education and Prevention Program, "Program Description and Background Information," November 1994, Pg. 3

⁸⁵ Nugent, Katherine, "A Model for Providing Health Maintenance and Promotion to Children from Low-Income, Ethnically Diverse Backgrounds", <u>Journal of Pediatric Health Care</u>, Vol. 2, No.4, July-August 1988, Pg. 175

seeking care except during severe crises..."86 Individual behavior change and self care assume that the individual or family has the resources, support, skills, information, knowledge, and ability to do so. Unfortunately, many poor families do not have the means to take responsibility for their health or make health promotion a high priority. Health care organizations, upon recognizing that barriers to behavior change exist and realizing that low income families have limited resources and other issues to contend with, need to implement measures that will help foster change, despite the barriers. For instance, health maintenance organizations should provide plastic mattress and pillow covers, equipment (such as peak flow meters, nebulizers, inhalers), and medication free of charge to those families enrolled in their asthma programs. As long as the families with asthmatic children remain in the program, medications, equipment, and plastic mattress covers should be completely covered. By providing these families with resources to take control of their child's health, they can begin to take control of their health and even make health promotion a higher priority in their lives. For health maintenance organizations the incentive for implementation of such a practice, is that in the long run, they may be able to reduce the asthma severity and hospitalization rates of their asthmatic clientele, and thus reduce health care expenditures. In addition, health maintenance organizations should consider providing their asthmatic clientele with transportation services (via bus, taxi, or van) to and from the physicians office and/or the asthma programs they are enrolled in. These transportation services can be partially covered or provided free of charge, "when medically necessary or when transportation is inaccessible."87 Implementation of this provision can help to eliminate access problems that families may face. However, a contract agreement between the public transit authority and health maintenance organizations would have to be established before such services could be included in the asthma programs or health plans of families with asthmatic children.

Health care providers, agencies, organizations, and policy makers must also realize that factors such as "dominant beliefs about illness, accessibility, stigma associated with seeking help, and organized barriers," can affect utilization of health care facilities, and thus behavioral change. This is particularly true for African Americans, Asian Americans, and Mexican Americans, who receive a significant amount of their health care outside of the

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⁸⁶ Gottlieb, Daniel & O'Connor, George, "Poverty, Race, and Medication Use Are Correlations of Asthma Hospitalization Rates: A Small Area Analysis in Boston", <u>Chest</u>, Vol. 108, July 1995, Pg. 34

 $^{^{87}}$ Office of Managed Care, Rhode Island Department of Human Services, "RIte Care Program", (Program Informational Packet), Pg. 4

⁸⁸ Thomas, Veronica, PhD., "Explaining Health Disparities Between African American and White Populations: Where Do We Go From Here?", Journal of the <u>National Medical Association</u>, Vol. 84, No. 10, Pg. 839

health care system. Similarly, it is crucial that an understanding of the "historical, cultural, and structural aspects of society that continue to oppress African Americans and other peoples of color be gained, since these factors greatly impact health behavior and the health system." Once an understanding of the factors that determine an asthmatic child and their family's utilization of health care has been gained, strategies to promote healthful behavior can be made.

Fostering behavior change is difficult, yet health care providers and those involved in asthma efforts will have to convince asthmatics and their families that there are practices which they can implement that can help reduce exposure to triggers and decrease the severity of the asthma. However, for this to occur, health care providers must think about how they will educate families. It should be noted that deciding upon the approach to be taken to educate asthmatic children and their families is the second research finding. As discussed in chapters two and three, education is a key component of asthma prevention. Many health care providers, organizations, and agencies believe that by providing parents and children with certain skills and information, families will be empowered to take control of their asthma, and that this is an effective way to reduce asthma incidence and prevalence. Several randomized controlled studies have even concluded that "education programs have effectively reduced the number of asthma episodes, emergency department visits, and hospitalizations of children, particularly in previously hospitalized children."90 Of course, the approach taken to educate parents and children is critical to efforts to provide the skills necessary to combat asthma. "Educational barriers may impair the ability to understand medical advice and learn appropriate self-management skills."91

