

The Importance of Place

Asthmatic Children's Perceptions of Inside and Outside Environments

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Executive Summary

Asthma is dramatically increasing among impoverished, inner-city child populations. Because asthma is an environmentally induced disease, it has the potential to influence children's understandings of and perceptions of place. I interviewed fourteen asthmatic and twelve non-asthmatic children in Providence between January and March 2001 to shed light on asthmatic children's understandings of illness and how the asthma experience influences and shapes their "sense of place."

For this qualitative study, I asked several questions: In what ways do children with asthma understand their illness? What is the influence of the asthma experience on environmental attitudes and perceptions? In what ways do these perceptions influence activities and daily life?

The interview was comprised of asthma related and place related questions, including a picture response activity and a Children's Health Locus of Control Scale, used to evaluate how much perceived control exists over one's health. The interview for the asthmatic children was about twenty minutes long and the interview for the non-asthmatic children did not include asthma-related questions and was about ten minutes long. I also interviewed parents, school nurses and teachers, and observed the children in their school environments.

Findings

My findings consist of two parts: ways in which children understand their asthma and ways in which children understand place.

Children with asthma expressed different attributes of and responses to the disease:

- They regard asthma as an interruption in daily life
- They express feelings of powerlessness over the disease
- They use reactive rather than proactive treatments
- They describe their asthma using "lived experiences" rather than clinical definitions

Asthmatic children reported three negative impacts of asthma on daily life:

- They spend less time outside
- They are restricted in their physical activity
- They spend less time with friends.

Children appeared to have adapted to their asthma and exhibited no awareness of negative stigmatization.

Asthmatic and non-asthmatic children valued similar places and similar aspects of places. All children appreciated places that were:

- Stimulating
- Offered freedom

- Comfortable
- Social
- Familiar
- Safe

Children rarely mentioned aesthetic aspects of place.

While asthmatic and non-asthmatic children valued similar places and similar aspects of places, there were fundamental differences between their reasons for valuing these places:

- While both groups referred to social aspects of places, asthmatic children emphasized family members while non-asthmatic children emphasized friends.
- Asthmatic children rather than non-asthmatic children negatively referred to places they regarded as isolating.
- Asthmatic children more consistently valued familiar places, while non-asthmatic children valued places that offered exploration.
- While all children valued “safe” places, asthmatic children referred to places as unsafe because they contained asthma triggers while non-asthmatic children referred to places as unsafe because they harbored violence.

The Children’s Health Locus of Control scale revealed similar scores for both populations; however, specific questions within the scale illuminated a tension between relegating control to figures of authority and taking personal responsibility over illness.

Recommendations

My findings lead me to conclude that asthma education programs are valuable in providing children with an understanding of their illness. I recommend that:

- Asthma education programs incorporate and validate “lived experiences” in their classes, as well as skills that foster self-empowerment and responsibility, important for impoverished children with and without asthma.
- Medical advocates and environmental activists narrow the gap between their respective projects and work together to combat asthma
- Reinvigorating inner city neighborhoods to provide community infrastructure and public open spaces can help to foster positive perceptions of outdoor environments

Subsequent researchers may want to interview parents of children with asthma, interview children of different socio-economic backgrounds, and evaluate the impact of intervention programs on children’s “sense of place.”

Introduction

The ways in which we interact with each other and the environment defines how we, as individuals, live our lives. We form a web of relationships: of self and place, place and experience, and self and experience (Wozniak, 1993). Environmental attitudes and perceptions are reflected in the ways in which people relate to the places around them, in the activities they choose to do, and the impact they have on the world.

Exploring “sense of place” is not new to environmental discourse. Environmental philosophers and theorists from Thoreau to Aldo Leopold to William Cronon have given voice to the importance of place on an individual level. It is within this theoretical framework that I approach the dramatically increasing problem of childhood asthma in Providence, Rhode Island.

Because asthma is an environmentally induced disease that is prevalent among an impoverished urban-based child population, it has the potential to influence children’s perceptions of place. I attempt to explore these influences and speculate on the implications that they may have on children’s lives. Understanding the common environmental perceptions of children with asthma can help to influence asthma intervention programs and inform people in helping these children obtain a sense of safety and stability in the world.

There are many questions that emerge. In what ways do children with asthma understand their illness? What is the influence of the asthma experience on environmental attitudes and perceptions? In what ways do these perceptions influence

activities and daily life? Below, I provide a brief synopsis of the problem and relevant literature, including childhood asthma in Providence, perceptions of illness, self and environment.

Childhood Asthma

Asthma is one of the nation's most common and costly diseases (Jackson, 1998). Fourteen to 15 million Americans, 5 million of whom are children, have asthma. Asthma is the most common cause of hospitalization in young children in the US, affecting more than one out of a hundred children and is also responsible for most of the school days missed among elementary school children (Jackson, 1998). In 1993, asthma accounted for an estimated 198,000 hospitalizations and 342 deaths among persons younger than 25 years old (Wilson, 1998).

What is even more disturbing is that the prevalence of asthma is on the rise. Over the past fifteen years, the number of children with asthma has doubled to total approximately 6 million. Deaths among asthmatic children increased 78% from 1980 to 1993. The estimated medical costs associated with asthma increased from \$4.5 billion to \$6.2 billion between 1985 and 1990 (Block, 1999).

Little is known about preemptive prevention of asthma, or why asthma levels are increasing. It is generally agreed that certain substances in the environment commonly trigger asthma symptoms, and most programs designed to control asthma address not only appropriate medications, but environmental triggers. Common environmental asthma triggers include dust mites, animal danders, cockroaches, molds, pollens, cigarette

smoke and indoor and outdoor air pollutants. Other well-known triggers are extreme emotions and temperatures, and exercise (Wood, 1996).

Asthma and Environmental Justice

“Whoever wishes to investigate medicine properly should proceed thus: in the first place to consider the seasons of the year, and what effects each of them produces. Then the winds, the hot and the cold, especially such as are common to all countries, and then such as are peculiar to each locality... One should consider most attentively the waters which the inhabitants use...and the mode in which the inhabitants live, and what are their pursuits, whether they are fond of drinking and eating to excess, and given to indolence, or are fond of exercise and labor” -- Hippocrates

Asthma disproportionately affects children living in underserved, urban communities. Inner-city children have the highest prevalence of asthma and the highest asthma hospitalization rates. Studies have shown that asthma mortality is higher among inner-city children than other children, higher among poor children than other children, and higher among African Americans than other groups (Brown, 1997).

Asthma hospitalization and mortality rates negatively correlate with family income; the highest rates are found in areas with the lowest incomes (Weiss, 1998). The Mt. Sinai School of Medicine study in New York City, one of the most frequently cited studies, found a huge discrepancy between the asthma risk for children in poor neighborhoods and the risk for children in wealthier neighborhoods (Claudio, 1999). The hospitalization rates were twenty-one times higher in poorer and minority (which often go hand in hand) neighborhoods. In neighborhoods in East Harlem, the rate of hospitalization was 22 per thousand per year. In high-income areas (sections of Manhattan), the rate was zero.

Not only are asthma rates correlated with low income and inner-city areas, but they are correlated with minority populations as well (Claudio, 1999). Whatever the explanation for this, it is clear that asthma is a case of environmental justice, as it significantly impacts poor, inner-city, minority and child populations.

Providence, Rhode Island, my case site, provides an extreme example of environmental injustice. There are over 20,000 asthmatic children in Rhode Island and about 15,000 of these children live in Providence (www.asthmainamerica.com). Minorities compose about 9% of the entire Rhode Island population, but compose more than 30% of the Providence population. While about 9% of the Rhode Island population is below the poverty line, in Providence more than 20% of the population is below poverty level (U.S. Census, 2000).

Inner-city Providence (the neighborhoods of South Providence, Elmwood, Washington Park and the West End) houses about 47,000 residents. Minorities account for about 72% of this inner-city population. A 1988 census showed that more than 75% of inner-city homes had incomes 200% below the poverty level (DeBuono & Cagen, 1993).

Immigrant populations in the urban core include: the Dominican-Republic, Puerto Rico, Central and South America, Liberia, Nigeria, the USSR and Haiti (Gurney & Simon, 1993). Poor and immigrant families tend to change housing situations more frequently than wealthier families. One Providence elementary school teacher told me that the turnover rate in her school was close to thirty students per month.

Indoor and Outdoor Environmental Triggers

Asthma educators generally target the home environment as being the source of preventable asthma triggers. Many scientific studies have demonstrated that asthma symptoms decrease after cockroaches, dust mites, and other indoor triggers have been eradicated from the home (McGowen, 1999).

Over 1.2 million U.S. families live in housing with severe or moderate physical problems, and 700,000 households are overcrowded (Doc4Kids, 1998). Many of these living spaces are teeming with asthma triggers. One asthmatic eight year old girl told me that whenever the “crack dealers” in her apartment start smoking, she and her mother escape to their car and circle the block until their home is safe enough to not affect the girl’s asthma. Many low income families are prone to live in homes that are infested with cockroaches, with roofs that leak water into the living areas, or whose neighbor’s smoke flows directly into their apartments through a hole in the wall.

Children in poverty suffer from more frequent and more direct exposures to toxic chemicals and other pollutants. They live in areas that contain toxic-waste landfills, power plants, heavy industry, and heavy pesticide use (McGowan, 1999). Even as asthma is increasingly discussed as an “indoor” problem, there are many environmental advocates who posit that asthma is one more side effect of outdoor air pollutants.

Air pollution contributes to respiratory problems, specifically asthma (MASS-PIRG, 2000; Pew, 2001). The Pew Commission (2001) estimates that by 2020, asthma can affect up to 29 million Americans, which is more than twice the current number, and that reducing the number of diesel vehicles could drastically reduce this number. AIR

public interest group (2001) found that ozone levels correlate with asthma rates, and that lower-income populations are located in closer proximity to outdoor environmental health hazards, like polluting power plants and toxic waste dumps.

The Atlanta Olympics in 1996 provided a natural experiment to study the relationship between automobile pollution and childhood asthma (NY Times, 2001). For two weeks the city closed downtown to private traffic, created a 24-hour mass transit system and encouraged businesses to stagger hours and allow telecommuting. As a result, serious episodes of asthma among children decreased. Asthma related emergency visits and hospitalizations decreased about 40%, and among H.M.O. patients, visits dropped by about 44%.

In 1996, inner-city Providence ranked among the worst 20% of all counties in the country for sulfur dioxide emissions. In 1997, it ranked among the highest 20% of all counties in the US for total environmental releases from manufacturing facilities (www.epa.com).

Because asthma management programs focus on indoor triggers, the link between outdoor air pollution and asthma may be neglected. This creates a gap between medical intervention programs and environmental activists. People subject to outdoor environmental hazards are told that asthma is controlled, not by eliminating the toxic fumes next door, but by cleaning their own homes. Asthma educators tend to focus on individual responsibility, whereas the environmental justice issue pertains to communities at large.

Impacts of Asthma on Daily Life

“When I lay down, I start coughing.” – 11 year-old boy with asthma

Asthma has many direct and indirect impacts on individuals’ lives. Children with chronic illness are at risk for behavioral problems, poor self-concept and social withdrawal (Austin, Patterson & Huberty, 2000). Chronic illness may also delay development and slow the development of early independence (Perrin, 1984).

A study conducted by Sehgal (2000) found a significant negative correlation between children’s Quality of Life scores and the number of school days missed due to asthma. In Providence in 1998, 49% of children missed school due to asthma, 48% had limited sports participation and other recreational activities, 36% had limited physical activities, 30% woke with breathing problems at least once a week, and 31% went to the emergency room for asthma attacks in the past year (www.AsthmainAmerica.com).

Numerous studies have found that the number of emergency room visits and missed school days would decrease substantially if asthma patients took better care of their asthma, by taking their medications, taking peak flow readings, and avoiding environmental triggers (Wood, 1995; Block, 1999). The average asthma patient living in Providence is uninformed about his or her asthma. One study found that more than half of the surveyed asthmatics thought it was possible to treat only asthma attacks and symptoms, and not take preventative measures (www.AsthmaInAmerica.com). More than 50% of surveyed children neglect to take their medications consistently (Block, 1999). If children learn to manage their asthma responsibly at an early age, they are more

likely to continue these habits for the rest of their lives (Block, 1999). It is evident that educational programs have much to offer and have the potential to save people's lives and livelihoods.

Asthma intervention groups have sprung up in Providence in response to the problem of childhood asthma. These groups provide families with educational materials about disease mechanisms, proper use of medication and symptom control, and how to identify and limit exposure to environmental triggers that exacerbate asthma. One group is the Draw a Breath Program¹, which works to improve children and families' understanding of asthma and their motivation to carry out their asthma management plans.

Conceptions of Illness

"Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place" (Sontag, 1978).

In my findings, I parallel children's understandings of illness with their understandings of place. The ways in which children understand their asthma is crucial for designing asthma education programs and exploring how children conceptualize themselves in the world. Studies have found that children who have negative feelings about having a chronic disease are more likely to engage in maladaptive coping behaviors than children who have positive feelings about having a chronic illness (Austin et al., 2000).

¹ Draw a Breath is based at Hasbro Children's Hospital, the pediatric facility of Rhode Island Hospital

Researchers studying children's conceptions of illness have unequivocally determined that illness understanding increases with age, that children with more mature understandings of illness report their symptoms immediately, and that as understanding of illness increases, so does knowledge about preventing illness and treating it rather than treating just the symptoms (Hansdottir, 1998).²

Stigmatizations of asthmatic children may contribute to negative feelings toward having asthma. Examples of stigmatization are "Children with asthma are weaklings who can not play sports" or "Children with asthma come from dirty homes." The effects of this kind of discrimination can be important to self-development and conceptions of self. Just the act of being labeled is "an effective means of suppression" (Elkind, 1978, p. 125). Growing up in a society of discrimination there is the risk, especially for young children, that they may begin to believe these constructed stereotypes. Rebelling against them can also be counter-effective to the individual's health. Stigmatization may be a contributing factor to children's non-compliance with medication.

Another element of understanding illness is the level of risk children associate with their asthma. Many theorists have lamented the apathy inherent in human nature: "The natural state of humankind vis-à-vis risk is apathy. Most people, most of the time, are apathetic about most risks, and it is very hard to get them upset" (Joffe, 1999, p. 190). Numerous studies regarding risk perception find most people to be overly optimistic about their susceptibility to danger (Joffe, 1999). Above 95% of the population exhibit

² It seems intuitive that environmental context influences concepts of illness, as it does concepts of self and place. One recent study compared Icelandic children's concepts of illness to those of Americans (Hansdottir, 1998). Icelandic children differed from Americans in language (Norse-based), area (cold and dark winters), and education (higher levels than U.S.). Surprisingly, few differences were found between groups in their perceptions of illness, indicating that age may be a more significant factor than environmental context.

unrealistic risk-related optimism (Taylor & Brown, 1994), meaning that people believe they are less at risk than the average person. For young children, this is even more extreme (Whalen, Henker, & O'Neil, 1994).

Risk perception is influenced by context. Conditions of poverty or unstable economic situations may predict increased exposure to environmental hazards, and also the likelihood of actively participating in risk management. There appears to be an association between low socioeconomic status, the tendency to minimize chronic health risks, a fatalistic attitude concerning health problems, and an external locus of control (Butler et al, 1999).

Asthma is an illness that is at times terrible and at other times benign. The environment, as well as the illness itself, can be regarded as risky. Both indoor environments and outdoor environments can trigger asthma. My study asks: Do children with asthma perceive certain environments to be more risky than do children without asthma? Are outside environments regarded as more or less risky than inside environments? What may be the repercussions of these perceptions on children's lives?

The challenge of risk education is to attempt to educate without instilling a sense of panic. For children in particular, risk must be discussed delicately (Kahnemann, 1982). Asthma triggers can be found almost everywhere, and it is important that children know to avoid these triggers if it is possible to do so, but without living in fear, or in a world in which the outside or inside environment is regarded as a threat.

Locus of Control

A large factor in the development of risk perception is the level of control individuals feel they have over their lives. Within the psychological literature, this is commonly referred to as “locus of control” (Nowicki-Strickland, 1973). If one has an internal locus of control, outcomes are perceived as the direct result of one’s behavior. If one has an external locus of control, one’s outcomes are regarded as under the control of others or of fate. Generally, individuals with an internal locus of control are regarded as “more potent, competent, and effective persons” (Sanders, 1982, p. 67). Studies have found that the perception of control over outcomes can decrease subjective pain, reduce the risk for anxiety and depression, increase persistence, decrease the physical and psychological effects of aging, improve immune system functioning, reduce susceptibility to heart disease, cancer and other illnesses, and possibly can even postpone death (Deuser, 1995).

Locus of control is frequently related to health and illness behaviors. Confidence in self-treatment and the probability of self-treatment can be related to the concept of locus of control. Perceptions of control are important also to people’s efforts to reduce a health risk or an environmental hazard (Mechanic, 1987).

Asthma has the potential to diminish one’s sense of control, as it infringes upon routine freedoms, privacy and mobility. Children with asthma are more dependent upon authority figures (Tanabe, 1997). Coping with chronic illness thus has the potential to foster a sense of helplessness in children, which runs counter to the development of self-

hood, crucial for inner-city youth (Brice-Heath et al, 1993). Cultivating a sense of personal control is also important for community mobilization and resistance efforts.

Deuser and Anderson (1995) posit that helplessness, or an external locus of control, is caused by “irreducible uncertainty” (p. 149). Children’s tendency to ask frequent “why?” questions is motivated by a desire for control. Asthma is an unpredictable and unexplainable disease. Many of the children I talked with did not understand why they had asthma or what exactly made it worse. Medical research fails to completely explain the causes and triggers of the disease as well. For children, asthma is one extremely relevant unanswered “why?” question. According Deuser and Anderson, this in itself may perpetuate a loss of perceived control.

Most studies, including this one, using children’s health locus of control administer the scale to multiple populations and score them comparatively (Neuhauser et al, 1978; Nowicki & Strickland, 1973). Parcel et al. (1978) administered the scale to two elementary schools with different socioeconomic status and ethnic differences. It was found that as grade increased, so did the mean scores, and that African-Americans and Mexican-Americans scored significantly lower than Anglo-Americans. There was very little difference between the scores of males and females. This finding is consistent with several studies that have indicated a relationship between ethnicity, socio-economic status, and locus of control.

Sense of Place

“By the time my children are ready to begin school, never mind graduate, they’re tired. They’ve been fighting the rats, and have had to shiver on account of the cold inside the building, and they fall and stumble on those broken-down stairs...the electricity, it doesn’t work half the time, and what can you see out of here, but the garbage that the city doesn’t care to pick up? No one says that when kids have to live in houses like this, and they have to live in neighborhoods like this, that it’s not the end for them before they can even start” (Anonymous mother in Coles, Wells, 2000).

Central to this study is a discussion of place. I believe that our perceptions of places are inseparable from our perceptions of ourselves, and that our relationships with places influence our actions and beliefs. The anthropologist Keith Basso (1996) emphasizes the importance of “sense of place” when he asks, “What do people make of places? The question is as old as people and places themselves, as old as human attachments to portions of the earth...Places, we realize, are as much a part of us as we are a part of them and senses of places – yours, mine, and everyone else’s – partake complexly of both.”

The creation of identity is an active process that is dependent upon our environment. Exploring “sense of place” is a self-exploration as much as it is an examination of the physical places. Proshansky, who studies child development, states, “Children learn about themselves through their interactions with their world; their most intimate physical environments communicate important messages to them about who they are and what they may aspire to be” (Elkind, 1974). Because the condition of

asthma is so closely linked to the environment, conceptions of place may be influenced by this illness experience, and prove meaningful for asthma and youth educators.

Relationship to place is not limited to the discipline of environmental theorists. It has become the philosophical backbone for environmental studies, psychology, geography, sociology, and education. Jean Piaget, a famous figure in the study of children's cognitive development, insisted that the individual and the environment can not be separated (Elkind, 1974). As adults and children, we tend to form attachments to places, and identify ourselves with place. Marc Fried (1999), studying working class communities, found that attachment to place is a characteristic feature of life in many poor, ethnic, immigrant communities.

The relationship between environmental perceptions and self is holistic and synergistic, an exchange that flows in both directions. One cannot be studied in isolation from the other, because the two act upon and influence each other dynamically. "Sense of place" is thus influenced by experiences, and experiences influence "sense of place." The asthmatic children in inner-city Providence generally do not have the same access as wealthier children to green spaces and "natural"³ environments, like state or national parks and hiking trips. Their experiences and perceptions of outside may be limited to inner-city environments.

There is a large body of literature demonstrating the psychological and physical benefits of experiencing "natural" environments (Kaplan & Talbot, 1988). Hartig (1991) found that groups engaged in natural areas performed highest on a proofreading task, and

³ I choose to quote "natural" because I regard our conceptions of natural and nature as cultural constructions. In this paper, I use the term "natural" to describe environments that mainstream society regards as less impacted by human activity.

Ulrich (1984) found that patients in hospital rooms with natural views from their windows recovered faster than those without windows. Still other studies explore exposure to nature within living environments and the importance of nature to children. Treed spaces have been found to be more supportive of children's play (Taylor & Wiley, 1998; Sullivan, 1997). Wells (2000) reported that a nearby "natural" environment plays a significant role in the well-being of children living in poor urban environments. She found a direct correlation between the naturalness of home environments (in terms of greenness) and children's cognitive functioning. It has also been proposed that exposure to natural environments helps direct attention, focus or concentration (Kaplan, 1988).

One of the most pertinent projects relating to my study investigated images of the neighborhood and activity patterns of chronically ill children (Holaday, Swan, & Turner, 1997). The researchers concluded that the neighborhood is one of the most influential settings for school age children and their social and cognitive development. For children, the neighborhood is a social universe. It is a context for interpersonal relationships and it is of a size that gives a sense of control.

Chronically ill children tend to have fewer friends, and play indoors and closer to home more frequently than healthy children (Holaday et al, 1997). Children with illness also feel more vulnerable to the outside, and their parents are more protective. Many children with chronic illness do not regularly exercise outside, and this tendency, combined with their parents' prohibitions can create a difference between the perceptions of the outdoors between chronically ill and healthy children. Chronically ill children described their neighborhoods more frequently than healthy children living in the same

neighborhoods as housing unfriendly people, being noisy, dirty, trafficked, and violent (Holaday, 1997).

Children with asthma grow up in a different world than do children without asthma. Environments provide opportunities and constraints that each individual perceives in unique ways. Asthmatic children all share a similar experience; they must be careful to avoid places and substances that aggravate their condition. The experience of asthma must influence the ways in which children develop a “sense of place.” Exploring children’s relationships with indoor and outdoor environments may shed light on this theoretical concept, and help influence asthma intervention programs shape a curriculum that promotes not only knowledge and self-maintenance of asthma, but greater comfort in the world.

In my next chapters, I outline the methodology of my study, present my findings, and finally discuss some implications and limitations of my research.

Methodology

This social science study utilized ethnographic and qualitative research designs. This type of research “features direct, qualitative observation of natural situations or settings using, mainly, the techniques of participant observation or intensive interviewing, or both” (Lofland & Lofland, 1995). I interviewed 14 asthmatic and 12 non-asthmatic children, parents of asthmatic children, and observed asthma education classes in order to explore children’s perceptions of asthma and the environment. My interview was structured as a combination of open and choice questions, including a Children’s Health Locus of Control Scale. I chose to use a qualitative framework because the concepts that I studied could be more easily articulated in this manner. Direct observations and conversations were crucial in attempting to understand the multifaceted reflections of children coping with chronic illness and constructing perceptions of place.

Participants

I interviewed fourteen asthmatic children who attended the Draw a Breath program at elementary schools (see Appendix 1), Hasbro Children’s Hospital and two Providence Housing Authorities between January 2001 and March 2001.⁴ I asked fifteen families to participate, and all but one consented to be interviewed. The children ranged

⁴ Four of these interviews were from the Hasbro classes, seven were at the elementary school classes, and three children were interviewed at Chad Brown or Manton Heights Housing Authorities.

in age from eight to twelve years old, and all were fluent in English. The average age of the fourteen children I interviewed was nine years old. Nine of the children were female and five were male. Six of the children were of Hispanic origin, four were white and four were African American. Most of these children had moderate to severe asthma.⁵ Many of them coughed and wheezed during their interviews, and at least seven of the children were reported to have visited the emergency room in the past month or had limited activity on a daily basis, due to asthma.

Of all the parents who attended the elementary school Draw a Breath classes, many had not graduated from high school and none had graduated from college. All but one of these parents had more than one child and several had more than two children. Though I did not collect economic information, most of the parents at the intervention classes indicated that they were members of Rite Care, a medical assistance program through the Rhode Island Department of Human Services that provides health services to children up to 250 percent of the Federal Poverty Level. Cathy Mansell, the director of Draw a Breath, estimated that the average income for each family is less than \$20,000 a year, and that most of these parents support five to six children. Many of them, she said, come for the free pizza.