Parents and asthmatic children are in need of appropriate and culturally relevant education and training, particularly African American, poor, and uninsured families. This is especially true since beliefs about illness and health are a part of the cultural and ethnic heritage of many families. Similarly, asthma education must also be linguistically and literacy-level appropriate. For instance, for low literacy level parents, there is a need to develop effective low literacy level asthma material, which can communicate the importance of asthma management in an easy-to-understand way. It does not make sense to bombard families of asthmatic children with asthma literature which they have difficulty understanding. If we are to reduce asthma rates, then educational information about asthma must be appropriate for the populations it targets. For instance,

⁸⁹ Ibid., Pg. 838

⁹⁰ National Heart, Lung, and Blood Institute, Office of Prevention, Education, and Control, National Asthma Education and Prevention Program, "Program Description and Background Information", November 1994, Pg. 3

⁹¹ Gottlieb, Daniel & O'Connor, George, "Poverty, Race, and Medication Use Are Correlations of Asthma Hospitalization Rates: A Small Area Analysis in Boston", <u>Chest</u>, Vol. 108, July 1995, Pg. 34

asthma information intended for low literacy level families which is written in a technical manner is inappropriate. Effective, appropriate material, would need to consist largely of illustrations, contain short sentences written in large print, and messages should be written in a simplistic manner.

If health care providers are to educate parents and children in such a way that they take control of their condition, they too must be convinced that proper patient education can result in behavior change. "Too often, physicians equate education with the simple provision of information, and when patients fail to change behavior on the basis of information alone, patient education is deemed ineffective."92 In order for behavior to change, a patient must be convinced by the physician of their susceptibility to asthma and the severity of their condition, the effectiveness of the techniques used to treat their condition, and believe in their individual ability to implement the techniques the physician has prescribed. If physicians are to change behavior, many will have to be re-educated about asthma signs, symptoms, management strategies, the impact of cultural differences on behavior, and how to communicate with patients. Dr. LeNoir argues that in addition to physician education, many physicians need to be made aware of asthma practice guidelines and need to gain a better understanding of pathophysiology. "Physicians place emphasis on the management of acute episodes, yet not enough emphasis is placed on dealing with the underlying causes of the disease. So they are treating asthma in response to symptoms instead of underlying conditions."93

The third research finding is, behavioral changes are inhibited by four factors: 1) an individual's mindset, 2) cultural practices, 3) understanding and communication problems, and 4) environmental, social, and structural conditions. An individual's mindset can be considered a major barrier to behavioral change, since it determines a person's actions. This factor inhibits behavioral changes specifically among indigent minority families. Indigent minorities in inner cities tend to use hospital emergency rooms as their primary source of medical treatment and tend to visit the emergency room of hospitals for crisis care. This type of behavior can pose a particular problem for asthmatic children, since constant care is needed to manage the disease. Dr. Zwetchkenbaum, who runs an Allergy, Asthma, and Immunology Clinic on the East Side of Providence, makes a similar point. He states, "even in the case of those RIte Care patients who have access to a primary care physician through their HMO, they still go to the hospital when they experience an asthma attack. So you see, in many instances it is the mindset of the patient which must be changed, if behavioral changes are to be witnessed. This is a very complicated and frustrating issue."94 A similar argument is made by Dr. Stanley Hoyt Block.

⁹² Bailey, "Asthma Prevention", Chest, Vol. 102 (3), September 1992, Supplement, Pg. 226S

⁹³ Ibid., Pg. 1004

⁹⁴ Interview with Dr. John Zwetchkenbaum

Dr. Block states, "in some urban centers, more than half of the children with asthma may receive their entire asthma medical care in an emergency room, without enrollment in a chronic, continuous asthma medical program which is so necessary to manage this difficult, chronic disease."95 Understanding the mindset of an asthmatic child and his/her family, is extremely important. By understanding the mindset of asthmatic children and their families, physicians, educators, and policy makers, may be able to develop some innovative measures which may help to change the behavior of those individuals and families who do not implement the management practices necessary to take control of their condition. To foster change in those asthmatic children and families, who do not access their primary care physician and instead depend on emergency rooms for medical care, HMOs can consider giving benefits if the families maintain enrollment in their asthma programs and seek care from a primary care physician on a regular basis. Benefits could include provision of medication and equipment free of charge or at reduced costs, in addition partial or full reimbursement for transportation expenses to and from doctors visits and/or the asthma program can be offered. (For those families with children enrolled in the RIte Care program fee-for-service benefits such as dental services, and certain mental services can be offered at reduced rates, if the families seek care from a primary care physician on a regular basis. In addition, lower fees can be charged for uninsured siblings of eligible children who also want to participate in the RIte care program. At present the state of Rhode Island "offers several buy-in provisions for uninsured siblings of eligible children." 96

Understanding the cultural practices that influence the lives of many ethnic families is another factor that can inhibit behavioral change. Aside from lifestyle habits, health outcomes are largely the result of customs. Health behaviors are culture bound, and thus cultural practices can interfere with parents seeking medical care for their asthmatic child and/or complying with their child's treatment regimen. Thus, there is a need for those involved in asthma efforts to be sensitive to the beliefs and values of those they serve.