I interviewed 12 children without asthma. I recruited non-asthmatic participants from the Providence Housing Authority's recreation centers⁶, where they were matched according to age and presumably income. Out of fifteen families asked to participate, twelve agreed to be interviewed. Eight of the non-asthmatic children were female, four

⁵ Classified by the Asthma Assessment Form in Appendix

⁶ The Providence Housing Authorities offer public housing to low or no income families. There are three developments: Hartford Park, Manton Heights and Chad Brown.

were male, and their ages averaged to about ten years old. I did not ask them to tell me their race or ethnicity, though some mentioned during the interview that they were from the Dominican Republic, Puerto Rico and the Caribbean. Most of the children were Hispanic or African-American.

My study design called for interviewing between ten and twenty respondents. I was able to conduct one to two interviews at every Draw a Breath class I attended. The number of interviews at each class was limited by the number of children within my age range that came to each class, as well as the time available to interview them.

In addition to these two young participant populations, I also opportunistically interviewed parents of the asthmatic children, school nurses and school physical education teachers to see if they noticed any impacts of asthma on children's behavior, feelings, relationships, or perceptions. This was useful to get a sense for how caregivers perceive asthmatic children, and to compare this with how the children may see themselves.

Instrumentation

The interview with the asthmatic children (see Appendix 2) lasted approximately twenty minutes. I tape recorded six of these interviews. The interview for the non-asthmatic children was identical to the former, except for questions pertaining to asthma. This interview was about ten minutes long.

Many of the questions were open-ended, and pictures were used as prompts. The interview consists of five overlapping components. One section focuses on favorite

activities and how the child feels about different outside and inside places. Another group of questions asks if the child prefers to play inside or outside and what kinds of activities s/he does outside. A third component addresses the child's understanding of his/her asthma, and what things and places make the asthma feel worse or better. A fourth component combines the "place" questions with the asthma questions, and asks if the asthma prevents any enjoyment of activities or places. Because these are potentially sensitive concepts to discuss with young children, I received outside help from child psychologists in compiling my interview questions.

The last section of the interview is a Children's Health Locus of Control scale (Parcel & Meyer, 1978), which I administered in order to assess the level of control the respondent perceives s/he has over his or her health. The scale is a series of 20 Yes or No questions. Each question was scored either internally (one point), externally (two points), or no response (one and a half points). Two studies were conducted to develop this scale, which was piloted by the researchers several times to determine reliability and validity.

A combination of open and closed ended questions seemed appropriate for this study. Many of the questions provided space for children to respond with comments about their feelings or personal observations. The closed questions, like the locus of control scale, were useful for quantitatively comparing the responses of the two young subject populations.

I was also able to review records of parent surveys reporting demographic information and severity of their child's asthma (see Appendix 3).⁷

In order to prepare for my role as researcher/interviewer, I helped with the

⁷ The parents who attended the Hasbro classes did not supply this information.

elementary school classes for three months before interviewing children.⁸ In this teaching assistant role, I began to feel more relaxed with the kids, and more prepared to interview them when the time came.

I interviewed asthmatic children at Hasbro Children's Hospital and the elementary schools before the classes began. Parents were given paperwork to fill out and I approached the parents during this interim and asked their consent to interview their child. I would then ask the child's permission, and if this was given, proceed with the interview.

After talking with parents and the recreation center coordinators for each Providence Housing Authority, I accompanied Brown student volunteers at Chad Brown and Manton Heights and interviewed children in these classes. Again, I chose children who were between the ages of eight and twelve, spoke English, and agreed to be interviewed. Three of these children turned out to have asthma, and I administered the asthma interview in these cases.

Data Coding and Analysis

In studying the results of my interviews and my observations, I located recurring themes and relationships. I studied my notes and listened to the taped interviews, and began to develop categories for the items I found. I abandoned themes that emerged only sporadically, and went back over my notes numerous times, finding new themes and comparing themes between the participant groups. Listening to the taped interviews I

⁸ It also took me several months to receive permission from the IRB boards at Brown University and Rhode Island Hospital to interview children.

was able to record pauses in speech, idiosyncratic language, and the speed and conviction of responses. I calculated averages for the quantitative responses, including the Locus of Control Scale.

Findings

I feel it is important to introduce myself for the reader to understand my research about asthma and sense of place. I came into the environmental studies department at Brown University after spending a semester backpacking in southern Arizona and taking academic courses on metaphysics and the relationship of religion and science. Suddenly I was seeing the world in an entirely new way. I found my intense love and loyalty to the earth echoed in the voices of poets and philosophers, and I began to contemplate the attachments I felt for the physical world. What exactly is this rapport we have with our environment? Everyone must have some sort of relationship to place, even if he or she is not living in Sierra Club calendar areas, and this relationship must be fundamental to caring for and respecting the earth. How else, I believed, could environmentalism truly be effective unless we as a species focus on reshaping the dominant worldview that places humans superior to the physical world, a paradigm that fosters dominance over and manipulation of the earth.

Ecopsychology, which has influenced my thinking, attempts to restore harmony between people and the earth and encourages the recognition of an ecological self that is expanded to include the natural world out of which we evolve. A broad conception of self is not new to this discussion. Psychology, which this study relies upon heavily, is literally the study of the soul, and the breadth of the discipline depends upon what we define as the borders of the self.

It was with vigor that I decided to concentrate in environmental studies, and I was committed to following my “sense of place” philosophizing. But Providence is nothing like the solitary Sonoran desert, or even like my idyllic California hometown. It seems a much harder challenge to appreciate and love your place, if it is an environment that can be experienced as oppressive, dangerous and violent. And in many communities in inner-city Providence, as in most urban centers, this was the case.

For me, the study of environmentalism is broadly the study of the earth, and more specifically the study of human relationship with the earth. Thus, Providence offers an “urban ecology,” a study of place that acknowledges the “natural” elements within city landscapes, and also provides a study of humanity’s impact on urban environments and the urban environment’s impact on humans. As the planet becomes increasingly industrialized, this type of anthropological environmentalism will become more salient.

Overview of the Participants and Procedure

I interviewed fourteen asthmatic children at elementary schools and Hasbro Children’s Hospital. They attended the workshops with siblings and parents, many of whom had come straight from work, were young and looked tired and worn-out. The children tended to be shy and hyperactive (in that order), and all had moderate to severe asthma. Many of them coughed and wheezed during their interviews.

It was clear that even if the asthmatic children were limited in certain respects because of their illness, they behaved like an average group of kids. They joked around

with each other, they became shy when they received a lot of attention, they jostled to get to the front of the food line.

The children at the elementary schools were eager to participate in the interviews, though as soon as I whipped out my pen and paper and tape recorder, they became reserved, and grew gradually more comfortable and talkative as the interview progressed.

Most of these interviews were conducted right next to family members, who overheard our conversation. Sometimes in the beginning of the interviews, when the children were still very shy, mothers would prod their child to answer my questions, saying things like, “Come on, honey. You know you love to go to the park!”

These interviews were held in school classrooms or the children’s hospital, places that the children were not accustomed to playing in. In contrast, I interviewed the twelve non-asthmatic children at the recreation centers of two housing authorities, which were certainly distracting environments. Whereas most of the asthmatic children appeared to regard me as having a certain amount of authority, and therefore respect, the children in the housing authorities were not as polite. I was interesting to them in that I was something new, and I was immediately included in their banter.

During the interviews, however, many of the non-asthmatic children were as shy as the asthmatic participants, and the interviews were so much shorter that by the time they began to participate more openly, I was almost finished asking questions.

The following section presents the findings of my study. They are organized into themes. This project began as a discussion of relationships, and my findings attempt not to untangle the relationships, but to present them in as clear a way as possible. I begin by presenting the ways in which children understand and describe their asthma. I then

discuss the impacts that children reported asthma has on their lives, and how, given these impacts, they may adapt to their illness. Next, I introduce the ways asthmatic and non-asthmatic children understand and describe place. Finally, I present the results of the Health Locus of Control scale.

Understanding Asthma

“Asthma will follow you if you run around” – 8 year old girl with asthma

The ways in which children with asthma understand and define their illness is important in predicting the influence it has on their daily lives and perceptions. Most of the asthmatic children I interviewed described asthma as an external force, which was experienced as an **interruption** in daily routines, or which induced feelings of **powerlessness** and **reactive treatments**, as opposed to proactive treatments of the disease.

Asthma as an Interruption

In each interview I asked the asthmatic children to tell me what asthma was, or how they would describe it to a friend. Definitions included:

- “Something that makes you so you can’t breath good sometimes.”
- “When you have to stop running because you can’t breath.”

- “You’ll go to the hospital and they’ll put oxygen in your mouth.”
- “[You have to stop what you’re doing because] you get sick and you can’t breath and you cough a lot.”

One girl told me that when she has trouble with her asthma she is forced to sit down: “Nothing else helps.”

Children characteristically described asthma as something that made them sick or go to the hospital, events that impact daily routines. Along these lines, almost half of the children I talked to said that they think about their asthma only when they’re sick, or when it is “interrupting.”

Feelings of Powerlessness

I was also interested in how the children *felt* about being interrupted by their asthma. Monica is a Hispanic twelve-year old girl with long black hair and enormous eyes, who attended the Hasbro class with her mother. She didn’t want to be taped, but was talkative during our interview. When I asked her what makes her asthma worse, she replied in frustration, “Every time I run, play, go to the gym, try to do something...”

This response, and many others, indicated feelings of powerlessness in the face of the disease. Children with asthma told me “I *have* to carry a pump,” “You *have* to take certain medicines,” and “I *have* to go to the hospital,” (my own italics) indicating perhaps that these actions are out of their personal control.

Debra is a thoughtful and friendly nine-year-old girl who wore a pair of thick, scratched glasses. Her curly black hair was ordered in tight, tiny braids. She confessed that when she learned that she had asthma, “I was scared. I never knew if I was going to get an attack.” Jess, another African-American girl, came with her mother to the Hasbro class. She is a talkative nine-year old who immediately showed me her report card. When I asked her what she thought asthma was she said bluntly, “I don’t really know...I just know that it can kill me.”

As these girls illustrated, fear of asthma is linked to conceptions of powerlessness. Leslie is a tall and mature-looking twelve-year-old, with a thick rope of brown hair. We talked at the hospital, and she told me that she gets scared “when I’m having an attack and nothing’s working and it’s the middle of the night and no one’s around.” Ida, a shy nine-year old girl, came to an elementary school class with her Spanish speaking grandmother. Her younger sister practically sat in my lap during the interview, absorbed in our conversation. Ida said that asthma scared her when she was sleeping, presumably because she was afraid of being surprised by an asthma attack while in a vulnerable situation.

Not only do these descriptions indicate that asthma interferes with routine activity, but they refer to asthma as an external force. For example, one nine-year old girl told me that “Asthma will follow you if you run around outside.”

Reactive Treatments

The goal of most asthma intervention programs is to control asthma so that it is not regarded as scary or unpredictable. When asthma is responsibly managed, trouble with breathing should not come as a surprise. But it was clear from talking about asthma with these children that the disease was experienced as something that they did not have control over, and this was evident in their treatment routines as well.

When I asked children what kinds of things they did to make their asthma feel better, they primarily gave me reactive, rather than active treatments. Most children told me that they do things like “lay down,” “take my pump,” “drink water” and “go to the hospital.” Only Leslie said, “I don’t do stuff that will trigger my asthma...[like] go near cats and dogs and run around.” Given that Leslie was one of the oldest children I interviewed, this indicates, and previous research confirms, that age has a direct correlation with management of illness (Hansdottir, 1998).

Are children afraid of their asthma?

At one elementary school class a boy who did not have asthma was joking around and laughing, and said, “When you put your head under your pillow you can die.” Another boy who did have asthma was disturbed by this comment and replied angrily, “What are you talking about? That’s not funny!” This second boy had visited the

emergency room several times because of his asthma, and being so close to death himself may have influenced his sensitivity toward this flippant remark.

Eight of the fourteen children I talked to admitted that having asthma sometimes scared them. All of these children had severe cases of asthma, but there were other children with severe asthma who told me that they were not scared by their disease. Mark, a Hispanic twelve-year old boy with a loud laugh and an omnipresent smile, told me that for a few weeks there was construction work right outside his bedroom window. While sleeping he stopped breathing, because the fumes aggravated his asthma. He was rushed to the hospital, and he said with pride, “I almost died.” This was in my early days of interviewing, before these stories became commonplace, and I was shocked. “Were you scared?” I asked him, and he responded nonchalantly, “Not really.”