As mentioned by Katherine Nugent, "beliefs about the causes of illness and the maintenance of health care are an integral part of the cultural and ethnic heritage of families and they influence perceptions of health promotion." So the promotion, deliverance, and provision of health care must be relevant and sensitive of the cultural and ethnic values and beliefs of the populations served. For instance, many African Americans, Asian Americans, and Mexican

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⁹⁵ Block, Stanley Hoyt, Inner-City Asthma: An Allergist's Perspective, <u>Rhode Island Medicine</u>, Vol. 76, April 1993, Pg. 191

⁹⁶ Office of Managed Care, Rhode Island Department of Human Services, "RIte Care Program", (Program Informational Packet), Pg. 2

⁹⁷ Nugent, Katherine, "A Model for Providing Health Maintenance and Promotion to Children from Low-Income, Ethnically Diverse Backgrounds", <u>Journal of Pediatric Health Care</u>, Vol. 2, No.4, July-August 1988, Pg. 176

Americans, rely on traditional healing practices and implement self care practices, as opposed to relying on formal health care. In the African American community for instance, many families consult with family members on health issues, visit with folk or lay healers, use home remedies, and other such self care practices. However, by developing culturally relevant education and promoting appropriate strategies for ethnically diverse families, it may be possible to change the behaviors of families with asthmatic children, and eventually see a decrease in asthma mortality and morbidity. The asthma material developed would need to include pictures/illustrations of children of color and talk about the importance of seeking care from our formalized health care system. Messages stressing the use of self care practices for minor health problems would be relayed, however, messages arguing that asthma is a serious disease, one requiring constant treatment, medication, and proper medication would be stressed. Asthma would need to be characterized as a major health problem, one that can not be treated with self care practices.

Understanding and communication problems are additional factors that can inhibit families and children from making necessary behavioral changes. These two factors are especially important, because they can impair one's ability to interpret medical advice and learn appropriate self-management skills. Communication and understanding can pose particular problems when dealing with non-English speaking families of asthmatic children. Physicians, such as Dr. Block and those at the Roxbury asthma conference, have expressed their difficulties in teaching non-English speaking families about equipment, medication, and the importance of avoiding asthma triggers. Still, doctors also admit that there are difficulties in trying to communicate with English-speaking patients. Yet, the reasons for communication problems must be shared by both physicians and patients. In the case of physicians, their time spent examining and speaking with each patient is limited. And as Samuel Booker states, "ten minutes with a patient isn't asthma education."98 And on the reverse side, as mentioned by Dr. Zwetchkenbaum, "patients often have a lot on their minds, and thus do not always absorb what they have been instructed to do."99 In order to contend with communication problems, physicians need to make sure that time is taken to educate the patient about medications, equipment, and treatment. For instance, during a visit with the patient should explain to the patient the correct way to use equipment such as inhalers, once this is done a nurse or a physician's assistant can take the time to show the patient how to use the medication properly, demonstrating on themselves, and then asking the patient to demonstrate what they've learned. By having a nurse or assistant demonstrate proper equipment use, as opposed to the physician, more time can be spent ensuring that the patient fully understands what they are to do, and allow the

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 $^{^{98}}$ Telephone interview with Samuel Booker of United Health Plans of New England

⁹⁹ Interview with Dr. John Zwetchkenbaum

physician to treat as many patients as possible. In addition, when giving instructions, physicians should always repeat them, and after, ask the patient if they have any questions and whether they understand what they must do. It might even be helpful to have the patient repeat the instructions back in the physician in their own words.