What struck me more than Mark’s air of bravado was what his parents must have experienced. All of the children I spoke with had been to the emergency room because of their asthma and several had had respiratory arrest. It must be terrifying for parents to witness their son or daughter almost die, and not once, but perhaps numerous times. Jess told me, “I feel bad for my mother, because she worries about me a lot.” Others said that their parents prevented them from going places, doing things and playing with friends because of their asthma.

At one of the Hasbro classes I watched several mothers relate with each other over their children’s asthma. “Every time my son coughs I’m scared he’s having an asthma attack, but maybe it’s just a cold or something’s caught in his throat,” one young mother said anxiously. Another mother nodded, and shared her own frustrations, “I don’t

know if she has a cold or asthma, or if she's taking enough medication? I'm totally confused!"

Because the children are so young, the bulk of the responsibility for managing asthma falls on the parents. It may well be that parents prevent their asthmatic children from engaging in certain activities because they pose a risk that they are not willing to take with their children's lives.

How do children define their asthma?

Sam is a small, energetic eight-year-old boy with a head of tight curls. He came to an elementary school class with his mother and remembers always having trouble with his breathing, but just recently discovered that he has asthma. When I asked him if he had heard about asthma, he responded, "Yeah."

"What do you think it is?" I asked.

He thought for a minute, "Hmm...I don't know."

Sam's mother overheard us and tried to help out, "Like if your friend asked you, if you were having an asthma attack and your friend asked, 'What's wrong?' what would you say?"

Sam started to laugh and exclaimed, "I'd say, 'I'm having an asthma attack!'"

Much to his mother's displeasure, she could not wrestle a clinical description of asthma out of him.

I interviewed all of the children except one before the Draw a Breath classes began, so they would be less inclined to parrot an answer they had heard in class. Tracy,

a nine-year-old girl, was bright and thoughtful. She and her mother were both pale, with dark circles under their eyes, and her mother struggled with a painful chronic disability that forced her to use crutches. I interviewed Tracy after the class as she was eating her dinner, and when I asked her what asthma was she did not give me a clinical description either. She put her pizza down and thought for a moment before answering confidently, “it's when you start coughing and you can't breath.” This response followed in the footsteps of the other children I interviewed, who either confessed that they did not know what asthma was (seven of the fourteen responses), or gave personal experience based explanations, the most frequent being “You can't breath.”

These responses are “lived effects” of the asthma experience (Kleinman, 1988). That children did not supply a medical definition of the disease is certainly characteristic of their developmental level, and indicates how age influences the understanding of disease (Hansdottir, 1998). All of the twelve year olds I interviewed provided definitions of asthma, and Sara, a twelve-year old with laryngitis whom I interviewed at Hasbro, whispered the most clinical and objective answer; “It's a disease in your lungs, if you do certain things to trigger asthma lungs tighten and you can't breath that long.”

On a related note, children also described asthma by applying their own personal asthma experience to “objectively” explain the disease. For example, children said if one has asthma:

- “You have to take certain medicines”
- “They give you an inhaler and if you get an attack you go to the hospital”
- “You can't breathe that much and when you play you get tired.”

In this way, individual experiences were understood to apply to a larger, general asthma experience.

The importance of “lived effects” was also apparent during the asthma classes. For example, at each class the leader (Jack Nassau) gave the children gray Styrofoam T-shaped tubes to serve as primitive lungs. He then handed out pipe cleaners, which the kids tightened around the lungs to exemplify tightening muscles, and some plastic green putty that the kids stuck in one end to illustrate mucus. Most of the children were distracted during this lesson, squabbling with each other and playing with their mucus, which inevitably ended up rolling across the floor or in someone’s mouth.

But when Jack asked the children to talk about their own personal experience with asthma, they were immediately captivated and eager to share their own experiences:

- “I wheeze.”
- “I can’t breath.”
- “My chest gets tight.”
- “It feels like I’m going to throw up.”

Impacts of Asthma

“The gas in a bus will make you start coughing and coughing and then you fall on the ground and have it, and they’ll take you to the hospital.” – nine year old boy with asthma

In the middle of one of the Draw a Breath elementary school classes, a couple of children asked to go to the bathroom. By this time, everyone was feeling pretty antsy, so we took a short break, and I accompanied the kids who needed to go to the restrooms. I started down the hall with about eight kids following along behind me, but once we

turned the corner, one of the boys shouted to the others, “Let’s race!” In a split second, all the children took off running. I remembered the joys of running through abandoned school hallways after hours, and I also had no idea where the restrooms were, so I sped up and joined them. When we finally got back to the classroom, we were all flushed and out of breath, but I was the only one who had raced down the halls who was not also wheezing.

I mention this story because it is a salient example of the impacts asthma has on children’s lives. In the interviews, asthmatic children emphasized three effects of asthma on their lives: **spending less time outside**, **spending less time being active**, and **spending less time with friends**, which is generally a result of the first two. At the beginning of every Draw a Breath class, Jack Nassau asked the children what they like to do when they feel good. Usually the kids yelled out responses, and the first activities listed were always sports or physical activities, like play soccer, football, baseball, run around, jump rope, etc. These are activities that tend to take place outside, which implies that there is a relationship between feeling good and being outside, as well as the outside being a place in which to be physically active.

Asthma Impacts Time Outside

Eleven of the fourteen children with asthma (79%) reported some limited access to outside environments due to their illness. Six of the fourteen told me that they experience the most trouble with their asthma when they are outside and six different children told me that if they did not have asthma they would spend more time than they

currently do outside. Some asthmatic children brought up that asthma interferes with their time outside without being prompted. For example, while talking about places she liked to go, Sara spontaneously brought up that she doesn't go outside very often because, "Outside I'm allergic to pollen and pets."

When I started developing my interview questions, I assumed that if children had trouble with their asthma outside that they would naturally prefer to spend less time outside. But the more I talked with these kids, the more complicated this issue became.

I asked all the children if they preferred to play inside or outside. This question received immediate confident responses. A few of them told me that they liked to play both inside and outside, but most children, including many who have trouble with their asthma outside, told me that they preferred to play outside. Eight of the twenty-six (30%) children preferred to play inside, including five of the fourteen asthmatic children (36%).

For some of these children, the asthma experience may have influenced these indoor/outdoor preferences. When I asked twelve-year old Debra this question, she said quickly, "Inside, because I get asthma outside, when I run around, or if it's really hot or really cold." But what may also be significant are the outside environments that members of both respondent populations are exposed to. Children living in inner city projects and low income housing generally do not have access to comfortable and safe outdoor environments. Also, it may be that asthma interferes with children's outside time, but it does not change an objective preference for outdoor environments. What we do know is that the asthma experience impacts *time* spent outside. It remains to be seen how this may influence perceptions of outside places.

Asthma Impacts Activity

As I mentioned earlier, children reported that they liked to be physically active (playing sports, etc.) when their asthma wasn't bothering them, implying that asthma prevents them from engaging in these activities. Several children I interviewed even made the connection between activity and place, which led me to believe that a lot of the trouble children experience outside is due primarily to activity. When I asked Sara if she had more trouble with her asthma inside or outside, she said, "It depends on what I'm doing." One nine-year-old boy replied to the same question, "Outside, because that's where I run around." Another nine-year-old girl gave me an identical response.

Monica told me that she had asthma when she was a baby, but it went away when she was seven and then reappeared when she was eleven. "It made me sad," she said, "I couldn't do the same things I used to do, like sports and run around with friends the way I used to." She had told me earlier that one of her favorite things to do was dance, and when I asked her if her asthma prevented her from doing anything she would like to do, she nodded, "Yeah...gym, skate, dance...because that's [dance] my favorite and I can't do it that much."

Sara agreed that her asthma prevents her from doing "sports, things physical, like running" and an eight-year-old boy told me, "Sometimes I can't play baseball."

Asthma Impacts Social Lives

There is a vast amount of research that values the importance of the social world on child development. Most children between the ages of eight and twelve spend time with friends running around outside, playing games and sleeping over at other peoples' houses, activities that are clearly inhibited by the asthma experience.

During the interview, Debra talked at length about the ways asthma interfered with her friendships. She told me, "When my asthma's bad my mom won't let me go out and play with my friend, and I feel bad, but she won't let me go outside..." and later said that she spends less time outside "cause when I go outside I can't run around and it doesn't make me feel good. Everyone else can run around but I can't and it makes me feel bad..."

I met Kate, a nine-year old girl with brown curly hair, at one of the elementary schools. Her mother was a friendly, interested woman with shoulder-length, graying hair, and chipped, crooked teeth. She listened to the interview, but refrained from participating. Kate reported dejectedly that she had just been excluded from a class field trip to a pottery shop because the smoke there would have aggravated her asthma. One eight-year-old girl told me that she has trouble with her asthma "at other people's houses, and playing, running around with other people." Asthma was reported to not only impact peer group interactions, but also family time. Two unrelated girls told me that they couldn't go their aunts' houses, "because she has cats" and "because she smokes."

(No boys discussed the social implications of asthma. This may demonstrate the greater importance of social relationships and connections to girls, which supports the observations of psychologists like Carol Gilligan and Nancy Chodorow.)

Do children adapt to their asthma?

About midway through my research I began to realize that I was asking the children to take on perspectives that they probably had never been asked to take on before. Did the children present an accurate profile of their asthma experience? I had asked them to perform some rigorous mental exercises in trying to understand what they would do differently if they did not have asthma. Many of them could not remember not having asthma, and must have had trouble trying to perceive how different their lives would be without it. In what ways have they, then, adapted to their illness?

Kate told me that she didn't think that her activity was at all affected by her asthma and said that she would spend the same amount of time outside as she did currently even if she did not have asthma. I thanked her for talking with me, and was about to leave when her mother said, "I was really surprised she said those things!"

"What do you mean?" I asked.

"She can't answer those questions because she doesn't remember what she was like before having asthma. She's too young to remember any differently. Asking kids those questions is hard because they only know how they are now and can't remember how they used to be. I remember she used to spend far more time outside than she does

now. I didn't think about it before hearing you ask those questions, but she's a lot different than she used to be.”

She proceeded to tell me that she used to have a really hard time getting Kate to come inside; “At her aunt's house, where she loves to go so much, there's a pool, and we used to think she would drown because she would never want to get out of the pool. Now it's a lot harder. She doesn't play around outside as much because of the asthma, and she's overweight because she can't exercise as much.”

This raises an important point. Many of the children I spoke with may have adapted to what I have described as “limited” activity within the world, and do not perceive their lives as any different than they “should” or could be.

Are children with asthma stigmatized?

At an elementary school class, Jack told the kids that after they completed an exercise, he would give them each a piece of candy. There was a young boy in the class that day who did not have asthma, and he asked innocently, “Can kids with asthma eat candy?” The other children in the class responded in a loud chorus, “Yes!”

I've talked with several adults who said that when they were children, if you had asthma “you were supposed to suck it up and be tough.” Asthmatic children were, and still are, stigmatized as being wimps and weaklings, though this stigma is shifting to portray asthmatic kids as also coming from dirty homes, given the emphasis on indoor asthma triggers. It is evident that asthma has a direct impact on the activities of children, and can be regarded as a disability. Do these factors stereotype children with asthma?

What I found was that though asthmatic children talked about the negative impacts of the asthma experience, they never mentioned that they felt slighted by their peers because of it. Instead, there was a degree of understanding and “normalcy” among the children that amazed me.

For example, I was taking some notes in the recreation room at Manton Heights and a couple of girls asked me what I was working on. I told them that I was studying children who had asthma, and wanted to talk with some kids who did not have asthma so that I could compare responses. “Elvin has asthma!” one of them yelled, and another one shrieked, “So does Anna! Anna has asthma too!” These girls were extremely good-natured; they did not appear to be picking on the asthmatic children, but involving them in what was going on, and displaying an impressive amount of asthma awareness in the process.

Asthma is not as uncommon a disease as it was in the past. In fact, two of the ten children I interviewed at Chad Brown had asthma, and one of the five children I interviewed at Manton Heights had asthma. This prevalence of about 20% is not out of line with other estimates of inner-city asthma rates in kids.

I talked with a P.E. coach at one of the elementary schools who said, “It’s not like it was twenty years ago. So many kids here have it, so they don’t feel singled out or anything.” Because so many children struggle with asthma, he said that they often come to gym and tell him, “I can’t jump rope today” or “My mom said I can’t run today.” “They’re not embarrassed by it,” he told me.