In terms of communication, there is also a need to assess and identify the individuals to whom information should be disseminated. In other words, there is a need "to assess the functions and role structure of the family. Who cares for the child most of the time? Who disciplines the child? And who makes the final decision for a family?"¹⁰⁰ Children are often brought to health care clinics and doctors offices, by day care workers, parents, relatives, siblings, neighbors, friends, and other care providers. "An assumption can not be made that intervention should be aimed at the individual accompanying the child."¹⁰¹ For instance, if a father accompanies his asthmatic child to the physicians office (but the mother and grandmother who are also the child's primary care providers are not present), then the physician should consider writing a note in a simplistic, non-technical manner, to the mother and grandmother to explain the interventions discussed during the visit. Such a note could serve as a reminder for the father, mother, and grandmother, and help ensure that all those involved in making health decisions for the child are included.

Another finding that pertains to communication and understanding is that innovative measures are often needed to collect information from families, as well as, to determine whether they agree and comprehend what is being said. The example used to illustrate this point is one which was raised in chapter 4. Ethnic groups, such as Asian Americans tend to be uncomplaining, respectful, and polite to strangers. Out of respect for others, they may say or nod yes, when in actuality they neither understand nor agree with the message being relayed.

Nevertheless, if communication problems are to improve and behaviors are to change, physicians must take the time to ensure that they are effectively communicating with patients. They must work with patients and consider their relationship with patients to be one based upon team work. Physicians, of all those involved in the fight to prevent asthma, have considerable influence over patients. If they can effectively communicate with patients, they can help foster behavior change. As Diane Brandlee of United Health Plans of New England states, those physicians who take the time to educate their asthmatic patients are extremely effective in keeping asthma hospitalizations to a minimum.

The impact of environmental, social, and structural conditions on behavior is the fourth factor which inhibits change. Behavior is key to asthma

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¹⁰⁰ Nugent, Katherine, "A Model for Providing Health Maintenance and Promotion to Children from Low-Income, Ethnically Diverse Backgrounds", <u>Journal of Pediatric Health Care</u>, Vol. 2, No.4, July-August 1988, Pg. 178-179

¹⁰¹ Ibid., Pg. 178

management, yet "the environmental, social, and structural conditions under which behaviors and attitudes are developed, reinforced, and expressed,"102 can affect change. Health care providers must come to realize that health behaviors are influenced greatly by factors such as lifestyle and availability of resources, and yet these factors are influenced by the environmental and social factors in which families live. It is because of the impact that environmental, social, and structural conditions have on behavior, that more emphasis must be placed on environmental, social, and structural factors. It should be noted that emphasis on environmental, social, and structural factors is the final finding of this research effort. Health care providers and policy makers must come to realize the difficulty in promoting behavioral change without altering the environmental factors and social conditions that affect families, especially low income families. There is a need for increased sensitivity to environmental, social, and structural conditions, especially when speaking of African Americans and other minorities of low social class position. "Blacks and others of low social class position may be exposed to a variety of environmental conditions which can contribute to asthma exacerbations leading to fatal episodes, including ambient air pollution, dust mites, cigarette smoke, pets, indoor molds, and cockroaches."103 "Also asthma is more common among children living in poverty, and social and environmental characteristics appear to exert substantial influences on rates among children who have their onset before age six." 104 Health care providers will need to focus on providing information that stresses the importance of smoking cessation as well as identifying and reducing exposure to triggers such as cockroach allergens, pet dander, and dust mite allergens. These are all triggers that specifically affect asthmatic children living in urban environments with high levels of outdoor and indoor air pollution and poor housing conditions. Health care providers, by implementing measures which encourage parents to quit smoking (or not smoke in the presence of an asthmatic child), remove old carpeting, cover mattresses, keep the house clean, and remove pets (or keep them out of the child's room), can help foster change and reduce an asthmatic child's level of exposure to likely triggers.

Asthma is a very complex condition, yet by recognizing and understanding some of factors discussed in this chapter, it may be possible to reduce asthma incidence, hospitalizations, and deaths. Nevertheless, this chapter

¹⁰² Thomas, Veronica, PhD., "Explaining Health Disparities Between African American and White Populations: Where Do We Go From Here?", Journal of the <u>National Medical Association</u>, Vol. 84, No. 10, Pg. 839

¹⁰³ Marder, David, "Effect of Racial and Socioeconomic Factors on Asthma Mortality in Chicago", Racial and Socioeconomic Factors in Asthma Mortality, <u>Chest</u>, Vol. 101 (6), June 1992, Supplement, Pg. 428S

 $^{^{104}}$ Weitzman, Michael, "Racial, Social, and Environmental Risks for Childhood Asthma," AJDC - Vol. 144, November 1990, Pg. 1192

only identifies some of the factors that must be changed. The next chapter presents recommendations for where changes can and should be made.

Chapter 6: Strategizing To Solve The Asthma Problem

A number of issues raised in chapter five help to further explain why asthma efforts have not been effective in reducing asthma prevalence and incidence. This chapter will expand upon the findings discussed in chapter five, and possible responses to the findings will be suggested. Potential strategies to address the problem of asthma will be discussed in terms of: 1) tertiary prevention 2) primary and secondary prevention, 3) educational approaches, 4) behavioral change and 5) school involvement.

Tertiary prevention of asthma is the last level of intervention, the level at which the child has already developed the disease and efforts are made to reduce disease frequency and intensity. Increased emphasis on tertiary prevention is a crucial component of asthma prevention if asthma hospitalization and death rates are to decrease. In terms of all of the recommendations to be discussed in this chapter, priority should be given to those that pertain to tertiary prevention. This is so not only because the onset of the disease has already occurred and the need therefore is immediate, but also because not enough is known about asthma causality to argue in favor of giving a higher priority to the primary and secondary levels. By providing families and asthmatic children with the proper skills and information necessary to take control of asthma symptoms, I am confident that a reduction in childhood asthma hospitalization and deaths is possible. However, in order to achieve this goal, emphasis must be placed on educating families about the importance of asthma prevention and behavioral change, and then developing innovative measures to foster such change.

In the previous chapter, the importance of the approach taken to educate families of asthmatic children was raised. The approach taken to educate families and asthmatic children is extremely important, and ineffective communication may help to explain why educational efforts have not been effective in reducing asthma morbidity and mortality. In the past, organizations, agencies, and health care providers have implemented various measures to relay the importance of asthma prevention and foster behavior change, yet their success has been limited. For this reason, organizations and agencies (specifically health maintenance organizations) and health care providers need to develop innovative measures which will more effectively relay to parents and children the importance of recognizing asthma symptoms, taking medication, reducing exposure to potential irritants, and taking control of the child's illness. Consideration should be given to educational approaches such as story telling, use of puppets, showing of videos, live demonstrations, and/or computer games. These measures are suggested because they are likely to appeal to children since they are forms of entertainment. There is also the point that children have a tendency to relate better to visuals and characters in stories, then just words.

United Health Plans of New England is an example of a health maintenance organization that realizes the importance of the approach taken to educate children. At United Health Plans puppets are used when lessons are given to children about identifying and controlling asthma. Dr. Zwetchkenbaum, of Rhode Island, also recognizes the importance of how families and children are approached with asthma information and worries that the educational approach that many doctors are taking is wrong. It is for this reason that he is developing an interactive CD-ROM game, that educates pre-adolescents about asthma in a language that kids understand. Nevertheless, it should be noted that the educational devices suggested, have not yet been evaluated to determine their level of effectiveness. For this reason, health maintenance organizations should implement these measures into their programs in order to test their effectiveness. The test will help to determine whether children respond better to visuals (i.e. videos, live demonstrations, puppets) and understand asthma more as compared to when instructions and lessons are given without the use of visuals. Children can be asked questions that pertain to the information relayed in videos, live demonstrations, and stories, in order to determine the effectiveness of these educational devices.

Behavioral and lifestyle changes, have been discussed throughout this thesis, since behavioral change is considered to be key to reducing asthma severity in asthmatic children. Yet, behavioral change is extremely difficult since changes are often inhibited by a number of different factors, such as economics, environment, lifestyle, cultural beliefs, information, and available resources.

In order to foster behavioral changes the following recommendations should be considered. First, physicians need to develop innovative measures to encourage families of asthmatic children to make changes. For instance, physicians should consider devising lists that contain important information for asthmatic children and their parents to follow. "These lists could include information about: 1) common asthma triggers which should be avoided, 2) medication prescribed by the doctor for the child, 3) common side effects of the medication, 4) what to do during an emergency, and 5) the telephone numbers of who to contact during an emergency." A "physician's list" could serve as a constant reminder to parents and children, and help make asthma a high(er) priority in a family's life.