But it is also true that asthmatic children tend to miss many school days and have interrupted sleep, which makes them more tired and distracted in the day, and are often

overweight because they do not exercise as frequently as non-asthmatic children. These indirect impacts of asthma may serve to negatively stigmatize asthmatic children more than the label of “asthmatic.”

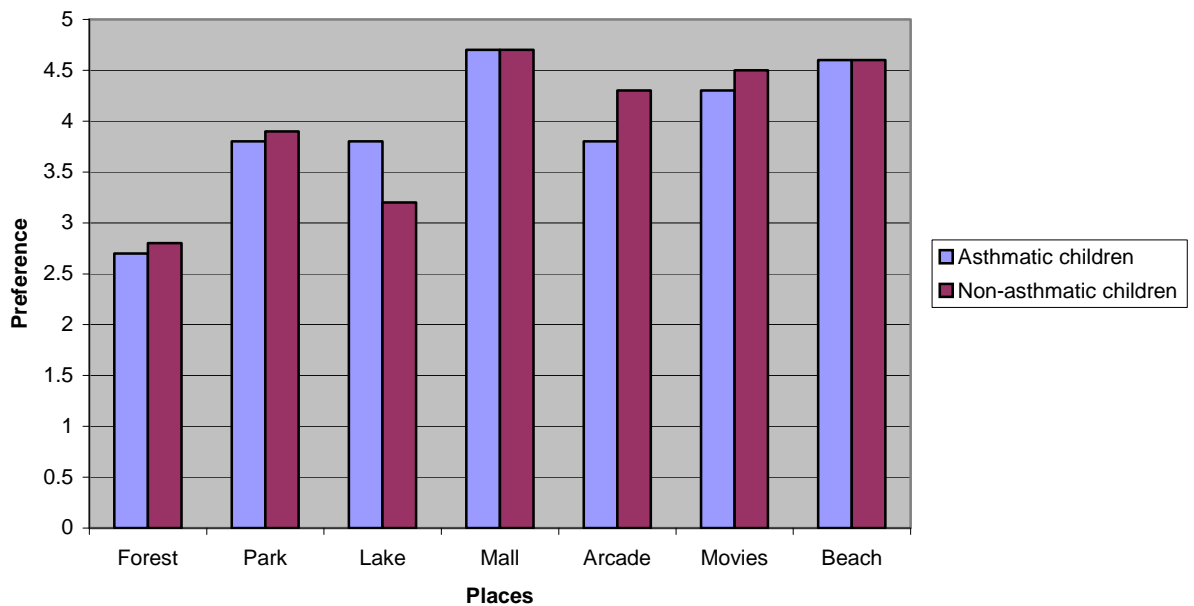
Sense of Place

“I don’t like being outside that much because I get asthma outside” – twelve year old girl

It is clear that asthma causes children to feel more vulnerable in certain environments. Children reported that they have more trouble with their asthma outside than inside and spend less time outside because of their asthma. How then, may asthma influence children’s perceptions of places?

I asked all of the children to tell me how much they would like to be in different places, sometimes using pictures as props. This procedure was initially intended to get a sense for whether they would generally choose indoor or outdoor places, but I gradually came to find the reasons for their choices more meaningful than the choices themselves. For example, I asked all the children to rate (using a visual “thermometer”) on a five-point scale how much they would like to be in a variety of places. The non-asthmatic children and asthmatic children gave almost identical responses (1 is a place they really don’t want to go and 5 is a place they really want to go).

Asthmatic and Non-Asthmatic Children's Ratings of Places



-Fourteen asthmatic children and twelve non-asthmatic children were interviewed

It was in talking with the children about *why* they preferred different places that themes and differences between the asthmatic and non-asthmatic children's perceptions of place emerged. These had to do with attributing negative or positive values to qualities of places. Children talked about places as being **stimulating**, offering **freedom**, being **aesthetically pleasing, comfortable, social, isolating, familiar, and safe**. I discuss each of these themes individually and list some ways in which perceptions of places appeared to differ between populations.

Stimulating Places

Children with and without asthma described places they liked as having things “to do.” Here is what some of the asthmatic children told me:

- “I’d like to go to the park [rather than the gym] because there are more things to do – it’s more fun.”
- “[The park] because it’s funner, there are more things to do.”
- “There are swings and I can run around.”
- “The gym, because I like playing basketball.”
- “I’d rather play outside than inside because I can do a lot of things outside. Like maybe I can ride my bike, because I can’t ride in the house, and because I can play ball.”
- “[The park] because there’s more things to do.”

Some of the non-asthmatic children said very similar things:

- “I’d rather be in the shopping mall [than the outside shopping place] because we could buy clothes.”
- “[The park] because it’s more fun.”
- “[The park] because I like to play on swings.”
- “[The gym] because I can basketball, and I love to play basketball, and I can run around and slide on the floor.”
- “[The park] because there’s not as much to do in a gym, you can’t run around as much...”
- “[The shopping mall] because outside is boring and inside you can get more stuff.”

Freedom

Children expressed an appreciation for places that offered freedom. This did not indicate that places had to offer a lot of room. Home environments offer a certain amount of personal freedom, even if they are physically small. Some asthmatic and non-asthmatic children told me that they were happiest at home because they were able to do what they wanted, and were insulated from asthma triggers and neighborhood violence. Ida told me that she would prefer to play in a gym rather than at a park because “I’ve got more room.” I pointed to the picture of the park and said, “But it looks like there’s a lot of room out there.” She paused and pointed to the gym, “Yes, but I like to play in there.” Ida also told me that she would rather be in a mall because “I can go wherever I want.” Places that are familiar and safe tend to afford a good amount of personal freedom, because there are fewer opportunities to be harmed.

Another example of children prioritizing places that allow personal freedom is a conversation I had at Manton Heights with Liz, a bold eight-year-old non-asthmatic girl with neatly straightened and curled hair. When I asked her to give me a place that she wouldn’t want to be that feels “uncomfortable” she responded immediately, “In jail.” I asked her to explain what she meant and she said, “It’s like, you’re stuck in a room and can’t do anything about it.”

Aesthetic Aspects of Place

We live in a world where “natural” environments are valued for their aesthetic beauty. Photographs of waterfalls and mountain scenes can be found on calendars, greeting cards and screen savers. It surprised me that the children rarely talked about valuing places for aesthetic reasons. A few children used the terms, “peaceful,” “welcoming,” “nicer,” and “pretty” to describe the outside photographs I showed them. One girl mentioned that she liked the trees in one of the outside pictures. But the aesthetic value mentioned the most frequently, and only by the children with asthma, was that places looked “clean.” For example, Steve, an asthmatic African American boy I talked to at the Manton Heights housing authority, used the terms “clean” and “dirty” to describe every place we discussed. Three asthmatic children described the picture of the mountain framed meadow:

- “[It’s] cleaner and nicer.”
- “There’s more fresh air.”
- “It looks cleaner.”

Comfortable Places

Both asthmatic and non-asthmatic children valued places that were comfortable:

- “[At my grandmother’s house] it’s fun, she keeps her house nice and warm.”
- “[I’d rather be inside shopping because] it’s much warmer.”
- “[I’d rather play in the gym because] it’s not cold, ummm, that’s it.”
- “[I’d like to be at the mall because] it’s warm, you don’t feel like you have to rush...”

This may be even more important for asthmatic children, because extreme temperatures can trigger asthma, and in this sense “comfort” is not as innocent a preference. For example, every school I visited was stuffy and overheated, and almost every time at least one child or parent would complain about the heat. One mother once said loudly, “My daughter’s asthma is acting up because it’s too hot in here.”

Social Places

Children with and without asthma clearly value places for their social aspects. The children I interviewed often conceptualized places by describing people in them, rather than the physical dimensions of the place. At the beginning of each interview I asked the children to tell me one thing they liked to do, and most of them, with and without asthma, listed different activities that are implicitly social, like play games or various sports. Spending time in the Draw a Breath classes and at the Housing Authorities also made me realize how valuable friends and family are to children of this age.

While waiting for the classes to begin, most of the children stuck close to their parents or siblings, and eyed the other children with shyness and suspicion. After they split from their parents, shyness gradually gave way to curiosity, which, depending upon the crowd, gave way to rowdiness. The Housing Authority kids were already comfortable with each other, and moved in packs and cliques. At Chad Brown, when a couple of the popular girls wanted to be interviewed, everyone demanded to be interviewed next. But once these girls no longer found me interesting and moved into another room to play a game, the recreation room was suddenly deserted, as almost all of the children migrated into that room after them.

Friends vs. Family

Though all children valued social connections, there were differences between asthmatic and non-asthmatic responses. It appeared that the non-asthmatic children referred to places that had friends, while the asthmatic children talked more about family members.

Three non-asthmatic children told me that their favorite activity was to “hang out” or “chill” with friends. One confident non-asthmatic girl told me that she would rather be at a mall than a downtown area because, “Most of my friends are at the mall.” A twelve-year old girl without asthma said that she would like to be at her grandfather’s house because “I can play with my cousins and with the computer, and watch TV.” Another ten-year-old girl without asthma told me that the place she felt the happiest was at her friend’s house.

None of the asthmatic children offered responses of this kind. When I asked the asthmatic children to tell me a place they would most like to be, thirteen of the fourteen (93%) wanted to be at their homes, relative's houses or countries of origin, where family members still reside. In contrast, six of the twelve (50%) non-asthmatic children gave me responses of this sort.

Isolating Places

Along the lines of "social" places, many of the children I talked with, specifically the asthmatic children, were repelled by places that could be regarded as isolating.

The two places that scored the lowest for both groups of children were "a forest" and "a lake in the mountains." This may be explained by a number of different factors. For example, most of the children do not have regular access to forests and lakes and the unfamiliarity of these places may be perceived negatively. But another element of both a forest and a mountainside lake is that they generally do not have people in them. Though I may appreciate the quiet and peacefulness, many people may find these places scary and isolating.

Though all children are probably sensitive to feelings of isolation, this may be complicated by asthma, because children with asthma must depend on others for help with their illness, especially if they are having an asthma attack. Several asthmatic children and only one non-asthmatic child straight-forwardly told me that they did not want to be in places that feel isolating.

I have two pictures of outside areas. One is of an uncultivated meadow surrounded by mountains, and another is a groomed lawn with a park bench, surrounded by trees. When I asked Jose, a friendly twelve-year old boy with asthma who came to the Hasbro class with his younger brother, mother and grandmother, to tell me which place he would rather be in, he chose the cultivated scene because “there would be people there.” Ida told me that a place she would feel uncomfortable or unsafe is “In a house when I’m alone.” She said later that if she didn’t have asthma, “I wouldn’t worry about being in the house alone because I wouldn’t have to worry about getting sick.”

Familiar Places

Many of the children I interviewed were initially painfully shy and after the first couple of questions talked more easily and openly with me. For the first fifteen minutes of the Draw a Breath classes, the children were quiet and attentive, but after that, depending upon the mixture of kids, Jack had to fight for attention as the children poked and prodded each other, made jokes and stole each other’s Styrofoam lungs and silly putty. This progression from inhibition to exhibition reflected levels of familiarity with being interviewed and with a teaching situation. Along this vein, when I asked children to explain why they didn’t want to be in specific places, many said it was because the places had unfamiliar people in them:

- “[I would rather be in a mall than outside] because there’s less strangers.”

- “[I wouldn’t want to be] at a stranger’s house because I don’t know the person.”
- “[I don’t like to be at school] because I don’t know a lot of people.”
- “[A place I don’t want to be] is around a lot of people...because I’m shy around people.”

Asthmatic children talked more frequently than non-asthmatic children about appreciating *places* for their aspects of familiarity. As I mentioned above, about 93%, as opposed to 50%, asthmatic children discussed the importance of home environments. Asthmatic children valued other familiar places as well. For example, Sam told me that he would rather play in a gym than a park “cause I play in one everyday, I go to the Boys and Girls Club usually when I’m not here.” Jess said that she would rather be at a park because “I’ve been around them a lot.” Kate told me that the place she felt the most comfortable was her aunt’s house. When I asked her why, she said, “I don’t know, I’ve been going there since I was three.” (Later Kate told me that a place she feels uncomfortable is at hospitals, and when I asked her why, she responded, “I’ve been to too many.”)