Physicians can encourage the use of "asthma diaries" to be kept by children to help them gain control of their disease, as well as a better understanding of the disease. The use of an asthma diary would not only benefit the child but also provide important information to the physician. "For the physician the diary could reveal patterns in a child's asthma. A physician may discover that a child's attack is after a combination of two activities, even though either of those activities alone does not cause an attack." And as Dr. Floyd Malveaux adds, "children who participate in their own asthma management are less likely to panic at the onset of an attack and less likely to be rushed to the

106 "Pediatric Asthma Deaths Continue to Increase", <u>American Family Physician</u>, Vol. 38, No. 3, Pg. 376

¹⁰⁵ Shuttari, Mir. F, "Asthma: Diagnosis and Management, American Family Physician, Vol. 52, No. 8, December 1995, Pg 2231

emergency room for every attack." ¹⁰⁷ The asthma diary is also a tool which could help improve physician-patient communication and help reveal the importance of team work (between physicians and patients) in managing asthma.

To help reduce asthma hospitalization and death rates, physicians also need to encourage the use of peak flow meters. Peak flow meters are very useful for monitoring a child's asthma, since "asymptomatic changes in peak flow often precede deterioration." Peak flow meters are not only helpful to the child, but also the physician. "Peak flow measurements greatly enhance the physician's ability to give a clinical assessment by telephone of an asthma exacerbation and the patient's response to treatment." Peak flow meters are another good example of how doctors and enough health care organizations can stress and foster self-management of asthma. As Jeanie G'Agostino, of Harvard Community Health Plan states emphasis is placed on teaching patients how to control of their condition. Each individual enrolled in the Harvard Community Health Plan asthma program, identifies his/her personal best peak flow level, so that participants can effectively monitor their asthma, keep asthma severity to a minimum, and take control of their condition.

Peak flow monitoring is a measure that physicians as well as those health maintenance organizations that don't encourage it, need to consider. By providing patients with peak flow meters free of charge and teaching them how to use the meters properly, health maintenance organizations and physicians can help foster behavioral change, and thus good asthma management practice. The incentive for this provision is that childhood asthma severity, and in turn hospitalization and death rates can be reduced.

Another major factor that has inhibited health promotion and asthma prevention is inflexibility in regard to medical appointments. Strict medical appointments pose tremendous problems for families who have children other than their asthmatic child, and who have employment and transportation problems. Heath care providers need to take this factor into consideration. If and when families miss appointments, they need to take the time to schedule a new appointment, nevertheless, it is equally important that a staff person from the physician's office (i.e. receptionist or physician's assistant) investigate why the appointment was missed and also attempt to reschedule the appointment. In addition, it might be beneficial to call the home of an asthmatic child the day before the scheduled appointment in order to remind them of their expected visit.

The last suggestion in terms of tertiary prevention pertains to the provision of environmental exposure assessments of the home. Health

¹⁰⁷ Ibid., Pg. 376

¹⁰⁸ Moffitt, John & Gearhart, Judith, "Management of Asthma in Children", <u>American Family Physician</u>, Vol. 50, No. 5, 1044

¹⁰⁹ Ibid., Pg.1047-1048

maintenance organizations, to promote tertiary prevention further, need to offer periodic home assessments for their asthmatic clientele. The Visiting Nurses Association of Rhode Island and United Health Plans of New England, are two organizations that perform environmental exposure assessments of the home during the first visit with a client. Samuel Booker of United Health Plans of New England argues that "home assessments of environmental triggers are vital. They allow us to identify from any to all of the triggers that a person can be exposed to."110 A reassessment of the home should occur after asthmatic children and their families have been taught the importance of reducing exposure to potential asthma triggers and been informed of the behavioral changes they should make. By reassessing the home environment, health maintenance organizations can better determine if the family is implementing environmental control measures. Reassessment of the home might confirm that old carpets have been removed, plastic mattress covers have been purchased, or that pets have been removed or confined to certain parts of the home. On the contrary, reassessment could also confirm that change has not occurred, and thus continued efforts must be made to spark change.