Exploration

There’s a story about a young boy who gets mad at his parents and decides he is going to run away from home. He announces his plan, puts on his backpack and proceeds to head out the door. When he reaches the end of the block he runs into some

neighborhood kids who are playing baseball, and he becomes involved in the game. A few hours go by, and all the other kids head back to their respective homes for dinner. The boy starts to feel cold and hungry, and his parents watch him from the window as he slowly walks back home. He opens the door in embarrassment, and when the family dog comes up to greet him, he says defiantly, "I see you still have that old dog!"

There is a tension between perceiving the danger in unknown places and having the desire to explore, and this was evident in the children's interviews. But while asthmatic children primarily emphasized that positive places were familiar and intimate, non-asthmatic children were attracted to unfamiliar places that provided opportunities to explore and see new things.

One eleven-year-old non-asthmatic girl said that she would rather play in a park because "it's bigger." A ten-year-old non-asthmatic boy said that he would like to be in the more cultivated outdoor place, "because it looks like a big maze that is fun to get out of." An eight-year old non-asthmatic boy told me that his favorite thing to do is to "go places." And another girl without asthma told me that she would prefer to be in the uncultivated outside place because she would like to climb the mountain.

While none of the asthmatic children told me that a place they would feel the happiest was a place they had never been before, several non-asthmatic children told me that they would be happiest in unfamiliar places. A twelve year old girl without asthma told me that one place she would be the happiest was at a Caribbean Island. I asked her if she had ever been there before and she said no, but that "I've heard a lot about it. Everyone says it's a great place to go." Two other non-asthmatic children said that they

would want to be at Disneyworld, where they had never been before. Granted, these places are easily idealized, but they are also full of strangers and are unknown territory.

Safe Places

Safety came up again and again, unprompted, when children described places they preferred to be. Most children associated safe places with home or family members. But while nearly all of the asthmatic children referred to places as unsafe in terms of their asthma (it's too cold, too hot, dirty, etc.), most of the non-asthmatic children mentioned finding places unsafe because of violence.

Asthmatic children told me that certain places felt unsafe or uncomfortable because they triggered their asthma, even before I began asking them questions about their illness. For example, one boy said, “[I wouldn't want to be in the bedroom] because there could be dust and stuff in there.” Jess told me that she feels safest at home because other places triggered her asthma: “Because my aunt has cats, and my friend has a golden retriever, but at my house...” “Nothing else to worry about?” I asked. “Yeah.”

The non-asthmatic children frequently explained their predilections for place based on them being less violent. For example, one nine-year old boy preferred to be in a shopping mall rather than an outside shopping area “because it's safer.” An eleven-year-old girl told me that she would be happiest in Puerto Rico “because my family is there and they protect me from stuff” and wouldn't want to be in New York “because a lot of bad stuff happens [there].” Another twelve-year-old girl said that she is the happiest at her mother's house because “my mom tells me to come inside when there are shootings

[in the neighborhood].” The same girl said that she would not want to be in “Providence Place Mall because there was just a shooting there.”

Intuitive Feelings for Place

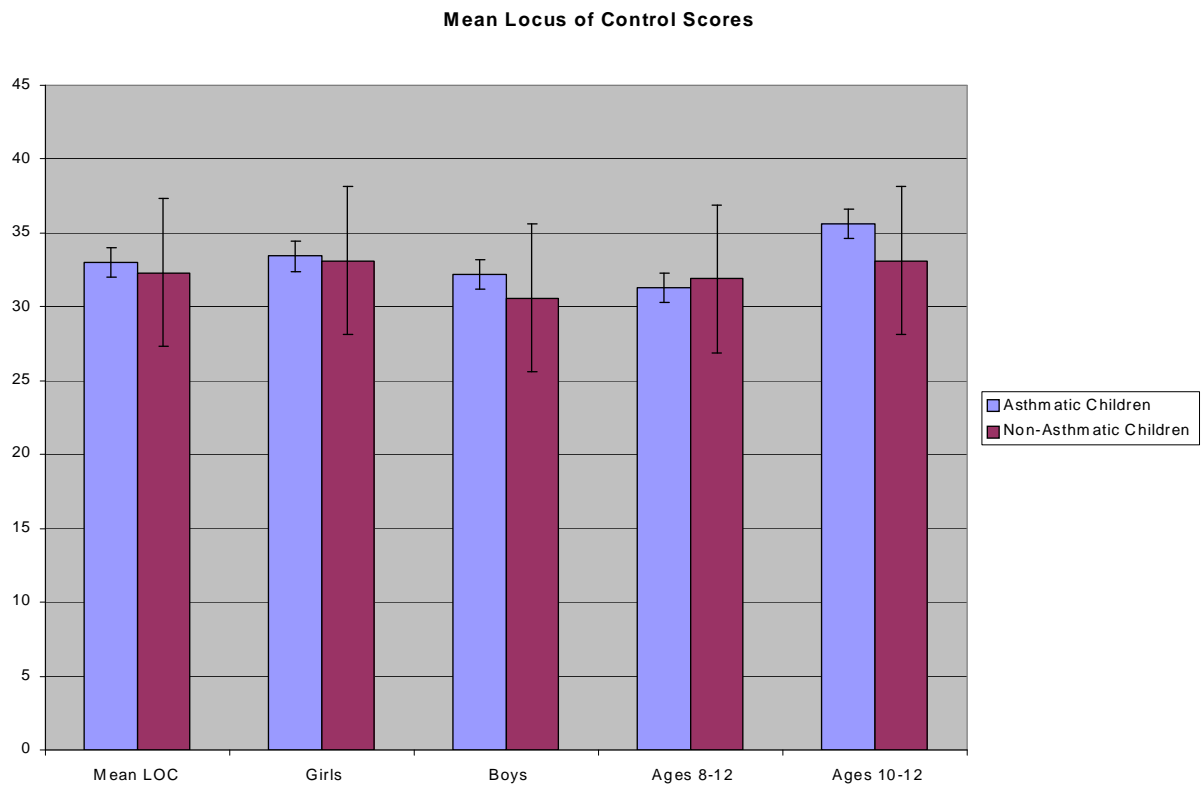
“Sense of place” is a subjective and experiential concept, and perceptions of place are often intuitive and difficult to articulate, especially among children who may have never been asked to think about these things before. Frequently when I asked children to explain why or why they did not want to be in a certain place, they said, “I don’t know” or “it’s better.” When I showed Sam a picture of an outside shopping place and an inside shopping place, he immediately told me that he would rather be in the mall. I asked him why, and he paused for a while, and finally said, “Cause...It’s got a toy store.” “What if the outside shopping place had a toy store?” He responded in frustration, “I don’t know, okay, that one [inside] because I have no idea.”

Locus of Control

There were some questions I asked within the Children’s Health Locus of Control Scale (Parcel, 1978) that I found particularly interesting. One of the yes or no statements was: “Good health comes from being lucky.” Only one of the fourteen asthmatic children (7%) agreed with this statement, while three of the twelve non-asthmatic children (25%) agreed. Thirteen of the fourteen asthmatic children (93%) and ten of the twelve non-asthmatic children (83%) agreed that: “I can do things to keep from getting

sick.” Nine of the fourteen asthmatic children (64%) and six of the twelve non-asthmatic children (50%) agreed with: “I can only do what the doctor tells me to do.” Three of the asthmatic children were quite adamant about their agreement with this statement. All but one asthmatic child and two non-asthmatic children believed: “When I am sick, I can do things to get better,” but children were mixed in response to “Other people must tell me what to do when I feel sick.” Five of fourteen asthmatic (36%) and five of twelve non-asthmatic children (41%) agreed with this statement.

Below I have the quantitative results, where I compared the mean scores between age groups and gender, as well as between asthmatic and non-asthmatic children. The possible range of scores was zero to forty, the highest score indicating a more external locus of control. The non-asthmatic and asthmatic children expressed similar levels of control over their health.



Discussion

Children with asthma are not able to participate in the world in the same ways as children without asthma. Their disease impacts time spent outside, time with friends and being physically active. It is also clear that asthma is perceived fundamentally as an environmental disease. Children described places as being responsible for making asthma better or worse. Because of the intrinsic environmental nature of the disease, and the impacts it has on everyday life, children with asthma develop different understandings of place. They are more sensitive to places that do not trigger asthma, and places that offer safety and family support. They appear to be less prone to explore new, unknown environments.

Previous studies support these findings. Block (1999) found that asthma limited physical and recreational activities, and Holaday's (1997) study found that chronically ill children play closer to home and feel more vulnerable away from home compared with healthy children.

Asthma is a disease that is not fully understood, and the fear and confusion expressed by both asthmatic children and their parents were amplified by this uncertainty. The impacts that the asthma experience has on being outside, physically active, socializing, and instilling fear are relevant in that they are intrinsic elements of self development and self perception. It is clear that asthmatic children are more vulnerable in the world than children who do not suffer from asthma. As asthma rates continue to increase among children in inner-city environments, the impacts that the disease has on

all aspects of children's lives become even more important.

In this section I reiterate the importance of asthma education and provide some recommendations for it, illuminated by the ways in which children reported understanding their illness. I then discuss the possible influences of asthma and poverty on "sense of place" and suggest a few specific applications of my findings.

Importance of Asthma Education

*"To write prescriptions is easy, but to come to an understanding with people is hard."
Kafka, 1919*

I asked Tracy what times her asthma scared her, and because I interviewed her after the class, she was able to tell me, "When I'm learning about it, like now." Children told me that they avoid things and places that are unknown, and it is the unknown that can be frightening or exciting. Asthma, understood as an unpredictable force that interrupts daily life, is a mystery and is unfamiliar. In this respect, children may not want to think or talk about their asthma. But it is only by familiarizing oneself with the disease that it can become less unpredictable and frightening. And, as discussed in my introduction, asthma education and learning to manage asthma can alleviate much suffering. In writing this, I am one voice joining a full chorus of asthma education advocates. What I hope to add in this discussion are a few ways that asthma education may be enhanced.

Incorporating “Lived Effects”

I realized that when I asked if children understood their asthma, I was asking if they understood their asthma as I understand it. Each one of them has created an explanation for their disease, whether or not they can articulate it. Martha Balsham (1993) wrote in her book, Cancer in the Community, that expressions of medical authority are often loaded with meanings about other things, “truth and legitimacy, power and resistance, self and identity” (p. 10). Professional views of illness are often regarded as superior to working class views.

I was chatting and drawing with a friendly Puerto Rican boy and his younger brother and sister before the beginning of an asthma class one day. The packet of information his mother received from Draw a Breath had a picture of lungs on it, and the boy started copying the picture with rainbow colored crayons. It was a perfect replication, and I asked him what he had drawn. “I don’t know,” he said, intent on coloring.

“I think they’re lungs,” I said, “At least, that’s what this is a picture of.” I pointed to his mother’s packet.

He didn’t seem very interested.

“Do you know where your lungs are in your body?” I asked. He paused drawing for a moment and then shook his head, “no.” I was fascinated and pushed on, “Well, do

you know where you get asthma?” No. “In your lungs!” I lectured, “What you just drew, when you have trouble with asthma, it’s your lungs that bother you!”

I thought that this must be a perfect lesson, associating a drawing with the medical definition of the illness. But what happened in those moments was that the boy completely disengaged with me. We had been talking comfortably up to that point, about Puerto Rico and school, but after the mini-lecture, he stopped talking to me.

I wrote in my notes that afternoon that I talked with a ten-year-old boy who knew nothing about his asthma. He didn’t even know that the illness occurred in his lungs!

Now I realize that of course he knew about asthma. He experienced asthma in a way that I never will, and I cannot judge his understanding as any less legitimate than a clinical understanding of illness.

I reported in my findings that children described their asthma by talking about their “lived effects.” The sensations of not being able to breath, or getting “pushed up” are more important to children than objective medical explanations of asthma. In the asthma classes, talking about their own personal experiences excited children. It is these direct experiences that are important for asthma educators to focus on and to not demean these by privileging a professional medical authority perspective. This also is reflected in previous research. Arthur Kleinman (1998) notes the importance of “lived effects” and illness narratives in understanding illness, and both Gochman (1985) and Jay (1988) show that direct experiences facilitate learning in general.

Being sensitive to these lived experiences may also enhance the management of asthma. Many children develop individual “danger signs” when their asthma is about to

worsen: their ears will turn blue, or they will start scratching their heads. Tuning into these signs is simply a matter of understanding and interpreting “lived effects.”

Feelings of Control

I found that children described asthma as an external force that they had little power over, and that asthmatic and non-asthmatic children scored similarly on the Locus of Control Scale. Feelings of control are particularly important for children with asthma because managing asthma is related to the control one displays over personal health. Cultivating a sense of responsibility can also help to build self-empowerment.