Health maintenance organizations, if they decide not to provide periodic environmental exposure assessments, should consider training people from local communities to complete the assessments. Respiratory therapists or nurses who are presently working for health maintenance organizations or who have worked for the organizations in the past, can be hired to train volunteers and to act as liaisons between the health maintenance organization and the volunteers. Volunteers, can include mothers of asthmatic children who are currently enrolled in their health maintenance organization's asthma program, persons who have had their home assessed in the past, members of asthma support groups, or persons from the community simply interested in volunteer work. Volunteers could undergo an intensive one day seminar, which includes information about asthma causing agents and information on how to properly assess a home. At the conclusion of the seminar, volunteers would have to take a written test and visit a minimum of two homes with the seminar instructor to assess. Once volunteers are ready to assess the homes without the instructor, they would need to be provided with a checklist of common triggers to look for during a home visit and work in teams of two (to better ensure successful home assessments). Volunteers, upon completion of each home assessment, would report to the liaison, who in turn would report to the health maintenance organization. The advantage of promoting this proposal is that a community's awareness, interest, involvement in the fight against asthma will most likely be raised, and a sense of community empowerment may also be gained. For health maintenance organizations, the advantage of promoting this proposal is that home assessments can confirm

¹¹⁰ Telephone interview with Samuel Booker of United Health Plans of New England

whether or not families of asthmatic children are implementing the measures necessary to reduce exposure to triggers and control their child's asthma.

In chapter five, the need for primary prevention was discussed. The argument was made that tertiary prevention can help reduce rising hospitalization and death rates, but, that if the rising rate of asthma incidence is to be reduced, then investment in primary prevention is a must. In other words, early identification and intervention of potential at-risk and underdiagnosed children is a must. Nevertheless, before investing in primary prevention, there is a need to raise the public's awareness of this disease. Asthma awareness education must precede primary prevention efforts, in order to make people care about the illness. And as mentioned, there is widespread agreement that the American public is largely uninformed about asthma. "The extent of ignorance and apathy is just not known."111 Organizations and agencies such as the NHLBI, EPA, and ALA, who are involved in promoting asthma awareness and prevention, need to make the public aware that asthma is a serious disease but also a treatable disease. In regard to messages about the seriousness of the disease, they need "to include information about prevalence and incidence of asthma, especially in high-risk populations."112 And in regard to messages about treating the disease, "messages could describe how effective management and communication with health care providers can reduce its impact."113

A perfect example of awareness education is the AIDS awareness campaign. The media, through the newspaper, television, movies, and music, have bombarded the American public with information on AIDS. The media, in addition, to schools, organizations, and agencies, involved in the fight against AIDS, have gone to great lengths to educate the public about AIDS. And if surveyed, I am confident that most people will agree that they are at least somewhat aware of AIDS, its effect on the human body, where to receive help if needed, and what they can do to reduce the likelihood that they will contract the disease. Of course, the promotion of an asthma campaign would differ from the AIDS campaign, in that the AIDS campaign is promoting an untreatable fatal disease. Famous athletes, musicians, and shoe companies such as Nike and Reebok, can be used to promote campaign messages about asthma. And since advertisement campaigns are costly, it may be in the best interest of health maintenance organizations, pharmaceutical companies, government agencies (such as the EPA, Department of Health, ALA, and the NHLBI), to consider sharing costs to advertise and promote asthma awareness.

As discussed in chapter five, emphasis has not been placed on primary prevention of asthma because not enough is known about disease causality or whether primary prevention can in fact reduce asthma incidence. And most

¹¹¹ Bailey, "Asthma Prevention", Chest, Vol. 102 (3), September 1992, Supplement, Pg. 227S

¹¹² Ibid., Pg. 227S

¹¹³ Ibid., Pg. 227S

organizations and agencies do not invest in primary prevention because it is both costly and time consuming Nevertheless, I will argue that primary prevention is not only important but also that there is some incentive to invest in it.

As Darryl Zeldin of the National Institutes of Health argues, because primary prevention has considerable potential to prevent the development of asthma, it is worth investing in. "Asthma costs the public about \$6 billion a year in emergency room visits, doctors visits, time missed from work, and hospital stays. A decrease in prevalence by 2 or 3% is enormous incentive to invest in primary prevention of the disease."114 However, I will agree that because investment in the development of primary prevention interventions is both costly and time consuming, that it does not make sense for health maintenance organizations, universities, or drug firms to invest in the development of primary prevention interventions. Instead, since government, has both the time and financial resources it should engage in primary prevention. Thus, my primary recommendation for primary prevention is in terms of research. Government institutions, such as the National Institutes of Health and the Center for Disease Control, should engage in research efforts which will provide more insight into asthma causality, the role of genetics in the development of the disease, and treatments which might prevent children and adults from developing asthma. And since primary prevention, "is prevention which hinders asthma from occurring in healthy individuals,"115 the population targeted for these studies does not matter. Nevertheless, since the poor, minorities, individuals with a family history of asthma, and children are disproportionately at risk and affected by asthma, it makes sense to include them in primary prevention research trials.