In Parcel’s study, the average score for children between grades 3 and 5 was 33.1, which is not significantly different from either the asthmatic or the non-asthmatic children’s averages obtained in my study. These quantitative results suggest that asthmatic children assume the same level of control over their health as others. More insight, however, came from exploring the responses to questions within the Locus of Control scale.

Judging by the responses to a number of these yes-or-no statements, it appears that asthmatic children are mixed about how much control they *should* adopt over their health compared to those with medical or parental authority. Children generally thought that they could do things to make themselves feel better, but also agreed that they could only do what the doctor tells them to do. The implications of this may be that many asthmatic children are capable of managing their illness, but are not necessarily confident in doing so. In this light, education programs that instill a sense of responsibility directly

to children may be very effective. Obviously, young children cannot be expected to assume all responsibility over their asthma. One approach is to teach children to watch for and report their characteristic “danger signs.” In doing this, children are assigned a proactive role in managing their asthma.

Valuing Place

“Requiring neither extended analysis nor rational justification, sense of place rests its case on the unexamined premise that being from somewhere is always preferable to being from nowhere.” – Keith Basso, Wisdom Sits in Places

I conducted this study from an environmental perspective, wherein I assume that the outside environment is intrinsically valuable, and important for self-development and connecting to the earth. The children I spoke with usually identified places as being important because they had stimulating, social, safe and familiar qualities, not because they were inside or outside. Obviously these qualities can be associated with inside and outside places, but it may be that I was searching for identification with outside environments that does not exist. This may be due to the young ages of the children I interviewed. It may be that valuing places for their aesthetic nature or pure existence is an indication of maturity. This may also be due to the children’s socio-economic status, which raises the question: How can we develop a rapport with the earth if our experiences with it are dirty and violent? How also might these children respond to conservationist or preservationist philosophies?

People in Places

Children highly value the social characteristics of places, and earlier I discussed studies that support this finding. The children I interviewed clearly appreciated outside places, like parks and beaches, but these are not necessarily the places they have routine access to. It may be that if safe outdoor environments are lacking, social interactions fill this place.

Self-development is dependent upon healthy peer group and family interactions. In this respect, the impact that asthma has on the social lives of children is important to consider. This may be easier to see in children from wealthier backgrounds, where asthma is less common and there is more risk of stigmatization.

In addition, social elements of place are especially important for children with asthma because they are often dependent upon the help of other people in treating their illness. The children with asthma emphasized family members rather than friends as being important elements of places, and it is family members who may be more responsible for helping with asthma attacks. It is thus safer for asthmatic children to spend time with figures of authority, who they can trust to take care of them, rather than friends who most likely would not be able to provide the same level of care. The dependence that chronically ill children generally have on their mothers is described by Carson's study (1992), who found that asthmatic children without their parents feel more socially isolated. This is important, in that children with asthma may not feel as safe or as comfortable with peer groups as children who do not suffer from asthma.

Along these lines, children with asthma are even more vulnerable in unpopulated places, because there they have no assistance whatsoever. Thus, natural scenes that others may regard as stereotypically pristine and beautiful may feel too isolating for asthmatic children, as well as being associated with asthma trouble. This creates a discrepancy between the environmental attitudes of asthmatic and non-asthmatic children, and may result in differing conservationist values as well.

A recurrent theme in environmentalism is that those who are involved in the conservationist movement tend to be from a select population that is white and affluent. People in poverty do not always have the luxury to be able to spend time in “natural” areas. Asthma has the potential to create an even more drastic division between people who involve themselves in land conservation and those who do not, by first occurring in low income populations and also helping to foster negative perceptions of “natural” places.

Again, when asthma is wisely managed, children may not be impacted so severely by their disease. Children who have their asthma under control may feel less vulnerable alone and away from family members and may achieve greater independence.

Safe and Dangerous Places

Asthmatic children find threats in environments that other people would describe as harmless. For example, children with asthma identified places as being clean more frequently than non-asthmatic children, which implies that they may be more intuitive to

certain aspects of place, given their environmental sensitivity. This could also indicate that asthmatic children identify dirty places as feeling unsafe.

This raises a profound question: How does an environment change from one of safety to one of danger? These associations certainly affect the ways in which these children interact with, and feel comfortable in, the outside world. Austin et al (1991) describe chronic illness in childhood as becoming a part of one's identity. Feelings about the chronic condition are related to feelings about the self, and the interdependent nature of self and environment has been popularized as a concept through the works of Piaget, discussed earlier in my introduction.

All children value places that offer freedom. Coping with asthma interferes with this freedom, and impacts also the perceptions of freedom in the outside world. I liken the ways in which children with asthma experience the world with the way I walk around outside in the winter. I am defensive against the cold, and my entire body feels withdrawn. In the summer I can more easily abandon myself to the outside world because it is more comfortable, and in a sense, safer.

I am speculating that asthmatic children must adopt a defensive attitude toward environments that aggravate their asthma, but I must also qualify that, as Kate's mother told me, most of these children don't remember what their lives were like before having asthma. They have adapted to this way of life, and for them it may not be different than it could or should be.

I found that children without asthma experience outside places as dangerous as well, due not to asthma, but to violent neighborhoods. A couple of weeks after my last

visit to Hasbro Children's Hospital I returned to Rhode Island Hospital to see Rosalind Wright, an Instructor of Medicine at Harvard Medical School, give a talk entitled, "Exposure to Violence and the Risk of Asthma in Children."

Dr. Wright began her talk by discussing the rise in prevalence and associated mortality of asthma shouldered primarily by minority, impoverished, inner-city children, and announced that conventional risk factors are not explaining enough of the problem. She introduced new risk factors, primarily stresses, as they are far higher and more consistent among low-income levels. These environmental stressors include exposure to crime, violence, poverty and lack of basic services. She and her colleagues conducted a study in East Boston, and found that exposure to violence kept coming up in responses to interviews. About 45% of the parents said that they keep their children inside more because of neighborhood violence, and more than half of the children reported spending less time outside because they were afraid of being hurt in neighborhood violence.

Dr. Wright posited that this exposure to violence as a form of developmental stress could be responsible for the increased risk of asthma in inner-city populations. As I listened to her speak, however, I realized that she was describing all of the children in my study, with and without asthma. And I realized that I have no real understanding of what it must be like to step outside my door and feel vulnerable in this way. When I ask how children with asthma perceive and relate to their environments, I am also asking how children living in poverty, in violence, amid indoor toxins and outdoor pollutants, as immigrants and minorities, view the world. Working to manage a chronic disease such as asthma is just one more complication. It may be that the issue of class, poverty and

violence overshadow some of the differences in terms of perceptions of dangerous and safe places, as well as feelings of control, for the children I interviewed.

Similar to asthmatic children, all children who deal with outside stressors, like neighborhood violence, experience less freedom in outdoor environments. In a sense, these children are trapped by invisible boundaries created by violence and environmental hazards. Wells (2000), in studying urban children's activities, found that the outside environment plays a highly significant role in terms of self-development, and Kaplan (1983) noted the importance of neighborhood communities in childhood development. Asthma and the inner-city experience may impact this environmental role in child development.

As the issue of urban sprawl comes to the forefront of city planning, problems within the urban core are being more closely scrutinized. Improving inner-city neighborhoods, by creating green spaces, parks and city gardens, encourages a more positive relationship with the outside. These developments may also contribute to cultivating an attachment to and investment in ones' home environment, by building trust and community infrastructure. This type of remediation benefits not only children with asthma, but sufferers of various environmentally induced diseases (lead poisoning, for example), and the community at large.

Environmental Justice and Empowerment

When we talk about children with asthma, we are generally referring to a specific population of people. It is appropriate to this discussion that we examine our assumptions about the poor, or even about the working class. There is an underlying

belief among professionals that the poor are failures, or that they are a problem that needs correction (Balshem, 1993), and there remains a tendency to locate the reason for poverty in the characteristics of the poor.

Asthma is an environmental justice issue, and it is a disease that is rooted in our political economy. The asthmatic children in my study and in this country are members of a population that is invisible. The majority come from impoverished and minority populations. My findings were greatly influenced by the similarities between my participant groups. The outside and inside environments that all of the children are exposed to include inner-city elements which impact perceptions of place, just as experiencing asthma impacts perceptions of place.

As I mentioned in my introduction, my study was inspired by ecopsychology, a study whose aim is to dissolve a worldview that places humans superior to the natural world. But asthmatic children, and more generally, inner-city children did not display attitudes of dominance over the natural world. Instead, they reported feeling vulnerable and unsafe in outside places. This is crucial. Outside places are regarded as harboring violence and asthma triggers, and are in these respects dangerous.

Another component of ecopsychology is a broad conception of self. The boundary between self and other is regarded as rather arbitrary, and this becomes meaningful because we take more responsibility for places and people when we see them as part of ourselves, or of a larger whole. The children I interviewed, inner-city youth, are often the least empowered members of our population (McLaughlin & Brice-Heath, 1998). Asthma, by restricting activities and by making certain environments feel vulnerable, complicates the development of an empowered self. A strong sense of self,

personal empowerment, and persistence are skills that help to foster the inner strength that is required to succeed in disadvantaged environments (McLaughlin & Brice-Heath, 1998). What appears equally important for all youth, and perhaps more crucial for impoverished children, is the development of a self that is comfortable in the larger world.

Additional Recommendations

It is clear that children living in inner city urban settings are more at risk for developing asthma and that poor children also do not have the same opportunities as more privileged children. I found from talking with school administrators and children, and studies confirm, that asthma is no longer rare in inner-city schools. Because of this, asthma and health education have every right to be included in school and community plans. Several parents reported that they were unhappy with their family's health care, and low income health care services tend to be poorly organized, have a dehumanizing atmosphere, and are generally disease oriented rather than preventative (Block, 1999). To compensate for this, schools can work with families, health and social service agencies and the community in a holistic effort to address education and the health and social service needs of the poor. Because of the impact of parents on children's health care attitudes (Carson, 1996), it makes sense to involve families in this effort as well.

As I mentioned above, children with asthma are members of a population that as a whole is disempowered. It may be useful for current school health education programs to shift their emphasis from focusing on health content to teaching skills that can lead to

children successfully making decisions about their health and encourage self-empowerment. An example of this could be group role-playing and problem solving exercises. This would be meaningful for all children, with and without asthma.

Another recommendation for children with asthma is to encourage exercise among asthmatic children. As my study found, and other studies have corroborated (Sehgal, 2000; Leickly, 1998), asthma impacts children's level of activity. Many of the children I interviewed were overweight, which in our society, can lead to self-image issues as well as health issues. Aerobic conditioning can lessen the prospect of an asthma attack by strengthening the lungs.

There are obviously wise ways in which asthmatic children can exercise and not exacerbate their asthma, and I do not have enough medical knowledge to specify how this should be done. But the success of the Asthma Swim and similar programs may be replicated in various inner-city communities. This would be another method of treating the asthma itself, rather than responding to its symptoms, as well as lessening the impact asthma has on children's activities, which are related to environmental perceptions.

Bridging the Asthma Gap

In this study I have been introduced to two camps. One, which includes Draw a Breath and the Environmental Health Advocacy Project in Providence, represents one method of addressing inner city asthma. These organizations are concerned with medical advocacy and focus primarily on eliminating triggers from indoor environments. The other camp, including activist groups like the Pew Environmental Health Commission

and US PIRG, attempts to curtail outdoor pollutants, by citing asthma as one of many consequences of overly polluted air.

These endeavors are far from being mutually exclusive. Environmental activism and asthma education are connected as deeply as I have shown that “sense of place” is tied to the asthma experience. Providing education is fundamentally important, in helping families to manage their asthma and increasing a sense of control over the disease. Focusing on the larger issues of place and outdoor pollution is important in curtailing the rate of asthma, encouraging political participation and community involvement, and transforming outside environments into places that are not regarded as dirty and threatening.

Limitations and Recommendations for Further Research

There were some limitations to my study. What is unique about qualitative research is that the researcher is the means through which the study is conducted. Thus, the lens the researcher brings to her work and the ways in which she interprets and understands her data influences the insights that are finally presented (Behar, 1996).

I am aware that the Draw a Breath environment may have influenced the ways in which these children responded and interacted, as well as my own presence being a continual confounder in the study. In both the interviews and in my observations, children may have responded differently than they would have otherwise done, because “the visiting Brown student” was there, scribbling in her notebook. However, I got the impression that whatever nervousness the children initially exhibited in the classes, they generally turned into a group of noisy and uninhibited youngsters.

The interviews themselves may have been limited by the class environment, which on several occasions was distracting and noisy. Many of the asthmatic children were also interviewed with their mothers present, which may have influenced some of their responses. Also, I assumed that the asthmatic and non-asthmatic children at the Children's Hospital, the elementary school classes, and the PHAs were coming from similar populations, when in fact they may not have been.

I found it important and valuable to work with children between the ages of eight and twelve, but there is also the question of reliability when interviewing children within this age group. For example, when I asked one eight-year old boy to tell me a place where his asthma felt bad, he responded, "At school." It was difficult to know whether or not the environment truly affected his asthma, or whether he simply did not like to go to school.

Before I administered the Locus of Control Scale I asked all of the children to answer according to how they really felt, and not how others may feel. This may have been challenging for the children to do. I was interviewing one boy who adamantly agreed with one of the statements, and to remind myself of this, I scribbled a star next to the number on my interview. I continued to ask him the statements, and eventually he cried, "Am I getting them all wrong?" He assumed that the star meant he had answered "correctly." The impression that the scale was a sort of "test" may have influenced the children's responses.

In addition, the most salient quotations often came from the most verbal kids, who don't accurately represent the entire participant group. Several of the children I

interviewed were shy and withdrawn, and I could not represent as effectively these children, who did not talk with me as openly as the others.

Also, I conducted these interviews over the winter months, when being outside was particularly uncomfortable. This may have influenced some children's responses to questions about inside and outside environments.

Both participant populations came from similar socioeconomic backgrounds, which makes it difficult to separate responses that are results of the asthma experience from those that are dependent upon impoverished living situations (a perfect example are the locus of control results). Because children with asthma and children living in poor, inner-city neighborhoods are both subject to threatening environments, interviewing children from different class backgrounds would be valuable as further research.

I also did not interview parents. Parents fundamentally influence their children's perceptions of illness and place (Butler, 1999). Because of this, another recommendation for further study is to interview parents, not only to gauge what their impacts on their children's experiences may be, but also to test for convergent validity or different perceptions between them and their children. The need for this was most evident in the conversation I had with Kate's mother, who told me that Kate's responses to my questions didn't match her own observations.

In addition to interviewing children from different socioeconomic backgrounds and parents, it would also be valuable to administer a similar interview to older children. As I mention above, the concepts that I asked the children to think about are challenging. Older children may be able to provide more sophisticated replies. Interviewing older children would also provide a comparison between the ways in which children of

different ages think about place. I found that children rarely mentioned aesthetic or intrinsic values of places, and wondered if this might be correlated with developmental level.

A final recommendation for further study would be to evaluate the impact of asthma education programs on children's feelings of control and perceptions of place. Given that children with asthma feel less comfortable in different, primarily outside, places, perhaps some method of intervention can help to alleviate feelings of vulnerability in outside environments. This type of study is probably the most important of all, as it can inform asthma education programs and help foster feelings of empowerment and comfort in the world.

Conclusion

“If the world is to be healed through human efforts, I am convinced it will be by ordinary people, people whose love for this life is even greater than their fear, people who can open to the web of life that called us into being, and who can rest in the vitality of that larger body.” Joanna Macy

A friend and I were talking about my project and she asked, “If you could put your suggestions on a billboard, what would it say?” I thought for a while, and said, “Stop Poverty. Stop Pollution. Stop Asthma.” Cathy Mansell once told me about a frustrated young mother whose son struggled with severe asthma. The woman gave her son the appropriate medications and cleaned up their home, but he continued to have frequent asthma attacks and ended up in the emergency room on a regular basis. Cathy went to visit the mother and son, and she discovered that they lived right next door to an illegal car garage, where an average of three cars were constantly left to idle and spew

exhaust into the air.

An important element of this study emphasizes the value of experience. The children I interviewed gave me insights into their lives that I would never have been able to predict. It also reminded me that it is only in seeing the bare mattress pads, the violence in the streets, the diesel traffic groaning under open windows, that we can get a clear picture of what we are addressing when we look at childhood asthma.

I have mentioned the value of education programs for asthmatic children, but what is even more important for reversing asthma trends is a restructuring of our political economy; a recognition of the relationship between asthma and poverty and social marginalization. Empowerment and education are just the first steps toward this means, which involve issues of disability politics and invisibility.

That said, what is also intrinsic to this study is the concept of place. Everndon (1993) writes, “Environmentalism, in the deepest sense, is not about environment. It is not about things but relationships, not about beings but Being, not about world but the inseparability of self and circumstance” (p. 142). Chronic illness in childhood becomes a part of one’s identity, and asthma is a disease that clearly impacts one’s relationship to places, most notably the outside world.

One of the strongest messages I received from both asthmatic and non-asthmatic children was that when they feel good they spend time outside, and that being outside makes them feel good. There is something intrinsically positive about the outside and about our relationship with the natural world. It is this awareness, often unconsciously realized, that drives environmentalism. We all make meanings for ourselves out of our lived experiences. This study sheds light on the meanings that children with asthma

make of the world and the places around them, as they are influenced by the asthma experience.

“The Peace of Wild Things”

*When despair for the world grows in me
and I wake in the night at the least sound
in fear of what my life and my children’s lives may be,
I go and lie down where the wood drake
rests in his beauty on the water, and the great heron feeds.
I come into the peace of wild things
who do not tax their lives with forethought of grief.
I come into the presence of still water.
And I feel above me the day-blind stars
Waiting with their light. For a time
I rest in the grace of the world, and am free.*

-- Wendell Berry

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www.epa.com

Appendix 1: Description of Draw a Breath

Draw a Breath, an asthma intervention program sponsored by Rhode Island Hospital, holds weekly classes at various Providence elementary schools. Over the course of a school year, the program visits twenty-four inner-city elementary schools. School nurses from each elementary school identify children with asthma and send them home with a recruitment letter for their parents. Draw a Breath follows up the letters with phone calls to encourage families to register for their after-school program.

Draw a Breath provides transportation to and from the school, dinner and baby-sitting money for the attending families. The classes for the parents are held in both English and Spanish and the children attend a separate English speaking class, taught by Jack Nassau, a child psychologist. All of the classes attempt to provide a medical understanding of asthma and lessons on maintaining and controlling asthma through medication and the recognition of common triggers. The classes are about three and a half hours long. The school visits are intended primarily for children coping with asthma, though non-asthmatic siblings often accompany their brothers and sisters to the classes.

Draw a Breath also holds classes at Hasbro Children's Hospital, which is an extension of Rhode Island Hospital. The hospital refers these children and parents to the classes after asthma induced emergency room visits, as do the Blue Cross and Neighborhoods insurance providers. The lessons are available in English and Spanish, but the parents and children remain together in the same class. Draw a Breath provides dinner, transportation and free parking. The classes run about three hours long and cover

the same principles as the elementary school classes, but are focused more towards the parents of children with asthma, and answer their questions and concerns.

The number of families that attend both of these classes varies. On average, there are about ten children at each elementary school class, and three or four are between the ages of eight and twelve. There are about five children at each Hasbro class, and one or two of these children are between the ages of eight and twelve, my selected age range. There are generally a few non-asthmatic siblings who attend each class with their parents and brothers or sisters.

Appendix 2: Children's Interview

The interview for non-asthmatic children consists of the first seven questions and the Locus of Control Scale

Introduction and assent: "Hello. My name is Kirsten. I am a student at Brown University and I am looking at how children feel about different places. I was wondering if I could interview you for about ten minutes. I will be asking you questions and recording your answers, but I won't ever use your name, and nothing you tell me will be identified with you. You can choose not to be interviewed, and no one will be upset with you if you decide to do this. If you would like to go ahead with the interview, you are free to stop at any time and you do not have to answer any questions you don't want to."

First, tell me three things you most like to do.

I wanted to talk with you a little bit about places. I know that different people like different places. For example, some people like to spend time walking around downtown, while others prefer going to the beach.

1. Do you prefer to play inside or outside?
2. How much time do you spend outside? (*Read aloud and check*)
 - a lot of time every day
 - some time every day
 - a little bit every day
 - a couple times a week
 - almost never
3. What kinds of things do you do outside? (*Check all that apply*)
 - play sports
 - walk places (to school, the store, etc.)
 - swim
 - exercise
 - sit/write/eat
 - other
4. If you could be anywhere in the world where you would feel the safest and happiest, where would it be? Why?
5. Picture yourself in a place where you feel uncomfortable or unsafe. Where are you?
6. I'm going to give you a list of places and I want you to tell me on a scale of one to

five, how much you would like to be in each place. Five is if you really would like to be there, and one is if you really would not want to be there. (*Use visual thermometer prompt*)

- a park
- a beach
- a video arcade
- a lake in the mountains
- the mall
- a forest
- a movie theater

7. Here are some pictures of different places. I don't want you to think about these exact places, but places that you know like them.

Here is a picture of a park and a picture of a gym. Would you rather play at a park or in a gym? Why?

Here is a picture of a shopping mall and a picture of a downtown shopping area. Where would you choose to be? Why?

Here are two pictures of different outdoor areas. (*Cultivated and non-cultivated*) Where would you rather be? Why?

Now I'm going to change the subject for a while.

1. Have you heard about asthma?
2. What is asthma?
3. How would you explain asthma to a friend?
4. How did you feel when you first learned that you had asthma?
5. How often do you think about your asthma? (*Read and check*)
 - all the time
 - sometimes
 - only when I'm sick
 - hardly ever
6. Does anything make your asthma feel better? (*Don't read list but check all that apply*)
 - taking medicine
 - staying away from things like cigarette smoke, pets, etc.
 - breathing slowly
 - being inside

- being outside
 - other
7. Does anything make your asthma feel worse? (*Don't read list but check all that apply*)
 - not taking medicine
 - exercising
 - triggers (smoke, pets, etc.) *write down which one(s)*
 - being outside
 - being inside
 - other
 8. Are there any places that make your asthma better? Which ones?
 9. Are there any places that make your asthma worse? Which ones?
 10. Do you get asthma attacks more often inside the house or outside the house?
 - inside
 - outside
 - about the same
 - don't notice
 11. Does your asthma ever keep you from doing anything that you want to do? What things?
 12. Do you try to make your asthma feel better? What do you do?
 13. Does having asthma ever scare you? At what times?

Now that we've talked about asthma for a bit, I'd like to come back some of the pictures we looked at.

1. (*For each picture ask*) Is this a good place for people who have asthma, a bad place for people who have asthma, or does it not affect people with asthma at all? Explain why.
2. If you didn't have asthma, would the place you would most like to be change?
3. If you didn't have asthma, would the place you would least like to be change?
4. Are there any places you avoid because you have asthma? What places?
5. Would you spend more time, less time, or the same amount of time outside than you do now if you didn't have asthma?

6. Is this the first time you've thought about how different places affect your asthma differently?

Here are some final questions. These are some statements about health or sickness. Some of them you will think are true and so you will say YES. Some you will think are not true and so you will say NO. There are no right or wrong answers. Be sure to answer the way you really feel and not the way other people might feel.

1. Good health comes from being lucky.....YES NO
2. I can do things to keep from getting sick.....YES NO
3. Bad luck makes people sick.....YES NO
4. I can only do what the doctor tells me to do.....YES NO
5. If I get sick, it is because getting sick just happens.....YES NO
6. People who never get sick are just plain lucky.....YES NO
7. My mother must tell me how to keep from getting sick.....YES NO
8. Only a doctor or a nurse keeps me from getting sick.....YES NO
9. When I am sick, I can do things to get better.....YES NO
10. If I get hurt, it is because accidents just happen.....YES NO
11. I can do many things to fight illness.....YES NO
12. Only the dentist can take care of my teeth.....YES NO
13. Other people must tell me how to stay healthy.....YES NO
14. I always go to the nurse right away if I get hurt at school.....YES NO
15. The teacher must tell me how to keep from having accidents at school....YES NO
16. I can make many choices about my health.....YES NO
17. Other people must tell me what to do when I feel sick.....YES NO
18. Whenever I feel sick I go to see the school nurse right away.....YES NO
19. There are things I can do to have healthy teeth.....YES NO

20. I can do many things to prevent accidents.....YES NO

We've talked a lot about asthma and places. Is there anything else you want to talk about, or anything the interview made you think about?

Thank you so much for spending your time talking with me. I hope that it was a fun experience!

Appendix 3: Asthma Assessment Form

Appendix 4: Interview Pictures

1. Park
2. Gym
3. Shopping mall
4. Outside shopping area
5. Cultivated outside picture
6. Uncultivated outside picture
7. Flowers
8. Bus
9. Room of smokers
10. Bedroom

11.