Still, there are primary prevention efforts that health maintenance organizations can consider investing in. For instance, they can advertise their asthma education programs to physicians and send out brochures and letters which encourage early identification and diagnosis of potential asthmatic children. In addition, they can target outreach efforts at children who have siblings already enrolled in health maintenance organization asthma programs. United Health Plans of New England is an example of a health maintenance organization that engages in primary prevention efforts such as this. According to Samuel Booker, most of United Health Plans of New England's primary prevention outreach efforts are through mailings and telephone calls. Twice they have engaged in mass mailings of brochures and letters to physicians. And a total of fourteen hundred primary care physicians, allergists, and ear, nose and throat physicians, received brochures about United Health Plans of New England asthma program and letters which encouraged them to spread word about the asthma program and pay more attention to diagnosing and identifying

 $^{^{114}}$ Telephone interview with Darryl Zeldin of the National Institutes of Health

¹¹⁵ Bailey, "Asthma Prevention", Chest, Vol. 102 (3), September 1992, Supplement, Pg. 216S

asthmatics. Samuel Booker considers these outreach efforts to be costly and time consuming, but argues that they are still worthwhile, since the result is raised awareness about the organization's asthma efforts.

Secondary prevention "detects asthma early when it is asymptomatic and when early treatment can prevent the disease from progressing," thus it may be more enticing to health maintenance organizations than investment in primary prevention. Secondary prevention efforts can include administering allergy and blood tests, taking chest x-rays, and conducting lung function measurement tests (i.e., bronchio challenge tests and peak flow monitoring) to children diagnosed with respiratory problems or asthma-like symptoms. This type of intervention may be very enticing to health maintenance organizations since early identification of asthmatics can result in reduced asthma severity and frequency, as well as hospitalization rates.

The final recommendation is to get the schools involved in asthma prevention efforts. A perfect example of this, is the Open-Airways Curriculum for Schools program. Aside from playing an educational role, schools are playing more of a social role, and thus they need to consider playing a role in asthma prevention. More and more schools in this country provide day care services for students with children, food, after school programs for elementary school children whose parents work, health care services (such as yearly eye and ear examinations), and transportation services. Children spend a significant amount of their day in school, thus schools should consider the role they can play in the lives of asthmatic children. As mentioned early in this research effort, over 1 million school-aged children suffer from asthma, making it the number one reason for school absenteeism in children in the United States. Asthma accounts for 10 million lost school days a year for children. In addition asthma can affect a child's academic and physical performance level as well as limit their involvement in activities. These reasons should provide enough incentive for schools to get involved in the fight against asthma. Aside from integrating a program such as the Open-Airways Curriculum into schools, a child's treatment plan can be integrated into schools. Children with asthma can come to school with an "asthma card". This card would include information about the necessary actions to be taken if and when an attack occurs, who to contact during an emergency, and what medications the child must take while at school. Since most school teachers do not know what actions to take if a child has an asthma attack, schools might consider inviting a health care provider or asthma educator to the school to provide the teachers with some training. A training section could include demonstrations on how to properly use asthma equipment such as peak flow meters and inhalers, as well as guidance on what measures to take during an emergency. The incentive for educating teachers and integrating asthma curriculum into schools, is that school absenteeism due to asthma may decrease.

¹¹⁶ Ibid., Pg. 216S

Conclusion

The goal of this research effort was to provide insight into the complexity of our nation's asthma problem. It was intended to provide explanations on why the educational interventions and prevention efforts of organizations such as the NHLBI, ALA, and EPA, have not been totally effective. But more importantly to help people understand the asthma paradox and why it exists. By doing so, my hope was that I could then make some recommendations which might help foster change. As mentioned throughout this work, asthma is a very complicated disease. Nevertheless, asthma prevention and a lessening of asthma's affect on children is possible. Hopefully, as a result of the research and analysis conducted on asthma and the programs involved in asthma prevention, a more effective way of educating parents and children about asthma can be identified, a way which will foster additional behavioral and in some cases lifestyle changes. I am confident that if the recommendations proposed in this paper are considered and implemented by those fighting against asthma, that they may be able to save a significant amount of the children who suffer and die from asthma each year.

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